DCU ICNP User Group / Health Services Executive

Data Development for Health and Social Care
Interim Report

Data Development for Health and Social Care HSE Interim Report

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1. Introduction

This interim report provides a summary of the reflections and activity completed in the DCU SNHS ICNP Working Group 1. The primary purpose of this report is to provide a progress update to key stakeholders on phase one of the developments of resources to support a national data dictionary and data model platform within the HSE. We also argue the case for a dedicated skilled team within HSE to deliver national strategic data architecture requirements. This group was formed to provide independent advice on semantic interoperability requirements in accordance with the HSE Enterprise Architecture Strategic Plan. Capitalising on existing resources such as the HSE knowledge and Information Plan (http://www.ehealthireland.ie/Knowledge-Information-Plan/Knowledge-and-Information-Plan.pdf) and HIQA National standards for safer information and care (https://www.hiqa.ie/healthcare/health-information/information-governance) , this document is structured in three sections and relates to the following topics;

Section one considers the need for high quality information and builds a case for a centralised HSE national platform to achieve integrated people centred care. It explains the rationale underpinning the formation of an informatics research cluster within the ICNP user group centre: *To support existing stakeholders within HSE ICT on phase one delivery of national data dictionary and data model platform*. Critical to achieving integrated care are the building blocks to realise a sustainable platform. One of these building blocks is to progress “inhouse skills and education” and lead rather than “be led” by vendors on eHealth deliverables. There is much investment happening and value for the tax payer is one core objective. Two of the building blocks relate to 1) semantic interoperability, and 2) a robust governance framework to support data management collection, storage and access procedures. Related detail on semantic interoperability constructs will be discussed in section two of this report, discussions on governance framework arrangements however are in progress nationally and only briefly introduced rather than deliberated on in detail. A standard for national health and social care data collections is in draft by the Health Information and Quality Authority and the national data dictionary and data model platform will be adopting the governance processes included in standard 5 of this document when complete. Finally section three will illustrate early thinking

,processes and development work which reflects initial progress on the creation of a data model for Summary Care Records (SCR) in Ireland for *as is* and *to be* architecture within the Office of the Chief Information Officer.

2. Section One

Information is increasingly referenced as a key utility in 21st century health and social care. In all OECD countries there is recognition that there is room for improvement in performance on health service delivery. Partly this is due to the rise in co-morbidity and multi-morbidity with the increasing demand for treatment of non-communicable diseases (OECD, 2015). Ireland as is the norm in many EU countries, is in the midst of a planned health and social care reform programme (eHealth Ireland), While engagement in eHealth is later than most EU member states, there is now visible progress as core requirements for integrated care such as the Individual Health Identifier (IHI) is legislated and deployed . Slower progress presents both opportunities and threats to Irish health and policy administrators. We are afforded on one hand an opportunity to learn from other EU member states experiences; however clinical staff are battle weary with numerous false dawns and inadequate delivery of anticipated benefits. Concurrently, policy analysts and health care administrators have limited access to structured data to inform policy, and address requests from EU data banks for health service surveillance across EU member states. Independent research with the academic community is providing and assisting HSE in identifying some of the “big picture” requirements, but more focused and funded initiatives are now required . As there is no conflict of interest, the academic community can also support HSE to realise key milestones and inform decisions in the early stages of progression towards an established Enterprise Architecture (EA) platform. This working group established in Q1 of 2016 stemmed from the formation of an ICNP Research and Development Centre established in DCU in January 2016. A key stated goal of this centre working activity is;

To promote uptake and use the ICNP and SnomedCT in line with national clinical objectives as outlined by the Integrated Services Framework in the Office of the Chief Information Officer Design Authority.

Here we provide an overview of short term activity completed in 2016 February - October. Informed by best evidence such as World Health Organisation (WHO) Action Strategy, and in line with strategic direction 3 and 5 of the WHO Integrated Care Interim Report, the report expands on the *need for* and *role of* cross functional teams (clinical academic and technical working groups) which can drive with the *Reorientation of the models of care that prioritise primary and community services and the co-production of health (Strategic direction 3) …..*in tandem with*… the creation of an enabling environment that brings together the different stakeholders to undertake the transformational change needed (Strategic direction 5*) (Adapted - WHO,2015).

Building Block 1
Defining the requirements; data and information in line with local, national and international policy….

Calling for a paradigm shift in how we deliver health and social care, the World Health Organisation presents a conceptual map (Figure 1) which reorients care and empowers people and their families to manage their individual health and wellness. The national data dictionary within HSE strives from the outset to consider development from this perspective optimising sustainability. People are living with rather than dying from chronic diseases, therefore shifting the balance of service delivery to integrated holistic care models that are inclusive of individuals, families and communities focusing on health promotion and prevention is required (McEvoy, 2015).

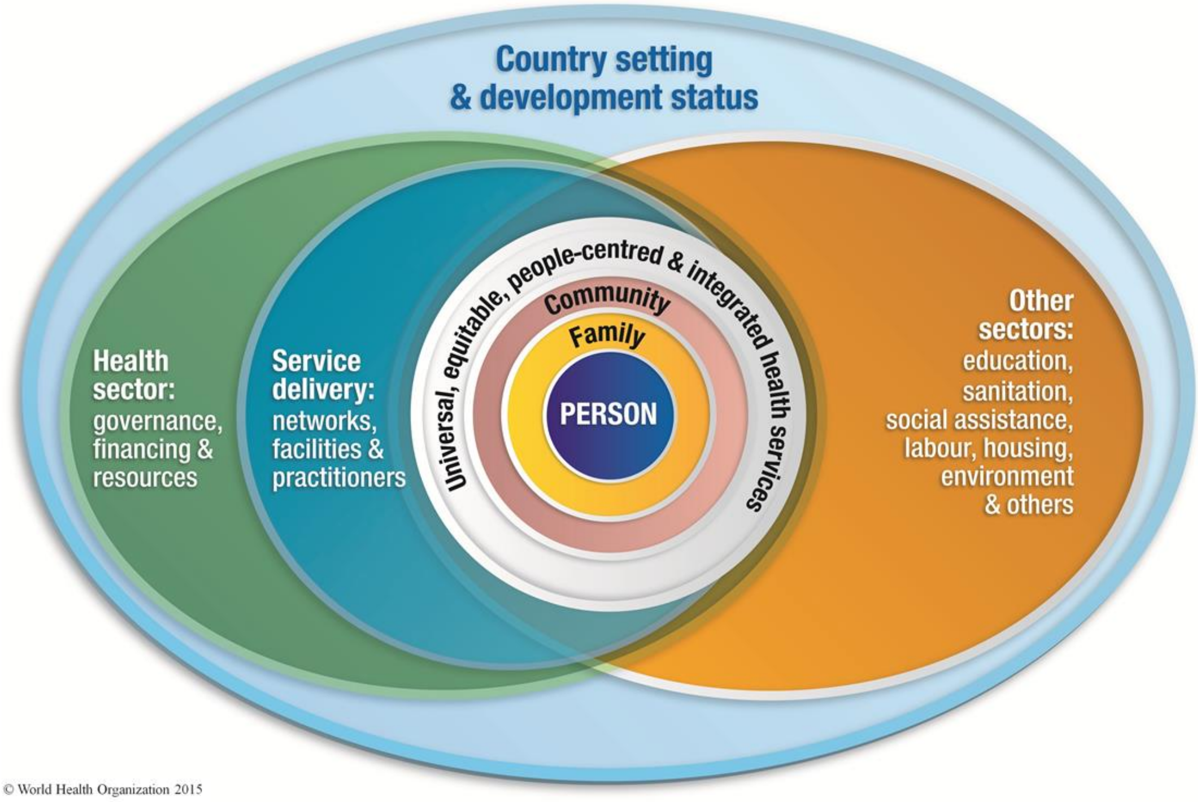

Figure 1 WHO 2015 Conceptual Map on Integrated Care

In regard to local and national requirements, early engagement with patient advocacy groups was considered important within the HSE User Group. As a consequence, HSE is collaborating with national procurement leads on MEDLIS, Business Intelligence and Nursing, as well as the chair of Irish Platforms for Patient Organisations Science and Industry (IPPOSI). This has led to some initial discussion on the inclusion of specific codes within the data dictionary such as Orpha codes for genetic mapping which are now under consideration. The need for a high level data model for summary care record was identified and on review of the evidence and discussions with core stakeholders, it was agreed to build version one of a summary care record model.

Building Block 2

Focus on "as is" and "to be" architecture; It is important to adopt a people centred narrative to under pin national data dictionary initiatives.

Decision - Include *"to be"* architecture classes in the summary care model version 1 on citizen centric care for example *personal health summary*.

Skill mix is high on the agenda in health care delivery in Ireland with a national rostering system in deployment. Additional and significant reports recently published (September, 2016) by a high level commission (ILO, WHO and OECD) on health employment and economic growth calls for an urgent investment in the health workforce , calling for leaders to have a focused plan and vision. Specifically they ask leaders to invest in skills with an expanding number of health workers, and **non-health workers especially focusing on delivering primary and preventative care** (Working for Health and Growth Expert Group Report p.19). Here, we explore the need for a dedicated and focused non health worker team on the development of a national data dictionary platform. As software vendors successfully procure and deploy health systems as part of the planned national reform programme, a core unit is required to strengthen the operations of the HSE enterprise architecture unit. Put simply, HSE needs to build the right team with the right skills to optimise deployment of software within HSE in order to translate commitments into realities. A skilled and educated team can lead deployment initiatives using an informed and clinically pragmatic approach, thus minimising vendor lock in, curtailing multiple API's and optimising efficiencies on future health service delivery for the tax payer. Key decisions need to be made by the HSE Enterprise Architecture group which can then inform the vendors on best approaches in contrast to vendors leading decisions relating to deployment and integrated care delivery.

In partnership with the ICN eHealth programme, the ICNP SNHS centre is advancing nurses' knowledge of, and involvement in, eHealth worldwide (Ref ICN eHealth). From a national perspective both the WHO Integrated Care Report and ICN eHealth Programme are reflected and actioned in national strategy and policy documents and service plans such as Healthy Ireland 2013-2025, eHealth Ireland Skill mix report 2016. Recognising that service providers are often unaccountable in the populations that they serve, and health data is often defined by powerful and affluent groups which focus on over medicalised models of care would suggest that independent groups can provide objectivity to inform progress (WHO adapted, 2015). We therefore argue the case that there is a need to maintain a balance in decision making processes in future health service analytics platform to inform policy and funding mechanisms.

Building Block 3 Workforce Planning
Create resources both human and technical to support a cross functional team with in house skills for data dictionary and data model development supported with national standards for information governance.

3. Section Two Quality Information What Is It?

Information and use of information in health and social care in Ireland is well documented and examined by the Health Information and Quality Authority (HIQA). Whether in hard or soft bound format, information is defined by HIQA as an important resource for service providers in planning, managing, delivering and monitoring high quality safe services. Key features required for information management is that quality information collected is accurate, valid, reliable, timely, relevant, legible and complete. For implementing and collecting electronic information in the health and social care domain, three approaches for uptake and use can be deployed. Firstly, clinical focused data for effective communication of health services in a Clinical Information System for example eReferral or assessment detail. Secondly, a data collection process for storage and retrieval for knowledge representation, such as expressing clinical knowledge in a guideline and care pathway. Thirdly, data which is collected for the development of a domain specific registry and use of the data for secondary analysis is to inform policy. When compiling subsets, there is a need to distinguish data into two distinct categories. Firstly, compiling subsets with a view to data entry (clinician lead) and secondly subsets designed with a view to data retrieval (funding policy and research driven). In this report the working group has focused solely on the first approach and subsequent draft models identified in section three are orientated towards a patient centric and clinically focused data model for a future integrated clinical information system to support direct care. Appendix 1 provides an example of draft core registry data for collection on data sets.

There are in existence many registries collecting data for health and social care for secondary use in Ireland (See Draft-information-management-standards-health-and-social-care-data-collections HIQA Table 1 p.10). Clinical reference terminology models such as ICNP® and SnomedCT® are now required to support direct care.

In order to build standardised data collection platform for patient centric and clinical direct care use the following resources are required.

Building Block 4 Technology and Functional Requirements	
Technological Requirement	**Functional Requirement**
Data dictionary Platform	Statement of Requirements and Application interface for mapping of semantic codes. The data dictionary will provide the overarching governance toolkit for clinical and business terms
Data model	See Appendix 4 for Draft Data Model SCR
Semantic clinical reference terminology	SNOMEDCT and application interface for sourcing and mapping codes
Service Orientated Architecture Platform	User interface for streaming multiple stakeholder reports

Table 2 Standardising Health and Social Care Data Platform within HSE

As stated in section one of this report appropriate data governance in information management is a critical requirement. Soon to be published HIQA Standards on National Health and Social Care Data Requirements Standard 5 on Use of Information will be used in future HSE Data dictionary development initiatives. As a rule the governance structures underpinning and supporting semantic interoperability services globally include the following rules which we would recommend adopting from the outset.

1. Concepts are atomic based and must be separated into constitutional components.

2. Concepts must be able to be combined into composite concepts: For example concepts can be organised into hierarchies and relationships
3. Concept permanence indicates that once a concept is created it cannot be deleted
4. Non redundancy applies to all concepts created there is one preferred way of representing a concept of ideas often stated as a *single source of truth*.

To deliver a national data dictionary and data model version 1 in accordance with national eHealth Strategic activity, a number of programmes will need to map into the data dictionary platform. This will require the development of different subsets. In the case of the detail identified in section 3 draft data model, all subsets created will be compiled with a view to data entry at clinical level. We anticipate that this will include loading 40 subsets/datasets to the data dictionary, and 2 subsets/datasets configured and implemented to an integrated information services platform during year 1. Determining the selection of a data entry and storage method will need to be decided upon, in addition to incorporating cross mapping frameworks with embedded data retrieval functions. The specific detail of these required functions have been factored into the data dictionary specification document. It is anticipated that this development work will evolve as our work with IHTSDO (International Health and Standards Development Organisation) continues to progress with SNOMED CT®.

4. Section Three Data Dictionary & Development of Data Model for SCR.

Activity completed over the past year by this group has very much focused on preparation to deliver eHealth Ireland requirements for semantic interoperability. Figure 2 *Overview of Work Completed* summarises the early thinking and development process completed within this DCU ICNP HSE User Group.

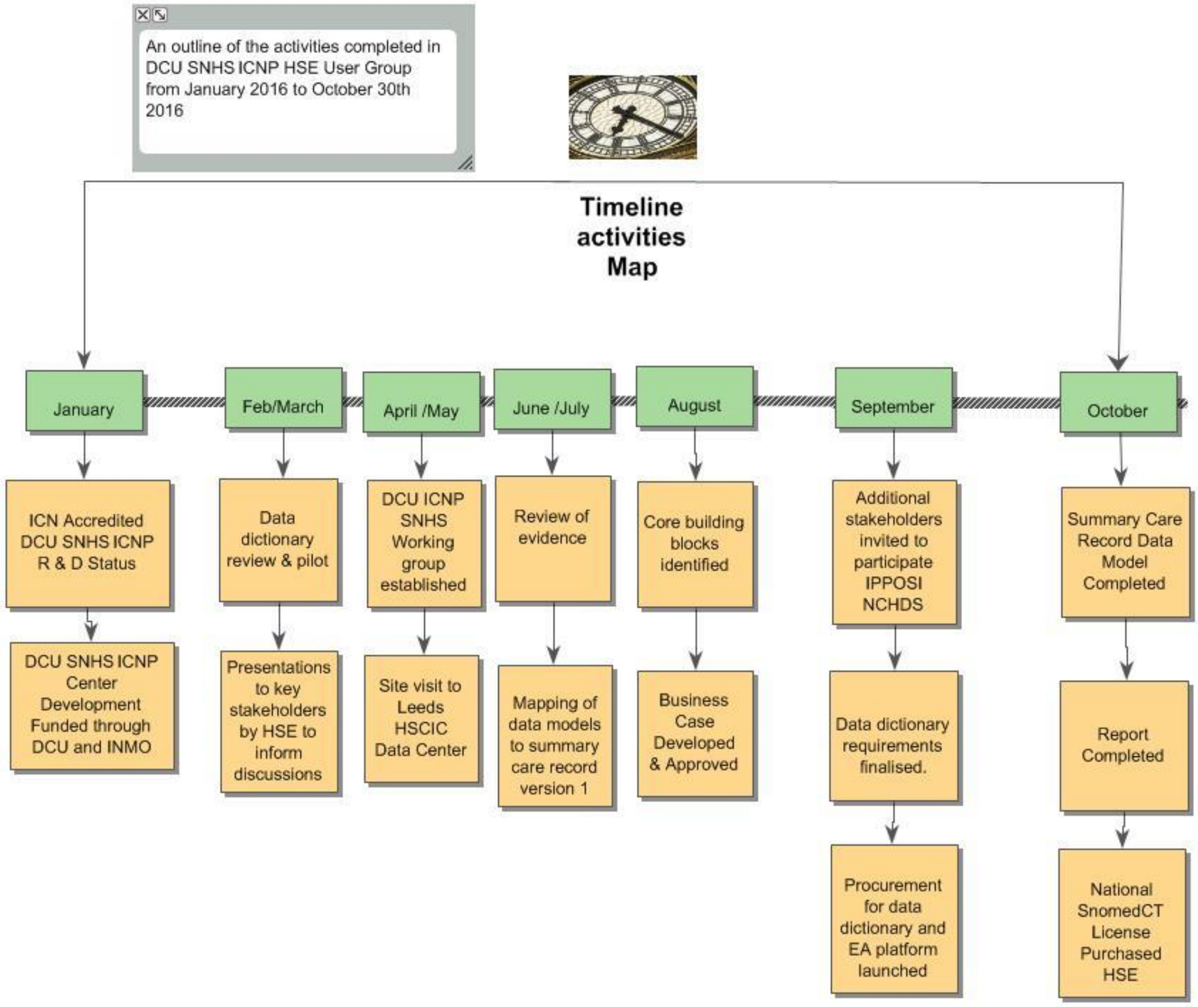

Figure 2 Timeline Activities Map

A review of the evidence , site visits to terminology centres in the United Kingdom Leeds Health and Social Care Information Centre (HSCIC), in addition to monthly meetings with core stakeholders highlights the need for a sustainable national data dictionary and data model platform within the HSE. The HSCIC very kindly shared with us there in house developed data models for Mental Health, Children's and Young People, and Community Information. On return from this site visit we created a Sandbox and began the process of developing our own data models (Appendices 2 and 3). These are further discussed later in this section. The data models are for illustrative purposes only and are not intended as a design document. This is very much specialist work and we believe that there is a knowledge deficit in Ireland in regard to the importance of establishing an effective data platform for optimal effectiveness and efficiency. The procurement process for the statement of requirements for data dictionary platform will be awarded to a vendor by December 2016. This data platform when implemented will provide HSE staff with a robust framework for structuring and organising data for use in line with national service programme agreements and HIQA information standards. While this important work progresses recognising the need for independent data models which can evolve organically is our preferred approach. For this reason the group agreed to develop a high level entity relationship model mapping potential core entities identified in the HSCIC domain data models with HSE requirements for a summary care record (SCR).

In this report Entity relationship diagrams are briefly explained as diagrams which can be used to establish a map between an object and a table in a data base. Entities also known as domain objects are often used to underpin business logic which then holds core meta-data or information about a system. An entity can be described as anything that exists or has existed or will exist in a data model. It normally has a named concept identity and an associated definition and is used to demonstrate relationships and links across tables to inform design discussions. Entity relationship diagrams are often created and used for semantic modelling. The draft entity relationship models developed in this working group are included as appendix 2 and 3. A Sandbox illustrative HSE Data Model for the SCR v1 is shown in Appendix 4.

Sustainable Data Models for National Programmes like Mental Health, Primary care, and Community care as in the UK HSCIC could be developed by the HSE with partners as the knowledge deficit diminishes.   For to be architecture we include emerging standards in development by HIQA e.g. *dispensing* and *Procedures* data set in addition to identified objects for inclusion such as *Event Summary* and *Personal Health Summary* (Evidence Source Australian Digital Health Agency)

5. Section Four Agreements and Governance Arrangements

The collaborative research and development initiatives such as reports meetings and presentations completed since January 2015 between HSE OCIO and SNHS ICNP User Group have been done so in the spirit of social partnership. In the interest of the tax payer there has been no conflict of interest or reimbursement to this centre for time investment and resources used. Future plans to advance SnomedCT® mapping in regard to data dictionary development requirements with HSE will need to be discussed and considered further for agreement.

5.1 Draft agreement for HSE Data Standards Collection in DCU ICNP User Group.

A formal agreement for HSE Data Standards Collection will be required to ensure Information Management standards for national health and social care data collections are in place. At the time of writing this report the Health Information and Quality Authority are developing an information management standard for health and social care data collection in Ireland. It is anticipated that this standard will be implemented in Q2 of 2017 and that the HSE National Data Dictionary and Platform will comply with standard 5 of this document in the following way.

1. The data dictionary is publicly available.
2. The data dictionary will include minimum data sets.
3. The data and information included in the national data dictionary will include nationally agreed definitions at domain and national level.
4. The data dictionary will be underpinned by health information standards to accommodate comparability, interoperability and sharing of information.

5.2 Developing Data Elements for inclusion in Data Dictionary

The data elements included in draft one of the data model framework included in appendix 4 are based on a series of meetings and mapping exercises of existing data models from the site visit to Leeds HSCIC and national procurement agendas for eHealth Ireland. The diagrams presented are illustrative and not for actual design of a data model for SCR v1 for the HSE.

6. Conclusion

This brief report provides a summary overview of work currently in progress in the SNHS ICNP HSE Group. A core instigator in achieving integrated holistic care within eHealth Ireland is access to information which is exchangeable and capable of supporting continuity of care across one to many systems. Information that is structured to deliver integrated care must be specifically defined and measurable. By adopting a people centred narrative which is clinically focused there is greater potential to unite often competing objectives of professional organisational and political stakeholder groups (Goodwin, 2016). From an informatics perspective, systems will need to be capable of electronically sharing data, facilitating patient access, supporting continuity of care, and streaming reports at different levels of aggregation (Coulter, Kramer Warren and Salisbury, 2016). From a technology perspective it must support both semantic and functional specifications for alignment and adoption of concepts to achieve a clinically practical approach which is sustainable for eHealth Ireland and the planned investments currently in process.

7. User Group

DCU	HSE	In Consultation with
Dr Pamela Hussey	Mr Martin Tully	Mr Derek Mitchell IPPOSI
Ms Elizabeth Adams	Mr Eamon Coyne	Dr Catherine Diskin NCHD's
Prof Anne Matthews	Mr Peter Connolly	Dr Damon Berry NSAI
Dr Markus Helfert	Mr Pat Kelly	Mr Richard Kavanagh HSCIC
Ms Anne Kirwan	Ms Helen Lambert	Ms Elaine Wooler HSCIC
Prof Anthony Staines		

Table 3 User Group and Key Stakeholders Consulted

Reference List

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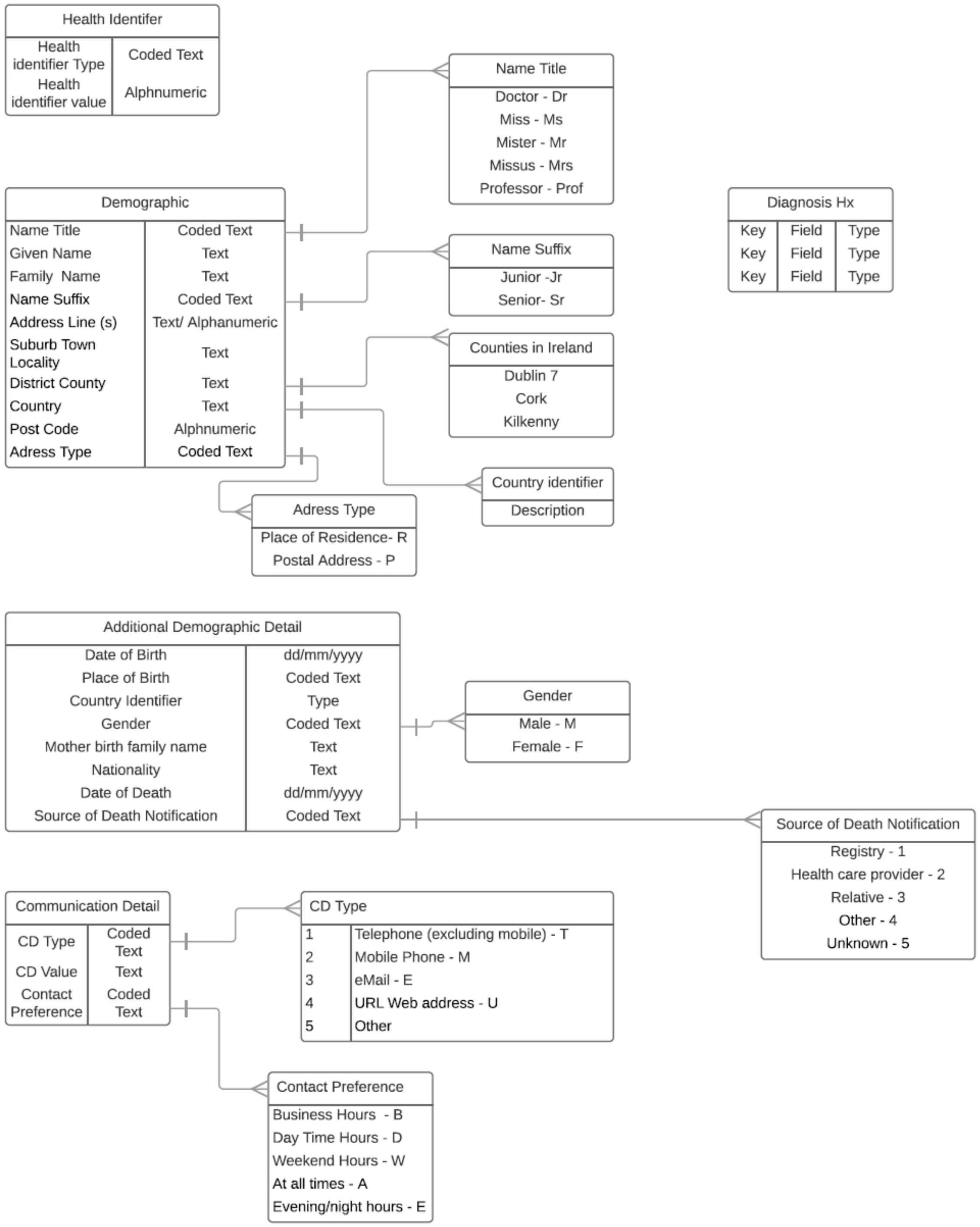
Appendix 1: Draft Core registry Data for Collection on New Data Sets

1. Title of Dataset
2. Identifier
3. Definition
4. Classification Structure
5. Administrative Status
6. Creation Date
7. Last date change
8. Change Description
9. Reference documents and available indexes
10. Concordance Tables
11. Available formats
12. Training materials
13. Languages
14. Relationships with other data sets
15. Correspondence address between revisions
16. Summary Information for inclusion in data dictionary
17. Relationships – conceptual structural and other relationships with terminologies
18. Maps to reference terminologies listing
19. Name of submitting organisation

Ref World Health Organization 2007 WHO Family of International Classifications: definition, scope and purpose Online Available from: http://www.who.int/classifications/en/FamilyDocument2007.pdf Accessed 29th September 2016.

Appendix 2: Data Model Mapping to HIQA Demographics and HSCIC Macro View



Health Identifer	
Health identifier Type	Coded Text
Health identifier value	Alphnumeric

Demographic	
Name Title	Coded Text
Given Name	Text
Family Name	Text
Name Suffix	Coded Text
Address Line (s)	Text/ Alphanumeric
Suburb Town Locality	Text
District County	Text
Country	Text
Post Code	Alphnumeric
Adress Type	Coded Text

Name Title
Doctor - Dr
Miss - Ms
Mister - Mr
Missus - Mrs
Professor - Prof

Name Suffix
Junior -Jr
Senior- Sr

Counties in Ireland
Dublin 7
Cork
Kilkenny

Country identifier
Description

Adress Type
Place of Residence- R
Postal Address - P

Diagnosis Hx		
Key	Field	Type
Key	Field	Type
Key	Field	Type

Additional Demographic Detail	
Date of Birth	dd/mm/yyyy
Place of Birth	Coded Text
Country Identifier	Type
Gender	Coded Text
Mother birth family name	Text
Nationality	Text
Date of Death	dd/mm/yyyy
Source of Death Notification	Coded Text

Gender
Male - M
Female - F

Source of Death Notification
Registry - 1
Health care provider - 2
Relative - 3
Other - 4
Unknown - 5

Communication Detail	
CD Type	Coded Text
CD Value	Text
Contact Preference	Coded Text

CD Type	
1	Telephone (excluding mobile) - T
2	Mobile Phone - M
3	eMail - E
4	URL Web address - U
5	Other

Contact Preference
Business Hours - B
Day Time Hours - D
Weekend Hours - W
At all times - A
Evening/night hours - E

Appendix 3: HSCIC Entity Relationship Macro View

Patient Demographics / Details
- Local patient identifier
- Accomodation type /status
- GP Practice Registration
- Master patient index & Risk indicators
- Employment status (MH)
- MH Crisis Plan
- Disability type (MH)
- Mental health co-ordinator (MH)

Referrals
- Service or Team Referral
- Referral to Treatment
- Service or team type referred to
- Onward Referral
- Other reason for Referral
- Field

Care contact & activities
- Care contact
- Care activity
- Indirect activity (MH)
- Other in attandance (MH)

Group Sessions
- Group session

Social Circumstances
- Special educational need identified
- Safeguarding vulnerable factor
- Child protection plan (CH)
- Assistive technology to support Disability Type (All)

Immunisations (CH)
- Coded Immunisation
- Immunisation

Care Clusters (Mental Health)
- Clustering tool
- Clustering assessment
- Care cluster

Diagnosis , Tests & Observations
- Provisional Diagnosis
- Primary Diagnosis
- Secondary Diagnosis
- Coded Scored assessment (Referral)
- Medical History (MH &CH)
- Anonymous Self Assessment (MH)
- Coded Scored Assessment contact (MH)
- Disability Type (CH)
- New born hearing screening referral (CH)
- Blood spot resulty (CH)
- Infant physical exam gp delivered (CH)
- Breast feeding status (CH)
- Observation (CH)
- Coded scorecard assessment (Contact) (CH)
- Anonymous self- assessment (CH)

Clinical coded terminology (MH)
- See Mental health fields

Hospital provider spells (MH)
- Hospital provider spell
- Ward Stay
- Hospital spell commissioner
- Mental health delayed discharge
- Assigned care professsional
- Restrictive intervention
- Assault
- Self harm
- Home leave
- Mental health leave of absence
- Mental health absence without leave

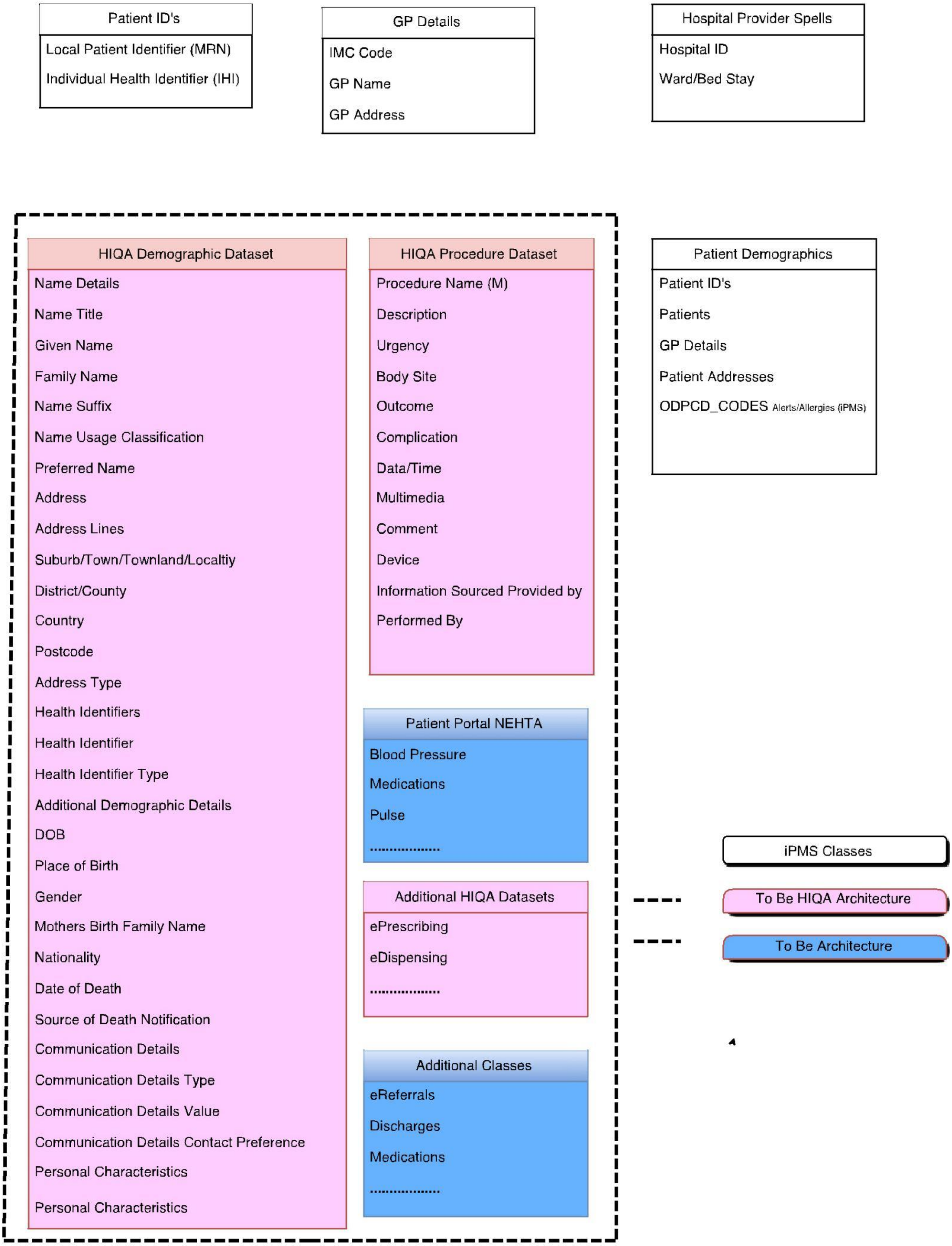
MHA Legal Status Classification Period
- MHA responsible clinician assignment
- MHA legal status classification period
- MHA conditional discharge
- Community treatment order
- Community treatment order recall

Care Programmes Approach (MH)
- MH Care programme approach review
- Care programme approach (CPA episode)

Header and Reference Data (MH)
- Header
- Field

Appendix 4: Foundational SCR v1 blueprint as defined by the HSE EA Team

This is not a Design Document it is for illustrative purposes only intended to stimulate the discussion around a SCR v1



Patient ID's
- Local Patient Identifier (MRN)
- Individual Health Identifier (IHI)

GP Details
- IMC Code
- GP Name
- GP Address

Hospital Provider Spells
- Hospital ID
- Ward/Bed Stay

HIQA Demographic Dataset
- Name Details
- Name Title
- Given Name
- Family Name
- Name Suffix
- Name Usage Classification
- Preferred Name
- Address
- Address Lines
- Suburb/Town/Townland/Localtiy
- District/County
- Country
- Postcode
- Address Type
- Health Identifiers
- Health Identifier
- Health Identifier Type
- Additional Demographic Details
- DOB
- Place of Birth
- Gender
- Mothers Birth Family Name
- Nationality
- Date of Death
- Source of Death Notification
- Communication Details
- Communication Details Type
- Communication Details Value
- Communication Details Contact Preference
- Personal Characteristics
- Personal Characteristics

HIQA Procedure Dataset
- Procedure Name (M)
- Description
- Urgency
- Body Site
- Outcome
- Complication
- Data/Time
- Multimedia
- Comment
- Device
- Information Sourced Provided by
- Performed By

Patient Portal NEHTA
- Blood Pressure
- Medications
- Pulse
- ....

Additional HIQA Datasets
- ePrescribing
- eDispensing
- ....

Additional Classes
- eReferrals
- Discharges
- Medications
- ....

Patient Demographics
- Patient ID's
- Patients
- GP Details
- Patient Addresses
- ODPCD_CODES Alerts/Allergies (iPMS)

iPMS Classes

To Be HIQA Architecture

To Be Architecture