Chapter 1
Development of an Interoperable-Integrated Care Service Architecture for Intellectual Disability Services: An Irish Case Study

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1.1 Introduction

There is much evidence to suggest that digital transformations are complex processes that are predisposed to fail. Only about one in four transformations succeeded in the short and long terms, and the success rate has been trending downward [4, 7, 54]. Policy makers and administrators charged with digital transformation at the enterprise level need to consider carefully corner stones on specific design approaches. For example, what judgements they make and what they base their core decision making on. Important decisions need to be influenced by a critical review of emerging evidence, what data analytics requirements are needed, with some focused consideration on how emerging technology can provide support at policy clinical and administration levels in short, medium, and long terms [16, 17, 22, 33]. The world is changing and we are now living in a post COVID-19 society. This is having an impact on how we live and how we work. Telehealth is emerging as key driver to support service delivery and with it access to shared electronic records. Such records will depend on quality data which must be underpinned by semantic interoperability to realize anticipated benefits [30]. From a business perspective, organizational change science theory specifically highlights the need to ground change programmes in state-of-the-art evidence, and to situate any change in context using co-participatory methods in order to fully understand the nature of the proposed challenges in any planned programme. The Captain's project [11] for example demonstrates how researchers are using innovative co-participatory

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S. Paul et al. (eds.), *Frontiers of Data and Knowledge Management for Convergence of ICT, Healthcare, and Telecommunication Services*, EAI/Springer Innovations in Communication and Computing,
https://doi.org/10.1007/978-3-030-77558-2_1

methods in design science through the adoption of living labs and stakeholder communities to advance transformation of systems using technology.

For planned transformation change, the COVID-19 pandemic increases this challenge and presents a global emergency which means more agile and responsive digital resources are required to assist in slowing down the virus transmission. Understanding the complexity and uncertainty of the environment and ensuring that emerging technology is flexible will be key. So too is the strategic fit of the science applied to underpin scheduled programme development and create targeted intervention for meaningful change [22]. In the midst of an ever increasing demographic trend of an ageing population, a pandemic, and a rise in non-communicable diseases, collaboration and cooperation of global research communities is key and has never been more necessary [54]. As a consequence of COVID-19 healthcare professionals are also now increasingly considered vulnerable citizens by policy administrators [56]. We build our systems development life cycle in the midst of a perfect storm and we need robust navigation to deliver sustainable solutions that are effective and provide a good Return On Investment (ROI). Health informatics standards provide guidance to weather this storm and therefore are used to underpin this case study.

1.2 About the CSDM Project

The CeIC[1] in partnership with the Adapt Research Centre[2] in Dublin City University (DCU) are tackling this uncertainty and complexity directly to impact on the aforementioned societal challenges of ageing population and global pandemic. CSDM aligns with the Shanghai Declaration [55] which aims to reorient health and social services to optimize fair access and put people and communities at the centre of policy development. This is particularly important for individuals who are socially underprivileged or with a disability.

Healthy lives and increased wellbeing for people at all ages can be only achieved by promoting health through all of the Sustainable Development Goals (SDGs), and by engaging the whole of society in the health development process including marginalized population groups [53, 55]. In this chapter, we provide insights from a case study in Ireland with our Intellectual Disability (ID) partner services which seeks to address social mobilization with innovative initiatives which help address issues to support our society. We look to service improvement initiatives providing core access to infrastructure for intellectual disability care services delivery. In this chapter, we provide insights on our progress for phase one of this initiative. At the core of the CSDM project, nursing leadership and vision are directing the strategic course and decision making of the research method. This approach is conducted in accordance with international best practice, values and vision of the

[1] https://www.dcu.ie/ceic.

[2] https://www.adaptcentre.ie/.

CSDM team which are decisively rooted in co-participatory care development and delivery processes. Embracing Open Innovation 2.0 principles is key to our work [12, 33]. Cultivating our initial research within the centre, in this chapter we offer a summary of our approach from a computer science perspective. We therefore provide a summary of a specific body of work in progress to deliver a common semantic data model (CSDM) designed using the state-of-the-art health informatics standards from ISO TC215 and CEN TC251 communities (see Table 1.1).

As nursing leadership is at our core, we consider it important to make the case to adopt and position nursing and health informatics theory to lead this interdisciplinary initiative. Drawing on Actor Network Theory (ANT) principles, we consider the nurse (or nurse practitioner) as a central person to communicate and make shared decisions with the patient and their care team to plan and execute a care plan that accounts for all the patient's health conditions. ANT helps us to distinguish how one factor may influence another within any given social process. Focusing on the nurse as an actor and an agent, where the actor is defined as a source of action, we will consider over time the impact and effect on adopted processes in the context of Intellectual disability services focusing case study initially on the development of a COVID-19 app as a non-human agent [5].

1.2.1 Case Study

In our identified Intellectual Disability (ID) partner services the site has a diverse set of care settings including Day service, Residential Services, Community Houses, Independent Living, Host Families—Home Sharing, and an Activity Hub which provides services to the clients and manages a variety of information using paper based and electronic based resources. Managing and providing services for a one-to-one service user and monitoring of patient health status and addressing service user needs has to date worked effectively. With advancement of COVID-19 restrictions implemented through national government guidelines as is the case elsewhere in the world, additional services were identified. Service providers nationally identified the need to enhance the process of work and care flow using digital in health and social care. For example, telehealth increasingly is identified as the primary communication for care delivery. Supporting telehealth and clinical decision making across this diverse healthcare setting is the need for electronic records for integration of care. Such records need to be designed to support interoperability so that data is accessible across and between different systems at the service level. Semantic interoperability allows machine to share, understand, interpret and use data without ambiguity. Lack of semantic interoperability in the healthcare domain is of a great concern, where the main objective is to exchange health-related information with explicit meaning that is shared between different stakeholders or policymakers [4]. The main hurdle in achieving semantic interoperability is the existence of different terminologies used by various coding systems, a lack of correlation among local coding systems and international coding systems which needs to be addressed. An ontology based approach with the standard controlled vocabulary helps tackle the interoperability issues where an explicit formal specification can provide guidance to interact with different systems [31]. A key to understand diverse data and knowledge and big data analysis is ontologies. Ontologies are widely used in biomedical domain and metadata standardization [28], and rigorously support data integration, sharing, re-usability, and computer-based data analysis and automated reasoning. Ontologies are also regarded as the foundation of knowledge representation and knowledge graph, a major field required to support the advancement of artificial intelligence [48]. Making health records meaningful will only be possible if we link the Electronic Health Record (EHR) to an authoritative clinical knowledge and then use natural language in the user interface as suggested by the IMIA working conference on clinical terminology [4]. This enables effective meaning-based retrieval and provides the evidence and associate details to support the adopted specific design approach for CSDM. Using a case study, we can demonstrate and provide guidance to advance knowledge to support eHealth practices.

1.3 Nursing Engagement in System Design

As the largest percentage of the professional workforce, nursing occupies 50% of the total headcount for many countries [57]. There is a wealth of evidence demonstrating the impact of registered nurses on healthcare outcomes for populations across a range of roles particularly missed care [10]. Building on discussion and opinion, the evidence reports that there is also much in the history of nursing which argues the case that the profession needs purposeful and focused engagement [38]. This is conceivable particularly when one considers the significant research completed to identify adverse outcomes on risk which has been published over the past 10 years [2, 34]. Traditionally, nursing has a strong history demonstrating their professions ability to deliver expertise in the realm of systems development and design for health and wellbeing. While the technology may be new, the challenges for generic systems design sadly remain. But without involving interdisciplinary healthcare viewpoint in system design, multi-billion pound losses can happen as evident in Lorenzo healthcare IT system deployed by National Health Service (NHS)-England [51].

Twenty first century healthcare policy advocates advancement of the role of nurse practitioners. The American Medical Informatics Association for example, estimates that as many as 70,000 nursing informatics specialists or analysts will be needed in the next 5 years [49]. From a sociology perspective, Trotter suggests that at its core nursing as a profession can be described as iconic providers of care which provide labour that is gendered and which seeks to support members of society who cannot care for themselves because of age, illness or disability [52]. Interventions such as care coordination with a wide range of people and organizations provide a layered understanding of the broad and variable set of service user needs. Arguing the case that nurses are adequately experienced in advising informing and are therefore experts in transforming the nature of care delivery itself [52]. In this

2 year study, we begin phase one engagement with nursing at the helm directing the development of a case study to advanced strategic tactics of the research.

1.4 Insights on Digital Transformation in Ireland

Ireland is in the process of procuring and deploying a national electronic health record (EHR) programme for the past 5 years. More recent attention focuses on shifting health and social care to the community in the form of a national implementation plan entitled *Sláintecare* [20, 29]. Recent study in the UK shows that Healthcare and social care integration is a key contemporary concept in the service delivery [1]. There is at the time of writing this chapter, however an absence of harmonization of big data which would allow policy analysts and healthcare workers to conduct big data analysis, to reduce costs of treatment, predict outbreaks of epidemics and support disease prevention at the national level. Ireland as a country has invested significantly in registry development in the past; however, data collection within the existing registries cannot support a common semantic data platform and therefore information can only be reported nationally in a fragmented and siloed way [33].

Drawing on relevant evidence we choose to blend Actor–network theory (ANT) principles with an ontology based model and knowledge transfer approach in order for us to be able to publish this research in the open source.[3] This initial work is illustrated through visualization on a graph database platform, GraphDB by Ontotext.[4] Presenting our research development outputs in this way helps build capacity in standards use and deployment through industry. It is important to recognize that this approach is not suitable for use with a relational database which is the more conventional approach in healthcare for data storage for secondary care delivery.

We also argue the case that future models of care aligned with our national and global policy will need to be linked with the Internet of Things (IoT) to advance self-management support and will require access to data across one to many healthcare settings. This can be only achieved if we use an ontology based model which is relying on linked data approach and strategically fits better for the digital patient's future requirements. According to market research there is currently in 2020 3.68 million smartphone users in Ireland.[5] On July 6th, 2020 the public health services app for tracing citizens with COVID-19 was launched in Ireland and passed one million registrations within 48 h of its launch [43]. In this context, we consider it important to focus on a case study approach to help us to understand and assist in the development of a model with intellectual disability services. A model where

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[3] https://bioportal.bioontology.org/ontologies/CONTSONTO.

[4] https://www.ontotext.com/products/graphdb/.

[5] https://www.statista.com/statistics/494649/smartphone-users-in-ireland/.

the terminology is motivated by case study scenarios that focus on clinical need and capable of supporting future service improvement. Phase one of this project reported here provides deliverables which offers the team a guidance so that we are able to understand requirements as well as identify limitations which helps us during modelling and future implementation of the systems development lifecycle.

1.5 Summary of Case Study Methodology Phase One

Phase one of the CSDM research project aims to set in place a framework to develop a system architecture that will be useful for other application scenarios in the future. Preliminary output of our research development work is available in open source domain.[6] Drawing on specific evidence such as the WHO policy on patient centred integrated care [54] and the work of Blobel [6–9], we also contribute to European Committee for Standardization (CEN) and ISO community working groups on health informatics [15, 35]. The nursing led team established a working group to define a use case and create and deploy an extension of Semantic Sensor Network (SSN) ontology [27] and Fast Healthcare Interoperability Resources (FHIR) [32] application programming interface (API) with an industry partner entitled Davra[7] in quarter 2 of 2020. Through initial analysis for sustainable health systems access, the following information was collated and critiqued.

1.5.1 Initial Requirements Gathering and Needs Analysis

Guided by Blobels' systems approach to interoperability [6] in combination with OntoClean methodology [25], the team created a formalized ontology and defined an information model to underpin the project in phase one. The information model for data, information, and action was adopted in partnership with focused discussion groups and an advisory board was identified with dedicated implementation team. Included in the advisory board are two Fulbright academic scholars with a background in doctoral nursing practice from the USA who provide insights into the project action and data management plan from a global perspective.

Some early key milestones from preliminary discussions included the need to develop a common business case underpinned by two communicating and cooperating principles. In our case these identified principals were *quality* and *relevance* to inform contributions and deliverables. The first principal was to ensure that identified contributions be as informative as is required for the purpose of exchange of semantic data. The second principal was to ensure that the contributions are

[6] https://opensource.org/.

[7] https://davra.com/.

focused on relevance of identified requirements with a view to avoiding obscurity of expression in community services. The team recognized the nature of this work in the context of a COVID-19 pandemic and considered the information cycle process in a phased manner to deploy existing or emerging knowledge, skills and capabilities within the team. Agreed agendas included building capacity for shared communications and dissemination of findings as part of the communication and cooperation process across the CSDM project. A critical review of the evidence to informed decision making on the case study provided the flowing information and action steps as detailed in the following Sect. 1.2.

1.5.1.1 Evidence and Action Steps

The ISO Reference Model for Open Distributed Processing (ODP) was used to analyse the emerging tools, resources and standards published on the various interoperability levels using core evidence from Blobel [6–9]. This provided a rigorous structure and pathway to build capacity and progress with the project specified requirements to deliver on the following goals in phase one. These standards are outlined in Table 1.1 using the various viewpoints for ODP with the exception of the technical viewpoint scheduled for review later in this case study development lifecycle. Goals and scoping review were considered both informally (Social participatory engagement processes) and formally (Informatics technical implementation processes).

Informal: To develop and report with advisory boards and dedicated implementation team a proof of concept research study for assessment of service users within a specific intellectual disability (ID) service. This person-centred initiative focuses on COVID-19, Referral and Healthy ageing initiatives. Design of an information data plan will be underpinned with related health policy—*Sláintecare*, eHealth Ireland and ID national policy. *Formal*: Drawing on ANT and co-participatory methods develop phase one of a Common Semantic Data Model (CSDM) for an emerging interoperable framework capable of accommodating different schemas for knowledge transfer on health informatics standards for digital health transformation with ID services.

1.5.2 Scoping Review and Mapping Exercise

In order to define the Interoperable-Integrated care Service Architecture (IISArc), a qualitative and quantitative analysis was carried out to investigate the correlation between different actors involved in the residential care service. We also investigated the correlation between several smart devices including IoT based services for residential care and the corresponding needs of the service users with COVID-19 through detailed clinical modelling and testing in a simulated environment [41].

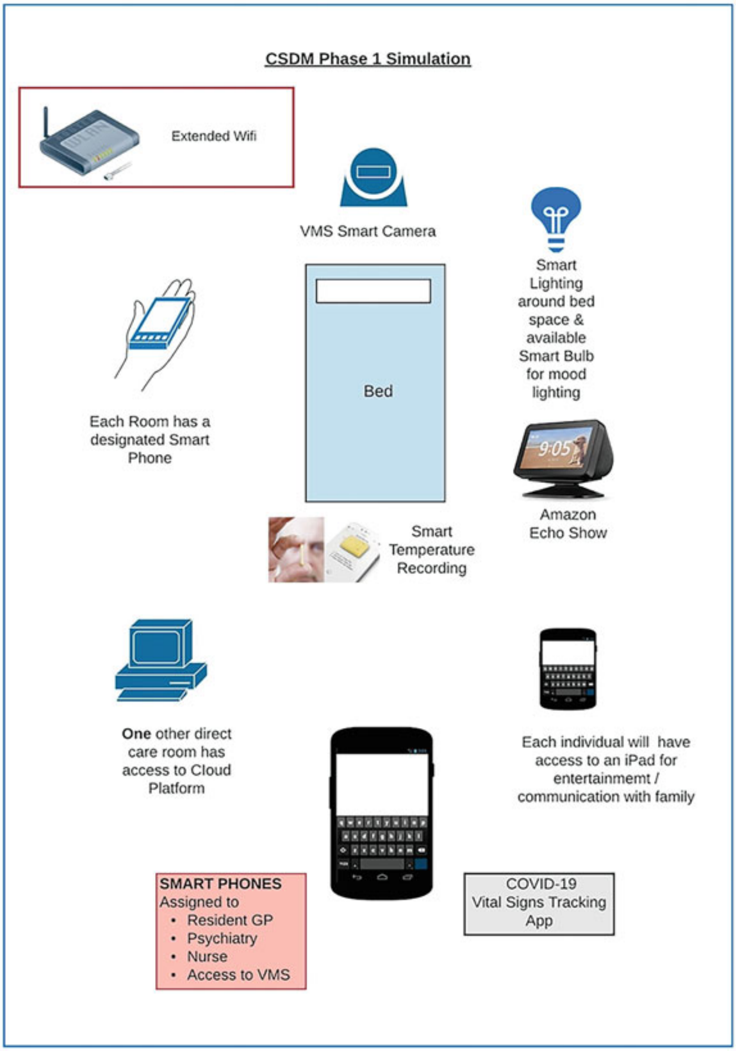

Fig. 1.1 Infrastructure view of a stimulated residential care unit

Figure 1.1 depicted typical arrangement of medical device, IoT, smartphone to collect patient observation data within our identified residential care unit.

This initiative was then tested in a day service with nurse practitioner leading a simulated exercise to test clinical workflow and impact of digital devices in context. As individuals with Intellectual disability (ID) are considered a vulnerable population group and COVID-19 cocooning was in process, for preliminary work conducted in phase one we opted not to directly involve the service users in the initial design process. The co-participatory group opted to work with nurse

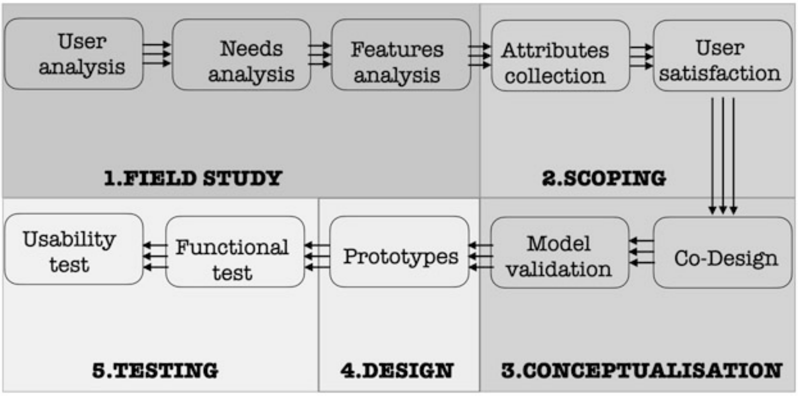

Fig. 1.2 Process flow schema adopted for the IISArc project

practitioners and healthcare professionals and experienced carers who provided detail for the mapping of the service. The plan being to provide a demonstrator to service users for review and comment and additional development as required once ethical approval has been obtained. Overall on-going design and workflow for IISArc, shown in Fig. 1.2 and comprise of the following five steps: (1) field study, (2) scoping, (3) conceptualization, (4) design and (5) testing.

Field Study An ethics proposal was drafted for the clinical engagement phase of the project. As no personal or identifiable records were to be used for the initial scoping review and mapping exercise in phase one, there was no anticipated risk associated with the study. Simulated data was created to demonstrate the testing and demonstration of the prototype. Primary users for phase one identified in the case are nurses and carers. Secondary users identified are the management team in the service, the individual clients with intellectual disability (ID) and the Industry partner Davra. User centric-design has been applied to develop the users' needs analysis based on evidence on COVID-19. It is anticipated that the project scope for phase one which has been developed in the ID services may be useful to address older person needs in the future. This aligns well with the overarching mission of the research team to ensure an adaptive, usable and understandable sustainable product is delivered which may be adapted for other domains in the future.

In Fig. 1.3, we will describe process, domain and context of use. We illustrate a summary view of how we are defining requirements of the information layer for semantic interoperability in the identified domain using a phased and step by step cyclical process. The context of use is defined with practitioners who consider workflow and data requirements for assessment of a COVID-19 service user. We consider a deteriorating service user who requires transfer from a social care residential unit to an acute care provider. Core data for transfer in line with national guidelines and specific care requirements for the intellectual disability domain are taken into consideration [30]. The user needs and feature analysis

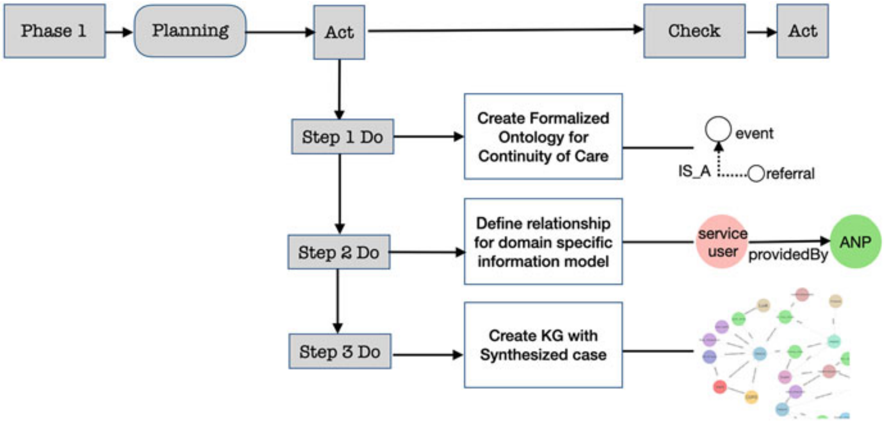

Fig. 1.3 Plan–Do–Study–Act adapted for CSDM

include focus group interviews and documentary analysis completed by health care practitioners which are conducted as phase one. This is followed by a series of steps which confirm with the practitioners the specific relationships between the various resource requirements for data transfer across different care settings. We consider the focus to be on assessment of service needs for an individual service user and referral of key information for transfer with the service user to support safe referral of care. The final step in this phase of needs analysis and scoping process relates to the development of the knowledge graph (KG) using synthesized cases for demonstration to the wider stakeholder group through planned dedicated workshops. At each step of the CSDM project, there is a check action to review and confirm that CSDM resource is aligning with the domain and context of use.

1.5.2.1 Informal Scoping

Initial attributes collection as part of a scoping phase was completed outside of the service with the experienced nursing group. The main objective being to understand which attributes aka data fields are needed for our initial conceptual model development. Key questions which we have used within the focus group discussions with service providers relate to the following: What are the most relevant and agreed requirements considered essential for day to day patient observation data collection? These reported data attributes are currently reported to be in form of paper or excel spreadsheets from existing information system deployed in the residential care facility. Step one and step two of the user and needs analysis was completed to identify the data attributes to create an initial conceptual model. An example of the data attributes identified and related to the COVID-19 app is available from FHIR [32]. For example, temperature and breathing are included in the FHIR observation detail and available in Sect. 1.5.3.3.

In adopting a hybrid approach to tackle the complexity of health and social care delivery two specific standards Fast Healthcare Interoperability Resources (FHIR) and Observational Medical Outcomes Partnership (OMOP) [32, 44] were used. FHIR has well-defined data structure (aka Resource) to capture patient observation data as well as other components involved in a care setting such as patient, diagnostic report, medication statement, etc. Detailed explanation on how this case study use FHIR is available in Sect. 1.5.3. OMOP was used to guide the dataset mapping coming from across care settings.

Design Principles Agreed key design principles adopted by CSDM are in accordance with core principles of health interoperability [4]. The project team will accommodate and store observational data to facilitate ongoing research which is:

- Suitability for purpose
- Data protection
- Rationale for domains
- Standardized Vocabularies
- Reuse of existing vocabularies
- Maintaining source codes

Initial scoping review of health informatics standards and resources used are presented in Table 1.1 under the Reference Model of Open Distributed Processing (RM-ODP) structure. RM-ODP is an architectural standard developed in the mid-1990s following 10 years of development work through the International Standards Community on architecture [39]. This standard explains the inter relations between the various viewpoints as the enterprise viewpoint linking with the system designer role, the information viewpoint which informs the information architect role, and the component developer which uses the computer viewpoint and the systems implementer role which uses the engineering viewpoint supported by the systems administrator role in the technology viewpoint. The technical viewpoint is not included in Table 1.1 as this review is scheduled for later in the project lifecycle when tested in the service context [6, 39].

1.5.2.2 Formal Scoping

Identification of the formal scoping and mapping exercise involved the analysis of the *Conceptualisation* model. This action step commenced with a focus on the co-design and model validation within the core research team and four focused co-participatory group discussions. These discussions were considered preliminary because of COVID-19; access to the services was delayed. The team opted to use ISO 22272 a Health Informatics Standard Methodology for analysis of business and information needs of health enterprises to support standards based architectures. These initial discussions explored the project from four specific perspectives to consider the *Business Impact Analysis*, *Concept Analysis*, *Information Analysis* and *Future Model Development*. In the context of CSDM this phase one analysis

Table 1.1 Summary table of standard and techniques use in our project

Standards and techniques	Category	Framework development utility
ISO 22272	Enterprise	Used to define Business mission aims and objectives, conceptual model and capacity building
Contsys ISO 13940 https://contsys.org/	Computer	Overarching ontology framework designed in OWL as a formalized web ontology (publish on May 2020) https://contsys.org/pages/Guest%20blog/FormalOntology
HL7 FHIR v.4 https://hl7.org/FHIR/	Computer	Used to specify attribute structure of Observation, Medication Statement, Medication Administration, Medication Diagnostic, Report, Patient
EHRcom ISO 13606	Engineering	Reviewed in terms of harmonization of HI standards to describe distribution of objects and applications across platforms
IHE CCR https://www.astm.org/Standards/E2369.htm	Information	Provides a patient health summary standard which facilitates timely and focused transmission of information across and between health professionals involved in the delivery of patient's care
Snomed-CT ICNP	Information	Formalized reference terminologies used for semantic mapping of concepts in health care systems
Protégé https://protege.stanford.edu	Engineering	A free, open source ontology editor and framework for building intelligent systems
Karma https://usc-isi-i2.github.io/karma/	Engineering	A data integration tool and aligning with Interoperability level-1 Technical automation. Semi automation of semantic mapping is important so that the semantic detail used is approved and validated by nurses
GraphDB http://graphdb.ontotext.com	Engineering	Used as a specification with common functions providing a technology-neutral architectural framework and database support

on the conceptual model refers to identifying the core design requirements for the ontological model which enables semantic interoperability [46]. This formal scoping also included a number of presentations of the evidence selected to support the CSDM project and a detailed explanation on how ontologies can support future models of integrated care development. A defined ontology can be viewed as a declarative model of a domain that defines and represents the concepts existing in that domain, their attributes and the relationships between them. It is typically represented as a knowledge base which then becomes available to applications that need to use and/or share the knowledge of the identified domain. In addition the emerging conceptual model used Web Ontology Language (OWL). In the domain of health informatics, an ontology [23] can be described as a formal description of a health-related domain. OWL offers a logic-based semantic markup language for publishing and sharing ontologies on the World Wide Web [45]. OWL 2 was used [19] and found useful for our project particularly in demonstrating specific detail of the case study with key stakeholders. OWL 2 was selected as it supports both qualified and unqualified cardinality restrictions. Its datatypes include various kinds of numbers, adding support for a wider range of XML Schema Datatypes (double, float, decimal, positive integer, etc.) and providing its own datatypes.

This was considered a useful resource to linked open data community. In addition to developing a preliminary conceptual model in OWL, the development team also conducted some terminology mapping as part of the *model validation process*. Specifically focusing on changing the values found in the source datasets into the values defined by the standard organization resources adopted in the project lifecycle. Typically data elements are stored in a database which consists of values such as a word, number or a date, a text string or a code. Each database uses values that are defined by the database designer, in this case an intellectual disability (ID) service provider. The defined set of codes can be called a reference terminology. In healthcare within Ireland existing widely used and adopted terminologies include International Classification of Diseases 10th revision (ICD-10), and more recently Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT) for diagnoses and intervention mapping. The CSDM development team considers it important to recognize that many databases contain values that are unique to their local environment [3, 4]; therefore, differences in codes and values can lead to inconsistencies where data are combined across many different local systems resulting in heterogeneous data collections. This reflects the challenges ahead for national programmes in adoption of national electronic health records (EHR) and why the European Union (EU) is focusing on ICT standardization in the EU with programmes such as the Elite S Scholarship [14] which is funding this research. What is required for existing data banks is cleaning of data for terminology mapping in order to convert local terms into standard terms that are used across all data partners or care centres in a healthcare network. Figure 1.4 provides a summary of the tooling used in this phase of the CSDM which addresses this issue by adopting language independent ontological model which helps to integrate data based on their semantic meaning rather terms.

1.5.3 Technical Implementation

Dissemination of information on the CSDM is provided on a phased basis with the ISO and CEN Community, for example publication of formal ontology for community of care is available with a supporting blog post on the Contsys Website.[8] For technical implementationFor technical implementation depicted In Fig. 1.4, provides a summary of CSDM intended implementation pipeline which includes tools and techniques on how we executed our work to date.

As we await ethical approval for data collection, we will then collect more data from different healthcare data sources through our identified service. We anticipate

[8]https://contsys.org/pages/Guest%20blog/FormalOntology.

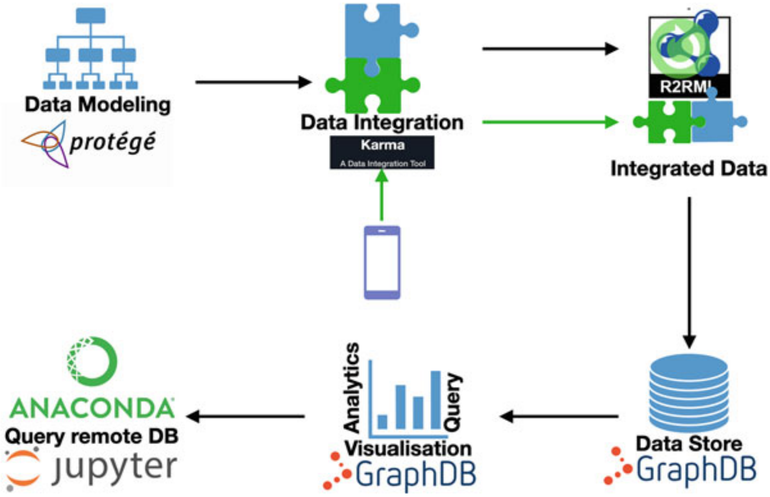

Fig. 1.4 Implementation pipeline used for CSDM

that this will be possible through planned fieldwork, such as workshop and survey activity as this approach has worked well for preliminary work conducted in phase one of this study. As required the development team will then set about cleaning the data collated using some software such as ontoRefin, which is a data transformation tool, based on OpenRefine[9] and integrated in the GraphDB Workbench [21]. Protégé [42] is a free, open source ontology editor and a knowledge management system, which will be used for designing and editing IISArc schema. Protégé provides a user-friendly graphical interface to define ontologies. In particular for defining the terminology and schema mapping Cellfie [36], a Protégé desktop plugin will be used for importing spreadsheet data into OWL ontologies for data integration tasks. As the research programme grows for large dataset we will use KARMA, for integration [26]. KARMA is an open source tool which enables to integrate data from different sources like XML, CSV, text files, web Application Programming Interface (API's). KARMA also generates RDB to RDF Mapping Language (R2RML) mapping file which can be reused again and again in case of feeding models with new data.

Other features under consideration for System Architecture of CSDM are as depicted in Fig. 1.5. We aim to connect with an existing local IT system called Clinical Information System (CIS); this is a particular in-house system of the service organization which has been in place for a number of years. The Geographical Information System (GIS) applications could be used to collect and locate service user and staff details including emergency management planning, and IoT devices to monitor service user's health and wellbeing. The local IT information system CIS

[9]https://openrefine.org/.

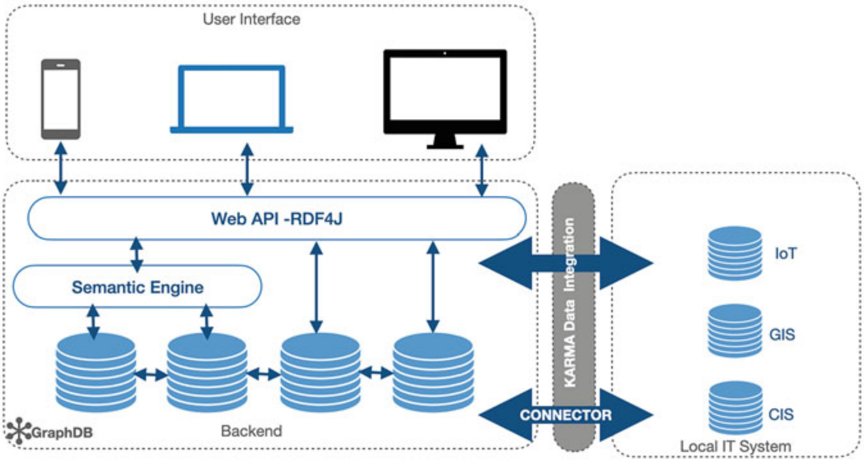

Fig. 1.5 System architecture of CSDM

could be connected with the GraphDB via a connector while KARMA could be used to harmonize the data. This could then facilitate access by staff and service users to information via organizational laptop, desktop or other mobile devices which are connected with the system via web API.

1.5.3.1 Data Modelling

As it is our first phase of the project, we mainly focus on data modelling part to generate initial IISArc ontological schema. Full formal ontology for continuity of care comprises around 138 classes.[10] Out of that main classes needed to capture our scenario are rather small. They are:

- *Healthcare actor* organization or person participating in healthcare. The involvement of the healthcare actor will be either direct (for example, the actual provision of care) or indirect (for example, at organizational level).
- *Subject of care* healthcare actor with a person role; who seeks to receive, is receiving, or has received healthcare. Synonym: subject of healthcare; service user; patient; client.
- *Healthcare profession* having a healthcare professional entitlement recognized in a given jurisdiction. The healthcare professional entitlement entitles a healthcare professional to provide healthcare independent of a role in a healthcare organization.

[10] see https://bioportal.bioontology.org/ontologies/CONTSONTO.

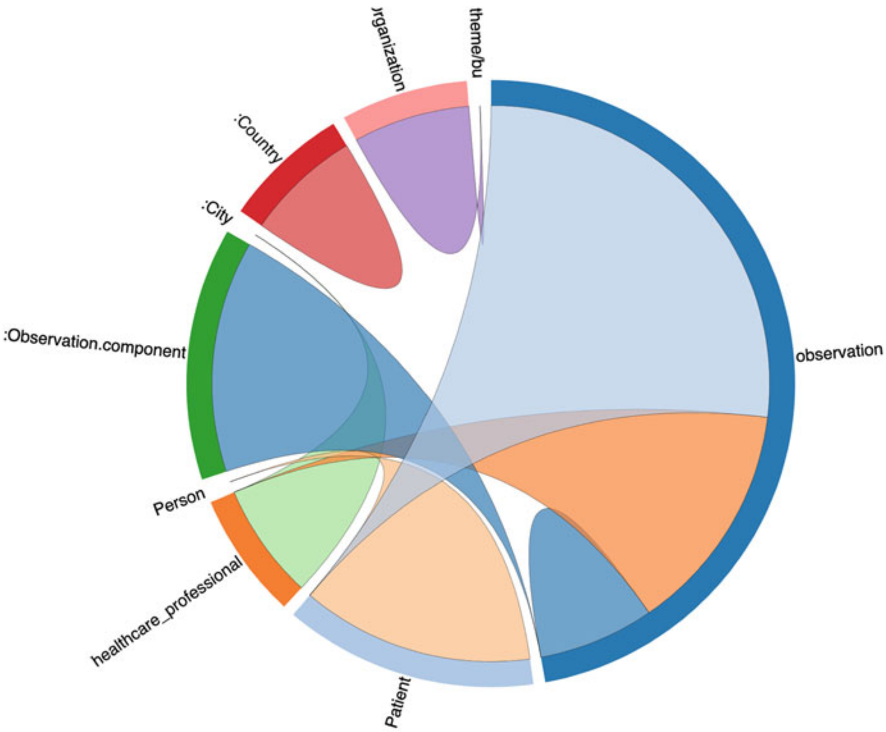

Fig. 1.6 Class relationship with Observation

- *Observation* Observations are a central element in healthcare, used to support diagnosis, monitor progress, determine baselines and patterns and even capture demographic characteristics. We reuse HL7 FHIR observation [32] Resource in our ontology which provides the details and data structure for capturing patient daily observation. Class relationship with *observation* class is depicted in Fig. 1.6. It represents class relationships among the nine classes which contain data and how they are interrelated with each other. We use Ontotext GraphDB [21] to generate this class diagram. The Class relationships diagram is based on the real statements (i.e. instance level) between classes and not on the ontology schema.

1.5.3.2 Ontology Alignment

Top-level ontologies provide domain-independent conceptualization, relations and axioms (e.g. categories like Event, Mental Object, Quality, etc.) in order to standardize the ontology creation by providing guideline based on a rigorous ontological commitment. Therefore, building the continuity of care ontology under

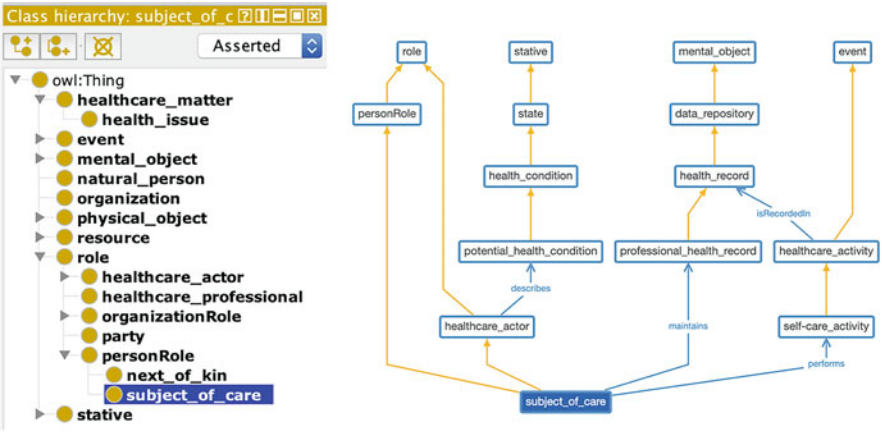

Fig. 1.7 Formal Ontology of continuity of care developed and visualized using Protégé ontology editor

a top-level ontology should contribute to improve its semantic interoperability with other existing ontologies. In our work, we use the top-level ontology Descriptive Ontology for Linguistic and Cognitive Engineering (DOLCE) [24] as a middle-out solution between degree of formalization and complexity, contributing to an effective practical solution. In spite of the benefit of top-level ontologies, their alignment and use is not trivial and requires some expert effort. The EU project Advancing Clinico-Genomic Trials (ACGT) [50] as well as other healthcare projects emphasize on need and benefit from top-level alignment.

DOLCE ontology classes such as stative, mental object, event, natural person and physical object preoccupied class hierarchy of our ontology. This helps to aggregate similar kind of classes of continuity care under one super class. The European Federation for Medical Informatics (EFMI) also emphasises the need for ontological scrutiny for continuity of care [40] however it is interesting to note we found no further progress in our review in the past decade. Our formal model tries to resolve those ontological issues as well with our collaborative work with the existing ISO 13940 community. Figure 1.7 depicted fragment of our formal OWL ontology in Protégé user interface.

1.5.3.3 Formal Model

In the research completed to date the expressiveness of our ontology model is *ALCHQ(D)* as per description logic (DL) scale. We opted not to exploit full power of DL-Full as supported by OWL language, rather we opted to use simple rule so that it is compatible with a GraphDB rule engine. This approach facilitates quick query execution time as we are cognisant that our model will have potential to expand exponentially in the future. In this section we provided details on the data structure of the class *observation* and property *person.gender* in Resource Description Framework (RDF) Turtle syntax. The observation class defined by FHIR Observation accommodates reuse of properties in order to facilitate our model for interoperability. This approach aligns with other EHR models using FHIR based specifications and supports cross border studies on intellectual disability (ID) clients in the future. Observation captures measurements and simple assertions made about a patient, device or other subject. The subject of observation is *Patient* class. The performer of observation is *healthcare_professional* class. Datatype restriction is encapsulated under property *person.gender*, where the data provider has to choose among gender value "Male", "Female" or "Transsexual" as it is a mandatory and important information needed by the service provider. It cannot be left blank and reasoner will able to detect in case of wrong information inserted in the system. The following excerpt demonstrates an example of this observation class detail in RDF turtle syntax.

observation(class)

```
http://ontologies.dcu_smh.ie/CeIC-SMH#Observation
EWS:Observation rdf:type owl:Class ;
    rdfs:subClassOf [ rdf:type owl:Restriction;
    owl:onProperty observation-definitions:Observation.performer;
    owl:someValuesFrom EWS:healthcare_professional],
    [rdf:type owl:Restriction;
    owl:onProperty observation-definitions:Observation.subject;
    owl:someValuesFrom EWS:Patient];
oboInOwl:hasDbXref
"https://www.hl7.org/fhir/observation-definitions.html
#Observation"^^xsd:anyURI;
rdfs:comment "Measurements and simple assertions made about
a patient,device or other subject."@en.
```

person.gender(property)

```
https://www.hl7.org/fhir/person-definitions.html#Person.gender
person-definitions:Person.gender rdf:type owl:DatatypeProperty ;
  rdfs:range [ rdf:type rdfs:Datatype ;
  owl:unionOf ( [ rdf:type rdfs:Datatype ;
  owl:oneOf [ rdf:type rdf:List ;
  rdf:first "Female"^^xsd:string ;
  rdf:rest rdf:nil]]
  [ rdf:type rdfs:Datatype ;
  owl:oneOf [ rdf:type rdf:List ;
  rdf:first "Male"^^xsd:string ;
  rdf:rest rdf:nil]]
[ rdf:type rdfs:Datatype ;
  owl:oneOf [ rdf:type rdf:List ;
  rdf:first "Transsexual"^^xsd:string ;
  rdf:rest rdf:nil]])] ;
  rdfs:comment "The gender might not match the biological sex
  as determined by genetics,or preferred identification.
  Note that there are other possibilities than M and F".
```

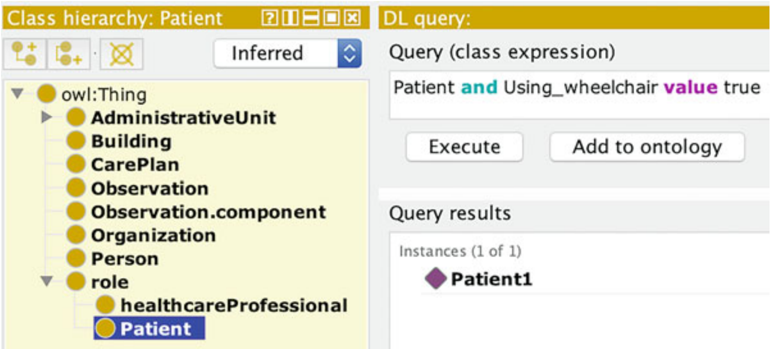

Fig. 1.8 DL Query execution with HermiT reasoner

1.5.3.4 Inference

OWL contain schema information in addition to links between different classes. This additional information and rules allow users to perform reasoning on the knowledge bases in order to infer new knowledge and expand existing knowledge. The core of the inference process is to continuously apply schema-related rules on the input data to infer new facts. This process was considered helpful in this case study for deriving new knowledge and for detecting inconsistencies. Example of automated inference using HermiT [47] reasoner is depicted in Fig. 1.8.

1.5.3.5 Knowledge Graph

Knowledge graph (KG) can be briefly explained as a graph with interconnected entities. KG became popular in early 2012 when Google started showing their search result as a Knowledge Graph which appeared on the right side of the page of your search result [13]. KG feature is available in all Graph database technology. In this case study, we obtain our initial IISArc KG using Ontotext GraphDB as shown in Fig. 1.9.

We can see how observation, patient and healthcare professional are connected. Here node represents entity and edge represents relation. Node with same colour means those entities belong to the same ontology class. On the right side of the illustration, we can see information related to particular node, in this case for *Diastolic blood pressure*. The user can click on different nodes to know detailed information related to that entity. It is a very intuitive way of visualization and also very helpful for healthcare professional or even healthcare management group to show workflow within identified residential care facility. Our initial interview with service providers indicates their satisfaction on our preliminary result. The next challenge is to formally evaluate the resource once additional data is entered from different settings.

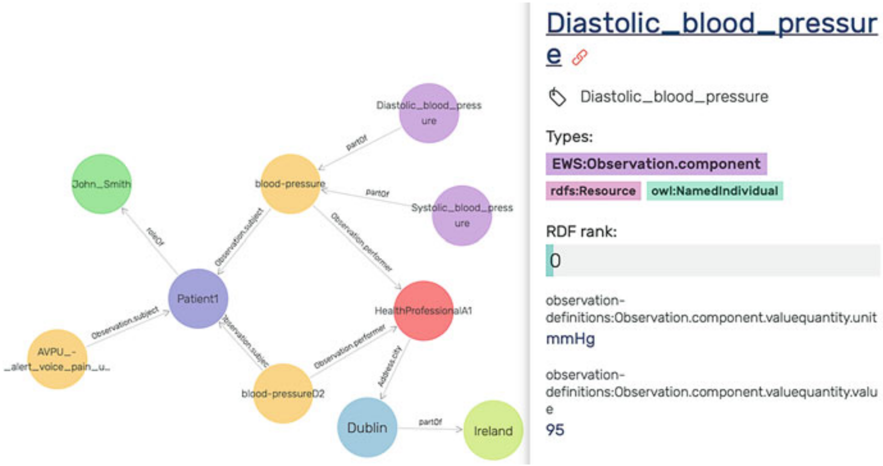

Fig. 1.9 Initial Knowledge Graph of IISArc visualized using GraphDB

1.6 Discussion

Considering the scope of the project and the need to identify alternative care delivery mechanisms in the era of COVID-19, this nurse led initiative recognized the need to deal with the challenges at the organizational level and devise innovative approaches to progress the CSDM project. Nurses are critical providers of care and therefore contextually understand the organization and what is required to achieve intended goals and service user outcome. The COVID-19 pandemic intensifies not only the economic needs of service provision but also the social needs of service users, and research needs to be cognisant of this when designing systems for new models of care delivery. Focused coordination and social distancing guidance on key requirements of COVID-19 can generate as many problems as they are designed to solve. It is therefore critical to approach the project with an interdisciplinary focus using a layered understanding of the existing and potential problems created by changing care delivery mechanisms. Simulation of planned transitions carries low risk and can be completed ahead of a study which requires ethical approval. This preliminary work has provided insights for the CSDM project and provides early indicator on the practical application and use of standards and technical reports for implementation of a common semantic data model for a complex healthcare network. As recommended by OECD [57], even though medicine has been successful at treating disease continual initiatives for service improvement must include assessment of the impact treatments have on people's lives. This makes outcomes valued by patients a key indicator of success.

1.7 Conclusion and Future Work

The European Union, aware of the poor uptake of health informatics standards, and associated fragmentation of health systems delivery has introduced the Elite S scholarship programme for future leadership in ICT standardization in Europe. In DCU through CeIC and Adapt Research Centers, researchers are working in partnership to accelerate the uptake and use of health informatics standards in Ireland. The COVID-19 pandemic has presented many challenges globally, and health researchers and policy analysts are reporting worrying results on predictive models for 2020–2021. Health and social care professionals are now classified as vulnerable populations by WHO [57]. It is critically important that such vulnerable employees are not unduly placed at risk, and in their respective practices that their time is not unduly wasted doing menial and repetitive tasks that can better be achieved using alternative and more efficient practices. Digital health systems and services can potentially provide some leverage in addressing some of the more outdated and repetitive routines that take up a significant HCP time. Co-participatory methods to advance appropriate design science of technology in context can potentially impact on service providers. Such systems once deployed can leave more time for important interventions that can address some of the more pressing needs in direct care provision. In addition to the longer term impact by providing data analytic and visualization for population outcome monitoring and policy planning.

During phase one development the CSDM team has identified opportunity in the current working processes with potential for service improvement. The next step is showcasing the benefit of using integrated-interoperable care service architecture (IISArc) to the wider audience. In this way the benefit of adopting graph database as part of a data storage and long term benefit to manage and retrieve service information can be realized. Additional benefit include but not limited to data harmonization and discovering new knowledge to inform targeted interventions. The second phase of development will test CSDM application from user satisfaction point of view using user experience (UX) dimension as proposed by Laugwitz [37] and as we implemented in our previous work on Semantic User Interface (SemUI) [18]. The questionnaire will be designed to understand different UX dimensions [37] along with the specific traits of *User Interface*. These UX dimensions perform a thorough assessment of the product using 6 scales with 26 terms. These scales were: Attractiveness, Perspicuity, Efficiency, Dependability, Stimulation, and Novelty. Final step will be to deploy our system on a cloud based server with the help of our industry partner Davra in order for us to conduct performance testing of the CSDM platform.

Acknowledgments This research has received funding from the European Union's Horizon 2020 research and innovation programme under the ELITE-S Marie Skłodowska-Curie grant agreement No. 801522, by Science Foundation Ireland and co-funded by the European Regional Development Fund through the ADAPT Centre for Digital Content Technology grant number 13/RC/2106 and DAVRA Networks.

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