

The Role of Academia in Reorientation Models of Care—Insights on eHealth

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Abstract: This paper provides a summary of progress on implementation research conducted to deliver evidence-based informatics infrastructure and guidance resources to advance integrated care in Ireland. (1) Background: The International Classification for Nursing Practice (ICNP[®]) R&D centre has progressed with its agenda to advance informatics theory and optimise the nursing contribution within eHealth Ireland. The centre has evolved as a formal multi-disciplinary research centre in Dublin City University expanding its research activity to become the Centre for eIntegrated Care (CeIC). The mission of the CeIC is to advance eIntegrated care in order to improve health and wellbeing of citizens; (2) Methods: In this paper, CeIC offers insights into the specific approaches adopted to realise this vision using Innovation 2.0 and Open Science as an emerging paradigm and rigorous methodology to drive transformational change; (3) Conclusions; we provide here a summary of our activity and discuss our experiences to date. We present detail on our progress through three core viewpoints namely (1) the individual and stakeholder engagement; (2) the development of technology infrastructure and (3) the political process considering the academic role in advancing informatics research. Our conclusions suggest that one needs to intrinsically link all three perspectives and provide focused interactions in order to bring about sustainable change for progression of eHealth.

Keywords: integrated care; informatics; innovation; health

1. Introduction

Health, as a complex and continuously evolving knowledge domain presents several challenges to the informatics community. One of these challenges is to design and create health technology to support and drive innovation to sustain a healthy society. The Centre for eIntegrated Care (CeIC) launched in May 2018, is engaged in developing and enriching national and international eHealth practices, policies and initiatives [1]. The purpose of our research is to create resources capable of evolving with, and for, contemporary health and social care needs and provide services, which support sustainability. Since the publication of the WHA69.24 resolutions in 2016, the adoption of the framework for people centred health services by national eHealth advisory groups is at different stages of deployment globally, and requires academic and innovative support initiatives to drive structural change [2]. National leaders are implementing policy and strategic implementation plans to reorient the models of care, and we advocate that nursing and allied healthcare professions have a critical role in the design process and implementation. Particularly in regard to clinical utility and patient safety. The overarching agenda for CeIC is to assist and produce resources for delivery of Sustainable Development Goal 3 (Ensure healthy lives and promote well-being for all at all ages) [3].

At the heart of eHealth national programs globally, is a need to reorient models of care and to provide infrastructure to support interoperability for care integration. Such an approach not only delivers better outcomes, but also informs future data analytics to enlighten health and social care

policy analysts' decisions on future investments. Tools and methods such as the Non-adoption or Abandonment of technology by individuals and difficulties achieving Scale-up, Spread and Sustainability Framework (NASSS), for example considers influences on the adoption, non-adoption, abandonment, and spread, scale-up of new technology adoption in health and social care [4]. Within Ireland we describe models of care as the way health services are delivered, they describe best practice care and services for a person, population group or patient cohort as they progress through the stages of a condition, injury or event [5].

The role of academia in supporting the transition to reorient care models includes the provision of evidence and scholarly activity in this changing landscape [6]. The context of health and social care delivery is now more than ever complex, difficult and dynamic terrain. This relates partially to the rise in supply and demand of health care resources to support global trends on Chronic Disease Management [7]. Competing agendas prevail, the global trend on chronic disease is rising, and for many health and social care teams, it is a struggle to maintain a reasonable person-centred care service [8]. And so, silo curative models persist and prevail, loading ever more pressure on existing service providers leading to battle-weary health care teams [2]. Academia provides a dedicated space for nurses and allied health care professionals to reflect on design approaches and consider critical perspectives to contextualise care, with a view to influencing patient outcomes using supporting emerging technologies.

Adopting a socio technical lens, the key principles underpinning our work is recognition that new models of care are multi-layered, multidimensional and can be demanding to deliver. To design effective infrastructure, we draw on realist and agile methodological approaches [9,10]. We consider underlying infrastructure to support contemporary health and social care planning needs to build in capacity for this complexity from the outset. Rather than look at individual specific projects defined by organisational boundaries which leads to vendor lock in and inhibits future large-scale data analytics, our approach supports the notion that form must follow function and at the system design level, development of core metadata can assist in making data open and interconnected for sharing across the World Wide Web [11]. In this paper, we provide insights on the role of how CeIC as part of the academic community is supporting the transition to eHealth and the Slaintecare Implementation Plan in Ireland by using agile methodologies and tools [5,12]. A second paper outlining the process of phase one development of a knowledge-based ontology to support our knowledge-based framework informed by available evidence, health informatics standards, and practitioner insights and wisdom has also been drafted [13]. Here, we show how academic partnerships as part of a community network was developed and used with cross-functional teams to inform phase one development of systems design methodology to inform models of care for Slaintecare [5]. We end the article with a discussion and conclusions.

2. Innovation 2.0 Collaborating for Shared Purpose

Innovation 2.0 methods recommend using six steps to underpin design science methodology. Specifically, the need to develop a shared purpose; create a vision, cultivate a clear understanding and focus, implement the project, evaluate, exploit, and disseminate results [10]. This paper presents detail on initial research relating to the visioning, understanding, and implementation steps to develop core data requirements in the form of catalogues designed to support Slaintecare [5]. Focusing on fieldwork and brokering partnership for understanding core requirements with key stakeholders we engaged initially with service management. Initial discussions clearly defined the need to have stakeholders actively contribute to design thinking to guide information requirements development. Meetings with leaders in ICT service delivery, made recommendations to progress with existing community networks to scale up collaboration and increase collective impact for a shared purpose to underpin systems design requirements. Sections 2.1–2.3 provides a summary of the activity completed from the perspectives' of the individual and stakeholder group, the design of technology infrastructure and the role of academia in advancing informatics research.

2.1. Organisational Stakeholder Engagement

As part of the agreed initial implementation phase, the CeIC launched a targeted stakeholder engagement initiative from 2017–2019. The adopted approach involved a co creation process for scalability of new products and services to support integrated care as defined by national policy documents such as Slaintecare [5]. Aligning with European Internet Foundation reports such as Digital World in 2025, which identifies mass collaboration as an emerging dominant paradigm [14]; we scheduled and participated in mash up workshops with focus groups of clinicians, industry and technology teams. We describe the notion of mash-ups as a collaborative idea generation method, in which participants develop with innovative concepts by combining different elements together in different ways. We established social scholars' groups to support digital innovation, and to assist CeIC in considering the use of data sharing initiatives across and between organisations.

Guiding our decisions was a need to progress implementation research on our agreed vision to advance seamless, timely and secure data for eIntegrated care in order to improve health and wellbeing for individuals. Using Open innovation 2.0 paradigm, iterative development cycles for service improvement were instigated. We worked on rapidly combining elements from existing projects to create core patterns to help stakeholders understand the complexity of integrated care. Specifically we focused on explaining why defined meta data was important in optimising delivery across and between services. From the clinician perspective, we wanted to help stakeholders understand the distinction between defining data requirements by individual project, and defining data requirements for interoperability for integrated care delivery. To achieve this, we introduced the notion of Models of Use and Models of Meaning [15]. Informatics theory relating to Models of Meaning and Models of Use describe the two models as follows.

Models of Use are existing forms and templates deployed operationally, and used routinely in a defined care environment by clinicians to support care delivery. For example, a defined template for a discharge summary record.

Alternatively, Models of Meaning present a framework to represent core information for reporting and statistical data analysis purposes. Models of Meaning therefore provides a format to process data and required information in a common standardised way thus providing timely access to information ([15] p. 194).

Demonstrating what information on a Model of Use looks like in practice and subsequently translating a specific Model of Use into a Model of Meaning to support interoperability proved a worthwhile activity for the understanding phase of the project. These two concepts Models of Use and Models of Meaning were used frequently in discussions as demonstrators to explain how platform and data innovation would work in practice. They also provided stakeholder groups with shared vision and purpose and a clear understanding on why a national health and social care data dictionary was required to support one to many research projects.

Commonly used design patterns in Innovation 2.0 include, a shared purpose, a platform, an ecosystem, an agreed plan for adoption, an agile production, an industrialising innovation and data driven innovation approach [10,16]. The related activities conducted by the team are mapped under these design patterns in Table 1. For example, in the agile design pattern approach, we provide scope to accommodate coevolution and present opportunities to focus on context specific needs for required efficiencies to support planned service improvements. The design pattern used within the project as a key area for improvement related to transition of care. We considered commonly occurring sets of problems and identified working draft solutions for reuse as design patterns [16]. Using the idea of a design pattern as an example to explain how to assemble metadata properties into larger structures such as core catalogues, while keeping this structure flexible and efficient for reuse across different organisational projects proved beneficial with stakeholders. Individual access to information during transition of care is required for more than one health care system at a time. We focused on design patterns to ensure clinical access to core data for clinical decision making using minimum core data sets e.g., a summary discharge record for transfer across and between service providers. Meta data relating

to identity was noted initially as a critical dependency to progress with integrated care. Considering national programme agendas, the detail and associated deliverables, which emerged from phase one stakeholder engagement activity, are provided in Table 1 under open Innovation 2.0 core patterns.

Table 1. Innovation 2.0 expected impact and application of results.

Active Design Patterns	Original Phase One
Platform	<ul style="list-style-type: none"> Technology level solution semantic and syntactic interoperability using defined ontology meta driven resources see technology infrastructure section phase one completed. Publications and reports recommending best approaches to national governance groups on state-of-the-art evidence-based approaches.
Ecosystem	<ul style="list-style-type: none"> Hosting and Participation within eHealth Ireland Ecosystem expanding industry engagement breaking down the silos. Developing new collaborations with industry and policy groups and citizens dedicated workshops and meetings to advance networking opportunities and research proposals [17].
Planning for adoption	<ul style="list-style-type: none"> Establishing small focused sub groups for example standardising nursing language sub group to inform wider national symposium discussions. Two Fulbright scholar awards granted creating proposals to support innovation in line with national strategic planning. Dedicated level 9 modules on Informatics in eHealth with readiness for engagement workshops. Raising awareness on core informatics and clinical requirements to advance sustainable integrated care agenda. Participating in national Higher Education Initiatives for cross institutional education on Self-Management Support Guidance Programme for health care practitioners at undergraduate level.
Agile production	<ul style="list-style-type: none"> Deployment of Quadruple Helix Optimising Stakeholder Engagement with PPI groups (Public and Patient Involvement), Dedicated meetings to review approaches and explain the value and importance of participating in defining information for interoperability. Centre for eIntegrated Care (CeIC) attendance as PPI workshops capacity building of team on PPI related actions [1].
Industrialising innovation	<ul style="list-style-type: none"> Focused industry engagement workshops. Funded Enterprise Ireland Research Grants Awarded to consider identity attributes and invest in development of innovations with industry to advance semantic and syntactic interoperability assets. Funded award to support co-ordination of EU funded proposal on digital transformation in health and social care. Submitted Horizon proposal on digital transformation for large-scale pilot of patient centre outcomes in 4 EU member states.
Data driven innovation	<ul style="list-style-type: none"> Publication and dissemination for transparency in research activity and knowledge transfer new website see https://www.ceic.ie/. Core Slainte data catalogues created. Delivery on independent transparent assets in the interest of the taxpayer.

2.2. Post Stakeholder Engagement Technology Infrastructure Development

CeIC sourced additional funding through public procurement in 2018. This instigated a scheduled number of developments. The CeIC conducted several targeted workshops with health service providers and industry partners engaged in delivery of eHealth in Ireland. This then led to focusing our attention on identity catalogues and categorising the key properties and attributes required to support ongoing development work in progress on identity services using specific identity metadata to support integrated care services. In addition, a scoping review to determine what the critical factors

relating to the creation of a meta data registry was to support the development of a sustainable health and social care data dictionary platform was completed. Initial work resulted in a briefing report, which is available to view online through the Information Architecture page [12]. The need to design a meta data registry framework with an associated emerging ontology meta model was agreed for completion. In accordance with agile methodologies, the preferred approach to develop the registry framework is to use an iterative development cycle underpinned by service requirements and planned service improvement initiatives. Using existing health informatics standards such as ISO 11179 and technical specification documents metadata repository requirements Meta Rep [18,19], an opportunity presented itself to create a set of core resources for mapping, testing and validation through existing projects in progress at the service level.

Additional initiatives in 2018, and 2019, as collaborations progressed within the centre resulted in the development of an EU consortium. This group through networking identified the need for specific data relating to Patient Related Outcome Measures (PROMs) and Patient Related Experience Measures (PREMs) as a priority for service improvement and maintaining patient centred care [20]. Progressing with the national and EU agenda for integrated care, CeIC opted to co-ordinate a proposal to conduct a large-scale pilot for patient centred outcomes resulting in the submission of a proposal to the EU in Q2 of 2019 with 12 European Partners.

Both the EU proposal and the national Slainte care agendas require a health and social care data dictionary to stand independent of individual project requirements and have potential to provide a sustainable and better return on investment in the longer term. Translating Models of Use into Models of Meaning within the data dictionary for Slaintecare was useful in providing a sense check for participants in comprehending the purpose of the dictionary. Developing both models therefore can provide not only support on multiple clinical projects for clinicians in defined care environments, but also can support future data science analysis for eHealth in the longer term. Models of Meaning are characterised as:

- (a) A framework to represent core information for reporting and statistical data analysis purposes.
- (b) A format to process data and required information in a common standardised way to support integrated care and timely access to information.
- (c) Delivery of a common representation of information, storage, and communication aligning with an evolving ontology model underpinned by context specific conceptual domains rather than defining requirements for siloed individual clinical projects [5,15].

From the national perspective and over a two-year time frame, CeIC created twenty-two catalogues in XIGT to support both syntactic and semantic interoperability. The catalogues are at various stages of completion at the time of writing this paper and have been submitted to the eHealth Ireland team to progress. On completion of initial testing, XIGT tooling was used to present draft catalogues to cross-functional teams for review and comment. Links to initial progress on development of Models of Meaning relating to demographic data as a key concept are presented in Table 2 and followed by Figure 1 below which illustrates a summary of the registration and demographic detail. The asterisk in Figure 1 indicates that Administered Item and Person are concepts that are defined in the Metarep ontology and FHIR ontology respectively [18,19].

Table 2. Links to emerging work on models of meaning.

Links to Emerging Work on Models of Meaning
http://theme-e.adaptcentre.ie/metarep/index-en.html
http://build.fhir.org/fhir.ttl

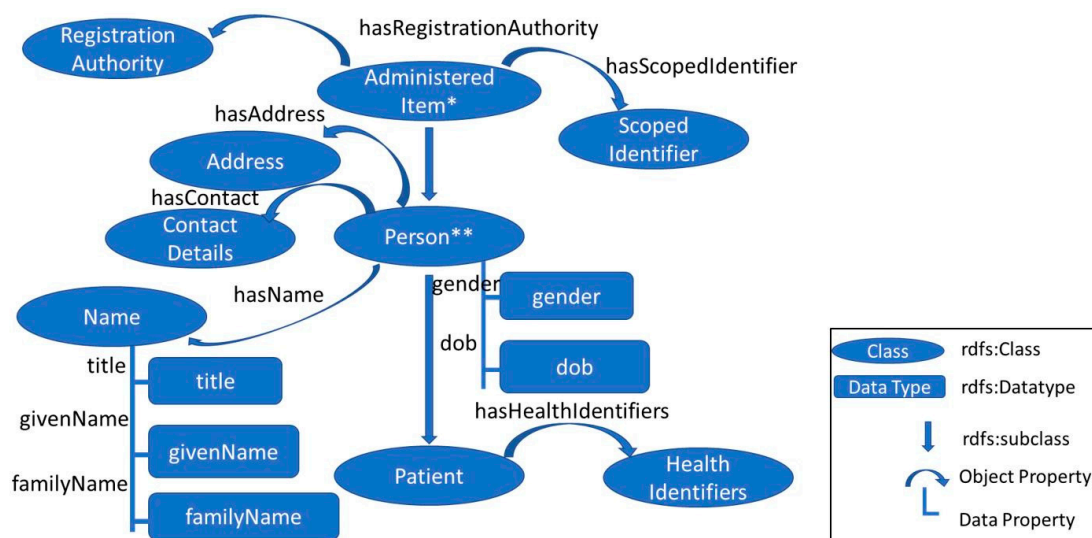


Figure 1. Conceptual model for demographic detail, aligned with metarep * and FHIR **, see Table 2.

2.3. The Political Process Considering the Academic Role in Implementation Research

The scale of the eHealth transition process within Ireland is immense. This is partly to do with the existing infrastructures and multiple systems, which are in place locally in established hospital groups and community health organisations. Academia has a role to play in supporting eHealth transition. Academic identity is changing, as we consider routine scholarly questions of what, how, and when in research implementation initiatives, such queries need to be supported with more pressing practicalities of who will conduct a particular approach and where can this approach be best deployed with best resources [1,21,22]. Evidence from OECD suggests that 80% of the value of innovation comes from the successful adoption of innovation with just 20% of the value coming from creativity activity [17]. This would suggest the factors required for adoption of innovation need careful consideration and time to increase the probability of successful acceptance [10]. Time that academics can provide through dedicated research centres, roles, and expertise. By adopting a quadruple helix using co-participation and socio technical approaches, we believe there is an opportunity for rapid scalability of extensible guidance to progress integrated care and address the challenges to implement Slaintecare [5]. As academic guidance is provided and disseminated, it offers opportunities for industry to create new products, create employment opportunities, and build capacity for sustainable service improvement agenda. Thus, providing a better return on investment for taxpayers in the longer term.

Traditionally implementation research approaches have had a tendency to think at a project level and use a focused linear approach. In defining system requirements this is often referred to as the Waterfall Model of Systems development and design. Each process and phase uses a well-defined linear approach. By adopting a realist approach, (which is theory driven as opposed to empiricist driven approach), the CeIC are keen to consider agile and co-participatory methodologies to guide sustainable research approaches for system design. Not seeking to deliver a package on time and within budget as a series of checks and balances, but accepting this process will be organic and each piece of the building block will be revealed over time with new insights requiring new tooling and methodologies that can be introduced Incrementally as required [9,17].

Our experiences to date suggest that to create an enabling environment for joined up community networks and operations for ICT requires time. It requires individuals to invest their time in creating communities to deliver on grand challenges. It also requires longevity and trust in the teams who give their time over a number of years with a focused and shared purpose. To support an evolving organic research agenda, we created a dedicated website interface to disseminate research, and support scholars' groups through formal and informal education both of which are evolving. The website design uses pillars mapped to the Horizon Innovation programme [23]. Pillar one relates to Open Science, pillar two Global Challenges

and Industrial Competitiveness and pillar three Open Innovation. This structure provides signposting and transparency to publish research activity and grey literature as it emerges using the embracing open science agenda as defined by the European Union optimising knowledge transfer. CeIC are advancing innovation networks through dedicated workshops and disseminating material via virtual infrastructures such as CeIC website [1]. Our goal is to provide transparency, nurture creativity and advance public private research by creating scholarly knowledge clusters and knowledge assets to advance open science. Thus, supporting and building greater capacity where it is most needed to address the challenges ahead. Figure 2 provides a screen shot of the CeIC website.



Figure 2. Screen shot of revised CeIC website.

3. Summary of Progress Phase One

3.1. Individual Stakeholder Engagement

The adopted individual stakeholder engagement approach included a co creation process for scalability of new products and services to support Slaintecare [5]. Table 1 above provides a summary of the activity as defined by Innovation 2.0 paradigm [10]. Activities relating to Innovation 2.0 core patterns such as transition of care, implementation of a summary care record, developing a shared purpose, defining specific platform requirements are summarised. As transition to eHealth Ireland progresses, well-articulated policy translation requires decisions to be made at a strategic level within services. Without clarity on decision making processes progress are hindered. Simply stated there is a lack of clarity on who is responsible for what. Recent policy reports that engaged in a public consultation recommends greater efficiencies are required, indicating that change will not be effective if structures and governance are not addressed together. This latest policy report recommends a reorganisation of services and geographic alignment of community health organisation and hospitals to support patient pathways in addition to greater clinical leadership to establish a clear line of responsibility and accountability ([24] p. 53). This report paves the way for six regional health bodies to deliver key Slaintecare commitments [5].

3.2. Technology Infrastructure Development

As the national Enterprise Architecture group progresses with defined core interoperability platform requirements' it is anticipated that the catalogues will be progressed through data governance groups and published with national eHealth Ireland web resources. A defined set of metadata using XIGT is emerging to support Models of Meaning for specific contextual domains relating to Slaintecare Implementation Plan [5]. Table 2 and Figure 1 above provides links and summarises initial work completed to date through academic partnership and collaborations [25,26].

This development work was mapped and informed progress with phase one XIGT catalogues in accordance with national service requirements. Key evidence informing this research included Slaintecare and ISO standards ISO 13940 Systems of Concept for Continuity of Care [5,27]. The team focused on the conceptual domain of identity for preliminary mapping and reviewed EU resources such as Art Décor [28] an open-source tool suite that supports the creation and maintenance of HL7 templates, value sets, scenarios and data sets. Key insights from this second round of development work was the need to create dedicated administration items within the emerging data dictionary and a structured leaf branch and tree formation for Conceptual Domain [18,19]. This work is explained further in a second paper, which provides an overview on healthcare standards analysis to support Slaintecare Ontology for Integrated Care in Ireland [13].

3.3. *The Political Process Considering the Academic Role in Implementation Research*

The Role of Academia in reorientation models of care is as much about social engineering, as it is about stakeholder engagement within organisations. Particularly when supporting deployment of technical infrastructure to support cloud based services for integrated care and service improvement. Historically however models of health and social care delivery and their associated operations in Ireland are embedded in de facto boundaries [21,22]. There are currently seven hospital groups and nine community health organisations in existence.

As citizens, we exist inside and outside the lines of bureaucracy, particularly in our roles as public servants where our role is to deliver care in hospitals and communities. Public systems are described as specific systems with boundaries more often lay claim to beliefs and customs associated with endorsements. Such beliefs and customs can impact directly on transformation and inhibit sustainable change. Smith and Varzi [21] define in detail the types of boundaries, which exist in our social world, one of which is entitled fiat boundaries. These boundaries can be associated with historical beliefs and customs including loyalty to specific organisational boundaries. It is therefore not surprising to see recent policy recommendations accepted by government to restructure services in Ireland for to geographically align hospital groups and community health organisations in Ireland to make the structures work around the population as opposed to the population working around the structures ([24] p. 82).

4. Discussion

Transforming models of care in our experience cuts across fiat boundaries and requires dedicated time and energy to not only recognise their existence, but to address the associated issues with breaching the boundaries, their established customs and associated routines. This requires a change in mindset and a strong focus on capacity building at organisational level to create a shared sense of national purpose for deployment of Slaintecare.

We consider scholarly disciplinary questions on the practicalities of who why and where needs to be well articulated and disseminated from the outset. For example, who are the best placed individuals to deliver transition, is there a compelling argument on why it is important, and where can it best be instigated [9,25]. Tools and methods to advance this approach are well defined in the evidence; one example is the NASSS framework, which considers influences on the adoption, non-adoption, abandonment, and spread, scale-up of new technology adoption in health and social care [4].

By using a quadruple helix of co-participation actions underpinned with socio technical methods, we believe there is potential for understanding context and rapid scalability of extensible guidance to support key stakeholders to progress integrated care agendas. Consideration of critical factors influencing adoption, recognising dependencies in context and understanding existing fiat boundaries all need to be respected. We are optimistic that future strategic planning of geographic re alignment has a clear understanding that this is the case, as strategic reports recommend suitable ICT is considered an essential prerequisite to any restructuring of services ([24] p. 82).

5. Conclusions

Dedicating time and energy to understanding local context and its associated fiat boundaries, exploring and discussing the possible interactions between fiat boundaries with different organisations engaged in integrated care deployment is considered an important activity by CeIC. Selecting specific design patterns which are core and therefore relevant to a number of stakeholders ensures that the centre's mission makes small but purposeful steps in progressing eHealth Ireland.

Our results to date articulate the need for an evolving meta data registry framework informed by core catalogues carefully selected to identify the key metadata required to make Slaintecare a reality. The need for an evolving metadata dictionary understood by different stakeholder groups is evident in our initial progress. If information is organised using a common Model of Meaning then this model needs to be understood by everyone who wants to interrogate the data ([15] p. 196). Academics through dedicated research centres can provide focused time and expertise in building capacity, providing guidance and supporting transition to new models of care. Governance and clear accountability on decision making to instigate and progress Slaintecare is critical across the services. This is reflected in the latest policy reports, which identify clinical governance and leadership as important factors to address accountability ([24] p. 53). We are hopeful that recent policy on public consultations will be acted upon to drive this change in a timely manner.

Being involved in multiple projects lends itself to being involved in everything, but having insight and impact into nothing. Therefore, we continue to focus on development of Slaintecare initiatives in order to support a shared purpose and action plan. We consider the three perspectives, which we have presented our initial progress on to be critically important to bring about sustainable change. Understanding individual and stakeholder groups their associated locally defined fiat boundaries and educational needs is essential. In this way, we can ensure the defined information and data requirements for design of technology have clear insight into context and associated dependencies to translate Models of Use into Models of Meaning. By linking all three perspectives through focused interactions, a more sustainable impact can be achieved. The academic role in this way can support eHealth transition through Slaintecare and build partnerships to deliver truly personal centred models of care.

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