

# Exploring the paradigm of co-produced research within the context of the COVID pandemic

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## **ABSTRACT:**

There has been a paradigm shift within research exploring autistic experience in recent decades towards greater participation, agency and voice for autistic researchers and the autistic community more generally (Fletcher-Watson et al, 2019). This approach has shown a greater focus on research oriented towards the priorities or preferences of the autistic community (Fletcher-Watson & Happé, 2019; Pellicano et al., 2014), curtails concerns regarding epistemic injustice and has influenced understandings of autistic ontology and neurology. Co-produced research, characterised by the inclusion of diverse stakeholders, builds trust between participants. Nonetheless, co-production in research requires careful planning and support (Stark et al., 2021), sometimes proving 'turbulent' and 'challenging' (Worsley et al., 2021). This chapter explores the experiences and reflections of a team of autistic and non-autistic researchers conducting co-produced research amid the global COVID-19 pandemic. With research practices and systems altered due to increased remote work, online communication, and limited in-person interaction, this topic is especially pertinent. With the increasing emphasis on involving members of the autistic community in research at all levels of development, the impact of the pandemic on how participatory research is carried out may be complex. This chapter has implications for planning and conducting co-produced research in our new reality, considering both the opportunities and obstacles it presents.

**Key words:** Autistic Experience; Co-Produced Research; COVID 19; Collaboration; Neurodiversity;

## **Main Body:**

### **Introduction:**

This chapter explores the experiences of mixed teams of autistic and non-autistic researchers in co-produced research during the COVID-19 pandemic. Given the rising emphasis on involving the autistic community in research and the significant shift in research modes due to the pandemic, it's vital to understand how these changes affect research collaboration. This chapter draws from the transformative paradigm (Mertens, 2007) and Kuhn's concept of paradigm shifts (Kuhn, 1962). The transformative paradigm underlines social justice in research, while Kuhn's concept suggests science is prone to “paradigm shifts” when new evidence challenges the existing framework. A paradigm encompasses shared beliefs and assumptions within a scientific domain, influencing research problem selection and the choices of methodological rules to be used (Kuhn, 1962).

The chapter contains two sections. The first discusses the dual paradigm shifts in research exploring autistic neurology during the pandemic: an increased focus on autistic participation

(Fletcher-Watson et al, 2018, Pellicano, Dinsmore & Charman, 2014) and the reshaping of co-produced research due to pandemic-driven changes. The second section shares experiences from a mixed neurotype research team during and after the pandemic, emphasising the strengths and challenges of planning and conducting research. The chapter concludes with recommendations drawn from these experiences.

## Section 1. The movement towards greater participation in research

Literature on autistic experience and autistic neurology has recently evolved to increasingly involve autistic individuals in research that is relevant to their personal experiences (Fletcher-Watson et al., 2018; Pellicano, Dinsmore & Charman, 2014). This development is likely due to a shift in the research paradigm towards more ethical and diverse methods, which take into account the effects on both the participants and the wider community that could be indirectly impacted (Botha & Frost, 2020; Fletcher-Watson & Happe, 2019). A transformative approach to participatory research can adopt varying degrees of involvement, which not only influences the course of the research but also empowers the autistic community (Mertens, 2007; Fletcher-Watson et al., 2018; Stark et al., 2020). This approach to research design, modes of collaboration, and roles for participants informed the approach adopted in the research carried out by the authors of this chapter.

Consequently, research models are emerging with different degrees of participation, from consultation to full co-production (Stark et al., 2020). Hill et al. (2016) outline six degrees of participation for autistic individuals:

- **co-option** (research participants are represented but not actively involved in the research);
- **compliance** (participants engage in activities but the researchers dictate the research design and procedures);
- **consultation** (research participants contribute viewpoints but researchers determine analysis and interpretation);
- **co-operation** (research cohort work with researchers to consider priorities for the study but researchers control the process);
- **co-learning** (participants and researchers share knowledge to evolve new thinking and share in the research process); and
- **coproduction/ collective action** (members of the community who are the focus of the research design and conduct the research as independent equals).

The move to supporting participant agency and autonomy in research aligns with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD: United Nations, 2006). These changes in participatory roles have significantly impacted research exploring the experiences of autistic people, influencing both theory and conceptualization of autistic

experience and approaches to supporting participation (Botha, 2021; Fletcher-Watson & Happe, 2018; Milton, 2012). The work undertaken by the authors of this chapter sought to adopt a strengths-based, collaborative approach. We based inter-personal team-work and communication interactions on neurodiversity-affirming viewpoints.

## 1.2. From Autism To Autistic Experience - A Shifting Paradigm

Research exploring autistic neurology has similarly undergone a significant paradigm shift in recent decades, moving from deficit-focused perspectives to a neurodiversity model. Prior understandings or definitions of autism, as seen within the commonly referenced Diagnostic and Statistical Manual of Mental Disorders DSM V, (American Psychiatric Association, 2013), emphasise a deficit-focused perspective of the differences underpinning the construct of autistic neurology (Walker, 2021). Such medical model-informed perspectives use pathologising medical language comprising deficits or impairments to describe autistic people.

However, the influence of autistic researchers and theorists has led to the emergence of the neurodiversity paradigm (Botha, 2020, Bottema-Beutel et al, 2021, Kapp et al., 2019; Milton, 2012; Pearson & Rose, 2021), which is conceptualised based on four pillars (Walker, 2021; Fletcher-Watson, 2022):

- Neurodiversity is naturally occurring,
- No one neurotype is better than another,
- Neurodiversity operates like other equality and diversity dimensions, and
- Strength is in diversity itself. There is a collective value in diversity.

This shift in perspective has also brought focus to cognitive and perceptual differences on autistic experiences and thinking (Bogdashina, 2016). One such autistic-led model which seeks to evolve understanding away from deficit-focused explanations of autistic neurology focuses on predictive coding in perception (Bervoets et al., 2021; Van de Cruys et al., 2014). This model focuses on autistic perception and proposes a difference in salience relating to how prediction error is integrated (Van de Cruys et al., 2014). These are surprise signals indicating a difference between incoming sensory stimuli from the environment relative to predictions made based on past experiences or existing beliefs (Friston and Kiebel 2009). The model proposes that autistic neurology integrates more prediction errors into perception, thus learning from and about the world in a distinctly different way than neurotypicals (Bervoets et al., 2021; Van de Cruys et al., 2014). This difference leads to the development of highly complex internal models and understandings of the world incorporating rich environmental details, resulting in a different developmental trajectory, learning style, and experience of the world. This leads autistic individuals to be more likely to be more perceptually aware of the uncertainty that exists in the world (Bervoets, Milton, & Van de Cruys, 2021). In contrast, it is proposed that neurotypical neurology is built to achieve this by filtering out what is judged as “non-salient” predictive errors, thus reducing uncertainty, albeit at the expense of developing a richer understanding of the world in all its detail. Given the design of most environments is suited to neurotypical

perception, not autistic perception, such perceptual mechanisms in excessively chaotic unpredictable environments can lead to perceptual overload for autistic individuals. Autistic neurology is built with different mechanisms such as engaging in physical actions such as stimming which can counterbalance the dysregulation caused by prediction errors and cognitive processes such as monotropism, which act on a similar mechanism to regulate uncertainty and remain in a state of homeostasis (Van de Cruys et al., 2014).

Monotropism has been proposed as a theory of differences in cognition and emphasises the role of a focused attention style, sensory experiences, deep focus, and flow states (Murray, Lesser and Lawson, 2005). Autistic individuals often exhibit strong interests and can achieve a state of flow during engaging activities (Tansley et al., 2021; Wood, 2021) which has been described as a preference for sustained, deep, and determined focusing of attention on specific interests or activity (Murray, 2019). The phenomenon is linked to the concept of flow defined as a state highly beneficial to wellbeing where the individual loses track of time by engaging in a challenging and enjoyable activity (Csikszentmihalyi, 1990; Milton, 2021).

At an interaction level, The Double Empathy Problem, a highly influential autistic-led theory proposed by Milton (2012), challenges previous cognitive-based theories that focused on hypothesised deficits in autistic neurology. In contrast, Milton (2012) suggests that social misunderstandings and communication challenges are a bidirectional phenomena, brought about through the actions and expectations of all social actors within the social environment (Milton, 2017). Interaction problems among autistic individuals and neurotypical individuals result from a disjuncture of communication culture and social expectations, values and perceptual differences between all communicating participants, inclusive of autistic and neurotypical individuals (Milton, 2017). The Double Empathy problem (Milton, 2012) proposes a bi-directional misunderstanding within social engagement that includes comprehension breakdowns on the side of all communicants, both autistic and neurotypical. There is an increasing research evidence base to support the role of bi-directional communication disjunctions within social interactions involving mixed neurotype communicator groupings (e.g. Crompton et al. 2020a). Further research shows that autistic individuals do not experience the same issues in connection, belonging and creating social relationships with other autistic individuals that they do with neurotypical individuals (Crompton et al. 2020b).

### 1.3. Impacts of the COVID Pandemic: Working environment

The COVID-19 pandemic had widespread implications, causing European education systems to implement alternative measures to address the social disruptions (Simuț et al., 2021). Responses included lockdowns, social distancing, and a shift to remote learning and working (Marinoni et al., 2020). Universities and research practices were significantly affected, relying heavily on technology for collaboration and learning.

The sudden transition to remote working brought both advantages and challenges. Workers experienced increased flexibility and diversity in their work environment but also faced skill and knowledge challenges in adapting to remote technologies (Carolan et al., 2020). Some autistic researchers, however, benefited from the opportunity to control their work environment, particularly sensory aspects that have been described in detail in the existing co-production literature as concrete barriers to participation in research (Stark et al., 2021). Remote working also eliminates commuting requirements, offering greater access and flexibility. However, it disrupted social networks, posed challenges to mental health, and exacerbated existing inequalities (Pellicano & Stears, 2020).

Oomen et al. (2021) found that both autistic and non-autistic individuals experienced challenges and negative impacts from the pandemic. While technology-enabled hybrid working had positive effects for some, others felt excluded and isolated due to these changes. Some individuals experienced an overall benefit of greater accommodation, while other individuals have experienced a net disadvantage of greater exclusion and isolation.

## Section 2: Co-produced research during remote working: Lessons and learnings

This section recounts the experiences of a mixed team of autistic and non-autistic researchers collaborating on two small-scale research projects exploring autistic experiences during the COVID-19 pandemic. Despite systemic and structural challenges, the projects, which were conducted entirely remotely, offered valuable insights into co-produced research involving diverse neurotypes. Various issues, including financial constraints, planning difficulties, and differing expectations, impacted the projects' timelines and processes. The experiences of the research team underscore the importance of understanding neurodivergent communication, as highlighted by Milton's (2012) Double-Empathy problem, to avoid potential misunderstandings in such collaborative research efforts.

### 2.1. Project Planning- Appropriate Resourcing and Preparation

The co-produced projects conducted by the current team faced limitations due to small budgets, hindering the recruitment of full-time researchers. However, this arrangement is not uncommon in co-produced research (See, for example, Stark, Ali, Ayre, Schneider, Parveen, Marais, Holmes and Pender, 2021). Previous studies have emphasised the importance of adequate resources and preparation for sustainable planning and execution of such projects (Kenny et al., 2023; Stark et al., 2021). Worsley et al., (2021) point out that engaging in co-produced research can present challenges and be a demanding experience. Well-funded participatory research involving diverse cohorts or disabled individuals often requires additional planning time and resources (Vaughan et al., 2020). In the current projects, there was funding available for small remuneration for autistic research team members, but it was insufficient to cover the time contributions of some members. Non-autistic researchers on the team were not formally paid, but some members were employed at a university and were thus on a salary.

One important learning from the projects being discussed was that clear and appropriate timelines are crucial for effective project management, allowing for realistic planning and availability coordination. In co-produced research, decisions are made through a democratic and non-hierarchical group agreement process (Stark, et al., 2021). It is, therefore, imperative that a project proceeds in line with an agreed timeline in order to ensure researcher availability, clear communication, and the maintenance of trust across the research team (Lonbay et al., 2021). This allows realistic and effective planning for the research tasks in a project and allows team members to plan their own time and availability. The current team faced challenges in this regard, as team members had other external commitments, such as full-time employment or participation in other large projects, impacting their level of contribution, further affecting project progress. Remote work exacerbated the need for timely and clear communication, requiring careful planning and ongoing monitoring. The research team experienced challenges due to differences in perception and a mismatch in what was considered clear communication in terms of amount, interaction type and detail relayed. The project timeline changed over time, leading to confusion regarding expectations and a lack of predictability and structure, something that members of the team found challenging over the course of the project.

A more sustainable approach would involve adequately resourcing project coordination and communication roles by assigning dedicated individuals supported with appropriate time and funding. This could include securing funding to hire a researcher solely for coordinating a Co-Produced project or allocating funds to a team member taking on these roles. Ensuring timely and comprehensive information flow to team members, considering their other commitments, is crucial.

## 2.2. Transparency of membership, roles, and engagement during “Choice points”

At the start of a co-produced project, it is crucial to transparently negotiate the composition, roles, and expectations for all involved, particularly to support predictability, planning and the development of intra-team trust. Co-produced research follows a democratic and non-hierarchical philosophy, emphasising shared decision-making and responsibility. However, differing perceptions, backgrounds, neurotypes, and communication profiles among stakeholders led to challenges and disagreements within the research team. Such ideological and cultural differences arose in the current projects, resulting in a team member stepping back and altering the team's composition. Operating within a system designed for hierarchical working, the research team experienced challenges from the onset with much debate relating to differing opinions of what co-production involved, and how power dynamics could be managed. Additionally, mutual understanding was challenging to reach with differing perceptual and communication differences forming a barrier, as differences in what was regarded as salient information varied across the research team members. Debates ensued regarding the details of the research process and how to maintain effective communication in recognition of potential disjunctures of perceptions across the team. This consideration is



particularly important in remote research collaborations, such as the work being described in the current chapter.

Given the non-hierarchical power structures and group-mediated decision-making processes, agreeing on participation and communication approaches is essential at the project's planning stage. Accommodating individual preferences and availability during different stages of the research process is advisable. Researchers within the team have varying levels of expertise and capacity to contribute, particularly in mixed methods research involving technical aspects. The literature emphasises the use of "choice points" (Vaughn & Jacquez, 2020) to support collaborative role selection at each research step, allowing team members to make informed choices about their involvement (Vaughan et al., 2020). The concept of choice points across the research design and completion process allows ongoing negotiation of approach and role across the project. This characterised the approach within both Co-Produced Research projects completed by the current team, with different team members choosing to take part in various stages of the project and instrument design, data collection, or analysis of data. In addition, team members' degree of participation changed over time depending on their availability.

### 2.3. Accessible and Agreed Communication

Remote co-produced research processes occasionally highlighted diversity in communication preferences and expectations within the research team. The loss of shared physical space from in-person meetings impacted the flexibility of communication approaches, a change that was augmented via the use of a range of online or visual communication (VC) tools. While there is an existing literature regarding challenges linked to physical environments for in-person meetings and how they can be made accessible (See Stark et al., 2021), there remains a lacuna of research regarding supporting accessible remote research collaborations.

Choice of communication platform, specifically Gmail and Zoom (and limited use of Discord, Telegram and ClickUp), posed challenges as they were not accessible or efficient for all team members, both autistic and non-autistic. These limitations affected participation and hindered information retrieval. Furthermore, the use of Zoom as the primary video conferencing platform lacked thorough discussion, and was adopted as a default rather than being a preferred method chosen by the full team. The use of high-bandwidth Visual Conferencing (VC) platforms, such as Zoom, was used following only shallow discussion at the outset. This is inadvisable as careful and flexible planning for the use of VC platforms and negotiation of modes by which any individual can participate should be negotiated at the outset. Making training available at this early stage, as necessary, would also support participation and accessibility. Such VC platforms can be perceptually overwhelming and challenging for some autistic individuals given the need to process multiple environments, facial expressions, and body language simultaneously with distortions and delays inherent in video communication (Zolyomi et al., 2019). Some experts from fields such as psychology, computer science, and neuroscience suggest a simple phone call could be a better option than the use of VC platforms,

in some situations. They caution that the inherent distortions and delays in video communication may lead to, or amplify existing feelings of isolation, anxiety, and disconnection.

Challenges or issues may relate to the digital encoding and decoding process of video images, which results in numerous disruptions, including blocking, freezing, blurring, jerkiness, and audio that is out of sync. These disturbances, some of which may be below our conscious awareness, confuse our perception and muddle the interpretation of subtle social cues. Given the previously discussed features of predictive coding which is relevant to autistic perception, such distortion may be experienced as an unpleasant barrier to participation (Van de Cruys et al., 2014). Given the perceptual processes with which the individual seeks to fill in the missing pieces, make sense of chaotic messaging, and predict responses from the environment, VC platforms may contribute to feelings of discomfort, anxiety, and fatigue for some individuals, and may be particularly relevant to the experience for some autistic individuals.

Some researchers have sought to develop processes to support prior planning and scaffolding in advance of meetings which utilise VC technology. For example, Zolyomi et al., (2019: see Figure 1) developed a framework which aimed to foster individualised planning and supports for the different stages of the VC meeting process. Such an approach proposed focusing on identifying individual stressors, or barriers prior to the meeting and developing strategies to address or minimise these (Zolyomi et al., 2019). However, such approaches are merely frameworks to support planning and currently need more evidentiary support for their efficacy. Universal Design for Learning (CAST: Universal Design for Learning Guidelines Version 2.0, 2011) emphasises the importance of individualised prior planning for appropriate support, with such support needing to focus on the preferences, interests, strengths and areas of support needed by the particular individual involved.

#### 2.4. Institutional barriers within higher education:

The culture and operational structure of higher education institutions can pose barriers to mixed teams of autistic and neurotypical researchers. The prevailing culture among many academic staff in higher education and researchers emphasises working according to upcoming deadlines or tight timelines, which may not align with the expectations or preferences for those working according to different expectations or value systems. Hierarchical communication and organisational systems, driven by accountability and research funding management, can contradict the egalitarian nature of co-produced research.

Transparent negotiation of university requirements is necessary, with clear communication *from the outset* that certain steps, roles, or requirements may be imposed on the work of the team from external bodies, such as universities or ethics committees. The forefronting discussion of the potential impact and implications of bureaucratic structures and processes is crucial to ensure that all members of the project team understand and accept the potential for unforeseen constraints. The composition of a project team of equals can feel less so when individual members are complying with a less visible system that can have a powerful influence

on decision making, process and timeframes. Such initial negotiations ensures transparency and allows for timely discussions regarding the implications on power relations among team members, decision making processes, or work commitments of particular team members.

Furthermore, it should be acknowledged that institutional systems within universities can systematically exclude neurodivergent individuals and disabled individuals (Shiels et al., 2021). Inflexible support systems and bureaucratic processes can cause delays in contract provision, financial remuneration, and access to essential resources for participation in remote co-produced research projects.

## Conclusion:

This chapter outlined an exploration of the experiences and challenges faced by a diverse team of autistic and non-autistic researchers who endeavoured to undertake a co-produced research collaboration during the COVID-19 pandemic. The experience underscored the necessity of meticulous planning, effective communication, and judicious resource management in such research. However, budget constraints led to less structured project coordination than initially hoped, which proved to be a challenge for members of the team. Developing a satisfactory process to support appropriate communication using technological supports or tools was also challenging, something that was augmented by differences in roles, expectations, and neurotype across the research team. It should be noted, however, that the team were often effective despite working exclusively together via online platforms and via text, which is a significant achievement given the complexity of the work involved.

Contemporary theories like the double-empathy problem (Milton, 2012), monotropism (Murray, Lesser, and Lawson, 2005), and predictive processing (Bervoets et al., 2021; Van de Cruys et al., 2014) offer useful guidelines for planning mixed neurotype co-research projects and supporting contextually appropriate communication processes to support trust and understanding within research teams (Stark et al., 2021). Differences in neurotype may lead to differing understandings of what constitutes “good” communication or “effective” planning, given predictive processing suggests differing perceptions and salience judgements across neurotypes.

The communication approach within the team evolved organically over the course of the project rather than being pre-defined. This was effective in solving problems in some situations, but communication in other instances was less responsive and effective than hoped. Also, as the approach developed across the project, certain practices were either dropped or adopted out of convenience rather than being collectively agreed upon. Essentially, the team was learning to collaborate effectively during the project, resulting in an experience that was more unpredictable than initially anticipated. This likely made the work of collaborating within this team more complex than needed on some occasions. A clear understanding of team

perspectives or values at the outset is also important, as some circumstances within the current research led to instances of conflicting non-negotiable values, which led to disagreements.

Finally, external factors can play a role in co-research team dynamics, such as the university's bureaucratic systems, which create hard-to-resolve challenges that would more effectively be addressed at the project's outset. In addition, contractual obligations and salaried status differences across a research team can create an unequal set of power dynamics. Awareness and discussion of such factors at the outset of a project is advised.

In conclusion, the chapter presents a detailed account of the research journey, illuminating the learnings, challenges, and the transformative power of collaboration. It serves as a testament to the importance of inclusivity, effective planning, and adaptability in research, especially in the face of unforeseen circumstances like a global pandemic. The experience of collaborating on these soon to be completed projects has provided each member of the team with a valuable insight into the nuanced and affective experience of co-production between autistic and non-autistic researchers. The honest discussion and debate challenged individual thinking and practice, prompting a level of detail and clarity that enhanced and evolved the team's understanding of the research design, process and outcome. The experiences and insights shared here will undoubtedly contribute to the ongoing literature exploring practices for collaborative and inclusive research practices.

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