Procuring Health Equity: Treatment Activists Fighting for Access to Medicines in Ukraine

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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor of Philosophy is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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ABBREVIATIONS

A2M	Access to Medicines
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
CSO	Civil Society Organisation
CL	Compulsory licence
DCFTA	Deep and Comprehensive Trade Agreement
EECA	Eastern European and Central Asia
EEU	Eurasian Economic Union
EU	European Union
FSW	Female Sex Worker
GF	The Global Fund to Fight AIDS, Tuberculosis and Malaria
HCV	Hepatitis C Virus
HIC	High Income Country
HIV	Human Immunodeficiency Virus
HRW	Human Rights Watch
IMF	International Monetary Fund
INGOs	International Non-Government Organisations
IP	Intellectual Property
ISDS	Investor-state-Dispute-Settlement
ITPC	International Treatment Preparedness Coalition
LIC	Low Income Country
LMICs	Low and Middle Income Countries
MIC	Middle Income Country
HIC	High Income Country
MMA	Make Medicines Affordable
MPP	Medicine Patent Pool
MSF	Médecins Sans Frontières
MSM	Men who have Sex with Men
OST	Opioid Substitution Therapy
PEPFAR	President's Emergency Plan for AIDS Relief
PLWH	People living with HIV

PrEP	Pre-exposure Prophylaxis
PWID	People Who Inject Drugs
R&D	Research and Development
SDG	Sustainable Development Goal
SPC	Supplementary Protection Certificate
TAC	Treatment Action Campaign
TB	Tuberculosis
TRIPS	Trade Related Aspects of Intellectual Property
UHC	Universal Health Coverage
UNDP	United Nations Development Project
UNICEF	United Nations Children's Fund
US	United states
USAID	United states Agency for International Development
USSR	Union of Soviet Socialist Republics
WBG	World Bank Group
WHO	World Health Organization
WTO	World Trade Organisation

Glossary

Acquired Immune Deficiency Syndrome (AIDS): A result of human immunodeficiency virus (HIV) infection. CDC definition of AIDS: Positive HIV serum test and T-cell count of under 200 per millilitre of blood or one or more opportunistic diseases or conditions.

Antiretroviral (ARV): Any substance or process that fights a retrovirus. HIV is a retrovirus. Antiretrovirals lower the amount of virus in the body to undetectable levels. This fights infection, improves the quality of life, and stops the person from passing on HIV through sexual contact. Dolutegravir, Raltegravir, Atripla, and Lopinavir/Ritonavir are some antiretrovirals mentioned in this research.

Human Immunodeficiency Virus (HIV): The virus that can cause AIDS.

Data Exclusivity: Data exclusivity protects a patent holder's data, which prevents other pharmaceutical companies/research institutions from using this data for commercial use. Therefore, inhibiting generic manufacturers from getting generic product market authorisation. TRIPS Plus provisions extend data exclusivity protections for patent holders.

Doha Declaration on TRIPS and Public Health: In 2001, World Trade Organisation member governments met to clarify any ambiguities around TRIPS and the right of each government to protect public health. The Doha declaration enshrines the use of pro-public safeguard provisions known as TRIPS flexibilities in order to enhance access to medicines and public health.

Generic Drugs: are medications that are produced to be the same as an approved brand name drug in dosage form, safety, administration and quality. Generic drugs are manufactured when the patent term of drugs is finished/ or has been released. This allows different generic manufacturers to produce the same drug, increasing competition and, consequently, decreasing prices.

Patents: provide the pharmaceutical company or research institute with the legal means to prevent others from making, using, or selling the new invention for a limited period of time.

A patent only gives an inventor the right to prevent others from using the patented invention and typically lasts 20 years. A licence holder is a pharmaceutical company or research institute that received market authorisation for a pharmaceutical.

Drug Procurement: is the process of purchasing or acquiring any pharmaceutical product for human use. This can be a complex process that can involve multiple steps, agencies and manufacturers that are often regulated by inadequate government policies.

Supplementary Protection Certificate (SPC): this certificate is often sought by patent holders who wish to gain back patent protection due to the time lost between gaining patent protection and market authorisation. An SPC can extend patent life up to a maximum of five years.

Trade-Related Aspects of Intellectual Property Rights (TRIPS): Implemented in 1995, the TRIPS agreement is a multilateral agreement on intellectual property that sets out minimum standards for patent protections to be implemented by each member state of the World Trade Organisation. This agreement also laid out provisions to deal with the enforcement of these intellectual property rights. Ukraine joined the World Trade Organisation in 2008.

TRIPS Plus: Despite the Doha Declaration, in recent years, there has been a proliferation of free trade agreements that have pressured many developing countries to implement heightened levels of intellectual property protection. These increased protections can have a negative impact on access to medicines. In the research, Ukraine implemented TRIPS Plus provisions in their Deep and Comprehensive Trade Agreement with the European Union in 2016.

Voluntary Licensing: This is the practice of a pharmaceutical company who owns the intellectual property rights of a medical technology voluntarily allowing alternative suppliers to enter the market with a generic, and often cheaper version of the technology in question. Voluntary licenses can take many forms including bilateral agreements between licensor and a licensee/s or multilateral agreements whereby multiple licensors and licensees make an agreement, as often facilitated by the Medicine Patent Pool.

Abstract

Procuring Health Equity: Treatment Activists Fighting for Access to Medicines in Ukraine.

Robert Lawlor

This study explores the strategies HIV and Hepatitis C activists within civil society organisations used to fight for their right to medicines before and after the Euromaidan Revolution.

The literature review brings together the latest research on social-political determinants of access to healthcare in Ukraine, on the evolution of HIV activism and civil society organisations in Ukraine, and on the exogenous influences of their access to medicine movement. This informs the following methodological chapter, which presents Political Process Theory as a guiding theoretical framework and reflexive thematic analysis as a methodological tool. Two findings chapters are based on nine interviews of treatment activists actively involved in the Ukrainian access to medicines movement between 20102021. Both chapters (*Who Holds the Reins of Power?* and *From USSR to a 'new' Ukraine* generated three key findings: 1) The Euromaidan Revolution coincided with a maturing, expert HIV and Hepatitis C civil society that was able to influence key state functions, but this window of opportunity for reform began to close as Zelensky's government commenced their tenure; 2) Treatment activism continues to be heavily reliant on international donors due to the growing diplomatic relationship between Ukraine and the European Union, and due to the huge financial, political and human capital needed to oppose the pharmaceutical industry; 3) Despite the EU-Ukraine Free Trade Agreement strengthening intellectual property rights, CSOs adeptly navigate the evolving knowledge economy and political system to continue ensuring access to lifesaving treatment. This study, which finished just before the Russian invasion of Ukraine, concludes by underscoring the importance of resource power, retaining political and social influence, and continuing toward a 'new Ukraine' to sustain the momentum of the participants' access to medicines activism.

1. Introduction

1.1. HIV and Hepatitis C in Ukraine

For more than four decades, HIV has posed a significant challenge to global health. UNAIDS set out an ambitious goal to end HIV/AIDS by 2030. To achieve this, UNAIDS set a 95-9595 target aimed at 95% of people living with HIV to be aware of their status, 95% of those aware to be on effective treatment, and 95% of those treated to have an undetectable viral load by 2025. When a person's viral load becomes undetectable, their immune system can function normally, but also, the likelihood of transmitting the virus to their sexual partner(s); the risk is zero, as evidenced by the Partner 1 and Partner 2 studies (Rodger *et al.* 2016, 2019). UNAIDS (2022) estimates that globally, 86% of all people living with HIV know their status; 89% of those who knew their status were accessing treatment; and 93% of those accessing treatment were virally suppressed. However, despite the relative access to effective HIV treatment, the UNAIDS report highlights that one person lost their life to AIDS every minute in 2021, with 10 million people living with HIV still not accessing treatment. Countries that have already reached their 95-95-95 targets include Botswana, Eswatini, Rwanda, Tanzania, and Zimbabwe (UNAIDS, 2022).

The focus of this research is Ukraine, which is recognised as having the second-largest HIV epidemic in the Eastern European and Central Asian (EECA) region (Fursa *et al.,* 2023; UNAIDS, 2022). According to statistics from the Centre of Public Health of the Ministry of Ukraine (PHC, 2022), in 2013, the treatment cascade was ill-performing at 56-42-91.

However, by 2021, the treatment cascade improved substantially to 69-83-94 (ECDC,2021). This demonstrates a doubling of people accessing treatment from 2013-2020, a relatively short amount of time. This highlights the significant progress Ukraine made. Unfortunately, Ukraine is still a long way off from meeting its 95-95-95 targets. For scale, in 2020, it is estimated that 15,658 people were diagnosed with HIV in Ukraine, which accounts for 15% of the WHO European region's total recorded cases (Vasylyev *et al.*, 2022). While antiretrovirals (ARVs) are now more accessible in Ukraine, challenges persist, such as stigma and discrimination, which have been found to lead to delayed treatment initiation or discontinuation (Demchenko, Sokolova & Buliga, 2020; Fursa *et al.,* 2023).

In their study, Demchenko, Sokolova & Buliga (2020) showed that 68% of survey respondents delayed treatment initiation and was most noticeably identified in key populations. While the lived experiences of people living with HIV and HCV are explored in this research, the study aims to identify the role of treatment activists in doubling access to lifesaving HIV treatment over eight years.

Additionally, this research examines activism around Hepatitis C (HCV) treatment, notably the price reduction of direct-acting antivirals (DAAs) like Sofosbuvir, which cures HCV. The scope of the research was increased to include activism related to increasing access to HCV treatment as exploratory research found an inextricable link to HIV/HCV activism in Ukraine, as well as the consideration of the high prevalence of HIV/HCV co-infection. HCV is an important public health issue in Ukraine, with an estimated prevalence rate of 3.5% in 2018 (Devi, 2020). If left untreated, chronic HCV infection can lead to the development of liver cirrhosis, liver failure, and death (Messina *et al.,* 2015; Spearman *et al.,* 2019).

However, DAAs have been shown to be highly effective at curing HCV infection, have very few side effects and can increase the overall quality of life for both people who inject drugs (PWID) and people co-infected with HIV (PLWHIV) (Benade *et al.,* 2022). Therefore, it is crucial to understand the ways in which treatment activists reduced the price of treatment to allow people with HCV to access this lifesaving treatment. Throughout this thesis, I use the term HIV/HCV civil society organisations (CSOs) interchangeably to reflect the integrated nature of the work in HCV and HIV communities, as outlined in later sections. My primary focus is on the work of HIV/HCV CSOs. However, this research also acknowledges other health-related organisations that have contributed hugely to the HIV/HCV treatment activism movement and broader health reforms addressed in this research. Therefore, from here on out, I will now refer to all CSOs involved in the movement as HIV/HCV CSOs. Additionally, when I refer to the access to medicines (A2M) movement, I am generally referring to HIV/HCV. However, during the times I use this messaging, it can be extrapolated to all health areas that are affected by inequitable access.

The next section will outline why medicines are priced so highly and what avenues treatment activists can explore to overcome the issue of high-priced medicines.

1.2. HIV/AIDS & Trade-Related Aspects of Intellectual Property

In 1995, the World Trade Organisation (WTO) established a global agreement on Trade R elated Aspects of Intellectual Property (TRIPS) (Matthews, 2003). The TRIPS agreement provides strict intellectual property protection to pharmaceuticals by establishing a minimum twenty-year monopoly over pharmaceuticals in WTO, effectively changing the global landscape regarding access to medical innovation (Smith, Correa & Oh, 2009). Prior to TRIPS, over fifty countries denied recognition of patents on pharmaceutical products. However, this new policy required lower-middle-income countries (LMICs) to start accepting patents on medicines for the first time, rendering them unaffordable and inaccessible (Sell, 2003; t' Hoen *et al.,* 2011). This monopolisation of medicines raised international concern as medicine development prioritised maximising profits over the health needs of those in LMICs (Haakonsson & Richey, 2007). The TRIPS agreement did incorporate provisions or flexibilities aimed at providing member states with a pathway to secure access to affordable medicines by limiting the IP rights of patent holders in a time of health emergencies (UNDP, 2006; Haakonsson & Richey, 2007).

Two such TRIPS flexibilities include compulsory licensing and parallel importing (UNDP, 2006). When a state issues compulsory licensing, it allows another pharmaceutical company to make a generic version of the patented product without the consent of the patent holder and can reduce the prices of medicines by up to 95% (World Trade Organization, 2001; Beal & Kuhn, 2012). Parallel importing allows countries to procure and resell medicines from other countries without the authorisation of the original seller. This permits countries to search for the lowest world price (Bart, 2008). For example, if a drug is cheaper in Brazil, a company or government agency in Kenya may buy medicines from there and resell the drugs in Kenya. While researchers optimistically predicted that the regular use of TRIPS flexibilities would increase coverage of ARVs, there was also a pessimistic view of these flexibilities being used to international pressure and fears of trade retaliation (Banta, 2001; t' Hoen 2002; Attaran, 2004; Beal & Kuhn, 2012).

The pharmaceutical industry contends that strong patent protection provides a financial return that incentivises expensive and financially risky research and development (R&D) of drugs (Atkinson & Jones, 2009). The industry argues that without the promise of substantial

financial returns, there would be little incentive to invest in risky innovation, resulting in a reduction of much-needed R&D (Abbott, 2002; Rajkumar, 2020). This is the main argument the pharmaceutical industry provides for the high cost of drugs. Despite this rationale for high drug prices, research shows that pharmaceutical companies spend more money on marketing their drugs, stock buybacks and dividends than they do on the research and development of novel, innovative, life-saving drugs (Gagnon & Lexchin, 2008; Lazonick *et al.,* 2017; Angelis *et al.,* 2023).[1]

In 1996, a year after the WTO established TRIPS, these trade policies were challenged by governments and civil society organisations around the world. These challenges were initiated as the introduction of the first efficacious ARVs to manage HIV received market authorisation but were unaffordable and inaccessible (t' Hoen *et al.,* 2011). Due to the high cost of ARVs and the exclusion of generic competition, the supply of life-saving medicines was mainly only available in high-income countries (t' Hoen, 2016). LMICs received limited access due to the pharmaceutical industry's unwillingness to reduce the price of ARVs to an affordable price (t' Hoen, Kujinga & Boulet, 2018).

This mobilised HIV/AIDS activists to forcefully engage with pharmaceutical companies and governments to focus on scientific knowledge production, drug pricing regulations and health policy development (Epstein, 1996; Smith & Siplon, 2006; Colvin, 2014). Today, millions of people living with HIV have access to antiretroviral therapy due to the radical efforts of formalised and informalised civil society who worked with key global health institutes to fundamentally change the dynamics of the pricing mechanisms for ARVs (Said & Kapczynski, 2011; UNAIDS, 2019). This research contributes to the overall research on access to medicines by identifying the role of HIV/HCV CSOs in securing access to many different classes of ARVs and DAAs in Ukraine.

[1] For more information regarding critiques of the current R&D innovation model, look to publications found on the Medicines, Law and Policy webpage - https://medicineslawandpolicy.org/2020/02/time-for-new-pharmaceutical-innovation-models/

1.3. Positionality and Study Conceptualisation

Positionality refers to the position a researcher has chosen to adopt within a given research study. It requires the researcher to consciously examine their own identity to allow the reader to assess the effect of their personal and/or professional characteristics and perspectives in relation to the study population, the topic under study and the research process (Savin-Baden & Major, 2013). Therefore, I present the following positionality statement and provide context for why I chose this research project.

Throughout this doctoral study, I have endeavoured to understand the role I played at each stage of the research process. I am an experienced activist with over ten years of experience working in the fields of HIV and access to medicines, campaigning nationally and internationally. I am passionate about health equity and believe that systemic changes to how we incentivise research and development are essential to ensure that medical innovations go to people who need them. My work towards delinking the cost of research and development and the end medical product is informed by the UN high-level paper on access to medicines (2016). Over the years, I have continued to observe the complacency in high-income countries towards global inequitable access to health technologies. As people in HICs generally, but not always, have relative access to essential medicines, we are less likely to mobilise against trade frameworks that allow the pharmaceutical industry to price medicines at exorbitant prices. I was first interested in doing a PhD that explored countries that do not have access to medicines, such as HIV/HCV treatment, and as a result, mobilise an access to medicines (A2M) movement that effectively reduces the price of medicines.

My work engagements have resulted in discussions with stakeholders encompassing government officials, the media, patient community groups and the pharmaceutical sector. A common misconception I've encountered is that AIDS is a health condition of the past due to treatment being widely available. Of course, this is false; as highlighted in the UNAIDS In Danger report (2022), one person died of AIDS every minute in 2021. Even with significant progress achieved globally in combating new HIV infections and AIDS-related deaths due to sustained efforts from the HIV community and international support, MICs still face challenges in accessing affordable generic medications.

Due to the financial status of MICs, they often receive less foreign aid for their HIV response and are often left out of pharmaceutical licence agreements that allow cheaper, generic medicines to be sold, bought or manufactured in their countries. Therefore, MICs struggle to gain access to life-saving HIV/HCV treatment in comparison to countries in Sub-Saharan Africa, which are more likely to avail of licence agreements. This results in MICs being an important academic endeavour to understand activist activity better, especially regarding campaigns to overcome intellectual property rights.

So why Ukraine? As a member of the European AIDS Treatment Group, I have travelled and worked in Kyiv, Ukraine, a number of times between 2016 and 2018. During my time in Kyiv, I met with Ukrainian colleagues and other members of HIV/HCV community organisations. I was not only struck by the particular socio-political issues they faced but more importantly, I was inspired by their level of success and their continued work towards reducing the price of medicines in Ukraine, notably the price of ARVs and DAAs. The literature on access to medicines in MICs has often concentrated on Latin America, India and South Africa.

Therefore, to improve my own understanding of access issues in MICs and to fill in the knowledge gap in the EECA region, I pursued this doctoral study to gain an understanding of the social, political and economic factors that nurtured such effective activism in Ukraine. It is also vitally important to mention that I do not speak Ukrainian. Therefore, when I speak of novelty in research or bridging the knowledge gap, I can only speak about research I am aware of that was written in English.

My personal and professional background has continued to shape the research I have undertaken. Specifically, my in-depth personal understanding of the lived experience of HIV and understanding of intellectual property have informed my interview questions, inclusion and exclusion criteria, recruitment strategy, interview technique and data analysis. As someone living with HIV since 2012, I have experienced many side effects of ARVs. The continuous cycle of starting new ARVs that made me feel sick and then feeling the anxiety of trying new treatments in fear of more side effects took its toll both physically and mentally.

Luckily, in Ireland, I have access to all available treatments. I am currently on my sixth option of HIV treatment. Thankfully, this option works perfectly for me. I believe that this

experience provided me with a deep empathy toward my fellow community members who experience similar treatment difficulties but who do not have access to as many alternatives. Therefore, I believe my own personal journey informed these research questions. For example, I believe it important to identify the evolution of the lived experience of HIV/HCV and how this coincided with the evolution of treatment access. When I was considering the inclusion criteria to answer my research question optimally, I kept it relatively broad to encompass any person who was involved in the Ukrainian access to medicines movement, specifically in the area of HIV/HCV. I believed that the research participants would primarily have backgrounds in donor relations, intellectual property law and human rights. While I have often interacted with the pharmaceutical industry, I did not seek their input in this study, anticipating a reiteration of well-established narratives that would not proactively help answer the research question.

The study excluded people who did not speak English due to my own limitation of not speaking Ukrainian. Initially, I believed this would be a major impediment to the strength or even the feasibility of my research as it would limit my sample pool and ability to access the literature on the topic. Of course, my inability to speak Ukrainian did restrict access to both. Yet, through discussions with Ukrainian colleagues at the start of my study, I was ensured that many HIV/HCV activists in Ukraine had proficiency in English as they often worked within the global community forums and worked closely with development agencies and funders in the English language.

However, I did find that much of the literature on the democratisation of post-Soviet states in my literature review came from American scholars who generally were influenced by neoliberal Western ideology. Additionally, many publications that I reference relating to experiences of stigma and discrimination, prevalence rates and health policy are often derived from reports from international organisations or media articles rather than Ukrainian academic journal articles. Therefore, it is important to state that this process of knowledge production without access to Ukrainian research may have influenced my nuanced understanding of Ukraine's HIV/HCV response. I further elaborate on my application of reflexivity to interrogate how my assumptions, worldview and lived experiences influenced my interview technique and data analysis in sections 4.11 and 8.5.

1.4. Rationale for Research

In this research, I seek to understand how treatment activists in Ukraine overcame and are still overcoming the issue of high drug prices of ARVs and DAAs. Ukraine is a compelling case for research for multiple reasons. Firstly, it is often characterised in the literature as a culturally conservative country that is hostile to key populations affected by HIV/HCV (Spicer *et al.,* 2011; Semigina, 2013; Durteste *et al.,* 2019; Sereda *et al.,* 2020; Demchenko, Sokolova & Buliga, 2020). Second, as highlighted in section 1.1, Ukraine is the second worst-performing country in the EECA region for new HIV infections and AIDS-related deaths (UNAIDS, 2022). Nonetheless, the availability of treatment for HIV has doubled from 2013 to 2021, an achievement largely accredited to HIV treatment activists reducing the prices of antiretroviral therapy (PHC, 2022).

Although there are many different dimensions to the access to medicines movement that could be considered for inquiry in this study, I specifically chose to focus on the availability and affordability of medicines. Wirtz *et al.* (2016), in their study on access to medicines for cardiovascular disease in low- and middle-income countries (LMICs), identified five key health system dimensions of access to medicines.

The first dimension is the availability of medicines, which pertains to the types of medicines are in stock at any given time and what types of medicines should be available. This dimension addresses issues such as procurement processes and governance, and the medical needs of people living with HIV/HCV. The second dimension is affordability, which concerns the ability of the healthcare system or the patient to pay for health products. Consequently, this dimension examines issues such as intellectual property, international donors, royalty payments, economies of scale and data collection methods. The third dimension is accessibility, which measures the ability of individuals to access care when it is needed. This dimension can focus on patient-specific challenges, social determinants of health, and health system limitations such as inadequate health infrastructure (Holland *et al.,* 2021). The fourth dimension relates to the acceptability or adoption of medicines, considering issues such as appropriate prescribing behaviours of doctors and potential adherence challenges with patients. The fifth dimension is the quality of medicines, which addresses whether medicines meet the quality specifications established by national or international regulatory guidelines (Wirtz *et al.,* 2016).

While each of these dimensions are crucial in ensuring that patients receive adequate medication, with assured quality, adequate information, and at an affordable price, this research cannot comprehensively examine all of them. Therefore, this study will primarily focus on the dimensions of availability and affordability. However, it is anticipated that the research participants will reference different dimensions in their roles as treatment activists.

This study's focus on the availability and affordability of medicines directly influences the inclusion criteria of this research. For instance, if the research explored the accessibility dimension such as how key populations interact with healthcare workers and how this affected their adherence to medication, it would recruit individuals actively working on the ground with sex workers, people who inject drugs and men who have sex with men. However, given that the primary focus is on availability and affordability, the recruitment strategy focused on individuals who manage intellectual property issues and have experience in the procurement of medicines, to ensure that they are affordable and available. The study's inclusion criteria are further discussed in section 4.3.

The focus remains on the affordability and availability of medicines as there has been limited research on the role of HIV/HCV civil society organisations in doubling HIV treatment coverage since 2010. Much of the current literature exploring HIV treatment activism in MICs is usually focused on South Africa, India, Latin America, Thailand and Malaysia (Timmermans, 2007; Correa, 2011; Pechacek, 2012; Cassier, 2013; Helfer, 2015; Shadlen, 2017; Son, Kim & Lee, 2019; Abbas 2022; Rathod, 2022). Therefore, this research explores what economic, social and geopolitical factors in Ukraine nurtured such effective access activism from 2010 to 2021. I've chosen this timeline for multiple reasons. Firstly, in my exploratory conversations with people working in the HIV/HCV field in Ukraine, 2014 was identified as a key moment for healthcare activism, including activism related to access to medicines. However, to get a fuller picture of the access movement, it was recommended that I start my research in 2010, as this was just before HIV/HCV organisations started to collaborate on projects.

1.5. Research Question and Objectives

The research question is presented as follows: How did HIV and Hepatitis C treatment activists fight for their right to medicines in Ukraine from 2010-2021?

The study's objectives are as follows:

- To examine the temporal relationship between the growth of HIV and HCV CSOs and the Euromaidan Revolution in creating a window of opportunity for healthcare reform
- To understand the significance of foreign aid and resource power for treatment activism in Ukraine
- To critically assess the tools available and the strategies used by treatment activists to reduce the price of medicines
- To analyse the implications of the EU-Ukraine Free Trade Agreement on intellectual property rights and how CSOs navigated these changes

Throughout this thesis, I refer to our human right to medicines, which is understood as access to therapeutics, vaccines and diagnostics and derives from our broader right to health and our right to benefit from scientific progress (Marks & Benedict, 2013). In this study, there is a particular focus on access to HIV and HCV treatment. However, there are references to other health-related issues.

1.6. Thesis Structure

This thesis comprises six chapters. This present chapter introduced the thesis by providing a background of the issues relating to intellectual property and access issues related to HIV and HCV treatment within the context of Ukraine. In Chapter Two, I present a critical review of extant literature focusing on three key components to contextualise Ukraine's access to medicines movement. The first section focuses on the socio-political determinants of access to healthcare in Ukraine. The second section examines the evolving role of HIV CSOs in Ukraine. The third section juxtaposes the Ukrainian HIV/HCV treatment activism and the global access to medicines movement. It also appraises the role of free trade agreements and the disparate strategic approaches in the global health architecture that influence this movement.

In Chapter Three, I present the study's methodological approach. This chapter provides a detailed description and justification for adopting the social movement theory, Political Process Theory as a guiding framework. Chapter Four provides in-depth details of the research process, including ethical considerations, data collection and Reflexive Thematic Analysis. Concluding this chapter, I provide insights into my own reflexivity journey through this research.

Chapters Five and Six report the study's findings. Both chapters are divided into three sections. In Chapter Five, the findings present a detailed analysis of Ukraine's evolution from a Soviet-governed state toward a new, pro-European orientated Ukraine. The first section outlines the findings related to the evolution of the social and treatment landscape for people living with HIV and HCV. In the second section, HIV/HCV activism and healthcare reform before and after the Euromaidan is outlined. In section three, the evolving relationship between the state and HIV/HCV CSOs is developed. In Chapter Six, the findings examine the intricate power dynamics between all stakeholders in Ukraine's A2M movement. The first section highlights the evolution of civil society from watchdogs to key participants in state functions. In the second section, the role of resource power in the access to medicines movement is unpacked. The last section highlights how treatment activists navigate trade and legal frameworks, the multifaceted strategies CSOs use, and the pharmaceutical industryCSO relationship.

Chapter Seven presents the study's findings as they relate to existing studies and highlights new insights that emerge from the research. Chapter Eight summarises the salient findings of the study and their relevance to academic literature, the study's strengths and limitations, and the implications for access to medicines activism and future research.

Chapter 2. Literature Review

In this chapter, I endeavour to synthesise and critique the extant literature that underpins this research. Focusing on three key areas, the literature review aims to establish a comprehensive backdrop for understanding the principal components of HIV/HCV treatment activism in Ukraine. The first section begins by looking into the research that examines how the social, political, economic and geopolitical conflict affects access to healthcare, the HIV response, and the lived experience of people living with HIV and HCV in Ukraine. The chapter then focuses on the evolving role and influence of civil society organisations, with a particular focus on HIV CSOs and their relationships with foreign aid donors and multilateral institutions. Finally, the chapter concludes by examining macro-level influences and barriers to gaining access to medicines, including free trade agreements, divergent objectives within the global health architecture and fractured global access to medicines movement.

2.1. Social-Political Determinants of Access to Healthcare in Ukraine

This section reviews studies that identify the socio-political attitudes towards the populations most vulnerable to HIV infection, including men who have sex with men, injecting drug users and female sex workers. In addition, significant influences affecting Ukraine's current healthcare model are explored, such as the Euromaidan Revolution, the residual effects of Soviet-era healthcare practices, and the implications of ongoing geopolitical conflict.

2.1.1. Ukraine and Public Health

The Ukrainian healthcare system ranked poorly among European nations in terms of efficiency, particularly with regard to access to treatment and preventive interventions, even comparatively to other post-Soviet countries (Romaniuk & Semigina, 2015; 2018; Marchese *et al.,* 2022). Research identified that organisational, financial and political inadequacies have hindered Ukraine's ability to address the health needs of its population (Gryga *et al*., 2010; Hale & Ortung, 2016; Lohvynenko *et al.,* 2019). From 1991 to 2012, while overall mortality rates dropped in the European Union by 6.7%, Ukraine witnessed a 12.7% increase, ranking it second in Europe for mortality rates (WHO, 2012). Similar trajectories are found in infectious diseases. Mortality rates from infectious and parasitic diseases between 1990 and

2015 increased from 11.78 to 21.67 deaths per 100,000 population, in contrast to other post-Soviet countries that had a decrease in mortality rates from 8.76 to 7 deaths per 100,000 within the same time period (Romaniuk & Semigina, 2015; 2018). In 2019, the Global Health Security Index, which ranks countries' abilities to prevent, detect and respond to epidemics and pandemics, Ukraine placed 94th out of 195 countries.

Understanding Ukraine's healthcare needs provides an important background for why healthcare reform is needed and the importance of HIV/HCV treatment activism. In their paper outlining the realities and prospects for medical reform in Ukraine, Melnychenko *et al.* (2021) argue that medical reform is not a goal in itself, but when implementing reforms, it is necessary to consider related processes, such as globalisation, macroeconomics, health specialisations and '*rights of property in business*', etc. Similarly, my focus as I progress through this literature review is not to take a personal position on medical reform in itself but to strive to understand the processes, actions, obstacles and motivations behind HIV/HCV CSO's pursuit of reform and access to medicines.

After the collapse of the USSR, Ukraine gained its independence in 1991 but continued to maintain deep socio-cultural and economic divisions. This division stemmed from people in eastern Ukraine identifying themselves as Ukrainian-Russian and western Ukraine looking to align themselves with Europe (Zhurzhenko, 2014; ACTED Report, 2017). However, this overly simplistic characterisation of Ukraine's soviet legacy and national identity fails to capture its complexity. Kravchenko (2016) provides a more nuanced examination of Ukraine's soviet legacies in state-building, recognising that these legacies are manifested in values, artifacts, landscapes, mythologies, memories and traditions from the past. Hrytsak (2004) and Kravchenko (2016) assert that historical legacies are pivotal in shaping the various patterns of post-communist economic, political, and cultural developments in Eastern Europe. Kuzio (2002) and Kravchenko (2016) contend that history is fundamental to the theory and practice of national (re)identification and state-building undertaken in all former soviet countries. These countries utilise their historical narratives, such as their "golden eras" and "usable past" to legitimise their newly independent states.

However, Kravchenko (2016) argues that Ukrainian history is uniquely specific due to its episodic and brief periods of sovereignty. The complexity is further exacerbated by Russia's historical repression of Ukrainian identity, employing methods such as official bans on people

promoting Ukrainian-ness which inevitably led to societal and cultural taboos, and self-censorship (Kravchenko, 2016). Therefore, describing Ukraine's national identity as merely divided into Ukrainian-Russian, Ukrainian-European, and Ukrainian segments oversimplifies the issue. Its complex history and relationship with identity is contributing to its search for the symbolic capital necessary for its ongoing nation and state-building process.

Yet study's do recognise that deep divisions in national and political identity has played a part in reducing political motivation to implement healthcare reforms. These study's argue that this has resulted in Ukraine continuing to organise its healthcare system in accordance with the USSR's Semashko healthcare model (Lekhan *et al.,* 2015; Sheiman, Shishkin & Shevsky, 2018). The main tenets of the Semashko model is central budgeting financing, hierarchical organisational structure, and a dominance of the public sector (Romaniuk & Semigina, 2015; Ukraine Health Reform Report, 2018). Under the Semashko model, the system promises a universal range of healthcare services that are publicly funded. Therefore, promising everyone access to free healthcare.

However, the reality of free healthcare is contested in the literature due to limited financial resources and an unsuccessful financial structure. The promise of universal healthcare is merely tokenistic (Mendel, 2017; Romaniuk & Semigina, 2018). A critical issue in Ukraine's healthcare system is the prominence of out-of-pocket payments spending on healthcare reached 45% of total healthcare expenditure in 2012 (Lekhan *et al.,* 2015) and 49% in 2018 - one of the highest rates in WHO's European region (Karol *et al.,* 2023). Out-of-pocket payments provide interesting insights into the importance of healthcare reform, but also of having access to affordable medicines. Furthermore, in 2018, the World Bank highlighted that the Ukrainian government spent 3.7% of its gross domestic product (GDP) on healthcare financing, in comparison to the European Union's average of 5.9%.

By 2017, public demand for healthcare reform was high, with a Ukrainian population survey showing health reform was in the top three reform priorities, as 92% of the respondents were afraid of developing financial difficulties due to the associated high costs of private healthcare (Stepurko & Semigina, 2017). Additionally, there is strong international pressure for Ukraine to reform their healthcare system from financial institutions such as the International Monetary Fund and The World Bank (see section 2.1.1.). However, it is important to note that there is a scholarly debate about the effectiveness of IMF programmes

on health systems in LICs. Studies have shown that their role may have been detrimental to the development of systems as their recommendations for privatisation can lead to issues such as reduced public health investment and challenges in recruiting and retaining medical professionals, ultimately leading to increased inequities in healthcare (Kentikelenis *et al.,* 2016; Stubbs *et al.,* 2017).

The IMF disputes these claims and argues that they improve health systems (Gupta, 2015). While these critiques of IMF intervention are focused on LICs, the authors suggest that reforming Ukraine's healthcare sector in line with guidelines from international financial institutions may result in worsening healthcare outcomes. Despite this, these pressures prompted the Ukrainian government to favour solutions that introduced rapid organisational change, financial restructuring and anti-corruption within the healthcare system (Korop & Lenskykh, 2018). However, there remains scepticism as to the success of reform implementation (Romaniuk & Semigina, 2018). Since Ukraine gained its independence, twenty-two proposed health reforms have been developed, but due to a lack of political will, there has never been a real appetite for systematic reform (Ukraine Health Reform, 2018). Additionally, evidence shows that politicians who oppose these health reforms are sympathetic to and supported by Russia, increasing anti-reform rhetoric on mainstream and social media (Shandra, 2017).

While this research does not focus solely on the nuances of Ukraine's state-building post-independence, the historical complexities and external influences on these processes provide significant insights into the country's civil society and governance frameworks, such as political will for healthcare reform. These insights are important for better understanding the socio-historical and political context of HIV/HCV civil society. Moreover, the literature highlights how post-Soviet scholarship on Ukrainian civil society often oversimplifies a multifaceted, nuanced, and historically intricate topic that remains central to Ukrainian identity and governance.

2.1.2. Strategies and Obstacles for Healthcare Reform in Ukraine

This section predominantly draws upon the work of Romaniuk & Semigina (2015) to better understand healthcare reform in Ukraine. In 2016, the Ukrainian government introduced the Concept of Reforming Health Care Financing, which aimed to reform primary healthcare financing by 2018, with full financial reform introduced by 2020 (Romaniuk & Semigina, 2018). However, a study by Luck *et al.* (2014) argues that financial restructuring goes far enough to change the healthcare paradigm. Therefore, it cannot meet the reform expectations of the Ukrainian public. In the Ukrainian National Health Reform Strategy 2015-2020, the Ukrainian Government outlines a reform package based on key pillars of financial restructuring, drug procurement, patient-centred, and strong civil society collaboration (National Reform Strategy, 2015).

Implementing these reforms was undertaken by acting Minister of Healthcare Ulana Suprun, who is American-born and carries dual Ukrainian/US citizenship (Romaniuk & Semigina, 2018). To highlight the strong political opposition to these reforms, in 2019, the district court of Kyiv decided to temporarily remove Suprun as acting Minister of Health due to her dual citizenship. The legal challenge against Suprun was initiated by a member of parliament, stating that she lacks the competencies to fulfil her role. Within a week, Suprun was quickly reinstated to her position after strong domestic and international pressure (UNIAN, 2019). Despite the opposition, Romaniuk & Semigina (2018) argue that this national strategy prioritised the reforms necessary for change. The first pillar focuses on shifting the financing of healthcare facilities to a '*money follows the patient'* principle (Romaniuk & Semigina, 2018). This financing system incentivises hospitals and primary healthcare facilities to provide the quality of care they provide to patients, as funding is based on the quantity of patients (Casale *et al.,* 2007). This principle was enforced to enable hospitals to see the link between money and their work, rather than being paid regardless of how many patients the healthcare providers see. Furthermore, it allows the patient to choose the healthcare facility that best fits their needs, creating a healthy marketplace competition within the sector (O'Reilly *et al.,* 2012).

Another key paradigm change is the drug procurement process in Ukraine. In 2015, the responsibility to procure vaccines, medicines and diagnostic tools in Ukraine was passed over to the United Nations Development Fund, United Nations Children's Fund and the U.K.

nonprofit Crown Agents (National Strategy Reform, 2015; Romaniuk & Semigina, 2018). Prior to this procurement arrangement, medicines were either too expensive or completely unavailable to patients (Semigina & Mandrik, 2017). It was estimated that the Ministry of Health lost about $100 million of its $250 million pharmaceutical procurement budget to corruption annually (Twigg, 2017). The shift in drug procurement has been estimated to have saved millions of dollars and also resulted in healthcare facilities facing fewer medical stockouts (Francis, 2017).

The strategy was also based upon a people-centred approach that advocated for strong collaboration between local authorities and civil society. This shift in hierarchical structure was pursued to ensure a healthcare system that thrived on mutual trust, dialogue and reciprocity (National Reform Strategy, 2015). This pillar of the reform strategy is in accordance with Ukraine becoming a member of the Open Government Partnership in 2011, which seeks to strengthen civil society participation and encourage decentralisation (Acted Report, 2017).

These reforms set out by the Ukrainian government are replicated on evidence-based solutions (Preker *et al.,* 2002; Bartlett *et al.,* 2012). However, researchers have warned that these reforms will confront many obstacles, including increased waiting times for specialist care (Antoun, Phillips & Johnson, 2011; Sandor *et al.,* 2016), limitations in allocation of sufficient funding for different health needs (Dubowitz *et al.,* 2011), and the difficulty changing prevailing habits amongst patients and reluctance to relinquish power and status by healthcare specialists (Oleszczyk *et al.,* 2012; Schafer *et al.,* 2016).
For the implementation of these reforms, economic prosperity and stability are fundamental. Yet, Ukraine's ever-evolving economic sphere has been subject to its ongoing conflict with Russia since 2014 (Stepurko *et al.,* 2013; Astrov *et al.,* 2022). For example, the regions annexed or affected by Russian aggression in 2014 account for 16% of Ukraine's GDP and have been shown to have negatively impacted funding to Ukraine's healthcare sector (ACTED Report, 2017).

Although the prospect of reform promised by acting Minister of Health Ulana Suprun and increased international pressure to implement reforms fully (Twigg, 2017), there is scepticism about its success (Romaniuk & Semigina, 2018). Additionally, evidence shows that politicians who oppose these health reforms are sympathetic to and supported by Russia,

increasing anti-reform rhetoric on mainstream and social media (Shandra, 2017). This overview of strategies to reform healthcare in Ukraine highlights the complex nature of reform in a politically contentious government. This is exemplified by all the efforts to undermine previous and current efforts to reform Ukraine's healthcare system. This historical precedence for failed reformations is an important signifier of the struggle HIV/HCV CSOs are enduring to build and sustain political relationships and fight for access to medicines.

The next section will explore the socio-political attitudes towards people who inject drugs, men who have sex with men, and female sex workers, populations that are most vulnerable to HIV infection in Ukraine.

2.1.3. Sex, Drugs and HIV in a Conservative Political Landscape

In this section, I review literature that explores how Ukraine grapples with its past by highlighting its link to the ramifications on key populations who are disproportionately affected by its ongoing HIV epidemic. Additionally, the role of social and political attitudes toward key populations is explored, along with how the key population's economic reality interacts with the lived experiences of HIV, influencing the overall efficacy of the HIV response.

2.1.3.1. People Who Inject Drugs and HIV in Ukraine

The HIV epidemic in Ukraine is still concentrated in the most-at-risk groups, with a prevalence of 20% among people who inject drugs (Dumchev *et al.,* 2018), 5.6% among men who have sex with men (IBBS, 2019) and 7% among female sex workers (Toker *et al.,* 2019), and those who have sexual contact with these key populations. However, there is a variation in prevalence rates across the literature due to the different data collection methods used and the stigmatisation of the groups in Ukraine (Morozova *et al.,* 2019; Trickey *et al.,* 2022). However, in this research, the prevalence rates outlined above provide a general indication of HIV prevalence in key populations. People who inject drugs (PWID) are the primary risk group for HIV infection. From 2005-2012, 44.9% of newly reported cases were attributable to injecting drug use (Vitek *et al.,* 2014), although the total number of new HIV infections declined to 22.6% of all new infections in 2018 (UNAIDS, 2018). This decline in proportion

reflects the fact that an increasing number of HIV infections are acquired through sexual contact.

Research on transmission rates shows that sexual transmission now accounts for approximately 73% of new transmissions in Ukraine (UNAIDS, 2018). HIV affecting the most marginalised in society is attributable to a general lack of access to opioid substitution therapy (OST) and HIV treatment among key populations in much of the country (Zaller *et al.* 2015), the ongoing conflict with Russia (Vasylyeva *et al.,* 2018), fragmented HIV care (Neduzhko *et al.,* 2017), and frequent human rights violations and high levels of HIV and drug user stigma (OSF Report, 2007; Demchenko, Sokolova & Buliga, 2020; Owczarzak *et al.,* 2023). International guidelines recommend the use of opioid substitution therapy (OST) as a key harm reduction tool for people who inject drugs, as research shows it successfully reduces opioid use, reduces sharing injection equipment by half and increases quality of life (Lawrinson *et al.,* 2008; Feelemyer *et al.,* 2014).

Additionally, OST has been shown to decrease unsafe sexual practices, reduce the likelihood of HIV transmission within highly prevalent communities and increase adherence to antiretroviral therapy (Lollis *et al.,* 2000; Gossop, Marsden & Steward, 2003; Lawrinson *et al*., 2008). Modelling studies that examine OST use in Ukraine show that increasing harm reduction services is the most cost-effective approach to controlling HIV (Alistar, Owens, & Brandeau, 2011; Bachiredy *et al.,* 2013; Zaller *et al.,* 2015).

In 2004, Ukraine introduced Buprenorphine as OST, followed by the use of methadone in 2008 (Golovanevskaya, Vlasenko & Saucier, 2012). However, the coverage of opioid substitution therapy remains low. In 2017, OST coverage was at 12% (UNAIDS, 2018). However, since 2018, the Ukrainian government committed to fully financing OST programmes, promising to fund access to over 11,385 people, making it the largest programme of its kind in the EECA region (UNAIDS, 2018). This highlights the evolution in Ukrainian governance, as over the past decade, many attempts to expand OST have been made but disrupted due to negative attitudes of some Ukrainian government officials and police enforcement towards PWIDs and services that provide harm reduction (Wu & Clark, 2013). Other identified barriers to OST are decision-makers believing that OST is an ineffective and dangerous intervention (Golovanevskaya, Vlasenko & Saucier, 2012),

Ukraine's harsh criminalisation of drug use (EMCDDA, 2016), and drug user registries (Boiko, Dvoriak & Altice, 2015).

In 2010, the Ministry of Health Ukraine passed a law which reduced the threshold of drug possession from 0.1g to 0.005g (EMCDDA, 2016). The criminalisation of drugs has been shown to fuel the HIV epidemic by hampering HIV prevention, reducing OST usage and preventing drug users from seeking help (BMJ, 2010; DeBeck *et al.*, 2017). Another deterrent to enrolling on an OST programme in Ukraine is its drug user registry policy. To receive OST, the person who injects drugs must sign on to a name-based registry which can negatively affect the person's chances of employment, receiving government documents, such as a driving licence and can increase police harassment (Boiko, Dvoriak & Altice, 2013; Altice *et al.,* 2016). Research has shown that law enforcement officers commonly harass harm reduction services, make copies of service users' personal information and arrest people who are coming in and out of treatment centres (Golovanevskaya, Vlasenko & Saucier, 2012).

UNAIDS (2023) highlights that as of December 2022, over 27,211 people were using OST. A study by Judice, Zadlada & Mbuya-Brown (2011) highlighted a contradiction between restrictive policies that are enforced by the government, which are counterproductive to evidence-based responses to reduce opioid addiction and HIV transmission. This contradiction presents a compelling argument for scepticism in the OST and HIV response. However, the large increase in OST users from 2018-2023, even during times of war, highlights the progressive strides the Ukrainian government is making to respond to opioid use and HIV transmission.

2.1.3.2. MSM and HIV in Ukraine

Within the men who have sex with men (MSM) community, HIV modelling studies show that transmission rates are on the rise (Barnett *et al*., 2000; Spindler *et al.,* rr2014; IBBS, 2020). Surveillance of HIV/AIDS diagnosis in Ukraine uses a case-reporting system (Spindler *et al.,* 2014) and is known for its under-reporting of HIV transmission rates among MSM (UNAIDS, 2014). From 2005 to 2011, there were only 494 cases of HIV diagnosis among MSM in Ukraine reported, which roughly represents 0.4% of all reported cases (Ministry of Health Ukraine Report, 2012). To overcome the barrier of self-reporting to

measure HIV prevalence amongst the MSM community, anonymous surveys and sentinel surveillance were used. In 2016, an estimated 176,000 MSM were living in Ukraine, with only 1,500 officially registered cases. However, sentinel studies show a prevalence rate as high as 6% (Postnov *et al.,* 2016). In contrast, self-reporting surveillance recorded only 36 MSM HIV cases in Odessa between 2005 and 2011 (Spindler *et al.,* 2014). For comparison, In 2022, MSM accounted for approximately 58% of first-time HIV diagnoses in Ireland (HPSC, 2023).

The stigmatisation of homosexuality in Eastern Europe has significantly affected the reliability of HIV epidemiological data for MSM and their access to prevention, antiretroviral therapy and support services (Bozicevic *et al.,* 2009; Takacs, 2013; UNAIDS, 2014; Demchenko, Sokolova & Buliga, 2020). In Ukraine, MSM are often subjected to stigma and discrimination from law enforcement, sexual health service providers and government officials (Barnett *et al.,* 2000; UNAIDS, 2012; Demchenko, Sokolova & Buliga, 2020). Governmental discrimination came to public attention when a bill was put forward to the Ukrainian government to prevent the promotion of same-sex relationships in an effort to follow the Russian-styled propaganda law (Stern, 2012).

The Ukrainian government and media have a history of portraying same-sex relations as amoral and as a threat to national security, citing that the spread of homosexuality will lead to the spread of HIV/AIDS (Martsenyuk, 2012; Stern, 2012). The Orthodox Church also harshly condemns homosexuality (Stan & Turcescu; Zorgdrager, 2013; Disser, 2014), which is significant as 78% of Ukrainians (approximately 35 million people) consider themselves Orthodox Christians (Pew Research Centre, 2017). This anti-homosexuality rhetoric stems from the Soviet period when homosexuality was illegal in the USSR and negatively affected the likelihood of MSM getting tested for HIV or self-reporting as MSM (Barnett *et al.,* 2000).

As a result, LGBT civil society organisations are the only organisations that are commissioning LGBT rights violations and health needs reports (Martsenyuk, 2012). A sentinel study looking into prevalence rates of HIV among MSM identified the lack of research into risk-factor knowledge within the MSM community as a potential inhibitor of progress in reducing HIV transmission (Spindler *et al.,* 2014). Additionally, current behavioural interventions are considered suboptimal, limiting the prevention and testing methods used to address the sexual health needs of MSM (Kasyanchuk *et al.,* 2017). The

WHO (2015) recommends the use of pre-exposure prophylaxis (PrEP) as a preventative tool for HIV acquisition. Despite its proven efficacy and the high prevalence rate of HIV within the MSM community, Ukraine does not subsidise PrEP (Dubov *et al.,* 2018). In a study looking into the attitudes and beliefs of MSM towards PrEP use in Ukraine, 77% of respondents would be willing to start affordable PrEP, with willingness dropping to 47% if prices remained high (Dubov *et al.,* 2018). PEPFAR is piloting a PrEP implementation. As of August 2020, there were 2,500 registered PrEP users in Ukraine (FrontlineAIDS, 2020).

In 2016, the Cabinet of Ministers of Ukraine passed a bill that identifies health and healthcare as a basic human right, regardless of sexual and gender orientation, yet discriminatory provisions against the LGBTQ+ community are retained within their Family Code of Ukraine (Nash Mir, 2019). In an opinion piece, Feder (2023) argues that recent legislation introduced in the Ukrainian Parliament, the Verkhovna Rada, to legalise same-sex partnerships and to prohibit anti-LBTQ hate speech is due to the LGBTQ community's military participation in the resistance to Russian occupation, and Ukraine's rejection of Russia's efforts to weaponise homophobia in support of its invasion.

Before Russia invaded Ukraine, the research highlights how the goal of health reform and reducing the prevalence of HIV are counterintuitive to the discriminatory social climate towards members of the most marginalised groups that are affected by HIV. Yet progress is being made in support of the LGBTQ community in Ukraine despite efforts from Russia, as highlighted by Feder (2023). This section illustrates a connection between societal and political attitudes towards MSM and the broader LGBTQ community, affecting the HIV response. Although this research does not explicitly look at the slowly changing societal and legislative attitudes toward MSM, it serves as an important indicator of the Ukrainian government's shift away from discriminatory practices of the past and toward more inclusive policies for the LGBTQ community.

2.1.3.3. FSW and HIV in Ukraine

Since the breakup of the Soviet Union, Ukraine experienced rapid growth in the drug and sex trade as it transitioned from communism to capitalism (Rhodes & Simic, 2005). This transitioning period brought an apparent increase in personal freedoms and mobility opportunities yet was marked by a decline in income and employment opportunities (Thorne *et al.,* 2010; Takacs, 2013). It is argued that the legacies of the social, economic and political dynamics of the 1990s continue to influence the high rates of sex work and affect the HIV risk environment for female sex workers in Ukraine (Corsi *et al.,* 2014). Importantly, in this research, when referring to Soviet legacies, the examples of FSW and PWID provide an interesting caveat. The economic downfall after the fall of the USSR directly affected the growth of these key populations rather than directly attributable to Ukraine's previous Soviet governance structures. However, as seen throughout this section, the social and political Soviet legacies also play a key role, especially in Ukraine's HIV response.

While HIV clinics in Ukraine do not officially register HIV cases among FSWs, surveillance studies have estimated that there were 80,100 female sex workers in Ukraine, with an HIV prevalence rate of 7% (Tokar *et al.*, 2019). Additionally, research shows a significant increase in seroprevalence amongst FSWs who are injecting drug users or have clients with a history of drug use (Taran *et al.,* 2011; Vitek *et al.,* 2014). A study investigating the determinants of HIV acquisition within the PWID community in Ukraine found that one third of every female PWID was a female sex worker (Iakunchykova & Burlaka, 2017). This offers valuable insights into the social and economic determinants influencing injecting drug use, sex work and HIV transmission in Ukraine.

Research highlights how the environmental risk for HIV acquisition among FSWs is compounded by structural factors stemming from Ukraine's political, economic, and social climate (Corsi *et al.,* 2014). Data indicates that women who are sex workers to fuel their injecting drug use exhibit less condom use and more sharing of needles than their male counterparts (Des Jarlais *et al*., 2013). Low income is significantly correlated with an increase in risk of contracting HIV as it dictates four other acquisition determinants such as location of solicitation, less condom use due to lower demand (Des Jarlais *et al*., 2012), and increased risk of violent customers, even from law enforcement authorities (Buszra *et al.,* 2011; Demchenko *et al.,* 2012; Reeves *et al*., 2017). Low income, high levels of stigma and

violence towards PWID and FSW highlight the increased vulnerability of sex workers in Ukraine, as complex social intersections increase their dependencies on clients and risky injecting and sexual behaviours (Kyrychenko & Polonets, 2005).

Research underscores that the high HIV prevalence among PWID, MSM & FSW in Ukraine cannot be mitigated by increasing access to condoms, medical services and informational support due to the interplay of geographical, social, economic and political factors (Kyrychenko & Polonets, 2005; Govindasamy, Ford & Kranzer, 2012; Neduzhko *et al.,* 2020). Ukraine has created a hostile environment for most at-risk populations that profoundly affects rates of HIV transmission, linkage to care and access to medicines (Strathdee *et al.,* 2010; Demchenko, Sokolova & Buliga, 2020).

This section focuses on socio-political factors that affect the quality of life of PLWH, rather than structural barriers to access treatment that is the primary focus of this research. However, understanding the totality of how political and social conservatism influences HIV transmission is important for this research as it identifies the prioritisation, political regard, and societal appetite for an effective HIV response. It also importantly provides a baseline picture of Ukrainian social norms and how these have evolved within the timeframe of this research, between 2010-2021. In the next section, the effects of conflict on the HIV response will be explored.

2.1.4. Protest, Conflict and HIV

In November 2013, Ukraine's pro-Russia president Viktor Yanukovych sought to increase economic ties with Russia by including Ukraine in the Russia-Eurasian Customs Union (Chavinska, Minescu & McGarty, 2017). This trading policy was in direct contrast to the electorate's majority support for further alignment with the European Union and to distance Ukraine from political ties with Russia (Pifer & Thoburn, 2013; Zelinska, 2017). This ProEurope versus Pro-Russia ideological war has been ongoing since Ukraine got its independence in 1991 (Pritzel, 1998) and created domestic political disputes as well as contrasting nationalistic narratives (Riabchuk, 2012; Musliu & Burlyuk, 2019).
This divergence between political policies and the wishes of the electorate initiated the Euromaidan protests in November 2013 (Pifer & Thoburn, 2013). This uprising differed from other protests in Ukraine, such as The Orange Revolution in 2004, which was started due to corruption in a presidential election (Reznik, 2016). The actions of Yanukovych denied the

Ukrainian people their dream of being more integrated with the EU (Matsivevsky, 2018). The Ukrainian government's reaction to the peaceful Euromaidan demonstrations did not involve compromise but instead enforced a ban on protests and increased the presence of armed law enforcement (Pifer & Thoburn, 2013; Wilson, 2014).

This resulted in a peaceful protest turning violent, with many protesters dying (Wilson, 2014; Kuzio, 2015). Yanukovych's pro-Russian policies and aggression towards the protestors led to the fall of his government (Chayinska, Minescu & McGarty, 2017). One week following the collapse of the government, President of Russia Vladimir Putin invaded and annexed the Ukrainian region of Crimea (Wilson, 2014). This annexation has been rejected by the United Nations and initiated a geopolitical dispute around Russian aggression (Soldak, 2014; Grant, 2017).

Furthermore, the Euromaidan protests and annexation of Crimea increased tensions between Ukrainians and pro-Russian separatists (Chavinska, Minescu & McGarty, 2017). In the Spring of 2014, the region of Donbas in Eastern Ukraine was overrun by pro-Russian separatists who seized government buildings, held unrecognised referenda and declared the independence of Donbas from Ukraine, resulting in a military retaliation (Gessen, 2014). Even though nationalistic tensions were high, the newly elected President, Petro Poroshenko, signed the EU Association Agreement stating *'it is a tribute to people who gave their lives and health to make this moment happen, and it is the strongest reminder that today's Europe is and must be able people's determination to live in a better and safer world'* (Smith-Spark, Brumfield & Krever, 2014)[2].

While these words may imply progression within the political sphere, Ukrainian political scholars are sceptical of the effectiveness of the Euromaidan protests in changing the political regime, arguing that leadership may have changed, but socioeconomic and corruption-related issues remained the same (Hale & Orrtung, 2016; Matsiyevsky, 2018). Additionally, while signing this EU agreement gave Ukraine increased access to the European Union market, it

[2] Information regarding Poroshenko's signing of the EU Association Agreement can be found here: https://edition.cnn.com/2014/06/27/world/europe/ukraine-crisis/index.html (accessed 01/05/2020)

also required Ukraine to enforce stricter intellectual property legislation, restricting access to medicines. This is further discussed in sections 2.3.3. and 6.2.1.2.

This section has demonstrated how the governmental, social, organisational, identity politics and economic factors interact to inform policies that affect HIV service delivery to Ukrainian citizens. The Euromaidan protests and the subsequent conflict that followed have left Ukraine at a crucial point in its response to HIV (see section 2.1.5. and 2.2.3.). For Ukraine to achieve the targets set out by Sustainable Development Goal 3, good health and well-being, research shows that several actions must be taken.

These actions include implementing radical political and healthcare reform, securing economic stability, increasing cross-boundary cooperation and conflict control, commissioning and implementing a detailed monetary transition plan and continuing to have a strong civil society presence. As the research above shows, the conservative landscape that stems from USSR ideology towards PWID, MSM, and FSW has still largely remained unchanged and negatively impacted the provision of evidence-based interventions to key populations. Additionally, to provide an accurate analysis of the experiences of HIV treatment activists, it is imperative that the socio-political attitudes towards the populations most vulnerable to HIV are explored. The next section will examine the relationship between civil society organisations, government agencies and foreign aid donors.

2.1.5. War and HIV in Ukraine

The occupation of Ukrainian territories by Russia in 2014 has led to political and socioeconomic uncertainty, adversely affecting the country's HIV response (Vasylyeva *et al*., 2018). The crisis resulted in the internal displacement of 1.8 million people (Sasse & Lackner, 2018). The Donbas region, which includes the oblasts of Donetsk and Luhansk, has historically reported the highest rates of HIV infections in Ukraine, accounting for around one-quarter of all PLWH on ARVs (Holt, 2015). The conflict has led to repeated disruptions to harm reduction and healthcare services (Pizzi, 2015), and mass internal displacement has been shown to have an impact on Ukraine's HIV epidemic (Duchenko, Deshko & Braga, 2017).

Russia's strict laws against the use of narcotics and psychotropic substances extend to prohibit the use of OST for medical use (Kazatchkine, 2014). In 2016, OST provision centres in Donetsk and Luhansk were closed due to limited stock of medicines (Alliance for Public Health, 2016). Similar disruptions to harm reduction services in Crimea occurred due to Russian troops setting up roadblocks at border lines, confiscating OST and disrupting the supply chain of OST and ARV medicines (Holt, 2014; Hurley, 2015). The Alliance for Public Health (2016) estimated that 900 people have lost access to OST due to disrupted supply chains. Potential negative consequences of these forced legal barriers to substitution therapy include returning to drug use, becoming imprisoned, and death due to drug overdoses and HIV/HCV-related complications (Kenarov, 2014; Mackey & Strathdee, 2015).

It is estimated that HIV diagnoses have risen sharply in Donbas, with rates rising to 30% from 26.5% in Donetsk and 7.3% from 3.2% in Luhansk since Russia's aggression in 2014 (Alliance for Public Health, 2016). An epidemiological survey showed that the conflict has shown a redistribution of HIV across porous boundaries rather than an increase *per se* in HIV rates across Ukraine (Vasylyeya *et al.,* 2018). However, this study contends that the current situation, without increased cross-boundary cooperation, increased funding, testing and OST service provision, without continued work of civil societies, or the reduction of risky behaviours of the army and political motivation, the epidemic could '*become a disaster*' (Vasylyeya *et al.,* 2018, Holt, 2018).

Ukraine has also experienced economic challenges since the Euromaidan Revolution, which has resulted in great fiscal challenges for the government and a reprioritisation of public fund allocation (Dñabrowki, Domínguez & Zachman, 2020). In 2015, the Ukrainian GDP decreased by approximately 7.5% (World Bank, 2015). Between 2014-2016, the Ukrainian economy continued to decrease on average 8-10% with a devaluation of 20% of the Hryvnia against the US$ (Global Fund, 2018). This decrease in GDP became a barrier for citizens to afford prevention and screening, increased levels of sex work and drug use, and affected the tendering procedures for the procurement of ART (Duchenko, Deshko & Braga, 2017).

Despite the economic downturn in Ukraine, then President Poroshenko signed an updated National HIV/AIDS Strategic Plan 2014-2018 that outlined a roadmap for the reduction of international funding from the Global Fund and INGOs over the coming years and increase domestic funding to their HIV/AIDS response (Duchenko, Deshko & Braga, 2017).

The government's commitment to the HIV response was evident, as domestic spending on the procurement of ARVs increased by 171% between 2014-2017 and increased the health budget of TB by 133% (Garmaise, 2018). Although promising, civil society organisations voiced concerns about the sustainability of prevention and social support programmes for key populations (Voskresenskaya, 2018). CSOs were concerned that a reduction in financial support from international donors like the GF would not be adequately counterbalanced by a rise in domestic funding, given the absence of a detailed and transparent transition plan (Duchenko, Deshko & Braga, 2017; Garmaise, 2018). The transition from international to national financing of HIV/HCV CSO services is examined as a component of this research.

After Euromaidan, HIV/HCV CSOs faced two parallel devastating complications for their HIV response: 1) the Russian annexation of Crimea, the ensuing civil war and mass internal displacement, and 2) Ukraine signing the EU Association Agreement, which strengthens intellectual property rights and negatively impacts A2M (see sections 2.3.2 and 2.3.3)**.** Therefore, research into wider socio-political determinants of access to healthcare inextricably links conflict and internal migration with government stability and macro-micro dialogue needed to enforce progressive reforms.

2.2. HIV Activism and Civil Society Organisations in Ukraine

This section lays the foundation for the examination of HIV/HCV CSOs by defining civil society and critically examining the emergence and development of CSOs in Ukraine. Additionally, research tracing the transformative role of HIV CSOs in Ukraine from their inception in the early 1990s until now is explored. A critical appraisal of the historical context and evolution of civil society organisations in Ukraine is outlined to provide insights into Ukraine's evolved socio-political relationships. Additionally, research outlining the evolutionary role of HIV CSOs from the early 1990s until now is explored. Literature focusing on the advantages and drawbacks of foreign aid is debated, providing insights into various schools of thought on how external financial support can influence policy development and guide local activism.

2.2.1. Defining Civil Society, Community and Rationale for Using the Term Civil Society Organisations

Civil society, alongside the government and private sector, is often characterised as one of three spheres of action (Edwards, 2011). It has been defined as a '*sphere of uncoerced human association*' within which individuals implement collective action around shared interests, purposes and values, which are often distinct from the needs of government and for-profit actors (WHO, 2007: Edwards, 2011, p.4). The concept of civil society has remained largely nebulous as there is no consensus on what constitutes 'civil society' (Palyvoda, Vinnikov & Kupriy, 2016). Different definitions seek to outline certain attributes, such as government, politics, social capital, cultural context, etc. (Ehrenberg, 1999; Hyden, Court & Mease, 2004; Edwards, 2009). In a United Nations Development Programme (UNDP) report (2017) entitled 'Defining civil society for Ukraine, the following definition captures the different dimensions of civil society most effectively (p.1):

> *'A civil society is a domain/area of social/civil relations beyond the household/ family, state and business, where people get together to satisfy and/or promote joint interests and to defend common values.'*

Civil society organisations (CSOs) are thus considered manifestations of civil society (Kohler-Koch & Quittkat, 2009). CSOs can vary in size and range and comprise many different public entities, including non-profit organisations, community groups, voluntary organisations, think tanks, research institutions, charities, faith-based organisations, and associated individuals (DFID, 2006). CSOs originally follow a bottom-up approach, as the initial motivation for implementing change stems from those who are disenfranchised by the state (Bayart, 1986). The United Nations (UN) comprehensively defines civil society organisations as:

> *'any non-profit, voluntary citizens' group which is organized on a local, national or international level. Task-oriented and driven by people with a common interest, civil society organisations (CSOs) perform a variety of services and humanitarian functions, bring citizens' concerns to Governments, monitor policies, and encourage political*

participation at the community level. CSOs provide analysis and expertise, serve as early warning mechanisms and help monitor and implement international agreements, including Agenda 2030 and the Sustainable Development Goals'. (accessed 20/10/2020)

As this research focuses on access to HIV/HCV treatment activism, it is directly related to two SDGs targets (UN, 2015):

SDG 3.3: End the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases.

SDG 3.8: Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.

The international HIV/AIDS response acknowledges the importance of CSOs in achieving these targets as they identify ways to reach marginalised communities, to implement innovative healthcare and outreach approaches, as well as to generate fiscal and legislative models, so as to enhance human rights, access to medicines and service provision for all people living with HIV (Malinowska-Sempruch, Bonnell & Hoover, 2006; Ooms & Kruja, 2019). Furthermore, Lee (2010) argues that CSOs shape policy agendas in favour of marginalised groups who have been neglected by the state/and or market. Therefore, when corporate conduct negatively affects population health, CSOs often advocate for appropriate regulatory reform. Therefore, due to the multifaceted functions and influential potential of HIV CSOs in targeting both state and market forces, I argue that people working in national HIV/HCV CSOs and regional HIV networks, and those that fund CSO activities, should be the focus of my recruitment strategy.

Civil society scholars argue that organisational analysis of CSOs needs to carefully examine their heterogeneous nature, as the range of internal structures varies greatly depending on the country's socio-political factors (Fatton, 1995; Kraszynska & Martin, 2016). Salamon and Anheier (1996), who are leading researchers in civil society scholarship, identified five key measurable characteristics that non-profit organisations share. These shared characteristics include (1) having an internal structure, (2) not being part of any government or public authority, (3) being self-governing, (4) being non-profit, voluntary participation, and (5)

seeking to serve the needs of the organisation or people it advocates on behalf (Salamon & Anheier, 1996; Palyvoda, UNDP, 2016). When discussing voluntary participation in civil society, the literature classifies voluntary membership to a CSO as a consensual act that is not legally required (Uphoff, 1993). This means that if members want to exit a CSO, they can do so without loss of status, public rights or benefits. The concept of voluntary participation rejects enforced compliance by government officials and incentives from the for-profit sector (Rosenblum & Post, 2002). A limitation of Salamon and Anheier's assessment of civil society is that it works within the confines of data gathered from registered CSOs and does not account for informal civic action (Krasynska & Martin, 2016). Informal CSOs are defined as organisations that are not registered with the government.

Therefore, their activities may not be formally recorded or published, they may not attend conferences or have an online presence, leading to an inaccurate depiction of civil society activity in Ukraine (Pollard & Court; Krasynska & Martin, 2016). Informal civil society consists of short-lived or spontaneous movements which address pressing issues of Ukrainian citizens on an ad hoc basis (Palyvoda, Vinnikov & Kupriy, 2016). In her paper, Nataliia Stepaniuk (2022) explores the role of informal civil society at the intersection of Ukraine's constrained state capabilities since gaining independence, the states limited response to the war in Donbas and its resulting military action and mass internal displacement.

Hellman (1998), Hellman, Jones & Kaufmann (2003) and Stepaniuk (2022) argue that Ukraine's state capabilities reduced with the rise of the oligarchy and how private firms captured public goods and services through exerted influence and/or collusion in the 1990s, directly affecting the socio-political realities and capabilities of an independent Ukraine. Stepaniuk's study (2022) found that as a result of reduced state capabilities, informal civil society during the Donbas war was characterised by a rapid mobilisation of volunteers who were not previously active in public life. Paramount to this informal mobilisation was its collaboration with private, professional and entrepreneurial networks. Krasynska & Martin (2017) and Stepaniuk (2022) argue that an examination of informal civic mobilisation is required to better understand survival during times when the state can't fulfil its core functions.

Linked with the idea of civil society taking on functions of the state, Zarembo & Martin (2023) highlight a passage in an article from The Economist (April 16, 2022) which states, 'Being Ukrainian is […] about the ability to come together when you feel that you need to and

to get things done'. The authors highlight this quote to complement their research findings that show significant events such as Euromaidan and the Russian invasion significantly boosted civil society like behaviours, including community mobilisation. The study uses the foundational work of Sarason (1974), McMillan & Chavis (1986) and Nowell & Byod (2010; 2014) to conceptualise sense of community (SOC) and sense of community responsibility (SOCR) as motivational factors behind formal and informal civic action.

SOC, as described by Sarason (1974), is the recognition that one is part of a supportive relationship network. McMillan and Chavis (1986) expanded this concept into a four-factor model: belonging, influence, need fulfilment, and shared emotional connection. This model suggests that to experience SOC, individuals must feel a sense of belonging, have the ability to influence the community, have their support needs met, and share values and emotional attachments with the community.

Nowell & Boyd (2010) added SOCR to this concept, linking it to behaviours like political participation and community engagement. SOCR posits that individuals come into community settings with their beliefs, norms, and values, as well as personal needs. When these align with the community, individuals develop feelings of belonging and responsibility towards that community, leading to engagement and collective action.

Zarembo & Martin (2023) argue that SOC and SOCR are essential for understanding informal spontaneous civic actions in Ukraine, often overlooked by formal measures of civil society. These concepts bridge the gap between formal and informal action, individual and collective, and attitude and action by emphasising the importance of pre-existing norms, values, and beliefs coupled with community-related variables like belonging and influence.

The findings suggest that SOC and SOCR are critical to understanding and facilitating community informal mobilisation, as they encapsulate the intrinsic motivations and interpersonal connections that drive such movements. This is also emphasised in Stepaniuk's (2022) paper that highlights 'in environments with high degrees of informality, everything functions through personal connections, making informal networks key to "getting things done" in public and personal life'. However, while the focus of SOC and SOCR is primarily on informal civic action, is it possible to demarcate formal and informal civic action through this lens? While financial incentives may skew motivations in more formalised civic actions, individuals working in CSOs may be similarly influenced by these interpersonal and

community driven factors. Therefore, this SOC and SOCR framework is a useful lens in which to interpret civic engagement inside and outside of formal participation contexts.

As highlighted in sections 1.3., 4.3.,4.11. and 8.3.2., my research had some limitations. Due to language barriers and interruptions caused by COVID-19, which affected my fieldwork in Ukraine, my engagement with informal civil society, particularly those who may have been involved in the HIV/HCV treatment movement, was severely restricted. Consequently, this research focuses primarily on formalised CSOs. The aim of this section is to provide the reader with a rationale for why I chose to focus on and recruit from HIV/HCV CSOs. The next sections will explore the this history of civil society and the evolution of HIV activism in Ukraine, and the integral role of international donor organisations in enabling civic action.

2.2.2. The History of Civil Society in Ukraine

During the Soviet era, the state strictly regulated the participation of their citizens in social and political processes, as well as limiting the provision of social services. (Weigle & Butterfield, 1992). Bociurkiw (1974) argues that these repressive measures eventually spurred dissident movements that defended human rights, public and political freedoms, independence and national liberation in the 1960s. The period of Perestroika, a political reform movement, in the late 1980s saw the rise of NGOs and movements that prepared the manpower necessary for a majority of political parties, public institutions and businesses and is considered a major factor for the fall of the USSR (Kuzio, 2000). Post-Soviet democratisation in Ukraine led to the creation of new socio-political and economic structures, yet theorists argue that it also resulted in the fragmentation of national identity. This generated feelings of insecurity, which led the way towards the collapse of old Soviet civil organisations, such as trade unions (Edwards, 2009). Therefore, this underscores that Ukraine’s independence was characterised by a lack of civil society organisations to help with the transition process. This emphasises the extent of Ukraine’s civil society organisations' development since its independence in 1991.

The consensus among development scholars is that a strong base of active citizens is needed for a successful democracy. Indeed, scholars acknowledge that active citizenship generates strong advocates for political, social and economic reform, as they exist between state, market and family but formalise under a common goal. (Hyden, 1997; Balsis *et al.,* 2001;

Encarnacion, 2002; Petrova, 2007; Cubitt, 2013). Civil society scholars such as Ronald Inglehart (1990) posit that the transition from communism brings about significant industrialisation and economic progress, fundamentally shifting people's perceptions of power structures and bolstering their resolve to challenge authority, a term he describes as social mobilisation. Contrary to Ingelhart's claims, Korybko (2021) challenges the notion that post-communist regimes inherently result in industrial and economic growth. Before the collapse of the USSR, Ukraine was one of the most industrially developed and prosperous countries in the bloc. However, swiftly after the fall of the USSR, oligarchs quickly captured control of the state, leading to the deterioration of living standards for its citizens (2.2.2) and the crumbling of the country's industry sector (Korybko, 2021). This distinction between Inglehart's and Korybko's accounts of post-USSR economic development underlines a western bias that tends to oversimplify the lived experiences of Ukrainians, framing soviet influence in a uniformly negative light.

Civil society in post-Soviet states was seen as a cornerstone for sustained democracies as they mobilised, questioned and challenged political policies, upheld constitutional order and set out political agendas by engaging with democratic elections (Toros, 2007; Cleary, 2016). However, O'Connell (1999) cautions against conflating the concepts of democratisation and civil society. While he notes that their development is a parallel process, O'Connell also emphasises that a vibrant civil society is the best indicator of, and a precondition for, a healthy democracy. USAID, an influential and major donor to post-Soviet countries, deemed the growth of vibrant CSOs essential to sustain Ukrainian democracy (Chandhoke, 2001; Petrova, 2007). The United States is known to have provided post-Soviet states with considerable resources, including for developing CSOs, to help facilitate the transition from a Soviet governed state toward market economies with liberal democracies (Tolstrup, 2013; Nitoiu, 2018).

Between the period of 1992-2000, the adoption of the law on civic associations became a catalyst for civil society formation which aimed to overthrow old Soviet-styled institutions and focused on human rights approaches to free speech and the right to assembly (Bilan & Bilan, 2011). However, the capacity to modify the policy direction of CSOs was limited due to economic issues, along with negative public attitudes towards CSOs, few volunteers, and inadequate domestic and international funding (Kuts, 2001). This era highlights the importance of resource mobilisation in ensuring the objectives of CSOs are able to be

followed through. Additionally, societal attitudes toward CSOs are crucial for their effectiveness as they directly affect voluntary contributions and support for campaigns.

Between 2000-2004, the unmet public expectations underscored the inadequate engagement between formal CSOs and state entities, leading to informal civic action, which resulted in the Orange Revolution (Solonenko, 2014). After the Orange Revolution (for more, see section 2.1.2.), the Freedom House, for the first time in its history, categorised Ukraine with a 'Free' status in relation to its political rights and civil liberties and was subsequently downgraded in 2011 (Kramer *et al.,* 2011). However, the expectations of increased democratisation, westernisation, socioeconomic advances and CSO participation failed to materialise after the Orange Revolution (D'Anieri, 2010; Shevel, 2015). Ghosh (2014) identified eight factors that compromised increased civic participation after the Orange Revolution. These included (1) the contentious nature of the term 'civil society' as it can be related to non-government organisations only; (2) the arduous and costly registration processes involved for new CSOs; (3) the omission of informal CSOs from statistical analysis; (4) the precarious state of Ukraine's middle-class, which acts as '*the backbone for civil society organisations*'; (5) state actor's influence and paternalism over CSO activity; (6) funding and staffing deficits; (7) dependencies of CSOs on the business and media sector, religious organisations and financial donors; (8) low level of acceptance and trust by Ukrainian society (Ghosh, 2014 p.3). To introduce a simpler, cheaper and quicker CSO registration process, amendments were made in the Civil Code and Economic Code (2013) that require two persons or legal entities to register a public association. The process is free of charge, and official registration can be granted within three days of registration (Duric, Simic & Hamelmann, 2016). Ghosh's analysis of CSO activity after the Orange Revolution highlighted the Ukrainian appetite for change and civic action but was impeded by both structural barriers and soviet legacies of distrust in civil organisations.

The landscape of Ukrainian civil society was further metamorphosed after The Euromaidan protests (also referred to as The Revolution of Dignity) of 2013-2014. The Revolution of Dignity mobilised civic activism under the tripartite principle of individual freedom, responsibility and dignity (Shapovalova & Burlyuk, 2018). Civic activism throughout Euromaidan was categorised as more informal, fluid, and more diverse than previous mass mobilisations in Ukraine (Krasynska & Martin, 2016; Shapovalova & Burlyuk, 2018). After the Euromaidan Revolution, a political vacuum ensued in conjunction with political

aggression from Putin and Russian separatists in Eastern Ukraine, leading to the annexation of Crimea and occupation of the oblasts, Donetsk and Luhansk (Shveda & Park, 2016). The reaction of CSOs to their humanitarian crisis, alongside their concurrent mobilisations around political and legislative reforms, increased the trust and legitimacy of their role within Ukrainian societal and political spheres (Gatskova & Gatskov, 2015; Shapavalova, 2017; Shapovalova & Burlyuk, 2018). However, Euromaidan scholars are wary of painting an optimistic picture of civil society reform, citing a lack of capacity to hold government to account (Cleary, 2016), lack of technical and operational expertise (Gatskova & Gatskov, 2016), and mobilisation under exported European, rather than Ukrainian values which distorts the discourse of cohesive Ukrainian values (Sviatnenko & Vinogradov, 2014; Krasynska & Martin, 2016).

While post-Soviet literature on the strength of CSO typically refers to post-communist civil society as weak, this study seeks to gain an understanding of how formalised HIV/HCV CSOs have successfully advocated for the reduction of key HIV/HCV medicines. There seems to be a contradiction, or certainly a contention, in the literature on the strength of civil society in an independent Ukraine. Firstly, the research shows the propensity of the Ukrainian people to rise up in protest due to their frustrations with government corruption, economic hardship and a willingness for change (Kuzio, 2005; Radnitz, 2010; Shapovalova & Burlyuk, 2018). Conversely, other scholars assert that post-Soviet civil society in Ukraine remains weak and ineffective (Howard, 2002; 2003; Way, 2014; Cleary, 2016; Gatskova & Gatskov, 2016). As highlighted by Krasynska & Martin (2017), Stepaniuk (2022), and Zarembo & Martin (2023) in section 2.2.1., informal civil society, that were not funded by the United States and which assume key state functions during times of national crises, are driven by forces that are personally, historically, and politically complex.

These contending dynamics extend far beyond the simplistic narrative of the Ukrainian people moving away from their soviet history. This underscores a prevalent western bias in scholarship that frequently reduces the actions and movements of civil society to a binary struggle against the remnants of soviet governance and toward a liberal market economy.

In focusing on the role of foreign aid in the formalisation of Ukrainian HIV/HCV CSOs, this research aims to contribute to the literature on the United States' and other funders' influence on Ukrainian democratic processes. However, it is important to recognise that by not focusing on informal civil society, this study may only be capturing part of the access to medicines

story. Understanding the full spectrum of civil society activity in Ukraine requires acknowledging the significant contributions of informalised movements, which operate independently of foreign funding and engage deeply with complex local realities.

Nevertheless, my emphasis on formalised civil society is driven by the study's focus on issues related to the affordability and availability of medicines, which are directly influenced by formalised HIV/HCV CSOs. Furthermore, practical constraints, including my inability to conduct my fieldwork in Ukraine significantly restricted access to informal civil society, thereby limiting my ability to incorporate their perspectives into this research

Therefore, this research adds to the literature on the effectiveness of CSO activity, influence and efficacy in Ukraine and the role of foreign aid in democratic processes.

2.2.3. HIV Activism in Ukraine

Following its independence, global expectations were high for the development of CSOs that would focus on HIV/AIDS-related issues (McGill, 2015). In 1991, the Ukrainian government (Verkhovna Rada) adopted the AIDS Law, which implemented policies on the prevention of AIDS and social protections for people living with HIV (PLWH) (Duric & Hamelmann, 2016). While limited, this law enabled the formation of HIV/AIDS CSOs, which focused prevention efforts and treatment services to the general public. Additionally, HIV CSOs aimed to shape health policy, combat HIV/AIDS stigma, and advocate for the protection of the human rights of PLWH through the capacity-building of grassroots and local communities (Duric & Hamelmann, 2016; Duchenko, 2017). The AIDS Law underwent amendments in 1998 and in 2001, obligated the government to enhance their response to the HIV epidemic. The AIDS Law ensured the government provided needle exchange programmes; free, voluntary and confidential HIV testing and counselling; the right to comprehensive HIV/AIDS education; the strengthening of stronger social protections for PLWHA; provision of free medical treatment and psychosocial support (OSF, 2007).

Furthermore, civil society organisations were led by people living with, or affected by, HIV/AIDS in Ukraine, which was a departure from Soviet-styled health responses, which usually involved a top-down approach. The HIV CSOs mirrored CSO structures that platformed leaders most affected by HIV, as seen around the world (Barnett & Whiteside,

1999; McGill, 2015). The AIDS Law initiated a fundamental transference of power from a hegemonic healthcare system towards a more integrated patient-centred service provision approach.

Qualitative research conducted by Tetyana Semigina (2015) delineates four key periods in the development of HIV/AIDS policy in Ukraine. Initially, in the early 1990s, when HIV stigma was high, when HIV testing was forced upon injecting drug users and when HIV-related services were restricted to health-based institutions, rather than CSOs (Semigina, 2015). Research shows that progress in national HIV responses is directly affected by high levels of social stigma towards marginalised groups and legislation that penalises activities such as sex work and injecting drug use (Vanable *et al*., 2006; Reeves *et al.,* 2017; Boily & Shannon, 2017). Stigma towards people living with HIV is an inhibitor for people to get tested due to fear of becoming stigmatised (Thapa *et al.,* 2018).

Stigma becomes a public health issue as people who don't know their status may inadvertently pass on the virus to others (Rodgers *et al.*, 2016; 2019). Additionally, research has shown that self-stigma can create difficulties with adherence to medication (Katz *et al.,* 2013), safer sex negotiation (Molina & Ramirez-Valles, 2013) and self-care (Vanable *et al*., 2006). While the AIDS law enacted during this period was congruent with international standards, the research identified the continued human rights violations of key populations, such as sex workers and IDUs (Bongiovanni, Sergeyev, & Semigina, 2013); structural stigma affecting the persistence of harmful policies towards the LGBTQ+ community, including stigmatising HIV prevention services (Pachankis *et al.,* 2015; Semigina, 2017).
This shows a clear distinction between policy and legislative contradictions, and how these contradictions subsequently have public health implications and affect the quality of life of PLWH.

The second period (mid 1990s-2004) was typified by government commitment to the prevention of HIV/AIDS and access to treatment for those living with HIV. However, these commitments were not reinforced with financial backing, coordination and collaboration (Judice, Zaglada & Mbuya-Brown, 2011; Semigina, 2015). This resulted in many national HIV/AIDS programmes not being effectively implemented, monitored or evaluated as they were often left to under-resourced civil society (Judice, Zaglada & Mbuya-Brown, 2011). At the end of the 1990s, local self-support groups began to coalesce into national HIV activist organisations with a specific focus on psychological support and access to HIV medical care

(Semigina, 2015). It is important to note that Semigina (2015) does not mention the costs of medicines as a potential barrier to access. Despite this, the government's inaction and limited financial contributions to the HIV response suggest the government's limited interaction with ARV procurement.

The third period (2005-2010) saw a proliferation of CSO activity due to funding received from over thirty international donors, including significant contributions from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GF) designated the International HIV/AIDS Alliance Ukraine as the regional Principal Recipient (McGill, 2017). The GF is an international financing and partnership health organisation that centres funding eligibility around the willingness of governments to engage with civil society organisations (Jürgens *et al.,* 2017).

The GF provided over 200 grants to 130 Ukrainian and international organisations to implement work that focused on localised prevention, care and support services and nationalised programmes on HIV treatment access, media campaigns and HIV/AIDS educational programmes (Semigina, 2009). As the regional Principal Recipient of the GF, the Ukrainian HIV CSO is responsible for implementing grants nationally and regionally, including to smaller organisations. Additionally, the CSO takes on the financial and programmatic responsibilities of the grant (Global Fund, 2020). Therefore, Ukrainian HIV CSOs became beneficiaries of huge financial resources and gained significant backing from powerful foreign aid donors.

This funding expanded CSO services nationwide, resulted in the introduction of Ukraine's first OST programme in 2008, and increased government spending on ARVs (Semigina, 2015). A UNAIDS report found that stigma and discrimination towards PLWHA in medical centres declined from 22% (2010) to 8% (2016), including stigma towards key populations as a result of major roles played by HIV CSOs (UNAIDS, 2018; Ooms & Kruja, 2019). International aid provided Ukrainian HIV/AIDS CSOs with the capacity to provide the vital services that the state failed to deliver and act as critical sensors of government policy.

As a result, foreign aid has somewhat shifted the locus of political power from the nation state to a form of 'multilevel governance' or 'global civil society' (Della Porta & Tarrow, 2005, p. 2). This transfer of institutional power from national to international institutions occurs particularly with economic institutions, such as the World Bank, International Monetary Fund

(IMF) and World Trade Organisation (WTO) (Della Porta & Tarrow, 2005), and health institutions that uphold international guidelines, such as UNAIDS, WHO and the GF (Ooms and Kruja, 2019). Further elaboration of power dynamics within transnational health bodies and financial institutions can be found in sections 2.2.5. and 5.2.2.2.

These transnational[3] Health Governing Bodies seek to integrate evidence-based international guidelines into local structures of care and prevention by encouraging the formation of global networks (Altman, 1999). The impact of Ukrainian HIV/AIDS CSOs was significantly amplified when they joined the UNAIDS Programme Coordinating Board, which oversees the agency's operations. The strategic alliance enabled CSOs to effectively communicate their objectives and collaborate closely with UNAIDS to establish and operationalise Ukraine's National AIDS Council (Putzel, 2004).

Additionally, a prerequisite of GF funding is that recipients must establish a Country Coordination Mechanism that provides HIV/AIDS CSOs the opportunity to regularly meet with national stakeholders, such as the Ministry of Health, local government bodies, the pharmaceutical sector, healthcare providers, epidemiologists, donors and other relevant key decision makers (Brugha *et al.,* 2004; Hanefeld, 2014). The convergence of foreign aid, health, and activism, extended the power of activists beyond the confines of localised politics. The power and position of the activist became situated within a spectrum; from local organisations to national government committees to global polity fora. However, the extent of this power that these new positions held among HIV activists is not documented within the literature.

The final period outlined by Semigina (2015) relates to anti-corruption advocacy and political action between 2010-2014. Political instability and conflict proved throughout this time period, remained the greatest barrier to healthcare reforms in 2010 that sought to strengthen primary and emergency care and change the model of healthcare financing (Lekhan *et al.,* 2015). This period is suggestive of the contentious relationship between HIV CSOs and then President Yanukovych's pro-Russian government. However, Semigina's (2015) delineation of HIV policy periods ends during the Euromaidan protests. Therefore, this research adds to the

[3] Transnationalism addresses the social, economic and political processes that occur beyond national borders (Villa-Torres et al., 2017).

body of literature by providing insights into the direction and impact of HIV CSOs post-Euromaidan.

After Euromaidan, as a result of strong global civil society action, Ukrainian CSOs were able to affect anti-corruption measures regarding state procurement of essential medicines and dispersed medical goods to occupied territories, not controlled by Ukraine, and advanced HIV/HCV/TB national plans (Duchenko, 2017). Furthermore, another key defining moment in Ukraine's access to medicines movement transpired: the commencement of technical discussions on access to medicines and intellectual property (IP) issues. HIV CSOs organised national meetings with international IP experts that sought to increase knowledge on the flexibilities of IP rights to improve access to treatment for people living with HIV in Ukraine (ITPC, 2015).

This was in retaliation to Ukraine signing an Association Agreement with the EU in 2014 and a Deep and Comprehensive Trade Agreement in 2016 which stipulated that Ukraine must agree to enforce stricter and more restrictive IP rights (DCFTA, 2016). In 2016, HIV CSOs pressured pharmaceutical company Merck to relinquish its patent on triple combination therapy, Atripla (MMA, 2016). Financial savings from the availability of generic Atripla were estimated to increase the procurement of annual treatment for an additional 2,800 patients (MMA, 2016). Further examination of intellectual property rights and patent opposition in Ukraine is detailed in section 2.3.2.

2.2.4. Access to Medicine Strategies in Lower and Middle Income Countries

In 1999, on Human Rights Day, the Treatment Action Campaign staged a 'die in' with a threefold mission; 1) to meet with CSOs to implement free access to AZT for pregnant women; 2) to make safe and efficacious HIV treatment free for PLWHA; and 3) to call on drug companies to lower the prices of lifesaving medicines (Mbali, 2013). The 'die in' was a strategy that symbolised a shared crisis between North and South, as it was a direct action that was famously used by ACT UP New York in the 1980s (Epstein, 1996). South African activists also emulated the ACT UPs model of treatment literacy (Heyward, 2009). In TAC's HIV in our Lives publication they define treatment literacy 'as understanding the major issues related to an illness or disease – such as the science, treatment, side-effects, and guidelines – so that the patient can be more responsible for their own care and will demand their rights when proper care is not available to them' (p.5). In 1999, activists from the Gay Men's Health

Crisis and ACT UP New York went to South Africa to train members of TAC to become treatment literacy activists (Heyward, 2009). Activists in the USA also focused on the trade pressures exerted by the US on LMIC attempting to enforce TRIPS flexibility measures (Smith & Siplon, 2006). South Africa's TAC and USA's ACT UP New York and the Health Global Access Coalition effectively used direct action and treatment literacy, to highlight the effects of health inequity, establish public sympathy, take on big corporations and gain the attention of American President Bill Clinton, and South African President, Thabo Mbeki (Smith & Siplon, 2006; Mbali, 2013; Baker, 2020).

The most notable success of countries enforcing TRIPS flexibilities into their national legislature occurred in India in 2004-05 (George, Sheshadri & Grover, 2009). A study examining the frequency of the use of TRIPS flexibilities between 2011 and 2016 identified 176 instances of government actions to ensure access to medicines (t' Hoen *et al.,* 2018). Out of these government actions, 100 concerned compulsory licensing, of which 81 were executed. Eleven compulsory licences were not executed as the threat of issuance resulted in the patent holder reducing the price or agreeing to provide a voluntary licence (t' Hoen *et al.,* 2018; Ooms & Hanefeld, 2019). For example, CSOs in Brazil and Thailand advocated for the issuance of compulsory licences for key ARVs. While their efforts didn't result in a compulsory licence being issued, the actions resulted in reduced prices for Nelfinavir and Efavirenz in Brazil and a withdrawal of the patent on Didanosine in Thailand (Galvão, 2005; Krikorian, 2017; Baker, 2020). This highlights the power compulsory licences provide treatment activists in price negotiations as they often result in price reductions or voluntary licence agreements (t' Hoen *et al.,* 2018).

The pursuit of patent oppositions has mobilised a network of stakeholders including legal advocates, such as Lawyers Collective and Initiative for Medicines, Access & Knowledge (IMAK) to challenge the novelty of new drugs, and CSOs that negotiate price reductions of ARVs, such as Indian Network for PLWHA and UNITAID (Halliburton, 2009). Using patent opposition as an activism tool, this network has successfully challenged four HIV drugs in India, reducing the prices by 51-87% and increasing low-cost generic ARVs to LMIC worldwide (Rathod, 2021). Other organisations, such as the International Treatment Preparedness Coalition (ITPC), have worked with HIV/HCV CSOs in Argentina, Thailand, Brazil and Ukraine on patent oppositions, helping to navigate drug price negotiations, and facilitating public-private policy discussions. These actions have drastically reduced the costs

of medicines, with an estimated $472 million each year in savings for health programmes (ITPC, 2020). However, one important issue to note with patent opposition is that pharmaceutical companies may stall the production and distribution of medicines until the status of patent opposition is determined, which may reduce the chance of gaining quick access to generic medicines (Abbott, 2018; Saez, 2018). While not exhaustive, the aim of this overview is to provide the reader with an insight into the successes, barriers and challenges that the global A2M movement faces, especially in MICs. The literature on MICs, as evidenced in this section, is based mainly on MICs such as South Africa, Brazil, India and Thailand. Therefore, this research aims to understand HIV/HCV treatment activism in Ukraine with the intention of adding to the overall body of knowledge of the access to medicines movement in different geographical regions.

2.2.5. Foreign Aid and Transnational Governing Bodies

Western financial aid (described as foreign aid throughout the thesis) aimed at assisting post-Soviet transformation has become a point of interest among Western scholars (Lubin & Ware, 1996; Wedel, 1998; Atlani-Duault, 2007; Pishchikova, 2011). Scholarship that analyses the effects that foreign aid has on recipient countries is predominantly categorised into two schools of thought; transitology and the 'sovereignty-undermined' thesis (Møller & Skaaning, 2012; Arévalo, 2023). Transitology is an academic examination of countries moving away from authoritarianism to democratic rule (Carothers, 2002). It argues for the systematic transformation of political, economic and social structures, suggesting that adopting neoliberal approaches to marketisation, privatisation, and globalisation will inevitably expedite these transitions (Desai, 1997; Lynn, 1999; Collier, 2011).

Transitologists classify foreign aid as a catalyst for political, economic and social reforms (Pronk, 2001). This school of thought is important for this current research, as it offers insights into the motivations and the agenda-setting practices designed by international donors. These agenda specifications also provide insight into the potential conflict that occurs between foreign aid donors, CSOs and national governments. Furthermore, it underscores the nuanced meanings of the word 'reform' as it is used throughout this dissertation. In future sections, I discuss Patent Law Reform. An Inglehart interpretation of patent reform might be the strengthening of intellectual property rights. However, an HIV/HCV treatment activist

might view reform as the introduction of measures to mitigate the adverse effects of intellectual property.

The second school of thought posits that foreign aid can contribute to the erosion of state sovereignty (Williams, 2000). Proponents of this view contend that determinants such as economic interdependence, advancements in technology, and integration of local CSOs with international CSOs are key processes involved in diminishing state sovereignty (Keohane & Nye, 1972; Gilpin & Gilpin, 1987; Peterson, 1992; Williams, 2000). Sovereignty-undermined scholars theorise that conditionalities that international economic institutions such as International Monetary Fund, World Trade Organisation, World Bank Group and health agencies such as WHO, UNAIDS, the Global Fund and PEPFAR place on foreign aid undermines or restricts the donor recipient's national sovereignty (King 2002; Hrycak, 2011; Pishchikova, 2011, Zhukova, 2013). Sovereignty-undermined scholars regard two components of foreign aid as tools of 'soft imperialism'.

The first tool is granting funding to projects that adopt guidelines which are based on Western values and experience (Hrycak, 2011)[4]. The second imperialistic tool is enlisting donor recipient CSOs to act as a watchdog for the implementation of international recommendations and guidelines (Atlani-Duault, 2008; Lee, 2010; Zhukova, 2013; Mikuš, 2015). Research examining the role of financial aid in the Ukrainian HIV/AIDS response has shown that the GF has played a highly influential role in changing health policies by providing CSOs with a seat at the table. This situation has left state officials dissatisfied with the violation of state sovereignty by using economic persuasion to compel movement in the 'right direction' (Semigina, 2009; Zhukova, 2013 p. 117). This is further articulated by Fioramonti & Heinrich (2007) who argue that foreign aid created a culture within civil society organisations that are '*more interested in pleasing foreign donors, than paying attention to what people need and what they say*' (p. 25).

[4] Research that examined the impact of financial aid on women's rights CSOs in Ukraine questioned USAID's ability to nurture local understanding of democracy and civic participation. This is because their democracy building programme bases its models of women's empowerment and self-help on American guidelines and practices. A case study of USAID's exported guidelines includes self-esteem building workshops as a solution to sex trafficking in Ukraine (Pishchikova, 2011).

The scope of the current research, however, does not probe into the pros and cons of these schools of thought but rather acknowledges that these features of foreign aid play a key role in the experience, strategies and opportunities of HIV/HCV treatment activists. For example, scholarship focusing on the increasing ties between global CSOs highlights the ethical considerations around global hegemonic responses to HIV/AIDS, as directed by foreign aid donors (Keck & Sikkink, 1998; Tilly & Tarrow, 2015; Smith, 2016).

It is now recognised that scholarship examining CSOs and foreign aid must go beyond investigating biomedicine, epidemiology and public health. Scholarship must seek to understand how these may influence matters of law, politics, trade, security and diplomacy (King, 2002; Brown, Craddock & Ingram, 2012). Controversies around the coercive nature of policy and trade demands accompanying financial aid have created a discourse on global health diplomacy (Kickbusch, Silberschmidt & Buss, 2007).

Global health diplomacy aims to understand how government, multilateral institutions, donors and CSO actors collaborate to position health in foreign policy negotiations and how they create new forms of global health governance (Kickbusch *et al.,* 2007; Labonté & Gagnon, 2010). Brown, Craddock & Ingram (2012) note that the rise of global health diplomacy is linked to the assertive role of Brazil, India, South Africa, Indonesia and Thailand on the issues of IP rights and access to medicines. The success of middle-income countries in overcoming international pressure to conform to WTO agreements suggests that critical examination of the role of HIV/AIDS CSOs should be investigated through a more heterogeneous lens.

This section has illustrated how the nature of Ukraine's HIV/AIDS civil society is determined by its distinct historical, geographical, social, economic and political structures. To provide an insight into Ukrainian ideas, values and modes of activism, this research is examining how activists balance service delivery and activism within a complex socio-political system. The next section explores the historical context of HIV treatment activism, the pharmaceutical industry and lobby in Ukraine, and current efforts of CSOs to change patent protection policies which aim to reduce the barrier of strong intellectual property rights.

2.3. Trade Agreements, Global Health Goals and an Evolving Social Movement

In an effort to understand Ukrainian HIV/HCV treatment activism within the global A2M movement, this section will examine the literature investigating the evolving global access to medicines movement, with a particular focus on activism in LMICs. It will outline the historical and current state of the movement, identifying challenges and barriers that CSOs face in their activism. Finally, external influences within the global health architecture affect the strategies and direction of treatment activism.

2.3.1. The Evolution of Global Access to Medicines Movement

Brook Baker (2020) outlines the three-phase evolution of the global access to medicine (A2M) movement. The three phases include; (1) global collaboration against a shared enemy, (2) the pursuit of TRIPS flexibilities, the Medicine Patent Pool, TRIPS Plus and internal conflict over advocacy strategies, (3) shifting focus of strategies and global partnerships, resulting in a more localised access to medicines movement in HIC.

The first phase occurred in 1996 after it was discovered that a triple combination of ARVs worked in controlling HIV. The initial phase of the A2M movement involved international cooperation between the Global North and Global South, unified in challenging their shared enemies: the TRIPS agreements, big pharmaceutical companies, and the exorbitant prices of ARVs (Baker, 2020). This North-South partnership evolved as ARVs were priced between $10,000 - $15,000 per person per year, making lifesaving treatment unattainable to the uninsured in HICs such as the USA, and people in the LMICs (t' Hoen, 2016; Moon & Balasubramaniam, 2018).

In 1998, international grassroots treatment activism gained momentum when South Africa aimed to leverage TRIPS flexibilities by amending its Medicines and Related Substances Act in 1997 (Heyward, 2009). However, this resulted in thirty-nine pharmaceutical companies suing the South African government, under Nelson Mandela's leadership, for trying to procure cheap, generic versions of first-line HIV drugs (t'Hoen, 2011). This gave rise to the grassroots group, Treatment Action Campaign (TAC) in South Africa championing the notion that equitable access to healthcare, and in particular HIV treatment, was a fundamental human right (Heyward, 2009). TAC contended that intellectual property rights were not

inherent human rights and that trade policies should serve the public interests, and not just protect profits (Heyward, 2009).

The costs for the generic version of these lifesaving medicines were reduced by 99% in 2000, from $10,000 to $300 per year (MSF, 2002). Although the generic price tag would have radically changed access to treatment and saved many lives, the lawsuit against South Africa was pursued relentlessly by the pharmaceutical industry (Sidley, 2001). This pressure was exacerbated by the US Trade Representative who regularly threatened trade sanctions against South Africa for, as they saw it, abusing the intellectual property rights of patent holders (Bond, 1999).

The global access to medicines (A2M) movement's position over this legal battle softened the hard stance of both the United states and the European Union on the strict enforcement of TRIPS, resulting in the signing of the 'Declaration on the TRIPS Agreement and Public Health' or Doha declaration (Drezner, 2009). The Doha Declaration aimed to clarify the legalities around the use of TRIPS flexibilities and affirmed that these flexibilities, including compulsory or government-use licensing, should be interpreted and implemented to assure access to medicines (Correa & Matthews, 2011; t' Hoen, 2018). The Doha Declaration was a defining moment for the A2M movement, as it was a result of a cohesive effort of activists from the Global North & South to advocate and negotiate global policy together to overcome the immense influence of US-EU corporate interests (Abbott, 2002).[5]

Baker (2020) posits that the second phase of the A2M movement occurred due to proponents of differing A2M strategies causing fractures in the global movement. The beginning of this phase saw activists campaigning around the world to ensure that their respective governments legislated for the incorporation of TRIPS flexibilities, with the most notable success occurring in India in 2004-05 (George, Sheshadri & Grover, 2009). The amended Indian Patent Act provided pro-public safeguards that increased patentability criteria for new medicines, allowed for patent opposition to occur and set guidelines for the issuance of compulsory and government-use licences (Mueller, 2007; Kapczynski, 2009). By 2008, 95% of ARVs that were procured by global donors were generic medicines produced in India (Waning,

[5] In addition to court cases brought against South Africa for attempting to implement TRIPS flexibilities, Thailand and Brazil also experienced immense pressures brought upon them by the USA for 'infringing' WTO rules (Ooms & Hanefeld, 2019)

Diedrichsen & Moon, 2010). This success story boosted the global A2M movement in LMIC and resulted in significant IP reforms in many countries (Baker, 2020).

Although the Indian Patent Act allowed for the wide use of TRIPS flexibilities, the Indian government added a clause that would make India TRIPS-compliant by 2005, reducing competition of newly patented drugs (Ram, 2006; Halliburton, 2009). Known as the 'pharmacy of the developing world', the aggressive patenting of new ARVs in India and other big generic manufacturing countries such as Brazil and Thailand, greatly affected the scaleup of second and third-line HIV treatment regimens (Dionisio & Messeri, 2008; Satyanarayana & Srivastava, 2010). To overcome this, LMIC civil society organisations sought another strategy for overly-patented drugs. One such strategy is pre-grant patent opposition.

This means that if a CSO or generic manufacturer considers a drug to not be sufficiently novel or unlawful, they have the opportunity to oppose patents before a patent application is granted l (Saez, 2018). As discussed later in this section, patent opposition is considered one of the more aggressive strategies used by HIV CSOs in Ukraine.

In addition to TRIPS flexibilities, the Medicines Patent Pool was established in 2010 to support the production and distribution of generic HIV/AIDS medicines (Burrone *et al.,* 2019). The Medicine Patent Pool is a public health organisation that relies on voluntary agreements from patent holders to licence medicines to generic manufacturers to ensure access to lifesaving treatment (Cox, 2012). This voluntary licensing brings cheaper medicines to the market quicker as generic manufacturers do not need to wait twenty years for the original patent to expire (t' Hoen *et al,* 2011). Between 2012 and 2018, the Medicine Patent Pool facilitated the distribution of generic medicines to 22 million people living with HIV throughout LMICs which included voluntary licences for thirteen HIV treatments (MPP, 2020).

However, HIV and A2M CSOs had to contend with another set of obstacles; Free Trade Agreements. Efforts were made by the US and EU to strengthen intellectual property rights via the introduction of TRIPS Plus provisions to Free Trade Agreements (El Said, 2021). TRIPS Plus provisions sought to reduce the enforcement of TRIPS flexibilities and broaden intellectual property rights by: 1) increasing the scope of patentability criteria; 2) inhibiting parallel imports; 3) Limiting the use of compulsory licensing; 4) Extending the patent life of

medicines; 5) extending data exclusivity and 6) allowing pharmaceutical companies to sue governments that pursued TRIPS flexibilities on the basis of damaging intellectual property investments via investor-state-dispute settlement courts (Islam *et al.,* 2019).[6]

As aforementioned, Baker (2020) claims that the second phase ends with fractions in the A2M movement. Tensions began to arise once voluntary licences began to be implemented. Opponents of the MPP contend that issuance of voluntary licences reduces the impact of key A2M strategies including patent reform, oppositions and compulsory licensing. Additionally, there was also fear that funding from international donor bodies would concentrate more on voluntary licences rather than other A2M strategies (Baker, 2018).

The most recent stage of A2M activism falls into two categories: expansion and contraction. Inequitable access to medicines is increasingly recognised as a universal challenge, no longer exclusively associated with LMICs, and no longer limited to certain disease groups (Sullivan *et al.,* 2011; Prasad, de Jesús & Mailankody, 2017). The high price of drugs affects all countries around the world and includes a growing number of diseases (Bermudez, 2017). Additionally, this stage includes additional A2M strategies that aim to overcome barriers to accessing medicines.

The first strategy includes delinking the costs and risks associated with the R&D of new drugs and the marketed price of these medicines by using alternative mechanisms to incentivise innovation other than intellectual property (Outterson *et al.,* 2016; UNHLP, 2016). The second strategy includes CSOs calling for greater transparency around the cost of research, development and production of medicines to enable governments to negotiate more effectively for affordable prices (Perehudoff & Sellin, 2019). Consequently, the A2M movement became more insular as HICs began to focus nationally on addressing high drug

[6] Jordan is used as a case study of negative consequences associated with the incorporation of TRIPS Plus provisions. In 2000, Jordan signed a free trade agreement with the USA that enforced a ban on parallel imports and increased data protection Oxfam has reported a 20% increase in costs of medicines in Jordan since 2000. Additionally, between 2002-2006, increased data protection has resulted in the delay of generic competition of 79% of newly launched medicines (Malpani, 2007).

prices (Baker, 2020). The further expansion of A2M strategies and less global cohesive actions created increased fractures within the global A2M movement.

This lack of global cohesion directly affects middle-income countries as their precarious financial situation reduces foreign donor contributions and can become a barrier to procuring cheaper drugs via the Medicine Patent Pool (Islam *et al.,* 2019). Although this section summarises Baker's anthology of the global A2M movement, he admits that his account isn't exhaustive. Similarly, this research does not aim to distract from Ukraine's A2M activism with an exhaustive overview. However, its aim is to contextualise the trade barriers, obstacles and opportunities that Ukrainian HIV treatment activists may face. The next section outlines the social, political, economic and health-related justifications for Ukrainian A2M strategies.

2.3.2. The Ukrainian HIV/HCV Treatment Movement

In 2000, antiretroviral therapy was first introduced to Ukraine but was only available in limited specialised HIV/AIDS clinics (Barnett & Whiteside, 2000). In 2005, the World Health Organisation estimated that 53,000 PLWH were in need of ARVs, but only an estimated 907 people were receiving treatment. The primary focus of donor bodies was to increase the procurement and uptake of ARVs (Barnett & Whiteside, 2000; Wafula, Agweyu & Macintyre, 2014). Access to healthcare and ARVs for people living with HIV in Ukraine was protected under the Ukrainian constitution and National HIV/AIDS Law. However, the reality for many people living with HIV was that they paid a large part of their HIV care and treatment themselves (HRW, 2006). The Open Society Foundation was one of the first philanthropic organisations to fund work related to access to medicines.

In 1990, a year before Ukraine independence from the USSR, the International Renaissance Foundation (IRF) was established in Kyiv (OSF, 2024). The IRF is Ukraine's base for the Open Society Foundation which has contributed over $230 million to various Ukrainian initiatives, with 100% Life being one of its main recipients. 100% Life, which was formally known as All Ukrainian Network of People Living with HIV/AIDS has been operational since 2001 to advocate on behalf of their own rights and access to care (100% Life, 2024). While this research focuses on access to medicines strategies after 2010, OSF highlights some access initiatives established by treatment activists before this timeline

In their 2007 report on HIV/AIDS policy in Ukraine, the OSF outlined key policy objectives of HIV civil society organisations. In 2007, Ukraine set an ambitious target to expand its ARV program from 17,000 individuals to 50,000 by 2010. This target was established by a consortium of governmental, non-governmental, and international organisations. Achieving this goal required addressing several critical policy issues focused on accessibility, such as protecting the human rights of key populations, developing a specialised healthcare workforce, eliminating out-of-pocket payments, and ensuring sustainable funding from the Ukrainian government.

The report also highlighted significant concerns regarding access to different lines of treatment. Due to budget constraints, only one standard regimen was available, as the high costs of second and third-line treatments made it prohibitively expensive to offer multiple lines of treatment as a result of patent barriers, and critical gaps in implementing and regulating TRIPS flexibilities (MSF, 2016). In 2004, 100% Life reported that the Ministry of Health was procuring ARVs at 24 times the price paid by the Global Fund, a disparity that further increased to 27 times in 2005. 100% Life advocated for the inclusion of a community representative on the medicine tendering committee to ensure a more transparent procurement process. Although their demands were not met, this advocacy underscores the efforts of HIV CSOs to improve access to medicines before the timeline of this research project.

Unfortunately, there is a dearth of literature detailing the access to medicines movement in the 1990s to 2000s. However, the OSF report (2007) makes it clear that since the formalisation of people living with HIV into 100% Life (formerly The Network of People Living with HIV), access to medicines has been a central agenda, particularly focusing on accessibility and overcoming issues related to the sustainability of funding and corruption within government procurement processes. The combination of the high costs of HIV treatment and the economic and health status of key populations living with HIV created obstacles and barriers to reaching the health equity target laid out by SDGs 3.3 and 3.8 (UN, 2015).

While this does not provide a comprehensive picture of activism before the timeline of this research, it is evident that further scholarly investigation is needed to explore this period and understand the socio-political context that shaped this form of activism.

The access to medicines movement was then affected by the outcome of the Euromaidan protests which resulted in Ukraine signing an Association Agreement with the EU in 2014,

followed by a Deep and Comprehensive Free Trade Agreement in 2016. The terms of these trade agreements stipulate that Ukraine must align more closely with EU intellectual property rules and must enforce stricter patent protections under TRIPS Plus Provisions (European Commission, 2016). TRIPS Plus provisions are disadvantageous for patients seeking treatment, as they strengthen data exclusivity protection.

They also allow pharmaceutical companies to pursue investor-state dispute settlement (ISDS). These are costly litigation cases that pharmaceutical companies can bring against governments if they believe that their use of TRIPS flexibilities is impacting their investments (Townsend, 2021). Parallel to these attempts to strengthen intellectual property rights, many CSOs organised to put pressure on the government to make reforms to the financing and procurement of drugs for certain illnesses, including HIV. One such group is the Reanimation Package of Reformations Coalition (RPR), which brings together over eighty CSOs. These CSOs have laid out policies which lobby the government, demanding that it use the window of opportunity after Euromaidan to implement reforms to drug procurement and patent laws. One campaign goal of the RPR was the creation of a centralised government organisation which aimed to transparently tender for the procurement of medicines (Semigina & Mandrik, 2017).

Since 2015, the responsibility of drug procurement in Ukraine has been temporarily handed over to international organisations such as UNICEF, UNDP, and Crown Agents, resulting in the state saving millions. Handing the responsibility of drug procurement to international bodies was a result of strong civil society advocacy (Semigina & Mandrik, 2017). The aim of this transition was to provide time for the Ukrainian government to increase the capacity of their Medical Procurement of Ukraine, to build on best international guidelines, and to introduce an online and transparent procurement system. UNDP also trained CSOs to act as gatekeepers of this new system by monitoring the availability and utility of procured medicines (Lukyanova, 2020).

In addition to creating a transparent and centralised procurement agency, the Ministry of Health introduced the Affordable Medicines programme in 2017. While the Affordable Medicines programme was implemented to reimburse medicines for non-communicable diseases, it highlights the government's commitment to ensuring access to safe, effective, and

affordable medicines (Ministry of Health Ukraine, 2018; Csanádi *et al.,* 2019).[78] However, while these steps are encouraging, they do not entirely address the issue of patent barriers and the high costs of medicines.

In 2015, an HIV CSO organised a roundtable that included academics, CSOs and representatives of Indian and Ukrainian generic manufacturers. The purpose of the meeting was to identify opportunities to utilise TRIPS flexibilities to overcome patent barriers and outline strategies to reform patent law (MMA 2015). The roundtable outlined their future advocacy goals and placed them into five categories; 1) intellectual property rights under TRIPS agreement and opposition procedures; 2) ways to overcome the low threshold for granting an extension on patents; 3) mitigation of strong data exclusivity protections of medicinal products enforced by TRIPS Plus provisions; 4) critical gaps in compulsory licensing regulation; and 5) strategies to invalidate patents (MMA 2015).As seen throughout this research, Ukrainian CSOs used different strategies to lower the price of treatment for HIV and HCV.

Between 2014 and 2017, 100% Life was the recipient of a grant that aimed to advance the International Treatment Preparedness Coalition (ITPC) project, 'Access to treatment for people living with HIV in middle-income countries', in collaboration with the National Intellectual Property Research Institute in Ukraine. The ITPC was founded in South Africa in 2001. It was awarded funding from UNITAID in 2014 to develop its Make Medicines Affordable (MMA) campaign. This campaign worked with a consortium of experts and national organisations in MICs to remove IP barriers to HIV treatment. The initial project included four middle income countries, including Ukraine. The project was then renewed in Ukraine and further expanded to 17 additional MICs in 2018 due to continued investment from UNITAID (ITPC, 2024).

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[7] The Ukrainian government set out to establish a Health Technology Assessment (HTA) regulatory body. An HTA critically and objectively assesses the consequences of reimbursing essential medicines by examining different parameters of the applications including efficacy, safety, cost-effectiveness and budget impact (Drummond *et al.,* 2008; Loblová, 2018). While there has been some progress in the development of a strong HTA system in Ukraine, it's scope and effectiveness are limited by frequent changes in healthcare governance that affect long-term investment in HTA capacity building and institutional building (Csanádi *et al.,* 2019) [8]In 2017, the Ukrainian government introduced an external reference pricing and reimbursement system, a practice that references the prices of medicines that are based on five neighbouring countries. This new system has shown to be effective in reducing the prices of medicines but is currently only focused on noncommunicable disease laid out in the Affordable Medicines Programme (Piniazhko *et al.*, 2018)

The framework of this project was endorsed by the WHO and aimed to enhance public awareness about the need for patent reform; introduce legislation that will eliminate obstacles to the implementation of TRIPS flexibilities and challenge patents for ARV drugs that do not meet innovation criteria for patentability (ITPC, 2015). These objectives are a clear indicator of the role health organisations such as WHO and ITPC play in the global A2M movement. While it is unclear in the literature why ITPC picked Ukraine as one of their initial implementing partners, it is hoped that this will be elucidated upon in the findings. However, as discussed below, the opposing forces of leading players in the global health architecture complicate the advocacy efforts of Ukrainian treatment activists.

2.3.3. Fighting for our Right to Medicines: Success and Challenges

In 2016, ViiV Healthcare signed voluntary licences for adult and paediatric formulations of HIV medicines Dolutegravir and Abacavir to the Medicine Patent Pool after activists threatened a compulsory licence (Standford, 2018). In 2017, Gilead Sciences extended its voluntary licensing agreements signed with the Medicine Patent Pool to include Ukraine, ensuring access to more ARVs. This means that key HIV ARVs, such as Tenofovir Disoproxil Fumarate, Tenofovir Alafenamide, Cobicistat, and Elvitegravir were allowed to be manufactured and sold by generic manufacturers (Medicine Patent Pool, 2017). This research seeks to understand the CSO-MPP relationship and what was involved in ensuring Ukraine was signed up to these licence agreements.

Price negotiations with industry are another effective strategy for governments and CSOs. In 2016, an HIV CSO successfully advocated for the pharmaceutical company, Merck to drop the patent protection on their triple combination drug, Atripla, effectively reducing the price from $354 per person per year to less than $95 (MMA, 2019). In 2019, an HIV CSO continued negotiations with Merck also resulted in the company reducing the price of their drug, Raltegravir by half (MAA, 2019). This research is interested in understanding the price negotiation tactics of HIV CSOs and their relationship with the pharmaceutical industry.

In Ukraine, HIV/HCV CSOs have also engaged in patent opposition as a strategic tool. Patent opposition, a legal mechanism that is only available in a select number of countries, allows the public to challenge the validity of a patent application, or to seek the revocation of a

granted patent (Marks & Benedict, 2013). In 2016, Ukraine spent 50% of their allocated HIV procurement budget on AbbVie's Lopinavir/ Ritonavir combination drug, which only covered 26,000 PLWHA (MMA, 2017). 100% Life brought patent opposition to this drug on the grounds that it does not meet legal requirements but has lost its case and appeals.

However, during the COVID-19 pandemic, AbbVie released all their patents on Lopinavir/Ritonavir for all indications around the world. This is projected to have a significant impact on access to ARVs in Ukraine (Mancini & Kuchler, 2020). In 2015, Gilead brought the Ukrainian government to court over violation of data exclusivity, a TRIPS Plus provision and won a settlement that allowed Gilead to keep Sofosbuvir on the market until 2020. However, the patent opposition by CSOs reduced the patent life by ten years (Bagcchi, 2015; Stafford, 2017). This is significant as it is estimated that 3.5% of the Ukrainian population has HCV (Devi, 2020). HIV CSOs were also the first in the world to oppose Merck's patent application for MK-8591 on the grounds of non-inventiveness (MAA, 2019). As few countries have legal mechanisms to oppose patents available to them as an activist tool, this research hopes to understand the processes and ramifications of using this particular strategy.

The Ukrainian access to medicines movement is illustrative of the importance of the macro and micro dialogue needed among all stakeholders to implement healthcare reforms. The political instability that was signified by the Euromaidan Revolution, opened a window of opportunity for CSOs to forge ties with subsequent government officials and to push for changes in the healthcare system. However, the growing power and influence of HIV/HCV treatment activists are met with countervailing forces, free trade agreements that push for the strengthening of IP rights and disparate ideologies within the global health architecture. The next section will examine the opposing forces within global health architecture that simultaneously assist and complicate the advocacy efforts of HIV treatment activists.

2.3.4. TRIPS Flexibilities and a Fractured Global Health Architecture

To emphasise the political tensions inherent in pursuing TRIPS flexibilities, this section will examine the differential A2M agendas set by influential bodies within the global health architecture. In a recent report, HIV CSOs[8] outline their definition of global health architecture as:

> *'[...] the constellation of actors whose primary purpose is to promote, restore or maintain health. Such actors may operate at the community, national, or global levels, and may include governmental, intergovernmental, private for-profit, and/or not-for-profit entities, inclusive of civil society, community organisations and communities affected by health challenges'.*

This research adopts this definition. The report highlights key institutions in the global HIV response such as the Global Fund, WHO, PEPFAR, UNAIDS, World Bank, International Monetary Fund and UNITAID. Two reports outline two key issues: 1) the disproportionate power granted towards the biggest financial contributors towards these institutions, and 2) a paradigm shift in the focus of foreign aid funding. Originally, the global health architecture used to support health budgets but now promotes economic growth, return on investment and an increase in private sector involvement (STOPAIDS *et al.,* 2020). This assertion is supported by Martins' & Ventura's (2023) paper arguing that neoliberal thinking and policymaking in global health have led to calls for Universal Healthcare Coverage that focus shifted towards financial feasibility instead of the protection of the right to health.

This refocusing of global health priorities highlights the entanglement and tensions between neoliberal market approaches and pro-public approaches to health. Møgedal, Alveberg & Pereira (2011) posit that the challenge global health architecture faces is not one of unity, but greater attention is required to understand what hinders resource management and collaboration between different stakeholders. The authors argue that all stakeholders in the

[8] This report was co-authored by five CSOs and one government agency. These include STOPAIDS, Civil Society Sustainability Network, Partnership to Inspire, Transform and Connect the HIV Response, AIDSFONDS, Frontline AIDS, & the U.K. Ministry of Foreign Affairs - https://stopaids.org.uk/wp-content/uploads/2020/01/HIV-Universal-Health-Coverage-and-the-future-of-the-global-health-architecture.pdf

architecture must embrace diversity and combine forces to reclaim functionality. Is this reimagined naive thinking when situated within trade systems that accentuate the power tug of war between intellectual property rights and the access to medicines movement?

Throughout this research the relationship dynamics between public health and market forces in MICs within the overall global health architecture are scrutinised, revealing a nuanced interplay of competing interests and priorities that shape health outcomes. For example, the relationship between neoliberal policies acting as an impediment to achieving universal health coverage is well documented (Mukhopadhyay, 2013; Chapman, 2016; Birn & Nervi, 2019). This is exemplified by the World Bank's conflicting roles. Its policies are competition-based and market-driven, and ostensibly support globally accepted health goals, such as universal health coverage (Moon & Ooms, 2017), despite these arguably inherent contradictions.

Significant imbalances exist within the power dynamics of influential donor countries, which is especially evident in the distribution of voting rights of each member country. Organisations such as the WHO and the Global Fund provide a balanced voting power between all stakeholders. In contrast, international financial institutes such as The World Bank and the International Monetary Fund have a voting system that disproportionality provides more voting rights to its largest donors (Vestergaard & Wade, 2015; Moon & Ooms, 2017). Similarly, the WTO has been criticised for facilitating weighted power toward more powerful trading blocs, especially during the COVID-19 pandemic (Narlikar, 2021). The World Bank and IMF voting structure has provided the United states, Japan, Germany, France and the United Kingdom with a combined total of 60% of voting rights (Vestergaard & Wade, 2015).

This is important when referencing Ukraine's advocacy efforts to increase the utility of TRIPS Flexibilities, as all these countries are the biggest proponents of strong intellectual property protections. In our globalised economy, industrialised nations that have dominance over intellectual property are the greatest financial beneficiaries of strong IP protection. The greatest proportion of intellectual property rights are based in the United states, the European Union, and Japan (Tusikov, 2017). Indeed, Ukraine became a beneficiary of a $17 billion (US Dollar) IMF loan package and a $3.5 billion World Bank aid package in 2014 after the

Euromaidan protests and the conflict that ensued (Wood, Martin-Prével & Moussea, 2014). The World Bank's aid package to Ukraine is an example of how financial aid is focused towards pro-corporate interests. This specific aid package aimed at high-priority reform measures in areas such as 'water supply, sanitation, power and roads, and *supporting the private sector'* (World Bank, 2014. p.1). Although these reform measures do not specifically point to the pharmaceutical industry, they highlight the incongruence between development policy shifting towards deep marketisation and HIV CSO efforts for a more pro-public and transparent market.

International initiatives, such as the Global Fund and UNITAID were established with the aim of increasing the uptake of ARVs by playing a vital role in the market dynamics of price reductions and drug procurements (Waning *et al.,* 2010; Costa Chaves *et al.,* 2015). In a report by FrontlineAIDS (2019), concerns were raised about the tendency of several global health agencies to encourage price negotiations and voluntary licences over the use of TRIPS flexibilities. In addition, funding opportunities for projects aiming to implement TRIP flexibilities have markedly decreased which used to be a priority area for the Global Fund. The report also states that this shift in focus may derive from time and budgetary constraints that are associated with pursuing TRIPS flexibilities versus diplomatic negotiations, such as pushing for voluntary licence agreements (FrontlineAIDS, 2019).[9]

MICs also face large international pressures, costly litigation cases, and relegation in watchlists that rate trade attractiveness when TRIPS flexibilities are pursued (Wibulpolprasert *et al,* 2011; t, Hoen *et al.,* 2018). This not-so-subtle contempt for the pursuit of globally recognised legal approaches to reducing the prices of lifesaving treatment is symbolic of a market-driven neoliberal agenda versus the global health mandate to ensure equitable access to medicines. This study of the case of Ukraine illustrates where HIV/HCV treatment activists situate themselves within a set of opposing and contradictory systems.

[9] UNITAID, Robert Carr Network Fund & AIDSFONDS are the global health agencies that are still focusing on projects that aim to implement TRIPS flexibilities (ITPC, 2020)

2.4. Conclusion

This chapter examined the implications of global, macro-level political, trade and economic forces and how they intersect with the evolving social, economic and political contexts in Ukraine, revealing the dynamic power structures in LMICs, the influence of neoliberal policy development, and a changing HIV/HCV treatment landscape. It underscored the challenging and multidimensional nature of HIV/HCV treatment activism in an emerging economy that is influenced by post-Soviet legacies, external economic and political pressures, and fragmented global access to medicine movement. However, there remains a scarcity of literature on HIV/HCV treatment activism in the EECA region, which possesses a particular historical, political and social background, all of which are integral to understanding effective mobilisation. This research seeks to navigate the broader political and social dynamics of Ukraine to help further understand the power interplay between macro and micro influences on HIV/HCV treatment activism.

The next chapter will outline the research methodology, including guiding social movement theory, the study's chosen analytical method, ethical considerations, the reflexivity of the researcher, and the data collection process.

Chapter 3. Theoretical Framework

3.1. Introduction

The last chapter provided a critical overview of the literature that explored the macro and micro-level political, economic and social factors impacting the HIV/HCV response in post-Soviet Ukraine, with a particular focus on HIV/HCV treatment activism. The chapter underscored the complex interplay of factors such as geopolitical conflict, neoliberal policies, global power dynamics, evolving national identities and political stability, all of which profoundly influenced the landscape of HIV/HCV activism.

Recognising the limited scholarship on the strategic approaches of HIV treatment activists in the EECA region, this research endeavours to fill this gap by offering a nuanced understanding of the positioning of HIV/HCV treatment activism within Ukraine's socio-economic and political context, as well as, within wider geopolitical influences. Therefore, to approach this, the methodological chapter is split into two sections. The first section critically appraises Political Process Theory as a guiding theoretical framework for studying activism and social movements. The second section outlines all aspects of the qualitative process, including the ethical considerations of this research, data collection and management, and interview settings. Furthermore, in Chapter 4, a description and justification of the analytical approach used in this study, Reflexive Thematic Analysis, is presented. Finally, in the reflexivity section, I turn the research lens onto myself and outline how my own identity, personal experiences and assumptions have influenced the research process.

3.2. A Guiding Theoretical Framework: Political Process Theory

To gain a deeper understanding of the access to medicines movement, I chose Political Process Theory (PPT) as a lens to understand the many different dimensions of activism and social movements. In this section, I provide an overall description of PPT by delineating its main components. I then critically appraise the theoretical framework by outlining its main limitations and provide options to modernise the framework to align more with contemporary global power structures beyond the conventional nation-state model. Lastly, I discuss the theoretical pluralism in social movement theory and provide a rationale for choosing PPT over other theories to guide the research.

3.2.1. Political Process Theory

Political process theory (PPT) was chosen as a theoretical guide for this research as it was conceptualised to understand the complex environments that determine the successes and failures of social mobilisations by investigating the 'when' of opportunities for intervention (Tilly, 1995; Goodwin & Jasper, 1999). According to the PPT model, the success of social movements can only occur when shifting political circumstances generate a window of opportunities for social movements to alter government policies and political structures (Tarrow, 1998; Glasberg & Shannon, 2011).

To better understand what constitutes a political opportunity, it can be categorised into either structural or dynamic opportunities. These categories relate to the limitations and possibilities that are created by factors external to interest groups but directly influence their ability to mobilise and affect change (Gamson & Meyer 1996; Koopmans, 1999). Structural opportunities refer to characteristics of political systems, including the capacity of the state to instigate policy change and the ability of institutions to access state authorities. As one can infer from the word 'structural', these opportunities are considered relatively consistent over time but are not invulnerable to change. In contrast, dynamic opportunities, which relate more closely to political opportunities, refer to volatility and vulnerabilities within political systems, such as divisions among political elites, diversification in the political system and electorate, loosening of repressive strategies enforced by the state and momentary crisis and events (Gamson & Meyer 1996; Fetner & Smith, 2007).

Therefore, according to PPT researchers, social movements are not driven primarily by external factors of political structures, whether they be collective or personal grievances or whether they possess the resources to mobilise (McAdams, 1982; Tilly, 1995; Koopmans, 1999). In fact, it is argued that political opportunities must occur first to enable social movements to exert change as they shift the degree of power inequality between the state and the challengers (Caren, 2007). Additionally, once social movements take advantage of these periods of power imbalance, they can further increase the political opportunities that induced initial mobilisation (Meyer & Staggenborg, 1996). The temporal nature of Ukraine's HIV/HCV treatment activism is a vital component of this research. As highlighted in the literature review, much of the price reductions on ARVs/DAAs and healthcare reforms

occurred after 2014. Therefore, understanding political opportunities presents an important lens through which to explore treatment and healthcare activism.

But why is examining political opportunities an integral component of investigating the emergence and development of social movements? Koopmans (1999?) outlines three independent claims that political opportunities make, including variations in political opportunities, determine the type of collective action; the type of opportunity is a direct result of the interaction of social movements with political and institutional actors; and opportunities are structurally shaped and not a product of strategic interactions.

Therefore, any examination of social movements must identify political opportunity as a precursor for mobilisation as it determines when, how much, and what kinds of mobilisations are possible (McAdam, 1982; Costain, 1992). As PPT remains the dominant research paradigm in social movement research, it has been subject to much criticism, with particular attention placed on political opportunities. A critical appraisal of political opportunity and its implications for this research can be found in 3.2.2.

While political opportunity constitutes much of the focus of political process theory, contemporary social movement research also combines analysis of mobilising structures, framing processes, protest cycles and contentious repertoires. These five elements of PPT are used to explain the mechanisms behind the emergence, acceleration and decline of social movements and provide an insight into the form that protests take and their subsequent movement outcomes (McAdams, 1982; Caren, 2007). PPT remains the best analytical tool to answer my research question as it focuses on the interaction between movement attributes, such as Ukraine's broader economic and political context and the organisational structures of HIV/HCV organisations.

The second element of PPT is the presence of pre-existing organisations that serve as mobilising structures for communities marginalised by the state (McAdams, 1982; Neal, 2007). Identifying the temporal nature of mobilising structures in social movements is integral to understanding the initiation and continuation of collective action, as argued by McAdams (1982)

In his book, Intellectual Property, Human Rights and Development – The Role of NGOs and Social Movements, Matthews (2011) examines whether NGOs from developing countries effectively collaborate with broader social movements to engage with IP policy issues at all levels of governance. While HIV/HCV treatment activism is primarily conducted within civil society organisations, a component of this research seeks to understand how treatment activism interacted with the Euromaidan Revolution. Yet, I hesitate to describe Ukraine's treatment activism as simply supplementary to Euromaidan. Treatment activism is frequently situated within the broader discourse of access to medicines movements, propelled by a range of actors from grassroots movements to formalised CSOs or both (Baker, 2020; Sismondo, 2020). It is argued that NGOs cannot substitute themselves for movements in terms of being a strong political force, as significant progressive change is seldom possible without sustained popular change (Pithouse, 2007; de Souza, 2013).

However, in this research, organisations typically referred to as NGOs are referred to as CSOs due to their strong membership base and community roots. For example, the 2019 report by 100% Life, an HIV CSO in Ukraine, notes their role in helping 292,734 Ukrainians, including providing services for 95,945 PLWH, leveraging its 24 regional branches and 15,000 associated members. The track record of HIV/HCV successes highlighted throughout this thesis demonstrates that significant progressive change can be achieved through formalised CSOs. Given HIV/HCV CSO's considerable influence in both social and political spheres, these CSOs are acknowledged as powerful mobilising entities capable of rallying a social movement.

Hence, I argue that this research views Euromaidan and HIV/HCV treatment activism as concurrent and interconnected movements. A key objective of this research is to identify how these two convergent movements interact and to understand their collective impact on the access to medicines movement.

Mobilising structures, such as civil society organisations, are prone to develop issues over time due to the resources they need to remain operational. Issues that may arise include a changing indigenous support base and shifting organisational priorities due to the primary focus on funding acquisition (McAdams, 2982; Corrigall-Brown, 2016) Conversely, mobilisation structures may strengthen over time due to the social networks of potential movement actors and current activists becoming denser (Gould, 1991; McAdam & Paulsen,

1993). Investigating pre-existing mobilising structures, such as HIV/HCV CSOs, and the interaction of human capital within these organisations over a period of time provides an understanding of the 'who' is being mobilised and how this affects the A2M movement.

The third element of PPT is the framing processes within social movement organisations to identify the current problems, articulate why change is necessary and how these changes can be achieved. These framings ultimately aim to achieve the goal of resonating and persuading an audience to take action against an injustice (Johnston & Noakes, 2005). McAdam defines framing as '*conscious strategic efforts by groups of people to fashion shared understandings of the world and of themselves that legitimate and motivate collective action*' (McAdam, McCarthy & Zald, 1996). This framing process is considered to be strategic and dynamic in nature and represents the cultural element that mediates between political opportunity and action (McAdam, McCarthy & Zald, 1996; Johnston & Noakes, 2005). This research aims to understand the interplay between conflicting public health and neoliberal agendas within political and healthcare systems and the strategic framing process of HIV/HCV CSOs that represent these communities left without access to medicines.

An understanding of the temporal nature of social movements is the fourth element of PPT, in the form of cycles of protest. Understanding the historical context of protests helps identify when a political system is vulnerable and receptive to movement demands, which in turn encourage protest amongst other interest groups (Tarrow, 1994; Staggenborg, 1998). McAdams (1995) posits that 'initiator' movements respond to political opportunities, but cultural effects rather than political opportunities then influence consecutive, 'spin-off' movements. Additionally, in an analysis of protest cycles, it is important to highlight that political opportunities, the strength of movement organisations and the cultural elements of movements may change or overlap over the lifetime of protest cycles (Tarrow, 1994; Minkoff, 1997; Staggenborg, 1998). This is relevant when examining the Ukrainian perspective of protests and political opportunity. In 2004-2005, the Orange Revolution lasted two months in Ukraine, which was then followed by the Euromaidan protests in 2013-2014. This research will identify if a relationship exists between these pro-democratic revolutions and the Ukrainian HIV/HCV treatment movement.

The final factor of PPT that is used to investigate the successes and failures of social movements is its repertoires of contention. Charles Tilly (1995) highlights that repertoires of contention are protest and action-related tools that are cultural in context and are valued based on their evidence of successes in previous movements. Contentious repertoires are collective ways in which groups can demand recognition, indicate the significance of their base support and promote their collective goals (Tilly, 2008; della Porta, 2008; Walker, Martin & McCarthy, 2008). For this research, it is critical to understand what repertoires of contention are being used in Ukraine's HIV/HCV treatment activism, if variations in collective actions are taking place, and what group actors perceive as successes and failures of their actions.

Due to the limited scope of this research, it is not possible to examine all of the elements of the PPT conceptual framework in detail. A particular focus will be placed on political opportunities and resource mobilisation/mobilising structures. Nonetheless, the PPT framework has helped guide the interview questions. The research participant's experiences will clarify the importance and relevance of each component of the PPT framework as they reflect on their treatment activism and the socio-political situation in Ukraine from 2010 to 2021.

3.2.2. Critical Appraisals of Political Process Theory

While political process theory has propelled a paradigm shift in social movement literature, it has not been met without criticism. Several prominent authors, including McAdams himself, have pointed to limitations in this theory. Firstly, there remains an incongruence between today's era of global interdependence and the historical context that placed too much emphasis on the centralised power of a nation-state as the primary level of analysis (Kriesi *et al.,* 1992). McAdams (1996, p. 34) argues that 'movement scholars have, to date, grossly undervalued the impact of global political and economic processes in structuring domestic possibilities for successful collective action.' Traditional definitions of the polity model assume that the structure of political opportunities is restricted to conventional political institutions (Tilly, 1978; Pellow, 2001). However, a contemporary examination of social movements must recognise that political opportunities are susceptible to broad structural forces which affect economic resources and political power (Smith & Fetner, 2007). Therefore, this theory must diverge from the concept of political opportunity primarily

opening and closing due to traditional means, such as election cycles and divisions amongst political elites (Ayres, 1996; Tarrow, 1998).

Proponents of greater global economic integration into PPT argue that the significant decline in state sovereignty has decentralised the state within the political process and now shares this power with transnational institutions, such as corporations (Logan & Molotch, 1987; McAdams, 1996; Boudreau, 1996; Pellow, 2001). This power shift can be observed by examining the implications of implementing free trade agreements and WTO regulations on nation-states. Thus, examining political opportunities must identify global economic influences on social movements.

This power-sharing dynamic directly influences this research project. The WTO's power to force nation-states to legally ratify its objectives, including adhering to its intellectual property laws (Nader & Wallach, 1996) and the EU-Ukrainian FTA that included TRIPS Plus provisions (as discussed in sections 2.3.4. and 6.2.1.2) raise the question - how has this decentralisation of state power affected the A2M movement? This question must be analysed by examining its effects on political opportunities and the tactical repertoire of confronting these changes.

David Pellow (2001), in his paper promoting the framework of the political-economic process, highlights four dimensions used to capture this phenomenon. The first is to question the state's role as the ultimate policymaking authority. The second is to place the role of business as a central player and focus of attention in social movements. For example, advocacy efforts by HIV treatment activists in Ukraine consist of allying themselves with generic manufacturers and negotiating price discounts with pharmaceutical companies. The third dimension is to identify that the primary goal of social movements is to challenge both political and economic forces. Lastly, the concept of political opportunities must include powerful corporate institutions in their analysis that routinely affect traditional political systems, which consequently directly affects the opportunities that are available to movements.

In a similar vein to Pellow's (2001) critique, Smith & Fetner (2007) argue that any analysis of social movements that do not account for the interconnectedness and interdependence of global systems will fail to recognise how global factors influence the emergence and

development of social movements which otherwise may appear to be national conflicts (Frank, Hironaka & Schoter, 2000). In addition to the ability of international institutions to undermine state sovereignty, they also have the capacity to strengthen democracy and social movements (Tarrow, 2001). International institutions with global mandates to address global problems, such as the implementation of UHC, develop symbiotic relationships with local social movement actors to hold governments accountable for the ratification of international treaties (Tarrow, 2001; Smith & Fetner, 2007).

In an attempt to simplify the political opportunity concept in an increasingly interconnected and interdependent world, Marks & McAdams (1996, p. 119) describe this as a multi-governance system. This embedding of national political processes within additional layers of international political processes has encouraged social movement actors to increase relationships with multilateral institutions and HIV networks, such as the Global Fund, UNAIDS, WHO, UNITAID, and GNP+, to increase their role in shaping the structures of global regulation and accountability (Parker, 2011; Clark, 2013). Therefore, in addition to the economic impact on the political process, the scope of this investigation is expanded to explore the integral role of multilateral institutions in creating political opportunity. Moreover, what impact do these institutions have on the resources mobilisation of the Ukrainian A2M movement, and what impact do these contributions have on their campaigning strategies?

The harshest critics of PPT, Goodwin and Jasper (1999), argue that the utility of political opportunity is impeded by its conceptual vagueness, which promises to explain too much, that it is overly structural, and that it has the propensity to analyse non-structural features as if they were structural. Additionally, the mischaracterisation of movement actors as interest groups rather than challengers of repressive cultural systems and promoters of progressive lifestyles and collective identities is contested in the literature (Goodwin and Jasper, 1999; Poletta,1999; Meyer, 2004; Raeburn, 2004; Taylor *et al.,* 2009).

As a result, the analysis is limited, as it does not provide a full understanding of movement emergence. Poletta (1999) cautions against placing the cultural (society) and institutional (state – and indeed, in our renewed version, international institutions) on an axis as it suggests that the state is non-cultural and, as a result, reduces the ability of the researcher to find meaning in their interrelations. As Goodwin and Jasper (1994) argue, both the state and

movement actors are suspended in a web of meaning and that society must guide the state towards their conception of 'what the state is, what it can and should do" (Friedland & Alford, 1991 p. 238). Recognising the critiques of PPT, this research aims to avoid potential pitfalls. Firstly, Poletta (1999, p. 69) suggests in her paper that conceptualising structure as culture would entail careful consideration towards the following:

> *'* [...] *the cultural traditions, ideological principles, institutional memories, and political taboos that guide the behavior of both political elites and challengers.'*

While there is agreement with Poletta's argument that cultural analysis is an intrinsic aspect of PPT, this research is reluctant to over-conceptualise the framework and increase the scope of this research. Analysing mobilising structures, framing processes, protest cycles, and contentious repertoires inherently provides cultural insights into HIV treatment activism in Ukraine. However, if this research worked to incorporate all of Goodwin & Jaspers' (1994) and Poletta's (1999) critiques regarding the analysis of political opportunity, it would direct this research towards their primary critical appraisals: conceptual vagueness and 'in danger of becoming a sponge that soaks up every aspect of the social movement environment' (Gamson & Meyer 1996, p. 275). Moreover, my position of being an 'outsider', compounded by the constraints of not conducting my fieldwork in Ukraine, and not speaking Ukrainian limits my ability to collect data about cultural narratives reliably.

3.2.3. The Knowledge Economy

In addition to the main tenets of Political Process Theory, key conceptual frameworks are used in this research to map out the global trade architecture and how treatment activists must navigate this to gain access to medicines. Furthermore, theory that focuses on the professionalisation of movements is examined.

The knowledge economy, a term first coined in the 1960s, describes an economic shift where knowledge and information production superseded traditional manual labour as the primary drivers of economic growth. The 'knowledge workers', focused on those engaged in intellectual labour producing ideas and information, which fundamentally transformed the labour landscape of technologically advanced HICs and MICs, such as India and Brazil (Drucker, 1959; Machulp, 1962; Godin, 2010; Donovan, 2024).

This transformation, while fuelling technological and economic advancement, has also brought to light significant concerns about the direction and motivations behind biomedical research and development (R&D). One critique outlines the heavy influence commercial interests have in shaping medical research priorities within this knowledge-driven economy. Intellectual property rights were enshrined within the TRIPS agreement (see 1.2.) to incentivise research and development of drugs within a market place. The issue arises when those affected by certain diseases are located in LMICs and are unable to generate the incentive for developing health technologies to overcome neglected diseases endemic in LMICs such as sleeping sickness or chagas disease (Pinheiro Astone, 2023). This is a result of the current system of innovation, which, in its current form, is intrinsically tied in with the market-based intellectual property system (Watal, 2021). There continues to be a profound concern that dependence on private funding skews research towards more profitable ventures. This skewness potentially overlooks or under-emphasises critical public health needs in favour of research areas that promise greater financial returns for pharmaceutical companies. Such commercial biases may limit the scope of research to fields that, although lucrative, are less relevant or urgent for public health (Watal, 2021). More relevant to this research is how intellectual property gives the IP holders the power to sell or withhold health technologies depending on countries ability to pay the price they place on these inventions.

Swaminathan *et al.* (2022) highlights how the current R&D ecosystem is a complex network of public laboratories, universities, private sector, non-profit organisations, and healthcare facilities, all funded by a mixture of taxpayers, philanthropic foundations, private investors, and pharmaceutical companies. These diverse funding and knowledge generating landscapes are shaped by public policies, free trade agreements and agencies overseeing intellectual property, regulatory standards, and reimbursement practices among others. As Swaminathan *et al.* (2022) argue, these stakeholders must reorient biomedical R&D to serve the global public interest more effectively. This reorientation involves critical reflections on the purpose of R&D, its methodologies, and the intended beneficiaries.

While this research does not look at alternative ways to incentivise research and development, it does examine the moving parts within the knowledge economy, such as the TRIPS agreements and free trade agreements, and ways in which treatment activists navigate it to overcome their unmet health needs.

3.2.4. Navigation Theory

The seminal work of Henrik Vigh (2006; 2009; 2010) is used in this research to better understand the concept of navigation and how people move in uncertain circumstances. Vigh's (2006; 2009; 2010) concept of social navigation provides a valuable analytical lens through which we can examine the interplay of agency, social forces, and change. This concept helps us understand how individuals move and manage within environments characterised by continuous social flux. Social navigation theory argues that we organise ourselves within a dynamic interactivity between the environment that people move in and how this environment changes before, after and during an act.

Therefore, social navigation requires a sense of prediction and adaption to the movements within our social surroundings. Vigh argues that if we navigated social environments based solely on present stimuli within our environment, we would live more mechanical, singular lives. As a result, individuals spend considerable time and effort understanding their social environment, anticipating changes, and adjusting their behaviours accordingly. This includes coping with social pressures and modifying one's actions based on both current possibilities and future trajectories. Furthermore, social navigation involves anticipating and adapting to change, often in unpredictable and emergent conditions – a motion within motion. It demands flexibility, adapting your social self to take on new functions, and a readiness to face new challenges, which Vigh argues is necessary for uncertain futures. This is useful for social movement research as it counteracts the usual conceptualisation of action as being performed on a strong, unwavering ground. This dual motion of individuals moving within and being moved by their environments adds depth to our understanding of access to medicines activism.

While Vigh's theory of social navigation is used heavily in his anthropological work on how youth navigate terrains of war in Guinea Biisau (2006), how West African migrants navigate life in Lisbon (2009) or the mobilising of young people towards conflict (2010), it can still be transposed to the research aims of this research. The theory provides insights into the interplay between objective structures such as the TRIPS agreements and FTAs and the subjective agency of the research participants. Social navigation provides an additional dimension to the analytical process as it entails an understanding of how activists orient, interpret, manoeuvre and define their social spaces in relation to the environments around them (Sand & Hakim-Fernandez, 2018). By understanding the motions between the research participants and the

constantly moving (geo)political, trade, and funding environments they're navigating, it helps to make sense of the opportunities, barriers and tactics available to treatment activists.

3.2.5. The Professionalisation of Civil Society Organisations: A Double Edged Sword?

The concept of professionalisation and its impacts on civil society organisations (CSOs) has generated diverse perspectives among scholars. The literature underscores a double edged sword effect, presenting both significant benefits and drawbacks, particularly in relation to CSOs' ongoing engagement with their grassroots or member base (McCarthy & Zald, 1977; Neumayr *et al.,* 2015; Bloodgood & Tremblay-Boire, 2016; Grömping & Halpin, 2019). This issue remains contentious within academic discourse, as CSOs function as intermediaries between society and political elites (Halpin, 2006; Albareda, 2018). Consequently, CSOs are expected to act on behalf of their members and supporters, necessitating a demonstration of their 'representativeness' (Halpin, 2006; Hollman, 2018).

Despite concerns regarding disengagement from the grassroots, scholars such as Heylen, Willems, and Beyers (2020) and Hwang and Powell (2009) contend that professionalisation is a natural trajectory for CSOs that achieve a certain size or influence. This process results in increased organisation, bureaucratisation, expertise, technical capacity, and strategic planning, which makes CSOs resemble businesses more and focus less on their member base.
The literature remains divided on whether professionalisation benefits or harms social movements. March & Olsen (1998) and Saurugger (2012) highlight this permanent tension between the expertise-representation gap. This gap signifies the discord between a CSO's increased structure, expertise, and organisation, and its members' sense of representation and engagement, leading to potential feelings of disenfranchisement.

Saurugger (2012) posits that professionalisation transforms CSO's strategies and operations. One notable change is the shift from contentious to conventional politics, moving from outsider to insider politics. Poletta *et al.,* (2021) expands on this by arguing that professionalised movements often transition from spontaneous, local actions to top-down strategies, which can continue to alienate grassroots supporters. This supports Harwood and Creighton's (2009) assertion that to survive and gain political support, CSOs conform to governmental business practices, side lining other forms of activism.

Additionally, Saurugger (2012) notes the rise of professional/expert careerists over committed amateurs within CSOs. While this perspective holds value, it oversimplifies the relationship between CSO workers and their member base, overlooking the skills and knowledge of grassroots members, particularly in health CSOs where members have expertise in their lived experiences and may also work in professional fields such as medicine or policy. Skocpol (2003) expands on this point by arguing for greater investment in member engagement, emphasising that policymakers prefer dialogue with representatives rather than talking heads. Furthermore, engaged members have shown to provide CSOs with political support, ensuring that they fight for policies that are beneficial to politician's constituents and attract greater public attention (Albareda & Braun, 2019).

Proponents of professionalisation argue that grassroots engagement is time-consuming, costly, and reduces flexibility to adapt to new interests (Hwang & Powell, 2009; Grömping & Halpin, 2019). By adopting professional standards, CSOs can gain legitimacy and exert more influence in policy discussions. Saurugger (2012) highlights that professionalised CSOs are often taken more seriously by policymakers and stakeholders, enhancing their advocacy effectiveness. Thus, the tension between professionalisation and member base engagement persists in the literature. However, Heylen, Willems, and Beyers (2020) found that CSOs combining strong membership involvement with professional staff could positively influence membership, addressing many concerns raised in the literature.

While this research does not primary focus on the organisational and decision making structures of HIV/HCV CSOs, this research does examine their relationships with the polity, funders, and the needs of people living with HIV (PLWH) and HCV. Professionalisation is particularly relevant as HIV/HCV CSOs in Ukraine have received significant international funding from entities such as The Global Fund, PEPFAR, ITPC, and Frontline AIDS during the study period. For instance, since 2007, PEPFAR has provided Ukraine with $320 million for its HIV response, much of which has supported 100% Life, Ukraine's largest member-based organisation for PLWH (PEPFAR, 2022). Therefore, understanding how these resources affected the working structures of these CSOs is important. Additionally, these HIV/HCV CSOs are transitioning from international to government funding. Thus, examining the professionalisation process of CSOs can offer critical insights into the exogenous and endogenous factors directing their work on access to medicines.

3.2.6. Rationale for Political Process Theory

In Methodological Practices in Social Movement Research, Donatella della Porta (2014) argues that social movement research is grounded in methodological pluralism. An acceptance of multiple legitimate research methods in the social movement field has resulted in the form of collective recognition that each research method has its strengths and limitations (Heaney, 2017). Leading social movement scholars such as Tilly (1978), McAdams, (1982), Tarrow (1994), and McAdams, Tarrow & Tilly (2001) attempted to create a universal standard explanation for social movement mobilisation. However, a universal theoretical framework obscures the diversity of social movements and the varied interactions they have with state actors and global governance structures. Therefore, a methodologically pluralistic approach to social movements keeps providing pieces of the puzzle towards a greater level of understanding of how and why we, as globalised citizens, attempt to change national and global policy (della Porta, 2014). As a result, selecting the most suitable methodological approach proved challenging as the field provides many 'lenses' through which to analyse the complex socio-political environment that affects the Ukrainian HIV/HCV treatment movement.

This research uses PPT, which encompasses a structural approach to social movements research, as it is the most suitable theoretical framework to act as a guide to answer my research question and objectives. A structural approach was chosen, rather than a primarily cultural or relational one, as it analyses institutionalised inequalities and how social movement actors from organisations to influence states, institutions, and corporations (Smith & Fetner, 2007). However, critics of PPT argue that the structural, cultural and relational aspects of social movements must not be seen as mutually exclusive but rather all critical elements for the development and functioning of social movements (Poletta,1999; Klotz, 2002).

3.2.7. Appraisals of Other Theoretical Frameworks

The critiques outlined in section 3.2.2. have been incorporated into political process theory by expanding its framework to provide a wider understanding of the Ukrainian A2M movement. When considering the appropriate theoretical framework to best answer the research question, relational research paradigms such as global governance network analysis were investigated as they provide insights into how different network structures empower and disempower movement actors and how different governance networks may affect performance and outcomes (Eilstrup-Sangiovanni, 2016). However, network analysis does not emphasise national historical protest cycles and how these inform and, perhaps, initiate social movements. Therefore, a relational approach is not used, as identifying the role of protest cycles on the Ukrainian A2M movement is a key research objective as it remains a determining factor of political opportunities and the tactical repertoire used to ensure the affordability of HIV treatment. However, understanding the interrelations between different governance networks is a key feature of this research and is examined in detail throughout this study.

Scholars also argue that culture plays an important role in social movement research when one tries to identify when culture becomes a counter-hegemonic force to the status quo (Swidler, 1995; Poletta, 2008). In a sense, this research explores historical protest cycles and political opportunities that can, in part, answer that question. However, focusing the research primarily on a cultural lens, such as identity theory, to understand HIV/HCV treatment activism, would limit the focus of the research. While this research is interested in exploring grievances around the lack of access to affordable HIV/HCV treatment and the evolving identity of Ukrainians and how that led to shifting governance structures, it provides a less multidisciplinary approach that is needed to answer the research question. Therefore, using a more structural approach, while also taking a more cultural lens into account, to research variations in political opportunities and resource mobilisation is better suited to answer what favourable conditions facilitate/d Ukraine's successful HIV treatment activism (Tarrow, 1998; McAdam, Tarrow, & Tilly 2004; Tilly, 2004).

This research uses PPT over the Contentious Politics theoretical framework due to its strict definition of what constitutes contentious collective action. Contentious politics, like PPT, is a structural framework that analyses collective action that challenges new or unaccepted

claims (Tarrow, 1998). Contentious politics scholars, such as Tilly (1978) and Tarrow (1998), analyse the dynamics of contentious collective action by focusing on the collective actions that represent 'potentially subversive acts that challenge normalized practices, modes of causation, or systems of authority' (Beissinger, 2002, p. 14; Ulfelder, 2005). Examples of such subversive acts of contentious collective action include riots, revolutions, civil disobedience, demonstrations, and strike actions (Tilly, 2008).

The hallmark of contentious politics is its focus on extra-institutional means to change governments or policies (Tarrow, 1998; Tilly, 2008). The Ukrainian A2M movement (as outlined in section 2.3.2) primarily uses institutional means to achieve its objectives. For example, contentious politics would be useful to identify how and why extra-institutional strategies were used to ensure the affordability and accessibility of medicines during the ACT UP NYC demonstrations in the 1980s and 1990s, or if this research was focused primarily on the Euromaidan Revolution. While healthcare reform in Ukraine follows on the tailwinds of the Euromaidan Revolution, the strategies employed in Ukraine's treatment activism and healthcare reform use both extra- and institutional means.

If the objective of this research was to primarily gain an understanding of the motivational drivers behind treatment activism and civil society change in Ukraine, the sense of community (SOC) and sense of community responsibility (SOCR), as further outlined in section 2.2.1., would serve as an appropriate theoretical lens. SOC and SOCR proved to be effective analytical tools in Zarembo & Martin's (2023) study examining spontaneous informal civic action in Ukraine, providing valuable insights into community participation and the strength of community engagement during times of crises.

Nowell & Byod (2014) argue that the SOC and SOCR framework is uniquely equipped to build an understanding of why people engage in collective action. If this research was investigating the establishment of the All Ukrainian Network of People living with HIV in 2001, or aiming to understand the participation dynamics with HIV/HCV CSO's membership base, this theoretical framework would be relevant.

Although it not directly applicable to this particular research question, the work of Sarason (1974), McMillan & Chavis (1986), Nowell & Byod (2014), and Zarembo & Martin, 2023

are included to provides important socio-cultural insights into civil society activity in Ukraine.

PPT is the best framework to guide the analysis of social movements by integrating political opportunity, mobilising structures, framing processes, and the historical aspects of a collective action that complements the Ukrainian A2M context. As the research develops, a greater understanding will evolve regarding the Ukrainian mobilisations around HIV/HCV treatment activism and where it fits into the overall critiques of PPT.

Chapter 4 Methodology

4.1. Introduction

This study aims to explore how HIV/HCV treatment activists gained access to essential medicines in Ukraine. A qualitative research approach was employed to provide a deep exploration into the decision-making processes of the activists, as well as their nuanced understandings of Ukraine's structural and societal landscape that supported their activism efforts. A quantitative approach, such as conducting surveys with activists, would not capture the richly detailed and nuanced data that is required to answer the research question and objectives. While quantitative research typically aims to test or validate theories and assumptions, this research is oriented towards providing an in-depth understanding of the topic of HIV/HCV treatment activism in Ukraine (Verhoef & Casebeer, 1997). Therefore, PPT was delineated in the last chapter as a theoretical framework to underline the multidimensionality and complexity of researching social movements and activism.

In this chapter, the data collection and management methods will be outlined, as well as details relating to the interviewing practices employed. The ethical considerations of conducting research on HIV/HCV treatment activism in Ukraine are also elaborated on. The following section describes and justifies Braun and Clarke's (2006, 2013, 2019, 2021, 2022) Reflexive Thematic Analysis, which is used as an analytical tool in this research. Finally, the aspect of reflexivity is addressed, underscoring my personal engagement in the research process and reflecting on how my own experiences and perspectives may have shaped the study's trajectory and findings.

4.2. Data Collection: Semi-Structured Interviews

To generate the appropriate data in which to answer the qualitative research questions, a semi-structured interview (SSI) approach was adopted. The SSI approach works within the context of this research as it aims to understand participants' understandings of the sociopolitical situation in Ukraine and their experiences in HIV/HCV treatment activism. SSI uses more general, open-ended questions than a structured interview, allowing the researcher to ask additional follow-up why or how questions (Bryman, 2008). This provides a space for the participants to delve into unforeseen territory which may not have been picked up with a

more structured rigid interview approach (Braun & Clark, 2013; Adams, 2015). To help guide this interview, three broad questions and sixteen core questions were established (see Appendix B). As this research approached participants from different organisations and specialisations etc., the interview guide remained malleable to optimise data collection based on each participant's level of knowledge within their specific field. For example, a participant specialising in donor relations may have different insights than an intellectual property lawyer in the access to medicines movement. Another potential approach would have been a focus group discussion but this would not have been appropriate for logistical, ethical and rational reasons.

Firstly, there was geographical diversity among the research participants making a focus group logistically impossible with the study's financial resources. Furthermore, as not all participants live with HIV/HCV, this may have affected the participant's comfort levels when speaking openly about their experiences. Finally, as two participants worked in donor agencies, the participants may have held back critiquing the role of donors in decision-making processes for fear of potential repercussions. Therefore, I decided that one-on-one semi-structured interviews served the research best and were the most ethical qualitative approach to pursue.

4.2. Sampling

This research used a snowball sampling method. This method involved asking research participants to recruit future participants from relevant acquaintances/work colleagues (Naderifar, Goli & Ghaljaie, 2017). As a member of the European AIDS Treatment Group (EATG), a regional network of HIV/AIDS activists, I met with the board to discuss the research project. As EATG is an open forum for all members, I was encouraged to use the forum to recruit for this research project and seek recommendations on research participants who fit the inclusion criteria. No ethical approval was required from within EATG. The recruitment message I sent to the EATG member email list included the plain language statement in English and Ukrainian. The members of the EATG list who fit the inclusion criteria and wished to participate in the research project contacted me directly via the EATG email platform using the contact details they feel most comfortable using. If the potential participant decided to participate in the project, a date and time were established for the interview.

Throughout the research process, I developed relationships with HIV/HCV community organisations. When a community organisation was willing to help with recruitment, a contact person was established, and they contacted potential research participants. This designated contact person had a copy of the plain language statement to provide to any potential participant to read in advance. If someone agreed to participate in the research, this person was provided with my contact details and those of my supervisors. As mentioned above, if someone agrees to partake in the interview, the researcher and participant establish a date and time for the online interview call.

3.3. Inclusion Criteria

The inclusion criteria for this research include HIV/HCV treatment activists who played a key role in the patent opposition and price reduction of HIV/HCV drugs in Ukraine. The participants must be above the age of 18. As this research was conducted in English, a high proficiency in the English language was necessary due to the complex nature of the research question and the detailed discussions needed to achieve the aims and objectives laid out in section 1.5. The interviews required in-depth discussions of procurement processes, challenges related to intellectual property, and the roles of multilateral institutions and free trade agreements was discussed.

Determining what constitutes a high proficiency of English is challenging. This challenge is further compounded by my inability to conduct fieldwork in Ukraine due to COVID-19 and Russia's invasion of Ukraine. While developing relationships with HIV/HCV CSOs, I asked them to recommend treatment activists who were willing and able to conduct an interview in English. This recruitment strategy and inclusion criteria could have been more flexible if I completed my fieldwork in Ukraine. Personal interactions with Ukrainian activists would have allowed me to better assess their ability to participant in the research project, rather than rely solely on recommendations. Due to financial restraints, translators were not used in this research. However, considering the limitations outlined, translators should be considered for future research involving online recruitment and interviews across different geographical and linguistic settings.

To ensure the participant could fully consent to the research project, the plain language statement and informed consent form were translated into Ukrainian.

4.4. Sample Size

To choose an appropriate sample size to answer the research question, I focused on a few considerations. Crouch & McKenzie (2006) argue that a small sample size of less than 20 participants enables the researcher to build stronger relationships with research participants, which enhances the validity and authenticity of the research. Another factor influencing sample size is estimating how many interviews are necessary to reach data saturation (Fusch & Ness, 2015). Failure to capture enough data can impact the quality and validity of the research (Bowen, 2008), while an over-saturation of data can lead to feelings of being overwhelmed (Kvale, 1994), resulting in difficulties communicating the results of research (Josselson & Lieblich, 2003). Guest, Bunce & Johnson (2006) investigated how many interviews were necessary for qualitative research that involved self-reporting of sexual behaviours and HIV prevention in reaching data saturation. This research claims data saturation was reached in a homogenous group after interviewing 12 participants. This conclusion was based on no more novel codes emerging. This study warns that poor data quality, heterogeneity of participants and unclear research goals/objectives can alter the number of participants necessary for data saturation. While aware of this limitation around the judgement of reaching data saturation, this study has clear research goals and objectives. Charmaz suggests that data saturation occurs when 'gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of your data no longer sparks core theoretical categories (Charmaz, 2006 p. 113). While my research focuses on key HIV/HCV treatment activists in national and international civil society organisations, heterogeneity may occur in participants depending on their HIV/HCV status, gender and work specialisation. These variables among research participants may increase the number of interviews needed to reach data saturation.

Another factor when considering the study's sample size was Braun & Clarke's (2021) paper posing the question of 'to saturate or not to saturate?' They argue that applying data saturation to reflexive thematic analysis risks framing the research in a neo-positivist empiricist viewpoint that focuses on values such as coding reliability. In interpretive qualitative research, such as Reflexive Thematic Analysis, determining sample size in advance of

analysis is inherently difficult as researchers often do not know what their analysis will be until it is done, particularly research that is inductive in nature (Saunders *et al.,* 2018; Sim *et al.,* 2018). Therefore, Braun & Clarke (2021) recommend the concept of information power as a pragmatic guide to sample size, i.e. the more relevant information a sample holds, the fewer participants are needed.

Taking into account these considerations, I chose not to set a predetermined sample size. Instead, I chose to wait and gauge the depth of interview participants' contributions and the quality of knowledge derived from the interviews. This would inform whether the data was sufficient in providing a rich, thematic generation process. After each interview, I wrote notes about my reflections on the interviews, and I transcribed the audio recordings. I stopped recruiting participants once it became clear that the research question and objectives had been adequately addressed and that no additional interviews would further contribute to the research.

4.5. Interview Setting

In light of the COVID-19 pandemic, a few complications arose. Initially, I intended to visit Kyiv as I was awarded the RISE Fellowship. This fellowship is awarded to researchers affiliated with DCU who are researching projects in Eastern Europe and Central Asia with a particular focus on social, economic and political transformation.

This scholarship provided funding for me to travel to Ukraine during the months of April and May (2020) to build relationships with HIV civil society organisations, co-generate my research questions with HIV activists, work on my methodology chapter and start the recruitment process. However, in accordance with government travel and health guidelines, this research trip was cancelled. The second and following trip was scheduled for September and October 2020. This trip aimed to conduct my interviews with HIV treatment activists. However, this trip was also cancelled. Therefore, I modified my methodology and ethical approach to overcome the limitations related to the COVID-19 pandemic.

Due to the COVID-19 pandemic, the interviews no longer took place in Kyiv, Ukraine. The interviews were conducted online. The preferred and most secure methods of communication are via the FaceTime and Signal applications. Both of these applications are considered

appropriately secure for interviews that discuss sensitive topics, as outlined in DCU's Zoom and Data Protection guidelines. However, these options were not available to all of the participants. If the research participant did not own an Apple product necessary for a Facetime interview, and if the participant did not use Signal, the option for an interview over Zoom was offered. The informed consent form notified the research participants of Zoom's privacy shortcomings when seeking consent. I also used a DCU Zoom account, which had configured corporate-level security measures. No online interviews were video recorded. Only audio recordings of the interview were used.

4.6. Ethical Considerations

This research received ethical approval from the Research Ethics Committee in Dublin City University. Research that examines the experiences of the activist can place a spotlight on organisational and individual dissident behaviour (Milan, 2014). However, since the Ukrainian Euromaidan protests, the strengthening and protection of civil society have been significant as the public demanded radical reforms to the oversight, accountability and transparency of government institutions and state policing (Pishchikova & Ogryzko, 2014). Another ethical consideration is that HIV/AIDS remains a highly stigmatised condition in Ukraine, which can affect an individual's relationships, work, and future (Demchenko, Sokolova & Bulgia, 2020). As living with HIV/AIDS isn't an inclusionary or exclusionary criterion for this research, there is a strong likelihood that someone living with HIV will participate. If participants become upset during the research process regarding their story of living with HIV, the researcher will take steps to ensure their well-being is prioritised. Before the commencement of each interview, the researcher will ask if the participant has any preferred support services within their organisations or organisations with which they are affiliated. If the participant wishes to speak to someone outside of their organisation, contact details for 100% Life Ukraine will be provided on the Plain Language statement, which will provide information regarding their availability of counselling and psychotherapy support.

This research also acknowledges that living with HIV is not the only vulnerability of the research participants. Other factors that may cause upset or agitation may include stressors relating to conservative government policies, work-related frustrations or oppressive social attitudes towards marginalised people, including sex workers, injecting drug users and men who have sex with men. Research examining transnational activism in the field of

development also places a spotlight on ‘linguistic imperialism’, which stems from English being the dominant language of transnational activism (Baillie Smith & Jenkins, 2017). Power relations within linguistics may arise from the required competencies of the English language for ‘development’ talk.

This may make the research participants feel vulnerable about interacting with researchers from higher-income countries where they receive financial aid (Batliwala, 2002). Additionally, when the research participants are not using their primary language in an interview setting, there is potential for concepts and meanings to be misinterpreted as they can move ‘problematically across cultures’ (Liamputtong, 2010, p. 146). This research seeks to interview people who are highly proficient in speaking the English language to avoid miscommunication or misinterpretation and to mitigate feelings of linguistic vulnerability.

This research examines how activists contest structural vulnerabilities to gain access to essential medicines. Therefore, this research is inherently vulnerable but may also conjure up feelings of empowerment by focusing on their positive contributions to the lives of people living with HIV/AIDS (Byrne-Armstrong, Higgs & Horsfall, 2001). Another ethical consideration that arose during the research process was after Russia invaded Ukraine in February 2022. After I interviewed nine participants, I determined I had enough information power to answer my research question. However, I still had some follow-up questions for the participants. Through discussions with my PhD supervisors, we collectively felt that it would be unethical to ask participants to answer these questions due to the catastrophic nature of the invasion (see section 8.5 for more).

4.7. Informed Consent

Each potential research participant was provided with a plain language statement and an informed consent form before the interview. Both the consent form and plain language statement conveyed as much information as possible clearly and concisely. The two documents were also translated into Ukrainian to ensure that participants could fully understand and consent to the research project. Additionally, at the start of the interview, the research participant was asked if they had any questions relating to the informed consent form or plain language statement.

Involving activists in research could have potentially detrimental consequences such as repression, surveillance, and endangerment to the research participant and their campaigns (Milan, 2014). Due to the nature of HIV treatment activism, the research participant may discuss highly sensitive issues such as sexuality, HIV status, illegal behaviour and political affiliations. In addition, using online interviews as a data collecting method brought up new ethical and data protection considerations. For example, this research asks sensitive questions regarding HIV, challenges and barriers to activism, and access to lifesaving medicines from a distance, which may cause distress. It was, therefore, crucial that I clearly communicated the potential risks of participation, that participation in this study was voluntary and that participants could withdraw at any time.

The consent forms were signed electronically and sent directly to my password-protected DCU email account. The signed consent form sent from the research participant's email was considered an affirmation that the participant signed the consent form.

4.8. Confidentiality

To safeguard the research participants' identities from unwanted attention and surveillance, confidentiality was a key component in the design and implementation of this research. To protect the participants' identities throughout the study, I only documented the participants' first names. Pseudonyms were allocated to each research participant, and I removed the names of geographical locations and names of the organisations. While I make mention of the 'the big three', 100% Life, Patients of Ukraine and Alliance for Public Health in this research, I do not prescribe an organisation to any participant interviewed in this study. I created a digital reference key to match the pseudonym of the research participant. This reference key was safely secured, in addition to the audio recordings and digital transcriptions. Before the interview, I discussed all the potential risks and benefits of partaking in this research and the processes in place to ensure confidentiality.

4.9. Data Management

My research project has an ethical regulatory obligation to protect the participant's sensitive private data and has complied with all relevant aspects of the General Data Protection Regulations (GDPR) and is guided by the DCU Data Protection Office and Research Support Office. (DCU Data Management Report, 2022). Although Ukraine is not within the European Union, the researcher and college institution are still bound by EU policy on data protection.

Files were stored securely and only accessed by the principal researcher. The files will be made available to the supervisors if they require access. As I collected data from my home office due to COVID-19-related restrictions, the data was stored securely for the lifetime of the restrictions and then safely moved to and filed in a secure locker in DCU. Following institutional guidelines, the data will be destroyed 5 years after project completion, allowing for dissemination during that time.

4.10. Reflexive Thematic Analysis

In this research I used Braun and Clark's Reflexive Thematic Analysis (RTA) (2006, 2013, 2019, 2020, 2021, 2022). RTA helped to achieve my research objectives as it is a method that identifies, describes, and interprets patterns of meaning within qualitative data (Braun & Clark, 2020). Furthermore, a main tenet of RTA is that the themes are a product of the researcher's interpretation and engagement with the data (Braun & Clark, 2021). The six phrases of RTA are delineated as follows: (1) data familiarisation and writing familiarisation notes; (2) systematic data coding; (3) generating initial themes from coded and collated data; (4) developing and reviewing themes; (5) refining, defining and naming themes; and (6) writing the report (Braun & Clarke, 2020). While this approach may seem to follow a sequential process, Braun and Clarke repeatedly argue against strict proceduralism within this method/ologies. Instead, the authors encourage researchers to consider these steps as practised-orientated tools to facilitate rigorous engagement with the data rather than a rigid analytical process (Braun & Clarke, 2006; 2021; 2022).

4.11. Reflexivity

Reflexivity is the process whereby the researcher turns the research lens onto oneself. As researchers, we collect and analyse data from the world in which we are entrenched (Emerson, Fretz & Shaw, 2011). Therefore, the researcher must acknowledge themselves as the research instrument and strive to understand the role of the self in the generation of knowledge, as our own personal beliefs, biases, and experiences can have a profound impact on our research (Dodgson, 2019). While I detailed my positionality in the introduction section, I kept a reflexive diary throughout the research process to give the readers insights into my research journey and how this may have interacted with the research process.

The interview questions were developed to align with the central research question and objectives, with guidance from PPT and the literature review. I made a particular reflection on the phrasing of a question that was inspired by a statement I encountered during an online webinar on access to medicines in the EECA region. A prominent Ukrainian HIV activist expressed that they do not believe the MPP works for middle-income countries.

> *'The MPP does not work in MICs? That seems like a sweeping statement. The literature shows that the MPP at least facilitates access to some medicines. Am I missing something?'* (Reflexive Journal - April 2020)

While it was always the intention to inquire about the role of the MPP in Ukraine, the activist's statement led me to reassess my assumptions about how people feel about the MPP. Consequently, I chose to pose the question regarding the MPP's effectiveness in what may be considered a provocative way.

Q) Recently, I heard a prominent Ukrainian HIV activist say that they do not think the MPP works for MICs. What do you think of this statement?

I reflected on whether asking the interview question in this manner elicited a more critical discussion of the MPP. Would a more neutral question like the one below have resulted in less comprehensive responses?

Q) What is your relationship with the MPP, and how has this impacted your access to medicines activism?

Alternatively, might my phrasing have steered the responses to be more critical and not provide a fair dialogue on the merits of the MPP? I do not strive to answer these hypothetical questions. Rather, I outline the process to illustrate the thought process behind formulating interview questions and how it may have influenced the findings. In section 7.4.4, a critical discussion of the MPP is outlined.

Journaling after interviews revealed how my own interview style shifted depending on the speciality of the research participants and whether they lived with HIV/HCV or not. For example, when interviewing people openly living with HIV who work more within the human rights field, I found my tone shifting toward a more energetic tone. For example, I noticed more energised conversations regarding answers that focused on how political, public and media spheres reacted to the participants' access campaigns. I believe this shift in tone is a result of the familiar. As a grassroots HIV and A2M activist in Ireland, campaigning and 'development' talk is generally both emotive and energetic. Mirroring this behaviour could result from the infectious nature of 'development' talk or stepping into familiar territory.

> '*My conversation today with a research participant who lived openly with HIV felt friendly and interpersonal. Interestingly, I've noticed that participants living with HIV/HCV would often expand on points 'off the record' to provide me with a more nuanced understanding of their lived experience. These interviews tend to last longer also, although that could be coincidental and just relate to more open time schedules. My conversation yesterday with a participant working in intellectual property law demanded more attention as detailed accounts in technical language were provided. Although I believe I have some knowledge of intellectual property rights, I felt slightly out of my comfort zone as this participant speaks in more legal terminology than I am used to - imposter syndrome most definitely kicking in (Reflexive Journal - June 2021).*

On the flip side, actively listening to topics that were not absolutely familiar to me was more of a challenge. In particular, the work on the Patent Law Reform was quite technical and demanded much of my concentration. However, throughout these moments of the interview

process, I was acutely aware of their importance. Despite the technicality, the information offered first-hand, comprehensive insights into the mechanisms involved in enacting change to IP rights. However, I felt out of my comfort zone as I was fearful that if something critical went above my expertise and over my head, I could miss out on a vital, nuanced element of their work.

Given the online format of the interviews, I took deliberate steps to build rapport with each research participant before commencing the interview. This initial engagement with the participants was designed to ensure that the participants felt more comfortable discussing a range of issues, including the evolution of HIV stigma, the experiences of people living with HCV and their access to medicines, and topics related to intellectual property and political relationships building.

During the preliminary conversations, the research participants and I briefly addressed our perspectives regarding COVID-19 restrictions and our feelings around governance during the pandemic. I also discussed my role as an access to medicines activist in Ireland and my involvement with the European AIDS Treatment Group (EATG), a prominent European HIV organisation active in the EECA region. By presenting myself as someone living with HIV, an activist working on intellectual property issues both nationally and internationally, and as an active member of the European Community Advisory Board, I aimed to establish credibility and a sense of camaraderie. I used my status as an insider and outsider to validate my understanding of the complex issues at hand and highlight my willingness to learn about their role in Ukraine's A2M movement.

I believe these efforts contributed to creating an atmosphere of openness and professionalism. As noted in the journal entries outlined above, the discussions were conducted using technical language when addressing specific issues such as supplementary protection certificates, free trade agreements, and data exclusivity. A more energetic tone was employed when delving into nuanced human rights issues affecting PLWH. For instance, some participants shared personal experiences of stigma and human rights abuses '*off the record*', which provided me with a deeper understanding of the social context of living with HIV/HCV in Ukraine. These confidential anecdotes, although not included in the research, underscore the trust and openness that characterised the interview environment.

Conversely, during the interview process, some participants remarked '*you probably already know this*' or '*I don't think I am adding to what you already know but …*'. To address this, I reassured the participants that their experiences and insights into the access to medicines movement in Ukraine were valuable, irrespective of my prior knowledge. I believe this intervention helped to alleviate the doubts of the participants and reinforce the significance of their contributions to this research.

I now present how I engaged with the six phases of Braun and Clark's RTA.

Phase 1: Data Familiarisation and Writing Familiarisation Notes:

I familiarised myself with the data by conducting every part of the data collection process, from developing interview questions, recruiting research participants, conducting online interviews and then transcribing them. As a result of the pandemic, the use of video calling became commonplace to carry out research interviews. This was both beneficial and a disadvantage for data collection and transcribing. Firstly, it was beneficial, as it facilitated the inclusion of people who worked as HIV/HCV treatment activists but who lived outside of Kyiv, Ukraine. The reliance on an internet connection introduced challenges, with some participants experiencing internet connection issues. Two times, participants had to disconnect from the interview and log back in. As a result, they had to start over and repeat what they said, essentially disrupting them from their stride and making rapport-building more difficult.

As suggested by Braun and Clark (2021), I did not take notes during my first playback of the interview recordings and actively listened to the research participants. For transcription purposes, the bad internet quality made some transcribing difficult, making some interview sections fragmented. However, after transcribing, listening to the interviews many times, and taking detailed notes, I felt engaged with the interview data before actively engaging with the analysis. I also used a reflexive journal during this stage to collect any thoughts I had on the research participants during the interview and transcription processes.

'*Transcribing interviews today was tricky as the internet cut off during this particular interview. The disruption notably affected the participant's stride. Also, the times when sentences were incomplete due to a patchy internet connection sometimes made it difficult to fill in the gaps. Worst of all, I could see how the patchy internet affected my ability to focus as I remember my eyesight kept moving towards the 'poor internet connection' notification. Perhaps I should have stopped the interview altogether and restarted it when the internet connection was improved for both of us. However, the internet issues occurred at the end of the interview, and we both agreed that it was ok to continue.' (Reflexive Journal - June 2021)*

Phase 2: Systematic Data Coding:

I started this phase by going line-by-line through each transcript. I took an active part in this process, as anything I identified as meaningful was initially coded and written in a column beside the transcripts (Maguire & Delahunt, 2017; Braun & Clarke, 2021). Overall, the interviews accumulated 91,313 words, resulting in a slow, difficult analytical process. However, each time I approached the data, I reviewed the analysis and generated codes with fresh eyes. It also encouraged me to write longer codes to remember my thought processes but also to provide insight into the nuanced socio-historical reasons behind many of the participants' experiences. I began to identify patterns in the data and colour-coded them alongside generating codes. For example, an initial code was political leadership. However, due to the political pluralism found within the Ukrainian government after Euromaidan, I knew I had to differentiate between the types of political leadership. Therefore, I wrote more nuanced notes typifying the political appointees' reformist or regressive attributes and how the participant regarded the politician.

Phase 3: Generating Initial Themes from Coded and Collated Data:

Reflecting on the codes generated in phase two, I continued to look over the whole dataset and used my notes to expand the identified patterns in the data. This resulted in the synthesising of related codes and placing them into potential themes and sub-theme categories. These themes were generated based on their salience to answering the overall research questions and not contingent on the number of codes referring to a particular phenomenon (Braun and Clarke, 2013). These themes were of a semantic and latent nature,

underscoring the explicit, objective truths of activism and governance in Ukraine and the interaction of the researcher's and participants' underlying ideas and assumptions about the complex nature of activism in the knowledge economy.

There was clear heterogeneity in the interviews, especially relating to the participant's different areas of expertise, such as donor relations, intellectual property rights, trade frameworks, human rights, etc. To counteract this, I tried to give a loose indication of prevalence and alternative views so the participants could 'talk' to each other in the findings section. For example, the salience of increased HIV/HCV CSO's influence on the political process was prominent in the interviews. However, ontological questions arose about how much authority a CSO should have in political processes and if growing professionalisation leads to a disconnection with a CSO's ground base. This provides an example of how I wove together differing perspectives to generate themes and subthemes, highlighting the evolution of CSO influence but also considering the undercurrent of perceived negative drawbacks with CSOs increasing authority.

Phrase 4: Developing and Reviewing Themes:

During this phase, I conducted a recursive review of the initially generated themes, relating them to the coded data items and the entire dataset (Braun and Clarke, 2020). Firstly, I reviewed the relationships between the coded data and interview transcripts to identify if the themes and sub-themes are of high quality and are meaningfully supported by the data. I then reviewed the themes in relation to the overall dataset to understand if the theme is appropriate to inform the interpretation of the dataset. This resulted in many initially generated themes being re-categorised as sub-themes as they ultimately told the partial story of an overall theme. For example, I originally categorised section 6.2.2.1 as an overall theme as the participant's complicated relationship with pharma was a salient point throughout the interviews. However, on reflection, it belonged as a subtheme situated within a larger exploration of CSOs interactions with the pharmaceutical industry as the word 'complicated' did not fully capture the importance, nor the nuanced and contextual nature of their relationship.

Phase 5: Refining, defining and naming Themes:

At this stage, I ensured that each developed theme and subtheme was expressly related to both the dataset and the research question. Areas of overlap in the findings were identified and refined. Each theme and subtheme were named to ensure they represented the data and research questions appropriately. Braun and Clarke (2006) argue that the names of themes and subthemes should be concise and give the reader an instant sense of what the theme is about. This was tricky in some instances but really brought to light what I truly described while the theme developed. For example, I initially had a theme of 'Shifting Procurement Powers' to outline the complex machinations associated with removing procurement powers from government control to international agencies. Reflecting on the name, I knew it did not give the reader a true insight into the purpose of the theme. Therefore, I changed it to 'Decentralised Procurement, International Procurement, Best Practice Procurement: Ukraine's Journey towards Transparency'. This instantly gives the reader insight into the moving nature of procurement powers. It gives a sense that Ukraine is evolving from corrupt to transparent practices. The reader begins to understand that shifting procurement powers is a conduit to highlight the sweeping reforms that are taking place.

Phase 6: Writing the Report:

During the write-up stage, I first established a structure to report the themes. Braun and Clark (2006; 2021) posit that themes should connect in a meaningful and logical manner, building a thesis that flows for the reader. To do this, it required an iterative process of revisiting earlier phases to ensure that the themes are representative of the data and answer the overall research question. The significance of the themes is further extrapolated by understanding their implications within broader social movements and access to medicines literature in the discussion chapter.

4.12. Conclusion

In this chapter, I present Political Process Theory, the theoretical framework adopted for this research. Additionally, I introduce the conceptual frameworks of navigation, the knowledge economy and the professionalisation of CSOs which will collectively guide this research. I have presented a rationale for selecting PPT as the most fitting social movement theory to answer the research question. I also explored the critical perspectives of PPT and underscored why it is necessary to modernise to suitably understand the dynamic of movements that engage with more actors to enact change, beyond the state, such as international corporations and multilateral institutions. Braun & Clarkes' Reflexive Thematic Analysis (2012; 2019; 2022) approach was selected for this research as it is a versatile and accessible method for interpreting qualitative data that facilitates the identification of recurring patterns or themes within a dataset. This reflexive approach to thematic analysis emphasises and values the active role of the researcher in knowledge production. Through engaging with reflexivity throughout the research journey, I aimed to give the readers insights into how much my positioning as the researcher shaped the findings. Furthermore, I provided insights into the research process including data collection methods, ethical considerations, and data management. The next two chapters present the findings of my research interviews.

Chapter 5. Findings I - From USSR to a 'new' Ukraine

Chapter 5 is made up of two sections. The first section highlights participants' perspectives on how the lived experiences of those living with HIV and HCV in Ukraine have evolved over the past twenty years. In the second section, the participants describe the political window of opportunity for sweeping reforms in Ukrainian governance, institutional and trade spheres. Overall, this chapter underscores the importance of Ukraine's desire to leave behind Soviet legacies, as it provides an opportunity for the participants to reimagine, and fight for a new, more progressive Ukraine. As I was not looking into the lived experiences of the research participants, I opted to collect data that would provide context to their involvement in HIV/HCV treatment activism only.

Table 1: Participants' Profiles

Name	Organisation Role	Year of Interview	Living with HIV/HCV	Country of Origin
Anna	HCV Organisation	2021	No	Ukraine
Irina	Donor	2021	No	Ukraine
Nastya	Human Rights/Access campaigner	2021	Yes HIV	Ukraine
Daniela	Human rights/Access campaigner	2021	No	Ukraine
Oleg	Donor	2021	Unknown	Ukraine
Davyd	Intellectual Property Lawyer	2021	Unknown	Ukraine
Ivan	HIV regional network	2021	Yes HIV	Russia
Oleksandr	Human rights/access campaigner	2021	Yes HIV & previously HCV	Ukraine
Pavlo	HIV regional network	2021	Unknown	Germany

5.1. The Evolution of the HIV and HCV Social & Medical Landscape

In this section, participants outline the experience of HIV and HCV stigmas, and how their organisations are attempting to overcome culturally ingrained 'Soviet thinking'. The participants highlight the tensions between public health, societal attitudes and cultural change, especially in relation to key populations. The evolution of access to ARVs and DAAs is also explored. Nastya, Anna and Oleksandr provide insights into Ukraine's treatment landscape for both HIV and HCV from between 2003 and 2020. These accounts foreground the complex interaction of history, culture, politics, and societal change when discussing the topic of access to medicines, public health and HIV/HCV.

5.1.1. HIV Stigma, Key Populations and Societal Change

Four research participants discussed their personal experiences or experiences of PLWH/HCV, and how it has evolved over time. These accounts provide an important, nuanced insight into Ukraine and how much it has evolved over the past few decades, critically bringing to light the role of activism, but why activism is needed in the first place.

Nastya, a research participant who lives with HIV, outlines the experiences that PLWH face in Ukraine.

> *Nastya: Some of my friends were on the street because their parents told, [...] you don't belong to this place anymore, so go and make a life with the people who gave you this disease. So some relatives cut all the connections. So some people were fired just because of this.*

Nastya indicates a complex interaction of different stigmas and how the interlinked and damaging nature of enacted, internalised and perceived stigma can lead to living '*every day under psychological pressure*'. Nastya further extrapolates on the experiences of HIV stigma, arguing that people are still stuck in the narrative of the twentieth century. Nastya underscores the failure of public health campaigns in changing the narrative that HIV exists outside of key populations when she mentions that the government or civil societies '[...] *didn't inform general populations'*. This relates to transmission rates being the highest among heterosexuals, albeit only considered a problem within the PWID community. This suggests

that Nastya identifies a link between the stigmatised identities of key populations, lack of HIV representation and a continued HIV stigma, *'[...] when I'm like in my white dress, my high heels, my like master's degree, nice position—oh, such a nice job. Yeah, it's so—she can't be HIV positive. But I can!.'*

Ivan highlights how the prevailing social values against key populations are still permeated throughout post-Soviet countries. He provides the example of his mother's ten-year journey of unlearning 70 years of '*Soviet Union thinking',* or conditioning of hatred towards homosexuality '*to understand*' his sexuality. This highlights the contention between granted legal protections for marginalised groups and cultural acceptance. Before the Russian invasion, attendance at Kyiv Pride grew from 50 participants in 2013 to 5,000 in 2018. Anna identified the Ukrainian gay rights movement as a barrier to cross-country collaboration on HIV projects in the EECA region. This discordance is defined by '*traditional*' countries opposing the more liberal, European way, '*we don't need key populations, we don't need to engage people there, we are fine with dealing with HIV. But we don't need this. Like in what they call Gay Europe.'*

While this may suggest that Ukraine is spearheading social reform for the LGBTQ+ community, Anna also highlighted that gay and bi people did not want to sign up for the subsidised PrEP programme as they did not want to be registered as a member of the LGBTQI+ community on a government database. This underlines the precarious position that Ukraine's LGBTQ+ community finds itself in. As they gradually distanced themselves from Post-Soviet ideology, some participants suggested that people still felt ruled by an untrustworthy government with a history of abusing power and criminalising marginalised groups. This has implications for important public health interventions. Is PrEP, a key HIV prevention tool, considered a poison chalice by the key populations that would benefit most? This suggests that making an effective preventive tool free is not the only pragmatic intervention for uptake. The participants argue that trust in the government and institutions plays a vital role.

Before the Russian invasion, key populations lived in a precarious space between legal and political uncertainty, through slowly shifting societal attitudes towards marginalised groups. While this research did not explore in depth the lived experiences of PLWH, the data highlights the participant's desires to celebrate their progress, outlining the ongoing issues

and distancing from the *'traditional'* Soviet mindset. A disconnect arose in the interviews in relation to the lived experience of PLWH. The participants who worked primarily on access to medicines identified the evolution of HIV through a more clinical lens, focusing on virological suppression and accessibility to medication.

The participants who lived with HIV engaged with a more holistic narrative around lived experiences, including societal attitudes towards PLWH, feelings of overcoming self-stigma and the need to pursue increasing quality of life indicators. All participants acknowledged that Soviet thinking about key populations and HIV is still prevalent in Ukraine and that its oppressive nature negatively affects their HIV response.

While articles often present a similar narrative that Ukraine is ridding itself of its soviet past by advancing LGBTQ+ equality (Toren, 2024) and contrast with Russia's continued defence of 'traditional values' against Western ideals (Reid, 2023), this dichotomy of Russia is bad, West is good for social equality oversimplifies a more complex reality. The reality is much more nuanced than what both anti Russia commentary and what the research participants may suggest.

Janssen & Scheepers (2019) identified religiosity, authoritarianism and traditional gender beliefs as some of the strongest socialising determinants to explain homophobia. Religion, in particular, is a powerful socialising force as it influences so many aspects of a person's life including religious practice, belief systems, experiences, knowledge and the ensuing consequences of religiosity (Stark & Glock, 1968). Studies have found that participation in religious communities or groups exposes people to more direct, negative attitudes towards homosexuality and to other ethnic minority groups (Schulte & Battle, 2004; Whitley, 2009; Janssen & Scheepers, 2018). Janssen & Scheepers' (2018) study also found that homophobic attitudes persist even countries that have become more secular, raising the question about the enduring influence of religion on moral attitudes post-secularisation.

Studies have shown how authoritarianism creates a divide between in-groups and out-groups, often categorising people from the LGBTQ+ community and other ethnic minorities as out-groups. This is part of a broader effort by authoritarian regimes to construct societies built on traditional values versus "non-traditional" sexualities (Altemeyer, 1998; Janssen & Scheepers, 2018; Morris, 2023). However, scholars also argue that everyday forms of

homophobia and heteronormativity have their origins in complex social phenomena and historical legacies beyond geopolitically-motivated hatred. Morris (2023) argues that Russian people appear to be more accepting towards privatised same sex relationships than what the polls may suggest, but the language of Russian propaganda is often reproduced and frequently echoed in social discourse. Furthermore, Oswin (2006) argues that western identity politics is not applicable to countries such as Ukraine and Russia given their limited histories of civic recognition of sexual identities.

Traditional gender beliefs also play a significant role in fostering homophobia. Scholars have highlighted how homosexuality poses a threat and violate the binary of masculine and feminine behaviours (Kite & Whitley, 1996; Janssen & Scheepers, 2018). Bureychak (2012) explores the complexities of masculinities in post-Soviet Ukraine arguing that the country experienced a patriarchal renaissance or a form of gender neo-traditionalism after it gained independence from the USSR. This shift is attributed to the ideals of the masculine being shaped by the historical figure of the 'Cossak' - a knight-like figure characterised by strength, fearlessness and an absence of weakness or emotion. This renaissance occurred after independence when there was huge unemployment and subsequently a larger distribution of jobs among men and women – removing the patriarchal ideal of the man as provider and fighter (Bureychak, 2012). While I do not intend to go into Ukrainian masculinity studies, this provides an insight into a renewed ideal of the masculine in independent Ukraine, and why this may contribute toward a homophobic society as there is a belief that homosexuality further threatens society's gender ideals.

The primary aim of this study is not to focus on the rate of progressive change for people living with HIV or its key populations. Yet, outlining the interplay between geographical tensions, historical legacies of the Soviet era, societal attitudes and public health outcomes helps marry the different dimensions which inform structural shifts in governance and the role of CSOs. The findings in this section also challenge the notion that the progression of the Ukrainian state and its HIV/HCV response is solely dependent on eliminating Soviet thinking and influences. It underscores the more complex and nuanced root causes of issues related to the stigmatisation of ethnic minority groups, including the LGBTQ+ community.

5.1.2. Selling a Kidney for a Liver: The Evolution of Access to HCV Treatment

Before the availability of the Direct-Acting Antiviral treatment Sofosbuvir on the Ukrainian market, Oleksandr claims that gaining access to interferon treatment seemed more hopeless than gaining access to HIV treatment, as he often was told:

> *Oleksandr: 'it's very expensive [...] around fifteen or sixteen thousand dollars. So it's like, as we always say, to sell one of your kidneys to buy treatment for your livers!*

Oleksandr highlights the stark challenges faced by people living with HCV. He compares an optimism around the potentiality of gaining access to ARVs once the CD4 count reaches a certain level, to the impossibility of gaining access to interferon treatment. He refers to the high cost of existing therapies as the main barrier to gaining access, and as a consequence, must '*just take some protectors*'. I assume that Oleksandr is referencing '*protectors*' as taking available treatments to mitigate most of the side effects of HCV. His analogy of '*selling one of your kidneys to buy treatment for your liver*' illustrates the absurdity and desperation of the situation where exorbitantly high-priced medicines demand that you sell a body part to pay for another.

The toxicity associated with interferon treatment is well documented. These studies show that interferon-based treatment can induce severe physical and psychiatric side effects, produce substantial detrimental effects on mental functioning, affect adherence to treatment and greatly reduce the quality of life (Dieperink, Ho, Thuras, & Willenbring, 2003; Hopwood & Treloar, 2005). This underscores the desperation and urgency people living with HCV experienced to 'sell one of your kidneys to buy treatment for your liver', a treatment that doesn't have a 100% success rate and negatively affects the patient's health and wellbeing (Manns *et al.,* 2001). Similar to the experience of PLWH, access to HCV treatment before establishing the National HCV Programme seemed conditional on the capitalistic dichotomy of money consuming/earning, another example of out-of-pocket payments being the antithesis of the Shamasko healthcare philosophy.

For Oleksandr, the Odyssey began with people being told there was no treatment, or that the substandard treatment was too expensive and could only be found elsewhere. Then, Interferon became available for some but remained conditional on disease severity, or on the

wealth of the person affected. The access story ends with access to a novel cure with little toxicity but may require out-of-pocket payments. This resulted from the Ministry of Economic Development and Trade of Ukraine refusing to grant intellectual property rights to Gilead for the HCV drug, Sofosbuvir.

Section 6.2.3.1 outlines the Sofosbuvir patent opposition case in more detail. This decision allowed generic competition, and the price of the lifesaving drug dropped three-fold by 2020. Yet, this price reduction was not fully subsidised by the Ukrainian government and is still considered burdensome. Anna mentions that 'it is not unimaginably burdensome for many'. She remembers when Ukraine became '*the place where people go to get treatment' [...] the whole thing that you can technically buy a treatment but it's not this unimaginable burden for many—it's been a really huge change, I find.'*

Anna clearly indicates how the financial cost of available treatments has decreased, thus generating broader accessibility to HCV treatments. Before the introduction of cheap DAAs, you needed to have stage four cirrhosis to be eligible for treatment. She also mentions how the introduction of an HCV National Programme (elaborated further in section 5.1.3) and reduction in the price of treatment means that more can avail of Sofosbuvir at a cost that is not ''*unimaginable burden for many*'. When asked about the extent of public expenditure on access to HCV treatment, Anna stated that it depends '[...] *on the budget and the budget every year is changing*.' Anna explains that approximately 10,000 out of the million people living with HCV in Ukraine were availing of state subsidised Sofosbuvir. However, this was expected to increase when the patent on Sofosbuvir ended in 2020. Each participant described the change in circumstances around access to treatment as fundamental, whilst also acknowledging that some barriers are still in place.

Firstly, it is apparent that a national programme for the elimination of HCV was only possible once the treatment price was reduced. Secondly, while public expenditure exists for access to treatment, some people are still required to self-finance some of the costs. Additionally, Anna's concern is that the procurement of access to treatment is linked to the uncertainty associated with an ever-changing government, and its healthcare expenditure commitments. Despite this uncertainty, the participants felt optimistic that the HCV programme was going in the right direction, and worries about the future of the elimination strategy were not prevalent within their interviews. However, it could be argued that this optimism contrasts

with literature highlighting key barriers to the elimination of HCV in Ukraine. Colombo *et al.,* (2019) identify barriers to eliminating HCV related to accessing diagnostics, insufficient epidemiology data, financial constraints, outdated national guidelines and a scarcity of second line DAAs. This highlights that although HCV/HIC activists fought for a reduction in the price of DAAs, there still remains considerable policy and financial gaps in reaching their goal of eliminating HCV. While the research participants did note that the HCV programme was going in the right direction, the significant barriers outlined in Colombo *et al.,* (2019) study suggests that discussions on the participant's policy wins could have diverted attention from ongoing policy needs.

While, it is evident from the above excerpts that access to HCV treatment has been radically changed for people in Ukraine, HCV remains a huge public health issue. Still, the experiences in terms of treatment have evolved, whether this is in relation to access to specialised healthcare workers and/or their access to treatment. Despite research showing persistent policy gap in achieving HCV elimination, it is remarkable how Ukraine transformed from a place where you had to '*sell a kidney for liver treatment*' to a health tourism hub for people to gain access to the relatively cheap HCV cure, Sofosbuvir.

5.1.3. System Changes, Integration and Collaboration

Anna recollects the significant shifts that occurred in HCV activism in 2011/2012. Increased resource allocation to the HCV movement provided the necessary financial, political and human capital to advance her CSO campaign goals. Anna is the only participant to discuss the consolidation of HIV/HCV organisations. I believe this may be due to Anna being the only participant to work primarily in an HCV CSO from 2010-2015, prior to consolidation. Anna begins by recalling her motivation for starting to work at the organisation and the attitude of her managers.

> *'And they are both, like, very powerful people who like 'we need to change the system'. And that was their approach. It's like, 'we need to change the system'.*

Anna adhered to the organisation's ethos, based on an understanding that effective HCV activism was predicated on changing the system. Admittedly, Anna laments that her small organisation could only do so much to 'change the system', but that all changed around

2011/2012 when HIV organisations started to take an interest in HCV. According to Anna, this consolidation was due to funding imposed by donors and generated active collaboration between her organisation, larger HIV organisations and the government. For Anna this consisted in a breakthrough: *'But I'm finding this was a big breakthrough* [...] *the subject became more vocal* [..] *More people would talk about this* [...] *It's definitely something that had an impact.*

Anna outlines two important points. The first is the chronology of activism is significant. The focus of this research is predominantly examining activism after the Euromaidan Revolution in 2014, but Anna highlights that much groundwork occurred beforehand with the integration of HIV organisational resources. Tangible outcomes of HCV activism were felt immediately after consolidation due to the collaborative nature of these forums, which encouraged the sharing of expertise and influence.

This form of dynamic interactivity is highlighted in Vigh's (2006; 2009) theory of navigation. For Anna, the motivational drive to '*change the system'* was constantly exposed to differing political environments before and after Euromaidan, alongside a more sympathetic and mobilised civic society (section 2.2.1.), and increased resources available throughout her period of treatment activism. While HIV and HCV are both blood borne infectious diseases with specific public health interventions and needs, the effective and novel collaboration between these relatively distinct areas demonstrate a high level of adaptability and manoeuvring to collectively address issues related to HIV and HCV. Vigh's (2006; 2009) concept of 'motion within motion' is exemplified in the consolidation of HIV/HCV activism which created a united movement toward equity. By increasing resources, specialised collaborations with CSOs in areas such as IP work and data collection, an access to medicines movement began to strengthen. This A2M movement then effectively capitalised on the political opportunities that arose after the Euromaidan Revolution.

This section did not go into the actions that CSOs took to ensure that a national programme and specialised healthcare existed, and that access to lifesaving treatments was readily available. However, it is evident that HIV and HCV organisations successfully navigated consolidation and a changing funding landscape to provide the human, financial and political capital to further the CSO's agenda. As Oleksandr, a person co-infected with HIV and HCV since 2003, expressed, the experience of gaining access to HCV treatment felt more

insurmountable than access to HIV treatment. The evolution of access to HIV treatment is further discussed in the next section.

5.1.4. HIV Treatment: A Golden Ticket to 100% Access

Oleksandr uses the analogy of a '*desert*' in 2003 to describe access to lifesaving HIV treatment in Ukraine when he says, '*I mean desert in terms of treatment, in terms of access to treatment, in terms of even proper information for people living with HIV or facing first ever in their lives with the HIV status'.* Oleksandr and Nastya agree that being diagnosed with HIV in the early 2000s resulted in a deadly waiting game, where there is 'a l*ack of everything. And lack of even understanding what to do maybe'*.

Due to the rationing of a limited supply of ARVs, PLWH had to wait until their CD4 count dropped below 200/ml to '*potentially gain access.*' Unlike in high-income countries, the availability of treatment was based almost solely on international donors. As Oleksandr states in his testimony, two ways of ensuring access to treatment included knowing influential people or a person's ability to bribe a doctor. Other access issues experienced by healthcare providers included ARV stock-outs or the inability to add more people to the HIV Medical register. In the early 2000s, gaining access to treatment was the equivalent of giving someone the '*golden ticket of life*' and was experienced more as a game of luck or privilege and not one based upon a public health and moral mandate, where PLWH were sold *'[...] a ticket to life.'* The participant's experienced this as a time of government abandonment, relying heavily on international and industry donations. Oleksandr also highlights that people recognised the need for access to treatment in 2003, but nothing was available: *'[...] there was nothing at the moment.'*

In 2011, Nastya's account was similar to Oleksandr's experience as she did not start treatment until her CD4 count declined to low levels. According to Nastya, the doctor pleaded with her to begin treatment as her blood markers made her a candidate to start treatment, an offer that would not have been made otherwise: *'If you will start right now we have free medications, free ARVs now. But if tomorrow they will not procure and you will need it, really like a need, we cannot prescribe it. So start it now.'* The doctor believed that the rapid decrease in Nastya's CD4 count might be a blip or a fault in the diagnostic machine, but it presented Nastya with an opportunity to start treatment: '*You have 147 [CD4 count] that we believe that*

it's a mistake, but it's your chance.' The participant stated that she felt pressured to start her treatment as the doctor explained that many people were waiting for treatment. Harrowingly, the availability of more treatment only became available when someone on ARVs died: '[...] *someone from this queue will have this treatment if someone will die'.* This highlights the neglect and inadequate machinations of the government procurement system as outlined by the queues mentioned: '*We have a queue for medications for most of the one thousand people'*. The above excerpts highlight that access to ARVs evolved from a *'desert'* in 2003 to limited availability dependent on a person's CD4 count, relationship with their doctor and if a previous person on ARVs died.

However, all research participants highlighted that by 2020, access to ARVs in Ukraine was almost universally accessible and was not conditional on CD4 count. Now PLWH in Ukraine has access to many different types of medicines, and old fears of treatment stockouts have been almost eradicated, as highlighted by Oleg, '*like, say, in 2014, 13 and 15, like, say, five years ago, there could be situations where like medical facilities could ration in a way or try to delay prescription of treatment for various reasons, like saying, oh, we're out of stock*.' Oleg identified that the burden of the state procurement budget has been reduced due to increased access to affordable treatment and less opacity in procurement processes, leading to '*less stealing by the state*.'

In this section, the participants' accounts span over 17 years, from 2003 to 2020. Within this timeframe, a noticeable shift in access to quality treatment regimens is evident. Coinciding with the increase in access to HIV and HCV treatment, Ukraine was experiencing paradigm shifts in governance and financial and community mobilisation structures. The next section provides an insight into the relationship between these paradigm shifts and access to medicines by examining the temporality of political opportunity.

5.2. The Temporality of Political Opportunity

In this subsection, we are going to see how participants make a connection between the window period for sweeping reforms in Ukrainian political and healthcare reforms and the momentum generated by the Euromaidan Revolution. Yet, the Revolution does not account for these reforms in their entirety. This section outlines how the movement towards a 'new

Ukraine' started prior to Euromaidan, what key healthcare and political reformations occurred post-Revolution and what factors precipitated its closure.

5.2.1. Activism Before the Revolution of Dignity

All participants in the research underlined the significance of the Euromaidan Revolution as a turning point for comprehensive healthcare reform. Euromaidan was significant as it represented the rapidly changing social atmosphere away from Soviet legacies, impacting corruption, top-down governance structures, and a failing healthcare system.

The participants emphasised that the HIV-positive community understood that access to treatment was a primary concern and goal for activists. However, before 2013, the capacity of activists to achieve these goals was hindered by political incompetence, corruption and a gradually maturing patient community. Yet, huge inequities regarding access to essential medicines existed, and the environment for effective activism was contentious and dangerous, as outlined by Irina:

> *'A special service security service General was blown up in his car for his investigation on the prices of TB drugs in Ukraine and neighbouring countries, showing that Ukraine was procuring some TB and HIV drugs twelve times more than neighbours in Moldova, Belarus, and even Russia.'*

Irina highlights two salient problems in Ukraine before Euromaidan. The first focuses on the dangerous environment for activists trying to overcome the opacity of drug pricing. The second is that Ukraine paid an estimated twelve times more for HIV and TB drugs than its neighbours. The motivation behind the General's assassination points to a conundrum faced by activists: must they put their lives in danger to save the lives of patients in danger? Despite the perceived and real dangers associated with activism, the participants highlight their ongoing efforts to reduce the prices of medicines.

Euromaidan was seen as a turning point by all participants regarding A2M activism, but Irina identifies two convergent timelines in relation to health activism. Irina believes intellectual property activism was maturing before Euromaidan, while other healthcare reformations occurred after the revolution. The knowledge gap of the role of intellectual property in

relation to access issues was beginning to be filled before 2014. In addition to the government, the principal recipients of The Global Fund would procure medicines for treatment provision to the HIV-positive community. Ukrainian CSOs, such as 100% Life and Alliance for Public Health Ukraine, would put out a tender for ARVs, *'They were buying from international. Like basically it was a model of international procurements done locally for Global Fund.'* The CSOs would put out a tender to GF pre-qualified manufacturers with key requirements including, *'For quality of the medicine, for the date of supply, etc. And we obviously are interested in selecting the cheapest one who will comply with all the requirements.'* This tendering process brought HIV activists face to face with intellectual property barriers to accessing affordable medicines as it prohibited them from procuring generic medicines. This initiated an interest in learning more about intellectual property and ways to circumvent the IP through effective activism.

Davyd references 2014 as a turning point for IP activism, not completely related to Euromaidan itself, but their interactions with procurement processes and increased funding streams that aimed to help overcome IP barriers. Davyd acknowledges a critical moment before Euromaidan, his organisation's work in procurement, introducing them to the issues related to intellectual property. This prompted activists to delve into IPRs, patent searches and access to medicines activism. Davyd highlights the importance of the ITPC Global funding stream his organisation received in 2014. The funding allowed his organisation to engage in activities specifically related to overcoming IP issues (further elaborated in sections 6.1.1 and 6.1.1.2). Additionally, Davyd acknowledges that the grant approval was based upon previous work that highlighted CSO competencies, including '*analysing patent status of medicines and looking through the laws, how and in what situation we could choose generic medicines, in what situation we are obliged to procure only patented medicines, etc.'*

One function of the Principal Recipients of the Global Fund in Ukraine, namely Alliance for Public Health Ukraine and 100% Life, is to procure ARVs for PLWH. This resulted in two procurement streams, one from government procurement and another from CSOs. Unlike CSO procurement processes, the government's procurement practices were mired in opacity and embedded in a web of corruption, as outlined in the interviews of Davyd, Irina, Oleg, Pavlo and Daniela, underscoring their desire for systemic change:

Daniela: Because before the Revolution of Dignity in 2014, we also monitored how the state procures medicines and we saw that up to 40 percent of state costs were laundered.

The state procurement process was described as a complex set of machinations. The local Department of Health centres and doctors estimated the quantities of medicines that needed to be procured. The Ministry of Health would then approve these estimations and be responsible for setting the procurement budget. The state procurement budget was co-created with the use of '*middlemen*' who would negotiate with pharmaceutical companies for pricing contracts and were found to add a percentage on top of the manufacturer's price. This additional percentage is then shared between government officials and other intermediaries.

The activists also acknowledged that the pharmaceutical industry was trying to influence these processes by partaking in these laundering schemes to receive preferential procurement deals. The difficulty for CSOs to dissect these complex and densely interwoven processes is that they were all shrouded in hidden agreements and secret negotiations. Thus, this decentralised procurement system created optimum conditions for a corrupt symbiotic relationship between the state and the pharmaceutical industry. As outlined by Irina, it is '*not only the very bad big pharma that manipulates the market and the government officials, but it—or the government officials as well who were trying to benefit the most from the pricing from whom they allow into the market'.*

Foreign aid organisations such as The Global Fund, OSF and ITPC etc., aided CSOs in better understanding the intentionally complex and corruptible Ukrainian procurement system. Sharing technical expertise with community activists created a culture of best practices and correlated to the professionalisation of activists while continuing to shine a light on government incompetencies and corruptive nature.

The concept of a maturing movement needs careful consideration. The formalisation of the All Ukrainian Network of People Living with HIV (now 100% Life) in 2001 marked a significant development. While this research primarily focuses on treatment activism between 2010-2021, it is noteworthy that the Open Society Foundation provided grants to 100% Life for medical procurement of ARVs, albeit in small numbers. However, this time period was also characterised by significant policy issues such as stigma and discrimination in healthcare

settings, unsustainable government financing of the HIV response, and widespread corruption in procurement processes. Despite the multitude of policy issues, 100% Life was also fighting for transparent drug procurement processes and access to second and third-line treatments (section 2.3.2.). This underscores that even though access to ARVs was severely limited, CSOs were fighting for improved access between 2001-2010 and suggests there was already a high proficiency in advocacy. Perhaps more aptly, concurrently to the onset of the Euromaidan reforms, HIV/HCV CSOs began to specialise in intellectual property rather than mature in their ability to enact change.

The next section will outline reformations to procurement of medical technologies, healthcare financing and patent law that occurred after the Euromaidan revolution and how these resulted in better access to HIV and HCV treatment in Ukraine.

5.2.2. Post-Euromaidan Reformations

All the participants agreed that the Revolution inspired society to believe that change can happen and that change 'should' happen for the betterment of Ukraine. Some of the most prominent transformational changes in society occurred in the healthcare sector. Three pillars of change facilitated these healthcare reforms: anti-corruption, transparency and accountability of government decision-making. The participant's felt reform was possible after Euromaidan, '*the Ministry of Health was much more open, and there was the whole sense of health reform and new game rules in the air.'* (Irina) The participants referred to different reforms within the healthcare and legal sectors, but for the purposes of this research, the changes most relevant to accessing medicines were typified as medical procurement and patent law reform.

5.2.2.1. Decentralised Procurement, International Procurement, Best Practice Procurement: Ukraine's Journey to Transparency

To address the challenges associated with a decentralised procurement system, three participants highlighted the need for the introduction of an electronic procurement system, the establishment of a centralised procurement agency and guidelines for transparent procurement practices. However, the participants understood that to get these systems operational, procurement responsibilities should be first re-assigned to international agencies.

CSOs understood that after the Euromaidan Revolution, introducing transparent procurement systems was a top priority for healthcare reform. International procurement removed procurement functions from the Ministry of Health and gave them to reliable, well-known international procurement organisations such as UNICEF, Crown Agents and UNDP. Importantly, this initiative was primarily led by civil society actors. The lead organisation spearheading this reform, Patients of Ukraine, developed a draft law and then advocated for, alongside other CSOs, the law to be passed in the Verkhovna Rada. This law was passed in 2015. The participants relate this win to the strong push to remove corruption from government agencies during the Euromaidan Revolution.

Daniela highlights how reassigning procurement responsibilities to international agencies resulted in the procurements of medications for thirty-eight treatment programmes helping, '*I think one-and-a-half million [of] people in Ukraine with different difficult diseases—tuberculosis, hepatitis, oncology, orphan diseases, etc.'* The results of this CSO-led reform bill undeniably showcased the systematic faults in the government procurement processes. As highlighted in the interviews, 40% of the procurement budget was laundered through the older, decentralised system. In comparison, the new system resulted in a 40% savings in the procurement budget. These figures relate to real-world benefits for PLWH in Ukraine as access to treatment for HIV '*grew from 50,000 to 113,000 without the need for an increased budget.*' This is possible due to an increased procurement pool reducing the price of medicines, including transparent processes and established relationships with manufacturers. While procurement was a major player in increasing access to treatment, it is important to note that concurrent activism related to price negotiations, IP and voluntary licensing agreements also played a fundamental role. These strategies will be further elaborated on in section 6.2.

However, this strategy was always recognised as a temporary one. The legislation to hand procurement powers to international agencies was time-sensitive and was planned to end in 2022. As a result, a consortium of CSOs created an independent national procurement agency named Medical Procurements of Ukraine. The function of this centralised agency was to ensure an efficient and cost-effective procurement system for medical supplies in Ukraine.

> *Daniela: They have a very strong and very good and positive director who was against corruption. They work using transparent procedures and using the best practices of international organisations.*

A key component of the Medical Procurements of Ukraine is ProZorro, an electronic procurement system that streamlines transparent procurement processes through a centralised platform. This electronic system helps to reduce the possibility of corruption and corporate favouritism because all procurement tenders and decisions are made available to the public.

> *Nastya: Really in 2014 we just got an opportunity, you know, for a lot of our dreams just come true [...] it's I think one of the best systems for public procurements right now in the world that made all the processes very transparent [...]*

For Nastya, ProZorro was a '*dream come true*' for several reasons. First, her organisation helped with its conception and is a testament to the organisation's political influence and technical experience. Secondly, the savings from ProZorro helped overcome many opportunity costs that occurred from the previous opaque and corrupt system by '*fixing its holes*'. Lastly, there is a strong sense of personal and national pride in operationalising a world-leading procurement system that is the antithesis of Soviet governance.

Before Euromaidan, participants regarded the procurement of medical technologies as a purposefully convoluted set of processes which make it easier for the money laundering of taxpayers' money. Studies indicate that the problem of systematic corruption is common in all countries which transitioned from a communist to a market economy in the 1990s (Langr, 2018). This study identified public procurement as a key state process which needed reform. The research participants highlight how '*middlemen*' or intermediaries in procurement schemes and abuse of tendering processes helped to embezzle up to 40% of the overall

procurement budget. Studies by Altsyvanovych & Tsymalenko (2018) and Langr (2018) also identified middlemen as 'corruption risks' in the procurement processes. They also identified other processes that government officials can manipulate for personal gain purposes, including the state's acceptance of incorrect information from tenders, lack of criteria for evaluating tender offers, bidding procurement contracts with limited participants, bid rigging, etc.

Ultimately, this resulted in patients not gaining access to lifesaving treatment, creating opportunity costs for other departments of the healthcare sector and nurturing an environment of continued corruption within political and private spheres. Moving procurement responsibilities to international agencies, setting up a national procurement agency that utilises best international guidelines and operationalising an open source electronic procurement system helped it to *'dissect this conglomerate and enabled—like and it trickled down to like specific narrow issues where we could, you know, get specifically, you know, at pricing, look specifically at how quantities of medicines are collected.*'

The concept of systematic corruption is based on the assumption that the institution is corrupt as a whole, lacking any principled principles (Balian & Gasparyan, 2017; Langr, 2018). The process of turning opaque processes into transparent systems felt like a '*dream come true'* for the participants as it seemed to '*dissect the conglomerate'* of power that allowed systematic corruption to exist for so long and to force principles of equity into the system. Importantly, these initiatives were all led by CSOs, specifically HIV CSOs, other patient organisations, and anti-corruption groups, and were enabled by the revolutionary reforms sought by the Ukrainian public during the Revolution of Dignity. The next section will examine the additional reforms within the healthcare sector.

5.2.2.2. Patent Law Reform

In 2020, the Reform of Patent Law was adopted by the Ukrainian government. Oleg and Davyd outline the main tenets of this reform. This law was aimed at harmonising Ukrainian patent law with EU IP frameworks after the signing of the EU-Ukraine FTA. Davyd explains the key aspects of this reform, including enhancing patentability criteria, simplifying the patent application process and strengthening enforcement mechanisms against potential infringement of IP. Enhancing the patentability criteria for patent applicants seeks to ensure

that genuine innovation is promoted by rewarding deserving inventions with monopolies. Additionally, it provided the activists with a formalised process to oppose patent applications before and after grant applications are processed. Streamlining the patent application process by introducing electronic filing and removing bureaucracy aims to get drugs onto the Ukrainian market sooner as previously '*patent application proceedings they're lengthy. You know, the patent office usually considers patent applications for two, three, sometimes four, five years*' (Davyd).

These patent reforms highlight how increasing patentability criteria and reverting temporal pressures on the pharmaceutical industry shifts power imbalances and provides more power to activists, generic manufacturers and government agencies. The capacity of treatment activists to effectively navigate and influence general trade frameworks is clearly outlined in this strategic manoeuvring. Arguably, harmonising IP frameworks with the EU would be considered negative to Ukraine's access to medicines movement as the European Union have traditionally been a strong proponent of IP rights. However, activists effectively utilised this opportunity of trade harmonisation to incorporate pro-public safeguards into IP law, streamline lengthy bureaucratic processes and increase the tools available to them to fight for access to medicines.

While the three reformations showcase seismic shifts that Euromaidan helped create in governance, financing and access to medicines, it did not occur solely to the capital of CSOs. These reforms were co-created and co-led by Minister of Health, Ulana Suprun. This highlights a multifaceted approach for CSOs as they closely engage with legal specialists, reformist government ministries, multilateral organisations within a quickly changing IP and trade landscape. This provides deep insights into the ability of HIV/HCV CSOs to understand and adapt to the socio-political environment, by anticipating and advocating for its changes, and adapting their strategies towards fulfilling their campaign goals (Vigh, 2006; 2009). For more information on Patent Law Reform see section 5.2.2.2. and 6.1.1.4. The next section will outline The Suprun Effect on healthcare and governmental leadership in post-Euromaidan Ukraine.

5.2.3. The Suprun Effect

Emblematic of the sweeping policy reforms in Ukraine Post Euromaidan was the governance strategy of Ulana Suprun, Ukraine's longest-acting Minister of Health from 2016 to 2019. The research participants paint a collective figure of Suprun as a competent leader, who collaborated closely with CSOs and worked towards freeing Ukraine of its endemic corruption. This section examines how participants perceive Suprun's tenure as a paradigmatic shift from Soviet governance. It also examines the evolution of the authenticity and trustworthiness of CSO activity and political mobilisation parallel to the era of genuine engagement from Suprun. Finally, the participants identify the saliency of Ulana Suprun's political downfall as a key factor in closing the political opportunity window in terms of healthcare reforms.

5.2.3.1. From Opposition to Partnership

The participants repeatedly mention Ulana Suprun as a catalyst for change. Ulana, who became Minister of Health in 2016, was reported to govern in a radically different way than her predecessors. Nastya described Ulana as an '*American citizen and she's a real a fighter with a spirit, a firefighter with the corruption*'. Nastya outlines three characteristics that separate Ulana's leadership from previous ministers. Firstly, Nastya mentions that Ulana is an American citizen which distances her from the Ukrainian mindset. Classifying Ulana as '*a real fighter with a spirit*' is also the inverse of the participant's feelings toward political incompetence or willingness for change as discussed in section 5.2.3.4.

Lastly, the perception of Suprun as 'a firefighter against corruption' portrays Ulana as a heroic and respected public figure fighting against the deadly fire of corruption. Throughout her tenure, Suprun worked in tandem with CSOs to develop and implement effective policies to improve public health.

> *Daniela: We started to be like more partners to the Ministry of Health and not in the opposition as before [...] I think Ulana Suprun became very open to all civil society organisations and she started to hear what we say and we understood that our points of view are more similar.*

The overall language from the research participants toward Suprun's governing strategies was all favourable. From the activist's viewpoint, the collaborative and constructive nature of the political/CSO relationship opened a channel of communication that aligned the government's priorities with those of the general public. According to Daniela, this shift in governance is a key result of the Revolution of Dignity. By opening strong dialogue channels with CSOs, the Ministry of Health showed the public that it was responsive to healthcare reforms that were transparent in procedure and open to scrutiny. All of these outcomes meet the expressed wishes of the Ukrainian people during the Revolution.

Anna references close political relationships as the single biggest medium of change for HIV/HCV activists. For example, Anna suggested that her organisation had '*almost*' direct access to the Minister of Health, Ulana Suprun. Anna believes cultivating personal rapport and building close relationships are significant drivers of effective campaigning in Ukraine. Pavlo, a research participant who worked closely with a Ukrainian organisation as an external consultant, corroborated Anna's viewpoint. Pavlo expressed amazement at how close CSOs were with government officials. In his interview, Pavlo found working with the Ukrainian CSOs '*very attractive*' as he could get a meeting with the Ministry of Health without a formal invitation, in stark contrast to his colleagues whose exclusive affiliation with the international agency necessitated going through a more lengthy, formal process.

The participants highlighted that one year into Ulana's tenure, the Ukrainian government provided a full budget for the state procurement of tuberculosis medication, and ARVs and allocated funding for OST for the first time. This all occurred just one year into Ulana's tenure and resulted from an open-table approach to new governance structures involving in-depth civic engagement. This evolution signifies a paradigmatic shift in CSO's sphere of influence and strategic operations. As highlighted by Saurugger (2012), professionalisation of CSOs often entails a shift from contentious to conventional politics, effectively changing the CSOs from outsider status to insider status. However, this process cannot be solely attributable to the professionalisation of CSOs. Arguably, this move towards a more collaborative approach is a consequence of both the contentious politics exemplified by Euromaidan and the increasingly expert and well-resourced CSOs that emerged as effective strategic partners. Therefore, Saurugger's (2012) paper which examined the professionalisation of EU CSOs did encompass the processes in which CSOs have access to political processes that have been traditionally closed off. This highlights an interesting

dynamic and symbiotic relationship between contentious and conventional political processes, as observed in this study.

This also challenges Harwood & Creighton's (2009) assertion that for CSOs to survive and achieve political support, they must work within governmental ways of doing business. The participant's argue that this approach to governance is '*a dream'* for treatment activists as Ulana Suprun inverted Ukrainian governance structures and partnered with CSOs to help implement and operationalise healthcare reforms. Therefore, it must be highlighted that during this phase of professionalisation in CSOs, this newer form of governance and activism was in its nascent phases in Ukraine and not necessarily beholden to strict, older ways of 'doing business'.

5.2.3.2. Watchdogs, Political Titans, or Both?

In this section, the dynamic role of CSOs in Ukraine's post-Euromaidan decision-making processes is explored. Additionally, the role of professionalisation of CSOs and how this may affect representativeness is outlined. Nastya, Oleg and Davyd underscore the challenging nature of activism in Ukraine, outlining their precarious relationships with political figures, their contributions as architects of progressive laws, and their responsibilities monitoring the implementation of these laws.

Nastya emphasises the inherent power dynamics in Ukraine's decision-making processes and the crucial role of civil society, particularly in creating, advocating for, and safeguarding the progress made post-Euromaidan. Nastya recognises that activists must exert their own power to protect these advances: '*And we didn't like let anyone destroy these small islands of safeness, transparency and honesty*'. The participant continuously espouses the corruptive nature of power and how it motivates politicians to create an environment conducive to their own personal gain. In this context, Nastya understands the activist's dual role: as a close collaborator with political institutions and as an antagonist, '*a fighter for freedom*'. This suggests that activists can see their involvement in decision-making processes not merely as a right but as a necessary means to challenge and balance the '*corruptible*' power dynamics that often lead to detrimental effects for PLWH.

The participants in this research challenge Saurugger's (2012) dichotomy between the expert careerist versus the committed amateur, particularly in the fields of HIV and access to medicines, where patient groups have historically played an active role in policy and programme decision making processes (Kaufman, 2019). This concept posits that the expert careerist are often disconnected from the needs of the populations that CSOs advocate for. While this assertion has merit, it is too generalisable and does not account for multifaceted roles that health activists frequently assume, especially those with lived experiences. As Nastya, a participant who lives with HIV, exemplifies this complexity; she is both a professional expert and an activist passionately fighting for the rights and health of her community.

Davyd further emphasises this point by commenting on civil society's role in creating, influencing and shaping policies that are in the best interest of the Ukrainian people. Davyd argues that the law often does not serve the people's best interests. Therefore, CSOs representing a pro-public ideology should play an active role in the propositions of new or established policies, as '*it is their foundational right to do so*'. Although Davyd does not live with HIV or HCV, his commitment to shaping policies for the benefit of the Ukrainian people underscores motivational factors aligned with Zarembo & Martin's (2023). Their research demonstrates how a strong sense of community engagement in Ukraine, as highlighted by Davyd, can develop feelings of responsibility towards the community, leading to political engagement. While Davyd's example does not directly challenge the careerist versus committed amateur binary, his interview provides valuable insights into the motivations and aspirations of CSO workers, that can transcend personal self-interests.

When discussing his CSO's strategy, Davyd uses the Patent Law Reform as an example to outline a mutually beneficial CSO-governmental relationship. Healthcare reform remained a priority during the 2016 election season. This allowed CSOs to push a '*populist*' argument that this reform will reduce the price of new, innovative medicines, *'that argument was easy to bring to the political parties because it is a very important issue for potential voters the reduction price for medicines'.*

Due to the limited financial resources in Ukraine, the government needed strategies to increase procurement and supply patients with medicines. Davyd's organisation acquired the intellectual capabilities for writing the legislation and provided the current and incumbent

politicians with a roadmap to increase access to essential medicines. By actively participating in government decision-making, Davyd understands the role of CSOs not only as checks on potential power abuses but also as integral players in the democratic functioning of the state.

Oleg also uses the example of Patent Law Reform to highlight the continued work of CSOs once bills are introduced into the legislature. Oleg believes that the introduction of this law shows that the government can show '*some rational thinking*', but continued activism needs to focus on the implementation of the adopted law reform and *'not just stay on paper.'*

Nastya, Davyd and Oleg provide a nuanced understanding of the role of a professionalised civil society in Ukraine's democratic processes and the motivations behind their activism. Collaborating with political institutions to create, influence and shape policies are key functions of CSOs in Ukraine. Yet, safeguarding the advances made post-Euromaidan through sometimes antagonistic approaches is also essential to counteract the corruptible and potentially regressive nature of unchecked power.

5.2.3.3. Monopolies Within Civil Society Organisations: Too Much Authority?

The interviews from the study shed light on the complexities and potential downsides of civil society organisations (CSOs) gaining substantial political influence and the process of professionalisation within the realm of activism. Ivan, Anna, and Oleksandr touch on the ontological dilemmas related to power dynamics in activism and social movements, discussing the transformation of civil society's role from grassroots action to institutional powerhouses with significant sway over policymaking.

Oleksandr worries about the impact of losing connections with the 'ground-level', meaning communities of people living with HIV/HCV. Oleksandr posits that the grassroots approach to activism has its role but acknowledges that the institutionalisation of movements can increase political power via CSO decision-making '*partnerships*'. This results in the subsiding power of the '*ground-level*', and the bureaucratisation of movements begins. Oleksandr equates this shifting of power and financial resources with a shift in the motivation behind the activism. He argues that the professionalisation of activism results in a growing need for increased technical expertise, inviting experts into the movement who may not have personal experiences with HIV or HCV. Additionally, activists who become more

bureaucratic and '*comfortable*' can also experience a change in motivation and rhetoric. This, Oleksandr argues, may shift the level of urgency and change the base agenda. Anna shares Oleksandr's concerns about organisations losing touch with HIV/HCV communities but sees it as a natural trajectory of the activism lifecycle, '*as soon as you sit at the table you're part of the system'* (Anna).

Oleksandr and Anna agree that the process of becoming part of the system is a result of necessitating the resourcing of human and political capital. The participants understand that there is a fundamental need to increase specialist knowledge and capabilities to navigate bureaucratic hurdles, articulate demands clearly and exert more influence over political processes. Oleksandr and Anna outline clearly the natural trajectory of CSO professionalisation and how it positively and negatively impacts activism which largely fits within the literature on the professionalisation of CSOs (Hwang & Powell, 2009; Saurugger, 2012; Heylen, Willems & Beyers, 2020; Poletta *et al.,* 2021). The professionalisation of CSOs is considered a double-edged sword that offers structural benefits and resources but can also compromise the authenticity, urgency and grassroots nature of activism. The participants concur with Van Deth & Maloney's (2012) conclusion that there must a balance must be found that preserves their founding spirit while harnessing the advantages of a more structured, formalised approach to effecting systemic change. This raises critical questions about the member based CSOs examined in this research project and the effectiveness of their engagement with their member base.

Ivan contends strongly that Ukrainian HIV CSOs do '*too many things with the government.*' Ivan compares the role of CSOs in Russia with those in Western Europe with respect to working with the government compared to the Ukrainian CSO approach. '*In Germany and Russia, you don't bring, you know, too much influence. Sometimes [...] for me it's like an authority.*'

Ivan's interview continuously reiterates this concept of Ukrainian CSOs as having too much authority or influence. Ivan agrees that organisations such as 100% Life do important work with successful outcomes but equates their work to that of government institutions, 'they do the job of Ministry of Health [...] now they are institute of health'. Ivan also differentiates Ukrainian activism from Russia's and Western Europe's by acknowledging their relationship and the enormous financial resources they receive directly from The Global Fund.

In his interview, Ivan does not fully articulate his grievances with respect to CSOs having too much authority. However, he does reference this power dynamic influencing the direction of international financial aid and the agenda-setting of CSOs. According to Ivan, organisations such as 100% Life focus '*too much on access to medicines and not enough on stigma and discrimination*'. Ivan extends this point by focusing on smaller CSOs who wish to tackle the issues of stigma and discrimination among key populations in Ukraine. To explain his point, Ivan analogises smaller CSOs to internet application start-ups who try to, '*combat with Google or Apple, you can forget it, you know, you're so small*.' By referencing Big CSOs in Ukraine with Big Tech monopolists, Ivan argues that the funding streams for CSOs have created a market environment that concentrates donor resources into a small pool of powerful CSOs and essentially reduces the diversification of funding streams to other CSOs and CSO priorities. As a result, the political and financial resources of these big CSOs make it difficult for upcoming, smaller CSOs to work within a market-controlled CSO environment as they hold a monopoly of donor funding. Ivan's assertion that HIV/HCV CSOs prioritise access to medicines over addressing stigma and discrimination may be due to a combination of factors including, a disenfranchised ground base, a limited and diversified pool of well-resourced CSOs and funder prioritisation. This provides an example of how CSO attention can be diverted towards important areas such as access to medicines, but at the expense of other significant issues affecting PLWH.

In this section, the research participants outline the tension between the necessity of professionalisation of activism to sustain the movement, navigate increasing bureaucratic hurdles and gain a 'seat at the table', and not losing connection with 'ground-level' communities. Despite acknowledging the huge contributions of big CSOs, Ivan expressed concerns regarding the diversification of funding streams to smaller CSOs and how current funding dynamics give market dominance to a few powerful players. The role of resource power and agenda setting is further elaborated in section 6.1.3.

5.2.3.4. Political Regression: Closing of the Political Opportunity?

All participants talked about the narrowing of the window of opportunity for healthcare reforms after Ulana Suprun left office due to the politically regressive acts of her successors. From 2019 to 2021, there were three new Ministry of Health appointments due to varying degrees of incompetency. The participants who worked closely with Ulana outlined how President Zelensky's cabinet of ministers regressed on the three pillars of governance adopted after the Euromaidan. The first minister after Suprun was Zoriana Skaletska whom Nastya viewed as incompetent or '*really dumb'* for not understanding how the new procurement system worked and refusing to sign procurement contracts for three months after the deadline,*'So this definition of stupidity as she started to sign documents after three months.'*

Nastya voices concerns about the potential of stockouts of lifesaving medicines because the new MoH did not sign procurement documents. The Minister of Health wished to understand better the procurement system. However, Nastya's view was that not signing the procurement documents was a dereliction of responsibility. After Skaletska was ousted at the beginning of the COVID-19 pandemic, the participants were concerned about the behaviour of the following MoH, Maksym Stepanov. Irina argues that Minister Stepanov acted similarly to Olha Boholomets, a cabinet minister who staunchly opposed Suprun's reforms and *'wanted a lot of money from state procurement'* before the Euromaidan Revolution.

Nastya also highlights the lack of progression in healthcare financing. Firstly, she celebrates the financial restructuring of the primary healthcare system as a triumph but blames the lack of progression of secondary healthcare due to a lack of '*political view of our President and all these dumb ministers we have now'*. This comparison of a competent and rational Suprun ministry versus an inferior Zelensky government is continued in Oleg's testimony relating to the introduction of the Patent Law Reform bill. While the participant's often cite Zelensky's government as the issue on many topics involved in this thesis, the political process is a complex set of machinations and involves various political leaders. While the effectiveness of Zelensky's and his cabinet's leadership are often called into question, it is important to note that governmental competencies such as harmonising trade agreements and passing legislation requires many different processes such as committee hearings, different round of legislation readings, etc. Therefore, while the participants may argue that Zelensky's

government are the main drivers of political regression, it is important to note the complexity of all the influential actors in Ukraine's political process.

For example, the healthcare financing and procurement bills were passed during Suprun's reign, closely following Euromaidan. However, while the patent law reform bill was supported by both the MoH and the Ministry of Trade, it went under more intense scrutiny by a parliament '*who just are not making rational decisions*. However, the bill did pass in 2021, but the participant's scepticism lies in its implementation.

> *Oleg: the problem is that the patent office is a very political organisation. So their head is appointed by the political party which is known to be very corrupt and very kind of—using any opportunity to have benefits, financial benefits from anywhere [...]*

The mixed stance on patent law reform within the Verkhovna Rada belies a strong sense of confidence in progressive, transparent and pro-public governance. The participant questions whether the Patent Office will enforce the reforms or revert to a non-transparent system that nurtures corruption by financially rewarding self-interests. Oleg also highlights feelings of worry towards regressive policies across all pertinent sectors including healthcare, anticorruption and IP reforms. The participants differ on whether the current government's motivations behind negatively influencing house reform or bad decision-making are rooted in their misunderstandings and incompetence, self-interest, a reduced enthusiasm to work with CSOs, or their different value-based systems. Regardless of the root cause of these regressive practices, there was an overall sentiment that the window of opportunity for reform was closing.

In 2015, the Ukrainian government and CSOs were energised to create and enact radical reforms. However, as time passed, the participants perceived the reformational 'firefighter spirit' disappearing with Zelensky's government. Initially, the public used the power of the Revolution and the resulting Russian invasion of Crimea and the Donbas region as a strong motivational factor to fight for a New Ukraine; for a better future for the country. Yet, evidently, from the participant's accounts, this sentiment was not enduring and seemed to leave political consciousness.

Daniela outlines the central role CSOs adopted during the nascent stages of the COVID-19 pandemic. As the government did not procure PPE for healthcare workers, '*no help from the state from the central level',* Daniela's organisation decided to *'substitute the state'.* The procurement of essential PPE supplies requires a huge amount of technical expertise to source scarce supplies, and adaptability to understand the rapidly changing procurement landscape, '*with our own sources we started to find where we can buy this or that.'* Additionally, Daniela suggests her organisation had an overall grasp of logistics and supply chain management to send procured items to hospitals that needed PPE,' *and even we transferred all this to the hospitals all over Ukraine'*.

These functions are traditionally identified as state functions and require a deep understanding of complex systems. Daniela further underscores this '*We just did our job, which we understood should be done because the government, you know, was not able to do it [...] nobody from the government told thank you to us and they don't know if they understand actually*'. This provides further credence to the idea that the government expects CSOs to take on these important functions and that CSOs understand their role in taking on government functions '*We just did our job*'. This suggests an infantilisation of government and that the knowledge and resource capabilities that ascended CSOs to pivotal leaders in the healthcare sector were a direct result of state passivity, regression and corruption. Daniela also conveys a belief that demoralisation was occurring in civil society and the general population after Zelensky came to power. The '*big window of opportunity*' after Euromaidan was closing and there was '*less and less enthusiasm from civil society*' remaining. According to Irina, this was also felt by the general public who would often talk about leaving the country as they did not see progress or opportunities in Ukraine. However, Irina also highlights the enduring nature of CSOs, *'but civil society still remains on the position and because we understand if we will leave, who will be here and who will fight for the country?*

The words of both Irina and Daniela also reflect the findings of the study of Zarembo & Martin (2023) which highlights Ukrainian's coming together when things need to get done. The participant's reinforce their commitments and motivations to take over the role of the government if the state fails to provide for the Ukrainian people. This research adds to Zarembo & Martin's (2023) study by showing how SOC and SOCR does not only motivate informal civil society, but also propels CSOs to continue working in demotivating or regressive environments for the Ukrainian people. Irina understands her role in fighting for

her country, even when this involves fighting on difficult and often shifting terrain highlighting a dynamic interactivity between internal and external motivations for 'fighting' and Ukraine political landscape.

5.3. Conclusion

The participants identified three seminal evolutions that helped Ukrainian HIV and HCV healthcare converge from Soviet governance to a 'New Ukraine'. The first relates to access to healthcare and social attitudes towards PLWH. The participants note that stigma has lessened in targeted places such as some healthcare settings, but also acknowledge that much work is still needed. Social stigma and levels of ignorance around HIV continue to remain stubbornly high and are identified as an area that needs more attention from CSOs. Every participant highlighted the extraordinary change in access to life-saving treatment, including ARVs and DAAs. This radical change occurred within a short timeframe, shifting the analogy of access to treatment from a 'desert' to Ukraine as a 'health tourism hub'. The 'New Ukraine' committed to a public health mandate by engaging with state procurement of medicines, and not relying solely on international agencies.

The Euromaidan Revolution, the ensuing annexation of Crimea and the war in the Donbas region are the second salient transformation. The Ukrainian people fought for a country to be governed on the principles of transparency, anti-corruption and accountability - the antithesis of Soviet governance. The Euromaidan Revolution, along with continued Russian aggression, increased societal and government trust in Ukraine's maturing and increasingly specialised CSOs. Lastly, the top-down governance model was changed to a partnership model between the Ministry of Health and CSOs. Converting the ideology of CSOs-as-opposition to government partners helped ensure that the main reforms were implemented and operationalised efficiently and transparently, ultimately leading to an increase in access to medicines and quality of life. However, this chapter also underscores the pros and cons associated with the professionalisation of CSOs, emphasising the need to maintain a balance between increased institutionalisation and active engagement with their ground base.

The chapter concludes by highlighting how the window of opportunity after the Euromaidan Revolution was closing with the introduction of Zelensky's government in 2019 - leading to

feelings of frustration and worry from the research participants. While the participants understood that there was no ‘magic bullet’ for increased access to medicines, multidimensional factors were in play. The next chapter will identify the role of power in HIV and HCV treatment activism.

Chapter 6. Findings 2 – Who Holds the Reins of Power?

In this 'Findings 2' chapter, the intricate power dynamics that shape governance, activism and the knowledge economy in Ukraine are explored. The chapter is presented in three sections, each section comprising themes and subthemes that emerged from the interviews with the research participants. The first section examines the complex dynamics behind the upward trajectory of CSO power in the post-Euromaidan era. The second section presents findings on how resource power has enabled and prohibited progressive change in the Ukrainian access to medicines movement. Lastly, the complex interactions of various key players in the knowledge economy and their implications for HIV/HCV treatment activism are unpacked.

6.1. Activism Amplified: How Resource Power Shapes the Access to Medicines Movement

The research participants identified resource power as a key enabler of change in Ukraine's access to medicines movement. In this section, the pivotal role of resource power will be discussed, including the strategies employed by activists, the collaborations it helps form, and the competition among CSOs it creates. In addition to the role of resource power in shaping the movement, it also opens the question of whose activism gets to be amplified, and why. This findings section illustrates the complex political power play at work within the international donor sphere via the lens of 'agenda setting'. By questioning who gets to set the agenda, the research participants explore the positioning of the Ukrainian activist within wider geopolitical contexts.

As highlighted by the research participants, funding from the International Treatment Preparedness Coalition (ITPC) is crucial for the sustainability of Ukrainian IP activism, but The Global Fund, USAID and PEPFAR which are funded primarily by the United states government and The Bill Gates Foundation, is more likely to not fund any IP activities. This section also identifies the successes, challenges and barriers to Ukrainian CSO's collaboration with their Eastern European and Central Asian (EECA) counterparts.

6.1.1. Foreign Aid, Intellectual Property and Donor Relations

The research participants underscore the geopolitical complexities that accompany international aid and IP activism. This section provides an insight into the aligned, neutral or conflicting interests of national governments, CSOs, HICs and donor agencies in relation to funding HIV/HCV treatment activism. It explores the role donor agencies play in fostering a funding market that creates either a collaborative or competitive atmosphere among Ukrainian CSOs. Davyd also adopts the term '*access limbo*' to underscore the precarity of access to medicines in middle-income countries and how donors can help overcome structural barriers to access.

6.1.1.1. The Donor's Role in CSO Relationships

The influence of foreign aid on the workings of CSOs in Ukraine is highlighted in this section by identifying the donor's power dynamic with CSOs seeking grants to implement projects. Irina, a programme manager at a philanthropic organisation, provides insight into the double-edged sword of donor involvement in the relationships of CSOs in Ukraine. Firstly, the performance indicators set by donors can have the effect of creating a competitive environment among CSOs that is not conducive to collaborative work to meet broader goals. Yet, Irina also provides examples of how, when approached strategically, donors can help bring CSOs together to work synergistically. Irina is the only research participant to broach this subject. Oleg also works for a donor organisation but focuses more narrowly on IP issues only.

Irina outlines the role donors can play in creating a contentious environment among Ukrainian CSOs - potentially siloing their work and enflaming relationships. Contrastingly, Irina also highlights how donors can help bring CSOs together to work synergistically, *'when performance indicators are linked to your budgeting it almost pushes grantees to the edge of being destructively competitive because they understand their performing on this grant secures or fails their next grant.*'

Irina's use of '*destructively competitive*' creates a sense of in-fighting among CSOs to ensure their organisation receives funding to survive in a super competitive environment, leading to heightened tensions among grantees. These results are consistent with Owczarzak's (2010)

study of HIV/AIDS CSOs in post-socialist Poland, which found that although designed to ensure accountability and effective use of funds, performance-based indicators can sometimes lead to unintended consequences. In Owczarzak's (2010) study, the funding model led to increased competition, fragmentation among CSOs, and feelings of bitterness, ultimately resulting in reduced cooperation and reduced effectiveness in taking care of their clients.

Irina also outlines that her organisation is a smaller donor and does not rely so heavily on '*set-in-stone*' indicators. Therefore, Irina can approach 'the big three' [100% Life, Alliance of Public Health, Patients of Ukraine] and say that they do not have to compete but work collaboratively. Irina argues that organisations all have their own niche and expertise and that their work should be complementary. Irina found that from her experience as a programme manager, CSOs work really well when they are constructive and open. But reiterates how donor agencies can feed into a culture of competitiveness, stress and strained relationship dynamics. This performance-driven model creates a high-stakes, competitive culture as it financially rewards organisations that achieve difficult structural changes in policy or execute large educational campaigns. To be granted these big financial rewards, Irina believes that smaller CSOs who do not have the financial, human or political capital of bigger CSOs find it difficult to sustain their organisations and their campaigns. This underscores the importance of designing funding mechanisms that not only hold CSOs accountable for reaching their goals but also encourage cooperation and unity among CSOs of all sizes within the HIV response.

6.1.1.2. Overcoming Access Limbo: The Role of International Donors in Ukraine's Intellectual Property Activism

The precarity of MICs accessing HIV/HCV is examined under the lens of '*access limbo*' as detailed by Davyd. In Chapter 4, the role of Euromaidan in catapulting healthcare reforms in Ukraine is examined. In this section, Davyd and Irina elaborate further on additional key factors involved in progressing Ukraine's access to medicines movement, including the central role of international donors.

Davyd argues that the limited financial resources in Ukraine, exacerbated by high numbers of people living with HIV/HCV, and being left out of voluntary licence agreements results in Ukraine existing in an 'access limbo'. He further explains 'access limbo' by highlighting

citizen's constant push for the government to cover all patients with medicines, but the government do not have sufficient financial resources to supply people with treatment and patents continue to be a barrier to generic, cheaper medicines. As Ukraine is a lower middle-income country, they are often left out of voluntary licences that are primarily donated to lower income countries. Davyd understands that funders such as ITPC Global, UNITAID and Third World Network focus on countries that are experiencing this 'limbo', as they suffer most from intellectual property and exclusion of licence agreements. This is particularly striking as countries, such as Ukraine, require specific focus as the WHO (2016) estimated that 70% of people living with HIV worldwide are based in MICs. Additionally, the HCV epidemic is concentrated in MICs, with the world's highest prevalence of HIV/HCV co-infection found in the EECA region (Woode *et al.,* 2016; Plat *et al.*, 2016).

Davyd highlights that donor funding for IP issues is essential as he is under '*no illusion*' that the Ukrainian government would fund their IP work and are reliant on '*donor funding like UNITAID*'. One reason for this includes the Ukrainian government's efforts to have closer ties to the European Union. As the European Union is pro-intellectual property rights, it would look unfavourable on the Ukrainian government if they were to fund IP activism. This is elaborated on in section 6.2.1. As a result, there is a heavy reliance on international donors, including UNITAID and ITPC Global, to allow them to continue IP activities.

From a chronological perspective, Davyd agrees that small funding streams for intellectual property existed before Euromaidan and were essential for upskilling HIV/HCV activists. These funding streams were related to the procurement of medicines which first introduced activists to patents, patent searches, intellectual property and access to medicines activism. As well as acknowledging Euromaidan in 2014, Davyd understands that ITPC's '*sufficient*' funding included programmes that improved their advocacy regarding strengthening patent criteria, submission of patent oppositions and other activities. Yet, this ITPC funding may not have been possible without funding and technical support from Irina's donor organisation prior to 2014. Both Irina and Davyd emphasise that the access to medicines movement was strengthening before the Euromaidan Revolution, which eventually provided a platform for specialised CSOs to engage constructively with government officials on access to medicines issues.

However, the participants did not elaborate on treatment activism beyond the initial responsibilities of ARV procurement using foreign aid. The OSF's (2007) report illustrates how 100% Life were trying to actively address government corruption in the procurement of ARVs since the mid-2000s. This form of activism is also not recorded in Tetyana Semigina's (2015) paper chronicling Ukraine's HIV policy focus. This is an important factor as this research continues to map the maturation or specialisation of treatment activism and how this converges with the political outcomes of the Euromaidan Revolution.

Irina also emphasises that treatment activists' ability to achieve progress was achieved by a confluence of factors. Irina argues that it was not a result of a '*magic bullet*' solution. The Revolution of Dignity resulted in a government that was receptive and committed to reform. In addition, thanks to funding from international donors, increasingly specialised patient communities existed that had a thorough understanding of legal, trade, procurement and IP issues. Irina expressed a belief that all these elements created a profound atmosphere that health reform is possible and a tangible sense of '*new game rules in the air*'.

Davyd and Irina illustrate the interplay between international donors, patient activism, pharma benevolence, and patient activism in navigating the '*access limbo*' often experienced by MICs. Their accounts highlight the key role of international donors in enabling the increased specialisation of HIV/HCV communities to be well-versed in legal, trade, procurement and IP matters. The enabling of meaningful change in Ukraine's healthcare reform is attributed to a confluence of factors, but both Irina and Davyd underscore the critical reliance of international donors to sustain IP activities. For the sustainability of IP activism, international donors must continue to fund IP activities as the Ukrainian government is unlikely to do so due to potential negative diplomatic consequences with the European Union.

6.1.1.3. The Geopolitics of Foreign Aid and Intellectual Property

This section highlights the often-conflicting interests and priorities of national governments, CSOs, HICs and donor agencies, especially in relation to the intellectual property of medical technologies. Davyd and Oleg underscore the reality of donors and HIC's hesitancy to fund IP activities, making it more difficult for CSOs to fight against the formidable financial and technical resources of the pharmaceutical industry.

According to Davyd, as the primary funder of the Global Fund (GF), the USA is not '*eager*' to fund IP activities. He considers their advocacy to get the GF to fund some IP activities in 2018 to be a big achievement.

> *Any big kind of developed country is criticising Global Fund, for example, saying, 'Don't fund any IP work again.' Like reinforcing it. This is a big problem. But in terms of national government, they are supporting it because they know that we need cheap drugs. (Oleg)*

Oleg corroborates this by suggesting a divide between the wishes of national governments and CSOs versus HIC's preferences for the spending of donor funds. Oleg emphasises the dearth of funding from USAID for IP projects and the shifting priorities of the GF on this topic. Oleg expressed a belief that these policies, resulting in the refusal of IP funding streams, are correlated to acting, powerful board members, including US officials and other donors, such as the Gates Foundation.

The influential role of the Gates Foundation is highlighted in much of the global health literature. Its economic strength, exemplified by its position as the WHO's second-largest funder from 2018-2019 (Crawford, 2021), has granted it significant sway over the health agenda. This influence, as argued by Hale, Held, and Young (2013), Birn (2014), McGoey (2015), and Mahajan (2018), has repercussions for the balance of power in global health. This influential private entity that is less accountable to public opinion leads to fragmentation and can complicate cooperation, especially as the Foundation's strategic decisions are often aligned with market dynamics that often perpetuate inequities (McCoy & McGoey, 2011; Browne & Rosier, 2023). For example, The Gates Foundation interceded with Oxford University after they made a public statement promising to donate the rights of the publicly funded COVID-19 vaccine to any drugmaker. The Gates Foundation persuaded Oxford University to enter an exclusive COVID-19 vaccine contract with AstraZeneca, giving the pharmaceutical company the majority of IP rights (Hancock, 2020; Neeraj, 2022).

Additionally, according to the European Corporate Observatory (2021), the European Commission leaned on the pharmaceutical and the Gates Foundation lobby to define its stance on pursuing the TRIPS Waiver, which would have temporarily waived all IP rights on COVID-19 health technologies. As a result, the European Commission opted for a market,

donation-based approach by not supporting the waiver, ultimately ignoring the wishes of over 100 LMICs and 350 CSOs and activists worldwide (Thambisetty *et al.*, 2022; Singh *et al.,* 2022). These examples of strong pro-IP protectionism ideology at the Gates Foundation underscores the significant influence of key players in the global health field, who can directly impact funding directions, particularly in projects aimed at overcoming IP barriers.

Oleg also highlights other obstacles to access to medicines activism, including the financial resources needed to understand if a newly patented compound meets the standard of the invention and then to succeed in removing the IP of medical technologies or negotiating a reduced treatment price. Therefore, a strong mobilised community and scientific and legal teams is required overcome pharmaceutical company's power, '*and if you don't have like people who are really experienced in IP litigation then you will lose very quickly the battle.'* Oleg notes that everyone knows of this issue of donor hesitancy in funding IP work in the access to medicines world, which is '*a very sad situation*.'

This reduced funding space seems counterintuitive to funders mission of achieving health equity and seeing a return on their investments. According to ITPC (2019), the main funders of IP activities in Ukraine since 2014, highlight that their investments exceeded their original annual target savings of $140M US dollars. Their funding and technical capacity building resulted in '[...] *an average price reduction of 67% across 15 target ARVs in the four countries and contributed to total annualized savings of $472M'* (MMA, 2019). The report finds that the cost savings are due to many different types of IP activities, but patent oppositions are significant reasons behind the reductions. The research participants highlight that although patent oppositions may be costly, funding these activities sees a return on investment, but ultimately, results in people gaining access to better medicines in MICs.

6.1.1.4. Foreign Aid, International Influence and Diplomacy

The political power of funding agencies and multilateral institutions became apparent in many of the interviews. The financing of projects provides power over CSOs, but in parallel, the participants identified a complex power system between donor agencies, governments and CSO campaigns. Daniela '*thank God'* for the interventions of international organisations, international missions and embassies of the EU and the United states for communicating directly with the Ukrainian government to '*prevent some bad space to be happening*'. This is

the context of Daniela discussing the regressive steps activists saw the Zelensky government committing. For example, Nastya highlights the role of funding agencies intervening in the procurement of medicines in March 2020 when the new MoH would not sign procurement forms, which would have led to stockouts of essential medicines, including ARVs and DAAs. The GF, CDC and USAID permitted 100% Life to change the '*economy*' of their grants and procure medicines to avoid stockouts. Daniela and Nastya highlight the collaborative and adaptive nature of donor agencies and CSOs and their role in superseding the neglective agency of the state.

Davyd provides another example of direct and indirect donor and multilateral institutions encroaching on state sovereignty. Indirectly, he indicates that the ITPC Global funding stream from 2014 helped CSOs to build and reform relationships with politicians over five years, including with the Ministry of Health and Ministry of Economic Development and Trade. Davyd recognises these relationships as fundamental in pushing for Patent Law Reform in the Verkhovna Rada. More directly, when the laws were under consideration in parliament, Davyd believes that the letters of support sent from UNDP, WHO and UNAIDS played a vital role in adopting the law, '*I guess without their support it wouldn't have happened.'* Confessing the vital role of international organisations in adopting the Patent Reform Law, Davyd underlines the importance and complexity of power relations between national governments, international influence and CSOs.

The actions of the organisations mentioned in this section may arguably align with William's (2000) contention that international CSOs, multilateral organisations and international funders can intervene in state politics to the extent of eroding state sovereignty (section 2.2.3.). However, the research participants clearly identify these international organisations as a lifeline to what is perceived as an increasingly regressive and incompetent government. Furthermore, the collaborative, flexible and effective nature of these funding bodies, as provided in the examples outlined, demonstrates that their inventions are directed by civil society. These interventions particularly focus on protecting the health of the Ukrainian people and highlight their influential in the Ukrainian political process.

6.1.2. From International to Government Funding: A New Formula for Autonomy?

A big question for MICs who receive funding from foreign aid is how and when the country will start to transition to domestic funding for its HIV response. The complexities of transition are outlined in this section. Pavlo, Nastya, and Ivan voice alternative viewpoints regarding the advantages, disadvantages and complexities associated with state funding, autonomy and power. The research participants provide insight into the impacts and implications of shifts from international to domestic funding of civil society organisations.

Pavlo believes that government funding civil society organisations is the natural trajectory of many movements but understands it upsets a delicate balance between continued resource mobilisation and preserving autonomy. From a power and state funding perspective, Pavlo highlights how state funding for services can potentially engender a restructuring of power dynamics within these CSOs. Financing these services, intentionally or not, can influence the actions and motivations of the HIV/HCV CSOs. Pavlo's assertion that '*the more money you get, the less critical questions you ask*' underscores this predicament. It implies a potential risk of self-censorship or avoidance of confrontation with the state to secure much-needed funding.

Pavlo believes that CSOs have two options. The first is to remove all its funding as it transitions from the Global Fund and make hundreds of people redundant. The second option is to work with the government to ensure the survival of '*the movement*' and the survival of their organisation. Pavlo does not answer whether state funding will affect HIV services or IP work but iterates a correlation between more funding and less critical engagement with decision-makers as funders.

Nastya's organisation successfully lobbied for the Global Fund to require the Ukrainian government to tender and fund CSO services as a condition of grant funding, thereby transforming the state as an active funder of HIV/HCV community functions. This underscores the powerful dynamic of CSOs and funders in their efforts to influence state functions and financings. The '*formula*' pushed by Nastya's organisation to create a '*market*' for tendering HIV CSO services included the 20-50-80 financing targets. Nastya explains that this entailed domestic funding for 20% of its HIV response in 2018, 50% in 2019 and 80% by 2020.

Nastya: And in 2020 it was eighty percent of everything. And it works.

By doing so, Nastya's organisation were not just securing resources, they were institutionalising their role as a key player in health policy and service delivery. In addition to highlighting her organisation's considerable influence in shaping this state tendering process, Nastya acknowledges the significant risks involved. She notes that if international donor agencies find discrepancies within their audits, the results would be a failure to continue with programmes and being blacklisted from future grant applications. However, if misuse of state funding occurs, '*some even mistakes will be with the state money you can go for jail easily*'. To overcome this and alleviate fears, Nastya's organisation provided many training sessions to educate their staff on the issues related to procurement, taxation, reporting and finances to ensure transparent and non-corruptible processes are in place. This indicates a relationship between organisations with greater financial resources and increased power to shape state policy and provide HIV services with heightened exposure to state scrutiny and control.

Ivan, on the other hand, presents a different perspective that emphasises the strategic choices made by organisations such as 100% Life in response to the funding paradigm shift. 100% Life constructed and oversaw '100% Life medical centres' around Ukraine, and Ivan interprets this as an attempt to consolidate power and establish its dominance in the tendering market. Ivan argues that by positioning themselves not just as advocates but as direct service providers, they are '*cleverly*' diversifying their power base. In doing so, they are ensuring that their organisation remains indispensable to the state and the communities they serve, regardless of the funding source. One possible negative for 100% Life with this new funding arrangement is that the state may pay less than the international donor agencies. However, overall, '*the monopoly of 100% Life will still be there*'. Ivan believes reducing funding will not impact 100% Life's sustainability but may impact smaller, less established organisations. Ivan felt it was important to clarify that he supports the 100% Life medical centres as they are essential alternatives to state-run clinics, which may be stigmatising for key populations living with HIV.

The question of how government funding may affect the power of CSOs to hold the government to account is examined. Additionally, the participants provide their insights into

who will fund IP activities. Oleg and Davyd are the two participants who weigh in on the question of possible conflicts of interest arising from the transition of HIV services from international to national funding.

Oleg did not foresee any conflicts of interest arising. He explained that despite the change in funding structure, the government remains appreciative of the role of organisations working within the intellectual property sphere. With very few entities in Ukraine possessing technical expertise in medical procurement and IP, Oleg affirms that the technical staff in the Public Health Centre under the Ministry of Health frequently consults CSOs for guidance on patent issues and drug procurement.

However, Oleg did caution against the potentiality of government retaliation against criticism of corruption. For example, if the Ministry of Health becomes aware that HIV/HCV CSO recipients of state funding are vocal about corruption in the sector, they might cut back on such funding, '*then they can kind of retaliate if they know that an organisation is criticising a lot corruption happening in government. So they can do it, I can imagine. For IP, no, it will not happen.'*

This potential for retaliation therefore calls into question the definition of CSO - from civil society to what? As elaborated on in section 2.2.1, Salamon & Anheier (1996) lay out five shared defining characteristics of CSOs, the most pertinent being that CSOs are not part of any government or public authority. Yet, this research shows that government funding will provide greater oversight into CSO financial activities and may reduce funding to essential HIV services if they call out government corruption. As highlighted by Pavlo, '*the more money you receive, the less critical questions you ask*'. Suppose HIV CSOs can only fulfil their service provision duties within the confines of not antagonising the state. This appears to create an existential threat to their existence as civil society, ultimately removing them from the grassroots and placing them in a semi-government service provision role.

Concerning conflicts of interest in IP work, Davyd states that the IP sub-group within overall HIV services receives no government funding. They rely heavily on donor funding from organisations such as ITPC and do not see conflicts of interest arising from government funding of HIV services. Oleg and Davyd both agree that they do not foresee conflicts of

interest for IP work but highlight possible ramifications for CSOs that criticise corrupt government practices.

6.1.3. Money and Power: Understanding the Agenda-Setting Dynamics of International Donor Agencies on CSOs

The power dynamics between international donor agencies and CSOs in shaping healthcare priorities within HIV and HCV spheres are explored. Nastya and Ivan, two research participants living with HIV, highlight gaps in a donor or CSO-driven approach to agenda setting, including areas related to psycho-social aspects of living with HIV. Irina, a programme manager for a philanthropic organisation, provides insight into the top-down approach of priority setting, and on how this may not always reflect the realities of the communities they are working on behalf of.

Section 6.1.1.1. outlines the role of international donor agencies in creating competitiveness and tension between HIV/HCV CSOs. Still, the research participants discuss further the donor's power, especially regarding agenda setting. Nastya delves into the role of donor agencies in setting healthcare priorities in Ukraine. The interviewee states that agencies, such as the CDC or USAID, provide substantial funding for medication procurement and treatment retention programs. However, they often neglect other vital areas like psychological support, '*but it's still not enough funding for psychological support because our international donors don't understand our troubles.'*

As someone living with HIV, Nastya is indicating a lack of competency or funding streams to address issues which go beyond achieving retention in care and virological suppression. Nastya also identifies the '*Western or Central European and African representatives*' as the steerers of these agendas within donor agencies and she believes these have a poor understanding of the local realities and needs. They heavily focus on key populations most affected by HIV, such as sex workers, men who have sex with men, and intravenous drug users, neglecting the broader population where HIV is increasingly prevalent. In Ukraine, about 70% of new HIV cases are from heterosexual relationships, not the so-called '*key populations*'.

The interviewee emphasises that the persistence of outdated views about HIV, for instance, that it's mainly a concern for key populations or that it's a death sentence, exacerbates stigma and discrimination. This lack of awareness leads to misinformation and fear and perpetuates stigma. Nastya criticises donor agencies for their narrow focus on buzzwords and metrics rather than addressing the real and evolving needs of people living with HIV. As a result, the interviewee argues, the funded programmes are often inadequate and misdirected in addressing misinformation, stigma and discrimination, resulting in real harm to the people they aim to help. Nastya calls for donors to better understand the social situation in Ukraine, focus more on education about HIV to the general public, increase U=U campaigns, and fight for the decriminalisation of HIV transmission to reflect the reality of living with HIV in the era of effective treatment.

Nastya's concerns regarding donor agencies' lack of focus on stigma campaigns are reflected in Ivan's interview. However, Ivan believes that the big HIV CSOs in Ukraine are the agenda setters as they often focus on immediate tangible issues such as medication pricing and access but do not prioritise tackling stigma. Ivan mentions his efforts to advocate for CSOs to promote the U=U campaign in Ukraine, which took a considerable amount of time.

> *'Ivan, we don't need it [...] You know, we have a problem with the medication. We need PrEP and that and that,' and no one wanted to speak about this.'*

This highlights the power CSOs have in prioritising campaigns. Ivan and Nastya argue that activists need to lobby larger CSOs and donor agencies to change their priorities to reflect the needs of the people they are advocating on behalf of. Nastya and Ivan also suggest that the bigger the organisation, the less '*on the ground*' knowledge they possess.

It is evident that the extensive professionalisation of CSOs by international funders can contribute to agenda setting that may disenfranchise the needs of the CSOs ground base. Arguably, Nastya's assertion that international donors may not fully comprehend the psychosocial aspects of living with HIV, or that community representatives from different geographical regions guiding the direction of international funding bodies may lack an understanding of local needs of the Ukrainian people, may only capture some of the story. As highlighted by Ivan, it was difficult for him to try and convince a large HIV CSO to campaign around U=U, a campaign that has shown

to be associated with better health outcomes and increase quality of life for PLWH (Okoli *et al.,* 2021).

Irina, as programme manager of a philanthropic donor organisation, provides another example of agenda setting. Irina's organisation is a network of thirty-seven foundations around the world that '*match the national work and advocacy and research with the global advocacy and research agenda in general. So they synchronise'.* Using this '*synchronised*' approach, her organisation designs its strategies to match national research and advocacy with global advocacy and its more generalised research. As a result of this forum, her organisation identified access to medicines movement as an important health issue to fund.

They identified four areas of concern in Ukraine: 1) budget allocation for procurement of medical goods; 2) how these budget allocations were spent - especially in relation to corruption; 3) intellectual property rights and everything related to it, including drug registration, market authorisation, what comes into the market, why it comes to the market, etc.; 4) the procurement cycle, such as quantification and logistics, and the management of the supply of the drugs which can contribute to ineffectiveness of the system. Using this national-global contextual strategy, this organisation understood the broader issues related to access to medicines in Ukraine.

As a result, CSOs were funded to work on these issues, as well as educate Ukrainian officials on the structural causes relating to the upstream and downstream barriers to access to treatment. Irina does not mention national CSOs' input into the priority setting of her organisation. The organisation's synchronised approach to inform their campaigns, targets, and indicators assumes a top-down approach to priority setting within this philanthropic organisation. On the other hand, unlike the Global Fund, it directly focuses on structural causes of unaffordable ARVs/DAAs. This is most likely a result of philanthropists' ability to be independent of global politics, such as IP protectionism.

Oleksandr attempts to identify why the Global Fund is moving toward pharmaceutical advocacy rather than IP activism funding streams for patent oppositions, etc. He suggests that one reason for this shift might be a result of significant changes in the treatment landscape, where medications have become more widely available, making the challenge more about infrastructure and funding rather than access to the medications themselves. Oleksandr believes that decisions on funding allocations, which ultimately set the agenda, are often a

result of complex negotiations among various donors, each with their own priorities, which are often implemented across a broad number of countries. Oleksandr, who sits on the community delegation of one of these big donor agencies, emphasised that he never asked to pay less attention to access to treatment. The delegation identified the broader need for providing basic services for PLWH, determined their health status, and then linked those in need to the appropriate care and treatment, especially those in key populations.

Oleksandr believes that the apparent decrease in funding of IP activism in the Global Fund may be due to a combination of factors: country actors not prioritising it in their proposals, changes in donor priorities, or funding being directed elsewhere because other initiatives have been deemed more urgent. He stresses that this doesn't mean treatment access has been entirely neglected but that funding strategies and allocation are complex, constantly evolving processes subject to various influencing factors. The Global Fund's principle of 'country ownership' allows self-determination in regard to priority setting, i.e. the GF does not deny funding based on its own priorities but respects the priorities set by the grantee governments themselves.

Oleksandr's account that the power in priority or agenda setting remains within national and community delegations is corroborated by Davyd's interview (section 6.1.3). In 2018, Davyd's organisation negotiated the inclusion of IP activities within a Global Fund funding application, alluding to an open and collaborative dynamic between CSO and donor agency in agenda setting. Therefore, it is disingenuous to place a complete burden of blame on the donors setting the agenda when the CSOs have demonstrated some degree of influence over funding priorities. Furthermore, this perspective shines a light on the internal dynamics of HIV CSOs, as illustrated by Nastya, who works within one, openly lives with HIV and is vocal about the policy and advocacy areas that require attention. Yet, there seems to be persistent emphasis on access issues and less on psychosocial issues. This raises questions about who sets the agendas within the CSOs and whose voices are prioritised. While this research did not aim to understand the relationship between HIV/HCV CSOs and their ground base, this section highlights a possible disconnection between the psychosocial needs of the ground base and the priorities established by both CSOs and their funders. This may reflect the expertise-representation gap described by March & Olsen's (1998) and Saurugger's (2012), showing an incongruence between a CSO's increased structure, expertise,

and organisation, and its members' sense of representation and engagement, even when PLWH are working in the organisations.

Oleg also argues that there is a power pecking order on the board of the GF, especially regarding funding for IP activities. The research participant argues that US officials and the Gates Foundation, play a pivotal role in orchestrating the direction of funding streams, trumping power from national and community delegations and ultimately removing resource power from IP activities (for more on the Gates Foundation see section 6.1.1.3.). This further illustrates the varying layers of power dynamics within the agenda setting processes among large HIV/HCV CSOs, their ground base and their funders.

These research participants underscore a continual power tug-of-war. Yet they provide an overarching understanding that funding strategies and allocation are complex, constantly evolving processes subject to various influencing factors. The next section outlines the research participants' understanding of the complex power dynamics within the knowledge economy that affect the access to medicines movement.

6.2. Working within the Knowledge Economy

At the heart of the knowledge economy (section 3.2.3.) is a pervasive belief that innovation should be awarded a monopoly to provide the inventors of new medical technologies with a just financial return. However, monopolising knowledge, especially knowledge pertaining to health technologies, as a key driver of economic growth through intellectual property rights, has led to increased prices of lifesaving medicines, delayed availability and increased costs for patients, taxpayers and health systems (Drucker, 1959; t'Hoen, 2016; t'Hoen, Kujinga & Boulet, 2018; Tenni *et al.,* 2022). Consequently, accessing health technologies innovations, intrinsically linked to market forces (Watal, 2021), and significant political pressures from HICs, underscores a conflict between the knowledge economy and international human right obligations to ensure everyone attains the highest possible standard of physical and mental health (Forman, 2016). This findings section endeavours to understand the complexities associated with navigating the ever evolving landscape of those who strengthen IPRs and those who hope to oppose them.

6.2.1. EU Trade, Data Exclusivity and Working Within Evolving Trade Frameworks

The challenging relationship between the Ukrainian access to medicines movement and the EU comprehensive free trade agreement is underscored by Oleg. The Euromaidan Revolution occurred under the proviso of a closer relationship with the European Union, resulting in a comprehensive free trade agreement. Oleg acknowledges that, like all trade agreements, '*probably some sectors won, some not'.* Intellectual property was one sector that the agreement tried to strengthen, adding '*peculiar*' provisions which were not favourable to accessing medicines, especially the inclusion of data exclusivity. Oleg argues that there were many political and social distractions after Euromaidan, the annexation of Crimea and the separatist movement in the Donbas region, '*we didn't really do any full-blown work to it [Free Trade Agreement] back in 2014/15 because kind of the country was fighting.'*

Despite this, Oleg was in dialogue with the Ministries of Trade and of Health to highlight the potential negative consequences of these provisions, of which there was support for CSO arguments in these Ministries. Oleg expresses his appreciation for the open dialogue between his organisation and the Ministries involved with the negotiating and implementation of the FTA. He suggests a didactic relationship whereby the MoT and MoH valued the input of

CSOs and sees them as key strategic partners in the negotiation process. This highlights the power activists had to influence the discussions by contributing to their talking points, including counterarguments. As a result, and despite the power imbalance between the EU bloc and Ukraine in these negotiations, Oleg recognises the efforts of the Ukrainian government to push back on some provisions.

Davyd provides an example of data exclusivity as one key provision in the FTA and how his organisation planned to work within the new framework. Data exclusivity allows originator pharmaceutical companies to gain '*five plus one year*' on the data needed to be shared with generic manufacturers to make cheaper versions of medicines. However, Davyd does not see data exclusivity as a big problem as patents provide pharmaceutical companies with '*twenty plus'* years of monopoly protection. However, Davyd concedes that data exclusivity does become a problem in situations where activists seek a compulsory licence or wish to file a patent opposition before the five or six years of data exclusivity is reached. This became an issue with the Sofosbuvir case as outlined in section 6.2.3.1.

Identifying it as a problem, Davyd and his organisation fought to reduce its impact, '*we unfortunately cannot cancel data exclusivity'.* However, as Ukraine signed a general framework of data exclusivity regimen, they incorporated some safeguard provisions. Currently, as Ukraine is not a primary market for the pharmaceutical industry, it often does not register new medicines on to the Ukrainian market until many years after the medicine was first registered in more profitable markets. The Ukrainian activists, using inspiration from MICs around the world, worked within the FTA general framework to keep data exclusivity but are advocating for safeguards to be introduced to remove data exclusivity unless drugs are registered at a quicker rate, Davyd explains that *'if they don't register their medicine after two years and one day after the first registration in the world then they don't receive data exclusivity.* Their current advocacy is to reduce the period of drug registration down to one, *'like is seen in Chile'.*

Jensen (1998) defines interactivity, *'the relationship between two or more people who, in a given situation, mutually adapt their behaviour and action to each other'* (p. 188). Vigh (2009) argues that this definition within social life scholarship provides a lens in which to see how action shapes social environments and social environments shape action. Oleg and Davyd highlights flexibility within existing trade frameworks that allow national governments such as

Chile and Ukraine to push for safeguards within newly enforced trade and legal frameworks. Oleg's work illustrates a sophisticated engagement with governmental policies and international agreements. Recognising the challenging provisions of the comprehensive free trade agreement (FTA) with the European Union, particularly those affecting access to medicines, Oleg engaged in continuous dialogue with Ukraine's Ministries of Trade and Health. His efforts aimed to highlight the negative impacts of data exclusivity and other provisions unfavourable to public health.

This interaction underscores a two-way influence: Oleg's expertise and organisational strength helped to build government relationships. In turn, the government's openness to dialogue and its efforts to push back against certain EU provisions influenced Oleg's strategies and actions. This reciprocal relationship created a continuous loop of interaction and adaptation, reflecting the essence of interactivity where social actions and environments constantly reshape each other.

Davyd's experience further illustrate this concept of interactivity. Faced with the restrictive provisions of data exclusivity within the FTA, Davyd and his organisation sought to mitigate and reshape its impact through strategic advocacy. Understanding that completely abolishing data exclusivity was unrealistic, they successfully incorporated provisions within the existing framework to speed up drug registration. The experiences of Oleg and Davyd demonstrate a high degree of interactivity, as outlined by Jensen (1998) and Vigh (2009). Their policy adjustments, dialogues, and strategies reveal a constant interaction between their activism and the broader social, political, and legal contexts.

6.2.1.1. Overcoming EU Influences: The Success of Supplementary Protection Certificates

Oleg expresses concern for the '*staunch opposition*' to the Patent Reform Law by EU representatives. According to Oleg, the EU employed various delaying and opposition tactics for the reform to be halted or for a commitment from the Verkhovna Rada that '*there will be not any kind of changes related to patentable subject matter or medicines, etc.*' While the Patent Law Reform ultimately passed without these stipulations, it asserts the European Union's pro-IP positioning within the overall access to medicines debate. It also underscores Ukraine's strength in undermining the EU's will when it has the backing of multilateral institutions (sections 5.2.2.2 and 6.2.1.1) and national CSOs. Since the introduction of TRIPS Plus provisions, HIV CSOs have fought to reduce its negative impact, such as data

exclusivity in the section above. However, the Ukrainian government did not receive well the proposals that civil society put forward due to the legal framework of the FTA and the precarious nature of political relationships with the EU. As a result, the CSOs focused on Patent Law Reform as they identified patent monopolies as more damaging than data exclusivity to the access movement. One focus of the Patent Law Reform important to the activists is supplementary protection certificates (SPC). Oleg's excerpt provides insight into the strategic mindset of HIV CSOs by identifying targets that are important and are out of the EU's trade deal sphere of influence.

Davyd explains that prior to the Patent Reform Law, pharmaceutical companies could apply for an SPC no later than six months before the patent expires. This means that pharmaceutical companies could potentially add up to another five years of patent protection on their health technologies just before the original twenty-year patent expires. This negatively influences access to generic, cheaper medicines as it affects the manufacturing plans of generic pharmaceutical companies and the strategic procurement plans of governments. However, the Patent Law Reform changed this provision, '*but now according to that new law they need to apply for SPC six months after their patent was granted. If they applied for a SPC we could oppose that SPC and so on.'*

In addition to 'changing the game', there is a retrospective element to this law. This means that companies that were approved a patent five or ten years ago still can not apply for an SPC as the six-month rule applies to these medicines too. Davyd argues that the law hands the reins of power from pharmaceutical companies to CSOs. Previously, CSOs and governments were in a 'constant state of apprehension' as they did not know whether pharma companies would apply for an SPC or not. This removed strategic planning powers from government officials and activists. This change in law places the burden of time sensitivity onto the pharmaceutical industry and not on those seeking access to cheaper medicines more quickly. Davyd also compliments the Ministry of Economic Development and Trade, which oversees the IP sphere as 'proficiently' competent in implementing these SPC amendments. This language appears to depart from previous rhetoric of a corrupt and incompetent government in relation to IP.

Oleg and Davyd exhibit a high degree of strategic navigation amidst changing trade agreements, increasing geopolitical conflict and Ukraine's growing diplomatic relations with

the EU. Recognising the limitations in addressing data exclusivity due to the FTA, the research participant's focused Ukraine's broader patent issue, such as SPCs that help prolong the life of a medicines patent protection. By shifting the responsibility of applying for SPCs to the pharmaceutical company within a tight window period, rather than a short time period for health CSOs to oppose a SPC, the activists highlight an ability to recognise the political, diplomatic, legal and trade landscapes and prioritise their activism accordingly to achieve a more significant impact.

6.2.1.2. Trade, Political Red Tape and Neutrality

On the question of how access to medicines activism during the negotiation and implementation of FTA agreements can affect political relationships, Davyd and Nastya acknowledge a symbiotic relationship between the political and CSO spheres. Oleg outlines implications for Ukraine retaining a sovereign patent office, and Nastya critiques the European Union on 'rational thinking' regarding its pharmaceutical policy.

Davyd posits that '*governments cannot do, especially in a country like Ukraine, it cannot do such things as we did because it could distort their relations, their negotiations with EU*.' This power dynamic differentiates the red tape of political relationship building with the independence of CSOs to push for '*whatever they think is necessary*'. Due to the imposing pressure of the pro-IP EU, the Ukrainian government would not actively oppose patent applications or submit proposals or applications seeking more pro-public safeguards as it would '*destroy their relationship with EU*'.

However, Davyd alludes to the strategic positioning of the government: neutrality. Although the government's hands are tied, they support civil society's position regarding different strategies to reduce the price of medicines. Davyd explains, '*I guess after we explained to the government benefits of our actions they became supportive, but its support was not manifested in any actions. But at least they were neutral and it helped us'.* By remaining neutral, the government didn't add more challenges or barriers to the workings of CSOs. Although still restrained to work within certain legal, trade and political frameworks, this neutrality allowed activists to continue working on their access to medicines initiative, which ultimately '*helped'* them. Davyd outlines a semi-symbiotic relationship between CSOs and the government, underlining a nuanced understanding of political red tape, and governmental neutrality and

how this affects the direction and effectiveness of their tactics. The government's strategic neutrality, as described by Davyd, allowed CSOs to push their agenda without direct governmental interference, even when the government could not overtly support them due to diplomatic pressures from the EU. This neutrality provided a conducive environment for activists to operate, illustrating an indirect yet effective navigation by both political and CSO actors to use diplomatic constraints to advance their goals.

Oleg provides an example of how the Ukrainian government actively sidestepped an EU '*push*' for more power over Ukrainian patent allocations. They requested that the Minister of Trade use the patent assessment reports of the European Patent Office rather than from the Ukrainian Patent Office. Oleg posits that this would essentially be a '*quasi-patent validation sort of arrangement'.* To further contextualise this, Oleg explains that the European region has three main patent offices: the European Patent Office, the Eurasian Patent Office based in Moscow and the Ukrainian Patent Office. Each country in Europe has their own patent office, but Oleg argues that they do not play any role in deciding if a monopoly will be granted as they use the reports from the three main patent offices outlined above. For example, Ireland, Georgia and *'even Morocco'* validate patent applications via the EPO assessment reports. The Ukrainian Patent Office *'retained its sovereignty [...] and this is a very important thing. So our kind of patent office really decides, okay, this company will have a monopoly, this not—sort of.'* An example of a sovereign Ukrainian patent office benefitting A2M activists is found in relation to the case of Sofosbuvir found in section 6.2.3.1. However, while it may be regarded as sovereign, Oleg discusses their concern regarding the patent office's political ties in section 5.2.3.4.

Nastya argues that the EU should not fear treatment activists but actively engage with them. She argues that the citizens of the EU also want '*a transparent and open and honest society to make big pharma to like reduce their appetites.'* Continuing her point, Nastya contends that if the EU as an institution wants to '*move on as well*', they have to grapple with the issue of high-priced medicines. This narrative that the EU needs to 'move on as well' suggests that Nastya believes the EU to be following behind Ukraine in its mission to protect '*justice and transparency*'. In response to the EU trying to influence the Patent Law Reform, Oleg believes that the EU '*could be a rational organisation, but it's very rational for their own interests*'. Oleg and Nastya perceive the EU as an irrational institution that follows its own interests, needs to work on transparency and work collectively to reduce the '*appetites*' of Big Pharma.

Henrik Vigh's (2009) concept of navigation as an analytical lens is useful when examining the actions of treatment activists within the ever evolving knowledge economy, as outlined in sections 6.1 to 6.2.1.2. These sections illustrate a fluid knowledge economy landscape that both shapes and is shaped by the treatment activists strategies and interactions with key stakeholders. This dynamic interactivity has shown to play a key role in their ability to fight for pro-public safeguards within trade agreements and patent laws.

6.2.2. The Pharmaceutical Industry – the Saviour, the Enemy, the Ignored

The relationship between the research participants and the pharmaceutical industry is explored, with particular emphasis on how it may affect access to medicines activism. The participants simultaneously consider the pharmaceutical industry greedy and at times, corrupt but also rationalise this behaviour as they understand pharma's positioning as profit-driven entities. Irina, Ivan and Oleg outline the many stakeholders involved in calculating a formula to maximise profitable returns while mitigating negative press. This formula, depending on optimal return for pharma, can present the pharmaceutical company as a saviour or villain. This impacts the way the participants perceive and negotiate with the industry. The pharmaceutical industry is also a big funder of HIV and HCV-related projects, and the participants outline their understanding of how this may create pharma-CSO conflicts of interest. Finally, for some HIV CSOs, the pharmaceutical industry does not impact their activism whatsoever, creating a sense of transient indifference if they are not considered a direct barrier to their advocacy.

6.2.2.1. Pharmaceutical Companies and Civil Society - A Complicated Relationship

The research participants outline their complicated relationship with the pharmaceutical industry, especially in relation to their IP activism. The participants mostly outline the 'corrupt' and 'greedy' profit-driven practices of the pharmaceutical industry. Yet, the fight against these practices does not result in the manifestation of hatred for the pharmaceutical industry. Nastya and Irina both agree that the costs of medication and pricing strategies of the pharmaceutical industry are predicated on a calculated formula which aims to optimise return and reduce negative public relations:

> *I love pharma [...] They're nice guys. They produce my medications [...] They're part of my life. But just, it's like with your kids, yeah? Sometimes they behave bad. Do you hate them from that? No. I just want them behave good and I will educate them.* (Nastya)

The complicated activist-pharma relationship is evident in the duality of pharma's character, 'nice guys' and misbehaved kids. Yet it suggests that Nastya believes CSOs are equity educators and can help facilitate pharma's growth in the areas of ethical and social responsibility.

Irina understands her relationship with pharmaceutical companies as a meeting of opposing teams with different objectives who must reach an agreement. This rational approach to activism detaches strong emotions or evil characteristics of those working in the pharmaceutical industry, '*I am not thinking about pharma as a bad guy*.' Instead, it provides an insight into the mutual understanding that both sides have targets to reach, and these opposing forces must reach a compromise. Irina considers these meetings similar to business dealings. An environment that relies heavily on rational logic, compromise and understanding of each other's objective. Irina compares her role as a donor to that of pharmaceutical representatives, '*Like you can demonise me for not giving a grant to one organisation versus another.'* Based upon the terms set out in her agency, she needs to use rational thinking and set parameters to choose between grantees, which does not make her evil but is the nature of the donor process. Ergo, Irina believes that people working within the pharmaceutical industry who she encounters are following processes and not characteristically '*evil or stupid*'.

This provides insights into two separate approaches to working with the pharmaceutical industry. Human rights activists like Nastya view their role as equity educators and people who can force the industry towards better practices using direct actions and legal responses (as highlighted with lopinavir/ritonavir and sofosbuvir in sections 6.2.5.2. and 6.2.3.1.). Irina, who identifies more as a behind-the-scenes advocate rather than an activist, upholds a more formalised, institutionalised approach to reducing the prices of medicines. Irina's business like perspective focuses on negotiation, compromise, and mutual understanding, rather than adopting a more radical stance. Therefore, this suggests that the relationship between the pharmaceutical industry and civil society goes beyond understanding the rationale behind the

pharmaceutical pricing model, but also pertains to their positioning within the access to medicines movement.

6.2.2.2. The Calculating Saviour or Villain?

The perception of the research participants toward the pharmaceutical industry and its pricing policies is important as it provides insight into how they may approach the pharmaceutical industry-CSO relationship. Irina believes that multiple factors influence pharma's pricing and marketing strategy formula in Ukraine. Firstly, Irina alleges that pharma companies use their connections to '*compete in corruption and in hidden agreements*'. However, the deeper these corrupt schemes go, the more investments are required to keep them operational and hidden. These corrupt, opaque schemes require a lot of financial, mental and human capacity to effectuate and may incur negative attention from CSOs. Therefore, a pharmaceutical company would assess the potential gains versus the potential losses they might derive from corrupt practices, maintaining protectionism, or evoking socially responsible measures such as price reductions or voluntary licences.

Irina interprets this approach to decision-making on pricing strategies as an equation weighted towards commercial interests. Irina argues that when financial benefits are balanced with potential risks or losses, then the pharmaceutical company will start engaging in a 'public good' dialogue, '*and when it equals, well, you can start pushing onto their social responsibility, the public good.'* However, these conversations are less likely to occur if commercial interests positively outweigh the potential losses of public dissatisfaction. Additionally, the latter continues to be true if a corporation believes that hidden agreements and corruption outweigh the risk of financial losses.

According to Irina, the 'behind-the-scenes' factors that often benefit commercial interests override any logical argument in favour of public health, *behind-the-scene factors and influences outweigh all your logic and all your clear arguments that are available*.' This indicates a pro-business equation-based approach to public health as a challenge for treatment activists. The equation provides opportunities for pharmaceutical companies to appear altruistic when implementing pro-public measures. However, Irina believes that this is a methodical approach to appeasing critics and, ultimately, results from an equation to sustain commercial interests.

However, Ivan argues that pharmaceutical companies are not the only calculating players in the price negotiation process. Ivan explains that each country has their own process for negotiating the price of medicines with pharmaceutical companies, yet, in some countries, the process is more corrupt than in others. Ivan compares German and Eastern European countries' negotiating processes. In Germany, there is a committee of physicians, NGOs, government, pharma, '*everybody*' at the table. He acknowledges that these are closed meetings but believes that it is a better forum as everyone's interests are listened to. In comparison, in the EECA region, the government is usually the only stakeholder to meet pharmaceutical companies behind closed doors, '*it's like in Russia, Ukraine, Kazakhstan, and Moldova, or other countries in East Europe and Central Asia. All governments are corrupt.'*

As a result, Ivan believes that the best process for price negotiation with pharmaceutical companies should be one that includes all stakeholders and has some regulation to avoid, *'so not just sit together like Robbie and Ivan and we decided about price.'* Similarly to Irina's argument of interest-weighted formulas in decision-making processes, Ivan argues that without regulated and inclusive pricing practices, corrupt practices will occur from both pharmaceutical companies and government officials seeking results benefitting their own commercial interests. Oleg provides a more sceptical view of price negotiating with pharma believing that a multistakeholder meeting with pharma wouldn't result in reduced price. He posits that if a pharmaceutical company has a full monopoly on a drug, *'you can say, oh, we need a discount, and they just say no and that's it. And it's all negotiations, basically'*. According to Oleg, leverage is needed or else, *'sometimes they just say, okay, we have standard price and that's that.'* One strategy often used to reduce the price of medicines is by calculating the volume of drug procurement for the next three or four years, locking the government into an advance purchase agreement. Oleg admits that when he's part of this process, *'it goes like this and it goes around and around and then it never ends.'* Irina, Ivan and Oleg underscore the need for new regulation, or a continued need to fight for leverage, to successfully disrupt pharma's formula and, ultimately, reduce the price of treatment.

In 2001, Resnik argued that pharmaceutical companies base their social responsibility mandate in LMICs depending on the prospects of a reasonable profit and the prospects of a productive business environment. Resnik argues that businesses exist within societies therefore, societies, including political and social spheres that care for equity should be able to influence the direction of business deals, so as to avoid their wrath. However, as

highlighted continuously with inequitable access to ARVs (t'Hoen 2011), Sofosbuvir (Morgan, Bathula & Moon, 2020) and COVID-19 technologies (Gleeson *et al.,* 2023), the desire to maximise profits often outweighs the objections of communities, health groups and politicians. Therefore, as highlighted by the research participants, without leverage, communities are at the mercy of pharma's monetary philosophy and argue for new pricing regulation. However, in the short term, activists must continue to seek leverage in price negotiations, to successfully reduce the price of medicines.

6.2.2.3. 'Pharma-Funded', Conflicts of Interests & Integrity

In section 6.1.2., the participants outlined the potential pitfalls of transitioning from international to domestic funding. In this section, the participants outline if conflicts of interest arise when their organisation and work are funded by the pharmaceutical industry. Anna reflects on her organisation's engagement with pharmaceutical companies, especially as they partially funded their HCV work. Anna acknowledges the '*problematic*' and delicate interplay between advocacy work and funding from pharma due to the potential rise in conflicts of interest. Yet Anna's organisation received pharma funding at the time when CSOs focusing on HCV were not eligible for funding usually allocated to HIV and TB (section 5.1.3). Anna provides the example of the EU primarily giving funding toward work focused on TB and HIV due to reasons of border security, '*because they just didn't want to have Ukrainians with TB in the European Union, let's be honest—it's all about like border control.'*

This limitation on funding streams results in CSOs having little option but to accept pharma funding, even though Anna understands the challenging relationship. However, Anna feels that in her case, the pharma-CSO partnership worked well due to their aligned goals. Anna's organisation wanted to create and implement a national HCV programme. According to Anna, pharma '*were interested in the topic to be moved and revived and being alive*' as the programme would ultimately result in larger procurement of their medicines. Anna believed that this symbiotic relationship gave the CSOs more power to avoid the promotion of the pharmaceutical companies, which can often be a condition of pharma funding. Therefore, her organisation were able to be '*very much aggressive'* when declining to promote their organisation, such as using their logos. Oleksandr reinforces Anna's argument that pharmaceutical companies should not dictate any conditions to the projects they fund, especially in relation to how these projects should be implemented. The pharma-CSO coordination of projects can involve discussing expected achievements of goals and if these

collaborations are mutually beneficial. Oleksandr argues that pharma should not have the power to tell CSOs how to do the project, and this principle must be established from the beginning.

Yet, Anna contends that this pharma-CSO power principle is not often followed. She often hears examples of how bad it is for initiatives, people and organisations being funded by pharma as it creates barriers for CSOs to criticise their funders. In essence, pharmaceutical companies financing initiatives when no other funding streams are available may be seen as financial saviours. However, Anna believes critical thinking is needed to identify if this pharma funding is a result of their commercial interests and how organisations may counteract, mitigate, or mutually benefit from it. Like Oleksandr, Anna believes that it is crucial for the integrity of CSOs who receive this funding to balance power by managing potential conflicts of interest from the beginning. Conversely, when discussing changing from international funding to national funding of CSO services, Ivan argued that we are less likely to ask more critical questions of those who provide the financial supports. In a similar vein, a study exploring the potential biases in healthcare practitioners when the pharmaceutical industry funds ongoing medical education found that while health professionals recognise the possibility of bias, they are often unable to detect it. This could be due to the subtlety of the bias resulting in healthcare professionals not realising they were influenced by their industry affiliations (Schofferman, 2011). Therefore, if the experience of healthcare professionals is extrapolated to the experience of CSO actors, it begs the question of whether this can directly affect CSO's relationship with the pharmaceutical industry and IP activism.

In their paper, McCoy and Gafton (2019) discuss the corporate capture of civil society. They argue that non state actors such as the pharmaceutical industry and the Bill and Melinda Gates Foundation work under the guise of health partnerships with various stakeholders including CSOs, to help increase CSO influence in the political process, but also to increase their influence in global health policies. However, the research participants see the pharma-CSO partnerships in a less nefarious way and are often identified as symbiotic relationships, if appropriate conditions are set to reduce conflict of interest.

Irina examines the integrity of people working within the pharmaceutical industry. Firstly, Irina argues that the pharmaceutical industry is not a homogenous group. She believes it is important to differentiate between ethical practices among different pharmaceutical

companies. Additionally, it is important to recognise varied degrees of integrity among individuals working as pharma representatives.

To illustrate this, Irina provides an anecdote of her friend who worked as a pharma representative for a prominent pharmaceutical company. As he worked up the ranks with his company, he realised that enhancing his sales and profits depended on his willingness to enter into informal, secret agreements. The day he quit was when *'it became obvious to them that one of their contracts, the large contracts that they've signed, actually had that corruption margin'.* Even though these informal agreements were '*legally is was cleared*', his personal morals stopped him from working within institutional norms, especially when they '*were selling the drug like twice the price it's usually on the market*'. This anecdote outlines the internal power struggle individuals have about actively participating in a system that encourages overpricing. Irina used this story as a reminder that while corrupt practices do exist in the pharmaceutical industry, some actively reject them. That there are people who choose personal integrity over personal gain.

The research participants demonstrate that the power of the pharmaceutical industry is not overarching but is a result of many varying influences. These include economic influences, a question of personal, industrial and CSO integrity, and public relations, but are ultimately dependent on pharma's formula to maximise profits without incurring too many losses.

6.2.2.4. 'Pharma Neutral' (for now)

The pharmaceutical industry is a key stakeholder in the access to medicines movement. Eight out of the nine participants in various ways, worked directly with pharma. Yet regardless of pharma's prominence in the movement, Daniela and Nastya identify areas where pharma isn't HIV CSOs' primary focus.

Daniela outlines why her organisation, which introduced international procurement, is able to completely bypass interactions with the pharmaceutical industry. The procurement of medicines goes through international agencies, such as UNICEF, Crown Agents etc. This effectively obviates their need to contact or build relationships with the pharmaceutical industry. As a result, Irina's organisation has taken a neutral stance with pharma, '*our connections with them are absolutely neutral at the moment*.'

Daniela's use of '*at the moment*' suggests that in the future, this may change if their organisation's strategy changes. Therefore, not interacting with pharma isn't necessarily a long-term strategy but is context-dependent. Additionally, remaining 'neutral' with the pharma industry provides a sense of how CSOs interact with pharma when they do not see them as an antagonist and there are other avenues to work around the industry. Despite this neutrality, Ukrainian pharmaceutical companies did initially resist Irina's organisation's efforts to internationalise the procurement process. The companies feared they would lose their share in the state procurement process to international manufacturers. Irina outlines a major barrier that Ukrainian manufacturers face due to the stringent quality and efficacy rules required by the international procurement agencies, mainly manufacturers requiring WHO prequalification - a requirement typically not achieved by Ukrainian manufacturers. As a result, no ARV was procured from Ukrainian manufacturers for over five years. However, when procurement powers were given back to the National Procurement Agency in 2020, they no longer required WHO prequalification. This decision raised safety concerns among CSOs, especially regarding Ukrainian-manufactured paediatric ARV formulations.

Daniela outlines the role of other organisations, such as 100% Life, who have appealed to Global Fund and the prequalified pharmaceutical companies they deal with to help source these medicines instead. Irina makes a distinction between 'dangerous' Ukrainian medicines versus 'safe' internationally procured medicines based upon WHO prequalification standards *'because it could be dangerous, you know, for the patients to be treated with their drugs, Ukrainian ones.'* This contrasts with Daniela's account of her trips to Ukrainian manufacturers, who believes that Ukrainian pharmaceutical companies *'actually meet good manufacturing practises (GMP) standards and they're of a quite high professional level and have technical capacities to do that.'* Daniela outlines her inspections of *'like super-clean sterile zones where like you have manipulators to mix components and produce.'* Despite this, Daniela knows of no compounds from Ukrainian manufacturers that the Ukrainian people have really benefited from and argues that a lack of communication and coordination between bodies involved in the transfer of knowledge and skills is available to create a strong native manufacturing base.

This highlights a complex shift in power dynamics of the Ukrainian pharmaceutical industry as international procurement reduced its market power due to the high standards of WHO prequalification. International procurement reduced the monopoly power of native

pharmaceuticals and reduced the activists' interactions with and attention to, Ukrainian pharmaceutical companies. Additionally, international procurement temporarily removed power from state bodies to engage in informal, corrupt procurement agreements with Ukrainian pharmaceutical companies due to internationally perceived inefficiencies in their manufacturing procedures. However, when the National Procurement Agency reclaimed procurement powers, they reinitiated national procurement resulting in CSOs re-asserting their efforts to work with the GF to procure from 'safe' international manufacturers. Daniela also highlights the lack of knowledge and skill sharing among different pharmaceutical bodies to reach international GMP standards, hampering the Ukrainian manufacturing of safe and efficacious medicines.

The literature on WHO prequalification is consistent with the views of the research participants, as it plays a critical role in ensuring that ARVs and other essential medicines meet high-quality standards. This is particularly important in LMICs where regulatory oversight is often lacking, where medicines can be unaffordable, and where patients often fail to gain access to treatment (t'Hoen *et al.,* 2014). The WHO (2018) estimated that around 10.5% of medical products in LMICs are substandard or falsified. Therefore, the WHO prequalification programme evaluates applications from manufacturers to ascertain whether their health products meet its standards of quality, safety, and efficacy and, to determine medicine suitability in LMICs (Blaschke, Lumpkin & Hartman, 2019).

Substandard and falsified medical products is a significant issue for HIV management as the quality of ARVs are vital in the management of HIV as it may result in many PLWH not receiving the correct treatment, risking poor health outcomes and drug resistance, and increase risk of mortality (Thi Do *et al.*, 2022). Furthermore, those unknowingly using substandard ARVs for the purpose of preventing onwards transmissions to their partners, or as pre or post exposure prophylaxis may remain unprotected against transmission (Thi Do *et al.*, 2022). In their study, t' Hoen *et al.,* (2014) estimated that every dollar invested in the prequalification programme saved $200 in public medicine procurement, highlighting a remarkable turn on investment and highlights the efficiencies of the programme.

Despite its impressive record, an overview of the WHO prequalification programme highlighted issues that may affect affordability and availability of medicines. One issue is the

annual fees incurred by manufacturers for pre-qualification, which may deter manufacturers from seeking prequalification if their profit margins are not perceived as sufficient (Leow, Hu & Hird, 2023). Such deterrents, including the costs associated with creating and maintaining sufficient high quality standards to achieve WHO prequalification may reduce the number of prequalified supply, subsequently decreasing competition. Additionally, as many countries are expected to move away from aid in the coming years (Jalles d'Orey & Prizzon, 2019), it remains uncertain whether MICs will continue to procure from WHO prequalified manufacturers, which may be more expensive than local manufacturers.

This research provides insights into this question, as there seems to be some political backsliding on health regulatory standards in drug procurement. Future research should explore these dynamics to support the sustained success of the WHO prequalification programme.

Despite Daniela's organisation understanding of issues relating to drug safety issues and WHO prequalification, her organisation takes a neutral stance with pharma and not interact with them, this is context-dependent. Despite this, CSOs continue to monitor and address issues related to drug procurement and regulatory compliance.

Nastya argues that Western and Central European countries ignore the abuses of the pharmaceutical industry due to the lack of out-of-pocket payments and the seemingly symbiotic relationship between governments, patents and pharmaceutical companies. Nastya believes that a cycle of satisfaction hinders the EU country's efforts to overcome high drug prices. This cycle includes the pharmaceutical industry being a major employer and taxpayer, fostering good relationships with governments. The patents allow pharma to keep the prices of medicines high via monopoly control, but PLWH gains access to ARVs for free as they are included in their national health services or insurance systems, *'so HIV positive people and, you know, key populations organisations they don't complain a lot because it's not from their pockets.'*

However, Nastya believes that this is to the detriment of PLWH due to the multitude of needs of the community that remain unmet. Nastya believes that countries in the EU should follow the example of Ukraine with respect to international procurement and place the savings into efforts to eliminate HIV transmission and increase the quality of life for PLWH. Nastya

believes that if EU HIV CSOs focused more on cheaper drug procurement and redistributed HIV finances toward unmet needs of the community, *'government and patients would be beneficial from it.'* However, Nastya argues, *'I think the big pharma wouldn't allow it'*, underscoring her thoughts on the power Big Pharma has on the decision-making processes of the EU.

This section explores the central role of the pharmaceutical industry in the access to medicines movement. The participants explore their complicated relationship with the industry, viewing it as an antagonist, as a commercially centred opponent or as an obstacle to bypass. Yet Pharma's power and influence are dependent on many varying factors that centre around pharma's calculated formula to optimise profits, the quality of Ukraine's health regulatory ecosystem and the strength of CSOs.

6.2.3. The Legal System: Friend or Foe?

In this section, the participants outline the power of the courts in deciding outcomes related to intellectual property. Three out of the nine participants specifically discussed the power of the legal system relating to campaigns aiming to get access to a generic version of Sofosbuvir, a cure for HCV and Ritonavir/Lopinavir, a widely used effective and safe ARVs.

6.2.3.1. Investor-state Dispute Settle Courts: The Case of Sofosbuvir

In section 2.3.4, the introduction of an Investor-state Dispute Settlement (ISDS) court in Ukraine was a condition of its FTA with the EU and the US. This provision grants private parties, such as the pharmaceutical industry the right to file lawsuits against states for state actions that might interfere with the industry's profits. The research participants highlight how ISDS was used in the case of Sofosbuvir.

Davyd uses the case of Sofosbuvir to highlight the instrumental role of the legal system in upholding intellectual property, creating '*a long struggle*' and '*threatening*' the Ukrainian government. It also highlights how activists used the courts to fight against the patentability of this drug. Davyd provides a summary of the case:

We submitted a patent opposition against one of their key patent applications. And the Ukrainian patent office issued a so-called preliminary refusal [...] So because it delayed the granting of the patent, one of the generic distributors of sofosbuvir they registered in Ukraine. And as a result the price for sofosbuvir dropped twofold from something like a thousand-and-a-half dollars per treatment course to seven hundred dollars [...] because generics of sofosbuvir has registered in Ukraine and they needed to compete. When it comes to data exclusively they were to slow to enter the Ukrainian market. And the funny fact that this generic company submitted their documents for registration earlier than Gilead.'

The legal threat pressured the government to seek an '*amicable*' settlement. An 'amicable' settlement was in opposition to the recommendations of the A2M activists, which resulted in activists continuing to use their legal rights to overcome this settlement. The main two conditions of the settlement included Gilead promising not to increase the price of their medicines, even after the registration of generic Sofosbuvir was cancelled. In return, the MoH agreed to cancel the registration of the generic. As a result, Gilead's Sofosbuvir was the only HCV Cure on the Ukrainian market. This pushed A2M activists to move forward with three patent oppositions.

Davyd explains that there are usually a lot of patent applications on one medicine, and their goal was to oppose three of them, namely the primary, strongest application for the drug's polymorph component. In August 2017, the Ukrainian patent office refused this patent. Removing Gilead's intellectual property monopoly '*leverage*' prompted them to extend their voluntary licence agreement to Ukraine (voluntary licensing is further developed in the next section 6.2.4). Davyd does question why Gilead did not include Ukraine in their initial licensing agreements in 2014/2015. He believes that activists had to force Gilead's hand to extend their voluntary licence to Ukraine.

According to Davyd, the Sofosbuvir case highlights how the legal system can be used as a barrier to access cheaper, more affordable medicines. It also showcased how activists used legal tools such as patent oppositions to fight for access to treatment. Davyd suggests that the courts were weaponised as a system to '*threaten*'. The A2M activists used the Ukrainian Patent Office to fight for the removal of IP rights of drugs that they do not believe reach patentability criteria, threatening their ability to procure more treatment. It is also an example

of pharmaceutical companies calculating their losses from generic competition to file lawsuits against the Ukrainian government as it threatens their profits.

The above excerpt also reiterates CSOs' role in bypassing government decisions and deciding to continue '*moving forward*' in their goals to overhaul the patents of Sofosbuvir. This is reminiscent of Hellman's (1998), Hellman, Jones & Kaufmann's (2003) and Stepaniuk's (2022) argument that Ukraine's reduced state capabilities when it gained independence was partly a result of oligarchic and private firms capturing state and public goods. As a result, informal civil society work together to take on core functions of the state during time of crises (Krasynska & Martin, 2017; Stepaniuk, 2022). The case of sofosbuvir highlights another dimension of state capture, the ISDS courts. There are many issues related to Investor-state Dispute Settlement (ISDS) procedures, a legal arbitration mechanism for a private investor, such as Gilead to sue a state for infringing on the value of their investments. ISDS are highlighted in the literature as a great concern in the context of public health and access to medicines due to the impartiality of arbitrators towards private investors making their claims, arbitrators that sit outside of national judicial systems (Baker & Geddes, 2017; Gleeson *et al.,* 2019; El-Said, 2020). Therefore, this provides another example of how external forces reduce the ability of the state to self-govern. It also reinforces this research's argument that formalised CSOs such as Davyd's organisation play a fundamental role in taking on state functions in the absence of government capabilities.

6.2.3.2. The Legal System Upholds the Law, but for Whom?

Throughout this research, a power struggle between the human right to health and intellectual property rights is unfolding. Therefore, the legal system plays a key role in deciding which argument is most compelling, leading to potentially major public health ramifications. Both Oleg and Nastya use the patent opposition case of Lopinavir/Ritonavir to question the legal system's adherence to a free and fair upholding of the law.

Nastya argues that the three year court case against pharmaceutical company, AbbVie's patent on Lopinavir/Ritonavir casts a critical light on the legitimacy of the Ukrainian courts. When I asked Nastya about the government's and publics' reactions to their direct actions (further

elaborated in section 7.4.5), Nastya likens the court's favourable treatment of AbbVie to corruption.

Nastya argues that the Ukrainian courts are one of the most corrupt judiciaries in the world and believes that AbbVie paid off those in the justice system to favour their patent evergreening practices, '*you know, we have one of the most corrupted court systems in the world. And like mostly like all this justice system it's very corrupted'.* Additionally, Nastya equates the legal system to a '*government institution*' insinuating a lack of judicial independence and the potentiation for government support of AbbVie, '*because they were paid by AbbVie.'* Nastya's description of her organisation's direct actions suggests that their main focus was to show all stakeholders that patents equal the unnecessary deaths of PLWH and needless use of funds.

Nastya's claim that the pharmaceutical industry bribes the Ukrainian courts to uphold their intellectual property rights cannot be verified and may be considered libellous, especially in the case of Lopinavir/Ritonavir. However, the perception from the research participants that the courts are being paid off by pharmaceutical companies or that the courts are influenced by politicians is important as it highlights their understanding of the environment the activists are working.

Oleg believes that the high cost of Lopinavir/Ritonavir is a really good case to highlight the costs associated with patent abuses because '*it was eating a lot of money*'. Oleg explains that these drugs were the most sold drugs in Ukraine in any state procurement at one point. The high volume of procurement and the high price of the two patented drugs resulted in *'Ukraine to overpay every day like a million hryvnas.'* Yet although this case may seem clear in acknowledging patent abuses, Oleg argues that without financial and technical resources, these cases are doomed to fail.

Oleg uses a battle-like analogy to characterise IP litigation. He posits that the outcome of the court case is dependent on the financial resources or strength of opposing teams. Both Oleg and Nastya argue that the pharmaceutical industry's huge financial resources can impact the outcome of these '*battles*'. According to the research participants, money can be used by pharma for bribery or having the resources to procure technical expertise, which could be difficult to sustain for three year long court cases.

Therefore, the participants in this section suggest that the court system overseeing intellectual property favours those with the most resources. Having the financial resources, alongside TRIPS Plus provisions imposed by the EU FTA, allows the pharmaceutical industry to weaponise the courts to act as a 'threat' against opposition to IP. Nastya also suggests that the pharmaceutical industry has the resources to bribe members of the justice system, effectively buying their pro-business stance on IP. However, it also suggests that trade rules allow CSOs to effectively oppose patents, but to do so, incredible levels of resource mobilisation are needed. Overall, these accounts suggest that the financial well-being of the pharmaceutical industry and CSOs is needed to leverage price negotiations and/or continue with long, drawn out IP litigation 'battles'. Furthermore, the activists' strategic navigation of the knowledge economy is highlighted by their success in achieving pre-grant opposition mechanisms as part of the Patent Law Reform (sections 5.2.2.2 and 6.2.1.). Pre-grant oppositions are a more cost effective and accessible route, as it circumvents the need for a legal team for long, protracted court cases. Pre grant oppositions have shown to be hugely successful in accelerating access to ARVs in MICs (Rathod, 2022). This underscores the treatment activists' ability to leverage and reshape the legal system to advance their mission of ensuring access to access to affordable, generic medicines.

6.2.4. Charity or Self-preservation: Medicine Patent Pool and Licence Agreements

This section provides a detailed insight into the perceived advantages and disadvantages of the MPP and voluntary licensing as tools for the A2M movement. It includes Irina's analysis of the multiple components necessary for the successful functioning of voluntary licensing agreements. It provides insights into the doubts that participants feel toward the strategic nature of VLs and the MPP's role in MICs. The section further discusses the emerging opaque processes of the MPP and what this means for treatment activists.

6.2.4.1. The Precarity of Middle-Income Countries and Voluntary licences

Designated as a lower middle-income country, Ukraine is precariously positioned in the pharmaceutical voluntary licensing landscape. To date, the Medicine Patent Pool (MPP, 2023) has facilitated the product availability of one HCV medicine and five ARVs with an additional DTG paediatric formulation in Ukraine. The MPP's success worldwide is undeniable with projected figures estimating 170,000 deaths will be averted and $3.8 billion US dollars will be saved throughout global health systems as a result of MPP licences by 2030. The role of voluntary licence agreements has been shown to reliably reduce the prices of medicines more sustainably than other mechanisms such as price discounts or tiered pricing (t' Hoen *et al.,* 2011; Juneja *et al.,* 2017; Baker, 2018; Simmons, Cooke & Miraldo, 2019). However, despite the MPP's success in LICs, four research participants highlight the MPP's strengthens and limitations in facilitating better access to health technologies in Ukraine. The role of voluntary licences in the access to medicines movement is expanded on in sections 2.3.4. and 7.4.4.

Firstly, Oleksandr outlines the '*unique role*' the MPP plays in Ukraine by '*covering the gap*' in communication between the pharmaceutical industry, multilateral institutions, health ministries and CSOs. For years, the dearth of communication between these remained unabridged. Oleksandr suggests that this may have been due to the financial constraints of CSOs, and governments with relatively small populations having limited bargaining power with the pharmaceutical industry, *'also so sometimes you don't have enough strong arguments to convince the industry or something.'*

Oleksandr believes that the MPP helps bridge this communication gap as it works as an intermediary with LMICs and pharmaceutical industries around the world. By working with the MPP, originator pharma companies allow generic manufacturers to make generic versions of their medicines, reducing the price of medicines, while the originator receives royalties in return. Therefore, by bridging this communication gap with many LMICs, the MPP increases its bargaining power with the pharmaceutical industry.

Ivan, Oleg and Davyd all agree that the MPP works incredibly well for low-income countries around the world. However, each participant also agrees that the MPP should be criticised for

their lack of support for MICs receiving voluntary licences. Ivan argues that the efficacy of the MPP in MICs is '*debatable*'.

Ivan argues that even despite *'exhaustive attempts'* at negotiations, the MPP cannot force the hands of the pharmaceutical industry to give licences to MICs creating an arduous path to access to medicines. Ivan explains that the pharmaceutical industry sees MICs as having the potential to pay higher prices for medicines and exclude them from licensing agreements. Additionally, Ivan argues that the pharmaceutical companies do not acknowledge other factors such as corruption within MIC governments, which often results in money never reaching the '*real recipient*'.

Ivan and Irina argue that there is an unwillingness within the MPP to work within complex systems which ultimately denies PLWH access to treatment. Oleg's account is congruent with Ivans adding that the MPP's inclusion and exclusion criteria for licence agreements can often be 'a*rbitrary and misguided*'. Davyd believes that the precarity of MICs paying for patented drugs, in addition to a lack of financial resources are the main reasons why donors such as ITPC focus their work in these regions, as IP most affects them. Therefore, the participants argue that while the MPP may be beneficial for LICs, its practical application appears more contentious, especially for countries caught in the middle.

This raises questions about the effectiveness of the MPP as an intervention to diffuse medicines globally within a restrictive, market-based knowledge economy. Although LMICs frequently seek donations and discounted prices for access to medicines, these measures often fall short. Prices remain prohibitively high, even with discounts and donation based approaches are typically not offered on a continuous basis. This becomes particularly problematic for chronic diseases that require lifelong treatment (Guilloux & Moon, 2000; Moon *et al*., 2011).

As highlighted in section 1.2., TRIPS flexibilities were expected to increase access to ARVs but fears of international pressure and trade retaliation prohibited their full utilisation (Banta, 2001; t' Hoen 2002; Attaran, 2004; Beal & Kuhn, 2012). Therefore, the MPP, a mechanism that provides originator companies with royalty payments and provides LMICs better access to medicines was supposed to bridge this gap between the profit driven knowledge economy and the unmet global health needs. However, the participants emphasise the financial barriers

faced by MICs and the limited effectiveness of the MPPs securing license agreements for MICs as significant shortcomings.

6.2.4.2. The Medicines Patent Pool: Pros and Cons

The topic of the MPP created a debate among five participants regarding its strengths and weaknesses, especially in the EECA region. Oleksandr, who has worked closely with the MPP as a community activist, strongly defended the MPP's role in Ukraine's access to medicines movement. Oleksandr cites ARV, Tenofovir, Lamivudine and Dolutegravir and the HCV cure, Sofosbuvir as two successful examples of MPP intervention. However, Oleksandr also caveats this by not attributing all of the success to the MPP*, 'they are just one player in this complicated field. However, they have uniquely bridged a gap that had existed for years.'*

Oleksandr acknowledges the complexity of the licence agreement landscape, its many moving parts and the MPP's role within it. It implies a similar sentiment to Ivan's statement in the above section about expectations of the MPP, '*There's an implicit understanding about what the MPP can or cannot do'.* While celebrating its role as an intermediary, it also highlights its limitations, and need for alignment with all stakeholders to attain voluntary licences. As provided in Davyd's example of Sofosbuvir, it took a huge number of resources to oppose key patents of Sofosbuvir, an attempted lawsuit and a settlement from the MoT to finally get Gilead to issue a voluntary licence.

Irina argues that the efficacy of the MPP isn't just about its existence but is an integral player in a multifaceted issue. Irina places an emphasis on all stakeholders to make voluntary licensing work effectively. Pharma, the state and CSOs need to coordinate to ensure that: pharma provides licence agreements; generic manufacturers can make the medicines; price expectations are met and aligned with budget allocations; and that corrupt practices are disrupted. Irina suggests that while the MPP's role as coordinator in this complex system is important, they often fall short, *'but the MPP needs to step up its efforts to navigate these complex dynamics.'*

Ivan agrees with Irina that the MPP needs to '*step up*' and that their approach is '*over simplified*'. They both agree that the MPP prefers to take the path of least resistance. Ivan argues that the MPP needs to do a better job at convincing the pharmaceutical industry to

licence promising drugs to MICS. Ivan believes that the MPP's '*intimate ties'* with pharmaceutical companies as its source of funding creates a circular dynamic that perpetually benefits countries with an established pharmaceutical industry, '*the MPP has demonstrated a reluctance to go against the interests of pharmaceutical companies.'*

Ivan suggests that the funders of MPP are protecting their own financial interests by pressuring the MPP to not go against the financial interests of the pharmaceutical industry. Oleg expands on this point arguing that the MPP is potentially a '*counter-strategy*' employed by the pharmaceutical industry to act as deterrence against compulsory licensing and patent oppositions, essentially stifling resistance to IP. Oleg considers voluntary licensing as the least aggressive way to get access to treatment as is it based on the benevolence of pharma. Conversely, compulsory licensing and patent oppositions are often lengthy and expensive endeavours with uncertain success rates and come with big international and pharmaceutical opposition.

While Irina outlined the critical factors needed for the MPP to work effectively, there is agreement among participants that the MPP must be more critical of exclusion practices of the pharmaceutical industry. The MPP financing by countries with *'robust pharmaceutical industries'* creates a power differential between pharma and MICs. The participants argue that this conflict of interest remains a critical issue in the access to medicines movement in MICs.

Davyd and Oleg identified another issue regarding voluntary licensing: originator pharmaceutical companies choose which generic manufacturers get to make the medicines. Both participants believe that this is a big limiting factor for the effectiveness of licence agreements facilitated by the MPP. Gilead has the authority to give manufacturing licence agreements to select generic manufacturers and exclude others from making the treatment, potentially creating an artificial supply issue. In comparison, if a compulsory licence is issued, a patent is opposed or expires, any generic manufacturer has the right to manufacture the health technology in question. Oleg expands on this point, highlighting that this limitation is '*dividing the generic manufacturers*'. It enables generic manufacturers to '*bully*' independent generic manufacturers. Gilead through its licensing agreements has the power to grant manufacturing exclusivity to generic manufacturers, potentially creating supply issues and divisions within the generic pharmaceutical industry.

In their study, Dave *et al.* (2017) warn that providing power to generic drug companies to control the prices of medicines in non-competitive markets will likely affect individual and societal health. While these studies are focused on the American generic market, the overall results and heeded warnings can be transposed to market dynamics in LMICs. Calls have long been made for the MPP to issue non-exclusive voluntary licence agreements (meaning a patent holder can issue licences to multiple generic manufacturers and in different geographical regions). Amin (2007), who works in IMAK, global access to medicines CSO, argues that to ensure competition truly, VLs should be nonexclusive and be provided to at least five to eight generic manufacturers. The research participants reiterate this call for greater generic competition.

In this section, the participants identified the importance of the MPP's co-ordinating role in facilitating voluntary licences. While Oleksandr argues that the MPP has benefited from the MPP, the other participants were more sceptical of its role in Ukraine. Oleg, Davyd, Ivan and Irina were critical of different elements of the MPP including its unwillingness to work in MICs, its close ties to the pharmaceutical industry, its source of funding and its selective licence agreements with generic manufacturers. Additionally, Oleg expressed scepticism about the establishment of the MPP. For him, voluntary licensing is a tactic by the pharmaceutical industry to discourage 'any fight' against IP and to increase positive PR for the industry.

6.2.4.3 A Bad Precedent: *How I can be a treatment activist if I don't know the price?*

Transparency of its licence agreements has always been considered a fundamental principle of the MPP. In this section, two research participants outline what opaque licence agreements mean for treatment activism. Oleg and Davyd both contend that the royalties that generic manufacturers must provide to originator companies for selling their products via voluntary licensing is a drawback. Depending on the licence agreements generic manufacturers must add on this price on top of their price which can result in prices of treatment dropping, but potentially being higher than if all IP was removed.

Additionally, both Oleg and Davyd are concerned with more opaque processes occurring at the MPP. Oleg provides an example of '*a worrying trend*' regarding voluntary licence agreements for DTG in the EECA region, namely Azerbaijan, Kazakhstan and Belarus. Oleg

explains that for over a year and a half, some CSOs were fighting for compulsory licensing of DTG, while some were pushing for voluntary licensing. The pharmaceutical company finally announced a licence agreement for DTG to these countries. While both Oleg and Davyd welcome this decision, they are concerned about two things. The first is the super high royalty rate and the second is the lack of transparency around the licence agreements. Oleg acknowledges that *'the strong part of MPP is transparency, of course.'* However, this agreement, for the first time, that Oleg and Davyd can remember made certain provisions of the agreement confidential.

> Davyd: *So we don't know what is royalty [...] whether it's ten percent or it's twenty percent or it's thirty percent or it's fixed sum [...] So it won't motivate companies, generic companies to like—it would be less motivating for them to reduce prices.*

Oleg also highlights that the cost price, as well as the royalty price in Kazakhstan, is confidential. Thereby creating a legal obligation for the Kazakh MoH to keep this price secret, shrouding previously transparent processes opaque. Davyd calls these agreements a *'dangerous precedent'.* Oleg believes that these new confidentiality agreements will work very well for monopolists but will work against treatment activists.

> Oleg: *How I can be a treatment activist if I don't know the price?*

Oleg and Davyd both exclaim their distrust of these new confidential agreements facilitated through the MPP. Previously hailed for their commitment to transparency, the participants argue that the MPP is regressing on its key principles. It also highlights the pharmaceutical industry's strategy of providing voluntary licence agreements when CSOs threaten the use of compulsory licences. However, now pharma is including confidential provisions in these agreements on pricing and royalty commitments, precluding treatment activists from seeing the cost savings of these agreements. Both Oleg and Davyd identify these practices as dangerous and damaging to the effectiveness of treatment activism.

Ironically, in 2020, Jayasree Iyer, executive director of Access to Medicine Foundation which oversees the Access to Medicines Index was quoted *'MPP's commitment to transparency and access to healthcare is an important gold standard for how products can be affordable and*

brought to populations most in need around the world.' Yet, the research participants highlight a concerning reneging on its foundational principle of transparency, arguing that the MPP must avoid future opaque licence agreements as they negatively impact the power of treatment activists and provides additional power to the industry. Baker (2020) also issued a warning about the lack of transparency in these licence agreements. However, he places much of the blame on the actions of ViiV Healthcare, and less emphasis on the role of the MPP, while my research places more emphasis on the role of the MPP in facilitating this agreement.

The MPP and voluntary licence agreements do offer potential benefits for Ukraine, as seen with the TDL and Sofosbuvir cases. However, the participants also identified the complex and challenging application of VLs in MICs. This section examines the strengths and weaknesses of the MPP, questions the motivation behind the functioning of voluntary licences and questions the opacity in recent licence agreements. Overall, the participants argue that the MPP should offer a more coordinated, strategic effort that continues transparent practices and commits to equity in MICs.

6.2.5. Treatment Activism: Reclaiming Power through Determination and Evidence-Based Arguments

Throughout the Literature Review and Findings chapters so far, the varied approaches to access to medicines activism have been well documented. The list includes building political relationships (sections 5.2.3.1. and 6.2.3.2.); using training and capacity processes to increase expertise and maturing civil society organisations (5.2.1.); working closely with multilateral institutions and donors (6.2.); using legal and trade frameworks to oppose patents (6.2.1.1. and 7.2.3.); passing the Patent Reform Law to reduce negative effects of TRIPS and TRIPS Plus provisions (section 6.2.1.); outsourcing procurement to international bodies (section 4.2.2.1.); negotiating prices directly with the pharmaceutical industry (section 6.2.2.); and working with the MPP to avail of voluntary licences (6.3.4.). Although this is an extensive review of how activists reclaim power from trade, legal and political frameworks to optimise healthcare for people living with HIV and HCV, it is not exhaustive. This section will examine how treatment activists use data and evidence-based arguments to enable change. Also, how CSOs construct the meaning of their goals is developed by examining how they

shape and interpret direct actions in a way that aligns with their goals. Finally, this section outlines the research participant's future pursuits within the treatment activist sphere.

6.2.5.1. Power in Numbers

This section underscores the multifaceted and multi-tiered advocacy strategies participants used to ensure access to treatment programmes; strategies that were not related to IP. Anna, Oleksandr and Irina outline the power of collective effort, a mature HIV/HCV community and open communication channels between all stakeholders. The research participants developed these characteristics by examining the data collection processes they needed to create robust national treatment programmes for HCV and HIV.

Anna argues that a national HCV programme was crucial for establishing the real need for treatments, enabling procurement processes, and applying pressure on budget demands. Anna underlines a direct correlation between the national programme which her organisation helped establish with a sharp decrease in the price of HCV treatment. The organisation primarily aimed to get people living with HCV to register on the official national HCV register and to create treatment guidelines.

> Anna: '*People didn't want to get registered because what's the point? There is no treatment. The government would say, 'We don't have patients. There is no one. Why would you get—why would we buy any treatment?'*

To break this cycle, Anna's organisation worked for many years 'training, educating, fighting' with doctors on their need to encourage PLWHC to register on the national register. Anna explains that doctors were reluctant to give correct information regarding how many patients with HCV they had due to personal issues, such as competition among peers, '*[...] as they said things like, 'maybe I have more [patients living with HCV] than that doctor. Why should I have like more? Why should I have less?' It was a lot about also competition.*'

Additionally, as also elaborated on in section 5.1.3, people in Ukraine were distrustful of the government having personal data. They did not want to be on a list in the curated and kept in the possession of the government. Anna relates this data collection issue to gay and bisexual men reluctant to join the free PrEP research programme, *'you had to publicly say that you're*

gay and you have risky sex, condomless sex risk, condomless sex, which of course nobody wanted.'

Oleg also highlighted that people who inject drugs did not want to sign up for the OST programme as they did have to publicly acknowledge that they use drugs which can create harmful outcomes. Despite these challenges, Anna's organisation persevered by educating and working with doctors, state departments and the community which ultimately helped lead to the conception of Ukraine's National HCV programme. This in turn created a HCV database that collected accurate prevalence data, which increased the procurement contracts, ultimately reducing the price of treatment and increasing access to those who need it.

Treatment activists' critical role in collecting data is stressed again by Oleg whose organisation used research efforts to bring evidence-based arguments to the Ukrainian government. In particular, Oleg's organisation contributed to generating data about key populations. For example, his organisation carried out the Integrated Bio-Behavioural Study which was used to create an understanding of the actual situation regarding Ukraine's HIV, HCV and TB epidemics.

Similar to Anna's approach, Oleg agrees that the data they collected was invaluable for advocacy efforts, as it allows CSOs to argue effectively for the implementation of more efficient and cost-effective treatments. Oleg provides two successful examples of demonstration projects affecting policy. Firstly, the procurement of medicines for people in the prison system was under the purview of the Minister of Justice, and not MoH, which Oleg calls a heritage of the Soviet Union. This departmental segregation resulted in many challenges for prisoners in accessing treatment and care. His organisation undertook a demonstration project that showed the public health benefits of a unified procurement system and care for people in the prison system, *'and we did it [...] now hundreds of prisoners can have this treatment, of course free of charge.'*

Another example includes his organisation using demonstration projects to encourage their government to stop procuring interferons. Their data showed interferons have a 47% cure rate, that the treatment was not working and that it was a waste of budget. Using evidence based advocacy, they then advised that they use more modern DAAs instead, '*modern treatment which is even cheaper but much more effective, please kind of consider this way.'* In

the two examples provided, Oleg clearly demonstrates the role data collection plays in their advocacy efforts to scale up first-line treatment and ensure wider access to people living with HIV and HCV.

Irina emphasises the role of having a '*mature'* and highly specialised patient community in creating a multistakeholder culture shift in relation to data collection practices and an openness to hearing evidence-based arguments. In 2013, in the pre-reform period, Irina argues that the MoH, local administrations and doctors started to listen to CSOs. Irina believes that their advocacy created a sense among all stakeholders that old practices are unacceptable, and that accurate, transparent data is necessary to account for all the patients and their treatment needs. Irina believes the strength of CSOs in Ukraine lies in their understanding of how '*quantities are collected, and they are transmitted to the Ministry of Health*'. This underscores the importance of competencies in research and treatment literacy, but also deep understanding of how to work within complex political and institutional processes.

Anna, Oleksandr, and Irina's testimonies underscore the critical role of evidence-based activism in advocating for a national HCV elimination program. Their efforts in creating and utilising comprehensive data collection processes have not only highlighted the real needs for treatments but have also facilitated significant policy shifts and resource allocations. Generating reliable evidence and fostering a culture of openness and working directly with key stakeholders is aligned with Rabehariosa, Moreira, and Akrich (2014) evidence based activism framework (conceptualised more in section 7.4.3). These actions also resonate with Vigh's (2006; 2009) concept of navigation, where continuous, strategic changes are made to manoeuvre through environments that affect actions and how their goals become actualised. In this case, the multifactorial approach to collecting data and increasing trust from various stakeholders highlights the adaptive and strategic strength of treatment activists in pre-reform Ukraine, which lacked access to affordable interferon treatment or Sofosbuvir.

6.2.5.2. Framings of Access Activism

Insights into the campaigning tactics of the HIV/HCV treatment activists are underscored, particularly regarding how they articulated the issues and how the campaigns were received by the intended target audience. Daniela and Nastya, activists from two separate organisations outline their strategies for getting their messages across. Pavlo offers his Westernised viewpoints on the framings involved during his tenure in Ukraine.

In Daniela's organisation, they use a multidisciplinary approach to their campaigning. Daniela provides the example of their recent direct actions for the registration of a draft law around the medicalised use of cannabis products. Daniela makes it clear that the success of their campaign wasn't just based on standing outside of parliament with '*boards with messages*'. The real strength of their organisation comes from unifying patient groups by organising communication and conversations within these groups. They find leaders within these groups who become the '*hero of the campaigns*' and become the speakers of their movement. Daniela gives the example of Saufika, a young girl who lives with epilepsy and as a result, cannot talk or move. Saufika's mother allowed Daniela's organisation to use Saufika's name to mobilise and unite members of the public and parliament to introduce Saufika's Law. This garnered much public and media attention which ultimately led to growing visibility of the issue within the Verkhovna Rada. Daniela's organisation builds trust with patient groups, educates, and empowers patient leaders, and helps to formalise their stories to create visibility, increase public sympathy and enact change at the legislative level, '*due to our action the head of the parliament told us that this draft law is registered.'*

Similarly, Nastya's organisation uses a multipronged approach to getting their message across. Nastya makes reference to their opposition to AbbVie's evergreening of Lopinavir/Ritonavir, *'during the three years of court with AbbVie, we were doing everything.'* Nastya refers to six different strategies to convey the negative consequences of prolonging the patent life of Lopinavir/Ritonavir. Firstly, Nastya's organisation set fake money on fire to reference the needless waste of taxpayers' money by the Ukrainian government and highlight '*what pharma is doing with our money*'. Secondly, they used data to highlight to the public how much more medicines could be procured if AbbVie did not evergreen the patent and allowed generic competition. Thirdly, they used soap bubbles to show that the price of the medicines is like blowing money into the air, *'this price, like these bubbles, it's unreal.'*

Again, this is to highlight the surreal nature of high-priced medicines, especially when the activists believe that the medicine does not deserve an extension of their IP. Nastya also references direct actions where they do imitations of killings to acknowledge the real life consequences of evergreening practices. Like Daniela's organisation, Nastya provides a platform for community members to speak to the media about their lived experiences and the importance of access. Lastly, they call out pharmaceutical companies profiteering from their medicines, creating a sense of vilification of the industry's practices, *'they make money on our lives, actually good money.'*

Pavlo, who originates from a Western European country referred to witnessing an HIV organisation utilising the *'imitations of killing*' campaign messaging and believed the hanging symbology as *'overstepping the limits in a way'.* Pavlo acknowledges that his belief is informed by his Western viewpoint. He also attributes his reasoning of '*ethical limits*' to being informed by seeing young homosexuals hanged in Iran. This creates a question of respectability within campaign messaging versus the life or death urgency felt by those in Ukraine. Do those of us who do not experience access limitations in the West have a right to judge the actions of those with limited access in Ukraine? As Nastya argues, the action is to clearly demonstrate that death is a direct consequence of IP barriers to accessing essential medicines. The hanging symbolism also insinuates that either the state or pharma are the prosecutors of these deaths. Pavlo's western viewpoint dismantles arguments of homogenous global access to medicines movement framings and recognises a variety of culturally acceptable forms of campaigning, irrespective of perceived respectability.

The use of stories of community members affected by lack of access is conveyed to the media while also attacking pharmaceutical companies as the villains - an industry profiteering off people's lives. The symbology of death has historically been used by HIV groups, such as ACT UP chapters in America and the Treatment Action Campaign in South Africa to denote the implications of pharmaceutical greed vis-a-vis their use of die-ins or by famously spreading the ashes of people who died of AIDS on the White House lawn (Grebe, 2011; Roth, 2017). However, the imagery of the noose around the head to highlight the life and death stakes of pharmaceutical company's evergreening practices was raised as a point of contention in the research, based upon the geographical location of the research participants. The participants with a more Western viewpoint found the imagery aggressive, shocking and '*overstepping the limits in a way*'. The Ukrainian-based activists believed it to be a valid

form of protest. This discrepancy can be thought of in two ways. Using ethical considerations from climate activism, Maltais (2013) argues that because activism often imposes costs on others, it is vital that activism in question is efficacious. Otherwise, the direct actions should reasonably be argued against. This research does not seek to debate the respectability of direct actions. However, the research participants importantly highlight the heterogeneity of activism around the world and how this may be influenced by cultural contexts and urgency of demands, such as access to lifesaving Sofosbuvir or Lopinavir/Ritonavir.

6.2.5.3. Activism Scanning: What is Next?

Participants give insights into their future pursuits in activism. Davyd, Nastya and Oleg outline their goals of expanding access to treatment, overcoming corruption and addressing continuing human rights violations of people living with HIV.

Davyd believes his future pursuits will go in four directions, the first will be the continuation of patent searches and oppositions; exploration of other public health safeguards; work of IP related to biologics and biosimilars; and continue to provide technical support to countries in EECA region. Davyd believes the Patent Law Reform will help prevent evergreening practices of new medical products coming on the market, but patent oppositions are still needed on drugs authorised prior to August 2020. The second direction is continuing to advocate for pharmaceutical companies to seek market approval in Ukraine shortly after they get approval in HICs. Currently, as mentioned in section 6.2.1, pharma companies have two years to seek approval in Ukraine or they do not receive data exclusivity. Davyd seeks to reduce this to one year. He also believes there are other regulatory avenues to explore such as the permittance of parallel importing, a process whereby Ukraine could import medical technology from another country without the permission of the IP owner. In terms of looking toward drugs in the pipeline, Davyd explains that biologic treatments for HIV will soon become first-line treatment and that the current Patent Reform Laws are focused on strong patentability criteria of small molecules. Therefore, future pursuits will also look to improve these laws to consider more complex, novel medical compounds. This highlights the evolving knowledge economy and the continued need to shape and reshape policies to keep up to date with new innovations and not fit for purpose legislation. Finally, Davyd would like to continue providing technical support to Georgia and Moldova. Currently, they are working with these countries to draft their own Patent Law Reform bills and help them to oppose

patents in their own country. This working relationship aims to help Moldova and Georgia *'to like replicate our positive experience, and not to make our mistakes.'*

Oleg is more sceptical of their current campaign wins. He acknowledges that the adoption of the Patent Law Reform bill indicates the government's '*willingness to consider rational ideas'*. While cautiously optimistic that this support will continue, he believes that future advocacy efforts must ensure that the government implement the reform rather than 'merely keeping it on paper'. Oleg's scepticism of the government continues with their 'weak' response to the COVID-19 pandemic. For Oleg, the primary issue that treatment activists need to focus on is the lack of transparency with the procurement of COVID-19 vaccines and PPE.

Reminiscent of pre-reform procurement activity, a scandal uncovered the use of 'middlemen' that helped facilitate corruption of the Sinovac vaccine which was purchased through a Ukrainian plant. Therefore, Oleg identifies the ongoing battle of transparency with the procurement of medicines as a key effort for the access movement in Ukraine in the future. This provides a sense of regression after the huge strides CSOs made in creating transparent processes for procurement. Oleg's concerns are consistent with Richter (2022), who argues that to prevent Ukraine's political backsliding, CSOs will continually respond to attempts that threaten to undermine their progress.

Additionally, Oleg believes treatment activists have a role in overcoming misinformation of COVID-19 medical technologies as there is huge vaccine hesitancy in their country. Oleg fears that even if they procure enough vaccines to vaccinate 70% of their population, that it may prove impossible to empower people to take it. This is an example of how affordability does not necessarily equal accessibility, and that treatment activists must also fight against issues such as misinformation.

Nastya, similar to Oleg identifies IP and procurement as major issues with access, but understands that accessibility to these medicines remains an important extension of her work. According to Nastya, human rights violations remain huge barriers to accessing the proper care, human rights violation—like the biggest barrier to accessing treatment right now.'. Therefore, Nastya aims to continue working on removing HIV non-disclosure laws and decriminalising both sex work and drug use. Nastya provides an example of non-disclosure

laws prohibiting people from accessing treatment. Currently in Ukraine, after your first consultation with an HIV doctor, the first thing that you sign is a document that states, 'that you're aware that it's according to criminal law you have to disclose your status to whoever your sex partner, and, yeah, and to medical staff if they will have to deal with your blood and something like that.' In reality, this means that if someone living with HIV has sex with someone who is HIV-negative, even where transmission does not occur, the HIV-negative person could put that person living with HIV in prison for not stating their HIV status. This remains true even if the person is undetectable and cannot pass on HIV.

The work of HIV treatment activists from 2010-2021 has now resulted in 'we have treatment for everyone now' for PLWH, and to a certain extent, people living with HCV. As lifesaving medicines have become more readily available, does this change the prioritisation of HIV/HCV CSOs to address the more psychosocial issues that are relevant and important to their ground base? Nastya, Oleg and Davyd all hope to continue fighting against IP rights to ensure access to treatment, especially drugs in the pipeline. Yet, Oleg and Nastya both identify external factors as key priority areas to ensure that people can gain access to the treatment that they fought so hard for. Future research should examine how a shift from international to national funding and better access to ARVs and DAAs influenced agenda setting in Ukraine.

This section outlined the iterative process of treatment activism in Ukraine. By opposing patents, drug by drug, and court case after court case, it highlights the high technical expertise, strong motivation of activists and huge financial resources needed to fight a continuous battle for access. Oleg's commitment to ensuring the Ukrainian government will enforce the Patent Law Reform and re-engage with anti-corruption activism against government mishandling of public funds highlights the precarious nature of Ukrainian progression. Lastly, both Oleg and Nastya extend their treatment activism to external influences affecting people accessing treatment including misinformation campaigns, criminalisation of key populations and criminalisation of HIV transmission.

Section 6.2 explored the research participants' experiences relating to power dynamics within the Ukrainian knowledge economy. Using the lens of the HIV/HCV treatment activists, this section navigates the intricate relationships of key protagonists in the access to medicines movement. The participants identify the EU FTA and its pro-IP provisions as negatively

impacting the access to medicines movement. Yet, they outline their strategies in working strategically within these new frameworks, overcoming barriers such as late registration of medicines, SPCs and data exclusivity. The complicated relationship between HIV/HCV CSO and pharmaceutical companies highlights the varying perceptions activists have toward pharma, influencing their approach to working with, against or remaining neutral with the industry. Nastya argues that the Ukrainian legal system is a corrupt political system that often upholds the law in favour of commercial interests.

The participants use examples of Lopinavir/Ritonavir and Sofosbuvir court cases as examples. Although processed through two separate courts, the participants experience the courts as pro-business. Conversely, the participants also outlined how they used their legal rights to oppose patents that they did not deem innovative enough as ways to circumvent the court's decision on Sofosbuvir. The participants use the legal system successfully in their work while also identifying it as a barrier to access. However, they ultimately believe that it's the person with the most financial resources who wins. This reinforces the importance of sustained funding for IP activities. The participants also examine the pros and cons, motivations and trajectory of the Medicine Patent Pool and the practice of voluntary licensing. Finally, various strategies activists engage to increase access and accessibility of ARVs and DAAs to affected communities are explored, including their understanding of gaps for future advocacy.

6.3. Conclusion

Chapters 4 and 5 present the findings from nine interviews with people closely involved with the Ukrainian access to medicines movement. These findings highlight the complex interplay of power dynamics, resource allocation, international influences and strategic advocacy efforts. A noticeable shift in power dynamics in Ukraine post-Euromaidan emanated from a maturing, well-resourced and expert patient community. CSOs took advantage of the Revolution, and its consequent receptive government officials, to become leaders in healthcare reform, including IP and procurement reforms. Concerns were raised regarding the dominance of CSOs in the funding market, and what consequences that may bring to broader HIV/HCV work needed in Ukraine. Resource power also emerged as a significant driving force in shaping the access movements' trajectory. The distribution of financial resources

raised questions regarding whose voices get to be amplified, whose concerns get precedence and whose does not get supported.

These questions are answered vis-a-vis the concept of 'agenda setting' and through EECA collaboration which both highlight the geopolitical and national complexities at play, where donors and CSOs can influence the direction of activism and knowledge sharing. The participants highlight the precarity of MICs, like Ukraine, when fighting for access to cheaper, generic life-saving medicines. Often as a result of being left out of licence agreements, the activists need to gain 'leverage' during price negotiations, by opposing patents or ending evergreening practices.

To navigate the intricacies of the knowledge economy, new trade frameworks and legal systems, the participants outline their ingenuity in both strategic engagement and resistance to these institutionalised barriers to accessing treatment. To continue their success, the participants highlight the ongoing need to sustain financial and international support due to the huge financial, political and human capital needed for their activism. While this research focuses on intellectual barriers to accessing HIV and HCV treatment, activists also underscore other advocacy efforts to increase access including data collecting, trust building, education campaigns and framing campaigns to gather public and political sympathy. The participants identify the pursuit of greater human rights protections for PLWH, ensuring the implementation of the Patent Law Reform, increasing capacity to oppose patents on future HIV biologic treatments and focusing on the COVID-19 pandemic as future access priorities.

The following chapter discusses the findings of the research in relation to the existing literature on the access to medicines movement in MICs and Ukraine and Political Process Theory. I will discuss the overall implications of the research and how it contributes to the field of access to medicines.

Chapter 7. Discussion

7.1. Introduction

This chapter discusses my research findings, contextualised within the relevant existing literature on the access to medicines movement and the democratisation of Ukraine. The aim is to provide a greater understanding of the socio-political context that underscored huge structural reforms in Ukraine between 2010 and 2021, emphasising greater access to HIV and HCV treatments. Previous research has touched on the broad, transformative role of HIV activism in Ukraine (Semigina, 2015). However, the research only grazed over the topic of access to medicines and lacked a comprehensive exploration of how activists were so effective within Ukraine's socioeconomic and geopolitical context. More recently, Richter's book on Competition and Intellectual Property Law in Ukraine (2023) examined Ukraine's access to medicine movement, but the research is focused primarily through an intellectual property lens and did not provide an in-depth analysis of the work of any particular health group. This research bridges this gap within the literature by providing insights into the national movement towards a new Ukraine, the influence of foreign aid in Ukraine's access movement, and how global diplomatic relations impacted the work of HIV and HCV treatment activists.

The chapter is divided into three sections relating to the study's key findings. The first section explores the coinciding phenomena of a maturing HIV/HCV civil society and the Euromaidan Revolution and how their combined impact influenced key structural reforms that helped increase access to medicines. Additionally, it discusses the duration of this window of opportunity stays open. The second section outlines the complex reasons why treatment activism heavily relies on international donors, including Ukraine's increasing diplomatic ties to the European Union and the large costs associated with opposing intellectual property rights. The third section outlines the adaptive strategies of CSOs as they navigate the shifting knowledge economy and political landscape in their ongoing fight for access to lifesaving treatments.

Russia's invasion of Ukraine occurred during the latter stages of the participant recruitment and interview phases. As a result, treatment activism that occurred toward the tail end of

COVID-19 restrictions and since the beginning of the invasion is referenced through extant literature but not by the research participants.

7.2. Reimagining Ukraine, Reimagining HIV/HCV: The Path Towards a Healthy Healthcare Sector?

The Euromaidan Revolution marked a pivotal moment for comprehensive structural reforms in Ukraine, especially in healthcare and access to medicines. Before the Euromaidan Revolution, systematic corruption and the wider socio-political environment were identified in this study as significant obstacles to overcome in pursuing healthcare reform. Yet, the HIV CSO activists interviewed in this study seemed to skillfully navigate these obstacles and amplify their influence on the Ukrainian government. Their influence continued to surge post-Euromaidan, especially with the appointment of Ulana Surprun as Minister of Health. The national feelings of '*new game rules in the air*' appeared to empower activists to push for structural reforms. Lastly, the scope and breadth of these structural reforms, in light of the window of opportunity, are discussed within the broader context of political opportunity.

7.2.1. The Evolving Landscape of HIV Stigma in Ukraine: Societal Barriers, Progressive Momentum and Grappling with its Past

The research findings on the lived experiences of HIV/HCV stigma are largely aligned with the literature outlined in sections 2.1 to 2.4. The study found that people living with HIV/HCV in Ukraine continue to experience high levels of internalised, perceived and enacted stigma (also found in Spicer *et al.,* 2011; Bongiovanni, Sergeyev & Semigina, 2013; Semigina, 2017). The reasons outlined in the research for continued high levels of stigma are multidimensional. Firstly, Ukraine's general population are still stuck with the narrative of HIV in the twentieth century. Regardless of the medical advancements in HIV treatment and the shifting epidemiological picture of HIV transmission, the general populace believes that HIV mainly affects PWID. The findings suggest that the government and CSOs' failure to educate the wider population on HIV and HIV-related stigma fuels misconceptions around living with HIV and HIV transmission and curtails progress in reducing HIV-related stigma. The interlinked levels of stigma and discrimination are also magnified through continued 'Soviet thinking' regarding key populations. One example provided in the research includes the personal account of a participant's mother who was indoctrinated into 'Stalin thinking' of

homosexuality. The mother found it difficult to accept her son's sexuality, taking 10 years to unlearn over seventy years of Soviet control of Ukraine.

As highlighted in section 5.1.1., the prominence of homophobia in Ukrainian society extends beyond its post-Soviet histories. Scholars identify many socialising determinants that continue to drive homophobia globally including religiosity, authoritarianism and strong beliefs around traditional gender roles (Kite & Whitley, 1996; Altemeyer, 1998; Schulte & Battle, 2004; Whitley, 2009; Janssen & Scheepers, 2018; Morris, 2023). Bureychak (2012) contends that after Ukraine gained independence, a form of gender neo-traditionalism occurred in society's attempt to deal with the considerable political, social, identity and economic upheaval that followed the fall of the USSR, which continues to exacerbate stigma. While post-Soviet legacies is a significant finding in this research for the ongoing stigma and discrimination faced by PLWH and key populations, the literature highlights that these legacies are just one dimension of a more complex issue that requires further scrutiny.

This research did not aim to provide an exhaustive list of reasons for the high levels of stigma towards key populations in Ukraine. However, it underscores an important finding that shows how high levels of homophobia has led to a reluctance within the MSM community to sign up for subsidised PrEP. To avail of the HIV prevention tool, a person must sign up to an official register, which the MSM community perceived as disclosing their sexuality to the government. An assessment examining the main barriers to implementing and scaling up PrEP in the EECA region did not identify registration for PrEP as an obstacle. To effectively widen the accessibility of PrEP, the assessment recommends comprehensive informational and advocacy campaigns to ensure a high demand from the community, backing from healthcare and field experts and mutual collaboration between governmental and CSOs. In addition, international technical and financial support to successfully scale up PrEP where necessary (Kornilova & Roshchupkin, 2019).

This research adds to this assessment by identifying the high levels of homophobia still experienced in Ukraine, cultivating continued mistrust with government institutions and resulting in the refusal to sign up for the PrEP programme. Data collection was also identified as a barrier for people starting HIV treatment in this study, as PLWH must sign a form before starting medication to confirm that they acknowledge their diagnosis. Therefore, if they have sex with someone without that person's knowledge of their HIV-positive status, they can

potentially be arrested under HIV non-disclosure laws. Stating that a person was a PWID on an official register is also identified as a deterrent for people signing up for OST or availing of HCV services in this research. These findings align with the Spicer *et al.* (2011) study that shows greater availability of services does not correlate with increased accessibility of services due to complex and interrelated barriers to HIV service utilisation that are remnants of Soviet times.

However, while the institutional and societal barriers to PrEP uptake are outlined, Ukraine and Georgia were the first countries to implement a PrEP pilot project out of 17 countries in the EECA region (Kornilova & Roshchupkin, 2019). Additionally, the increasing attendance at Kyiv Pride indicates momentum for the rights of marginalised communities, particularly the LGBTQ+ community, in Ukraine. KyivPride, in their 2022 Manifesto, did recognise this momentum and argued it is only possible within democratic boundaries. The manifesto stated a clear distinction between Ukraine and 'autocratic' states', *'we call on everyone, from governments to people on the streets of European cities, to imprint on their memory the geographical line on the border between Ukraine, on one side, and Russia and Belarus on the other, because it is not just a separation line between the states, but also a boundary between the territory of freedom and a zone of oppression.'* This quote was made after the timeframe of this research. I included it into the research as it suggests that the Ukrainian LGBTQ+ community felt that social and political change was more likely in a more free, democratic society, a society that removed itself further from its Soviet past.

In this study, CSOs seek to change the narrative and lived experience of people living with HIV/HCV by grappling with its past. Using their resources and influence, they engage with and educate all stakeholders, including the government, health practitioners, and patients, on the advancements of HIV medication and teach tolerance to key populations. In 2023, the Verkhovna Rada fully adopted law 6364 in its first plenary, which aims to modernise Ukraine's approaches to HIV prevention, testing and treatment based on WHO guidelines.

The key outcomes of this law would highlight Ukraine's willingness to protect key populations by explicitly prohibiting the humiliation of key populations, such as MSM. Other positive steps include the introduction of PrEP into a legal framework, granting everyone universal access to HIV services irrespective of their legal status, and the MoH introducing progressive regulations related to testing procedures, diagnosis and other aspects of HIV

management. This draft law that is being debated in parliament is due to long advocacy efforts and collaboration between the government and HIV CSOs (HIV Justice Network, 2023). If this law passes, it will overcome many of the barriers identified in this research and firmly place Ukraine as a leader in the EECA region in their HIV response. If fully adopted, the enforcement of this law and its effect on Ukraine's HIV epidemic are grounds for future study.

7.2.2. HIV and HCV Treatment Evolution

The desperation of people living with HCV trying to access treatment is highlighted in this research analogously to needing to sell a kidney to afford treatment to save their liver. Outlined in the findings is a treatment landscape that went from a treatment 'desert' from the early 2000s - 2015 to a health tourism hub for people seeking to access the cheaper, generic HCV cure, Sofosbuvir. Early pegylated interferon treatment roughly cost 15,000 dollars, completely out of reach for most people living with HCV in Ukraine. This is particularly concerning as HCV prevalence estimates range from 3-5% of the population, with injecting drug use as one of the leading causes of transmission (Devi, 2020; Antoniak *et al.,* 2022). Unlike HIV, untreated HCV is not always life-threatening but has been shown to increase comorbidity, including increased fatigue, reduced physical and social functioning and limitations in emotional and physical roles (Carithers, Sugano & Bayliss, 1996).

The efforts of HCV/HIV CSOs to encourage the Ukrainian government to establish its first HCV programme are highlighted in section 5.1.3. As a result, procurement numbers increased and gave those negotiating prices of treatment more leverage with pharma to reduce the treatment price. The introduction of the generic HCV cure, Ledipasvir/Sofosbuvir, which has a cure rate of almost 100%, a very low side effect profile and a 12-week regimen, is estimated to cost, including laboratory costs, travel to the clinic, etc., roughly $750/patient. This estimate is based on the assumption of generic drug pricing (Antoniak *et al.,* 2022). This is a far cry from the $15,000 for pegylated interferon treatment that was not guaranteed to be effective. As a result, people living with HCV from countries that do not have access to cheap Ledipasvir/Sofosbuvir go to Ukraine to get treated, as the costs are not unimaginable burdensome. This phenomenon was also seen in Egypt, where famous soccer player Lionel Messi aggressively pushed a Tour n' Cure holiday package to Egypt to be cured of HCV by availing of their cheap, generic Sofosbuvir (El-Faizy, 2017). The only reference to medical

tourism in Ukraine is found at heath-tourism.com, which claims 13 million people travelled to Ukraine for tourism in 2016, of which 3% went for medical purposes. Dental, cosmetic and reproductive procedures were identified as the main medical areas of interest. Future research could explore the economic benefits health tourism could bring to the Ukrainian economy regarding DAAs.

Unlike the experiences of those who lived with HCV, gaining access to antiretroviral therapy was difficult but not impossible. Although older ARVs were available, there was very limited capacity. For example, in 2011, one way identified in this study to gain access to treatment was to wait for someone on ARV therapy to die to access their medications. The study found that there were some feelings of hope of getting access to treatment as a PLWH had to wait until their CD4 count reached below 350 cells/μL. This strategy of starting people on treatment once their immune system reached a certain level was in line with the WHO guidelines (2015). However, the findings of the START Study in 2015 found that starting treatment immediately, regardless of CD4 count, provided net benefits to health and health expenditure over starting treatment once CD4 cells declined to 350 cells/μL. The changing WHO guidelines on the initiation of ARV coincided with the growing scientific consensus of U=U (Rogers, 2016; 2019), the Euromaidan Revolution, international procurement, and HIV CSOs' activism reducing the prices of medicines through price negotiations and patent oppositions. Each factor contributed to the ready availability of ARVs for anyone who needs it.

7.2.3. Consolidating Activism to Navigate a Complex Socio-Political Landscape

This study identified the importance of activists gaining a seat at the table as a sea-change moment for Ukrainian governance structures post-Euromaidan. However, before the Revolution of Dignity, the findings outlined a form of Soviet-styled top-down governance that impeded collaborative CSO-government relationships. HIV and HCV CSOs, who were primarily funded by foreign aid, would often see themselves in opposition to the Ukrainian government.

The danger associated with digging into government procurement contracts is highlighted in this study. The example provided was a special service security general who was investigating the price of TB drugs in Ukraine, which was blown up in his car. The

investigation found that Ukraine was buying ARVs and TB drugs for twelve times the price of neighbouring countries in the EECA region. The findings did not elaborate further on the investigation or who ordered the murder. However, it is reminiscent of the murder of the journalist Georgy Gongadze, who was investigating corruption at the heart of President Kuchma's administration in 2000. The killing of Georgy is considered one of the main motivations behind the Orange Revolution (Foley, 2006). This does not provide an overall picture of CSO-government relations. Yet, it is an important backdrop to the environment that activists needed to navigate when seeking to overcome the opaque, corrupt practices of the state, such as the procurement of HIV/TB treatment.

Yet activists navigated this landscape to push the Ukrainian government to increase access to treatment. One example of this in the research is the consolidation of HCV efforts with HIV CSOs. Donors provided funding streams to increase HCV CSOs' collaboration with more resourced and influential HIV community groups, which increased their platform to talk to decision-makers. Pooling together resources and expertise, these organisations started to conduct targeted training for healthcare professionals, patients, and activists. They used evidence-based arguments to integrate HCV treatment prevention services into harm reduction programmes. Oleksandr's organisation conducted bio-behavioural studies to gain an epidemiological picture of how many people live with HIV, HCV and TB in Ukraine. They then empowered people living with HCV to seek care, sign up to the national register and demand access to treatment. By working directly with medical professionals, using evidence-based data with political representatives and empowering the communities they represent, the Ukrainian Government responded by announcing its first National Targeted Programme of HCV Prevention, Diagnostics and Treatment in 2013. The correlation between the inception of the National HCV Plan in 2013 and the shifting of procurement powers from state to international agencies in 2015 to the rapid increase in HCV treatment coverage is apparent despite the COVID-19 pandemic and the Russian invasion. According to the Coalition for Global Hepatitis Elimination (2023), 268 people were treated for HCV in 2013. That increased to 12,780 people in 2022.

While the state seemed receptive to the campaigning of HCV/HIV CSOs, activists argued that the plan did not go far enough and only allocated funding that would cover 20% of the existing treatment needs while not funding diagnostics in the state budget at all (APH, 2016).

This study highlights the ever changing landscape that activists must adapt to as pre-Euromaidan Ukraine had a difficult and sometimes dangerous social, historical and political landscape. Yet, this environment influenced activists multiple tactics to achieve their goals, including working alongside their ground base to educate, collect data, link patients to care and continue to build relationships with politicians. As a result, the first National HCV Plan was developed. Although the plan fell short of the activists' goals, it highlights the relationship HIV/HCV CSOs had with the government before Euromaidan. This influence was aided by trust building and educating all stakeholders and mobilising the ground base to demand better access to treatment. The continued fight of CSOs toward eliminating HIV and HCV underscores Vigh's (2006; 2009; 2010) concept of navigation. The multiple processes of motion between activists, the political process and society is a constant that shapes their visions of their goals and requires a high degree of adaptation.

Arguably, HIV and HCV CSOs do not comply with Lutsevych's (2013) assertion that Western-funded organisations are not anchored in society and use their access to domestic policymakers to influence policies without having a constituency or 'ground base'. Lutsevych's paper corresponds to Ukraine's failure to 'finish' the Orange Revolution and advance structural reforms. One reason for this failure, Lutsevych argues, is that CSOs did not close the gap between their organisation and Ukrainian citizens. This resulted in the continued marginalisation of the CSO sector from the policy process and hindered community mobilisation between the Orange and Euromaidan Revolutions, limiting reforms after the former. Lutsevych (2016) agrees that CSOs do exist that work closely with their constituencies, including Patients of Ukraine, which unites 30 members representing 120 organisations, including people living with serious health conditions themselves. I argue that another example is the HIV CSO 100% Life, which is the largest patient-led organisation in Ukraine, working in 25 regions in Ukraine (100% Life, 2019).

Procurement of health technologies was also another feature of consolidation. HIV CSOs used funding from the Global Fund to procure ARVs for people living with HIV. These organisations would locally use international best practice guidelines during the tendering process. It was estimated that state procurement of certain drugs in 2012 was 1.5-3 times higher than those purchased by patient organisations in Ukraine (UNAIDS, 2014). The participants posit that working directly with these processes introduced CSOs to medical procurement systems and issues relating to intellectual property and access to cheaper,

generic medicines. HIV/HCV CSOs consolidated treatment service and provision, including procurement of treatments with government institutions.

Additionally, the consolidation of HIV/HCV organisations through funding mechanisms helped to pool expertise from all stakeholders, including those living with HCV, ultimately resulting in the development of Ukraine's first National HCV Plan. I argue that HIV/HCV CSOs' tactic of becoming experts in state functions and indispensable key players in Ukraine's public health infrastructure increased their influence with key decision-makers, even before the governance reform post-EuroMaidan. Their work directly opposed the Soviet system, which aimed to suppress collective action and critical thinking. It highlights that there was strong CSO activity before Euromaidan that set the foundation for post-Euromaidan structural reforms, with many spearheaded by HIV CSOs. The surge in CSO influence is intrinsically linked to the integral role of foreign aid. A deeper analysis of this connection is examined in section 6.1. The next section outlines the significance of Euromaidan in driving key structural reforms, particularly those that enhanced access to ARVs and DAAs.

7.2.4. Embedded Corruption and The Case of Procurement

This study highlights the extent of corruption within the procurement process, underscoring the corruption as practised 'in every single level of the process' by the pharmaceutical companies, middlemen and government officials. The findings highlight pervasive corruption in all spheres of Ukrainian life, emphasising the significant challenge of addressing structural changes and shifts in cultural attitudes. This finding builds on a body of knowledge that acknowledges systematic to casual corruption in Ukraine. Transparency International conducted a Global Corruption Barometer (2011) and found that 30% of Ukrainian citizens said they offered bribes in the previous year. Ukraine has increased their rating in the Transparency International Corruption Perceptions Index year on year, which studies perceived levels of public sector corruption.

However, with an index rating of just 33/100 in 2022, Ukraine still remains firmly in the red among countries that experience high levels of corruption. Corruption is still felt, particularly within the healthcare sector. In 2017, a nationwide poll highlighted that medical institutions are leaders in everyday corrupt practices (DIF, 2018). Batyrgareieva, Babenko & Kaija (2019) argue that citizens perceive corruption in healthcare as an acceptable mechanism to

save time, avoid extra worries and guarantee a good result that has its own market price. Although free anti-corruption authorities exist, there remains a lack of readiness for the population to expose corrupt medical practices and act as citizen watchdogs. Furthermore, Batyrgareieva, Babenko & Kaija's (2019) study found that Ukrainian citizens favour legislative changes with stronger enforcement measures to restrict corrupt practices. The pervasiveness of corruption within all spheres of Ukrainian life came through in this study, too. Similar to the Ukrainian citizens in the DIF report, this study found that participants believed they could counteract corruption by removing opaque processes that government officials utilise for their own personal gain. An example exemplified in this research (section 5.2.2.1.) shows how the MoH used middlemen or intermediaries in the drug procurement processes to embezzle up to 40% of the overall procurement budget.

To counteract this, civil society organisations worked directly with the Verkhovna Rada after the Euromaidan Revolution to reform state procurements into public procurement (Psota *et al.,* 2020). To create public procurement processes that are transparent, the activists fought for the Ukrainian government to hand over procurement powers of medical technologies, including ARVs and DAAs, to international agencies. During this time, CSOs worked closely with the government and businesses to introduce an e-procurement system, ProZorra. An electronic, open-source government procurement system that the participants believe to be one of the most transparent and innovative in the world. The activists understood that the international agencies were only contracted to procure medicines until 2022. Therefore, the activists established the National Procurement Agency, which would integrate best practices of international organisations to foster a transparent procurement system, with the intention of removing avenues for future Ministries of Health to abuse.

The concept of systematic corruption is based on the assumption that the institution is corrupt as a whole, lacking any principled principles (Balian & Gasparyan, 2017; Langr, 2018). Therefore, based on this study's contribution to this issue, it seems plausible to argue that the strategy of temporarily transferring procurement powers from the state was warranted. CSOs were also concurrently establishing ProZorro, a transparent procurement system that allows CSO oversight, which is an appropriate response to the pervasive corruption found within the post-Soviet, opaque procurement system. In 2020, under the new Zelensky government, the new National Procurement Agency started to take procurement programmes back from international agencies, and CSOs quickly noticed that the new MoH, Stepanov, took control

of the Agency and developed technical assignments in such a way that awarded procurement contracts to certain companies.

The research findings provide an example of selective procurement contracts for COVID-19 vaccines. Many vaccines and manufacturers were proposed, but the MoH forced the National Procurement Agency to choose only the Chinese vaccine, Sinovac and not others. Another example in this research includes Ulana Suprun's successor, MoH Skaletska, who refused to sign procurement contracts for three months, endangering many people's lives by potentially creating medical stockouts of lifesaving treatment. The work of CSOs and international donors ultimately prevented this from occurring, but the findings show that political incompetence, as well as corrupt practices, failed the new procurement system. The successes associated with handing over the procurement of medicines to international agencies are undeniable (statistics presented in section 5.2.2.1.) but raise questions on its sustainability due to the embeddedness of corruption and perceived incompetence within Ukrainian politics.

7.2.5. Regime Change or a Temporary Blip?

This research found that the post-Euromaidan period was characterised by significant political mobility, allowing for substantial and radical reforms in the health sector. Ulana Suprun's tenure in the Ministry of Health symbolised a political window of opportunity where comprehensive health reforms could be co-constructed with civil society and implemented. This period marked a paradigmatic shift from prior governance models and was characterised by a transformative approach to policymaking, an openness to CSOs, changing healthcare financing and a commitment to combating corruption. Existing literature on the political outcomes of the Euromaidan Revolution argues that despite regime change, the core political and systemic structures remained the same (Kononczuk, 2015; Szostek, 2017). Matsiyevsky (2018) argues that Ukraine's 'hybrid political regime' survived the political changeover from Yanukovych to Poroshenko's government. Scholars researching hybrid regimes often argue about the attributes of these governance structures.

However, there is a general agreement that they are often characterised by having competitive elections but with a weak rule of law and a high prevalence of informal politics in political processes. Examples of informal politics in political processes include the state being influenced by clientelism, corruption and secretive deals among the elites (D'Anieri, 2007;

Kuzio, 2015; Hale & Orttung, 2016; Matsiyevsky, 2018). The influence of informal politics in political processes is also found in this research, especially in relation to procurement and healthcare reform processes before Euromaidan.

Additionally, a paper by Sadowski & Pohorola (2017) argues that revolutionary events, such as the Orange Revolution and Euromaidan, did not substantiate big changes to the political elite. However, the research findings show that CSO activists believed Ulana Suprun was a reformer who worked together with CSOs to push for healthcare reforms and public oversight, which directly opposes the concept of regime continuity. Giving CSOs 'a seat at the table' provided government officials with the HIV/HCV community's technical expertise, oversight and link to the wider public, which aided them in their pursuit of creating and implementing wide-ranging reforms as highlighted throughout this research. Matsiyevsky (2018) agrees that some of the post-Euromaidan elected officials could be considered reformers. However, Matsiyevsky (2018) also argues that for Ukraine to continue on a path of true reform and to break out of regime hybridity, the parliament needs to consist of at least 50% of reformers. While it remains unclear how Matsiyevsky came to this conclusion, my research findings do suggest that a small number of reformers, such as Suprun in the Ministry of Health, results in a temporary shift in governance behaviours and leads to unsustainable reforms.

This research found that Suprun's tenure did not go without strong resistance, adding to the literature on the resilience of hybrid regimes in post-Soviet states and their attempts to hinder governance reform (Meyer, 2006). Despite the successful activism highlighted in this research, the continued resistance against reform underscores the entrenched power structures and the complex interplay between formal and informal systems in Ukraine, highlighting the difficulties in implementing and sustaining reforms in such political environments. The study found that the departure of Suprun in 2019 signalled a narrowing of this political window for reform. The CSO activists argue that Ulana's successors reverted to less progressive, competent, and transparent governance methods.

This research identifies three regressive steps from Suprun's successors. The first impact was felt on policy reform momentum, as highlighted by the strong opposition to adopting the Patent Law Reform bill. The second impact involved the incompetence of the new Minister of Health to fulfil their procurement duties, as highlighted in both the cases of procurement of

ARVs and COVID-19 vaccines/PPE. Additionally, the political appointments of the Ukrainian Patent Office and National Procurement Agencies provided avenues for a return to opaque practices and a perceived reintroduction of corrupt practices. Lastly, the collaborative nature between government officials and CSOs began to wane, as highlighted by advocacy efforts to introduce Saufika's Law. President Zelensky's administration was perceived as lacking the vision and commitment to sustain the momentum generated post-Euromaidan. Yet, the findings show that the help of CSOs and international agencies such as UNAIDS and the GF were key pillars of resistance against informal politics that aimed to keep the Ukrainian polity status quo.

This research finds that the CSO activists believed that the window of opportunity was closing with the start of Zelensky's tenure. As mentioned in section 7.2.3., Lutsevych (2013; 2014; 2016) argues that CSOs in Ukraine function more as private consulting companies to the government and less like inclusive democratic institutions. As a result of the professionalisation of movements and the distancing from their ground base, the public become marginalised from policy processes in between revolutions. As a result, advancing structural reforms or 'finishing the revolution' is impossible without CSOs closing the gap between their organisation and citizens. Furthermore, Skaaning (2006) and Matsiyevsky (2018) argue that political regime change occurs when there are new players within political institutions, and they accept and follow the new rules of the game. Yet, this research shows that reformers such as Suprun are more transient figures within Ukrainian politics. While my findings do not clarify why HIV/HCV CSO activists believe political regression is occurring, they do indicate that they are fighting for their country despite the shifting and increasingly challenging political terrain. Their persistence highlights the enduring nature of political hybridity in Ukraine and their crucial role in persistently pushing against the restrictive political structures.

The temporal nature of political opportunities is well catalogued in PPT scholarship, and the research findings generally sit well within the framework (Tarrow, 1998; McAdam et al., 2001; Goodwin & Jasper, 2004; Tilly & Tarrow, 2006; McAdam & Tarrow, 2011; Edwards, 2014). In contrast to resource mobilisation theory, PPT posits that regardless of how well organised or resourced activists are, they will not get anywhere without a favourable political context (Gamson, 1980; Tarrow, 1998; Koopmans, 1999; Edwards, 2014). My findings refute this assertion. HIV/HCV CSOs effectively collaborated with government officials in an

unfavourable political context before the Euromaidan. For example, before 2014, they advocated for creating and implementing an HCV elimination programme, which helped increase procurement contracts and reduce prices of interferon treatment and DAAs.

Additionally, as highlighted in section 6.2.1., HIV CSOs were using GF funding to procure ARVs during the mid-2000s. These organisations have consistently advocated for more transparent governmental procurement process and greater community oversight of these mechanisms. Taking on the procurement processes, introduced them to issues relating to intellectual property and access to medicines. The study found that this procurement work prior to Euromaidan resulted in HIV CSOs receiving an ITPC grant, which was fundamental in building expertise and influence in the area of intellectual property activism. Yet, the research findings show that these achievements were limited in scope. On the other hand, this research found that changing procurement powers to international agencies, creating the transparent ProZorro system and CSOs gaining more influence in decision-making processes would not have been possible without the anticorruption, pro-European movement of Euromaidan. Therefore, this research sits between Resource Mobilisation Theory and Political Process Theory. It highlights how strict theoretical frameworks of social movement theories may neglect the nuanced examination of complex systems necessary for systematic change. Future research should examine if Euromaidan's spirit of 'new game rules in the air' and Suprun's governance legacy continue to inspire reformist activism, especially considering Russia's invasion of Ukraine.

7.3. Overcoming the 'Access Limbo' Conundrum: A Question of Resource

This research highlights the precarious position faced by middle-income countries like Ukraine regarding access to medicines. The 'access limbo', as described in this research, underscores the paradoxical situation where middle-income countries, despite their relatively higher GDPs compared to low-income nations, face pronounced challenges accessing affordable medicines due to IP restrictions. Voluntary licence agreements are primarily directed at low-income countries. This inadvertently penalises countries like Ukraine, making it harder for governments to provide affordable treatment to their citizens, as illustrated by this research.

The term 'access limbo' aptly describes the impasse where the government is pressured to provide affordable treatment, yet IP barriers preclude access to cheaper, generic versions of medicines. This dynamic creates an unsustainable tension between the need for affordable healthcare and the confines of intellectual property rights. This is particularly egregious when understood within the overall literature on IP barriers to inventions patented in HICs. Research highlights that as a result of IP, HICs that are most often home to patent holders have associated higher levels of employment, sales growth, and productivity (Balasubramanian & Sivadasan, 2011; Farre-Mensa *et al.*, 2019). At the same time, evidence suggests that less than 5% of inventions patented in HICs are also patented in LMICs (Fink, Hall & Helmers, 2018; Fink & Raffo, 2019). While these studies do not focus primarily on patents of health technologies, they do illustrate the global inequities that are often associated with IP and access to inventions.

For example, the Access to Medicines Index (2021) estimates that less than half of patented essential medicines are covered by pharmaceutical companies' access strategies in LMICs, including medicines in the pipeline that do not have future access plans. This is despite 70% of people living with HIV worldwide are based in MICs and the highest prevalence of HIV/HCV co-infection is found in the EECA region (WHO, 2016; Woode *et al.,* 2016; Plat *et al.*, 2016). The difficulty arises when considering the vast human, financial, and political capital HIV/HCV CSOs need to try to overcome the obstacles of IP, as highlighted in this research. This section outlines this research’s findings on the complex interplay between foreign id, diplomacy, donor relationships, CSO activity, and CSO-as-donor dynamics.

7.3.1. The Heterogeneity of Foreign Aid and its Impact on HIV/HCV Activism

Foreign aid was identified in this study as fundamental to the success of many HIV/HCV advocacy projects in Ukraine. Yet, this research also shows that the relationship between aid donors and the recipients is layered with complexities that, at times, impact the effectiveness of CSOs in fulfilling their missions or, indeed, refocusing the CSO's goals and objectives. The findings highlight two ways in which the heterogeneity of Foreign Aid donors can encourage or nurture synergies among CSOs. Still, they can also simultaneously engender an overly competitive and destructive CSO sector.

Firstly, the findings show that the imposition of performance-driven indicators as requirements for future funding opportunities from larger donor agencies, such as PEPFAR and the GF, generally includes conditions. This research highlights how these performance driven models can often create high levels of competition among the main HIV CSOs in Ukraine. These results are consistent with Owczarzak's (2010) study which highlighted how performance based indicators led to increased competition, fragmentation among HIV CSOs, and feelings of apathy rather than creating an environment conducive to effective collaboration.

Conversely, this research provides an example of how large funders helped create increased collaboration between HIV/HCV CSOs (section 5.1.3.). In The Lancet Commission's paper on advancing global health and strengthening the HIV response in the era of the SDGs, Bekker *et al.,* 2018 outline how lessons from the HIV response are paving the way for eliminating HCV. In particular, the HIV principles of treatment as prevention and effectively using a rights-based approach to accessing treatment services. Furthermore, the Lancet Commission (2018) modelled different scenarios for the incremental integration of HIV and non-HIV-related services, such as screening for HIV and NCDs in Kenya and South Africa, screening of HIV and other STIs in India and harm reduction services and ARVs for PWID in Russia. Each model showed improvements in HIV and broader health outcomes. The successful integration of HIV/HCV CSO advocacy goals via funding streams was shown to be highly effective in this research. This research adds to the Lancet Commission's paper as it provides an example of how HIV CSOs' growing expertise in patent oppositions helped the HCV community by using its knowledge and resource power to overcome Sofosbuvir's patent protection. This underscores the importance of designing funding mechanisms that not only hold CSOs accountable for reaching their goals but also encourage cooperation and unity within the HIV response. The research findings show that this aid model is already used by smaller and often philanthropic donors, referenced in this study, such as ITPC and OSF. The findings show that they place less emphasis on performance indicators and, as a result, encourage the main HIV CSOs to foster better collaboration in Ukraine and within the EECA region.

Secondly, the heterogeneity in size and resource power of the donor agencies is also raised as a concern in this research regarding their influence on the CSO operational landscape. Large donors, equipped with their vast financial resources, often dominate the donor market. The

research shows that this benefits HIV/HCV CSOs who engage with service delivery, research and demonstration projects and continue to professionalise their organisation. Yet, for issues such as access to medicine initiatives, which are primarily funded by smaller funders, the resource divide raises questions about the sustainability of initiatives which are primarily focused on structural change. Research has often cited the pros and cons of foreign aid shaping the CSO sector (Edwards, 1999; Shumate, Fulk, & Monge, 2005; Kapilashrami & O Brien, 2012; Harmer *et al.,* 2013; Zhukova, 2013; Banks, Hulme & Edwards*,* 2015; Dupuy, Ron & Prakash, 2016).

This research shows the benefits of increased professionalisation due to GF funding. Gaining a 'seat at the table' was enabled by the CCM coordination pre-condition of GF funding (section 2.2.3.). Yet, increased respect and trust for CSOs from Ukrainian society and government officials stemmed from their ability to put forward rational draft laws, provide services for PLWH and take on state functions, such as procurement and data collection. However, in 2007, UNAIDS warned HIV CSOs that their dual role as implementers of large programmes and services for the GF risks undermining their effectiveness in advocating for the HIV community. While this research highlights effective HIV/HCV CSO activism from 2010-2021, the findings do not necessarily refute this claim. If the HIV/HCV organisations needed to rely solely on large funders such as GF or PEPFAR to fund A2M activities, questions remain about the ability of CSOs to leverage power against the pharmaceutical industry and reduce the price of ARVs/DAAs. Ibrahim & Hulme (2010), McGill (2017) and Bekker *et al.* (2018) all argue that CSOs that focus more on service delivery and advocacy tend to focus less on policy or systemic change, which is essential to the success of the A2M movement.

On the question of professionalisation, the findings in this study do highlight activists' concern that continued professionalisation of HIV/HCV activism is distancing organisations from their 'ground base'. This is further discussed in sections 3.2.5. and 5.2.3.3. The research indicates that some needs of the HIV community are not being met, as the focus remains primarily on gaining access to medicines, while neglecting the psychosocial issues faced by PLWH. While the primary aim of Patients of Ukraine's is to improve access conditions for various health issues, the broader remit of 100% Life has been critiqued in this research for operating within a narrowed scope.

This research posits that this is a result of funder prioritisation, lack of funder awareness of the psychosocial issues of PLWH and suggests a disconnect between CSOs and the needs of their ground base. The disconnection between HIV/HCV CSOs and their ground base were not discussed in absolutes in this research. However, if funding priorities are partly influenced by CSO interventions, then the insufficient attention toward overcoming issues of stigma and discrimination indicates a potential contention between the needs of CSOs membership and the management of CSOs. This finding broadly relates to the expertise-representation gap discussed by March & Olsen (1998) and Saurugger (2012).

Furthermore, the research highlights the necessity for HIV/HCV CSOs to find a better balance between professionalisation and ground base engagement. Heylen, Willems & Beyers (2020) paper found that CSOs that combine membership with professional staff yield positive outcomes for the organisation. Therefore, this research contributes to the existing literature on professionalisation by emphasising the need for a more balanced and healthy approach to civil society organising.

These studies do not provide much insight into why this phenomenon occurs. My study highlights that the GF hesitates to fund A2M activism due to the USA's strong commitment to intellectual property. Yet, despite this, effective A2M activism continues to occur in Ukraine due to the heterogeneity of funders which fund different aspects of Ukraine's HIV response. This removes primary policy decision-making powers from the dominant funders within the donor market and, along with an open dialogue with CSOs, democratises the decision-making power within CSOs.

7.3.2. A Domestically Funded Identity Crisis

The research explored the perceived implications of HIV CSOs moving from an internationally financed third sector to a nationally or domestically financed sector. Firstly, in 2017, HIV CSOs lobbied the Global Fund to require the Ukrainian government to be a primary funder of HIV CSOs by tendering for their services. As a result, by 2020, the Ukrainian government funded 80% of HIV services from CSOs. In a UNAIDS (2020) feature story, Igor Kuzin, the Acting Director of the Centre for Public Health of the Ministry of Health of Ukraine, said:

'The transition plan provides an opportunity to continuously strengthen links between government and non-governmental organisations [...] Non-governmental organisations are moving away from their former role of volunteer activists and are starting to carry out professional social work and are accountable for its results. And the state, in turn, purchases their services through the public procurement system'

My research findings present differing views on state funding implications: 1) it finds that state funding is a natural progression for many movements but stresses the delicate balance between gaining resources and maintaining autonomy; 2) there was optimism around the further institutionalisation of 'CSOs' role in service delivery and health policy; 3) there is a fear that this funding mechanism helps to consolidate market power of large, more established CSOs but creates a more challenging environment for smaller CSOs to sustain their activities; 4) if audits show CSO mismanagement of government funds, it could lead to jail time - rather than ruined relationships with international funders, increasing levels of accountability and government oversight; 5) ongoing IP activities would not reduce funding to HIV CSOs as the Ukrainian government would never fund these activities directly, but continue to need treatment activists' expertise.

A qualitative study entitled 'Lost Transition' was commissioned by the Open Society Foundation (2017), examining the withdrawal of the Global Fund in upper-middle-income countries in South Eastern Europe, including Macedonia, Montenegro, and Serbia. The results show that these countries faced challenges in maintaining HIV services due to budget cuts. GF withdrawal also resulted in less integration of civil society in drafting and implementing sustainable HIV responses. The situation was exacerbated by funding cuts, leading to service suspension, loss of human resources, and depletion of institutional capacity as experienced staff left. My research found that the salary offered by the Global Fund helped HIV and other health-related CSOs to recruit highly experienced and educated staff members who could navigate difficult bureaucratic, logistical and trade landscapes. The findings found that people working in HIV CSOs were often paid more than people working within the Verkhovna Rada. Therefore, budget deficits in the future may impact the high level of expertise accumulated by HIV CSOs to continue navigating complex systems. The OSF report does suggest that sustainability bridge funding, such as Ukraine's 20-50-80 approach, should help mitigate much of what was experienced in Macedonia, Montenegro, and Serbia. My research adds to this OSF report on the GF existing countries within Eastern Europe by

focusing on the perceived issues that may arise in the future. Yet, during the data collection phase of this research, the funding transition was still in its infancy.

Another issue that arose in the research is that a conflict of interest may arise if HIV CSOs actively call out the government for corrupt practices. Therefore, this transition from international to government funding raises the question around the definition of CSO - from civil society to what? As elaborated on in section 2.2.1, Salamon & Anheier (1996) lay out five shared defining characteristics of CSOs, the most pertinent being that CSOs are not part of any government or public authority. Yet, this research shows that government funding will provide greater oversight into CSO financial activities and may reduce funding to essential HIV services if they call out government corruption. As highlighted by a research participant, '*the more money you receive, the less critical questions you ask*'. This is particularly important considering the political backsliding, as highlighted in section 5.2.3.4. In a recent paper, Richter (2022) shows that the leverage of western organisations, along with the expertise and swift reaction of Ukrainian CSOs, is fundamental in the containment of political backsliding attempts in Ukraine. An example of this highlighted in this study shows how the GF and UNAIDS helped to counteract the potential stockouts caused by the MoH refusing to sign procurement contracts on time (also section 5.2.3.4). Suppose HIV CSOs can only fulfil their service provision duties within the confines of not antagonising the state. This appears to create an existential threat to their existence as civil society, ultimately removing them from the grassroots and placing them in a semi-government service provision role. It also reinforces and furthers Harwood & Creighton's (2009) argument that the survival of CSOs depends on their ability to work within governmental ways of doing business. This evolution of funding arguably shifts the CSOs priorities further towards service delivery and less about critical engagement with the political process to achieve targets or prevent political backsliding.

Despite this, the research found an overall optimistic viewpoint from the participants regarding the new funding situation. However, this research did not interview enough HIV or other health-related community organisations about the success of this new funding system, so conclusions can not be drawn from this sample.

7.3.3. Funding Power and Autonomy

This study illustrates how the power dynamics related to foreign aid also extend to state sovereignty. This study shows that the engagement of international organisations, missions, and embassies from donor countries, such as the EU and the United states, with the Ukrainian government emphasises the leverage held by donors in shaping state policies. The interventions by these bodies during the procurement of medicines in March 2020 underscore their role in circumventing state neglect and bureaucracy, highlighting their potential to supersede state authority in critical situations. Another dimension of donor influence highlighted in this research is their encroachment on state sovereignty, both directly and indirectly. An example provided in this study of indirect influence includes the role of ITPC funding in helping to reshape relationships with key ministries, including the Ministry of Health and Ministry of Economic Development and Trade, to initially push for legislative reforms, such as the Patent Law Reform. The direct influence is evidenced by the role of international bodies like UNDP, WHO, and UNAIDS in the legislative adoption of the Patent Law Reform, as highlighted in section 6.1.1.4.

Scholarship on foreign aid focuses on the complex interplay of power, strategy and altruism in inter-state relations. Lancaster (2007) argues that the provision of foreign aid from HICs to LMICS was developed to better the human condition through economic stabilisation, poverty reduction and long-term growth. However, Lancaster believed that human betterment was not an end in itself but a means to a diplomatic end to influence national interests and international security. Therefore, the question arises - whose interests do foreign aid donors follow? Due to the heterogeneity of donors and multilateral influence in Ukraine, it is important to distinguish between the types of foreign aid. Bilateral aid is the direct assistance one nation provides to another and is mostly overseen and managed by the donor (Riddell, 2014). Proponents of bilateral aid believe that it is an effective and strategic geopolitical tool to be used in foreign policy (Apodaca, 2017).

Tarnoff & Lawson (2016) posit that foreign aid, especially bilateral aid, is a carrot and a stick approach to diplomacy as it creates a sense of dependency for the recipient country, ultimately shifting the power dynamic in the direction of the funder. PEPFAR, an American funding body that provides bilateral and multilateral financial assistance to the HIV response

in LMICS, has invested over $320 million US dollars in Ukraine since 2007 (PEPFAR, 2022). PEPFAR works closely with multilateral organisations that are more prominent within this research's findings. Multilateral aid is dispensed through international organisations, such as the United Nations Development Programme, the Global Fund, UNAIDS, the WHO, and the World Bank, etc. The primary difference lies in the degree of control exerted by the donor country. While bilateral aid allows donor countries significant leverage in determining how their contributions are used, multilateral aid undergoes a collective decision-making process, diminishing the direct influence of individual donor states (Headey, 2008).

This is consistent with the findings in my research. The meaningful, close relationship between civil society and multilateral organisations such as UNAIDS, the Global Fund, and the MPP is often cited in this research. The multi-stakeholder model of multilateral organisations provides the CSO activists with a voice to influence key decision-making processes, as identified by a quick reallocation of funds for the procurement of ARVs/DAAs and COVID-19 equipment during a time of government negligence (section 5.2.3.4). Another example includes multilateral institutions such as UNAIDS, UNDP and WHO pushing for adopting the Patent Law Reform. This reform introduced long-awaited legal instruments that benefit the Ukrainian A2M movement, such as opposition to patents before and after they are granted and changing the timeline for SPC application (section 6.2.1.1). This law aimed to harmonise Ukrainian IP law with European IP law. However, the collaborative workings of CSOs with multilateral organisations allowed for the pro-public amendments to be adopted too.

Yet, this relationship isn’t always conducive to collaboration, as outlined in section 7.3.1. The research found that CSOs successfully pushed for some A2M-related funding from the GF in 2018, but largely, their efforts are actively denied as big funders such as the GF, PEPFAR, and USAID are hesitant to fund IP activities, i.e. activism that seeks structural change. This research aligns with Palmer & Morgan (2006) who argue that foreign aid is a flexible, influential tool to safeguard the status quo or to influence change based on the interests of donor countries and philanthropists.

To bring it all together, this research finds that large donors are happy to provide financial assistance for procuring medicines. Yet, they are hesitant to provide further funding to overcome intellectual property obstacles using TRIPS flexibilities, preferring to seek more

business-friendly, amenable voluntary avenues to reduce the price of medicines. This highlights that although the CSO activist has an influential voice within the multilateral funding systems, the main donor countries, as well as large philanthropists, have a more dominant voice within the decision-making processes. This research highlights the prominent voice of the Gates Foundation in orchestrating the funding streams and directing decision-making processes. As outlined in section 6.1.1.3, The Gates Foundation has consistently leveraged its influential power in global health institutions to advocate strongly for intellectual property rights and promoting market dynamics as the primary solution to solving health crises (Hale, Held, and Young, 2013; Birn, 2014; McGoey, 2015; Mahajan, 2018; Thambisetty *et al.*, 2022).

This research shows that the foreign aid landscape isn't monolithic: its nature in Ukraine varies depending on the aid channel but not necessarily on the wishes of the CSOs or the Ukrainian government. This research adds to the overall literature on aid and underscores the important influence of aid on state sovereignty and CSO effectiveness.

7.4. Ingenuity in the Face of the Knowledge Economy

In the emergent knowledge economy (see sections 3.2.3 and 6.2.4.1), there's a deeply rooted belief that innovation should be granted a monopoly to ensure the inventors of new medical technologies receive a fair financial return. The centrality of intellectual property (IP) and its effects on access to medicines form the backdrop for understanding the tensions between proponents of stringent IP rights and their critics. In their paper, Moon, Bermudez & t'Hoen (2012) lay out the intellectual property rights landscape. Before the 1990s, there was a great variation in the type of patents that were granted. High-income countries, on average, granted patent rights between 15-17 years, while LMICs granted patents between 5-10 years. The authors highlight that all countries, including Western European countries, often made special exceptions to food, medicines and agricultural technologies (Moon, Bermudez & t'Hoen, 2012). However, the introduction of the TRIPS agreement in 1995 (outlined in more detail in section 1.2) required all WTO members to harmonise their intellectual property laws and provide a minimum twenty-year patent term for new technologies. This research adds to the timeline outlined in Moon, Bermudez & t'Hoen's (2012) paper as it highlights the continued efforts of trading blocs, like the EU and North America, to increase IP rights via bilateral and multilateral FTAs. The continued harmonisation process is identified through the

strengthening of IPRs, such as the introduction of data exclusivity. More importantly, this research identifies how treatment activists worked within general trade frameworks and overcame strong European pressure to limit the effects of strengthened IP provisions.

The Euromaidan Revolution, which signified Ukraine's leaning towards the EU, resulted in the signing of an Association Agreement that included a provision for a Deep and Comprehensive Free Trade Area. According to this agreement, it is a framework for Ukraine to 'modernise' its trade relations and for an '*extensive harmonisation of laws, norms and regulations in various trade-related sectors* (EEAS, 2014)'. When the TRIPS agreement was ratified in 1995, most countries other than North America and the EU did not have data exclusivity. However, it became more common due to TRIPS-plus provisions forced upon nations signing up to bilateral or multilateral trade agreements with the two trading blocs (Palmedo 2021). While health groups such as MSF have been ringing the alarm on data exclusivity since 2004, recent publications have found a correlation between TRIPS Plus provisions and associated increase in medicine prices, delay in availability and overall increase in costs to patients and governments (Shadlen, Sampat & Kapczynski, 2020; Palmedo 2021; Tenni *et al.,* 2022; Palmedo, 2023). In a recent paper, Palmedo (2023) found that between 1996-2014, pharmaceutical import prices were, on average, 14-20% higher than in countries which do not grant data exclusivity.

The research highlights how the prioritisation of the ongoing political and geopolitical crises affecting Ukraine created a challenging backdrop for treatment activists to engage with the Association Agreement process fully. Yet, despite these challenges, government officials would often seek the council of activists concerning certain IP provisions, highlighting the influential role that HIV/HCV activists played in trade policies post-Euromaidan. Initially, the research found that data exclusivity was not a big priority for the treatment activists as it usually provides monopoly power for 5-6 years, while patent protection provides twenty years. Similar to Palmedo's study (2023), this research highlights the difficulty in foreseeing the costs associated with data exclusivity, as it typically only becomes apparent years after the introduction of the provision. However, the treatment activists in this study identified it as becoming a problem when patent protection is removed via compulsory licensing or patent opposition. In 2006, The European Commission identified data exclusivity as an additional obstacle to procuring a supply of generic Tamiflu during a H5N1 bird flu outbreak in the event of individual member states issuing a compulsory licence. The COVID-19 pandemic

continued to shine a spotlight on this IP barrier within the EU, and as a result, the European Commission has proposed a harmonised approach to compulsory licensing, with the possibility to suspend data exclusivity (t'Hoen, 2023; McMahon, 2023). However, the EUwide compulsory licence proposed in this legislation would only be meant for the EU market (European Commission, 2023; t'Hoen, 2023). This highlights a clear hypocrisy regarding EU trade frameworks. The European Commission only regards data exclusivity as an issue once the reality of TRIPS Plus provisions negatively affects them in any real way. Ukraine would still be required to uphold data exclusivity under the Association Agreement.

This research highlighted how treatment activists used this general TRIPS plus framework to their advantage. The pharmaceutical industry often incorporates a staggered medicine registration approach. For example, a drug that is first prescribed in Germany may take two years to be prescribed in Romania (Martuscelli, 2023). Research shows multiple factors for this staggered approach, but it comes largely down to a large amount of time and paperwork involved in getting individual governments to approve and pay for new medicine. Therefore, the pharmaceutical industry initially focuses on HICs that have a large market, as these countries are more likely to use more of their highly priced products than LMICs (Kamphuis *et al.*, 2021; Martuscelli, 2023).

This research found that activists fought to introduce a safeguard within the general data exclusivity framework to counteract this. If a pharmaceutical company does not register a new medicine two years after first registering the drug in another country, Ukraine will not grant data exclusivity on that medicine. This research found that the introduction of this stipulation was inspired by other countries worldwide, such as Chile. However, the deadline for a pharmaceutical company to register a new medicine in Chile after first registering it in another country is one year (Timmermans, 2007). This research found that a future priority for treatment activists in Ukraine is to reduce their time frame from two years to one year, with an intended result of more timely access to medicines. However, unlike Chile, Malaysia and Colombia, Ukraine has no provision that waives data exclusivity when a compulsory licence is issued. I argue that this should be a future goal of treatment activists in Ukraine (t'Hoen, Boulet & Pascale, 2017).

Using Vigh's concept of navigation (see sections 3.2.4.), it is evident that HIV/HCV CSOs in Ukraine possess a strong ability to strategically adapt to the dynamic and ever changing

forces in their social environment and within the knowledge economy. The socio-political landscapes of trade agreements, increasing geopolitical conflicts, Ukraine's growing diplomatic relations, shifting societal attitudes towards CSOs, new funding mechanisms and changes within Ukrainian parliament are in continual flux throughout the time period of this research project. Despite these challenges, the research underscores the activist's profound understanding of these shifting landscapes, demonstrating their ability to achieve their goals, adjusting their targets and devise future strategies.

Furthermore, the activists exhibit a high degree of dynamic interactivity (sections 5.1.3 and 5.2.3.4.), illustrating how shifting landscapes impact the agency of the activist and how the political and social landscapes are impacted by the activists. Navigation within social movements is inherently non-linear and involves constant interaction between many stakeholders. This research argues that successfully navigating the knowledge economy involves a didactic reshaping and influencing of political processes, pharmaceutical relationships, legislation and foreign aid.

Moreover, the capacity of treatment activists in this study to adapt and engage with these evolving landscapes underscores the fluid and interactive nature of the knowledge economy. Their strategic adaptability and proactive engagement with continuously changing environments highlight the complex and interactive dynamics at play, reaffirming the importance of flexible and informed activism in achieving sustainable outcomes.

This adds to the limited literature examining synergistic avenues to overcome TRIPS-plus provisions, delayed registration of medical technologies, the patchwork of IP policies in MICs and how the concept of navigation provides insights in the various forces affecting treatment activism.

7.4.1. European Union versus Ukraine: The Case of Patent Law Reform

This research found that the EU's staunch pro-IP stance is evident in its resistance to Ukraine's Patent Reform Law. Notably, however, Ukraine's ability to pass this reform suggests a nuanced interplay between national interests, backed by international organisations and CSOs, and external geopolitical pressure. The research found that the treatment activists

categorised the Patent Law Reform into two categories: short and medium-term perspectives. Stricter patentability criteria and streamlining compulsory licensing processes are considered medium-term outcomes of the Patent Law Reform. Increasing patentability criteria is a strategic move as the Ukrainian Intellectual Property Institute has historically had a low innovation threshold for granting patents to medicinal products. Between 2000-2015, Ukraine granted 8.22% of all its national patents towards medicines, which is much higher in comparison to Germany and France (Standeford, 2018). Another issue found in my findings relates to the lengthy patent application proceedings, as it may take the Ukrainian Patent Office anywhere between 2-5 years to consider patent applications. The interviews in this research were conducted just after the Law reform was passed. Therefore, the outcomes remain to be unseen but are expected to bring significant price reductions.

The TRIPS Agreement specifies that 'patents may be granted only to inventors who show that their creation (1) is novel, (2) embodies an ‘inventive step’ and (3) is ‘capable of industrial application’' (El-Said & Kapczynski, 2011; WTO, 2023). The TRIPS agreement also allows WTO member states to define these specificities in their national legislation individually - providing significant scope for countries to preserve their own public health interests (Velasquez, 2015). In addition to increasing the patentability threshold, countries such as India, in 2005, introduced pre and post-grant oppositions.

This allowed generic pharmaceutical companies and CSOs to file patent oppositions against a published application and against a patent that was granted. This modified patent opposition system has been considered instrumental in increasing access to cheaper, generic medicines, including key ARVs Tenofovir Disoproxil Fumarate, Lopinavir and Ritonavir, Atazanavir, Lamivudine and Zidovudine, Lamivudine, Zidovudine and Abacavir, and Raltegravir (Rathod, 2022). However, in his paper, Rathod (2022) found that between 2008-2020, roughly 3,600 pre-grant oppositions have been filed, and approximately 950 have been dealt with conclusively. The primary reason provided in the paper is the lack of examiners and controllers to quickly adjudicate the high volumes of patent oppositions, creating issues for patent opposers, those seeking patent approval, and patients waiting for their treatment. Therefore, this research argues that future research is needed to examine the potential unintended consequences of these streamlined patent opposition procedures in Ukraine.

Another major aspect of the Patent Law Reform was the application process for SPCs. The study found that previously, pharmaceutical companies could apply for SPCs six months before the patent expires. As a result, government officials and CSOs were always anxiously awaiting to see if a pharmaceutical company would seek to evergreen their patent protection. This affected access to medicines as it did not provide CSOs and government officials time to create and implement a plan to offset the damages of the SPC. My findings show that treatment activists, through the amendments in the Patent Law Reform, placed the time burden of SPCs back on the pharmaceutical company by requiring them to apply for an SPC six months after the patent was granted.

This provided HIV CSOs time to see if an SPC was applied for and allowed them time to oppose the SPC. Additionally, the retrospective element of this law means that medical products granted patents even five or ten years ago can no longer apply for SPCs as they missed this newly introduced six-month rule. In 2017, MSF wrote a technical brief on SPCs outlining their position that SPCs unjustifiably result in unaffordable prices for longer periods of time in Europe. MSF outlined policy recommendations to abolish SPC mechanisms. However, if the mechanisms were to stay in place, MSF recommended policies that could bolster SPC opposition procedures. Ukraine, therefore, becomes the latest example of countries opposing evergreening practices of the pharmaceutical industry. A study by Hu *et al.* (2020) examining the high sales revenue versus R&D investments for Sofosbuvir, Trastuzumab, and Imatinib argues that the EU's SPC system may operate on a flawed assumption: that extended exclusivity is required for pharmaceutical companies to recoup R&D costs due to delays in market approval. Admittedly, Hu *et al's.* (2020) study only examines a few case studies. However, it highlights the tug of war between the industry's prerogative to optimise profits balanced against CSOs' push to oppose these practices.

The research also found that simultaneous to the introduction of the Patent Law Reform, treatment activists discussed with government officials another mid-term goal: the introduction of streamlined procedures for issuing a compulsory licence into Ukrainian IP law. This is significant because despite compulsory licensing being a right of all WTO members to use in the case of public health emergencies, this research found that Ukraine had no previous precedent of utilising this TRIP flexibility. My findings also show that, regardless of evidence of a CL precedent, treatment activists threatened to use CL to provide them leverage within price negotiations with pharma to reduce the price of medicines or expand

their voluntary licence agreements to Ukraine. This tactic has proven useful, as highlighted in Medicine Law and Policies TRIPS Flexibilities Database (2023), which shows that the threat of a CL often results in price reduction, medical donation or increased voluntary licence agreement.

However, a recent paper by Ukrainian IP scholar Olga Gurgula (2023) argues that due to the ongoing health crises as a result of the ongoing Russian invasion, Ukraine must waive all IP rights on essential medicines and that compulsory licence procedures are not sufficient to overcome all IP barriers. Gurgula (2023) identifies three main constraints to the efficient use of CLs. 1) compulsory licences are granted on a product-by-product basis, often on medicines that have multiple patents and can lead to lengthy procedural processes, which is counterproductive in times of emergencies; 2) CLs only target patents and not other IPRs such as data protection (’t Hoen, Boulet, & Baker, 2017; McMahon, 2023), as well as trade secrets, copyright, designs and trademarks. This limitation of CLs has also been identified in IP literature as a major obstacle to global equitable access to mRNA COVID-19 vaccines (Thambisetty *et al.,* 2022); 3) It is still uncertain whether a CL would apply to SPCs as they are different form of patent protection; 4) The royalties that governments are required to pay to patent holders after issuing a CL is considered an enormous barrier. As a result, Gurgula (2023) argues for an IP waiver on all essential medicines, which, under Article 73 of the TRIPS Agreement, is permitted during times of war.

Theoretically, this waiver would ultimately allow local manufacturers to produce and potentially import generics and biosimilars of essential medicines which are desperately needed in Ukraine. This research found that the threat of compulsory licences has proven effective as leverage in CSO negotiations with the pharmaceutical industry. As a result, the treatment activists believe that the streamlined CL procedural process will inevitably lead to price reductions in the future. However, two recent, serious and far-reaching situations that affect Ukraine, such as global access to mRNA COVID-19 vaccines and CLs inefficiencies in times of war, add to the literature on the limitations of compulsory licensing (Gurgula & Hull, 2021; Gurgula, 2023; McMahon, 2023). As the status of compulsory licensing and its efficiencies in Ukraine remain unknown, it is an important area for future research. This research recommends, in light of the current EU compulsory licensing strategy, to add data and market exclusivity as provisions in Ukrainian CL guidelines.

Two causes for concern are raised within this research regarding the success of the Patent Law Reform. The first is that the European Patent Office has proposed to the Ukrainian Minister of Trade to reuse their patent assessment reports. This would mean that the Ukrainian Patent Office, which is currently not beholden to any regional patent office, would agree to a quasi-patent validation system led by the EPO. If this were to occur, it would potentially affect Ukraine's sovereign ability to examine patent applications more stringently - as is the case with Georgia. However, the Ukrainian Patent Office continues to remain autonomous, highlighting its continued opposition to some European demands. The second cause for concern is that the head of the Ukrainian Patent Office is a political appointee. The research highlights scepticism relating to the new leadership and whether they will transparently implement these new rules. Therefore, this research should be used as a starting point for future research examining the role of the Ukrainian Patent Office in enforcing the Patent Law Reform, especially as Ukraine continues to gain closer ties to the European Union.

7.4.2. The Legal System and Access to Medicines

This research underscores how the Ukrainian legal system plays a pivotal role in determining the fate of intellectual property and the access to medicines movement. Two characteristics of the legal system were identified as key obstacles to overcoming IP rights in Ukraine: 1) the TRIPS Plus provisions and consequent Investor-state Dispute Settlement courts that result from EU and US trade agreements with Ukraine; 2) the court system requiring huge amounts of financial resources to oppose patents.

This research examines the case of Sofosbuvir which exemplifies the legal system's instrumental role in both upholding intellectual property and providing tools to overcome it. Initially, in 2015, without filing a patent or data exclusivity in Ukraine, Gilead found itself without leverage to overcome the cheaper, generic alternative that first came onto the market. Consequently, Gilead resorted to legal strategies by authorising its data exclusivity and invoking the TRIPS Plus provision to bring Ukraine before an Investor-state Dispute Settlement (ISDS) court. The investment dispute was logged under the US-Ukraine Bilateral Investment Treaty (Peterson & Williams, 2017). Gilead was planning to sue the Ukrainian government for $800 US dollars for loss of profits. This placed immense pressure on the government, compelling them to seek an '*amicable*' settlement, contrary to the activists'

recommendations. The settlement's core conditions included Gilead's commitment to keeping medicine prices unchanged, even after the deregistration of generic Sofosbuvir. Consequently, Gilead's branded Sofosbuvir became the sole HCV cure available in Ukraine.

The issues related to Investor-state Dispute Settlement (ISDS) procedures and TRIPS Plus provisions have been raised as a great concern in the context of public health and access to medicines within the literature. Each of the studies references Gilead's threat of an ISDS lawsuit against the Ukrainian government as a 'chilling' example of an ISDS effect on health policies within their studies (Baker & Geddes, 2017; Gleeson *et al.,* 2019; El-Said, 2020). However, each study falls short of outlining the Ukrainian A2M activist's next move: to initiate three patent oppositions. Their objective was to challenge Gilead's strongest application for the drug's polymorph component. In August 2017, the Ukrainian Patent Office rejected this patent, effectively dismantling Gilead's patent monopoly. However, the data exclusivity still was upheld until 2020. Regardless, this positive result compelled Gilead to extend its voluntary licensing agreement to Ukraine, a topic further explored in section 6.2.3.1. This study reiterates the research into the chilling effect of the ISDS, or even the threat of an investor dispute arbitration, in limiting governments and civil society to prioritise public health. However, the research adds to the literature by acknowledging the role patent oppositions can play in the activist toolbox to overcome these obstacles. The case of Sofosbuvir is unlikely to be generalised in many MICs due to the high costs and expertise associated with patent oppositions. However, the example exemplifies what is possible, as well as highlighting the tenacity of A2M activists in Ukraine.

The difficulty for treatment activists is compounded by the research findings that show huge amounts of financial resources and technical expertise are needed to oppose patents. Understanding the costs associated with opposing patents and their effects on the accounts of CSOs is difficult as it is often a collaborative process between Ministries of Health and Trade, international NGOs, patient organisations and generic pharmaceutical companies (Biehl e*t al.,* 2009). Additionally, the costs associated with different oppositions such as patent term extension opposition, pre-grant opposition and post-grant opposition can all vary, especially depending on the country in question (Abbas, 2022).

However, according to ITPC (2019), the main funders of IP activities in Ukraine since 2014, highlight that their investments exceeded their original annual target savings of $140M US

dollars. Their funding and technical capacity building resulted in '[...] *an average price reduction of 67% across 15 target ARVs in the four countries and contributed to total annualized savings of $472M'* (MMA, 2019). The report finds that the cost savings are due to many different types of IP activities, but patent oppositions are significant reasons behind the reductions. This research highlights that although patent oppositions may be costly, funding these activities sees a return on investment, but ultimately, results in people gaining access to better medicines in MICs.

There is much research that examines the role of civil society in opposing patents with case studies generally focusing on Latin America, South Africa and India (Pechacek, 2012; Cassier, Gaudillière & Hess, 2013; Helfer, 2015, Shadlen, 2017; Abbas 2022; Rathood, 2022). However, there is limited research identifying the A2M social movement in the EECA region. This research therefore helps bridge this gap. In essence, this research contributes to the broader understanding of the intricate dynamics surrounding legal disputes between the pharmaceutical industry and civil society organisations. It underscores the importance of recognising the role of patent oppositions as a formidable strategy for activists and the ongoing challenges they face in advocating for greater access to medicines in middle-income countries.

7.4.3. The Access Movement and its Relationship with Pharma

The role of the pharmaceutical industry is undeniable in the Ukrainian HIV/HCV response. A majority of the research participants have had direct engagements with this industry in differing forms. The research grapples with the activists' perception of the pharmaceutical industry, often describing it as avaricious and corrupted, while understanding that these are natural attributes of a business. Additionally, the pharmaceutical industry is a vital funder of important projects that continue to spur on the Ukrainian HIV/HCV advocacy.

The research highlights the potential conflicts arising from pharmaceutical funding. This often puts CSOs in a quandary, compelling them to accept funding from an industry they frequently critique. Evidence from this research shows that CSOs that have pharmaceutical funded projects with shared objectives, such as the creation of the National HCV Programme empower CSOs to not take on any undue influence from the industry. The research findings assert that pharma should not dictate the operational aspects of sponsored projects and calls

for a more regulated collaborative model, focusing on mutual benefits without compromising project autonomy. The research on pharmaceutical funding and their interactions with healthcare professionals is documented in the literature as a key driver of prescribing bias, correlating to higher prescribing rates but lower prescribing quality (Pellegrino & Relman, 1999; Coyle *et al*., 2002; Kassierer, 2005; Lo & Field, 2009; Schofferman, 2011; Brax *et al.,* 2017; Larkin *et al.,* 2021). There remains a dearth of research on pharmaceutical funding and the behaviour changes that CSO actors may incur, especially in relation to access to medicines activism.

In 2022, UNAIDS identified a funding gap of 9 billion US dollars to address the HIV response in LMICs. The ever-present funding challenge in the global HIV response inevitably ensures the ongoing need for pharmaceutical-funded projects and will continue the debate about power relationships between industry and civil society. The study's findings show that conflicts of interest can occur but highlight the need for a more strategic approach, stressing the importance of managing conflicts of interest from the outset to maintain the integrity of recipient organisations.

Another facet of the pharmaceutical industry raised in this research is its corporate calculus in determining the prices of medicines. The research finds that activists perceive the industry's pricing decisions are most frequently weighted towards maximising profits rather than considering potential political and social fallout. However, socio-political consequences are part of pharma's overall calculus, just not dominant variables. This reasoning is also reflected in the literature which indicates pharmaceutical pricing strategies are not based on recouping costs associated with R&D, but instead mirror their exploitation of market dominance for profit maximisation (Avorn, 2015; Woods *et al*., 2016; Morgan, Bathula & Moon, 2020; Wouters *et al.*, 2022).

This research underscores the complex relationship between the global HIV/HCV response and the pharmaceutical industry. While activists often view the pharmaceutical industry with scepticism, acknowledging its profit-driven motives, they also recognise its essential role in funding critical advocacy projects. This duality presents inherent conflicts, as CSOs navigate the delicate balance of accepting necessary funding while striving to maintain autonomy and integrity. The research underscores the need for a more regulated and strategic collaboration model that ensures mutual benefits without compromising the operational independence of CSOs.

Additionally, the industry's pricing strategies, primarily focused on profit maximisation, further complicate this relationship, highlighting the necessity for ongoing strategic management of conflicts of interest to uphold the credibility and effectiveness of the access movement.

7.4.4. Critical Discussion on the Role of the Medicine Patent Pool in Middle-Income Countries

The Medicine Patent Pool (MPP) has emerged in this research as an innovative approach to addressing the challenges of IP and access to medicines. Yet, the research presents both the significant advantages and perceived pitfalls of the patent pooling mechanism for both Ukraine and all MICs.

A modelling study by Morin *et al.*, 2021 shows that voluntary licences that are 'access orientated' have resulted in both economic and health benefits for people in LMICs. Despite this, research highlights that inclusion into MPP licence agreements mainly depends on countries' income groups and negotiations with originator pharmaceutical companies, regardless of countries specific health or medical supply needs (Wang, 2022; Mermelstein & Stevens, 2022). My research highlights the MPP's integral role in Ukraine in bridging the communication gap between all stakeholders, opening a dialogue between originator and generic pharmaceutical companies, governments and CSOs.

However, my research also finds that the MPP is oversimplified in its approach and recommends it '*steps up*' to navigate the complex dynamics found within MICs. The research posits that to make voluntary licensing work, pharmaceutical companies, government bodies, and CSOs must collaborate to ensure that: pharmaceutical firms offer licensing agreements; generic manufacturers are capable of making the medications; pricing and associated royalties align with budgetary considerations; and corrupt activities are curtailed. The findings show that this intermediary role is vital in contexts such as Ukraine, where previously, limited bargaining power and financial constraints would impede effective communication between CSOs and the pharmaceutical industry. However, this research also highlights the MPP's tenuous ability to compel pharmaceutical companies to grant licence agreements.

Thailand and Malaysia, two other MICs with a high prevalence of HIV and HCV, are often used as examples of being excluded from MPP licences and price discounts, resulting in their need to enforce TRIPS flexibilities (Hassan & Chan, 2019; Son, Kim & Lee, 2019). This qualitative research adds to the literature by providing the Ukrainian experience. For example, in Ukraine, an estimated 3.5% of the population lives with HCV, which is much higher than the European average of 1.5% (Devi, 2020). Yet, despite this high prevalence, Ukraine was left out of Sofosbuvir's licence agreement from 2014 - 2018. However, as highlighted in section 6.3.3, Gilead only extended the licence agreement to Ukraine after threatening an $800 million US dollar lawsuit, regaining its IP status and then CSOs filing three successful patent oppositions. Studies such as Douglass *et al.,* 2018 argue that Malaysia's issuance of a compulsory licence for Sofosbuvir resulted in Gilead responding by including Malaysia, Ukraine, Belarus and Thailand in their licence agreements. However, my research discounts this overarching claim and provides a nuanced look into how pressure from treatment activists forced Gilead into including them in the licence agreement. However, Douglass *et al.,* (2018) article's overall point that the threat of a compulsory licence and patent oppositions often lead to voluntary licence agreements is also found in the case of Ukraine.

In addition to the arbitrary and opaque nature of the licence agreement selection process, the research identified other concerns regarding the MPP. In 2020 a licence agreement was eventually signed for the addition of HIV treatment Dolutegravir between ViiV Healthcare and Azerbaijan, Belarus, Kazakhstan and Malaysia. However, this occurred only after years of pushing for compulsory licences and voluntary licences. This research highlights the lack of transparency relating to the royalty rate tied to this licence agreement as a '*dangerous precedent*'. The royalty rate is expected to be considerable, yet without the full details of the agreement being made available to activists, they feel as if they are unable to advocate effectively for price reduction. The licence agreement royalty rate usually oscillates between 5-10% (Baker, 2020). The standards for royalty payments are neither provided in TRIPS nor by the WHO, allowing patent holders to negotiate with generic producers, possibly leading to increased costs which are inevitably passed on to patients (Raju, 2016).

My findings found that treatment activists were unsure whether the rates in this opaque agreement could reach 20% or 30%, or even if it would be a fixed sum per pack of treatment, which would be a considerable barrier to cheap generics entering the market. In comparison

(Amin, 2007) believed that a healthy royalty rate should be anywhere between 05.%-5% based upon factors, such as when the VL is granted in relation to patent expiry and the novelty of the compounds. Therefore, for the first time in the research relating to MPP outcomes, the question of cost savings and positive health outcomes with voluntary licence agreements comes under intense scrutiny. Future research should examine the long-term outcomes of this decision-making process, similar to those conducted by Morin *et al.,* 2020.

Another issue related to the MPP which arose in the research is the selective licensing agreements with generic manufacturers. The example provided in the research is the case of the Sofosbuvir licence agreement. Although it extended it licence agreement to Ukraine, only pharmaceutical companies in China, India and South Africa were able to supply generic Sofosbuvir due to their licence agreements with Gilead. Pharco, the pharmaceutical company which originally sold generic Sofosbuvir to Ukraine was bullied by other generic manufacturers into not selling unlicenced generics to Ukraine. Overall, the research highlights how choosing a limited number of pharmaceutical manufacturers to supply drugs can reduce generic competition, and as a result, not lower the price as much as possible. Additionally, the research highlights how this approach divides the generic pharmaceutical industry. Research shows that effective generic competition ensures the prices of generic drugs are lowered (Dave *et al.,* 2017).

In a study by Dave, Hartzema & Kesselheim (2017), a correlation was observed between the price of generic drugs and the number of generic manufacturers supplying the medicines. In their study, they see a more pronounced price reduction for the first three generic manufacturers supplying the same drug. Other studies show that competition in generic drug markets can vary based on factors such as market size, manufacturing consolidation and the type of medical technology (Snoga, La-Viola & Sanchez, 2019; Frank, McGuire & Nason, 2021). Despite these varying factors, by intentionally reducing the generic market, the MPP is creating a non-competitive environment which has been shown to damage individual and societal health outcomes (Dave *et al.,* 2017). Therefore, this research highlights the need for the MPP to issue non-exclusive license agreements to ensure that generic medicines are truly affordable.

The research identified some scepticism related to the motivations behind the MPP. My findings argue that licence agreements may be a '*counter-strategy*' employed by the pharmaceutical industry to sidestep governments, CSOs and generic manufacturers' strategies to remove IP rights from patent holders. This assertion is backed up by research that argues that VLs are rarely voluntary but are rather a result of civil society pressure (Raju, 2016). Arguments have been made that voluntary licences may ironically result in entrenching the IP rights of the patent holders. VLs enable patent holders to manage competition and collect royalties in countries that may have insufficient patent protection (Gore *et al.,* 2023). This study identified that the MPP has made significant strides in improving access to medicines in Ukraine by facilitating communication between all stakeholders. Yet, it faces considerable challenges. These include limited influence over pharmaceutical companies, complexities in operating within MIC environments, issues of transparency and potential conflicts of interest, and the risk of unintentionally undermining more aggressive IP opposition strategies. As the MPP begins to widen its horizons and facilitate voluntary licences for non-communicable diseases (Writz *et al.,* 2017; Burrone *et al.,* 2019), future research should continue scrutinising the mechanisms and effects of future MPP licence agreements.

This research adds to the growing literature by recommending that the MPP enhance its effectiveness by addressing these challenges, particularly by adopting a more assertive stance in negotiations, ensuring greater transparency in its operations, and working more effectively within the complexities of MIC environments. This approach will better serve the broader objectives of access to medicines and public health in middle-income countries.

7.4.5. Civil Society's Role in Trust-Building and Messaging for Access to Medicines

The research findings highlight the indispensable role HIV/HCV CSOs play in facilitating trust, mediating communication between stakeholders, and advocating for healthcare reforms. While this research focused on intellectual property activism, other methods were employed by CSOs to achieve greater access to treatment. Integral to these non-IP activities, their contributions range from data collection to direct actions to highlight gaps in the system and rally public support. My findings highlight an overall ambivalence from government officials and healthcare professionals in the collection of epidemiological data on people living with HCV in Ukraine. The activists within this study acknowledged that the negligence of collecting this data was not only an oversight but a critical impediment to procuring cheaper

HCV treatments. The research reveals that the HCV CSOs' data collection process was influenced and often compromised by socioeconomic factors.

The reluctance of people living with HCV to voluntarily register their HCV status to a state register is due to high levels of mistrust, especially among PWIDs. Concurrently, healthcare professionals refused to proactively collect data due to competition among peers, as detailed in section 5.1.3. Moreover, the dearth of accurate data on HCV prevalence culminates in the hesitancy of government officials to allocate funding to procure expensive medicines they believed were unnecessary. Therefore, HCV organisations took a multifaceted approach to train, educate and fight healthcare professionals to underscore the importance of encouraging people living with HCV to register on the national register. Also, they engaged with the HCV community to empower them to sign up to the register and to self-advocate for access to treatment. This concerted effort ultimately led to the inception of the Ukrainian government's first national HCV elimination programme. Importantly, this resulted in larger procurement contracts for HCV treatment that led to price discounts.

In their 2014 paper, Rabehariosa, Moriera & Akrich conceptualise 'evidence-based activism' to capture the ways that 'patient' organisations (in this study recognised as HIV/HCV CSOs) engage with knowledge production and mobilisation. Rabehariosa, Moriera & Akrich (2014) evidence-based activism conceptual model consists of five main points: 1) CSOs involved in evidence-based activism gather experiences to create experiential knowledge, forming groups and defining their concerns; 2) These organisations combine official knowledge with experiential insights, making the latter politically relevant, often to engage other stakeholders and address health concerns; 3) By doing so, they redefine existing perceptions of health conditions and issues, leading to the identification of areas in science that have been overlooked or remain unaddressed, linking their involvement in health politics to knowledge politics; 4) The causes championed by these organisations, as well as the definitions of conditions and the identification of affected individuals, are results of their knowledge focused activities; 5) To facilitate these shifts in understanding, CSOs integrate themselves into expert networks, partnering with specialists, health authorities, and medical professionals, steering towards a reform-minded approach rather than a strictly adversarial one. In my research (section 5.1.3), instances such as gathering HCV prevalence data, spearheading projects for ARV procurement in the Ukrainian penitentiary system and coordinating a study to determine the superiority of DAAs over interferon treatments

underscore the adeptness of HIV/HCV CSOs in employing evidence-based activism. This aligns with the conceptual model proposed by Rabehariosa, Moriera, & Akrich (2014).

The strategic communicative approaches employed by activists in this research offer a rich understanding of the interplay between activism, cultural context, and the socio-political framing of health-related issues in Ukraine. A multidisciplinary approach for legislative reform is identified through the lens of direct actions outside the Ukrainian parliament and/or courts, demanding the registration of a draft 'Saufika's' Law or the revocation of IP rights of Lopinavir/Ritonavir. The underpinning strength of the campaign to introduce medical cannabis into Ukraine was through the effective use of patient leaders. The story of Saufika, a young girl who lost her ability to speak and walk due to epilepsy, was used as a poignant focal point for the campaign. Aptly naming the draft law Saufika's Law is a tactic that significantly amplified public and parliamentary awareness. The CSO campaigning strategy transcends mere advocacy, delving into the realms of building trust with patient groups, empowering leaders within these communities, and leveraging personal stories to catalyse legislative change.

The art of storytelling has long been recognised not merely as a conduit for transmitting knowledge, traditions, and cultural norms, but also as a force in catalysing social change (Ganz, 2001; Amsterdam & Bruner, 2000; Prasetyo 2017). Sharing stories, as noted by Ganz (2001), plays an instrumental role in sculpting individual and collective identities, fostering agency, and equipping people with the tools to navigate novel challenges and envision alternative trajectories for their futures. As underscored by Amsterdam & Bruner (2000), stories often depict protagonists on a mission, propelling them towards objectives of significance, challenging them to either innovate and forge new paths or face defeat. There is theoretical crossover with social movement theorists who argue that framing affects how issues are understood and portrayed, providing a rich understanding of how social problems are constructed and how change can be enacted (Mhazo & Maponga, 2022). Social movements often identify 'injustice' and 'motivational' frames as an adopted strategy to advocate for change and employed as a call to arms (Gamson, 1995; White, 1999; Benford & Snow, 2000).

In the case of Saufika, the young girl's lack of access to lifesaving medical cannabis is the injustice and Saufika's Law is the motivational framing. The research found that the parliament accepted to register the draft law. A recent Politico article by Melkozervoa (2023) highlights that the Russian invasion has created more urgency around the introduction of medical cannabis in the Verkhovna Rada, as it is often used to treat people who suffer posttraumatic stress disorder. Therefore, the activism behind Saufika's Law helped to expedite the issue within the Verkhovna Rada during the time of war.

Similarly, other CSOs in the research employed a multifaceted approach to challenge the patent extension practices of pharmaceutical company AbbVie regarding Lopinavir/Ritonavir. This campaign encompasses various symbolic tactics, including the burning of fake money and the use of soap bubbles, to metaphorically represent the financial imprudence and surreal pricing strategies of the pharmaceutical industry. Additionally, the staging of 'imitations of killings' serves as a dramatic representation of the grave consequences of pharmaceutical patent policies, effectively highlighting the life-and-death stakes involved in access to essential medicines. Data is also used to quantitatively highlight how much more medicines could be procured if the patent was removed, ultimately highlighting how many lives could be saved by removing IP protection.

The research shows various tactical approaches were used to overcome access barriers. McAdams (1983) argues that protesters' tactical choices are often strategic and are based on calculations. Taylor & Van Dyke (2004) suggest that tactics are defined by the activists 'taste for action' and select actions to match that taste, highlighting an interplay between power and repression that ultimately facilitates the actions of activists (Tilly & Tarrow, 2007). Both Saufika's Law and the campaign to stop the evergreening practices of AbbVie used the voices of the people most affected, advocated for their right to treatment and effectively utilised the media in their campaigning.

The messaging around the two campaigns is similar: lack of access means serious health issues and even death. However, the images and representations used differ widely. This highlights the heterogeneity of campaign framings in healthcare activism both globally and within Ukraine itself. Although the literature outlining the mobilising role of social media in social movements is growing (Castells, 2015; Hwang & Kim, 2015; Kidd & McIntosh, 2016; Brünker *et al.,* 2020), a limitation of this research is that it did not examine the use of social

media in supporting these campaigns. In fact, there remains a dearth of information regarding the role of social media in access to medicines movement, and future research may be warranted.

7.4.6. Future Pursuits Disrupted

The research shows that desired future endeavours of CSO activists include activities related to access to medicines, fighting for greater human rights protections of people living with HIV, safeguarding the reformative progress made counteracting the regressive tendencies of the Verkhovna Rada, and ensuring the implementation and actualisation of passed bills and legislations.

After the data collection phase of this research, Russia enacted a full-scale invasion of Ukraine resulting in considerable disruption to daily life, high levels of death and injury and damage to essential public and social services (WHO, 2022; Friedman, Smyrnov & Vasylyeva, 2023). Research is already estimating the long-term effects on new and existing health problems, including HIV (McKee & Nagyova, 2022; Friedman, Smyrnov & Vasylyeva, 2023). Yet despite these challenges, civil society is largely credited to ensuring that people living in Ukraine are able to continue receiving HIV, TB and services for PWID (Rachynska *et al.*, 2022; Hayes, 2022; Cairns, 2023; Gvozdetska, 2023). During the Russian invasion, the resilience and adaptability of HIV civil society organisations in Ukraine became evident. Despite the turmoil, they quickly adjusted their services to address the emerging needs of the population.

The primary focus was to ‘first save lives’, and HIV CSOs took the forefront in these efforts. Their activities ranged from evacuating people from conflict zones and offering temporary shelters to ensuring consistent access to medical services, including for HIV, TB, and PWID (Rachynska *et al.*, 2022; Hayes, 2022). Rachynska *et al.* (2022) argue that the success of HIV CSOs can be attributed to several factors. First, their ability to adapt to the community's immediate needs. The absence of complex bureaucratic hurdles provided them an edge in swiftly redirecting their efforts. Secondly, their previous experiences, especially during the COVID-19 pandemic, gave them a blueprint on how to efficiently adjust services. The protocols and innovations developed during the pandemic became handy in the conflict situation. Lastly, the support from flexible donors like the Global Fund was crucial. Their

willingness to adjust funding based on the changing needs on the ground was instrumental for CSOs (Rachynska *et al.*, 2022; Hayes, 2022). However, during a session at the EACS conference in Warsaw (2023), Olga Gvozdetska, the acting Deputy Director General of the Public Health Center of Ukraine's Ministry of Health, warned the services were beginning to falter. Gvozdetska adds that in 2023, no funding for HIV services came from the Ukrainian government. Funding for the HIV response primarily came from PEPFAR and the GF. Additionally, Gvozdetska says that if the war was to end today, the cost of rebuilding Ukraine's healthcare sector would amount to $10 billion dollars (Cairns, 2023; Gvozdetska, 2023).

Unfortunately, and with a heavy heart, it appears that the desired future pursuits of HIV/HCV activists outlined in section 6.2.5.3. seem like a distant dream from their current reality. The efforts of HIV/HCV CSOs in my research, in addition to their ongoing work to upkeep HIV and other health-related services, show the importance of continued financial aid to help fund these initiatives. It is my sincerest hope that when the war ends and Ukraine begins to rebuild, it will be built upon the vision of Ukraine's civil society which has continually pushed for a more democratic, transparent and just governmental, judicial and social order.

7.5. Conclusion

The intricate relationship between the socio-political context of Ukraine, the transformative role of HIV/HCV activism, and the overarching challenges of accessing medicines form the crux of this research. Significant findings from the research show that while historical events such as the Euromaidan Revolution catalysed structural reforms in the healthcare sector, the underlying issues of intellectual property rights and their implications for access to medicines have remained complex and multifaceted. The study shines a spotlight on the pivotal role played by HIV/HCV activists in navigating these complexities, especially within the backdrop of international trade agreements, geopolitical crises, and evolving intellectual property landscapes. Moreover, the research also emphasises the significant influence of international donors and diplomatic ties in shaping Ukraine's access movement. The challenges posed by corrupt governance structures, intellectual property rights and TRIPS Plus provisions, especially within the realm of global health emergencies, underscore the pressing need for a proactive approach to safeguarding public health over corporate profiteering. As Ukraine continues its journey towards a rebuilt and reimagined healthcare

landscape, the insights from this research serve as a beacon to other MICs, illuminating the intertwined challenges and pathways of activism, diplomacy, and policymaking in ensuring equitable access to life-saving treatments.

8. Conclusion

8.1. Introduction

This chapter presents the principal findings of the study, highlighting its contribution to the academic literature on political process theory, HIV/HCV activism in Ukraine and access to medicines in MICs. The strengths and limitations of the research are then presented. Furthermore, the chapter will explore avenues for future research inspired by insights from this research. Finally, recommendations for treatment activists, policymakers and funders are outlined.

8.1.1. Contribution to literature and theoretical understandings of PPT

Political process theory, despite being criticised for its ambiguity and complexity (Somma, 2023), provides valuable insight into the multidimensionality of activism, especially when examining political opportunities. Political opportunity is a vital factor when examining activism, as it represents the context or norms in which a social movement operates (Jami & Peoples, 2022). The Euromaidan exemplified this, as it paved the way for health CSOs to play an influential role in government decision-making processes. Anti-corruption, prodemocracy and pro-European trade agreements were key features of the emergence of the Euromaidan Revolution. This helped to facilitate CSOs removing key powers from the state, such as medical procurement and handing them to international organisations such as UNDP, UNICEF and Crown Agents. Meanwhile, CSOs made significant changes like the creation of ProZorro, an online procurement system that enhances transparency and ensures pro-public procurement processes.

The opinions of HIV/HCV CSOs were sought during the negotiations of the EU-Ukraine Association Agreement. Additionally, they played an active part in developing, pushing for, and implementing progressive legislation between 2015 and 2019. Despite HIV/HCV treatment activists being positively affected by their closer working and personal relationships with government officials, the EU-Ukraine Association Agreement negatively affected their work due to the strengthening of IP rights. Although the FTA remains a barrier to treatment activism, the relationships between state and civil society allowed for pro-public provisions, such as stronger patentability criteria and clarifications on pre and post-patent oppositions to be drafted into the Patent Law Reform.

However, in 2019, the window of political opportunity began to close with the tenure of Zelensky's government. As highlighted by Zelensky's government rejection of the draft Patent Law Reform bill four times. Thankfully, the bill, with its pro-public amendments, ultimately passed thanks to the interjection of UNAIDS and the WHO, signifying the influence multilateral organisations have over policymaking.

McAdam (1982) and Costain (1992) argue that social movements must identify the conditions of a political opportunity as they determine the when, how much, and what kinds of mobilisations are possible. The significant challenge for researchers is to pinpoint the exogenous factors, including political opportunities that influence the development of specific social movements and in what ways. This research contributes to the understanding of the conditions favourable to effective social movements, particularly in the Ukrainian context, where the Euromaidan Revolution facilitated access to medicines. Nonetheless, it also reveals that activism can operate independently of such political shifts, focusing on technical expertise and strategic initiatives beyond state-level interactions. Although the Euromaidan Revolution, in part, resulted in many people living with HIV/HCV in Ukraine gaining access to more medicines, it does not paint a picture of the whole access story. HIV/HCV treatment activism was also conducted without intervention from the opportunities induced by Euromaidan. As shown in Appendix I, strategies such as price negotiations, CSOs procuring medicines, data collection methods, and patent oppositions were done independently from the Euromaidan Revolution.

This concurrent movement is a result of the technical expertise and funding received from OSF and ITPC. Therefore, this research also contributes towards the literature that critiques PPT (for critiques, see section 3.2.2.). This study challenges the notion that social movements primarily contest state decisions, highlighting instead that access to medicines movements often address corporate and trade issues. Therefore, the PPT is insufficient in fully understanding access to medicines movements, as the aim is not to primarily contest the decisions of the state alone (Pellow, 2001; Goldstone, 2004; Smith & Fetner, 2007; Caruso, 2015). The nation-state as the ultimate decision-making power is contested in this research, as states must conform to the rules and regulations laid down by the World Trade Organisation. Although TRIPS flexibilities provide WTO member states with the right to challenge intellectual property rights through compulsory licensing or parallel importing, Ukraine has never used these provisions, even during times of health emergencies, such as its HIV/HCV

epidemics. Therefore, HIV/HCV CSOs needed to leverage some power to force patent holders to reduce the price of medicines. Therefore, these mobilisations for change are not centred on the state but on corporations. This provides a unique contribution to the PPT scholarship. This research found that political neutrality helped treatment activists pursue patent opposition and leverage power by threatening compulsory licences. Interestingly, this research identified a symbiotic relationship between the state and independent social movements to fulfil healthcare objectives, a dynamic not commonly explored in social movement theory, which traditionally views movements as adversaries to government entities. Some recent literature examines cases of state-Mobilised Movements, wherein social movements are fuelled by the state, such as the January 6th riots incited by President Donald Trump (Ekiert & Perry, 2021). However, I have not read social movement literature focusing on the state's reliance on social movements that evolved independently to advance its healthcare agenda. The literature often sees social movement actors as challengers to the state in the name of disadvantaged and excluded communities (Tilly, 1978; McAdam, 1982; McAdam, McCarthy & Zald, 1996; Tarrow, 2007; Caren, 2007). Yet, my research highlights that civil society mobilising for change plays imperative dual roles of supporters and antagonists to the state where the state is not the primary target of the movement in question.

The study recognises the integral role of foreign aid and multilateral institutions in empowering CSOs to exert pressure to enact change, such as shifting procurement powers, mobilising and adapting resources to deal with government negligence (section 5.2.3.4.) and pressuring the government to adopt pro-public safeguards into the Patent Law Reform (section 6.2.1.1.). Therefore, this research aligns with David Pellow's (2001) more modernised political-economic approach to PPT (section 3.2.2.). Pellow’s framework advocates for a more nuanced understanding of social movements where both political and economic forces are challenged.

This research makes a compelling argument for modernising PPT to better understand the complex interplay of political, economic, global systems and social factors in social movements. It underlines the need to go beyond traditional state-centric models to include the roles of corporate entities, international donors and multilateral institutions in shaping activism and movement outcomes, particularly in the context of access to medicines research in MICs. This research also illuminates an interesting power dynamic: the interdependence of the state on treatment activism. This occurs when the state is stuck between its international

diplomatic obligations and its commitment to securing access to cheaper, more affordable medicines.

8.1.2. Contribution to Theory on HIV/HCV Treatment Activism in MICs

First and foremost, the findings of this research corroborate existing literature that posits intellectual property and TRIPS Plus provisions as barriers to accessing affordable lifesaving medicines in LMICs (Baker, 2008; Jung & Kwon, 2015; Islam *et al.,* 2019; Tenni *et al.*, 2022). In Ukraine, as is the case globally, HIV/HCV CSO activists have been at the forefront of the access to medicines movement to challenge the monopoly power of the pharmaceutical industry. These successes can be identified in a number of ways in the literature. Firstly, Dunchenko, Deshko & Brage (2017) argue that Ukrainian HIV/HCV CSOs are regional leaders in the EECA region for proactively combatting the impacts of HIV, HCV, PWID, TB and other STIs. My research acknowledges and builds on this view, emphasising the innovative efforts of Ukrainian CSO leaders in negotiating drug prices, working within complex systems and their intellectual property activism that exceeds those observed elsewhere in the region.

Scholars such as Krikorian & Torreele (2021) and Kapczynski (2019) recognise the successes of early rights-based HIV/AIDS activism in reshaping the access to medicines landscape. However, they remain critical of the evolution of this movement as it transitioned from grassroots movements towards a more technocratic, less confrontational and more market friendly approach to health that arguably overlooks deeper systemic flaws. The authors argue that this new model of activism focuses too much on voluntarism within the donor and pharmaceutical industry and does not address the root cause of systemic issues. This critique suggests that HIV/HCV treatment activists are navigating within a global framework with which access to medicines issues will continue to be systematically reproduced (Marks, 2011; Kapczynski, 2019).

While this may be a valid critique, the immediacy with which activists must act to secure price reductions demands the use of repertoires of contention that are known to reduce the prices of medicines in the short term, such as price negotiations and patent oppositions. However, the research fails to explore the Ukrainian HIV/HCV CSO's long-term goals regarding intellectual property and may warrant further exploration in future research. Further contributing to the literature, this study highlights the raising concerns regarding the

‘goodwill’ of the pharmaceutical industry through its licence agreements vis-a-vis the Medicine Patent Pool. My findings are aligned with the research that shows MICs such as Ukraine have a legal right to issue a compulsory licence for pharmaceutical products, yet they are hesitant to issue them due to fears of trade retaliation, coupled with the complexities of issuing a CL (Wong, 2020; Gurgula, 2022).

Despite this, my research found that treatment activists often use the threat of a CL as power leverage during price negotiations with pharmaceutical companies. Yet, MICs are still often reliant on voluntary licensing agreements, which the pharmaceutical industry does not issue due to the country's income status (Wong, 2020; Krikorian & Torreele, 2021). Some critics have argued that such agreements under the MPP licence agreements can deter the use of TRIPS flexibilities, respond to access challenges on an ad hoc basis, do not tackle the financialised pharmaceutical profit-driven model, and centre the charity of the pharmaceutical industry as a solution to the access issue (Kennedy, 2015; Krikorian & Torreele, 2021).

My research adds to the critical perspective of the MPP by underlining two main frustrations and concerns within the activist community. The first concerns the arbitrary and non-transparent reasonings behind the exclusion criteria of voluntary licence agreements. The second regards the MPP's very first non-transparent licence agreements between ViiV Healthcare and five countries in the EECA region, undermining the MPP's fundamental principle of transparency and the activist's ability to advocate for price reductions if needed. This research argues that these precedents could endanger future licence agreements, particularly those in MICs who often must fight to be included in territory licence agreements.

8.2. Summary of Key Findings

This study adopted Braun and Clarke’s reflexive thematic analysis approach to explore how HIV/HCV treatment activists fought for access to lifesaving medicines in Ukraine. Reflexive thematic analysis is conceptualised as a reflection of the researcher’s interpretive analysis of the data is based on the intersection of (1) the dataset, (2) the theoretical assumptions of the analysis, and (3) the analytical skills/resources of the researcher (Braun & Clarke, 2019). With my positionality and reflexivity in mind, the study’s key findings are summarised as follows:

The first key finding provides deep insight into the converging parallel movements of the Euromaidan Revolution and HIV/HCV civil society fighting for access to medicines. These movements, though emerging independently, benefited greatly from each other. Post Euromaidan reformist attitudes in political and social spheres markedly increased the influence of HIV/HCV CSOs in key decision-making processes, paving the way for changes in state procurement and patent law, and initiating discussions on the enforcement of TRIPS flexibilities. These achievements were underpinned by years of sustained global funding, which was instrumental in cultivating a mature, expert civil society capable of taking on state functions during times of crises, challenging pharmaceutical monopolies, and embedding pro-public safeguards into health legislation. Therefore, the strength of Ukraine's HIV/HCV treatment is attributed to a combination of external factors and serendipitous events colliding. Furthermore, the study noted a diminishing movement for reform in the Verkhovna Rada from the beginning of Zelensky's term in 2019. This raises an important question regarding the direction of Zelensky's leadership post-conflict: will his administration continue to engage collaboratively with civil society, or will the government retreat to prior governance models?

The second principal finding underscores that notwithstanding the transition from international to domestic funding of HIV service provisions, substantial external financial support remains essential for treatment activists to challenge the pharmaceutical industry's pricing of medicines effectively. Engaging in patent oppositions at any stage of the patent application process necessitates a considerable amount of financial support and technical knowledge. This is particularly true if patent opposition cases go to the courts. The research indicates that such legal proceedings are often protracted and generally favour the side with the most resources, such as having a strong legal team, a solid scientific basis for opposing 'inventiveness' and sustained government relationships. Due to Ukraine's growing diplomatic ties to the European Union, as highlighted by the Association Agreement, it is apparent from the findings that HIV/HCV activists understand that it remains highly unlikely that the Ukrainian government will provide funding for IP activities. Therefore, it remains imperative that MICs left out of licence agreements continue to get external funding for IP activities. Lastly, the treatment activists adeptly navigated the general trade framework established by the EU-Ukraine Association Agreement. Despite the enforcement of data exclusivity, activists cleverly leveraged this requirement to their advantage, pressuring pharmaceutical companies to register medicines for the Ukrainian market more quickly. Furthermore, the Patent Law

Reform was intended to harmonise Ukraine's IP laws and regulations with those of the European Union. Treatment activists used this opportunity to add pro-public safeguards to the draft law. These included provisions to shorten the duration for pharmaceutical companies to apply for a supplementary protection certificate, have stricter patentability criteria and improve pre and post-patent opposition processes. Thanks to the external influence of multilateral institutions, these amendments were successfully integrated into the bill, which was finally adopted. This underscores the ingenuity of treatment activists in navigating the knowledge economy but also the influential role of multilateral institutions in guiding legislative reform in Ukraine.

8.3. Strengths and Limitations of the Study

8.3.1. Strengths

This research adds to the overall body of knowledge focusing on the access to medicines movement in Ukraine and in middle-income countries, especially in relation to countries in the EECA region. The capacious framework of PPT informed the multidimensional lens through which to study HIV/HCV treatment activism. Research on HIV activism or access to medicines in Ukraine is generally siloed in either a sociological or intellectual property lens. My research bridges this gap as it employs an interdisciplinary theoretical lens. This enables a more complete exploration of the dynamic nature of activism, the background of CSO activity, intellectual property rights, the implications of trade frameworks and international relations, activist strategies and the socio-economic motivations behind the converging movements of the Euromaidan Revolution and HIV/HCV treatment activism. Additionally, existing literature exploring treatment activism in MICs predominantly focuses on regions outside of EECA. This research not only fills the geographical gap but also draws attention to the unique interplay between HIV/HCV activists across EECA's distinct regional hubs, where most countries in the region are often omitted from voluntary licence agreements.

Therefore, I hope that this research stands as a springboard for future access to medicines research in the EECA region. Additionally, as scholarship will inevitably examine the rebuilding of post-war Ukraine, this research provides an interesting snapshot of the strength of Ukrainian civil society, healthcare activism and governance structures moments before Russia invaded Ukraine.

This research garnered insights from participants with a wide range of expertise, skillsets and personal experiences related to HIV/HCV treatment activism. The research participants provided perspectives of people working in international donor agencies, people who worked in intellectual property activism and counselled on trade frameworks, human rights activists, people living with HIV and HCV, and individuals who worked in regional HIV networks, each providing deep insights into the Ukrainian HIV/HCV treatment activist movement.

My own positioning in the research is situated firmly within the insider and outsider continuum, bringing advantages and disadvantages to this research. Being someone living with HIV, who is a member of a European HIV network and co-founder of Access to Medicines Ireland, I believe was greatly advantageous to this research project. Firstly, my personal and difficult journey with HIV treatment fostered a deep empathy for the Ukrainian HIV/HCV community, who, at one time, had limited treatment access while HICs had a healthy supply. My professional background allowed me to engage deeply with complex issues during interviews, discussing market dynamics, trade and activist strategies. As a member of a European HIV network, I had direct access to two Ukrainian HIV activists who partially co-designed my research during the exploratory phase and approved the proposed interview questions. This encouraged me as I understood that the research question and overall design would ensure that the knowledge produced would make sense and be relevant to Ukrainian activists' worldview and, where possible, could potentially be integrated into activist practice. Overcoming this challenge is a key recommendation in Bodini *et al.* (2020) paper on methodological challenges in activism research, as mutual meaning-making involves the epistemological shift from seeking an objectivist truth to co-creating knowledge that will be useful in practice.

In Kara's (2018) article, the ethical imperative of disseminating research is emphasised. The responsibility extends beyond academia to new, diverse audiences, necessitating a reconsideration of how findings are communicated. It also involves translating research into policy and practice in the real world (Kara, 2015; 2018).

In my role as co-founder of Access to Medicines Ireland, I am often engaging in various forums discussing access-related issues. I believe this research has enriched my work in Access to Medicines Ireland. For example, I was able to disseminate my preliminary research findings during an Access to Medicines Speaker Tour I organised in 2022. Using my own

personal story and the findings from my research, I empowered students to join me in Dáil Éireann (Irish Parliament) to lobby the Irish government to support a Pandemic Treaty that has equity, transparency and community at its core and not market-driven forces. Drawing on the research findings, I was able to highlight to politicians the exclusion of MICs in licence agreements, the importance of community mobilisation and having a seat at the table, and how untenable TRIPS flexibilities and patent oppositions are in times of a global crisis due to the huge financial, human and political costs associated with each.

Additionally, I was able to use my platform to talk about my research on The Jennifer Zamparelli Show, a morning pop culture show, and as a keynote speaker at an Irish Global Health Network conference. I believe that working within the movement and being an 'insider' provided me with platforms to ethically engage with the research through discussions with politicians on policy recommendations and by disseminating the research outside and inside the usual conference and journal article forums.

8.3.2. Limitations

The study has limitations that should be acknowledged when considering its findings. The primary limitation of this research arises from my 'outsider' status. Despite sharing a similar professional background and an HIV-positive status with some research participants, I am a researcher on the outside looking towards Ukraine's socio-political environment. My cultural, social and political perspectives developed from living as a white gay man living in Dublin, Ireland - a high-income country that benefits greatly from its large pharmaceutical industry - may have affected the research participant's comfort levels in the interviews, as I ask about their access issues from my privileged position. This is particularly true as the interviews occurred during the COVID-19 pandemic, when global inequitable access to medical technologies occurred again, widening the Irish-Ukrainian access experience. To overcome this, in the interview preamble, discussions around global initiatives to fight global inequities were discussed to increase trust. Despite efforts to build trust, as much as one can in online interviews, my outsider status may have affected the willingness of participants to answer certain questions due to distrust, their comfort levels, or because they felt that I would not understand answers that require a large degree of local knowledge.

My inability to establish relationships with treatment activists in Ukraine significantly constrained my capacity to engage potential candidates for this research project. This research

required a high proficiency in English due to the complicated and nuanced subject matter of intellectual property, free trade agreements and international funding mechanism, etc. Had I been in Ukraine, access to various treatment activists could have afforded me the opportunity to better assess research participants' ability to answer the research questions sufficiently. As this was not possible, I relied on the suggestions of the research participants using a snowball sampling method and the recommendations of the EATG. Future research using online interviews should acknowledge this limitation and seek funding to employ translators.

Facets of social movement theory, such as framings of protests and historical cycles of protest, as it applies to the Ukrainian HIV/HCV treatment activism, call for an in-depth knowledge of the Ukrainian culture and language. In an attempt to overcome this, I was awarded a RISE Fellowship, which provided me with the opportunity to complete five to six months of fieldwork in Ukraine. My goal was to build relationships with HIV CSOs and local activists. To gain a deeper understanding of the lived experiences of the HIV/HCV communities and understand the culture of activism better. However, the onset of the COVID-19 pandemic stopped these plans from occurring. This setback left me feeling ill-equipped to research and develop these components of PPT. The language barrier also meant that my access to participants and Ukrainian literature was significantly reduced. My inability to read academic publications written in Ukrainian may have affected my nuanced understanding of HIV activism or the evolution of CSOs. However, I uphold that the research participants recruited in this study are of the highest calibre and were at the forefront of the HIV/HCV access movement, ensuring rich data collection.

When adopting my methodology to online interviews due to the pandemic, I was concerned that the virtual format might reduce my relationship-building potential with the participants, potentially impacting the depth of our conversations. However, I was pleasantly surprised. These interviews proved to be highly effective, yielding detailed and valuable insights. However, in two of the interviews, the internet faltered and disrupted the flow of the interview twice in each one. This impacted my time with the two participants and took the interviews out of their flow. However, with the patience and good grace of the interviewees, we were able to regain lost time and get the interview back on track. After my ninth interview, I felt confident that I had addressed my research question and the objectives to a satisfactory level. Nonetheless, I had intended to follow up with a few participants for clarification on some specific points, such as:

How exactly do voluntary licensing agreements divide generic manufacturers?

What exactly were the troubling provisions in the EU Association Agreement that you mentioned?

However, after Russia invaded Ukraine, my supervisors and I decided that it would be unethical to pursue these lines of inquiry further.

Finally, a common critique of social movement literature highlights its limited generalisability, as most social movement studies focus on specific cases rather than a large number of them (Crist & McCarthy, 1996). Yet, this study does not aim for generalisability. The overall research design, including the personalised and interpretative nature of using reflexive thematic analysis, supports this. However, it is important to highlight for those reviewing this thesis to consider. The active role of the researcher in the research process, especially the analysis, suggests that the codes and themes interpreted by one researcher may not be reproduced by another, underscoring the study's unique context-specific insights rather than broader applicability (Braun & Clarke, 2019; 2022). Despite this, some important implications and learnings arose from this research that can be applied to future research and all stakeholders in the access to medicines movement.

8.4. Implications and Recommendations

8.4.1. Implications for Future Research

Throughout the findings and discussion chapters, I highlighted areas of interest that could be explored further. The following are three proposed avenues for future research that bear relevance and warrant further investigation.

- A study examining the consequences of the Russian invasion on Ukraine's HIV/HCV response:

Emerging academic literature on HIV and A2M in wartime Ukraine focuses on the epidemiology of HIV within the context of internal displacement and migration or critically examines Ukraine's sovereign rights within the TRIPS agreement to ensure access to all medical technologies during a time of crisis. Newspaper and online articles are available and highlight the crucial function of HIV CSOs in maintaining a strong HIV response, and reports

are showing services are beginning to feel the strain. An analytical exploration using a mixed-method approach should be conducted. Firstly, a quantitative analysis should explore the experiences of HIV CSOs in different regions around Ukraine with a specific focus on the role of foreign aid in their HIV response. A qualitative inquiry should interview all key stakeholders, including HIV services users, HIV/HCV CSO activists and those working in international donor agencies to provide a nuanced understanding of what is happening on the ground.

- An inquiry into the impact of pharmaceutical industry funding on HIV CSO activities and its impact on access to medicine activism:

This study revealed that potential conflicts of interest may arise when the pharmaceutical industry funds HIV-related projects. As Ukrainian HIV/HCV CSOs benefit from international and domestic funding, their financial engagements with the pharmaceutical industry are limited. Yet, this is not reflective of many HIV organisations around the world, which are heavily reliant on the pharmaceutical industry to sustain activities. Existing literature highlights the influential role pharmaceutical funding plays in the prescribing bias of healthcare professionals, both consciously and unconsciously. Yet, there is little research examining if a connection exists between pharmaceutical funding and activists' critiques of the industry. This research would add to the body of knowledge by providing important insights into another dimension of the evolution of HIV activism and access to medicines movement.

- A comparative analysis of HIV CSOs benefitting from ITPC funding:

The importance of funding from the International Treatment Preparedness Coalition (ITPC) in supporting intellectual property-related activities within Ukraine has been a key observation in this research. Furthermore, this study also found that the reformist nature of the Euromaidan Revolution greatly improved the access to medicines movement. In 2018, the ITPC expanded its grant from four countries to seventeen over four continents. Therefore, I argue that a comparative study of HIV CSOs which benefit from ITPC funding in MICs across the four continents should be examined, aiming to understand the nature and scale of the global access to medicines movement in different trade blocs, government structures, activism cultures, and the impact of significant national events, such as Euromaidan.

Additionally, it should evaluate the role played by foreign aid and multilateral institutions in the different regions and how they interact with the access to medicines movement.

8.4.2. Recommendations for Treatment Activists

This research highlights the crucial role of treatment activists in leveraging power to challenge the pharmaceutical industry's entrenched interests across trade, political and market spheres. Firstly, strengthening the partnerships between HCV and HIV CSOs was seen as a critical manoeuvre that helped to propel HCV activism more into the political and social mainstream. The mutual exchange of expertise, resources, and collaborative initiatives solidified a united movement to fight for access to Sofosbuvir while also facilitating education and relationship-building with all stakeholders, including politicians, healthcare professionals and the HCV community. Therefore, this research recommends that CSOs, where appropriate, increase partnerships and adopt integrated approaches to increase their influence and effectively navigate social and political challenges.

Data activism was prominent in the HIV/HCV movement. Effective procurement contracts are contingent upon the availability of reliable data. However, the stigma and discrimination associated with HCV hindered PLWHCV from registering nationally or disclosing their status to their doctors. In response, HCV activists educated politicians, healthcare professionals and the community on the importance of signing up to the national register and empowering the HCV community to demand access to treatment. While this approach does not relate directly to intellectual property, it exemplifies strategies that ensure better access to medicines in the context where reliable epidemiology data is not available due to sociopolitical reasons. Additionally, pilot and demonstration studies were a regular part of HIV/HCV advocacy, reforming policy on the procurement of ARVs in the penitentiary system and demonstrating the superior efficacy of DAAs over interferon treatments. Therefore, this research recommends that activists should explore using data more effectively to increase access and accessibility of medicines.

In countries that have signed trade agreements with the United states or Europe that have TRIPS Plus provisions, this research highlights ways in which to work within general trade frameworks. One tactic highlighted in this research is to use data exclusivity to your advantage. Ensure that data exclusivity is only allowed when a pharmaceutical company registers a drug in your country within one year of their initial registration elsewhere. This

will incentivise expedited drug registration and, hopefully, quicker access to medicines. Additionally, restricting applications for supplementary protection certificates to a six-month period after initial drug registration exerts time pressure on the pharmaceutical company to file an application. It also provides CSOs and generic manufacturers with ample time to oppose the SPC application.

Opposing patents in the courts can be timely and costly with an uncertain outcome. Therefore, this research recommends advocating for the introduction of streamlined prepatent opposition procedures in your national patent office if this option does not currently exist in your country. Additionally, enforcing stricter patentability criteria provides CSOs and generic manufacturers with greater scope to oppose patent applications based on the grounds of genuine innovations regarding new drugs or formulations.

When necessary and feasible, transferring procurement responsibilities from the state to international agencies such as UNDP, UNICEF, and the Crown Agents can provide the time for CSOs to install a world-leading, transparent procurement system for future governments. Additionally, when procurement powers were transferred to international agencies, access to medicines for people living with HIV/HCV increased as they procured from many different generic manufacturers and had a bigger procurement pool. This demonstrated to the HIV/HCV CSOs the benefits of good procurement procedures and inspired change.

8.4.3. Recommendations for Policymakers

As signatories to the Sustainable Development Goals, it is incumbent on all governments to ensure equitable access to medicines as specified in SDG 3.8, 'access to safe, effective, quality and affordable essential medicines and vaccines for all' as a central component of universal health coverage (UHC).

This research highlights several approaches governments, especially those in MICs, can employ to honour their commitment. An important step is recognising the significant contribution that civil society organisations play in public health, especially regarding their role in reducing the prices of exorbitantly priced medicines. For CSOs to effect change, they require access to technical and financial resources to leverage power against the pharmaceutical industry. Therefore, it is imperative that governments work closely with

international donors and facilitate more efficient pathways to issue a compulsory licence or utilise other TRIPS flexibilities.

During trade agreement negotiations, governments must firmly reject signing provisions that inhibit the use of TRIPS Flexibilities or remove the ability to oppose patents. Increasing patentability criteria ensures that countries only grant intellectual property rights to medicines that show true novelty or inventiveness and do not incentivise slight formulation tweaks of older medicines. Governments should be supportive of legal protections in their intellectual property law that prioritise public health, recognising the detrimental effects of TRIPS Plus provisions and Supplementary Protection Certificates on access to medicines. In instances where governments feel that they are unable to reduce the prices of medicines proactively, they should either support or not obstruct the efforts of CSOs fighting for greater access to medicines. Finally, policymakers must demand more favourable pricing agreements from the pharmaceutical industry to ensure a tangible impact on the availability of affordable medicines for their populations.

8.4.4. Recommendations for International Donors

Securing funding for access to medicines initiatives in MICs remains a top priority, particularly for countries left out of licensing agreements. A concern that emerged in the research is the reluctance or unwillingness of international donors to fund intellectual property activity, as they preferred to work with more market-friendly approaches such as seeking price negotiations or voluntary licence agreements. However, countries such as Ukraine are continually left out of licence agreements unless they force a pharmaceutical company's hand. Therefore, to ensure an effective HIV response, funders must ensure that they appropriately fund activities related to intellectual property. Finally, where appropriate, this research found that it is advantageous to finance initiatives that integrate and support further collaboration between CSOs working in different but interconnected health areas.

8.4.5. Plans for Dissemination

The robust and cross cutting recommendations of this research for various stakeholders, including treatment activists, policymakers and funders, as well as the novelty of this research within the existing literature necessitates a strong dissemination plan across both CSO and academic channels.

Throughout this research project, I have actively disseminated the study's findings to diverse audiences in Ireland. As highlighted in section 8.3.1., I delivered talks at five Irish universities concerning the ongoing Pandemic Treaty negotiations at the World Health Organisation. During this tour, I presented my key findings, emphasising how a voluntary licensing approach does not ensure health equity and is insufficient for creating a rapid response to future pandemics, particularly in MICs.

I gave a keynote speech at the Irish Global Health Network's conference in 2022 where I discussed my findings and issues relating to access to medicines to Dr. Mike Ryan, Executive Director of the World Health Organisation's Health Emergencies Programme. Furthermore, I presented my research at the Targeting Therapies, Stratifying Public Health: Public, Patient & Activist Perspectives conference in University College Dublin and for the Chartered Physiotherapists and Healthcare Professionals in International Health and Development group. I have also submitted an abstract to the HIV Research for Prevention Conference 2024.

Currently, I am developing two academic papers intended for publication in high impact, peer-reviewed journals. The first paper offers a comprehensive critique of the medicine patent pool and its effectiveness in middle income countries. The second paper examines the application of political process theory in contemporary access to medicines movements. Lastly, to provide a thorough overview of this research, I am seeking opportunities to contribute a chapter to an edited academic book.

In addition, I have developed a policy brief outlining the key findings of this research project and its implications for policy and treatment activism. I am in discussions with EATG to disseminate this policy brief during their next training webinars and at our next in-person meetings. I have also been in discussions with Frontline AIDS, an organisation based in the U.K. who fund HIV CSOs in Ukraine. We are organising a webinar to discuss the research findings and to disseminate the policy brief. Given this organisation works closely with Ukrainian HIV/HCV CSOs, I am hoping to use this opportunity to facilitate further

dissemination opportunities among Ukrainian HIV/HCV CSOs. While this research was not intended to be generalisable, I believe the policy and activism recommendations have significant cross pollination potential to positively influence other movements across different geographical locations. Therefore, I am seeking advice from EATG and Frontline AIDS on what health activism areas would benefit most from these recommendations and the best ways to disseminate the policy brief.

Finally, I have shared my research with the UNITAID communities delegation, of which I am now a member. UNITAID funds key organisations mentioned in this research, such as ITPC and the MPP. The UNITAID board comprises of 12 voting seats, where the communities delegation holds one vote. This is the equivalent voting power as countries such as France, Brazil and the United Kingdom who also sit on the board. During my time with the community's delegation, I have raised issues such as the ongoing need to fund the work of ITPC and have posed critical questions to representatives of the MPP regarding their non-disclosure agreements for DTG with Azerbaijan, Malaysia, Kazakhstan and Belarus. Therefore, this research and its recommendations are being highlighted and fought for at some of the highest levels of influence.

8.5. Reflexivity

As I conclude this thesis, I reflect on the overall qualitative research journey that has informed the production of knowledge regarding the research question of how HIV/HCV treatment activists fought for their right to health in Ukraine. The nature of reflexive thematic analysis underscores the role of the researcher's co-construction of the data alongside the research participants. My interpretive lens, influenced by my worldview, insider and outsider status, and personal experiences, was pivotal to the research outcomes.

Throughout this research, I navigated many emotional and life-changing events. I knew undertaking a doctorate was a significant challenge. However, the COVID-19 pandemic not only affected the research design, my personal life and fears for the health of my loved ones, but it also impacted my work within Access to Medicines, continuously advocating for Ireland to support a TRIPS waiver. The pandemic spotlighting the recurrent issue of intellectual property as a barrier to global equitable access to COVID-19 technologies reenergised my research commitment. I believe that each study that shines a light on the inadequacies of our current trade and global health architecture helps to propel the access to

medicines movement forward. Additionally, from the exploratory research, I knew that the global access to medicines movement had valuable insights to learn from Ukrainian treatment activists.

The process of doing a PhD during a pandemic did take an emotional toll. Over the past five years, as I progressed through this study, I have experienced many positive and negative emotions. The emotions often shifted from joy and excitement for engaging in a research topic that I am passionate about. Feelings of stress and anxiety often balanced these emotions, such as when I had to adapt my PhD to an online interview approach rather than experiencing six months of fieldwork in Ukraine.

In February 2022, Russia invaded Ukraine. On a personal level, the Russian invasion was difficult to comprehend on an emotional and cerebral level. Transcribing interviews and rehearing the aspirations and future endeavours of the research participants while aware of the destruction and disruption caused by the invasion was heart-wrenching. In my personal conversations with Winnie Byanyima, the executive director of UNAIDS, about Ukraine's situation, Winnie told me that some HIV activists were on the Kremlin 'hit list'. Of course, it didn't surprise me that Russia sees HIV activists as a threat. As this research shows, the goals and ambitions of HIV activists have always been the antithesis of Russian governance structures. Of course, I am still continually inspired by the tenacity of HIV/HCV and other health activists who ensured that, despite the war, PLWH/HCV still had access to treatment and also adapted their work to provide basic needs for the Ukrainian people. Yet, Winnie's words left me with enduring fear for the well-being and safety of the research participants. Of course, my own feelings do not compare to those experienced by every Ukrainian. Yet, I knew that I needed to grapple with these emotions.

In my reflexivity journal, I questioned whether these emotions of fear, empathy and loss for the Ukrainian people, and in particular, the research participants, impacted my overall analysis. I became distinctly aware of the research's critiques of the Zelensky government, which contrasts significantly with his wartime image. I questioned whether the findings of his governance style would be considered harmful or distasteful in light of his extraordinary work mobilising the world to Ukraine's call. Furthermore, I wondered if the research participants would no longer wish for me to portray their leader in a negative light. However, the closing of the political window of opportunity is a fundamental finding in this research and highlights the temporal nature of sweeping periods of reform. Therefore, I know it was

vital to incorporate into this research as it presents an overall argument that to fulfil the dreams of civil society, the government must recognise civil society organisations as essential contributors to Ukraine's reconstruction.

8.6. Conclusion

This study has identified the importance of understanding CSOs' essential role in mobilising change and safeguarding the reformative progress made, counteracting the regressive tendencies of unchecked power, and ensuring the implementation and actualisation of passed bills and legislations. By identifying the convergence of the HIV/HCV treatment activist movement and the Euromaidan Revolution, this research extends the literature on access to medicines movement in the EECA region and MICs as a whole by outlining Ukraine's unique experience. This study illustrates the interdisciplinary nature of HIV/HCV treatment activism in post-Soviet states and also for researching the topic. Recognising the limited scholarship on the strategic approaches of HIV/HCV treatment activists, especially in postSoviet settings, this research endeavoured to fill this gap by offering a nuanced understanding of activists' positionality within intricate geopolitical, trade and social systems.

Originally, this research focused on activism that aimed to overcome intellectual property that acted as barriers to HIV/HCV medicines. However, as highlighted throughout this research, their approach was not only multifaceted and expertly handled but was necessitated when the state was in dereliction of its duties. The unrelenting resolve of CSOs illustrated their pivotal role in political processes as both collaborators and antagonists, influencing and shaping policies while also ensuring the safeguarding of achieved reforms against potential regression. Intellectual property and trade frameworks were only part of the story.

The key findings from this research will be used as a stepping stone for further research on HIV/HCV treatment activism in Ukraine and, more broadly, within the EECA region. The research adds to PPT scholarship by highlighting its limitations as a theoretical guide when researching activism that holds global trade frameworks and corporations in contention, and not necessarily the state. Additionally, it adds a new dimension to social movement theory: to research independent social movements that help the state reach its goals when it is immobilised by international diplomacy and fears of trade retaliation. The insights and ingenuity of Ukrainian HIV/HCV CSO activists can be used as a guide for treatment activists

around the world. Additionally, this study provides useful insights for policymakers and donors to understand their role in the access to medicines movement in MICs.

My parting thoughts on my work is that it can help illuminate the constant battle for CSOs to uphold the values and gains of reformative change and how they are a beacon of light, keeping the spirit of transformation ablaze within society and sustaining a vision for a progressively reformed future. I hold a firm conviction that when the Russian invasion ends and Ukraine begins to rebuild, it will be the heart of civil society that will spearhead the resurrection of Euromaidan's call for a renewed Ukraine.

Bibliography

100% Life (2019) *100% Life Annual Report 2019*. Available at: https://network.org.ua/wpcontent/uploads/2020/07/100-life_report_2019_web_eng.pdf (Accessed: 5 October 2022).

100% Life (2023) 'Ukraine: New protective HIV law adopted, but criminal liability for HIV exposure or transmission remains'. Available at: https://www.hivjustice.net/news-from-othersources/ukraine-new-protective-hiv-law-adopted-but-criminal-liability-for-hiv-exposure-ortransmission-remains/ (Accessed: 11 November 2023).

Abbas, M. (2022) 'Twenty Years After Doha: An Analysis of the Use of the TRIPS Agreement's Public Health Flexibilities in India', *SSRN Electronic Journal* [Preprint]. Available at: https://doi.org/10.2139/ssrn.4525016.

Abbott, F.M. (2002) 'The Doha Declaration on the TRIPS Agreement and Public Health: Lighting a Dark Corner at the WTO', *Journal of International Economic Law*, 5(2), pp. 469–505. Available at: https://doi.org/10.1093/jiel/5.2.469.

Abbott, F.M. (2018) 'Let International Competition Negotiations Sleep a While Longer: Focus on Tools and Capacity', *IIC - International Review of Intellectual Property and Competition Law*, 49(3), pp. 259–266. Available at: https://doi.org/10.1007/s40319-0180683-5.

Access to Medicine Foundation (2021) *2021 Access to Medicine Index*. Available at: https://accesstomedicinefoundation.org/resource/2021-access-to-medicine-index (Accessed: 24 April 2023).

ACTED (2017) *Ukraine Country Strategy Paper*. ACTED. Available at: https://www.acted.org/wp-content/uploads/2018/04/acted-ukraine-country-strategy-20172019.pdf (Accessed: 25 July 2019).

Adams, W.C. (2015) 'Conducting Semi-Structured Interviews', in *Handbook of Practical Program Evaluation*. John Wiley & Sons, Ltd, pp. 492–505. Available at: https://doi.org/10.1002/9781119171386.ch19.

Albareda, A. (2018) ‘Connecting Society and Policymakers? Conceptualizing and Measuring the Capacity of Civil Society Organizations to Act as Transmission Belts’, *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations*, 29(6), pp. 1216–1232. Available at: https://doi.org/10.1007/s11266-018-00051-x.

Albareda, A. and Braun, C. (2019) ‘Organizing Transmission Belts: The Effect of Organizational Design on Interest Group Access to EU Policy-making’, *JCMS: Journal of Common Market Studies*, 57(3), pp. 468–485. Available at: https://doi.org/10.1111/jcms.12831.

Alistar, S.S., Owens, D.K. and Brandeau, M.L. (2011) ‘Effectiveness and cost effectiveness of expanding harm reduction and antiretroviral therapy in a mixed HIV epidemic: a modelling analysis for Ukraine’, *PLoS medicine*, 8(3), p. e1000423. Available at: https://doi.org/10.1371/journal.pmed.1000423.

Alliance for Public Health (2016a) ‘Over 5% of Ukrainians are infected with hepatitis C - Alliance for Public Health’. Available at: https://aph.org.ua/en/news/over-5-of-ukrainiansare-infected-with-hepatitis-c/ (Accessed: 10 October 2022).

Alliance for Public Health (2016b) *Situation Report on the status of OST as well as HIV/TB/HCV prevention and treatment programs in Donetsk and Luhansk oblasts. Review of 2015 activities*. Available at: https://aph.org.ua/wpcontent/uploads/2016/07/SitRepJan2016_Alliance_en.pdf (Accessed: 10 October 2020).

Altemeyer, B. (1998) ‘The Other “Authoritarian Personality”’, in *Advances in Experimental Social Psychology*. Elsevier, pp. 47–92. Available at: https://doi.org/10.1016/S0065-2601(08)60382-2.

Altice, F.L. *et al.* (2016) ‘The perfect storm: incarceration and the high-risk environment perpetuating transmission of HIV, hepatitis C virus, and tuberculosis in Eastern Europe and Central Asia’, *Lancet (London, England)*, 388(10050), pp. 1228–1248. Available at: https://doi.org/10.1016/S0140-6736(16)30856-X.

Altman, D. (1999) ‘Globalization, Political Economy, and HIV/AIDS’, *Theory and Society*, 28(4), pp. 559–584.

Altsyvanovych, O.V. and Tsymbalenko, Y.Y. (2018) ‘Theoretical and categorical analysis of the concept of public procurement and corruption risks in their implementation in Ukraine’, *Public administration aspects*, 6(9), pp. 92–103. Available at: https://doi.org/10.15421/151858.

Amin, T. (2007) *Voluntary licensing practices in the pharmaceutical sector: An acceptable solution to improving access to affordable medicines?* IMAK. Available at: https://msfaccess.org/sites/default/files/2020-10/IP_Voluntarylicences_fullbrief_Oct2020_ENG.pdf (Accessed: 21 April 2023).

Amsterdam, A.G. and Bruner, J.S. (2000) *Minding the law*. Cambridge, Mass.: Harvard Univ. Press.

Andrade, P.V. de and Carapinha, L. (2010) ‘Drug decriminalisation in Portugal’, *BMJ*, 341, p. c4554. Available at: https://doi.org/10.1136/bmj.c4554.

Angelis, A. *et al.* (2023) ‘High drug prices are not justified by industry’s spending on research and development’, *BMJ*, p. e071710. Available at: https://doi.org/10.1136/bmj2022-071710.

Antonenko Z, Martsynovska V. (2022) HIV infection in Ukraine: information bulletin (ВІЛінфекція в Україні: інформаційний бюлетень). Kyiv: Public Health Center of the Ministry of Health of Ukraine.

Antoniak, S. *et al.* (2022) ‘Treatment outcomes and costs of a simplified antiretroviral treatment strategy for hepatitis C among Hepatitis C Virus and Human Immunodeficiency Virus co-infected patients in Ukraine’, *JGH Open*, 6(12), pp. 894–903. Available at: https://doi.org/10.1002/jgh3.12839.

Antoun, J., Phillips, F. and Johnson, T. (2011) ‘Post-Soviet Transition: Improving Health Services Delivery and Management’, *Mount Sinai Journal of Medicine: A Journal of Translational and Personalized Medicine*, 78(3), pp. 436–448. Available at: https://doi.org/10.1002/msj.20261.

Apodaca, C. (2017) ‘Foreign Aid as Foreign Policy Tool’, in Apodaca, C., *Oxford Research Encyclopedia of Politics*. Oxford University Press. Available at: https://doi.org/10.1093/acrefore/9780190228637.013.332.

Arévalo, E.E. (2023) ‘Towards a theory of dependent democracy’, *Thesis Eleven*, p.

07255136231202057. Available at: https://doi.org/10.1177/07255136231202057.

Astone, D.P. (2023) 'Scarcity, Property Rights, Irresponsibility: How Intellectual Property Deals with Neglected Tropical Diseases', *Law and Critique*, 34(1), pp. 145–164. Available at: https://doi.org/10.1007/s10978-022-09324-3.

Atkinson, J.D. and Jones, R. (2009) 'Intellectual property and its role in the pharmaceutical industry', *Future Medicinal Chemistry*, 1(9), pp. 1547–1550. Available at: https://doi.org/10.4155/fmc.09.138.

Atlani-Duault, L. (2007) *Humanitarian aid in post-Soviet countries: an anthropological perspective*. London; New York: Routledge (Central Asian studies series, 10).

Attaran, A. (2017) 'How Do Patents And Economic Policies Affect Access To Essential Medicines In Developing Countries?', *Health Affairs* [Preprint]. Available at: https://doi.org/10.1377/hlthaff.23.3.155.

Avila, C. (2021) 'Implementing health financing policies to overhaul the healthcare delivery system in Ukraine', *Journal of Hospital Management and Health Policy*, 5(0). Available at: https://doi.org/10.21037/jhmhp-20-97.

Avorn, J. (2015) 'The $2.6 Billion Pill — Methodologic and Policy Considerations', *New England Journal of Medicine*, 372(20), pp. 1877–1879. Available at: https://doi.org/10.1056/NEJMp1500848.

Ayres, J.M. (1996) 'Political Process and Popular Protest', *The American Journal of Economics and Sociology*, 55(4), pp. 473–488. Available at: https://doi.org/10.1111/j.15367150.1996.tb02646.x.

Bachireddy, C. *et al.* (2014) 'Integration of health services improves multiple healthcare outcomes among HIV-infected people who inject drugs in Ukraine', *Drug and Alcohol Dependence*, 134, pp. 106–114. Available at: https://doi.org/10.1016/j.drugalcdep.2013.09.020.

Bagcchi, S. (2015) 'Campaigners challenge patent applications for hepatitis C drug in five countries', *BMJ*, 350, p. h2938. Available at: https://doi.org/10.1136/bmj.h2938.

Baillie Smith, M. and Jenkins, K. (2017) 'Civil society activists and vulnerability in South

India: the relational politics of life history methods and development research', *Social & Cultural Geography*, 18(7), pp. 951–970. Available at: https://doi.org/10.1080/14649365.2016.1216157.

Baker, B. and Geddes, K. (2017) 'The Incredible Shrinking Victory: Eli Lilly v. Canada, Success, Judicial Reversal, and Continuing Threats from Pharmaceutical ISDS', *Loyola University Chicago Law Journal*, 49(2), p. 479.

Baker, B.K. (2008) 'Ending Drug Registration Apartheid: Taming Data Exclusivity and Patent/Registration Linkage', *American Journal of Law & Medicine*, 34(2–3), pp. 303–344. Available at: https://doi.org/10.1177/009885880803400209.

Baker, B.K. (2018) 'A Sliver of Hope: Analyzing Voluntary Licences to Accelerate Affordable Access to Medicines Symposium: In Honor of Hope Lewis: International Law, Local Justice: Human Rights Transformed', *Northeastern University Law Review*, 10(2). Available at: https://heinonline.org/HOL/P?h=hein.journals/norester10&i=717 (Accessed: 10 November 2023).

Baker, B.K. (2020) 'Access to Medicines Activism: Collaboration, Conflicts, and Complementarities'. Rochester, NY. Available at: https://papers.ssrn.com/abstract=3538270 (Accessed: 10 November 2023).

Balasubramanian, N. and Sivadasan, J. (2011) 'What Happens When Firms Patent? New Evidence from U.s. Economic Census Data', *The Review of Economics and Statistics*, 93(1), pp. 126–146.

Balian, A.G. and Gasparyan, A. (2017) 'What Drives Politicians to Run for Office: Money, Fame or Public Service?', *NISPAcee Journal of Public Administration and Policy*, 10(1), pp. 9–38. Available at: https://doi.org/10.1515/nispa-2017-0001.

Balsis, C. and Porro, J. (2001) *A Decade of Change: Profiles of USAID Assistance to Europe and Eurasia*. USAID Bureau for Europe and Eurasia.

Banks, N., Hulme, D. and Edwards, M. (2015) 'NGOs, states, and Donors Revisited: Still Too Close for Comfort?', *World Development*, 66, pp. 707–718. Available at: https://doi.org/10.1016/j.worlddev.2014.09.028.

Banta (2001) ‘Public Health Triumphs at WTO Conference’, *JAMA*, 286(21), p. 2655. Available at: https://doi.org/10.1001/jama.286.21.2655.

Barnett, T. *et al.* (2000) ‘The HIV/AIDS epidemic in Ukraine: its potential social and economic impact’, *Social Science & Medicine (1982)*, 51(9), pp. 1387–1403. Available at: https://doi.org/10.1016/s0277-9536(00)00104-0.

Barnett, T. and Whiteside, A. (1999) ‘HIV/AIDS and development: Case studies and a conceptual framework’, *The European Journal of Development Research*, 11(2), pp. 200–234. Available at: https://doi.org/10.1080/09578819908426744.

Bart, T.N. (2008) ‘Parallel Trade of Pharmaceuticals: A Review of Legal, Economic, and Political Aspects’, *Value in Health*, 11(5), pp. 996–1005. Available at: https://doi.org/10.1111/j.1524-4733.2008.00339.x.

Bartlett, W., Bož ikov, J. and Rechel, B. (eds) (2012) *Health reforms in south east Europe*. Houndmills, Basingstoke, Hampshire; New York: Palgrave Macmillan (New perspectives on south-east Europe).

Batliwala, S. (2002) ‘Kinsey Dialogue Series #4: Claiming Global Space: Global Grassroots Movements’, *Participatory Research & Practice* [Preprint]. Available at: https://scholarworks.umass.edu/cie_participatoryresearchpractice/7.

Batyrgareieva, V.S., Babenko, A.M. and Kaija, S. (2019) ‘Corruption in medical sphere of Ukraine: current situation and ways of prevention’, *Wiadomosci Lekarskie (Warsaw, Poland: 1960)*, 72(9 cz 2), pp. 1814–1821.

Bayart, J.-F. (1986) ‘Civil Society in Africa’, in *Political Domination in Africa*. Cambridge: Cambridge University Press.

Beall, R. and Kuhn, R. (2012) ‘Trends in Compulsory Licensing of Pharmaceuticals Since the Doha Declaration: A Database Analysis’, *PLOS Medicine*, 9(1), p. e1001154. Available at: https://doi.org/10.1371/journal.pmed.1001154.

Beissinger, M. (2002) *Nationalist Mobilization and the Collapse of the Soviet state*. New York: Cambridge University Press.

Bekker, L.-G. *et al.* (2018) 'Advancing global health and strengthening the HIV response in the era of the Sustainable Development Goals: the International AIDS Society—Lancet Commission', *The Lancet*, 392(10144), pp. 312–358. Available at: https://doi.org/10.1016/S0140-6736(18)31070-5.

Benade, M. *et al.* (2022) 'Impact of direct-acting antiviral treatment of hepatitis C on the quality of life of adults in Ukraine', *BMC Infectious Diseases*, 22(1), p. 650. Available at: https://doi.org/10.1186/s12879-022-07615-9.

Benford, R.D. and Snow, D.A. (2000) 'Framing Processes and Social Movements: An Overview and Assessment', *Annual Review of Sociology*, 26, pp. 611–639.

Bermudez, J. (2017) 'Contemporary challenges on access to medicines: beyond the UNSG High-Level Panel', *Ciencia & Saude Coletiva*, 22(8), pp. 2435–2439. Available at: https://doi.org/10.1590/1413-81232017228.29362016.

Biehl, J. *et al.* (2009) 'Judicialisation of the right to health in Brazil', *The Lancet*, 373(9682), pp. 2182–2184. Available at: https://doi.org/10.1016/S0140-6736(09)61172-7.

Bilan, Y. and Bilan, S. (2011) 'The Formation of Civil Society in Ukraine After the Orange Revolution', *Economics & Sociology*, 4(1), pp. 78-86,126. Available at: https://doi.org/10.14254/2071-789X.2011/4-1/8.

Birn, A.-E. (2014) 'Philanthrocapitalism, past and present: The Rockefeller Foundation, the Gates Foundation, and the setting(s) of the international/global health agenda', *Hypothesis*, 12(1). Available at: https://doi.org/10.5779/hypothesis.v12i1.229.

Birn, A.-E. and Nervi, L. (2019) 'What matters in health (care) universes: delusions, dilutions, and ways towards universal health justice', *Globalization and Health*, 15(Suppl 1), p. 0. Available at: https://doi.org/10.1186/s12992-019-0521-7.

Blaschke, T.F., Lumpkin, M. and Hartman, D. (2019) 'The World Health Organization Prequalification Program and Clinical Pharmacology in 2030', *Clinical Pharmacology and Therapeutics*, 107(1), pp. 68–71. Available at: https://doi.org/10.1002/cpt.1680.

Bloodgood, E. and Tremblay-Boire, J. (2016) 'Does government funding depoliticize non-governmental organizations? Examining evidence from Europe', *European Political Science Review*, 9(3), pp. 401–424. Available at: https://doi.org/10.1017/S1755773915000430.

Bociurkiw, B.R. (1974) ‘Soviet Nationalities Policy and Dissent in the Ukraine’, *The World Today*, 30(5), pp. 214–226.

Bodini, C. *et al.* (2020) ‘Methodological challenges in researching activism in action: civil society engagement towards health for all’, *Critical Public Health*, 30(4), pp. 386–397. Available at: https://doi.org/10.1080/09581596.2019.1650892.

Boily, M.-C. and Shannon, K. (2017) ‘Criminal law, sex work, HIV: need for multi-level research’, *The Lancet HIV*, 4(3), pp. e98–e99. Available at: https://doi.org/10.1016/S23523018(16)30219-3.

Bojko, M.J. *et al.* (2015) ‘'Bureaucracy & Beliefs': Assessing the barriers to accessing opioid substitution therapy by people who inject drugs in Ukraine’, *Drugs: Education, Prevention and Policy*, 22(3), pp. 255–262. Available at: https://doi.org/10.3109/09687637.2015.1016397.

Bond, P. (1999) ‘Globalization, pharmaceutical pricing, and South African health policy: managing confrontation with U.S. firms and politicians’, *International Journal of Health Services: Planning, Administration, Evaluation*, 29(4), pp. 765–792. Available at: https://doi.org/10.2190/4MA6-53E3-LE1X-C1YY.

Bongiovanni, A., Sergeyev, B., and Semigina, T. (2013) *End of Project Performance Evaluation of the Ukraine HIV/AIDS Service Capacity Project (USCP) Final Report*. USAID. Available at: https://pdf.usaid.gov/pdf_docs/PDACW003.pdf (Accessed: 24 November 2021).

Boudreau, V. (1996) ‘Northern Theory, Southern Protest: Opportunity Structure Analysis in Cross-National Perspective’, *Mobilization: An International Quarterly*, 1(2), pp. 175–189. Available at: https://doi.org/10.17813/maiq.1.2.9573307817475237.

Bowen, G.A. (2008) ‘Naturalistic inquiry and the saturation concept: a research note’, *Qualitative Research*, 8(1), pp. 137–152. Available at: https://doi.org/10.1177/1468794107085301.

Bozicevic, I. *et al.* (2009) 'Prevalence of Sexually Transmitted Infections Among Men Who Have Sex with Men in Zagreb, Croatia', *AIDS and Behavior*, 13(2), pp. 303–309. Available at: https://doi.org/10.1007/s10461-008-9436-7.

Braun, V. *et al.* (2022) 'Doing Reflexive Thematic Analysis', in S. Bager-Charleson and A. McBeath (eds) *Supporting Research in Counselling and Psychotherapy : Qualitative, Quantitative, and Mixed Methods Research*. Cham: Springer International Publishing, pp. 19–38. Available at: https://doi.org/10.1007/978-3-031-13942-0_2.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), pp. 77–101. Available at: https://doi.org/10.1191/1478088706qp063oa.

Braun, V. and Clarke, V. (2012) 'Thematic analysis.', in H. Cooper et al. (eds) *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological.* Washington: American Psychological Association, pp. 57–71. Available at: https://doi.org/10.1037/13620-004.

Braun, V. and Clarke, V. (2013) *Successful qualitative research: a practical guide for beginners*. Los Angeles: SAGE.

Braun, V. and Clarke, V. (2019) 'Reflecting on reflexive thematic analysis', *Qualitative Research in Sport, Exercise and Health*, 11(4), pp. 589–597. Available at: https://doi.org/10.1080/2159676X.2019.1628806.

Braun, V. and Clarke, V. (2020) 'Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches', *Counselling and Psychotherapy Research*, 21(1), pp. 37–47. Available at: https://doi.org/10.1002/capr.12360.

Braun, V. and Clarke, V. (2021a) 'One size fits all? What counts as quality practice in (reflexive) thematic analysis?', *Qualitative Research in Psychology*, 18(3), pp. 328–352. Available at: https://doi.org/10.1080/14780887.2020.1769238.

Braun, V. and Clarke, V. (2021b) *Thematic Analysis: A Practical Guide*. SAGE.

Braun, V. and Clarke, V. (2021c) 'To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales', *Qualitative Research in*

Sport, Exercise and Health, 13(2), pp. 201–216. Available at: https://doi.org/10.1080/2159676X.2019.1704846.

Braun, V. and Clarke, V. (2021d) 'To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales', *Qualitative Research in Sport, Exercise and Health*, 13(2), pp. 201–216. Available at: https://doi.org/10.1080/2159676X.2019.1704846.

Brax, H. *et al.* (2017) 'Association between physicians' interaction with pharmaceutical companies and their clinical practices: A systematic review and meta-analysis', *PLOS ONE*. Edited by J.M. Wright, 12(4), p. 0175493. Available at: https://doi.org/10.1371/journal.pone.0175493.

Bregtje, K. *et al.* (2021) *Access to medicines in Europe delays and challenges for patient access: delays and challenges for patient access*. LSE Consulting. Available at: https://doi.org/10.21953/0ZAZ-K994.

Brown, S. and Rosier, M. (2023) 'COVID-19 vaccine apartheid and the failure of global cooperation', *The British Journal of Politics and International Relations*, 25(3), pp. 535–554. Available at: https://doi.org/10.1177/13691481231178248.

Brown, T., Craddock, S. and Ingram, A. (2012) 'Critical Interventions in Global Health: Governmentality, Risk, and Assemblage', *Annals of the Association of American Geographers*, 102(5), pp. 1182–1189.
Brugha, R. *et al.* (2004) 'The Global Fund: managing great expectations', *The Lancet*, 364(9428), pp. 95–100. Available at: https://doi.org/10.1016/S0140-6736(04)16595-1.

Brünker, F. *et al.* (2020) 'The Role of Social Media during Social Movements – Observations from the #metoo Debate on Twitter', in. *Hawaii International Conference on System Sciences*. Available at: https://doi.org/10.24251/HICSS.2020.288.

Bryman, A. (2008) 'Of methods and methodology', *Qualitative Research in Organizations and Management: An International Journal*, 3(2), pp. 159–168. Available at: https://doi.org/10.1108/17465640810900568.

Bureychak, T. (2012) '13. Masculinity in Soviet and Post-Soviet Ukraine: Models and Their Implications', in O. Hankivsky and A. Salnykova (eds) *Gender, Politics and Society in*

Ukraine. University of Toronto Press, pp. 325–361. Available at: https://doi.org/10.3138/9781442685871-017.

Burrone, E., Gotham, D., Gray, A., De Joncheere, K., *et al.* (2019) 'Patent pooling to increase access to essential medicines', *Bulletin of the World Health Organization*, 97(8), pp. 575–577. Available at: https://doi.org/10.2471/BLT.18.229179.

Cairns, G. (2023) *HIV services in Ukraine resilient but starting to feel the strain*, *aidsmap.com*. Available at: https://www.aidsmap.com/news/oct-2023/hiv-services-ukraineresilient-starting-feel-strain (Accessed: 20 April 2023).

Caren, N. (2007) 'Political Process Theory', in G. Ritzer (ed.) *The Blackwell Encyclopedia of Sociology*. 1st edn. Wiley. Available at: https://doi.org/10.1002/9781405165518.wbeosp041.

Carithers, R.L., Sugano, D. and Bayliss, M. (1996) 'Health assessment for chronic HCV infection: Results of quality of life', *Digestive Diseases and Sciences*, 41(S12), pp. 75S-80S. Available at: https://doi.org/10.1007/BF02087879.

Carothers, T. (2002) 'The End of the Transition Paradigm', *Journal of Democracy*, 13(1), pp. 5–21. Available at: https://doi.org/10.1353/jod.2002.0003.

Casale, A.S. *et al.* (2007) ''ProvenCareSM': A Provider-Driven Pay-for-Performance Program for Acute Episodic Cardiac Surgical Care', *Annals of Surgery*, 246(4), p. 613. Available at: https://doi.org/10.1097/SLA.0b013e318155a996.

Cassier, M. (2013) 'Pharmaceutical Patent Law In-the-Making: Opposition and Legal Action by states, Citizens, and Generics Laboratories in Brazil and India', in J.-P. Gaudillière and V. Hess (eds) *Ways of Regulating Drugs in the 19th and 20th Centuries*. London: Palgrave Macmillan UK (Science, Technology and Medicine in Modern History), pp. 287–317. Available at: https://doi.org/10.1057/9781137291523_13.

Castells, M. (2015) *Networks of outrage and hope: social movements in the Internet age*. Second edition [revised]. Cambridge Malden, MA: Polity press.

Chandhoke, N. (2001) 'The 'Civil' and the 'Political' in Civil Society', *Democratization*, 8(2), pp. 1–24. Available at: https://doi.org/10.1080/714000194.

Chapman, A.R. (2016) ‘Assessing the universal health coverage target in the Sustainable Development Goals from a human rights perspective’, *BMC International Health and Human Rights*, 16(1), p. 33. Available at: https://doi.org/10.1186/s12914-016-0106-y.

Charmaz, K. (2006) *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. London: Sage.

Chaves, G.C. *et al.* (2015) ‘Strategies for price reduction of HIV medicines under a monopoly situation in Brazil’, *Revista de Saúde Pública*, 49(0). Available at: https://doi.org/10.1590/S0034-8910.2015049005459.

Chayinska, M., Minescu, A. and McGarty, C. (2017) ‘'The More We Stand For – The More We Fight For': Compatibility and Legitimacy in the Effects of Multiple Social Identities’, *Frontiers in Psychology*, 8. Available at: https://www.frontiersin.org/articles/10.3389/fpsyg.2017.00642 (Accessed: 9 November 2023).

Clark, B.Y. (2013) ‘Multilateral, regional, and national determinants of policy adoption: the case of HIV/AIDS legislative action’, *International Journal of Public Health*, 58(2), pp. 285–293. Available at: https://doi.org/10.1007/s00038-012-0393-6.

Cleary, L. (2016) ‘Half measures and incomplete reforms: the breeding ground for a hybrid civil Society in Ukraine’, *Southeast European and Black Sea Studies*, 16(1), pp. 7–23. Available at: https://doi.org/10.1080/14683857.2016.1148410.

Collier, S.J. (ed.) (2011) *Post-Soviet Social: Neoliberalism, Social Modernity, Biopolitics*. Princeton University Press. Available at: https://doi.org/10.23943/princeton/9780691148304.002.0007.

Colombo, M.G. *et al.* (2019) ‘Consensus on management of hepatitis C virus infection in resource-limited Ukraine and Commonwealth of Independent States regions’, *World Journal of Gastroenterology*, 25(29), pp. 3897–3919. Available at: https://doi.org/10.3748/wjg.v25.i29.3897.

Colvin, C.J. (2014) ‘Evidence and AIDS activism: HIV scale-up and the contemporary politics of knowledge in global public health’, *Global Public Health*, 9(1–2), pp. 57–72. Available at: https://doi.org/10.1080/17441692.2014.881519.

Corporate Europe Observatory (2021) *The Commission's pharma echo chamber*. Available at: https://corporateeurope.org/en/2021/05/commissions-pharma-echo-chamber (Accessed: 8 May 2023).

Correa, C. and Matthews, D. (2011) *The Doha Declartion Ten Years on and Its Impact on Access to Medicines and the Right to Health*. Discussion Paper. United Nations Development Project. Available at: https://qmro.qmul.ac.uk/xmlui/bitstream/handle/123456789/3109/MATTHEWSTheDohaDeclaration2011FINAL.pdf?sequence=2&isAllowed=y (Accessed: 10 October 2019).

Correa, C.M. (2016) 'Pharmaceutical innovation, incremental patenting and compulsory licensing', *South Centre*, 41.

Corsi, K.F. *et al.* (2014) 'Gender differences between predictors of HIV status among PWID in Ukraine', *Drug and Alcohol Dependence*, 138, pp. 103–108. Available at: https://doi.org/10.1016/j.drugalcdep.2014.02.012.

Costain, A.N. (1992) *Inviting women's rebellion: a political process interpretation of the women's movement*. Baltimore London: Johns Hopkins university press.

Cox, K. (2012) 'The Medicines Patent Pool: Promoting Access and Innovation for LifeSaving Medicines through Voluntary licences', *UC Law Science and Technology Journal*, 4(2), p. 291.

Coyle, S.L. and for the Ethics and Human Rights Committee, American College of Physicians–American Society of Internal Medicine* (2002) 'Physician–Industry Relations. Part 1: Individual Physicians', *Annals of Internal Medicine*, 136(5), p. 396. Available at: https://doi.org/10.7326/0003-4819-136-5-200203050-00014.

Crawford, J. (2021) *Does Bill Gates have too much influence in the WHO?*, *SWI swissinfo.ch*. Available at: https://www.swissinfo.ch/eng/politics/does-bill-gates-have-too-much-influencein-the-who-/46570526 (Accessed: 20 May 2023).

Crist, J. and McCarthy, J. (1996) 'If I Had a Hammer': The Changing Methodological Repertoire of Collective Behavior and Social Movements Research. *Mobilization: An International Quarterly* 1, 1 (1), pp. 87–102. doi: https://doi.org/10.17813/maiq.1.1.72370r876m1k4693

Crouch, M. and McKenzie, H. (2006) 'The logic of small samples in interview-based qualitative research', *Social Science Information*, 45(4), pp. 483–499. Available at: https://doi.org/10.1177/0539018406069584.

Csanadi, M. *et al.* (2019) 'Health Technology Assessment Implementation in Ukraine: Current Status and Future Perspectives', *International Journal of Technology Assessment in Health Care*, 35, pp. 1–8. Available at: https://doi.org/10.1017/S0266462319000679.

Cubitt, C. (2013) 'Constructing civil society: an intervention for building peace?', *Peacebuilding*, 1(1), pp. 91–108. Available at: https://doi.org/10.1080/21647259.2013.756274.

Cykert, S. *et al.* (1997) 'Primary Care Physicians and Capitated Reimbursement Experience, Attitudes, and Predictors', *Journal of General Internal Medicine*, 12(3), pp. 192–194. Available at: https://doi.org/10.1046/j.1525-1497.1997.012003192.x.

Daniele, D. and Daniela, M. (2008) 'Impending Flop for Brand Antiretrovirals in the Emerging Markets?', *The Open AIDS Journal*, 2, pp. 68–71. Available at: https://doi.org/10.2174/1874613600802010068.

D'anieri, P. (2007) 'Ethnic Tensions and state Strategies: Understanding the Survival of the Ukrainian state', *Journal of Communist Studies and Transition Politics*, 23(1), pp. 4–29. Available at: https://doi.org/10.1080/13523270701194896.

D'Anieri, P.J. (ed.) (2010) *Orange revolution and aftermath: mobilization, apathy, and the state in Ukraine*. Washington, D.C. : Baltimore: Woodrow Wilson Center Press : Johns Hopkins University Press (Woodrow Wilson Center Press).

Dave, C.V. *et al.* (2017) 'High Generic Drug Prices and Market Competition: A Retrospective Cohort Study', *Annals of Internal Medicine*, 167(3), p. 145. Available at: https://doi.org/10.7326/M16-1432.
Dave, C.V., Hartzema, A. and Kesselheim, A.S. (2017) 'Prices of Generic Drugs Associated with Numbers of Manufacturers', *New England Journal of Medicine*, 377(26), pp. 2597–2598. Available at: https://doi.org/10.1056/NEJMc1711899.

David Kramer *et al.* (2011) *Sounding the Alarm: Protecting Democracy in Ukraine A Freedom House Report on the state of Democracy and Human Rights in Ukraine*. Freedom

House. Available at: https://freedomhouse.org/sites/default/files/inline_images/98.pdf (Accessed: 5 May 2021).

DeBeck, K. *et al.* (2017) 'HIV and the criminalisation of drug use among people who inject drugs: a systematic review', *The Lancet HIV*, 4(8), pp. e357–e374. Available at: https://doi.org/10.1016/S2352-3018(17)30073-5.

Demchenko, I., Sokolova, L. and Bulgia, N. (2020) *The People Living with HIV Stigma Index 2.0: Ukraine*. PEPFAR, p. 103.

Democratic Initiatives Foundation (2018) *The fight against corruption in Ukraine: public opinion*. Available at: https://dif.org.ua/en/article/the-fight-against-corruption-in-ukrainepublic-opinion (Accessed: 10 October 2022).

Des Jarlais, D.C. *et al.* (2012) 'Are females who inject drugs at higher risk for HIV infection than males who inject drugs: An international systematic review of high seroprevalence areas', *Drug and Alcohol Dependence*, 124(1), pp. 95–107. Available at: https://doi.org/10.1016/j.drugalcdep.2011.12.020.

Des Jarlais, D.C. *et al.* (2013) 'Gender disparities in HIV infection among persons who inject drugs in Central Asia: A systematic review and meta-analysis', *Drug and Alcohol Dependence*, 132, pp. S7–S12. Available at: https://doi.org/10.1016/j.drugalcdep.2013.06.028.

Desai, P. (1997) *Going Global: Transition from Plan to Market in the World Economy*. MIT Press.

Deth, J.W. van and Maloney, W.A. (eds) (2012) *New participatory dimensions in civil society: professionalization and individualized collective action*. London: Routledge (Routledge / ECPR Studies in European Political Science, 77).

Devi, S. (2020) 'Ukrainian health authorities adopt hepatitis C project', *The Lancet*, 396(10246), p. 228. Available at: https://doi.org/10.1016/S0140-6736(20)31639-1.

Dieperink, E. *et al.* (2003) 'A Prospective Study of Neuropsychiatric Symptoms Associated With Interferon-α-2b and Ribavirin Therapy for Patients With Chronic Hepatitis C', *Psychosomatics*, 44(2), pp. 104–112. Available at: https://doi.org/10.1176/appi.psy.44.2.104.

Disser, N. (2014) ‘Uprooting homophobia: Grassroots activism in Ukraine & Russia’, *International Politics Reviews*, 2(2), pp. 110–117. Available at: https://doi.org/10.1057/ipr.2014.15.

Dñabrowski, M., Domínguez-Jiménez, M. and Zachmann, G. (2020) *Six years after Ukraine’s Euromaidan: Reforms and challenges ahead*. Research Report 2020/14. Bruegel Policy Contribution. Available at: https://www.econstor.eu/handle/10419/237649 (Accessed: 9 November 2023).

Do, N.T. *et al.* (2023) ‘The quality of antiretroviral medicines: an uncertain problem’, *BMJ Global Health*, 8(3), p. e011423. Available at: https://doi.org/10.1136/bmjgh-2022-011423.

Dodgson, J.E. (2019) ‘Reflexivity in Qualitative Research’, *Journal of Human Lactation*, 35(2), pp. 220–222. Available at: https://doi.org/10.1177/0890334419830990.

Douglass, C.H. *et al.* (2018) ‘Pathways to ensure universal and affordable access to hepatitis C treatment’, *BMC Medicine*, 16(1), p. 175. Available at: https://doi.org/10.1186/s12916018-1162-z.

Drezner, D.W. (2009) ‘The Power and Peril of International Regime Complexity’, *Perspectives on Politics*, 7(1), pp. 65–70.

Drucker, P.F. (1959) *Landmarks of Tomorrow*. Harper and Row, New York.

Drummond, M.F. *et al.* (2008) ‘Key principles for the improved conduct of health technology assessments for resource allocation decisions’, *International Journal of Technology Assessment in Health Care*, 24(3), pp. 244–258; discussion 362-368. Available at: https://doi.org/10.1017/S0266462308080343.

Dublin City University (2022) *Research Data Management Plan: guidance and resources*. Available at: https://www.dcu.ie/sites/default/files/inline-files/rdm_guidance_feb-2022_0.pdf (Accessed: 10 August 2022).

Dubov, A. *et al.* (2018) ‘Stigma and Shame Experiences by MSM Who Take PrEP for HIV Prevention: A Qualitative Study’, *American Journal of Men’s Health*, 12(6), pp. 1843–1854. Available at: https://doi.org/10.1177/1557988318797437.

Duchenko, A., Deshko, T. and Braga, M. (2017) ‘Crisis management by HIV/AIDS nongovernmental organisations in the post-Euromaidan Ukraine led to opening new

horizons', *Drugs and Alcohol Today*, 17(3), pp. 149–156. Available at: https://doi.org/10.1108/DAT-032017-0013.

Dumchev, K. *et al.* (2018) 'Trends in HIV prevalence among people injecting drugs, men having sex with men, and female sex workers in Ukraine', *International Journal of STD & AIDS*, 29(13), pp. 1337–1344. Available at: https://doi.org/10.1177/0956462418784096.

Dupuy, K., Ron, J. and Prakash, A. (2016) 'Hands Off My Regime! Governments' Restrictions on Foreign Aid to Non-Governmental Organizations in Poor and Middle-Income Countries', *World Development*, 84, pp. 299–311. Available at: https://doi.org/10.1016/j.worlddev.2016.02.001.

Duric, P., Simic, D. and Hamelmann, C. (2016) 'Towards domestic financing of national HIV responses lessons learnt from Serbia'. Available at: https://testeresearch.qmu.ac.uk/handle/20.500.12289/4571 (Accessed: 10 November 2023).

Durteste, M. *et al.* (2019) 'Anxiety symptoms and felt stigma among young people living with perinatally or behaviourally-acquired HIV in Ukraine: A cross-sectional survey', *PLOS ONE*, 14(1), p. e0210412. Available at: https://doi.org/10.1371/journal.pone.0210412.

Edwards, G. (2014) *Social movements and protest*. Cambridge New York: Cambridge Univ. Press (Key topics in sociology).

Edwards, M. (1999) 'International Development NGOS: Agents of Foreign Aid or Vehicles for International Cooperation?', *Nonprofit and Voluntary Sector Quarterly*, 28(1), pp. 25–37. Available at: https://doi.org/10.1177/089976499773746410.

Edwards, M. (2009) *Civil society*. 2nd ed. Cambridge: Polity Press.

Edwards, M. (ed.) (2011) *The Oxford handbook of civil society*. 1. issued as paperback. Oxford: Oxford Univ. Press.

EEAS (2014) *EU–Ukraine Association Agreement 'Quick Guide to the Association Agreement'*. Available at: https://www.eeas.europa.eu/sites/default/files/071215_euukraine_association_agreement.pdf (Accessed: 18 May 2023).

Ehrenberg, J. (1999) *Civil society: the critical history of an idea*. New York, NY: New York Univ. Press.

Eilstrup-Sangiovanni, M. (2016) *Global Governance Networks*. Edited by J.N. Victor, A.H. Montgomery, and M. Lubell. Oxford University Press. Available at: https://doi.org/10.1093/oxfordhb/9780190228217.013.30.

Ekiert, Grzegorz *et al.* (eds) (2020) 'state-Mobilized Movements: A Research Agenda.', in *Ruling by Other Means: state-Mobilized Movements*. 1st edn. Cambridge University Press, pp. 1–23. Available at: https://doi.org/10.1017/9781108784146.

El Said, M. (2020) 'Radical Approaches During Unusual Circumstances: Intellectual Property Regulation and the COVID-19 Dilemma', *Development*, 63(2–4), pp. 209–218. Available at: https://doi.org/10.1057/s41301-020-00257-x.

El Said, M. (2022) 'The Impact of 'TRIPS-Plus' Rules on the Use of TRIPS Flexibilities: Dealing with the Implementation Challenges', in C.M. Correa and R.M. Hilty (eds) *Access to Medicines and Vaccines*. Cham: Springer International Publishing, pp. 297–327.

El Said, M. and Kapczynski, A. (2012) *Access to Medicines: The Role of Intellectual property Law and Policy*. Working Paper. UNDP.

El-Faizy, M. (2017) *Tour n' Cure: Egypt launches medical tourism campaign to eradicate hepatitis C*, *France 24*. Available at: https://www.france24.com/en/20171005-egypt-invitesforeigners-visit-egypt-be-treated-hepatitis-c (Accessed: 10 October 2023).

Ellsbury, K.E. and Montano, D.E. (1990) 'Attitudes of Washington state primary care physicians toward capitation-based insurance plans', *The Journal of Family Practice*, 30(1), pp. 89–94.

Emerson, R.M., Fretz, R.I. and Shaw, L.L. (2011) *Writing ethnographic fieldnotes*. 2nd ed. Chicago: The University of Chicago Press (Chicago guides to writing, editing, and publishing).

Encarnación, O.G. (2002) 'On Bowling Leagues and NGOs: A Critique of Civil Society's Revival', *Studies in Comparative International Development*, 36(4), pp. 116–131. Available at: https://doi.org/10.1007/BF02686335.

Epstein, S. (1996) ‘Impure science: AIDS, activism, and the politics of knowledge’, *Medicine and Society*, pp. 1–466.

European Centre for Disease Prevention and Control. (2022) *Continuum of HIV care: monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia: 2021 progress report.* LU: Publications Office. Available at: https://data.europa.eu/doi/10.2900/34829 (Accessed: 7 November 2023).

European Commission (2023) *Proposal for a regulation of the European Parliament and of the Council on compulsory licensing for crisis management and amending Regulation (EC) 816/2006*. Proposal for Regulation. European Commission.

European Monitoring Centre for Drugs and Drug Addiction (2016) *Ukraine country overview*. Available at: https://www.emcdda.europa.eu/countries/ukraine_en (Accessed: 8 November 2023).

European Union (2016) *EU-Ukraine Deep and Comprehensive Free Trade Area*, *Mission of Ukraine to the European Union*. Available at: https://ukraine-eu.mfa.gov.ua/en/2633relations/torgovelno-ekonomichne-spivrobitnictvo-ukrayina-yes/zona-vilnoyi-torgivli-mizhukrayinoyu-ta-yes (Accessed: 21 November 2019).

Farre-Mensa, J., Hegde, D. and Ljungqvist, A. (2019) ‘What Is a Patent Worth? Evidence from the U.S. Patent 'Lottery'’. Rochester, NY. Available at: https://doi.org/10.2139/ssrn.2704028.

Fatton, R. (1995) ‘Africa in the Age of Democratization: The Civic Limitations of Civil Society’, *African Studies Review*, 38(2), p. 67. Available at: https://doi.org/10.2307/525318.

Feder, J.L. (2023) *Opinion | How Russia’s War Against Ukraine Is Advancing LGBTQ Rights*, *POLITICO*. Available at: https://www.politico.com/news/magazine/2023/03/07/russias-war-ukraine-advancing-lgbtqrights-00085841 (Accessed: 12 May 2023).

Feelemyer, J.P. *et al.* (2014) ‘Changes in Quality of Life (WHOQOL-BREF) and Addiction Severity Index (ASI) among participants in Opioid Substitution Treatment (OST) in Low and Middle Income Countries: An International Systematic Review’, *Drug and alcohol dependence*, 134, p. 10.1016/j.drugalcdep.2013.10.011. Available at: https://doi.org/10.1016/j.drugalcdep.2013.10.011.

Fink, C., Hall, B.H. and Helmers, C. (2018) ‘Intellectual Property Use in Middle Income Countries: The Case of Chile’. Rochester, NY. Available at: https://papers.ssrn.com/abstract=3131058 (Accessed: 13 November 2023).

Fink, C. and Raffo, J. (2019) ‘What Role for Intellectual Property in Industrial Development?’, in C. Correa and X. Seuba (eds) *Intellectual Property and Development: Understanding the Interfaces: Liber amicorum Pedro Roffe*. Singapore: Springer, pp. 119–136. Available at: https://doi.org/10.1007/978-981-13-2856-5_7.

Fioramonti, L. and Heinrich, V.F. (2007) ‘How Civil Society Influences Policy: A Comparative Analysis of the CIVICUS Civil Society Index in Post-Communist Europe’. Rochester, NY. Available at: https://doi.org/10.2139/ssrn.2100418.

Foley, M. (2006) ‘The Orange Revolution Loses Its Zest’, *Index on Censorship*, 35(1), pp. 11–14. Available at: https://doi.org/10.1080/03064220600577119.

Forman, L. (2016) ‘The Inadequate Global Policy Response to Trade-Related Intellectual Property Rights: Impact on Access to Medicines in Low- and Middle-Income Countries Symposium: Clinical Trials and Access to Essential Medicines in African Countries’, *Maryland Journal of International Law*, 31, pp. 8–20.

Francis, D. (2017) ‘Meet Ulana Suprun: Ukraine’s Top Doctor Takes on Tax Chief and Corrupt System’, *Atlantic Council*, 17 April. Available at: https://www.atlanticcouncil.org/blogs/ukrainealert/meet-ulana-suprun-ukraine-s-top-doctortakes-on-tax-chief-and-corrupt-system/ (Accessed: 8 November 2023).

Frank, D.J., Hironaka, A. and Schoter, E. (2000) ‘The Nation-state and the Natural Environment over the Twentieth Century’, *American Sociological Review*, 65(1), pp. 96–116. Available at: https://doi.org/10.1177/000312240006500106.

Frank, R.G., Mcguire, T.G. and Nason, I. (2021) ‘The Evolution of Supply and Demand in Markets for Generic Drugs’, *The Milbank Quarterly*, 99(3), pp. 828–852. Available at: https://doi.org/10.1111/1468-0009.12517.

Friedland, R. and Alford, R. (1991) ‘Bringing Society Back In: Symbols, Practices, and Institutional Contradictions’, in W. Powell and P.J. DiMaggio (eds) *The New Institutionalism in Organizational Analysis*. Chicago: University of Chicago Press, pp. 232–267.

Friedman, S.R., Smyrnov, P. and Vasylyeva, T.I. (2023) 'Will the Russian war in Ukraine unleash larger epidemics of HIV, TB and associated conditions and diseases in Ukraine?', *Harm Reduction Journal*, 20(1), p. 119. Available at: https://doi.org/10.1186/s12954-02300855-1.

FrontlineAIDS (2020) *Ukraine: HIV Prevention Shadow Report*. Available at: https://hivpreventioncoalition.unaids.org/wp-content/uploads/2022/02/FrontlineAIDS_Ukraine_FINAL.pdf (Accessed: 10 May 2022).

FrontlineAIDS, Make Medicines Affordable and ITPC Global (2019) *The Problem With Patents: Access to Affordable HIV Treatment in Middle Income Countries*. FrontlineAIDS. Available at: https://frontlineaids.org/wp-content/uploads/2020/01/The-problem-withpatents_pages_web2.pdf (Accessed: 10 October 2020).

Corrigall-Brown, C. (2016) 'Funding for Social Movements', Sociology Compass, 10 (4), pp. 330-339. Available at: https://doi-org.dcu.idm.oclc.org/10.1111/soc4.12362

Fursa, O. *et al.* (2023) 'Cross-sectional HIV and HCV cascades of care across the regions of Ukraine between 2019 and 2020: findings from the CARE cohort', *Journal of the International AIDS Society*, 26(9), p. e26166. Available at: https://doi.org/10.1002/jia2.26166.

Fusch, P. and Ness, L. (2015) 'Are We There Yet? Data Saturation in Qualitative Research', *The Qualitative Report* [Preprint]. Available at: https://doi.org/10.46743/21603715/2015.2281.

Gagnon, M.-A. and Lexchin, J. (2008) 'The Cost of Pushing Pills: A New Estimate of Pharmaceutical Promotion Expenditures in the United states', *PLOS Medicine*, 5(1), p. e1. Available at: https://doi.org/10.1371/journal.pmed.0050001.

Galvão, J. (2005) 'Brazil and access to HIV/AIDS drugs: a question of human rights and public health', *American Journal of Public Health*, 95(7), pp. 1110–1116. Available at: https://doi.org/10.2105/AJPH.2004.044313.

Gamson, J. (1995) 'Must Identity Movements Self-Destruct? A Queer Dilemma', *Social Problems*, 42(3), pp. 390–407. Available at: https://doi.org/10.2307/3096854.

Gamson, W. (1995) ‘Constructing social protest’, in *Social Movements and Culture*. NEDNew edition. University of Minnesota Press. Available at: https://www.jstor.org/stable/10.5749/j.ctttt0p8 (Accessed: 14 November 2023).

Gamson, W.A. and Meyer, D.S. (1996) ‘Framing political opportunity’, in D. McAdam, J.D. McCarthy, and M.N. Zald (eds) *Comparative Perspectives on Social Movements*. 1st edn. Cambridge University Press, pp. 275–290. Available at: https://doi.org/10.1017/CBO9780511803987.014.

Ganz, M. (2001) ‘The Power of Story in Social Movements’. *In the Proceedings of the Annual Meeting of the American Sociological Association*, Anaheim, Carlifornia.

Garmaise, D. (no date) *Ukraine starts transition away from Global Fund support without a detailed transition plan*. 330. Aidspan. Available at: https://aidspan.org/ukraine-startstransition-away-from-global-fund-support-without-a-detailed-transition-plan-oig-says/ (Accessed: 25 October 2020).

Gatskova, K. and Gatskov, M. (2015) ‘Third Sector in Ukraine: Civic Engagement Before and After the 'Euromaidan'’, *Voluntas* [Preprint]. Available at: https://doi.org/10.1007/s11266-015-9626-7.

George, J., Sheshadri, R. and Grover, A. (no date) ‘Intellectual Property and Access to Medicines: Developments and Civil Society Initiatives in India’, in FORD and ABIA (eds) *Civil Society Resistance in the Global South*. ABIA/FORD Foundation, pp. 110–127.

Gessen, K. (2014) ‘Why not kill them all?’, *London Review of Books*, 10 September. Available at: https://www.lrb.co.uk/the-paper/v36/n17/keith-gessen/why-not-kill-them-all (Accessed: 9 November 2023).

Ghosh, M. (2014) *Civil Society in Ukraine: In Search of Sustainability*. Berlin: FriedrichEbert-Stiftung.

Gilpin, R. and Gilpin, J.M. (1987) *The Political Economy of International Relations*. Princeton University Press. Available at: https://www.jstor.org/stable/j.ctt19wcct3 (Accessed: 10 November 2023).

Glasberg, D.S. and Shannon, D. (2011) *Political sociology: oppression, resistance, and the state*. Los Angeles, Calis: Sage/Pine Forge.

Gleeson, D. *et al.* (2019) 'Analyzing the impact of trade and investment agreements on pharmaceutical policy: provisions, pathways and potential impacts', *Globalization and Health*, 15(S1), p. 78. Available at: https://doi.org/10.1186/s12992-019-0518-2.

Godin, B. (2010) 'The Knowledge Economy: Fritz Machlup's Construction of a Synthetic Concept', in R. Viale and H. Etzkowitz (eds) *The Capitalization of Knowledge*. Edward Elgar Publishing. Available at: https://doi.org/10.4337/9781849807180.00019.

Goldstone, J.A. (1980) 'The Weakness of Organization: A New Look at Gamson's The Strategy of Social Protest', *American Journal of Sociology*, 85(5), pp. 1017–1042.

Goldstone, J.A. (2004) 'More social movements or fewer? Beyond political opportunity structures to relational fields', *Theory and Society*, 33(3/4), pp. 333–365. Available at: https://doi.org/10.1023/B:RYSO.0000038611.01350.30.

Golovanevskaya, M., Vlasenko, L. and Saucier, R. (2012) 'In Control?: Ukrainian Opiate Substitution Treatment Patients Strive for a Voice in Their Treatment', *Substance Use & Misuse*, 47(5), pp. 511–521. Available at: https://doi.org/10.3109/10826084.2012.644117.

Goodwin, J. and Jasper, J.M. (1999) 'Caught in a Winding, Snarling Vine: The Structural Bias of Political Process Theory', *Sociological Forum*, 14(1), pp. 27–54. Available at: https://doi.org/10.1023/A:1021684610881.

Gore, C. *et al.* (2023) 'Negotiating public-health intellectual property licensing agreements to increase access to health technologies: an insider's story', *BMJ Global Health*, 8(9), p. e012964. Available at: https://doi.org/10.1136/bmjgh-2023-012964.

Gossop, M. *et al.* (2003) 'The National Treatment Outcome Research Study (NTORS): 4-5 year follow-up results', *Addiction (Abingdon, England)*, 98(3), pp. 291–303. Available at: https://doi.org/10.1046/j.1360-0443.2003.00296.x.

Gould, R.V. (1991) 'Multiple Networks and Mobilization in the Paris Commune, 1871', *American Sociological Review*, 56(6), pp. 716–729. Available at: https://doi.org/10.2307/2096251.

Govindasamy, D., Ford, N. and Kranzer, K. (2012) 'Risk factors, barriers and facilitators for linkage to antiretroviral therapy care: a systematic review', *AIDS*, 26(16), p. 2059. Available at: https://doi.org/10.1097/QAD.0b013e3283578b9b.

Grant, T.D. (2015) 'Annexation of Crimea', *American Journal of International Law*, 109(1), pp. 68–95. Available at: https://doi.org/10.5305/amerjintelaw.109.1.0068.

Grebe, E. (2011) 'The Treatment Action Campaign's Struggle for AIDS Treatment in South Africa: Coalition-building Through Networks', *Journal of Southern African Studies*, 37(4), pp. 849–868.

Grömping, M. and Halpin, D.R. (2019) 'Does group engagement with members constitute a "beneficial inefficiency"?', *Governance*, 32(3), pp. 511–529. Available at: https://doi.org/10.1111/gove.12388.

Guest, G., Bunce, A. and Johnson, L. (2006) 'How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability', *Field Methods*, 18(1), pp. 59–82. Available at: https://doi.org/10.1177/1525822X05279903.

Gurgula, O. (2023) 'Invoking Article 73 TRIPS in good faith: no recourse to 'security exceptions' for Russia's violation of TRIPS', *Journal Of Intellectual Property Law and Practice*, 18(6), pp. 418–431. Available at: https://doi.org/10.1093/jiplp/jpad032.

Gurgula, O. and Hull, J. (2021) 'Compulsory licensing of trade secrets: ensuring access to COVID-19 vaccines via involuntary technology transfer', *Journal of Intellectual Property Law & Practice*, 16(11), pp. 1242–1261. Available at: https://doi.org/10.1093/jiplp/jpab129.

Gvozdetska O. (2023) *The impact of war in Ukraine on the sustainability of HIV care and prevention services.* 19th European AIDS Conference, Warsaw, plenary presentation, parallel session PS7.

Haakonsson, S.J. and Richey, L.A. (2007) 'TRIPs and Public Health: The Doha Declaration and Africa', *Development Policy Review*, 25(1), pp. 71–90. Available at: https://doi.org/10.1111/j.1467-7679.2007.00360.x.

Hale, T., Held, D. and Young, K. (2013) 'Gridlock: From Self-reinforcing Interdependence to Second-order Cooperation Problems', *Global Policy*, 4(3), pp. 223–235. Available at: https://doi.org/10.1111/1758-5899.12068.

Halliburton, M. (2009) ‘Drug resistance, patent resistance: Indian pharmaceuticals and the impact of a new patent regime’, *Global Public Health*, 4(6), pp. 515–527. Available at: https://doi.org/10.1080/17441690902796449.

Halpin, D.R. (2006) ‘The Participatory and Democratic Potential and Practice of INnterest Groups: Between Solidarity and Representation’, *Public Administration*, 84(4), pp. 919–940. Available at: https://doi.org/10.1111/j.1467-9299.2006.00618.x.

Hanefeld, J. (2014) ‘The Global Fund to Fight AIDS, Tuberculosis and Malaria: 10 years on’, *Clinical Medicine*, 14(1), pp. 54–57. Available at: https://doi.org/10.7861/clinmedicine.14-1-54.

Harmer, A. *et al.* (2013) ‘'BRICS without straw'? A systematic literature review of newly emerging economies’ influence in global health’, *Globalization and Health*, 9(1), p. 15. Available at: https://doi.org/10.1186/1744-8603-9-15.

Harwood, R.C. and Creighton, J.A. (2009). *The organization-first approach: How programs crowd out community*. Dayton, OH: The Kettering Foundation.

Hassan, M.R.A. and Chan, H.-K. (2019) ‘Comment on: 'Projections of the Healthcare Costs and Disease Burden due to Hepatitis C Infection Under Different Treatment Policies in Malaysia, 2018–2040'’, *Applied Health Economics and Health Policy*, 18(1), pp. 139–140. Available at: https://doi.org/10.1007/s40258-019-00543-x.

Hayes, R. (2022) *Community organisations have formed the backbone of the HIV response in Ukraine*, *aidsmap.com*. Available at: https://www.aidsmap.com/news/aug-2022/communityorganisations-have-formed-backbone-hiv-response-ukraine (Accessed: 20 April 2023).

Headey, D. (2008) ‘Geopolitics and the effect of foreign aid on economic growth: 1970–2001’, *Journal of International Development*, 20(2), pp. 161–180. Available at: https://doi.org/10.1002/jid.1395.

Heaney, M.T. (2017) ‘Methodological Practices in Social Movement Research’, *Contemporary Sociology: A Journal of Reviews*, 46(1), pp. 57–59. Available at: https://doi.org/10.1177/0094306116681813q.

Heinrich, A. (2022) 'The Emergence of the Socialist Healthcare Model After the First World War', in F. Nullmeier, D. González De Reufels, and H. Obinger (eds) *International Impacts on Social Policy*. Cham: Springer International Publishing (Global Dynamics of Social Policy), pp. 35–46. Available at: https://doi.org/10.1007/978-3-030-86645-7_4.

Helfer, L. (2015) 'Pharmaceutical Patents and the Human Right to Health: The Contested Evolution of the Transnational Legal Order on Access to Medicines', in T.C. Halliday and G.C. Shaffer (eds) *Transnational Legal Orders*. London: Cambridge University Press, pp. 311–339.

Hellman, J.S. (1998) 'Winners Take All: The Politics of Partial Reform in Postcommunist Transitions', *World Politics*, 50(2), pp. 203–234. Available at: https://doi.org/10.1017/S0043887100008091.

Hellman, J.S., Jones, G. and Kaufmann, D. (2003) 'Seize the state, seize the day: state capture and influence in transition economies', *Journal of Comparative Economics*, 31(4), pp. 751–773. Available at: https://doi.org/10.1016/j.jce.2003.09.006.

Heylen, F., Willems, E. and Beyers, J. (2020) 'Do Professionals Take Over? Professionalisation and Membership Influence in Civil Society Organisations', *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations*, 31(6), pp. 1226–1238. Available at: https://doi.org/10.1007/s11266-020-00214-9.

Heywood, M. (2009) 'South Africa's Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health', *Journal of Human Rights Practice*, 1(1), pp. 14–36. Available at: https://doi.org/10.1093/jhuman/hun006.

Higgs, J., Byrne-Armstrong, H. and Horsfall, D. (eds) (2001) *Critical moments in qualitative research*. Oxford ; Boston: Butterworth-Heinemann.

Hoen, E.F.M. 't *et al.* (2011) 'Driving a decade of change: HIV/AIDS, patents and access to medicines for all', *Journal of the International AIDS Society*, 14(1), pp. 15–15. Available at: https://doi.org/10.1186/1758-2652-14-15.

Hoen, E.F.M.t' *et al.* (2014) 'A quiet revolution in global public health: The World Health Organization's Prequalification of Medicines Programme', *Journal of Public Health Policy*, 35(2), pp. 137–161. Available at: https://doi.org/10.1057/jphp.2013.53.

Hoen, E.F.M. 't (2023) 'The European Commission's compulsory licensing proposals are sensible but do not go far enough | Medicines Law & Policy'. Available at:

https://medicineslawandpolicy.org/2023/08/the-european-commissions-compulsorylicensing-proposals-are-sensible-but-do-not-go-far-enough/ (Accessed: 13 October 2023).

Hoen, E.F.M. t'*et al.* (2018) 'Medicine procurement and the use of flexibilities in the Agreement on Trade-Related Aspects of Intellectual Property Rights, 2001-2016', *Bulletin of the World Health Organization*, 96(3), pp. 185–193. Available at: https://doi.org/10.2471/BLT.17.199364.

Hoen, E.F.M. t' (2016) *Private Patents and Public Health: Changing Intellectual Property Rules for Access to Medicines*. AMB.

Hoen, E.F.M.t', Boulet, P. and Baker, B.K. (2017) 'Data exclusivity exceptions and compulsory licensing to promote generic medicines in the European Union: A proposal for greater coherence in European pharmaceutical legislation', *Journal of Pharmaceutical Policy and Practice*, 10(1), p. 19. Available at: https://doi.org/10.1186/s40545-017-0107-9.

Hoen, E.F.M. t'., Kujinga, T. and Boulet, P. (2018) 'Patent challenges in the procurement and supply of generic new essential medicines and lessons from HIV in the southern African development community (SADC) region', *Journal of Pharmaceutical Policy and Practice*, 11, p. 31. Available at: https://doi.org/10.1186/s40545-018-0157-7.

Holland, L. *et al.* (2021) 'The patient's medication access journey: a conceptual framework focused beyond adherence', *Journal of Managed Care & Specialty Pharmacy*, 27(12), pp. 1627–1635. Available at: https://doi.org/10.18553/jmcp.2021.27.12.1627.

Holt, E. (2014) 'Fears over future of opioid substitution therapy in Crimea', *The Lancet*, 383(9923), p. 1113. Available at: https://doi.org/10.1016/S0140-6736(14)60234-8.
Holt, E. (2015) 'Health care collapsing amid fighting in east Ukraine', *The Lancet*, 385(9967), p. 494. Available at: https://doi.org/10.1016/S0140-6736(15)60186-6.

Holt, E. (2018) 'Conflict in Ukraine and a ticking bomb of HIV', *The Lancet HIV*, 5(6), pp. e273–e274. Available at: https://doi.org/10.1016/S2352-3018(18)30106-1.

Hopwood, M. and Treloar, C. (2005) 'The Experience of Interferon-Based Treatments for Hepatitis C Infection', *Qualitative Health Research*, 15(5), pp. 635–646. Available at: https://doi.org/10.1177/1049732304273932.

Howard, M. M. (2002) 'The Weakness of Postcommunist Civil Society', *Journal of Democracy*, 13(1), pp. 157–169. Available at: https://doi.org/10.1353/jod.2002.0008.

Howard, M. M. (2003) *The Weakness of Civil Society in Post-Communist Europe*. Cambridge University Press.

HPSC (2023) *HIV in Ireland: Latest trends to end 2022*. Health Protection Surveillance Centre. Available at: https://www.hpsc.ie/az/hivandaids/hivdataandreports/2022reports/HIV_trends_to%20end%202022_final.pdf (Accessed: 8 October 2023).

Hrycak, A. (2011) 'Contradictory Outcomes of US Aid to Women's NGOs (Kateryna Pishchikova)', *Anthropology of East Europe Review*, 29(2), pp. 260–261.

Hrytsak, Y. (2004) 'On Sails and Gales, and Ships Sailing in Various Directions: Post-Soviet Ukraine', *Ab Imperio*, 2004(1), pp. 229–254.

Hu, Y. *et al.* (2020) 'Supplementary protection certificates and their impact on access to medicines in Europe: case studies of sofosbuvir, trastuzumab and imatinib', *Journal of Pharmaceutical Policy and Practice*, 13(1), p. 1. Available at: https://doi.org/10.1186/s40545-019-0198-6.

Human Rights Watch (2006) *World Report 2006: Ukraine Events of 2005*. Available at: https://www.hrw.org/world-report/2006/country-chapters/ukraine (Accessed: 10 October 2019).

Hurley, R. (2015) 'At least 80 people have died in Crimea since Russian law banned opioid substitutes, says UN special envoy', *BMJ*, 350, p. h390. Available at: https://doi.org/10.1136/bmj.h390.

Hwang, H. and Powell, W.W. (2009) 'The Rationalization of Charity: The Influences of Professionalism in the Nonprofit Sector', *Administrative Science Quarterly*, 54(2), pp. 268–298. Available at: https://doi.org/10.2189/asqu.2009.54.2.268.

Hwang, H. and Kim, K. (2015) ‘Social media as a tool for social movements: the effect of social media use and social capital on intention to participate in social movements’, *International Journal of Consumer Studies*, 39(5), pp. 478–488. Available at: https://doi.org/10.1111/ijcs.12221.

Hyden, G. (1997) ‘Civil society, social capital, and development: Dissection of a complex discourse’, *Studies in Comparative International Development*, 32(1), pp. 3–30. Available at: https://doi.org/10.1007/BF02696304.

Hydén, G., Court, J. and Mease, K. (2004) *Making sense of governance: empirical evidence from sixteen developing countries*. Boulder (Colo.): Lynne Rienner publ.

Iakunchykova, O.P. and Burlaka, V. (2017) ‘Correlates of HIV and Inconsistent Condom Use Among Female Sex Workers in Ukraine’, *AIDS and behavior*, 21(8), pp. 2306–2315. Available at: https://doi.org/10.1007/s10461-016-1495-6.

Ibrahim, S. and Hulme, D. (2010) ‘Has Civil Society Helped the Poor? A Review of the Roles and Contributions of Civil Society to Poverty Reduction’. Rochester, NY. Available at: https://papers.ssrn.com/abstract=1590909 (Accessed: 13 November 2023).

Inglehart, R. (1990) *Culture Shift in Advanced Industrial Society*. Princeton University Press. Available at: https://doi.org/10.2307/j.ctv346rbz.

Islam, Md.D. *et al.* (2019) ‘Impacts of intellectual property provisions in trade treaties on access to medicine in low and middle income countries: a systematic review’, *Globalization and Health*, 15(1), p. 88. Available at: https://doi.org/10.1186/s12992-019-0528-0.

ITPC Global (2015) *Activists in Ukraine hold critical roundtable on patent barriers on medicines*, *ITPC Global*. Available at: https://itpcglobal.org/2015/06/03/activists-in-ukrainehold-critical-roundtable-on-patent-barriers-on-medicines/ (Accessed: 18 October 2020).

ITPC global (2020) *Removing IP Barriers in Middle-Income Countries*, *ITPC Global*. Available at: https://itpcglobal.org/property/intellectual-property-middle-income-countries/ (Accessed: 10 October 2020).

ITPC (2024) ‘Make Medicines Affordable’, *ITPC Global*. Available at: https://itpcglobal.org/our-work/make-medicines-affordable/ (Accessed: 10 June 2024).

Jalles d'Orey, M.A. & Prizzon, A., 2019. *Exit from aid: An analysis of donor experiences*. ODI Report. London: Overseas Development Institute (ODI).

Janssen, D.-J. and Scheepers, P. (2019) ‘How Religiosity Shapes Rejection of Homosexuality Across the Globe’, *Journal of Homosexuality*, 66(14), pp. 1974–2001. Available at: https://doi.org/10.1080/00918369.2018.1522809.

Jami, W. A. and Peoples, C. (2022) ‘Political opportunity, democracy, and 40 years of protest, 1981–2020: A cross-national analysis’, *Social Science Quarterly*, 103(6), pp. 1440– 1458. Available at: https://doi.org/10.1111/ssqu.13202.

Jensen, J. F. (1998). ‘Interactivity: Tracking a New Concept in Media and Communication Studies’, *Nordicom Review,* 19, 185-204.

Johnston, H. and Noakes, J.A. (eds) (2005) *Frames of protest: social movements and the framing perspective*. Lanham: Rowman & Littlefield Publishers, Inc.

Josselson, R. and Lieblich, A. (2003) ‘A framework for narrative research proposals in psychology’, in *Up close and personal: The teaching and learning of narrative research*. Washington, DC, US: American Psychological Association (The narrative study of lives), pp. 259–274. Available at: https://doi.org/10.1037/10486-014.

Judice, N., Zaglada, O. and Mbuya-Brown, R. (2011) ‘HIV Policy Assessment: Ukraine’, *Futures Group, Health Policy Project* [Preprint]. Available at: https://www.healthpolicyproject.com/pubs/7_Ukraine_Policy_Assessment_FINAL_7_18_11_acc.pdf (Accessed: 22 October 2020).

Juneja, S. *et al.* (2017) ‘Projected savings through public health voluntary licences of HIV drugs negotiated by the Medicines Patent Pool (MPP)’, *PLOS ONE*. Edited by E.J. Beck, 12(5), p. e0177770. Available at: https://doi.org/10.1371/journal.pone.0177770.

Jung, Y. and Kwon, S. (2015) ‘The Effects of Intellectual Property Rights on Access to Medicines and Catastrophic Expenditure’, *International Journal of Health Services*, 45(3), pp. 507–529. Available at: https://doi.org/10.1177/0020731415584560.

Jürgens, R. *et al.* (2017) 'Human Rights and the Global Fund to Fight AIDS, Tuberculosis and Malaria', *Health and Human Rights*, 19(2), pp. 183–195.

Kapczynski, A. (2009) 'Commentary: Innovation Policy for a New Era', *The Journal of Law, Medicine & Ethics*, 37(2), pp. 264–268. Available at: https://doi.org/10.1111/j.1748720X.2009.00370.x.

Kapczynski, A. (2019) 'The Right to Medicines in an Age of Neoliberalism', *Humanity Journal* [Preprint]. Available at: https://humanityjournal.org/issue10-1/the-right-tomedicines-in-an-age-of-neoliberalism/ (Accessed:05 October 2023).

Kapilashrami, A. and O'Brien, O. (2012) 'The Global Fund and the re-configuration and reemergence of 'civil society': Widening or closing the democratic deficit?', *Global Public Health*, 7(5), pp. 437–451. Available at: https://doi.org/10.1080/17441692.2011.649043.

Kara, H. (2015) *Creative Research Methods in the Social Sciences: A practical guide*. Policy Press. Available at: https://doi.org/10.51952/9781447320258.

Kara, H. (2018) *Research Ethics in the Real World: Euro-Western and Indigenous perspectives*. Policy Press. Available at: https://doi.org/10.51952/9781447344780.

Kassirer, J.P. (2005) *On the Take: How Medicine's Complicity with Big Business Can Endanger Your Health*. Oxford University Press. Available at: https://doi.org/10.1093/acprof:oso/9780195300048.001.0001.

Katz, I.T. *et al.* (2013) 'Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis', *Journal of the International AIDS Society*, 16(3S2), p. 18640. Available at: https://doi.org/10.7448/IAS.16.3.18640.

Kaufman, J. (2019) 'Civil Society Involvement in National HIV/AIDS Programs', in Z. Wu et al. (eds) *HIV/AIDS in China*. Singapore: Springer Singapore, pp. 427–440. Available at: https://doi.org/10.1007/978-981-13-8518-6_22.

Kazatchkine, M. (2014) 'Russia's ban on methadone for drug users in Crimea will worsen the HIV/AIDS epidemic and risk public health', *BMJ*, 348(1), pp. 3118–3118. Available at: https://doi.org/10.1136/bmj.g3118.

Keck, M.E. and Sikkink, K. (1998) *Activists Beyond Borders: Advocacy Networks in International Politics*. Cornell University Press.

Kenarov, D. (no date) *Crimea: With or Without Drugs*, *Pulitzer Center*. Available at: https://pulitzercenter.org/stories/crimea-or-without-drugs (Accessed: 10 October 2020).

Kennedy, N. (2015) 'Merck's HIV patent agreement ignites criticism', *SciDev.Net*. Available at: https://www.scidev.net/global/news/merck-hiv-patent-agreement-monopoly-criticism/ (Accessed: 10 May 2023).

Keohane, R.O. and Nye, Jr., J.S. (eds) (1972) *Transnational Relations and World Politics:* Harvard University Press. Available at: https://doi.org/10.4159/harvard.9780674593152.

Khagram, S., Riker, J. and Sikkink, K. (eds) (2002) *Restructuring World Politics: Transnational Social Movements, Networks, and Norms*. Minneapolis: University of Minnesota Press.

Kickbusch, I., Silberschmidt, G. and Buss, P. (2007) 'Global health diplomacy: the need for new perspectives, strategic approaches and skills in global health', *Bulletin of the World Health Organization*, 85(3), pp. 230–232. Available at: https://doi.org/10.2471/BLT.06.039222.

Kidd, D. and McIntosh, K. (2016) 'Social Media and Social Movements', *Sociology Compass*, 10(9), pp. 785–794. Available at: https://doi.org/10.1111/soc4.12399.

King, K. (2002) 'Banking on Knowledge: The new knowledge projects of the World Bank', *Compare: A Journal of Comparative and International Education*, 32(3), pp. 311–326. Available at: https://doi.org/10.1080/0305792022000007472.

Kirton, J. J. (ed.) (2017) *Global Health*. 1st edn. Routledge. Available at: https://doi.org/10.4324/9781315254227.

Kite, M.E. and Whitley, B.E. (1996) 'Sex Differences in Attitudes Toward Homosexual Persons, Behaviors, and Civil Rights A Meta-Analysis', *Personality and Social Psychology Bulletin*, 22(4), pp. 336–353. Available at: https://doi.org/10.1177/0146167296224002.

Klotz, A. (2002) ‘Transnational Activism and Global Transformations: The Anti-Apartheid and Abolitionist Experiences’, *European Journal of International Relations*, 8(1), pp. 49–76. Available at: https://doi.org/10.1177/1354066102008001002.

Kohler-Koch, B. and Quittkat, C. (2009) ‘What is civil society and who represents civil society in the EU?—Results of an online survey among civil society experts’, *Policy and Society*, 28(1), pp. 11–22. Available at: https://doi.org/10.1016/j.polsoc.2009.02.002.

Koopmans, R. (1999) ‘Political. Opportunity. Structure. Some Splitting to Balance the Lumping’, *Sociological Forum*, 14(1), pp. 93–105.

Kornilova, M. and Roshchupkin, G. (2019) *Pre-exposure prophylaxis for HIV prevention in Europe and Central Asia. Monitoring the implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia – 2018/19 progress report*. Stockholm: ECDC.

Korybko, A. (2021) ‘Ukraine is dying a deindustrialized death’, *Foreign Policy News*. Available at: https://foreignpolicynews.org/2021/09/01/ukraine-is-dying-a-deindustrializeddeath/ (Accessed: 8 July 2023).

Krasynska, S. and Martin, E. (2017) ‘The Formality of Informal Civil Society: Ukraine’s EuroMaidan’, *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations*, 28(1), pp. 420–449. Available at: https://doi.org/10.1007/s11266-016-9819-8.

Kravchenko, V. (2016) ‘Fighting Soviet Myths: The Ukrainian Experience’, *Harvard Ukrainian Studies*, 34(1/4), pp. 447–484.

Krementsov, N. (2017) ‘The Promises, Realities, and Legacies of the Bolshevik Revolution, 1917–2017’, *American Journal of Public Health*, 107(11), pp. 1693–1694. Available at: https://doi.org/10.2105/AJPH.2017.304092.

Kriesi, H. *et al.* (1992) ‘New social movements and political opportunities in Western Europe’, *European Journal of Political Research*, 22(2), pp. 219–244. Available at: https://doi.org/10.1111/j.1475-6765.1992.tb00312.x.

Krikorian, G. and Torreele, E. (2021) 'We Cannot Win the Access to Medicines Struggle Using the Same Thinking That Causes the Chronic Access Crisis', *Health and Human Rights*, 23(1), pp. 119–127.

Krikorian, G.P. (2017) 'From AIDS to Free Trade Agreements: Knowledge Activism in Thailand's Movement for Access to Medicines', *Engaging Science, Technology, and Society*, 3, p. 154. Available at: https://doi.org/10.17351/ests2017.42.

Kuchler, H. and Mancini, D. P. (2020) 'AbbVie drops patent rights for Kaletra antiviral treatment', *Financial Times*. Available at: https://www.ft.com/content/5a7a9658-6d1f-11ea89df-41bea055720b (Accessed: 10 August 2023).

Kuts, S. (2001) *Deepening the roots of civil society in Ukraine. Findings from an innovative and participatory assessment project on the health of Ukrainian civil society*. Kyiv: CIVICUS Ukraine.

Kuzio, T. (2000) *Ukraine: Perestroika to Independence*. London: Palgrave Macmillan UK. Available at: https://doi.org/10.1057/9780333984345.

Kuzio, T. (2005) 'Nation Building, History Writing and Competition over the Legacy of Kyiv Rus in Ukraine', *Nationalities Papers*, 33(1), pp. 29–58. Available at: https://doi.org/10.1080/00905990500053960.

Kuzio, T. (2015) 'Competing Nationalisms, Euromaidan, and the Russian-Ukrainian Conflict', *Studies in Ethnicity and Nationalism*, 15(1), pp. 157–169. Available at: https://doi.org/10.1111/sena.12137.

Kvale, S. (1994) *InterViews: An introduction to qualitative research interviewing*. SAGE.

KyivPride (2022) *KyivPride Manifesto 2022*, *Facebook*. Available at: https://www.facebook.com/kyivpride/posts/4965376506905872/ (Accessed: 11 November 2023).

Kyrychenko, P. and Polonets, V. (2005) 'High HIV risk profile among female commercial sex workers in Vinnitsa, Ukraine', *Sexually Transmitted Infections*, 81(2), pp. 187–188. Available at: https://doi.org/10.1136/sti.2004.011890.

Labonté, R. and Gagnon, M.L. (2010) ‘Framing health and foreign policy: lessons for global health diplomacy’, *Globalization and Health*, 6(1), p. 14. Available at: https://doi.org/10.1186/1744-8603-6-14.

Lancaster, C. (2007) *Foreign Aid: Diplomacy, Development, and Domestic Politics*. Chicago: The University of Chicago Press.

Langr, I. (2018) ‘Public Procurement in the Systemic Corruption Environment: Evidence from the Czech Republic’, *NISPAcee Journal of Public Administration and Policy*, 11(2), pp. 53–79. Available at: https://doi.org/10.2478/nispa-2018-0013.

Larkin, J. *et al.* (2021) ‘GPs’ perceptions of their relationship with the pharmaceutical industry: a qualitative study’, *BJGP Open*, 5(5), p. BJGPO.2021.0057. Available at: https://doi.org/10.3399/BJGPO.2021.0057.

Lawrinson, P. *et al.* (2008) ‘Key findings from the WHO collaborative study on substitution therapy for opioid dependence and HIV/AIDS’, *Addiction*, 103(9), pp. 1484–1492. Available at: https://doi.org/10.1111/j.1360-0443.2008.02249.x.

Lazonick, W. *et al.* (2017) ‘US Pharma’s Financialized Business Model’, *SSRN Electronic Journal* [Preprint]. Available at: https://doi.org/10.2139/ssrn.3035529.

Lee, K. (2010) ‘Civil Society Organizations and the Functions of Global Health Governance: What Role within Intergovernmental Organizations?’, *Global Health Governance: The Scholarly Journal for the New Health Security Paradigm*, 3(2) http://blogs.shu.edu/ghg/files/2011/11/Lee_Civil-Society-Organizations-and-the-Functionsof-Global-Health-Governance_Spring-2010.pdf.

Leow, A., Hu, J. and Hird, T. (2023) *An overview of WHO Prequalification: Process, usage, and potential improvements*. Rethink Priorities.

Liamputtong, P. (2010) ‘Performing Qualitative Cross-Cultural Research’, in D. Matsumoto and F. Vijver (eds) *Cross-Cultural Research Methods*. Cambridge University Press, p. 146.

Lo, B., Field, M.J. and Institute of Medicine (eds) (2009) *Conflict of interest in medical research, education, and practice*. Washington, DC: National Acad. Press.

Löblová, O. (2018) ‘What has health technology assessment ever done for us?’, *Journal of Health Services Research & Policy*, 23(2), pp. 134–136. Available at: https://doi.org/10.1177/1355819617725545.

Logan, J. R. and Molotch, H. L. (1987) *Urban fortunes: the political economy of place*. 1. pr. Berkeley, Calif.: Univ. of California Press (Sociology Urban studies).

Lollis, C. M. *et al.* (2000) ‘Sex, Drugs, and HIV: Does Methadone Maintenance Reduce Drug Use and Risky Sexual Behavior?’, *Journal of Behavioral Medicine*, 23(6), pp. 545–557. Available at: https://doi.org/10.1023/A:1005555519831.

Lopes de Souza, M. (2013) ‘NGOs and social movements’, *City*, 17(2), pp. 258–261. Available at: https://doi.org/10.1080/13604813.2013.777551.

Caruso, L. (2015) ‘Theories of the Political Process, Political Opportunities Structure and Local Mobilizations. The Case of Italy’, *Sociologica*, (3), pp. 0–0. Available at: https://doi.org/10.2383/82471.

Lubin, N. and Ware, M. (1996) *Aid to the Former Soviet Union: When Less Is More*. JNA Associates.

Luck, J. *et al.* (2014) ‘Patient and provider perspectives on quality and health system effectiveness in a transition economy: Evidence from Ukraine’, *Social Science & Medicine*, 114, pp. 57–65. Available at: https://doi.org/10.1016/j.socscimed.2014.05.034.

Lukyanova, N. (2020) ‘UNDP role in reforming the health procurement system in Ukraine’. Available at: https://www.undp.org/sites/g/files/zskgke326/files/migration/ua/c8165247e207b2b8cf05c3c271735dba597cced2d717d66e585e938647bba85e.pdf (Accessed: 15 May 2021).

Lutsevych, O. (2013) *How to Finish a Revolution: Civil Society and Democracy in Georgia, Moldova and Ukraine*. Briefing Paper. Chatham House.

Lutsevych, O. (2014) ‘Ukraine’s rebirth pangs’, *The World Today*, pp. 48–49.

Lutsevych, O. (2016) ‘Civil society versus captured state: a winning strategy for sustainable change’, *Development in Practice*, 26(5), pp. 646–656. Available at: https://doi.org/10.1080/09614524.2016.1188885.

Lynn, N. J. (1999) ‘Geography and Transition: Reconceptualizing Systemic Change in the Former Soviet Union’, *Slavic Review*, 58(4), pp. 824–840. Available at: https://doi.org/10.2307/2697200.

Kasyanchuk, M. *et al.* (2017) *Monitoring of behavior and HIV prevalence among men having sex with men as the component of HIV second generation surveillance*. ICF ‘Alliance of Public Health’, p. 85. Available at: https://aph.org.ua/wpcontent/uploads/2015/06/ANALYTICAL-REPORT.pdf.

Machlup, F. (1962) *The production and distribution of knowledge in the United States*. Princeton: Princeton Univ. Press (278).

Mackey, T. K. and Strathdee, S.A. (2015) ‘Big Events and Risks to Global Substance Using Populations: Unique Threats and Common Challenges’, *Substance Use & Misuse*, 50(7), pp. 885–890. Available at: https://doi.org/10.3109/10826084.2015.983008.

Maguire, M. and Delahunt, B. (2017) ‘Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars.’, *All Ireland Journal of Higher Education*, 9(3). Available at: https://ojs.aishe.org/index.php/aishe-j/article/view/335 (Accessed: 11 November 2023).

Mahajan, M. (2018) ‘Philanthropy and the nation-state in global health: The Gates Foundation in India’, *Global Public Health*, 13(10), pp. 1357–1368. Available at: https://doi.org/10.1080/17441692.2017.1414286.

Make Medicines Affordable (2015) *How to provide HIV treatment to all*, *Make Medicines Affordable*. Available at: https://makemedicinesaffordable.org/how-to-provide-hiv-treatmentto-all/ (Accessed: 9 October 2019).

Make Medicines Affordable (2017) *Ukraine: HIV patients appeal against deadly patent monopoly*, *Make Medicines Affordable*. Available at: https://makemedicinesaffordable.org/ukraine-hiv-patients-appeal-against-deadly-patentmonopoly/ (Accessed: 10 October 2019).

Make Medicines Affordable (2019a) *Advocacy in Ukraine results in drastic price reduction for HIV drug, raltegravir*, *Make Medicines Affordable*. Available at:

https://makemedicinesaffordable.org/advocacy-in-ukraine-results-in-drastic-price-reductionfor-hiv-drug-raltegravir/ (Accessed: 10 October 2019).

Make Medicines Affordable (2019b) *Ukraine: First civil society organization to oppose Merck's patent application (MK-8591) on the grounds of 'obviousness'*, *Make Medicines Affordable*. Available at: https://makemedicinesaffordable.org/ukraine-first-civil-societyorganization-to-oppose-mercks-patent-application-mk-8591-on-the-grounds-of-obviousness/ (Accessed: 9 September 2019).

Malinowska-Sempruch, K., Bonnell, R. and Hoover, J. (2006) 'Civil society-a leader in HIV prevention and tobacco control', *Drug and Alcohol Review*, 25(6), pp. 625–632. Available at: https://doi.org/10.1080/09595230600944578.

Malpani, R. (2007) *All costs, no benefits: How TRIPS-plus intellectual property rules in the US-Jordan FTA affect access to medicines*. Briefing Paper. OXFAM. Available at: https://oxfamilibrary.openrepository.com/bitstream/handle/10546/114080/bp102-all-costs-nobenefits-trips-210307en.pdf%3Bjsessionid%3D089750820CF675173F0C3204C369D63F%3Fsequence%3D1 (Accessed: 12 October 2019).

Maltais, A. (2013) 'Radically Non-Ideal Climate Politics and the Obligation to at Least Vote Green', *Environmental Values*, 22(5), pp. 589–608.

Manns, M. P. *et al.* (2001) 'Peginterferon alfa-2b plus ribavirin compared with interferon alfa-2b plus ribavirin for initial treatment of chronic hepatitis C: a randomised trial', *The Lancet*, 358(9286), pp. 958–965. Available at: https://doi.org/10.1016/S0140-6736(01)06102-5.

March, J.G. and Olsen, J.P. (1998) 'The Institutional Dynamics of International Political Orders', *International Organization*, 52(4), pp. 943–969. Available at: https://doi.org/10.1162/002081898550699.

Marks, G. and McAdam, D. (1996) 'Social movements and the changing structure of political opportunity in the European union [1]', *West European Politics*, 19(2), p. 119. Available at: https://doi.org/10.1080/01402389608425133.

Marks, S. (2011) 'Human Rights and Root Causes', *The Modern Law Review*, 74(1), pp. 57–

78.

Marks, S.P. and Benedict, A.L. (2013) ‘Access to medical products, vaccines, and medical technologies’, in J.M. Zuniga, S.P. Marks, and L.O. Gostin (eds) *Advancing the Human Right to Health*. Oxford University Press, pp. 305–324. Available at: https://doi.org/10.1093/acprof:oso/9780199661619.003.0022.

Martins, J. and Ventura, D. de F.L. (2023) ‘The political economy of global health and public policies’, in *Handbook on Critical Political Economy and Public Policy*. Edward Elgar Publishing, pp. 476–488. Available at: https://www.elgaronline.com/edcollchap/book/9781800373785/book-part-9781800373785-47.xml (Accessed: 5 November 2023).

Martsenyuk, T. (2012) ‘The state of the LGBT Community and Homophobia in Ukraine’, *Problems of Post-Communism*, 59, pp. 51–62. Available at: https://doi.org/10.2753/PPC1075-8216590205.

Martuscelli, C. (2023) ‘What single market? Why Romanians get new medicines 2 years after Germans’, *POLITICO*, 2 October. Available at: https://www.politico.eu/article/romaniasingle-market-medicine-drugs-disease-germany-ilness/ (Accessed: 3 November 2023).

Matsiyevsky, Y. (2018) ‘Revolution without regime change: The evidence from the postEuromaidan Ukraine’, *Communist and Post-Communist Studies*, 51(4), pp. 349–359.

Matthews, D. (2003) *Globalising Intellectual Property Rights: The TRIPS Agreement*. Routledge.

Matthews, D. (2011) *Intellectual property, human rights and development: the role of NGOs and social movements*. Cheltenham: Edward Elgar.

Mbali, M. (2013) ‘Introduction: South African AIDS Activism and Global Health Justice’, in M. Mbali (ed.) *South African AIDS Activism and Global Health Politics*. London: Palgrave Macmillan UK (Global Ethics Series), pp. 1–23. Available at: https://doi.org/10.1057/9781137312167_1.

McAdam, D. (1982) *Political Process and the Development of Black Insurgency, 1930–1970*. Chigaco: University of Chicago Press.

McAdam, D. (1996) ‘Conceptual origins, current problems, future directions’, in D. McAdam, J. D. McCarthy, and M. Zald (eds) *Comparative perspectives on social movements: political opportunities, mobilizing structures, and cultural framings*. Cambridge [England] ; New York: Cambridge University Press (Cambridge studies in comparative politics), pp. 23–41.

McAdam, D., McCarthy, J. D. and Zald, M. N. (eds) (1996) *Comparative Perspectives on Social Movements: Political Opportunities, Mobilizing Structures, and Cultural Framings*. 1st edn. Cambridge University Press. Available at: https://doi.org/10.1017/CBO9780511803987.

McAdam, D. and Paulsen, R. (1993) ‘Specifying the Relationship Between Social Ties and Activism’, *American Journal of Sociology*, 99(3), pp. 640–667. Available at: https://doi.org/10.1086/230319.

McAdam, D., Tarrow, S. G. and Tilly, C. (2001) *Dynamics of contention*. Cambridge: Cambridge university press (Cambridge studies in contentious politics).

McCarthy, J.D. and Zald, M.N. (1977) ‘Resource Mobilization and Social Movements: A Partial Theory’, *American Journal of Sociology*, 82(6), pp. 1212–1241. Available at: https://doi.org/10.1086/226464.

McCoy, D. and Gafton, J. (2020) ‘Civil Society and Global Health’, in C. McInnes, K. Lee, and J.R. Youde (eds) *The Oxford handbook of global health politics*. New York, NY: Oxford University Press, pp. 350–360.

McCoy, D. and McGoey, L. (2011) ‘Global Health and the Gates Foundation — In Perspective’, in S. Rushton and O.D. Williams (eds) *Partnerships and Foundations in Global Health Governance*. London: Palgrave Macmillan UK, pp. 143–163. Available at: https://doi.org/10.1057/9780230299474_7.

McGill, S. (2015) ‘Challenges of NGO-to-state Referral in the Delivery of HIV Prevention Programs in Ukraine Supported by the Global Fund’, *Central Asian Journal of Global Health*, 4(2), p. 213. Available at: https://doi.org/10.5195/cajgh.2015.213.

McGill, S. (2016) 'NGO Hybridisation as an Outcome of HIV Services Delivery in Global Fund-Supported Programmes in Ukraine', *Voluntas: International Journal of Voluntary and Nonprofit Organizations*, 27(4), pp. 1853–1870.
McGill, S. (2017) 'Partners or donors: The perceived roles of Global Fund Principal Recipient NGOs in HIV prevention programmes in Ukraine', *Journal of Eurasian Studies*, 8(1), pp. 97–105. Available at: https://doi.org/10.1016/j.euras.2016.11.005.

McGoey, L. (2015) *No such thing as a free gift: the Gates Foundation and the price of philanthropy*. London New York: Verso.

McKee, M. and Nagyova, I. (2022) 'When the guns fall silent… Priorities for health in postwar Ukraine', *European Journal of Public Health*, 32(4), pp. 517–518. Available at: https://doi.org/10.1093/eurpub/ckac090.

McMahon, A. (2023) 'EU's compulsory licensing proposals, patents and crisis preparedness – Some steps in the right direction but more to do for future pandemic preparedness', *Journal of Medical Ethics blog*. Available at: https://blogs.bmj.com/medical-ethics/2023/05/04/euscompulsory-licensing-proposals-patents-and-crisis-preparedness-some-steps-in-the-rightdirection-but-more-to-do-for-future-pandemic-preparedness/ (Accessed: 13 November 2023).

McMillan, D.W. and Chavis, D.M. (1986) 'Sense of community: A definition and theory', *Journal of Community Psychology*, 14(1), pp. 6–23. Available at: https://doi.org/10.1002/1520-6629(198601)14:1<6::AID-JCOP2290140103>3.0.CO;2-I.

Medicine Patent Pool (2017) 'The Medicines Patent Pool Welcomes Extension of MPPGilead HIV Licences to Include Belarus, Malaysia and Ukraine - MPP'. Available at: https://medicinespatentpool.org/news-publications-post/the-medicines-patent-poolwelcomes-extension-of-mpp-gilead-hiv-licences-to-include-belarus-malaysia-and-ukraine (Accessed: 11 October 2019).

Medicines Patent Pool (2020) 'Impact - MPP'. Available at: https://medicinespatentpool.org/progress-achievements/impact (Accessed: 10 February 2021).

Melkozerova, V. (2023) 'Ukraine races to save its medical cannabis supply', *POLITICO*, 27 July. Available at: https://www.politico.eu/article/ukraine-medicine-cannabis-law-healthcare-volodymyr-zelenskyy-war-epiprosvita/ (Accessed: 20 October 2023).

Mendel, I. (2017) ‘In Ukraine, health care is free (except when it’s not)’, *POLITICO*. Available at: https://www.politico.eu/article/ukraines-ailing-health-care-system-underfundedcorrupt-inaccessible/ (Accessed: 20 November 2021).

Mermelstein, S. and Stevens, H. (2022) ‘TRIPS to Where? A Narrative Review of the Empirical Literature on Intellectual Property Licensing Models to Promote Global Diffusion of Essential Medicines’, *Pharmaceutics*, 14(1), p. 48. Available at: https://doi.org/10.3390/pharmaceutics14010048.

Messina, J. P. *et al.* (2015) ‘Global distribution and prevalence of hepatitis C virus genotypes’, *Hepatology (Baltimore, Md.)*, 61(1), pp. 77–87. Available at: https://doi.org/10.1002/hep.27259.

Meyer, D. S. (2004) ‘Protest and Political Opportunities’, *Annual Review of Sociology*, 30, pp. 125–145.

Meyer, G. (ed.) (2006) *Formal institutions and informal politics in central and eastern Europe: Hungary, Poland, Russia and Ukraine*. Leverkusen Opladen: Budrich.

Mhazo, A. T. and Maponga, C.C. (2022) ‘Framing access to essential medicines in the context of Universal Health Coverage: a critical analysis of health sector strategic plans from eight countries in the WHO African region’, *BMC Health Services Research*, 22(1), p. 1390. Available at: https://doi.org/10.1186/s12913-022-08791-9.

Mikuš, M. (2015) ‘Indigenizing 'civil society' in Serbia What local fund-raising reveals about class and trust’, *Focaal*, (71), pp. 43–56. Available at: https://doi.org/10.3167/fcl.2015.710105.

Milan, S. (2014) ‘The Ethics of Social Movement Research’, in D. Della Porta (ed.) *Methodological Practices in Social Movement Research*. Oxford University Press, pp. 446–464. Available at: https://doi.org/10.1093/acprof:oso/9780198719571.003.0018.

Ministry of Health Ukraine (2017) *Affordable Medicines*. Available at: http://en.moz.gov.ua/affordable-medicines (Accessed: 10 October 2020).

Ministry of Health Ukraine (2018) *Healthcare Reform*, *KEY STEPS TO TRANSFORMING*

UKRAINIAN HEALTHCARE. Available at: http://en.moz.gov.ua/healthcare-reform (Accessed: 8 November 2023).

Minkoff, D.C. (1997) 'The Sequencing of Social Movements', *American Sociological Review*, 62(5), pp. 779–799. Available at: https://doi.org/10.2307/2657360.

Møgedal, S., Alveberg, B. and Pereira, C. (2011) 'The global health architecture – for the benefit of all?', *Tidsskrift for Den norske legeforening* [Preprint]. Available at: https://doi.org/10.4045/tidsskr.11.0750.

Molina, Y. and Ramirez-Valles, J. (2013) 'HIV/AIDS stigma: measurement and relationships to psycho-behavioral factors in Latino gay/bisexual men and transgender women', *AIDS care*, 25(12), pp. 1559–1568. Available at: https://doi.org/10.1080/09540121.2013.793268.

Møller, J. and Skaaning, S.- E. (2012) *Democracy and Democratization in Comparative Perspective: Conceptions, Conjunctures, Causes, and Consequences*. London: Routledge. Available at: https://doi.org/10.4324/9780203083994.

Moon, S. and Balasubramianiam, T. (2018) 'Carving Out the Right to Health to Promote Access to Medicines and Tobacco Control in the Trade Arena', *in* B. Meier, L.O. Gostin, and M. Robinson (eds) *Human Rights in Global Health: Rights-Based Governance for a Globalizing World*. Rochester, NY. Available at: https://papers.ssrn.com/abstract=3197773 (Accessed: 10 November 2023).

Moon, S., Bermudez, J. and Hoen, E. t' (2012) 'Innovation and Access to Medicines for Neglected Populations: Could a Treaty Address a Broken Pharmaceutical R&D System?', *PLoS Medicine*, 9(5), p. e1001218. Available at: https://doi.org/10.1371/journal.pmed.1001218.

Moon, S. and Ooms, G. (2017) 'Will markets be master or servant to health at the World Bank?', *BMJ (Clinical research ed.)*, 359, p. j4676. Available at: https://doi.org/10.1136/bmj.j4676.

Morgan, S. G., Bathula, H. S. and Moon, S. (2020) 'Pricing of pharmaceuticals is becoming a major challenge for health systems', *BMJ*, p. l4627. Available at: https://doi.org/10.1136/bmj.l4627.

Morin, S. *et al.* (2021) 'The economic and public health impact of intellectual property licensing of medicines for low-income and middle-income countries: a modelling study', *The Lancet Public Health*, 7(2), pp. 169–176. Available at: https://doi.org/10.1016/S24682667(21)00202-4.

Morozova, O. *et al.* (2019) 'Divergent estimates of HIV incidence among people who inject drugs in Ukraine', *International Journal of Drug Policy*, 73, pp. 156–162. Available at: https://doi.org/10.1016/j.drugpo.2019.07.023.

Morozova, O. *et al.* (2023) 'Treatment of opioid use disorder in Ukraine during the first year of the Russia–Ukraine war: Lessons learned from the crisis', *International Journal of Drug Policy*, 117, p. 104062. Available at: https://doi.org/10.1016/j.drugpo.2023.104062.

Morris, J. (2023) 'How homophobic propaganda produces vernacular prejudice in authoritarian states', *Sexualities*, p. 136346072211446. Available at: https://doi.org/10.1177/13634607221144624.

MSF (2002) *Patents, prices & patients: the example of HIV/AIDS | MSF*, *Médecins Sans Frontières (MSF) International*. Available at: https://www.msf.org/patents-prices-patientsexample-hivaids (Accessed: 12 January 2019).

MSF (2016) *Untangling the Web of Antiretroviral Price Reduction*. Medecin Sans Frontieres. Available at: https://msfaccess.org/sites/default/files/MSF_assets/HIV_AIDS/Docs/HIV_report_Untangling-the-Wed-18thed_ENG_2016.pdf (Accessed: 19 March 2019).

MSF (2017) *Briefing note on supplementary protection certificates (SPCs)*. Technical Brief.

Mueller, J. M. (2007) 'Taking TRIPS to India — Novartis, Patent Law, and Access to Medicines', *New England Journal of Medicine*, 356(6), pp. 541–543. Available at: https://doi.org/10.1056/NEJMp068245.

Mukhopadhyay, I. (2013) 'Universal Health Coverage: The New Face of Neoliberalism', *Social Change*, 43(2), pp. 177–190. Available at: https://doi.org/10.1177/0049085713492281.

Musliu, V. and Burlyuk, O. (2019) ‘Imagining Ukraine: From History and Myths to Maidan Protests’, *East European Politics and Societies*, 33(3), pp. 631–655. Available at: https://doi.org/10.1177/0888325418821410.

Myers, D.J., Cress, D.M. and Raeburn, N. (eds) (2004) ‘Working It Out: The Emergence and Diffusion of the Workplace Movement For Lesbian, Gay, and Bisexual Rights’, in *Authority in contention*. 1. ed. Bingley: Emerald Group Publishing Limited (Research in social movements, conflicts and change, 25.2004), pp. 187–230.

Nader, R. and Wallach, L. (1996) ‘GATT, NAFTA, and the subversion of the democratic process’, in J. Mander and E. Goldsmith (eds) *The case against the global economy*. San Francisco: Sierra Club Press, pp. 92–107.

Naderifar, M., Goli, H. and Ghaljaie, F. (2017) ‘Snowball Sampling: A Purposeful Method of Sampling in Qualitative Research’, *Strides in Development of Medical Education*, 14(3). Available at: https://doi.org/10.5812/sdme.67670.

Narlikar, A. (2021) ‘Holding Up a Mirror to the World Trade Organization: Lessons from the COVID-19 Pandemic’, *Global Perspectives*, 2(1). Available at: https://doi.org/10.1525/gp.2021.24069.

Nash Mir and Nash Mir Center (2019) *Overcoming obstacles. LGBT situation in Ukraine in 2018*. LGBT Human Rights Nash Mir Center, p. 61. Available at: https://gay.org.ua/publications/Situation-of-LGBT-in-Ukraine-2018-ENG.pdf (Accessed: 8 July 2020).

National Audit Office (2006) *Department for International Development: Working with NonGovernmental and other Civil Society Organisations to promote development*. London. Available at: https://webarchive.nationalarchives.gov.uk/ukgwa/20170207052351/https://www.nao.org.uk/wp-content/uploads/2006/07/05061311es.pdf (Accessed: 05 November 2020).

Neduzhko, O. *et al.* (2017) ‘Factors Associated with Delayed Enrollment in HIV Medical Care among HIV-Positive Individuals in Odessa Region, Ukraine’, *Journal of the International Association of Providers of AIDS Care*, 16(2), pp. 168–173. Available at: https://doi.org/10.1177/2325957416686194.

Neduzhko, O. *et al.* (2020) ‘Modified Antiretroviral Treatment Access Study (MARTAS): A Randomized Controlled Trial of the Efficacy of a Linkage-to-Care Intervention Among HIVPositive Patients in Ukraine’, *AIDS and behavior*, 24(11), pp. 3142–3154. Available at: https://doi.org/10.1007/s10461-020-02873-7.

Neeraj, V. (2022) ‘Patents, Pandemics, and the Private Sector: The Battle Over Public Health Norms During COVID-19’, *Journal of Public & International Affairs* [Preprint].
Nitoiu, C. (2018) ‘The European Union’s 'Ideal Self' in the Post-Soviet Space’, *Europe-Asia Studies*, 70(5), pp. 692–710. Available at: https://doi.org/10.1080/09668136.2018.1465529.

Neumayr, M., Schneider, U. and Meyer, M. (2015) ‘Public Funding and Its Impact on Nonprofit Advocacy’, *Nonprofit and Voluntary Sector Quarterly*, 44(2), pp. 297–318. Available at: https://doi.org/10.1177/0899764013513350.

Nowell, B. and Boyd, N. (2010) ‘Viewing community as responsibility as well as resource: deconstructing the theoretical roots of psychological sense of community’, *Journal of Community Psychology*, 38(7), pp. 828–841. Available at: https://doi.org/10.1002/jcop.20398.

Nowell, B. and Boyd, N.M. (2014) ‘Sense of Community Responsibility in Community Collaboratives: Advancing a Theory of Community as Resource and Responsibility’, *American Journal of Community Psychology*, 54(3), pp. 229–242. Available at: https://doi.org/10.1007/s10464-014-9667-x.

O’Connell, B. (2000) ‘Civil Society: Definitions and Descriptions’, *Nonprofit and Voluntary Sector Quarterly*, 29(3), pp. 471–478. Available at: https://doi.org/10.1177/0899764000293007.

O’Donovan, N. (2024) *Pursuing the Knowledge Economy: A Sympathetic History of High-Skill, High-Wage Hubris*. 1st edn. Agenda Publishing. Available at: https://doi.org/10.1017/9781788215169.

Ooms, G. and Hanefeld, J. (2019) ‘Threat of compulsory licences could increase access to essential medicines’, *BMJ (Clinical research ed.)*, 365, p. l2098. Available at: https://doi.org/10.1136/bmj.l2098.

Ooms, G. and Kruja, K. (2019) ‘The integration of the global HIV/AIDS response into universal health coverage: desirable, perhaps possible, but far from easy’, *Globalization and Health*, 15(1), p. 41. Available at: https://doi.org/10.1186/s12992-019-0487-5.

Open Society Foundation (2007) *HIV/AIDS Policy in Ukraine: A Civil Society Perspective*. Available at: https://www.opensocietyfoundations.org/publications/hivaids-policy-ukrainecivil-society-perspective (Accessed: 17 June 2020).

Open Society Foundations Public Health Program. (2017) *Lost in Transition: Three Case Studies of Global Fund Withdrawal in South Eastern Europe*. New York: OSF.

Open Society Foundation (2024) *The Open Society Foundations in Ukraine*. Available at: https://www.opensocietyfoundations.org/newsroom/the-open-society-foundations-in-ukraine (Accessed: 10 March 2024).

Oswin, N. (2006) ‘Decentering Queer Globalization: Diffusion and the “Global Gay”’, *Environment and Planning D: Society and Space*, 24(5), pp. 777–790. Available at: https://doi.org/10.1068/d63j.

O’Reilly, J. *et al.* (2012) ‘Paying for hospital care: the experience with implementing activity-based funding in five European countries’, *Health Economics, Policy and Law*, 7(1), pp. 73–101. Available at: https://doi.org/10.1017/S1744133111000314.

Orttung, R. W. and Hale, H. E. (2016) *Beyond the Euromaidan: Comparative Perspectives on Advancing Reform in Ukraine*. Stanford: Stanford University Press.

Outterson, K. *et al.* (2016) ‘Delinking Investment in Antibiotic Research and Development from Sales Revenues: The Challenges of Transforming a Promising Idea into Reality’, *PLOS Medicine*, 13(6), p. e1002043. Available at: https://doi.org/10.1371/journal.pmed.1002043.

Owczarzak, J. (2010) ‘Activism, NGOs, and HIV Prevention in Postsocialist Poland: The Role of 'Anti-Politics'', *Human Organization*, 69(2), pp. 200–211. Available at: https://doi.org/10.17730/humo.69.2.v8132n668713242k.

Owczarzak, J. *et al.* (2023) ‘The Relationship Between Intersectional Drug Use and HIV Stigma and HIV Care Engagement Among Women Living with HIV in Ukraine’, *AIDS and behavior*, 27(6), pp. 1914–1925. Available at: https://doi.org/10.1007/s10461-022-03925-w.

Pachankis, J. E. *et al.* (2015) 'Hidden from health: structural stigma, sexual orientation concealment, and HIV across 38 countries in the European MSM Internet Survey', *AIDS (London, England)*, 29(10), pp. 1239–1246. Available at: https://doi.org/10.1097/QAD.0000000000000724.

Palmedo, M. (2021) 'Evaluating the Impact of Data Exclusivity on the Price per Kilogram of Pharmaceutical Imports', *Global Development Policy Center* [Preprint], (048).

Palmedo, M. (2023) 'Evaluating the Impact of Data Exclusivity on the Price of Pharmaceutical Imports', *Journal of Globalization and Development*, 14(1), pp. 1–20. Available at: https://doi.org/10.1515/jgd-2021-0016.

Palmer, G. and Morgan, T. C. (2006) *A Theory of Foreign Policy*. Princeton University Press. Available at: https://www.jstor.org/stable/j.ctt7stbg (Accessed: 13 November 2023).

Palyvoda, L., Vinnikov, O. and Kupriy, V. (2016) 'Defining civil society for Ukraine'. Available at: https://doi.org/10.13140/RG.2.1.3606.6169.

Parker, R. (2011) 'Grassroots Activism, Civil Society Mobilization, and the Politics of the Global HIV/AIDS Epidemic', *The Brown Journal of World Affairs*, 17(2), pp. 21–37.

Pechacek, J. T. (2012) 'The Past, Present, and Future of South Africa's Patent System', *Cybaris: An Intellectual Property Law Review*, 3, p. 188.

Pellegrino, E. D. and Relman, A. S. (1999) 'Professional Medical Associations: Ethical and Practical Guidelines', *JAMA*, 282(10), p. 984. Available at: https://doi.org/10.1001/jama.282.10.984.

Pellow, D. N. (2001) 'Environmental Justice and the Political Process: Movements, Corporations, and the state', *The Sociological Quarterly*, 42(1), pp. 47–67. Available at: https://doi.org/10.1111/j.1533-8525.2001.tb02374.x.

Peterson, L. E. and Williams, Z. (2017) *Gilead Pharma corp withdraws investment arbitration after Ukraine agrees to settlement of dispute over monopoly rights to market antiviral drug*. Available at: https://www.bilaterals.org/?gilead-pharma-corp-withdraws (Accessed: 15 June 2023).

Peterson, M. J. (1992) ‘Transnational Activity, International Society and World Politics’, *Millennium*, 21(3), pp. 371–388. Available at: https://doi.org/10.1177/03058298920210030901.

Petrova, V. P. (2007) ‘Civil Society in Post-Communist Eastern Europe and Eurasia: A Cross-National Analysis of Micro- and Macro-Factors’, *World Development*, 35(7), pp. 1277–1305. Available at: https://doi.org/10.1016/j.worlddev.2006.09.019.

Pew Research Center (2017) ‘1. Orthodox Christianity’s geographic center remains in Central and Eastern Europe’, *Pew Research Center’s Religion & Public Life Project*, 8 November. Available at: https://www.pewresearch.org/religion/2017/11/08/orthodox-christianitysgeographic-center-remains-in-central-and-eastern-europe/ (Accessed: 8 November 2023).

Pifer, S. and Thoburn, H. (2013) *Viktor Yanukovych: Losing Europe...and Losing the Ukrainian Public?*, *Brookings*. Available at: https://www.brookings.edu/articles/viktoryanukovych-losing-europe-and-losing-the-ukrainian-public/ (Accessed: 9 November 2020).

Piniazhko, O. *et al.* (2018) ‘External Reference Pricing in Ukraine: Implementation and Impact’, *Value in Health*, 21, p. S24. Available at: https://doi.org/10.1016/j.jval.2018.07.184.

Pishchikova, K. (2011) *Promoting democracy in postcommunist Ukraine: the contradictory outcomes of US aid to women’s NGOs*. Boulder, Colo.: Lynne Rienner publ.

Pishchikova, K. and Ogryzko, O. (2014) *Civic Awakening: the Impact of Euromaidan on Ukraine’s Politics and Society*. Working Paper 124. FRIDE.

Pizzi, M. (2015) *War in Ukraine threatens to worsen HIV crisis*. Available at: http://america.aljazeera.com/articles/2015/1/26/war-in-ukraine-threatens-to-worsen-hivcrisis.html (Accessed: 10 October 2020).

Platt, L. *et al.* (2016) ‘Prevalence and burden of HCV co-infection in people living with HIV: a global systematic review and meta-analysis’, *The Lancet Infectious Diseases*, 16(7), pp. 797–808. Available at: https://doi.org/10.1016/S1473-3099(15)00485-5.

Pollard, A. and Court, J. (2005) *How Civil Society Organisations Use Evidence to Influence Policy Processes*. Working Paper 249. London.

Polletta, F. (1999) ‘'Free Spaces' in Collective Action’, *Theory and Society*, 28(1), pp. 1–38.

Polletta, F. *et al.* (2021) ‘Personal Storytelling in Professionalised Social Movements*’, *Mobilization: An International Quarterly*, 26(1), pp. 65–86. Available at: https://doi.org/10.17813/1086-671X-26-1-65.

Porta, D. della (2008) ‘Research on Social Movements and Political Violence’, *Qualitative Sociology*, 31(3), pp. 221–230. Available at: https://doi.org/10.1007/s11133-008-9109-x.

Porta, D. della (ed.) (2014) *Methodological Practices in Social Movement Research*. Oxford University Press. Available at: https://doi.org/10.1093/acprof:oso/9780198719571.001.0001.

Porta, D. della and Tarrow, S. (2005) ‘Transnational Protest and Global Activism: People, Passions’, in A.F. Blackwell and D. MacKay (eds) *Power*. Cambridge University Press.

Postnov, O. *et al.* (2016) ‘MSM community mobilization for HIV prevention in Ukraine: the effectiveness of Mpowerment behavioral intervention’, in. *21st Internation AIDS Conference*, Durban, South Africa.

Prasad, V. and Mailankody, S. (2017) ‘Research and Development Spending to Bring a Single Cancer Drug to Market and Revenues After Approval’, *JAMA Internal Medicine*, 177(11), pp. 1569–1575. Available at: https://doi.org/10.1001/jamainternmed.2017.3601.

Prasetyo, Y. (2017) ‘From Storytelling to Social Change: The Power of Story in the Community Building’. Rochester, NY. Available at: https://doi.org/10.2139/ssrn.3094947.

Preker, A. S. *et al.* (2002) ‘Effectiveness of community health financing in meeting the cost of illness’, *Bulletin of the World Health Organization*, 80(2), pp. 143–150.

Make Medicines Affordable (2016) *Price of HIV Drug Atripla Set to Drop*. Available at: https://makemedicinesaffordable.org/price-of-hiv-drug-atripla-set-to-drop/ (Accessed: 9 September 2019).

Prizel, I. (1998) *National Identity and Foreign Policy: Nationalism and Leadership in Poland, Russia and Ukraine*. 1st edn. Cambridge University Press. Available at: https://doi.org/10.1017/CBO9780511582929.

Pronk, J. P. (2001) ‘Aid as a Catalyst’, *Development and Change*, 32(4), pp. 611–629.

Available at: https://doi.org/10.1111/1467-7660.00219.
Psota, V. *et al.* (2020) 'Competition in Public Procurement in the Fight Against Corruption: Analysis of an Example of Ukraine', *Intellectual Economics*, 14(1), pp. 89–112. Available at: https://doi.org/10.13165/IE-20-14-1-06.

Putzel, J. (2004) 'The global fight against AIDS: how adequate are the national commissions?', *Journal of International Development*, 16(8), pp. 1129–1140. Available at: https://doi.org/10.1002/jid.1167.

Rabeharisoa, V., Moreira, T. and Akrich, M. (2014) 'Evidence-based activism: Patients', users' and activists' groups in knowledge society', *BioSocieties*, 9(2), pp. 111–128. Available at: https://doi.org/10.1057/biosoc.2014.2.

Rachynska V. *et al.* (2022) *Community-led humanitarian and HIV/TB interventions in the emergency response to the war in Ukraine*. 24th International AIDS Conference, Montreal, poster EPLBF01.

Radnitz, S. (2010) 'The Color of Money: Privatization, Economic Dispersion, and the Post-Soviet "Revolutions"', *Comparative Politics*, 42(2), pp. 127–146.

Raju, K.D. (2017) 'Compulsory v Voluntary Licensing: A Legitimate way to Enhance Access to Essential Medicines in Developing Countries', *Journal of Intellectual Property Rights*, 22, pp. 23–31.

Ram, P. (2006) 'India's New 'Trips-Compliant'' Patent Regime Between Drug Patents and the Right to Health', *Chicago-Kent Journal of Intellectual Property* [Preprint].

Rathod, S. K. (2022) 'Patent Oppositions in India', in C.M. Correa and R.M. Hilty (eds) *Access to Medicines and Vaccines*. Cham: Springer International Publishing, pp. 151–182. Available at: https://doi.org/10.1007/978-3-030-83114-1_6.

Reeves, A. *et al.* (2017) 'Gender violence, poverty and HIV infection risk among persons engaged in the sex industry: cross-national analysis of the political economy of sex markets in 30 European and Central Asian countries', *HIV Medicine*, 18(10), pp. 748–755. Available at: https://doi.org/10.1111/hiv.12520.

Reeves, A. *et al.* (2017) ‘National sex work policy and HIV prevalence among sex workers: an ecological regression analysis of 27 European countries’, *The Lancet HIV*, 4(3), pp. e134–e140. Available at: https://doi.org/10.1016/S2352-3018(16)30217-X.

Reid, G. (2023) ‘Russia, homophobia and the battle for “traditional values”’. Available at: https://www.socialeurope.eu/russia-homophobia-and-the-battle-for-traditional-values (Accessed: 15 April 2024).

Reshetnikov, V. *et al.* (2019) ‘Analysis of the Financing of Russian Health Care over the Past 100 Years’, *International Journal of Environmental Research and Public Health*, 16(10), p. 1848. Available at: https://doi.org/10.3390/ijerph16101848.

Resnik, D. B. (2001) ‘Developing Drugs for the Developing World: An Economic, Legal, Moral, and Political Dilemma’, *Developing World Bioethics*, 1(1), pp. 11–32. Available at: https://doi.org/10.1111/1471-8847.00004.

Reznik, O. (2016) ‘From the Orange Revolution to the Revolution of Dignity: Dynamics of the Protest Actions in Ukraine’, *East European Politics and Societies*, 30(4), pp. 750–765. Available at: https://doi.org/10.1177/0888325416650255.

Rhodes, T. and Simic, M. (2005) ‘Transition and the HIV risk environment’, *BMJ*, 331(7510), pp. 220–223. Available at: https://doi.org/10.1136/bmj.331.7510.220.

Riabchuk, M. (2012) ‘Ukraine’s 'muddling through': National identity and postcommunist transition’, *Communist and Post-Communist Studies*, 45(3/4), pp. 439–446.

Richter, H. (ed.) (2023) *Competition and Intellectual Property Law in Ukraine*. Berlin, Heidelberg: Springer Berlin Heidelberg (MPI Studies on Intellectual Property and Competition Law). Available at: https://doi.org/10.1007/978-3-662-66101-7.

Richter, M. M. (2022) ‘The Diversity of Actors in Reform Backsliding and Its Containment in the Ukrainian Hybrid Regime’, *Politics and Governance*, 11(1). Available at: https://doi.org/10.17645/pag.v11i1.5862.

Riddell, R. C. (2014) ‘Does Foreign Aid Really Work? An Updated Assessment’. Rochester, NY. Available at: https://doi.org/10.2139/ssrn.2409847.

Rodger, A. J. *et al.* (2016) 'Sexual Activity Without Condoms and Risk of HIV Transmission in Serodifferent Couples When the HIV-Positive Partner Is Using Suppressive Antiretroviral Therapy', *JAMA*, 316(2), pp. 171–181. Available at: https://doi.org/10.1001/jama.2016.5148.

Rodger, A. J. *et al.* (2019) 'Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multicentre, prospective, observational study', *Lancet (London, England)*, 393(10189), pp. 2428–2438. Available at: https://doi.org/10.1016/S01406736(19)30418-0.

Romaniuk, P. and Semigina, T. (2018) 'Ukrainian health care system and its chances for successful transition from Soviet legacies', *Globalization and Health*, 14(1), p. 116. Available at: https://doi.org/10.1186/s12992-018-0439-5.

Rosenblum, N. L. and Post, R. C. (2002) *Civil Society and Government*. Princeton University Press. Available at: https://doi.org/10.2307/j.ctv1ddd0qb.

Roth, B. (2017) *The Life and Death of ACT UP/LA: Anti-AIDS Activism in Los Angeles from the 1980s to the 2000s*. 1st edn. Cambridge University Press. Available at: https://doi.org/10.1017/9781316226940.

Sadowski, I. and Pohorila, N. (2017) 'Do Revolutions Bring Revolutionary Changes? Replacement in the Ranks of Ukraine's Parliament, 1990–2014', *International Journal of Sociology*, 48(1), pp. 6–33. Available at: https://doi.org/10.1080/00207659.2018.1414498.

Saez, C. (2018) *Truvada case shows civil society's success with pre-grant opposition*, *Make Medicines Affordable*. Available at: https://makemedicinesaffordable.org/truvada-caseshows-civil-societys-success-with-pre-grant-opposition/ (Accessed: 18 March 2019).

Salamon, L. M. and Anheier, H.K. (1996) *The emerging nonprofit sector: an overview*. Manchester, UK: Manchester University Press (Johns Hopkins nonprofit sector series, 1).

Sand, A.L. and Hakim-Fernández, N. (2018) 'Ephemeral Socialities: Social Navigation among Young Danes', *kult-ur*, 5(9), pp. 57–80. Available at: https://doi.org/10.6035/Kult-ur.2018.5.9.2.

Sándor, J. *et al.* (2016) 'Capitation-Based Financing Hampers the Provision of Preventive Services in Primary Health Care', *Frontiers in Public Health*, 4. Available at: https://doi.org/10.3389/fpubh.2016.00200.

Sarason, S.B. (1974) *The psychological sense of community: Prospects for a community psychology*. Cambridge, MA, US: Brookline Books (The psychological sense of community: Prospects for a community psychology), pp. xii, 290.

Sasse, G. and Lackner, A. (2018) 'War and identity: the case of the Donbas in Ukraine', *Post-Soviet Affairs*, 34(2–3), pp. 139–157. Available at: https://doi.org/10.1080/1060586X.2018.1452209.

Satyanarayana, K. and Srivastava, S. (2010) 'Patent Pooling for Promoting Access to Antiretroviral Drugs (ARVs) - A Strategic Option for India', *The open AIDS journal*, 4, pp. 41–53. Available at: https://doi.org/10.2174/1874613601004020041.

Saunders, B. *et al.* (2018) 'Saturation in qualitative research: exploring its conceptualization and operationalization', *Quality & Quantity*, 52(4), pp. 1893–1907. Available at: https://doi.org/10.1007/s11135-017-0574-8.

Saurugger, S. (2012) 'The professionalization of the EU's civil society: a conceptual framework.' In *New participatory dimensions in civil society* (pp. 69-83). Routledge.

Savin-Baden, M. and Major, C. H. (2023) *Qualitative Research: The Essential Guide to Theory and Practice*. Taylor & Francis.

Schofferman, J. (2011) 'The Medical–Industrial Complex, Professional Medical Associations, and Continuing Medical Education', *Pain Medicine*, 12(12), pp. 1713–1719. Available at: https://doi.org/10.1111/j.1526-4637.2011.01282.x.

Schulte, L.J. and Battle, J. (2004) 'The Relative Importance of Ethnicity and Religion in Predicting Attitudes Towards Gays and Lesbians', *Journal of Homosexuality*, 47(2), pp. 127–142. Available at: https://doi.org/10.1300/J082v47n02_08.

Sell, S. K. (2003) *Private Power, Public Law: The Globalization of Intellectual Property Rights*. Cambridge University Press.

Sellin, J. and Perehudoff, K. (2019) 'WHO Fair Pricing Forum: Watching for Drug Industry Accountability', *Health and Human Rights Journal*. Available at:

https://www.hhrjournal.org/2019/04/who-fair-pricing-forum-watching-for-drug-industryaccountability/ (Accessed: 3 February 2021).

Semigina, T. (2009) *Tracking Global HIV/AIDS Initiatives and their Impact on the Health System in Ukraine*. Global HIV/AIDS Initiatives Network.

Semigina, T. (2015) 'HIV-activism in a Post-socialist state: The Case of Ukraine', *KyivMohyla Law and Politics Journal*, 0(1), pp. 113–133. Available at: https://doi.org/10.18523/kmlpj52659.2015-1.113-133.

Semigina, T. (2017) 'Is Zero Discrimination possible? Voices from Ukraine', in *Getting to Zero: Global Social Work Responds to HIV*. IASSW, UNAIDS, pp. 255–280.

Semigina T, Mandrik O. (2017) Drug procurement policy in Ukraine: is there a «window of opportunity»? *Visnyk Akademiyi pratsi, sotsial'nykh vidnosyn i turyzmu,* 1, pp. 25–38.

Semigina, T. and Network, G. H. I. (2009) *Tracking Global HIV/AIDS Initiatives and their Impact on the Health System in Ukraine*. report. Royal College of Surgeons in Ireland. Available at: https://doi.org/10.25419/rcsi.10776551.v1.

Sereda, Y. *et al.* (2020) 'Stigma and quality of co-located care for HIV-positive people in addiction treatment in Ukraine: a cross-sectional study', *Journal of the International AIDS Society*, 23(5), p. e25492. Available at: https://doi.org/10.1002/jia2.25492.

Shadlen, K. C. (2017) *Coalitions and Compliance: The Political Economy of Pharmaceutical Patents in Latin America*. Oxford University Press.

Shadlen, K. C., Sampat, B.N. and Kapczynski, A. (2020) 'Patents, trade and medicines: past, present and future', *Review of International Political Economy*, 27(1), pp. 75–97. Available at: https://doi.org/10.1080/09692290.2019.1624295.

Shandra, A. (2017) *Healthcare reform in Ukraine under attack of old mafia clans*, *UaPost - Ukrainian American Media*. Available at: https://www.uapost.us/en/blog/healthcare-reformin-ukraine-under-attack-of-old-mafia-clans/ (Accessed: 8 November 2023).

Shapovalova, N. *et al* (2017) 'Ukraine: Civic Volunteerism and the Legacy of Euromaidan', *GLOBAL CIVIC ACTIVISM IN FLUX*, ed by Richard Youngs, Carnegie Endowment for International Peace, pp. 47–52.

Shapovalova, N. and Burlyuk, O. (eds) (2018) *Civil society in post-Euromaidan Ukraine: from revolution to consolidation*. Stuttgart: ibidem-Verlag (Soviet and post-soviet politics and society, vol. 193).

Sheiman, I., Shishkin, S. and Shevsky, V. (2018) 'The evolving Semashko model of primary health care: the case of the Russian Federation', *Risk Management and Healthcare Policy*, Volume 11, pp. 209–220. Available at: https://doi.org/10.2147/RMHP.S168399.

Shevel, O. (2015) 'Orange Revolution and Its Aftermath: Mobilization, Apathy, and the state in Ukraine, edited by Paul D'Anieri', *Canadian-American Slavic Studies*, 49(2–3), pp. 401–404. Available at: https://doi.org/10.1163/22102396-04902023.

Shumate, M., Fulk, J. and Monge, P. (2005) 'Predictors of the International HIV/AIDS INGO Network Over Time', *Human Communication Research*, 31(4), pp. 482–510. Available at: https://doi.org/10.1111/j.1468-2958.2005.tb00880.x.

Shveda, Y. and Park, J. H. (2016) 'Ukraine's revolution of dignity: The dynamics of Euromaidan', *Journal of Eurasian Studies*, 7(1), pp. 85–91. Available at: https://doi.org/10.1016/j.euras.2015.10.007.

Sidley, P. (2001) 'Drug companies sue South African government over generics', *BMJ: British Medical Journal*, 322(7284), p. 447.

Sim, J. *et al.* (2018) 'Can sample size in qualitative research be determined a priori?', *International Journal of Social Research Methodology*, 21(5), pp. 619–634. Available at: https://doi.org/10.1080/13645579.2018.1454643.

Simmons, B., Cooke, G. S. and Miraldo, M. (2019) 'Effect of voluntary licences for hepatitis C medicines on access to treatment: a difference-in-differences analysis', *The Lancet Global Health*, 7(9), pp. 1189–1196. Available at: https://doi.org/10.1016/S2214-109X(19)30266-9.

Singh, Bawa *et al.* (2022) 'COVID-19 and Global Distributive Justice: 'Health Diplomacy' of India and South Africa for the TRIPS waiver', *Journal of Asian and African Studies*, 58(5), pp. 747–765. Available at: https://doi.org/10.1177/00219096211069652.

Sismondo, S. (2020) 'Access to Medicines, Access to Markets', *Frontiers in Sociology*, 5, p. 58. Available at: https://doi.org/10.3389/fsoc.2020.00058.

Skaaning, S. -E. (2006) ‘Political Regimes and Their Changes: A Conceptual Framework’, *CDDRL Working Papers* [Preprint]. Available at: http://cddrl.fsi.stanford.edu/publications/political_regimes_and_their_changes_a_conceptual_framework (Accessed: 13 November 2023).

Smith, J. (2016) *Civil Society Organizations and the Global Response to HIV/AIDS*. London: Routledge. Available at: https://doi.org/10.4324/9781315412771.

Smith, J. and Fetner, T. (2007) ‘Structural Approaches in the Sociology of Social Movements’, in B. Klandermans and C. Roggeband (eds) *Handbook of Social Movements Across Disciplines*. Boston, MA: Springer US (Handbooks of Sociology and Social Research), pp. 13–57. Available at: https://doi.org/10.1007/978-0-387-70960-4_2.

Smith, R.A. and Siplon, P.D. (2006) *Drugs into bodies: Global AIDS treatment activism*. Westport, CT, US: Praeger Publishers/Greenwood Publishing Group (Drugs into bodies: Global AIDS treatment activism), pp. xiv, 196.

Smith, R. D., Correa, C. and Oh, C. (2009) ‘Trade, TRIPS, and pharmaceuticals’, *The Lancet*, 373(9664), pp. 684–691. Available at: https://doi.org/10.1016/S0140-6736(08)61779-1.

Smith-Spark, L., Brumfield, B. and Krever, M. (2014) *Ukraine signs EU deal that sparked months of upheaval; extends cease-fire*, *CNN*. Available at: https://www.cnn.com/2014/06/27/world/europe/ukraine-crisis/index.html (Accessed: 11 October 2019).

Snoga, J., La-Viola, B. and Sanchez, C. (2019) ‘Containing Generic-Drug Costs’, *US Pharm*, 44(6), pp. 32–35.

Soldak, K. (2014) *In A Time Of Crisis, Ukrainians Abroad Unite*, *Forbes*. Available at: https://www.forbes.com/sites/katyasoldak/2014/04/10/in-a-time-of-crisis-ukrainians-abroadunite/ (Accessed: 12 October 2019).

Solonenko, I. (2014) ‘Ukrainian Civil Society from the Orange Revolution to Euromaidan: Striving for a New Social Contract’, in *OSCE Yearbook 2014*. IFSH, pp. 291–235. Available at: https://ifsh.de/file-CORE/documents/yearbook/english/14/Solonenko-en_S.pdf (Accessed: 10 August 2019).

Solonenko, I. (2015) ‘Ukrainian Civil Society from the Orange Revolution to Euromaidan: Striving for a New Social Contract’, in Institute for Peace Research and Security Policy at the University of Hamburg / IFSH (ed.) *OSCE Yearbook 2014*. Nomos Verlagsgesellschaft mbH & Co. KG, pp. 219–236. Available at: https://doi.org/10.5771/9783845260945-219.

Somma, N. M. (2023) ‘Resource Mobilization and Political Process Theories in Latin America’, in F.M. Rossi (ed.) *The Oxford Handbook of Latin American Social Movements*. 1st edn. Oxford University Press, pp. 35–53. Available at: https://doi.org/10.1093/oxfordhb/9780190870362.013.3.

Son, K. -B., Kim, C. and Lee, T. -J. (2019) ‘Understanding of for whom, under what conditions and how the compulsory licensing of pharmaceuticals works in Brazil and Thailand: A realist synthesis’, *Global Public Health*, 14(1), pp. 122–134. Available at: https://doi.org/10.1080/17441692.2018.1471613.

Spearman, C. W. *et al.* (2019) ‘Hepatitis C’, *The Lancet*, 394(10207), pp. 1451–1466. Available at: https://doi.org/10.1016/S0140-6736(19)32320-7.

Spicer, N. *et al.* (2011) ‘'It’s risky to walk in the city with syringes': understanding access to HIV/AIDS services for injecting drug users in the former Soviet Union countries of Ukraine and Kyrgyzstan’, *Globalization and Health*, 7(1), p. 22. Available at: https://doi.org/10.1186/1744-8603-7-22.

Spindler, H. *et al.* (2014) ‘Underreporting of HIV Transmission Among Men Who Have Sex with Men in the Ukraine’, *AIDS Research and Human Retroviruses*, 30(5), pp. 407–408. Available at: https://doi.org/10.1089/aid.2013.0237.

Stafford, N. (2017) ‘Sofosbuvir faces fresh patent challenge in Europe’, *BMJ (Clinical research ed.)*, 356, p. j1632. Available at: https://doi.org/10.1136/bmj.j1632.

Staggenborg, S. (1998) ‘Social Movement Communities and Cycles of Protest: The Emergence and Maintenance of a Local Women’s Movement’, *Social Problems*, 45(2), pp. 180–204. Available at: https://doi.org/10.2307/3097243.

Stan, L. and Turcescu, L. (2000) ‘The Romanian Orthodox Church and Post-Communist Democratisation’, *Europe-Asia Studies*, 52(8), pp. 1467–1488.

Standford, D. (2018) ‘Ukraine Eyes Patent Law Reform After Civil Society Push On Medicines Access’, *Intellectual Property Watch*. Available at: https://www.ipwatch.org/2018/04/30/ukraine-eyes-patent-law-reform-civil-society-push-medicines-access/ (Accessed: 10 November 2019).

Stark, R. and Glock, C.Y. (1968) *American piety: the nature of religious commitment*. Berkeley, Calif.: Univ. of California Pr (Patterns of religious commitment, 1).

Stepaniuk, N. (2022) ‘Wartime Civilian Mobilization: Demographic Profile, Motivations, and Pathways to Volunteer Engagement Amidst the Donbas War in Ukraine’, *Nationalities Papers*, pp. 1–18. Available at: https://doi.org/10.1017/nps.2021.82.

Stepurko, T. *et al.* (2013) ‘Informal payments for health care services – Corruption or gratitude? A study on public attitudes, perceptions and opinions in six Central and Eastern European countries’, *Communist and Post-Communist Studies*, 46(4), pp. 419–431. Available at: https://doi.org/10.1016/j.postcomstud.2013.08.004.

Stern, D. (2012) ‘Ukraine takes aim against 'gay propaganda'’, *BBC News*, 9 October. Available at: https://www.bbc.com/news/magazine-19881905 (Accessed: 8 November 2023).

STOPAIDS *et al.* (2020) *HIV, Universal Health Coverage, and the Future of the Global Health Architecture. A civil society discussion paper on key trends and principles for evolution*. Discussion Paper. Available at: https://stopaids.org.uk/wpcontent/uploads/2020/01/HIV-Universal-Health-Coverage-and-the-future-of-the-globalhealth-architecture.pdf (Accessed: 10 June 2021).

Strathdee, S.A. *et al.* (2010) ‘HIV and risk environment for injecting drug users: the past, present, and future’, *Lancet (London, England)*, 376(9737), pp. 268–284. Available at: https://doi.org/10.1016/S0140-6736(10)60743-X.

Sullivan, R. *et al.* (2011) ‘Delivering affordable cancer care in high-income countries’, *The Lancet Oncology*, 12(10), pp. 933–980. Available at: https://doi.org/10.1016/S14702045(11)70141-3.

Sviatnenko, S. and Vinogradov, D. A. (2014) ‘Euromaidan Values from a Comparative Perspective’, *Social, Health, and Communication Studies Journal*, 1(1), pp. 41–61.

Swaminathan, S. *et al.* (2022) ‘Reboot biomedical R&D in the global public interest’, *Nature*, 602(7896), pp. 207–210. Available at: https://doi.org/10.1038/d41586-022-00324-y.

Swidler, A. (2000) ‘Cultural Power and Social Movements: Originally published in Social Movements and Culture, vol. 4, 1995’, in L. Crothers and C. Lockhart (eds) *Culture and Politics*. New York: Palgrave Macmillan US, pp. 269–283. Available at: https://doi.org/10.1007/978-1-349-62965-7_15.

Takács, J. *et al.* (2013) ‘Effects of Stigmatization on Gay Men Living with HIV/AIDS in a Central-Eastern European Context: A Qualitative Analysis from Hungary’, *Sexuality research & social policy: journal of NSRC: SR & SP*, 10(1), pp. 24–34. Available at: https://doi.org/10.1007/s13178-012-0102-5.

Taran, Y. S. *et al.* (2011) ‘Correlates of HIV Risk Among Injecting Drug Users in Sixteen Ukrainian Cities’, *AIDS and Behavior*, 15(1), pp. 65–74. Available at: https://doi.org/10.1007/s10461-010-9817-6.

Tarnoff, C. and Lawson, M. (2016) *Foreign aid: An introduction to U.S. programs and policy*. Congressional Research Service Report. Available at: http://nationalaglawcenter.org/wp-content/uploads/assets/crs/R40213.pdf. (Accessed: 20 May 2023).

Tarrow, S. (1998) *Power in Movement: Social Movements and Contentious Politics*. Cambridge University Press.

Tarrow, S. (2001) ‘Transnational Politics: Contention and Institutions in International Politics’, *Annual Review of Political Science*, 4(1), pp. 1–20. Available at: https://doi.org/10.1146/annurev.polisci.4.1.1.

Tarrow, S. (1994) *Power in movement: social movements, collective action, and politics*. Cambridge, England; New York: Cambridge University Press (Cambridge studies in comparative politics).

Taylor, V. *et al.* (2009) ‘Culture and Mobilization: Tactical Repertoires, Same-Sex Weddings, and the Impact on Gay Activism’, *American Sociological Review*, 74(6), pp. 865– 890.

Taylor, V. and Van Dyke, N. (2007) ‘'Get up, Stand up': Tactical Repertoires of Social

Movements', in D.A. Snow, S.A. Soule, and H. Kriesi (eds) *The Blackwell Companion to Social Movements*. Oxford, UK: Blackwell Publishing Ltd, pp. 262–293. Available at: https://doi.org/10.1002/9780470999103.ch12.

Tenni, B. *et al.* (2022) 'What is the impact of intellectual property rules on access to medicines? A systematic review', *Globalization and Health*, 18(1), p. 40. Available at: https://doi.org/10.1186/s12992-022-00826-4.

Thambisetty, S. *et al.* (2022) 'Addressing Vaccine Inequity During the COVID-19 Pandemic: The TRIPS Intellectual Property Waiver Proposal and Beyond', *The Cambridge Law Journal*, 81(2), pp. 384–416. Available at: https://doi.org/10.1017/S0008197322000241.

Thapa, S. *et al.* (2018) 'Stigma reduction in relation to HIV test uptake in low- and middleincome countries: a realist review', *BMC Public Health*, 18, p. 1277. Available at: https://doi.org/10.1186/s12889-018-6156-4.

The Global Fund (2018) *Global Fund Grants to Ukraine*. Audit Report. Available at: https://www.theglobalfund.org/media/7122/oig_gf-oig-18-003_report_en.pdf (Accessed: 21 October 2020).

The Global Fund (2020) *UKRAINE Mid-term Assessment Global Fund Breaking Down Barriers Initiative*. Geneva, Switzerland. Available at: https://www.theglobalfund.org/media/10269/crg_2020midtermassessmentukraine_report_en.pdf (Accessed: 9 August 2021).

The World Bank (2015) *Ukraine Economic Update*. Available at: https://www.worldbank.org/content/dam/Worldbank/document/eca/ukraine/ua-macro-april2015-en.pdf (Accessed: 21 October 2020).

The World Bank (no date) *World Bank Group statement on Ukraine*. Available at: https://doi.org/10/world-bank-group-statement-on-ukraine.

The World Health Organisation (2007) *Commission on Social Determinants of Health: Civil Society Report*, p. 145. Available at: https://www.who.int/publications/m/item/commissionon-social-determinants-of-health-civil-society-report (Accessed: 25 October 2020).

Thorne, C. *et al.* (2010) 'Central Asia: hotspot in the worldwide HIV epidemic', *The Lancet Infectious Diseases*, 10(7), pp. 479–488. Available at: https://doi.org/10.1016/S14733099(10)70118-3.

Tilly, C. (1978) *From mobilization to revolution*. New York: McGraw-Hill.

Tilly, C. (1995) 'To Explain Political Processes', *American Journal of Sociology*, 100(6), pp. 1594–1610.

Tilly, C. (1997) 'Contentious politics and social change', *African Studies*, 56(1), pp. 51–65. Available at: https://doi.org/10.1080/00020189708707860.

Tilly, C. (2004) *Social movements, 1768-2004*. Boulder: Paradigm Publishers.

Tilly, C. (2008) *Contentious Performances*. 1st edn. Cambridge University Press. Available at: https://doi.org/10.1017/CBO9780511804366.

Tilly, C. and Tarrow, S. (2015) *Contentious politics*. Second edition, fully revised and updated. New York, NY: Oxford University Press.

Timmermans, K. (2007) 'Monopolizing Clinical Trial Data: Implications and Trends', *PLOS Medicine*, 4(2), p. e2. Available at: https://doi.org/10.1371/journal.pmed.0040002.

Tokar, A., Sazonova, I., *et al.* (2019) 'HIV testing behaviour and HIV prevalence among female sex workers in Ukraine: findings from an Integrated Bio-Behavioural Survey, 2013–2014', *Sexually Transmitted Infections*, 95(3), pp. 193–200. Available at: https://doi.org/10.1136/sextrans-2018-053684.

Tokar, A., Osborne, J., *et al.* (2019) ''Virus Carriers' and HIV testing: navigating Ukraine's HIV policies and programming for female sex workers', *Health Research Policy and Systems*, 17(1), p. 23. Available at: https://doi.org/10.1186/s12961-019-0415-4.

Tolstrup, J. (2013) 'When can external actors influence democratization? Leverage, linkages, and gatekeeper elites', *Democratization*, 20(4), pp. 716–742. Available at: https://doi.org/10.1080/13510347.2012.666066.

Toren, D. (2024) 'Ukraine Distances Itself from Russia in Advancing LGBTQ+ Equality | Wilson Center', *The Russia File*. Available at: https://www.wilsoncenter.org/blog-post/ukraine-distances-itself-russia-advancing-lgbtq-equality (Accessed: 15 April 2024).

Toros, E. (2007) ‘Understanding the Role of Civil Society as an Agent for Democratic Consolidation: The Turkish Case’, *Turkish Studies*, 8(3), pp. 395–415. Available at: https://doi.org/10.1080/14683840701489274.

Townsend, B. (2021) ‘Defending access to medicines in regional trade agreements: lessons from the Regional Comprehensive Economic Partnership – a qualitative study of policy actors’ views’, *Globalization and Health*, 17(1), pp. 1–14. Available at: https://doi.org/10.1186/s12992-021-00721-4.

Transparency International (no date) *Global Corruption Barometer - 2010/11*, *Transparency.org*. Available at: https://www.transparency.org/en/gcb/global/globalcorruption-barometer-2010-11 (Accessed: 10 August 2022).

Traugott, M. and McAdam, D. (eds) (1995) ‘'Initiator' and 'Spin-off' Movements: Diffusion Processes in Protest Cycles’, in *Repertoires and cycles of collective action*. Durham: Duke University Press.

Treatment Action Campaign (2007) *HIV in our Lives*. Treatment Action Campaign, p. 85. Available at: https://www.tac.org.za/wp-content/uploads/2020/04/HIVInOurLivesEnglish.pdf (Accessed: 4 May 2020).

Trickey, A. *et al.* (2022) ‘Impact and cost-effectiveness of non-governmental organizations on the HIV epidemic in Ukraine among men who have sex with men’, *AIDS (London, England)*, 36(14), pp. 2025–2034. Available at: https://doi.org/10.1097/QAD.0000000000003347.

Tusikov, N. (2017) ‘Transnational non-state regulatory regimes’, in P. Drahos (ed.) *Regulatory theory: foundations and applications*. Acton, ACT: Australian National University Press, pp. 339–353.

Twigg, J. (2017) ‘Ukraine’s Health Sector’. Available at: https://www.csis.org/analysis/ukraines-health-sector (Accessed: 8 November 2023).

Ukraine Can Eliminate Hepatitis: National Hepatitis Elimination Profile (2023). Coalition for Global Hepatitis Elimination. Available at: https://www.globalhep.org/sites/default/files/content/page/files/2023-07/National%20Hepatitis%20Elimination%20Profile-Ukraine-final-27June.pdf (Accessed: 20 September 2023).

Ukraine Ministry of Health (2016) *National Health Reform Strategy for Ukraine 2015-2020*. Available at: http://en.moz.gov.ua/strategy (Accessed: 8 November 2023).

Ulfelder, J. (2005) 'Contentious Collective Action and the Breakdown of Authoritarian Regimes', *International Political Science Review / Revue internationale de science politique*, 26(3), pp. 311–334.

UNAIDS (2014) *Reduction of HIV-related stigma and discrimination*. UNAIDS, pp. 4–8. Available at: https://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_stigma_en.pdf (Accessed: 12 September 2021).

UNAIDS (2016) *On the Fast-Track to end AIDS: 2016-2021 Strategy*. Available at: https://www.unaids.org/sites/default/files/media_asset/20151027_UNAIDS_PCB37_15_18_EN_rev1.pdf (Accessed: 20 May 2022).

UNAIDS (2018a) *Global AIDS Monitoring 2018: Ukraine*. UNAIDS, p. 5. Available at: https://www.unaids.org/sites/default/files/country/documents/UKR_2019_countryreport.pdf (Accessed: 5 October 2021).

UNAIDS (2018b) 'Miles to go - The response to HIV in eastern Europe and central Asia'. Available at: https://www.unaids.org/sites/default/files/media_asset/miles-to-go_easterneurope-and-central-asia_en.pdf.

UNAIDS (2018c) *UNAIDS Data 2018*. UNAIDS. Available at: https://www.unaids.org/sites/default/files/media_asset/unaids-data-2018_en.pdf (Accessed: 20 October 2020).

UNAIDS (2020) *20–50–80 to reach 100 in Ukraine*. Available at: https://www.unaids.org/en/resources/presscentre/featurestories/2020/november/20201106_ukraine-20-50-80 (Accessed: 21 January 2022).

UNAIDS (2012) *UNAIDS Ukraine Harmonized AIDS Response Progress Report*. Available at: https://www.unaids.org/sites/default/files/country/documents/ce_UA_Narrative_Report[1].pdf (Accessed: 18 November 2019).

UNIAN (2019) *Kyiv's court rules to reinstate Suprun as Ukraine's Acting Health Minister*. Available at: https://www.unian.info/society/10446378-kyiv-s-court-rules-to-reinstatesuprun-as-ukraine-s-acting-health-minister.html (Accessed: 8 November 2023).

United Nations (2015) *THE 17 GOALS | Sustainable Development*. Available at: https://sdgs.un.org/goals (Accessed: 5 May 2023).

United Nations (2020) *Civil Society*, *United Nations*. United Nations. Available at: https://www.un.org/en/civil-society/page/about-us (Accessed: 20 October 2020).

United Nations (2016) *United Nations Secretary-General's High Level Panel on Access to Medicines*. United Nations. Available at: https://www.unsgaccessmeds.org/final-report (Accessed: 3 February 2019).

United Nations Development Programme (2017) *Defining civil society for Ukraine: Summary of the Research Report*. Available at: https://www.undp.org/ukraine/publications/definingcivil-society-ukraine (Accessed: 25 October 2019).

Uphoff, N. (1993) 'Grassroots organizations and NGOs in rural development: Opportunities with diminishing states and expanding markets', *World Development*, 21(4), pp. 607–622. Available at: https://doi.org/10.1016/0305-750X(93)90113-N.

U.S. Department of state (2022) 'PEPFAR Investing US $13 Million to Reach Ukrainians in Need with Life-Saving HIV Treatment', *United states Department of state*. Available at: https://www.state.gov/pepfar-investing-us-13-million-to-reach-ukrainians-in-need-with-lifesaving-hiv-treatment/ (Accessed: 20 March 2023).

USAID (2021) *Survey of Ukrainian Population Regarding Trust in the Judiciary and Other Branches, Judicial Independence and Accountability, Perception of and Reporting Corruption*. Survey Results. Ukraine. Available at: https://newjustice.org.ua/wpcontent/uploads/2021/06/2021_Survey_Population_Report_ENG.pdf (Accessed: 10 September 2022).

Vanable, P.A. *et al.* (2006) 'Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women', *AIDS and behavior*, 10(5), pp. 473–482. Available at: https://doi.org/10.1007/s10461-006-9099-1.

Vasylyev, M. *et al.* (2022) 'Unified European support framework to sustain the HIV cascade of care for people living with HIV including in displaced populations of war-struck Ukraine', *The Lancet HIV*, 9(6), pp. e438–e448. Available at: https://doi.org/10.1016/S23523018(22)00125-4.

Vasylyeva, T. I. *et al.* (2018) 'Molecular epidemiology reveals the role of war in the spread of HIV in Ukraine', *Proceedings of the National Academy of Sciences of the United states of America*, 115(5), pp. 1051–1056. Available at: https://doi.org/10.1073/pnas.1701447115.

Velásquez, G. (2015) *Guidelines on patentability and access to medicines*. Research Paper 61. Geneva: South Centre.

Vestergaard, J. and Wade, R.H. (2015) 'Still in the Woods: Gridlock in the IMF and the World Bank Puts Multilateralism at Risk', *Global Policy*, 6(1), pp. 1–12. Available at: https://doi.org/10.1111/1758-5899.12178.

Vigh, H (2006). *Navigating terrains of war: Youth and soldiering in Guinea Bissau.* Oxford, Berghahn Books.
DOI : 10.1515/9781782387275

Vigh, H. (2009) 'Motion squared: A second look at the concept of social navigation', *Anthropological Theory*, 9(4), pp. 419–438. Available at: https://doi.org/10.1177/1463499609356044.

Vigh, H. (2010) 'Youth Mobilisation as Social Navigation. Reflections on the concept of dubriagem', *Cadernos de Estudos Africanos*, (18/19), pp. 140–164. Available at: https://doi.org/10.4000/cea.110.

Villa-Torres, L. *et al.* (2017) 'Transnationalism and health: A systematic literature review on the use of transnationalism in the study of the health practices and behaviors of migrants', *Social Science & Medicine*, 183, pp. 70–79. Available at: https://doi.org/10.1016/j.socscimed.2017.04.048.

Vincent Rajkumar, S. (2020) 'The high cost of prescription drugs: causes and solutions', *Blood Cancer Journal*, 10(6), p. 71. Available at: https://doi.org/10.1038/s41408-020-0338-x.

Vitek, C. R. *et al.* (2014) ‘Slowing of the HIV Epidemic in Ukraine: Evidence from Case Reporting and Key Population Surveys, 2005–2012’, *PLoS ONE*, 9(9), p. e103657. Available at: https://doi.org/10.1371/journal.pone.0103657.

Voskresenskaya, E. (2018) *The HIV epidemic in Ukraine*, *Health Europa*. Available at: https://www.healtheuropa.com/hiv-epidemic-ukraine/83554/ (Accessed: 25 October 2020).

Wafula, F., Agweyu, A. and Macintyre, K. (2014) ‘Trends in Procurement Costs for HIV Commodities: A 7-Year Retrospective Analysis of Global Fund Data Across 125 Countries’, *Journal of acquired immune deficiency syndromes (1999)*, 65(4), pp. e134–e139. Available at: https://doi.org/10.1097/QAI.0000000000000053.

Walker, E. T., Martin, A.W. and McCarthy, J. D. (2008) ‘Confronting the state, the Corporation, and the Academy: The Influence of Institutional Targets on Social Movement Repertoires’, *American Journal of Sociology*, 114(1), pp. 35–76. Available at: https://doi.org/10.1086/588737.

Wang, L. X. (2022) ‘Global drug diffusion and innovation with the medicines patent pool’, *Journal of Health Economics*, 85, p. 102671. Available at: https://doi.org/10.1016/j.jhealeco.2022.102671.

Waning, B. *et al.* (2010) ‘Intervening in global markets to improve access to HIV/AIDS treatment: an analysis of international policies and the dynamics of global antiretroviral medicines markets’, *Globalization and Health*, 6(1), pp. 1–19. Available at: https://doi.org/10.1186/1744-8603-6-9.

Waning, B., Diedrichsen, E. and Moon, S. (2010) ‘A lifeline to treatment: the role of Indian generic manufacturers in supplying antiretroviral medicines to developing countries’, *Journal of the International AIDS Society*, 13, p. 35. Available at: https://doi.org/10.1186/1758-265213-35.

Way, L. (2014) ‘Civil Society and Democratization’, *Journal of Democracy*, 25(3), pp. 35–43. Available at: https://doi.org/10.1353/jod.2014.0042.

Watal, J. (2021) ‘Innovation, Intellectual Property, and Global Health’, in I. Kickbusch, D. Ganten, and M. Moeti (eds) *Handbook of Global Health*. Cham: Springer International Publishing, pp. 2683–2716. Available at: https://doi.org/10.1007/978-3-030-45009-0_115.

Wedel, J. R. (1998) *Collision and collusion: the strange case of Western aid to Eastern Europe, 1989-1998*. 1st ed. New York: St. Martin's Press.

Weigle, M. A. and Butterfield, J. (1992) 'Civil Society in Reforming Communist Regimes: The Logic of Emergence', *Comparative Politics*, 25(1), pp. 1–23. Available at: https://doi.org/10.2307/422094.

White, A. M. (1999) 'Talking Feminist, Talking Black: Micromobilization Processes in a Collective Protest against Rape', *Gender and Society*, 13(1), pp. 77–100.

Whitley, B.E. (2009) 'Religiosity and Attitudes Toward Lesbians and Gay Men: A Meta-Analysis', *International Journal for the Psychology of Religion*, 19(1), pp. 21–38. Available at: https://doi.org/10.1080/10508610802471104.

Wibulpolprasert, S. *et al.* (2011) 'Government use licences in Thailand: The power of evidence, civil movement and political leadership', *Globalization and Health*, 7, p. 32. Available at: https://doi.org/10.1186/1744-8603-7-32.

Williams, D. (2000) 'Aid and sovereignty: quasi-states and the international financial institutions', *Review of International Studies*, 26(4), pp. 557–573. Available at: https://doi.org/10.1017/S026021050000557X.

Wilson, A. (2014) *Ukraine crisis: what it means for the West*. New Haven: Yale university press.

Wirtz, V.J. *et al.* (2016) 'Access to Medications for Cardiovascular Diseases in Low- and Middle-Income Countries', *Circulation*, 133(21), pp. 2076–2085. Available at: https://doi.org/10.1161/CIRCULATIONAHA.115.008722.

Wirtz, V. J. *et al.* (2017) 'Essential medicines for universal health coverage', *The Lancet*, 389(10067), pp. 403–476. Available at: https://doi.org/10.1016/S0140-6736(16)31599-9.

Wong, H. (2020) 'The case for compulsory licensing during COVID-19', *Journal of Global Health*, 10(1), p. 010358. Available at: https://doi.org/10.7189/jogh.10.010358.

Woode, M. E. *et al.* (2016) 'Potential market size and impact of hepatitis C treatment in low- and middle-income countries', *Journal of Viral Hepatitis*, 23(7), pp. 522–534. Available at: https://doi.org/10.1111/jvh.12516.

Woods, B. *et al.* (2016) 'Country-Level Cost-Effectiveness Thresholds: Initial Estimates and the Need for Further Research', *Value in Health*, 19(8), pp. 929–935. Available at: https://doi.org/10.1016/j.jval.2016.02.017.
Word, J., Prével, A. and Mousseau, F. (2014) *Walking on the West Side*. The Oakland Institute. Available at: https://www.oaklandinstitute.org/sites/oaklandinstitute.org/files/OurBiz_Brief_Ukraine.pdf (Accessed: 20 October 2021).

World Health Organisation (2015) *Pre-exposure prophylaxis (PrEP)*, *Global HIV Programme*. Available at: https://www.who.int/teams/global-hiv-hepatitis-and-stisprogrammes/hiv/prevention/pre-exposure-prophylaxis (Accessed: 9 November 2019).

World Health Organisation (2018) A study on the public health and socioeconomic impact of substandard and falsified medical products. WHO: 4–8.

World Health Organisation (2022) *Ukraine emergency*. Available at: https://www.who.int/emergencies/situations/ukraine-emergency (Accessed: 20 May 2022).

World Trade Organisation (2023) *Standards concerning the availability, scope and use of Intellectual Property Rights. Article 27*. Available at: https://www.wto.org/english/docs_e/legal_e/27-trips_04c_e.htm (Accessed: 12 May 2023).

Wouters, O. J. *et al.* (2022) 'Association of Research and Development Investments With Treatment Costs for New Drugs Approved From 2009 to 2018', *JAMA Network Open*, 5(9). Available at: https://doi.org/10.1001/jamanetworkopen.2022.18623.

World Trade Organisation, *Ministerial conferences - Doha 4th Ministerial - TRIPS declaration* (2006). Available at: https://www.wto.org/english/thewto_e/minist_e/min01_e/mindecl_trips_e.htm (Accessed: 7 November 2023).

Wu, Z. and Clark, N. (2013) 'Scaling up opioid dependence treatment in low- and middleincome settings', *Bulletin of the World Health Organization*, 91(2), pp. 82-82A. Available at: https://doi.org/10.2471/BLT.12.110783.

Zaller, N. *et al.* (2015) 'Geographic variability in HIV and injection drug use in Ukraine:

Implications for integration and expansion of drug treatment and HIV care', *The International Journal on drug policy*, 26(1), pp. 37–42. Available at: https://doi.org/10.1016/j.drugpo.2014.09.004.

Zarembo, K. and Martin, E. (2023) 'Civil society and sense of community in Ukraine: from dormancy to action', *European Societies*, 0(0), pp. 1–27. Available at: https://doi.org/10.1080/14616696.2023.2185652.

Zelinska, O. (2017) 'Ukrainian Euromaidan protest: Dynamics, causes, and aftermath', *Sociology Compass*, 11(9), p. e12502. Available at: https://doi.org/10.1111/soc4.12502.

Zhukova, V. (2013) 'Racializing Europe: Transnational and National Dimensions of Biopolitics, Health and HIV/AIDS. The Case of Ukraine.', *PhD dissertation., Central European University* [Preprint].

Zorgdrager, H. (2013) 'Homosexuality and hypermasculinity in the public discourse of the Russian Orthodox Church: an affect theoretical approach', *International Journal of Philosophy and Theology*, 74(3), pp. 214–239. Available at: https://doi.org/10.1080/21692327.2013.829649.

Appendices

Appendix A
Timeline of Access to Medicines Activism in Ukraine
(MMA, 2015; MMA, 2017; MMA 2019)

2013-2014:

- Euromaidan Protests

2014:

- Ukraine signing an Association Agreement with the EU
- Reanimation of Reformation Coalition was formed
- 100% Life became Ukrainian partner to UNITAID's project, 'Access to treatment for people living with HIV in middle-income countries'
- ViiV Healthcare extend coverage of voluntary licences for paediatric and adult formulations of DTG and ABC to include Ukraine 2015:
- Ukrainian Drug Procurement responsibilities given over to international organisations
- 100% Life roundtable to set out goals for patent reform and TRIPS Flex ● 100% start filing patent oppositions to Gilead's HEP C drug, Sofosbuvir 2016:
- EU-Ukraine, Deep and Comprehensive Free Trade Agreement signed
- TRIPS Plus provisions introduced
- Merck reduced their price of triple combination therapy, Atripla after lobbying from HIV CSOs
- 100% challenge the secondary patents of Lopinavir/Ritonavir. They lost the case and their appeals.
- 100% Life held a meeting on patent law reform and access to medicines with Ukrainian Ministry of Economic Development and Trade, Ministry of Health, UNDP, UNICEF, generic drug companies and patent law experts 2017:
- Affordable Medicines Programme was launched
- External reference pricing and reimbursement system was introduced
- Gilead Sciences extend coverage of voluntary licensing agreements for TDF, TAF, COB & EVG to include Ukraine

- Ministries of Health and Economic Development and Trade created a joint working group on issues related to IP and access to medicines and agreed to take part in patent reform activities after the 2016 meeting.
- Gilead brought Ukraine to court for revoking its patents using TRIPS Plus Provisions. The court case was settled, and Gilead continues to have data exclusivity rights until 2020.

2018:

- The Ministry of Economic Development and Trade of Ukraine refused the patent of Gilead's HEP C drug, Sofosbuvir 2019:
- Merck reduced the price of their drug, RTG by half.
- 100% Life becomes first CSO to oppose Merck's patent application for MK-8591 2020:
- Ukraine re-establishes control of drug procurement
- AbbVie release all patents for Lopinavir/Ritonavir
- COVID-19 Pandemic

Appendix B

Interview Guide

The research question is presented as follows: How did HIV and Hepatitis C treatment activists fight for their right to medicines in Ukraine from 2010-2021?

The study's objectives are as follows:

- To examine the temporal relationship between the growth of HIV and HCV CSOs and the Euromaidan Revolution in creating a window of opportunity for healthcare reform
- To understand the significance of foreign aid and resource power for treatment activism in Ukraine
- To critically assess the tools available and the strategies used by treatment activists to reduce the price of medicines
- To analyse the implications of the EU-Ukraine Free Trade Agreement on intellectual property rights and how CSOs navigated these changes.

To answer the research questions, the following questions will be asked:

What is the life of people living with HIV/HCV in Ukraine like today? Has this changed over time?

Do you think that HIV treatment activism evolved over the past 20 years?

Do you see 2014 as a turning point in your activism? Did the Euromaidan Revolution help your activism?

What role has the government played in your advocacy efforts to reduce the price of medicines and an overall reform to the patent system?

What role has the market played in your activism efforts, such as Big Pharma, TRIPS Plus provisions, Ukraine - EU Association Agreement.

Can you identify the role that multilateral institutions, such as UNDP, UNAIDS, WHO have played in your activism efforts?

How much of a role did international donors play in your access to medicines activism? OR as someone who works in a donor agency, what role did you play in HIV/HCV treatment activism in Ukraine?

What strategies did your organisation use to fight for the reduction in the price of HIV medications?

What strategies did your organisation use to seek reform of your patent system?

Recently, I heard a prominent Ukrainian HIV activist say that they do not think the Medicine Patent Pool works for MICs. What do you think of this statement?

Has collaboration taken place within the EECA region? If yes, has this helped inform the strategy of your work? If not, why not?

What were your campaigning methods and how has the government/pharma/public responded to your campaigning methods?

What obstacles have you faced in your advocacy?

Do you believe that your advocacy efforts have been successful?

What plans do you have for your future access to medicines activism?

Appendix C
Professional Achievements

This portfolio provides the reader with additional information regarding my professional, personal and research achievements to date, such as publications, awards, conference papers, public broadcasts, and stage performances.

Book Publications

Lawlor, R. (2021) Being Irish: Personal Reflections on Irish Identity Today. *The Liffey Press. P.142-144*

Teaching - DCU Modules

EN207 Ireland, Sex, and Text
LC279 Representing Otherness
LC583 Gender, Sexuality, and Migration

Teaching - External Modules

The Voice Programme, 2018-2023: Greater Involvement of People Living with HIV in HIV Clinical Trials

Are We Prepared for the Next Pandemic? Case studies of HIV, MPOX, COVID-19 and AMR

Research Awards:

Best poster award at IASSCS Conference 2016, The Helix, Dublin City University: 'The Virtuous Paedophile: Criminals or Victims of their Desires?'

Performances:

I co-created a play called *Rapids*, a stage production performed in The Project Arts Centre depicting the lives of people living with HIV in Ireland https://www.irishtimes.com/culture/stage/rapids-review-an-artful-antidote-to-the-resurgenceof-hiv-1.3253969

I consulted on and starred in a documentary movie called *How To Tell A Secret,* which explores the act of disclosure of being HIV positive and the stigma that drives people to withhold their status in contemporary Ireland. It was nominated for Best Documentary at the Irish Film TV Awards 2022, screened at movie festivals and HIV conferences worldwide, got a cinema release in Ireland, and is available on Netflix from December 1st, 2023.

https://www.imdb.com/title/tt18258632/?ref_=tt_mv_close

https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(23)00062-0/fulltext

Broadcasts:

PozVibe Podcast: Noel Walsh HIV Award (2023)

I am co-host of the PozVibe Podcast where we platform the voices of people living with HIV and our allies and around the world to share their stories. It recently won an HIV activism award at the Irish Gay and Lesbian Awards.

The Late Late Show, 2023

I was invited back on to the Late Late Show for Ryan Turbidy's last night as host. It was a huge honour to celebrate Ryan's work and to discuss my work since I was last on in 2019.

Tonight Show Virgin Media, 2023

On the Tonight Show on Virgin Media, I discussed the experiences of people living with HIV in Ireland today.

Politico Europe, 2022: MonkeyPox deals a fatal blow to global health security

'Until we get a handle on our global systems. Until we stop fighting for just incrementalism within policy … we're not going to get a handle on any of the big pandemics or epidemics that are happening around the world,' said Robbie Lawlor, co-founder of Access to Medicines Ireland. 'Unfortunately, the systems that we have now are not fit for purpose.'

I was honoured to have contributed to such an important article. It is time for systemic change; otherwise, we are doomed to constantly relive mistakes of the past & present - AIDS/COVID19/MPX.

https://pro.politico.eu/news/153032

Politico Europe, 2022: Anger and anxiety stalk EU's monkeypox vaccine lottery

Contributed to this article about community responses to Monkeypox during a time of government inaction, artificial vaccine scarcity, and chronic underfunding of sexual and community health services.

https://www.politico.eu/article/monkeypox-europe-relives-the-mistakes-of-covid-and-thestigma-of-hiv/

The Jennifer Zamparelli Show RTE 2FM, 2022

Discussed intellectual property, vaccine hoarding, and structural racism as reasons pertaining to global shortages of MPOX vaccines, therapeutics, and diagnostics.

https://www.rte.ie/radio/2fm/clips/22130202/

The Independent, 2022

Featured as one of The Independents 22 activists to watch in 2022

https://www.independent.ie/life/22-activists-to-watch-in-2022-from-countering-racism-tosaving-the-planet-the-people-fighting-for-change-in-ireland-41277842.html

Jennifer Zamperelli 2FM, 2021
I chat with Jennifer about Channel 4's 'It's A Sin' and discuss living with HIV in today's Ireland.
https://player.fm/series/jennifer-zamparelli/robbie-lawlor-hiv-activist

The Late Late Show 2019

Rapids tour promotion: Shaun Dunne, playwright of Rapids and I joined Ryan Tubridy to promote the nationwide tour of Rapids and to increase awareness of HIV in Ireland.

https://twitter.com/rtelatelateshow/status/1096548781699420161?lang=en

Jennifer Zamperelli 2FM 2019

Discussions on HIV with Robbie Lawlor and Dr Dominic Rowley: I chat alongside infectious disease consultant Dr Dominic Rowley about Ireland's growing HIV crisis, and what interventions are needed to reverse the trends.

https://www.rte.ie/radio1/podcast/podcast_jenniferzamparelli.xml

RTE Culture 2019

What it means to live HIV positive in Ireland: An article I wrote discussing my experiences with other people living with HIV as I collected their testimonies to be used in Rapids.

https://www.rte.ie/culture/2019/0207/1028115-rapids-what-it-means-to-live-hiv-positive-inireland/

The Irish Times 2018

50 people to watch in 2018: One of four activists mentioned to watch out for in 2018 due to my HIV prophylaxis advocacy.

https://bit.ly/2xq9V8Z

GCN 2018

Queer Irish to Watch out for in 2018

https://gcn.ie/queer-irish-watch-2018/

Sunday Business Post 2018

A feature of my work on U=U and its effect on serodiscordant couples

https://www.businesspost.ie/magazine/positively-charged-430975

The Sunday Telegraph 2018

An article entitled, ‘Why young people must be more HIV aware’. A feature where I discussed how essential inclusive and comprehensive relationship and sex education is for young people. I also discussed my research and the effects antiretrovirals have on those living with HIV (Print version only).

Drivetime RTE Radio 2018
Promoting our annual Access to Medicines Conference and its primary outcomes

Conference Papers:

On World AIDS Day 2023, I will speaking at two events at the Community and UK Leadership in the Global HIV Response. For the first event, I will be MC for a panel as part of the press conference launching UNAIDS’ 2023 World AIDS Day Report ‘Let Communities Lead’, with speakers such as Winnie Byanyima, Executive Director of UNAIDS and Solange Baptiste, Executive Director of ITPC. I will then speak on a panel entitled, ‘Shifting power to place communities at the centre’.

SEX Pan!cs, Dublin City University, October 2023: Chairing a roundtable discussion entitled, ‘Unravelling Sex Panics: A Roundtable on HIV Empowerment, Stigma, and Community Resilience in Ireland’. My paper is entitled, ‘Too much or too little panic? Community mobilisation in an era of looming pandemics.’

Chartered Physiotherapists and Healthcare Professionals in International Health and Development, 2023: HIV, Access to Medicines & A Movement Towards Health for All

National Virus Reference Lab, UCD 2023: Learning from Pandemics of Past and Present: Insights on Access to Medicines, Intellectual Property and Shaping the Pandemic Treaty

Irish Global Health Network Conference 2022:
I was invited to be a keynote speaker, alongside Dr. Mike Ryan from the World Health Organisation to discuss the themes of leadership, representation & inclusion in relation to pandemic preparedness and response.

https://globalhealth.ie/ighn-conference-2022-programme/

AIDS Conference, 2022:
I spoke at 2 satellite sessions at the AIDS conference on how U=U should be used as a health equity tool in global policy-making and fund allocation.

Why and how to educate about U=U in clinical, advocacy and community spaces

https://conference.aids2022.org/my-agenda-1?coday=2022-07-29&embed=

U=U Summit: Rapid-fire Case Studies: Promoting U=U Globally

https://www.ashm.org.au/wp-content/uploads/2022/06/DRAFT-Summit-Program-Overviewv.7.pdf

UCC Law Society, 2021

Intellectual property and access to COVID-19 technologies – lessons learned from the HIV pandemic

Comhlamh First Wednesday, 2021
Just Health: Challenges and Hope for real solidarity one year into a global pandemic - During this webinar, I outlined the reasons why the Irish Government should sign up to the WHO's COVID Technology Access Pool initiative (CTAP) and avoid mistakes of AIDS pandemic. Other speakers included Dr Mike Ryan, Executive Director of the WHO Health Emergencies Programme, Nadine Ferris France, Executive Director of the Irish Global Health Network and David Weakliam, Global Health Programme Director, HSE.

https://www.youtube.com/watch?v=Mt5Vlj16OzA

Association of Medical Students Ireland - 'Let's Talk About Sex' Sexual and Reproductive Health & Rights Symposium 2021

I presented a talk entitled, ‘Why AIDS isn't over Patents, Activism and Human Rights.’

https://www.eventbrite.ie/e/lets-talk-about-sex-ii-tickets-137112301585

Comhlamh First Wednesday 2020
Health & Wealth: Solidarity and justice in developing and delivering vaccines for COVID-19

https://comhlamh.org/blog/health-wealth-solidarity-and-justice-in-developing-and-deliveringvaccines-for-covid19/

European Health Forum Gastein 2019
Transforming HIV responses in Europe: Focus on disruptive community actions

https://www.ehfg.org/blog/2019/10/03/transforming-hiv-responses-in-europe-focus-ondisruptive-community-actions-w5/

European HIV Seminars 2019
Patient’s Role in HIV Research and Care Delivery: Outlining the theoretical and practical benefits of including the patient advocates into the research process.
https://europeanhivseminars.com/schedule/

Access to Medicines Conference 2019
Patient advocate's role in achieving equitable access to affordable and safe medicines
https://www.accesstomedicines.ie/conference-report

Irish Aid 2018, World AIDS Day, Smock Alley, Ireland
Father Michael Kelly’s Annual Lecture on HIV: Panel Discussion on ‘Leaving No One Behind’
https://smockalley.com/leaving-no-one-behind/

Royal College of Surgeons Ireland 2018
Presenting a feedback session of the International AIDS Conference
https://www.hivireland.ie/highlights-and-follow-up-session-to-international-aids-conference2018/

International AIDS Conference 2018, RAI Conference Centre, Amsterdam

The Lack of Political Engagement is Driving HIV Underground: A Call for Activism in the Political Arena

Access to Medicines Conference 2018
International and National Perspective on Issues Accessing Antiretroviral Treatment/Prophylaxis

It Ain't Over: America's Role in the International AIDS Response 2018
I provided seminars in universities to empower students to lobby key decision makers for increased funding to the Global Fund
University of Connecticut, Harvard University
Offices of Senators Murphy, Marky
Office of Representative Katherine Clarke

Appendix D
Informed Consent Form (English)

Informed Consent Form

Research Project: Procuring Health Equity: How HIV Treatment Activists are Fighting for Their Right to Medicines in Ukraine.

The principal investigators of this research are Mr. Robbie Lawlor (Ph.D. candidate), Associate Professor JeanPhilippe Imbert (supervisor), and Professor Anne Matthews (supervisor). This research establishes through semistructured interviews, an understanding of the role of activism in starting and maintaining a social movement under a common goal of access to medicines. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. If you do not understand some of the words or concepts, the researcher will take time to explain them as the interview process proceeds and you are encouraged to ask questions at any time.

We intend to protect the confidentiality of your responses to the fullest possible extent, within the limits of the law. Any personal data, such as name and contact details that you disclose will be kept in an encrypted, passwordprotected computer file. In accordance with the European Union's GDPR, your personal data will only be disclosed for the purposes of preventing and investigating offenses or the apprehension of prosecuting offenders; required urgently if perceived damage to participant's health or the health of others; required under law, legal advice or legal proceedings; consent from the research participant. Data will be stored securely for the lifetime of the project and securely destroyed following Dublin City University's institutional guidelines of 5 years after project completion.

Participant – please complete the following (Circle Yes or No for each question)

I have read the Plain Language statement (or had it read to me)	Yes/No
I understand the information provided	Yes/No
I have had an opportunity to ask questions and discuss this study	Yes/No
I have received satisfactory answers to all my questions	Yes/No
I am aware that my interview will be audiotaped	Yes/No

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. Your decision to participate or not, or to withdraw, will not affect any relationship you may have with this University. Your data will be safely destroyed once your consent is withdrawn. No financial rewards will be provided to participants of this study.

Signature:

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project

Participants Signature: _____

Name in Block Capitals: _____

Witness: _____

Date: _____

Appendix E
Informed Consent Form (Ukrainian)

Форма поінформованої згоди

***<u>Дослідницький проект</u>*: *Забезпечення рівноправ'я в питаннях охорони здоров'я*: *як активісти в сфері лікування ВІЛ-інфекції борються за своє право на лікарські препарати в Україні*.**

Основні дослідники цього проекту: пан Роберт Лоулор (кандидат на здобуття ступеню Ph.D.), доцент ЖанФіліпп Імбер (куратор) та проф. Енн Метьюс (куратор). Дослідження проводиться шляхом збору усної інформації про розуміння ролі активізму для започаткування та підтримки успішного соціального руху, загальною метою якого є доступ по лікарських препаратів. Вам не потрібно буде приймати рішення про участь у дослідженні сьогодні. Перед тим як приймати рішення ви можете поговорити про це дослідження із тим, з ким вважаєте за потрібне. Якщо вам незрозумілі якісь слова чи поняття, дослідник пояснить їх вам в процесі інтерв'ю, впродовж якого ви можете ставити будь-які питання. У зв'язку із пандемією COVID19 бажано, щоб інтерв'ю проводилось на платформах Facetime та Signal, вони вважаються програмами з високим рівнем захисту завдяки функції наскрізного шифрування. Якщо ви не маєте доступу до цих програм, тоді інтерв'ю відбудеться в Zoom. Однак слід розуміти, що Zoom має недоліки щодо захисту особистої інформації. Мій обліковий запис у DCU Zoom дає гарантії збереження таємниці приватного життя, але засоби захисту Zoom захищають не так добре як ті, що є на платформах Facetime та Signal. Відеореєстрації інтерв'ю проводитись не буде, але з вашого дозволу ми запишемо аудіо, щоб мати точну інформацію, яку ви нам надасте.

Ми маємо намір максимально захистити конфіденційність наданої вами інформації відповідно до того, як це передбачено законодавством. Всі особисті дані, наприклад ім'я, прізвище, контактна інформація, які ви надаватимете, зберігатимуться у зашифрованому комп'ютерному файлі під паролем. Згідно Загального Регламенту із захисту персональних даних Європейського Союзу (GDPR) ваші персональні дані будуть розкриті лише з метою запобігання чи розслідування правопорушень чи затримання злочинців; вимагатимуться в негайному порядку у разі загрози здоров'ю учасника чи здоров'ю інших осіб; вимагатимуться згідно закону, юридичної консультації чи судового розгляду; за згодою учасника дослідження. Ці данні безпечно зберігатимуться впродовж тривалості дослідження та будуть надійно знищені відповідно до норм Дублінського муніципального Університету через 5 років після закінчення даного проекту.

Шановний учаснику, заповніть наступну форму (обведіть Так або Ні по кожному питанню)

Я прочитав (-ла) “Положення простою мовою” (або мені його прочитали)	Так/Ні
Я розумію надану інформацію	Так/Ні
В мене була можливість поставити запитання та обговорити це дослідження	Так/Ні
Мене задовольнили відповіді на всі мої запитання	Так/Ні
Я знаю, що буде зроблений аудіозапис мого інтерв’ю	Так/Ні
Мені вже виповнилося 18 років	Так/Ні
Мій рівень володіння англійською мовою достатній для участі	Так/Ні

Участь у цьому дослідженні є абсолютно добровільною. Брати участь чи ні — вибір лише за вами. Ваше рішення щодо участі чи щодо припинення участі жодним чином не вплине на ваші можливі стосунки із вказаним Університетом. У разі якщо ви заберете свою згоду на участь, ваші дані будуть безпечно знищені. Фінансова винагорода учасникам цього дослідження не надається.

Підпис:

Я прочитав (-ла) та зрозумів (-ла) інформацію, надану в цій формі. Дослідники відповіли на мої питання, надали необхідні пояснення. В мене є екземпляр цієї форми. З огляду на вищезазначене, я даю згоду на участь у цьому дослідницькому проекті

Підпис учасника: _____

Ім’я та прізвище великими друкованими літерами: _____

Засвідчив (-ла): _____

Дата: _____

Appendix F

Plain Language statement (English)

PLAIN LANGUAGE STATEMENT

Mr. Robert Lawlor (Ph.D. candidate)
School of Applied Languages and Intercultural Studies
Dublin City University (DCU)
Phone: 00353831657466
Email: Robert.lawlor29@mail.dcu.ie

Associate Professor Jean-Philippe Imbert (Supervisor)
School of Applied Languages and Intercultural Studies
Dublin City University (DCU)
Phone: 0035317005676
Email: jean-philippeimbert@dcu.ie

Project: Procuring Health Equity: How HIV Treatment Activists are Fighting for Their Right to Medicines in Ukraine

Introduction
You are invited to participate in the above research project, which is being conducted by Mr. Robert Lawlor (Ph.D. candidate), Associate Professor Jean-Philippe Imbert (Supervisor) and Professor Anne Matthews (Supervisor) of the School of Applied Languages and Intercultural Studies in Dublin City University. This research establishes through semi structured interviews, an understanding of the role of activism in starting and maintaining a successful social movement under a common goal of access to medicines. This project has been approved by Dublin City University's Research Ethics Committee.

What will I be asked to do?
Should you agree to participate, we would ask you to participate in an in-depth interview of about 40-60 minutes in the English language, so that we can get a more detailed picture of your experiences working in the area of access to medicines. With your permission, the interview would be digitally recorded so that we can make an accurate record of what you say.

How will my confidentiality be protected?
We intend to protect the confidentiality of your responses to the fullest possible extent, within the limits of the law. Your name and contact details will be kept in a separate, password-protected computer file from any data that you disclose. Your contact details will only be accessible to the lead investigator. In the final report, you will be referred to by a pseudonym. We will remove any references to personal information that might allow someone to guess your identity, however, you should note that as the number of people we seek to interview is very small, it is possible that someone may still be able to identify you. Digital and written data will be safeguarded in a secure room in Kiev International Institute of Sociology while the research is ongoing in Ukraine. The data will then be securely transported and securely locked in the School of Applied Languages and Intercultural Studies in Dublin City University for five years from the date of publication, and will be destroyed after this time.

What are the legal limitations to data confidentiality?
In accordance with GDPR, disclosure of personal data will only be permitted for purposes of preventing and investigating offences or apprehending prosecuting offenders; required urgently if perceived damage to participant's health; required under law, legal advice or legal proceedings; consent from the research participant.

Benefits of taking part in the research study
There is no direct personal benefit to participants. However, participation can encourage participants to reflect on their positive contributions to the lives of people living with HIV and helping to build a more complete picture of effective activism. Reflecting on life stories during the interview process can provide a safe space for the activist to remember their campaigning experiences which can help with their professional and personal development. Research shows that reflecting on past experiences can create positive emotions, such as relief in sensitive research topics. No financial rewards will be provided to participants of this study.

What are the risks of taking part in the research study?
Due to the limited number of HIV treatment activists in Ukraine, total anonymity cannot be guaranteed. This may result in some aspects of the participant's experiences becoming recognizable to others even though every care will be taken to keep the participant's identity confidential. To maximize safety, the research participants' data will be safely secured and not shared with third party individuals or organisations. While the participant has full control over what they wish to disclose, highly sensitive issues such as such as sexuality, HIV status and political affiliations may arise. Recollection of these sensitive issues may generate unwanted feelings for the participant. If these feelings arise, please contact the number for 100% Life Ukraine to access their counseling and psychological health services.

How will I receive feedback?
After the completion of this research, a brief summary of the findings will be available to you in English on application to the researcher at the School of Applied Languages and Intercultural Studies, DCU. It is also possible that the results will be presented at academic conferences and in published papers. After publication of the Ph.D., the research findings will be published on DORAS, DCU's online open access journal, in journal articles and conferences relating to the research topic.

Do I have to take part?
Participation in this study is completely voluntary. Voluntary participation means that if you wish to withdraw at any stage, or to withdraw any unprocessed data you have supplied, you are free to do so without prejudice. Your

decision to participate or not, or to withdraw, will not affect any relationship you may have with Dublin City University. Your data will be safely destroyed once your consent is withdrawn.

Where can I get further information?
Please contact the researchers, using the contact details above, if you have any questions or if would like more information about the project.

If you have any concerns about the conduct of the project which you do not wish to discuss with the research team, please contact Dublin City University's Research Ethics Committee on ph.: 00353 (1) 7008000 or via email: rec@dcu.ie.

If you feel upset after having completed the study or find that some questions or aspects of the study triggered distress, talking with a qualified clinician may help. If you feel you would like assistance, please contact 100% Life for information regarding their counselling and psychological health services. To contact Ukraine's 100% Life main office, call +38 (067) 341 98 37 or email info@network.org.ua.

How do I agree to participate?
If you would like to participate, please indicate that you have read and understood this information by signing the consent form and returning it to the researcher in person or via email. The researchers will then contact you to arrange a mutually convenient time for you to complete the interview.

How was this research funded?
This research was made possible by funding from The School of Applied Languages and Intercultural Studies in Dublin City University. The researcher was also awarded an Horizon 2020's, Rise Fellowship.

Signature:

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project

Participant's Signature: _____

Name in Block Capitals: _____

Witness: _____

Date: _____

Appendix G
Plain Language statement (Ukrainian)

ПОЛОЖЕННЯ ПРОСТОЮ МОВОЮ

Пан Роберт Лоулор (кандидат Ph.D.)
Школа прикладних лінгвістичних та міжкультурних наук
Дублінський муніципальний Університет (DCU)

Тел.: 00353831657466
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Доцент Жан-Філіпп Імбер (куратор)
Школа прикладних лінгвістичних та міжкультурних наук
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***Дослідницький проект:* Забезпечення рівноправ'я в питаннях охорони здоров'я: як активісти в сфері лікування ВІЛ-інфекції борються за своє право на лікарські препарати в Україні**

Вступ
Запрошуємо вас взяти участь у вищезазначеному дослідницькому проекті, що проводять пан Роберт Лоулор (кандидат Ph.D.), доцент Жан-Філіпп Імбер (куратор) та професор Енн Метьюс (куратор) Школи прикладних лінгвістичних та міжкультурних наук Дублінського муніципального Університету. Дослідження проводиться шляхом збору усної інформації про розуміння ролі активізму для започаткування та підтримки успішного соціального руху, загальною метою якого є доступ по лікарських препаратів. Цей проект погоджений Комітетом з питань етики проведення досліджень Дублінського муніципального Університету.

Що мене попросять зробити?
Якщо ви погодитесь на участь, ми попросимо вас взяти участь у глибинному інтерв'ю тривалістю близько 40-60 хвилин, що проводитиметься англійською мовою, щоб краще зрозуміти ваш досвід роботи з питань доступу до лікарських препаратів. З вашого дозволу інтерв'ю буде записано на цифрові носії, щоб у нас був точний запис сказаного вами.

Як буде захищена моя конфіденційність?
Ми маємо намір максимально захистити конфіденційність наданої вами інформації відповідно до того, як це передбачено законодавством. Ваші ім'я, прізвище та контактна інформація зберігатимуться у зашифрованому комп'ютерному файлі під паролем окремо від інформації, яку ви надаватимете. Доступ до ваших контактних даних буде лише у Головного дослідника. У остаточному звіті буде зазначений лише ваш псевдонім. Ми видалимо будь-які посилання на ваші особисті дані, які могли б допомогти комусь встановити вашу особу, однак, ви повинні взяти до уваги, що кількість людей, в яких ми хотіли би взяти інтерв'ю, є малою, ймовірність того, що хтось встановить вашу особу, залишається. Цифрова та письмова інформація надійно зберігатиметься в спеціальному кабінеті у моєму домашньому офісі. Коли Університет відновить свою роботу, ця інформація буде передана та зберігатиметься у Школі прикладних лінгвістичних та міжкультурних наук Дублінського муніципального Університету із дотриманням належних вимог впродовж п'яти років з дня її публікації, після чого її буде знищено.

Які є правові обмеження в питаннях конфіденційності даних?
Згідно Загального Регламенту із захисту персональних даних Європейського Союзу (GDPR) ваші персональні дані будуть розкриті лише з метою запобігання чи розслідування правопорушень чи затримання злочинців; вимагатимуться в негайному порядку у разі загрози здоров'ю учасника чи здоров'ю інших осіб; вимагатимуться згідно закону, юридичної консультації чи судового розгляду; за згодою учасника дослідження.

Переваги участі в дослідженні
Безпосередньої особистої користі для учасників немає. Однак це може спонукати учасників зробити позитивний вплив на життя людей, які живуть із ВІЛ, та допомогти внести вагомий вклад у справу ефективного активізму. Під час інтерв'ю активіст може почуватися абсолютно безпечно, розповідаючи історії із власного життя та досвіду участі в кампаніях, що сприятиме його (її) професійному та особистому розвитку. Дослідження свідчать про те, що згадка про минулий досвід викликає позитивні емоції, такі як полегшення стосовно можливості обговорення делікатних тем дослідження. Фінансова винагорода учасникам цього дослідження не надається.

У чому ризик участі в цьому дослідженні?
Через обмежену кількість активістів у сфері лікування ВІЛ-інфекції в Україні, повну анонімність гарантувати неможливо. Тому інші особи можуть здогадатись про учасників через описаний ними досвід, однак робитиметься усе можливе для того, щоб зберегти їх конфіденційність. Для посилення безпеки дані учасників дослідження надійно захищатимуться та не передаватимуться третім особам чи організаціям. Учасники мають повний контроль над тим, що вони бажають розкривати, але можуть підніматися такі делікатні питання як сексуальність, ВІЛ-статус та політичні уподобання. Торкання цих делікатних тем може викликати в учасників небажані почуття. Якщо такі почуття виникнуть, зверніться, будь-ласка, до "100% Життя" в Україні для отримання консультації та психологічної підтримки. Однак з огляду на пандемію COVID-19 такі послуги можуть бути обмежені лише телефонними дзвінками та повідомленнями. Будьласка, зверніться на вебсайт "100% Життя" network.org.ua/en/, щоб бути в курсі їх поточного обсягу послуг.

Як я отримаю зворотній зв'язок?
Після закінчення дослідження при зверненні до дослідника Школи прикладних лінгвістичних та міжкультурних наук Дублінського муніципального Університету ви отримаєте короткий звіт про результати дослідження англійською мовою. Можливо, ці результати презентуватимуться на наукових конференціях та будуть опубліковані у виданнях. Після публікації Ph.D. результати дослідження будуть опубліковані в онлайнових журналах з відкритим доступом DORAS, DCU, в статтях та на конференціях з відповідної тематики.

Чи повинен (повинна) я брати участь?
Участь у цьому дослідженні абсолютно добровільна. Добровільна участь означає, що якщо на якомусь етапі ви забажаєте припинити участь чи забрати будь-які ще необроблені дані, ви можете безперешкодно це зробити. Ваше рішення щодо участі чи щодо припинення участі жодним чином не вплине на ваші можливі стосунки із Дублінським муніципальним Університетом. Якщо ви заберете свою згоду на участь, ваші дані будуть безпечно знищені.

Де я можу взнати додаткову інформацію?
Якщо у вас виникли питання або ви хочете отримати більше інформації про цей проект, зверніться, будьласка, до дослідників: контактна інформація вказана на початку.

Якщо вас непокоять якісь питання стосовно цього проекту, які б ви не хотіли обговорювати із командою дослідників, ви можете звернутись до Комітету з питань етики досліджень Дублінського муніципального Університету за тел.: 00353 (1) 7008000 або по електронній пошті rec@dcu.ie.

Якщо після закінчення участі в дослідженні ви почуваєтесь засмученим або якщо якість питання чи аспекти дослідження викликали стрес, вам допоможе консультація досвідченого лікаря. Якщо ви відчуваєте, що вам потрібна допомога, зверніться, будь-ласка, до "100% Життя" для отримання консультації та психологічної підтримки. В головний офіс "100% Життя" в Україні можна звернутись за тел.:+38 (067) 341 98 37 або по електронній пошті info@network.org.ua.

Як фінансується це дослідження?
Це дослідження стало можливим завдяки фінансуванню Школою прикладних лінгвістичних та міжкультурних наук Дублінського муніципального Університету. Дослідник також отримав дослідницьку стипендію Horizon 2020's.

Підпис: Я прочитав (-ла) та зрозумів (-ла) інформацію у цій формі. Дослідники відповіли на мої питання, надали необхідні пояснення. В мене є екземпляр цієї форми. З огляду на вищезазначене, я даю згоду на участь у цьому дослідницькому проекті

Підпис учасника: _____

Ім'я та прізвище великими друкованими літерами: _____

Засвідчив (-ла): _____

Дата _____: