Understanding Integrated Care

…..it's about getting the harmony right

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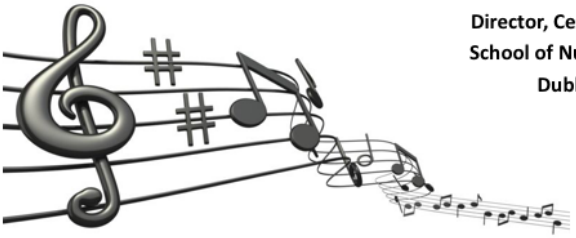
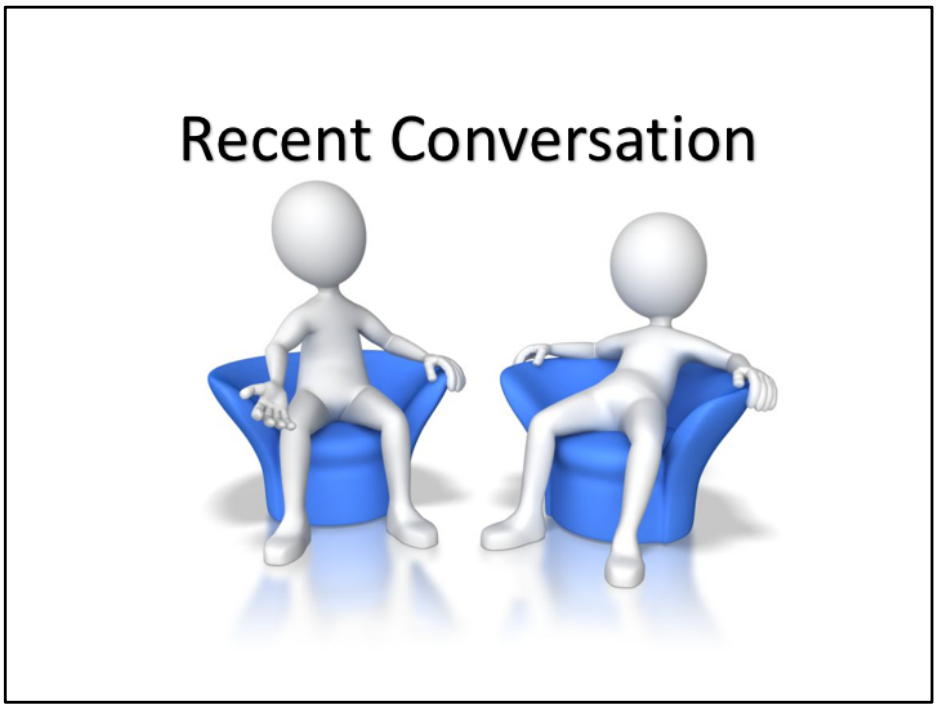
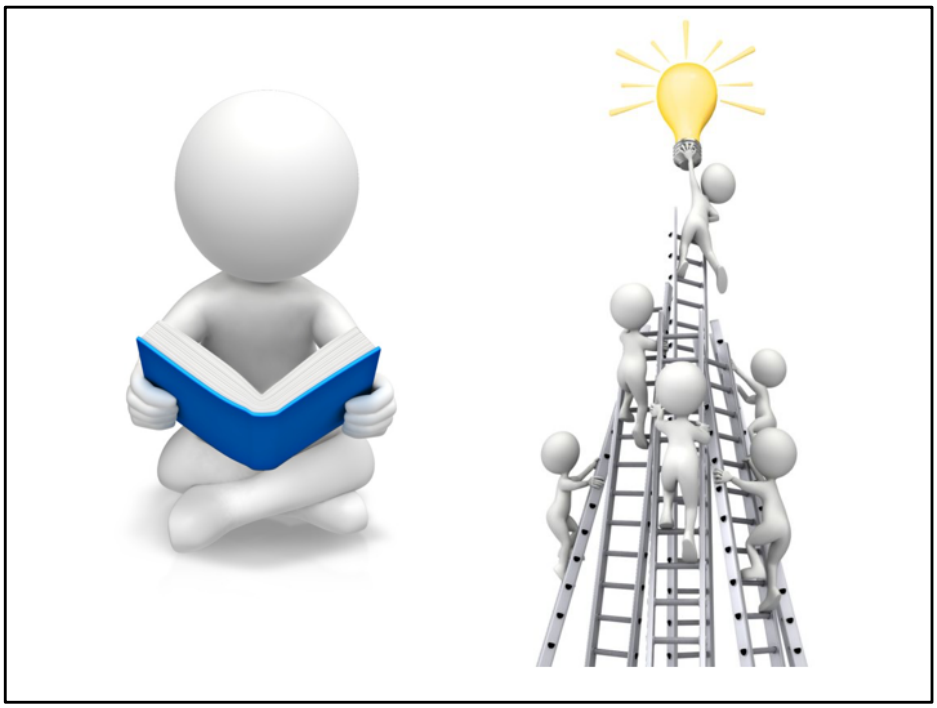


"his out-of-the-box thinking, quick wit and love of good single malt". (The Scotsman Nov 2012)



I was thinking about a conversation I had recently with a colleague from Australia when talking about the impact of the research projects we invest our time on. The conversation progressed with my colleagues suggesting that any contribution on any given project can be considered a success from three key points of view.

Firstly, the project is a success if it delivers what it intended to deliver and has achieved its aims and objectives, Secondly it's a success if the team have learned from the mistakes they have made along the way and take these valuable lessons with them and apply them to future projects



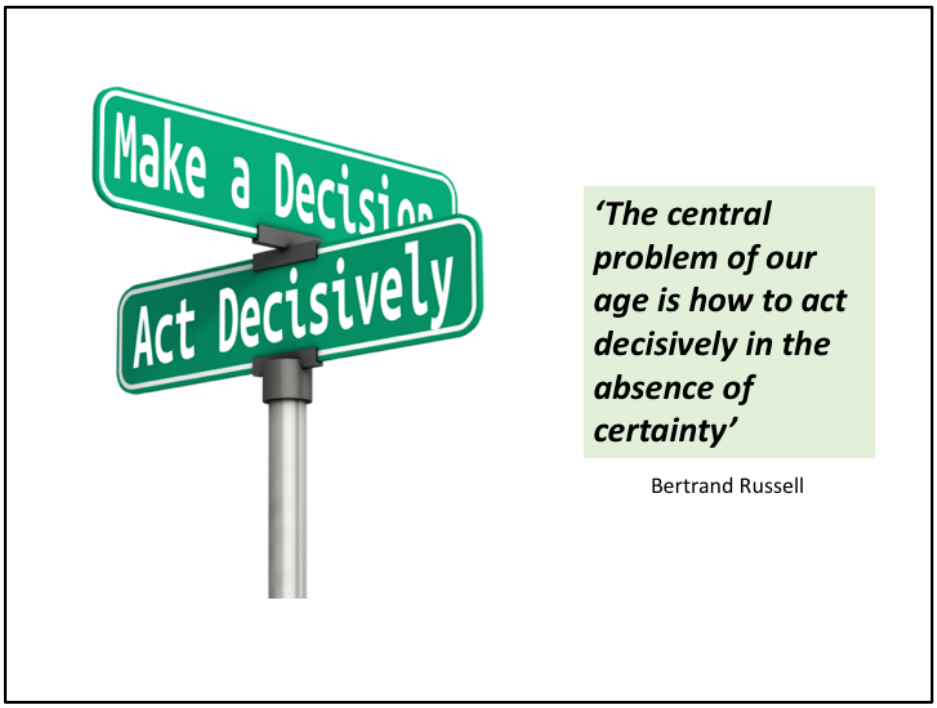
Thirdly, and perhaps most importantly , whatever has been achieved within the original project provides insight to others in future work that is yet to be developed. Along the way I have had plenty of experience with projects from each of these perspectives with success considered from varying degrees, and I suspect that this is the case with many of us in the room here today who have worked in Health informatics over time.

Derek Hoy taught me a lot, particularly when I consider the short space of time we spent in each other's company. He provided great insight in terms of creativity and innovation and its practical application to computer science to many individuals.

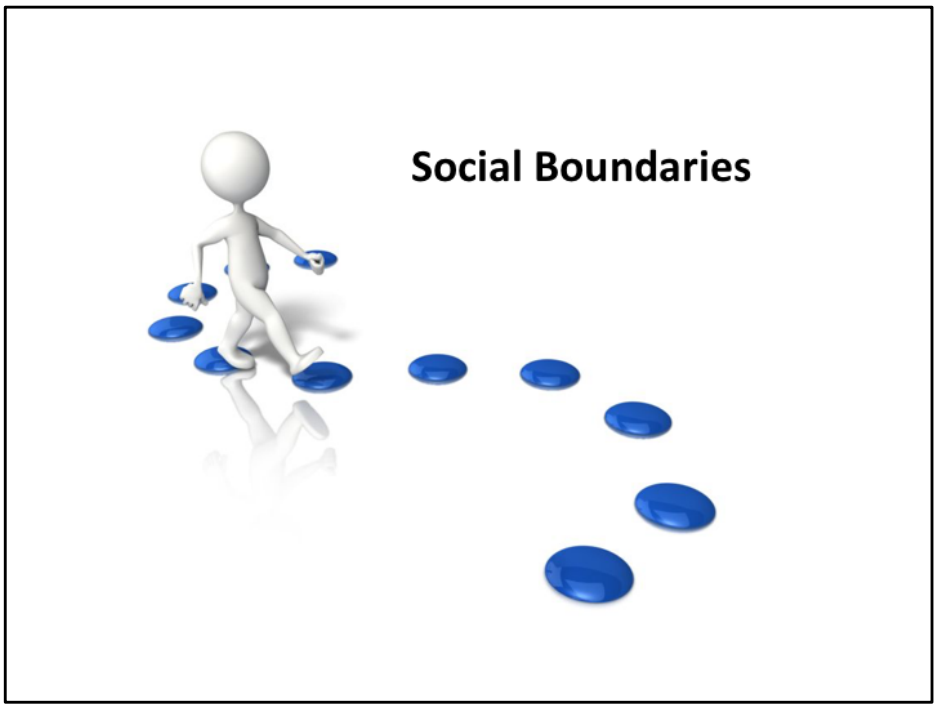
I remember Derek and I sitting in a hotel in Dublin drawing diagrams and mapping out innovative approaches to advance nursing in eHealth. Snowcloud http://snowcloud.github.io/ct-snowhite/ was one that Nick and he worked on which aligned with the OpenEHR approach of clinical templates. We tried to gather key players together in community setting and had some success , but as is often the case keeping the momentum going was difficult.

This is why I am indeed honoured to be asked to do this talk today and to share my experiences of working with Derek. Despite the short time we spent together Derek was a man who shaped my thinking and with his passing thought me a valuable lesson "*I am careful what I invest my time in now Pam*"

Lesson 1 Invest time with individuals that you know you can work with and initiatives that are worthwhile. In a space where there is information overload it is particularly important to select, focus and invest your time on what is important this may mean you need to focus your attention on a set of one or more key topics. For the past two years the topic I now focus on is facilitating digital infrastructure for integrated care. If this task is done well it is unseen or undetected by clinicians. Its falls into the background. If it is done badly it creates an unworkable solution in any given project.



According to Bertrand Russell *The central problem of our age is how to act decisively in the absence of certainty.* Nursing I fear is not on solid ground these days. People living with rather than dying from chronic disease presents Health and social care policy analysts with many challenges. At a time when the nursing voice should be at its strongest we stare at the digital patient as if it were a new species foreign and alien to us. There are for sure pockets of innovation and success stories , but globally nursing lags behind other disciplines. Perhaps we need to consider the pioneers who embraced research and delivered much in the interest of individualised health care. Perhaps we are afraid to make key decisions as they may impact or shape sustainability for contemporary nursing. Individuals who have produced seminal work such as Corbin and Strauss who defined trajectory models for chronic disease management or sociologists such as Kathy Charmaz in her publication Good Days and Bad Days provided great insight into self-concepts of chronic illness. Such seminal work has still much to offer us in terms of creating digital tools and the way we design clinical templates for new models of care. Such initiatives can provides us with great insights on what we can instigate today. In this presentation I present some work that continues to shape my thinking.



Silo curative fragmented models of care will not provide us with answers. I could provide significant figures here which I am sure you have all seen in recent media reports. There is no doubt we are living in a time of uncertainty but one way to act decisively to see through the fog is to progress the integrated care agenda. We live in a time where boundaries are super imposed on us in our society. Those who define the boundaries carry with them great responsibility to not only define both the social boundaries of our society , but also the systems design and the systems created which govern it. Taking lessons to heart such as current challenges with boundaries we face such as Brexit I suggest the health informatics community needs to focus carefully and to act decisively. We may not be able to shift the boundaries that exist but we certainly need to be aware of their existence and we should try and manage them.

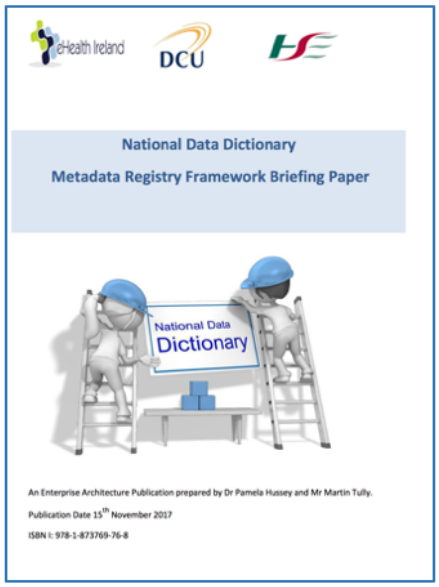
This brings me to the title of this paper and the man who inspired me to write it. Dr Derek Hoy, I can still hear him telling me he is very careful with his time and what he invests his energies in. One thing he did spend his time doing was playing a tune on the fiddle. And that got me thinking about the relationship between music and its structural form. Considering how well composed music creates a wonderful harmonised and integrated sound. What lessons can the health informatics community learn when we consider the delivery of Traditional Celtic music and its associated form?

How we can achieve integrated care acting decisively in design in order to get the harmonies right?

The rest of this paper is structured using music and specifically Celtic or as we call it in Ireland Trad music as a specification (in the broadest sense!) of how we can provide insights into achieving integrated care. A set of principles to manage boundaries or at least recognise them for what they are because in all cases its about acting decisively in design in order to get the harmonies right.

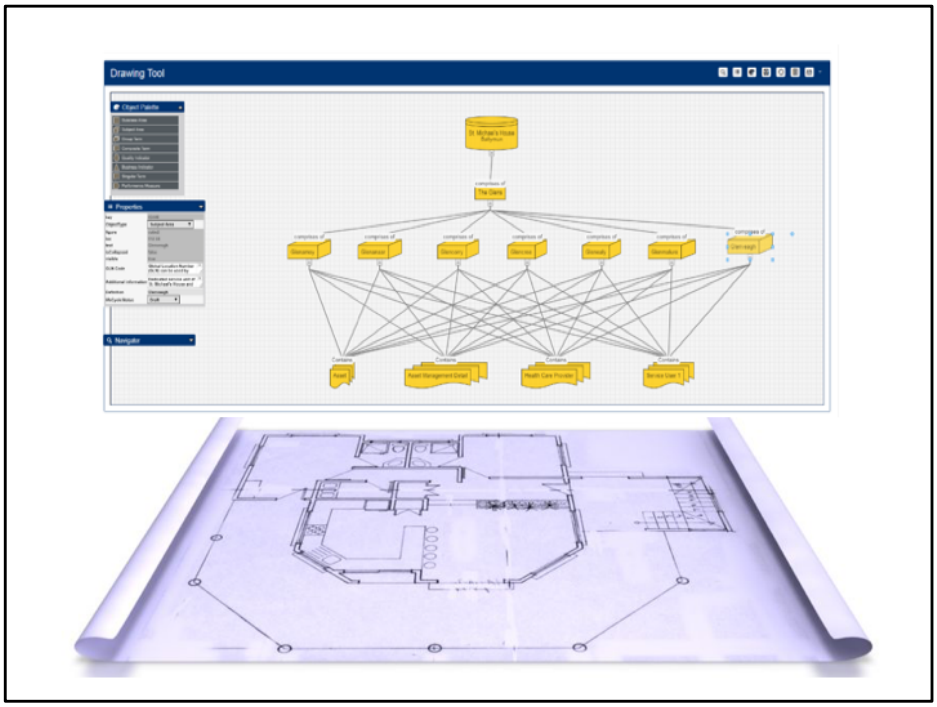
As is the case in most music the student of Celtic tunes learns the tune by breaking it down into a series of technical steps. The rhythm, the style, and the key are just some examples. Anyone who plays Celtic music will tell you there is a big difference in time signature between a gig and a reel. A reel is 4/4 and a gig is 6/8 I know this as I checked with my niece Sharon Hussey who is gifted traditional musician.
For our colleagues who attempt harmonisation in care selecting the right standards (signatures) for each step the technical, the semantic, and the functional specifications for integrated care are required to achieve interoperability and optimise harmonisation.
One standard that I have found consistently and particularly useful is RM ODP a Reference Model for Open Distributed Processing (RM-ODP) which provides a co-ordinating enterprise architecture framework for the standardisation of open distributed processing. As a practicing nurse for 20 years I need everything to be simply broken down into bite size components. The RM-ODP viewpoints developed in the 90's makes sense to me and provides a framework of reference to situate all components required for an enterprise architecture. There are other frameworks available such as TOGAF but from a clinical perspective and to deliver integrated care RM-ODP provides the key processes required to make sense of the core ICT requirements. Some of these ideas are now expanded upon in the next few slides .

What are the key elements for a good Celtic music session? Firstly, we need to have experienced musicians who understand the importance of team participation and cohesion. The experienced musicians lead by example and provide space for playing certain suites of tunes in a cycle that progresses with ease between one to many sets of tunes – key message here is that the interface is seamless and managed there are no surprises and the musicians know by name the tunes as they are well rehearsed over time. All musicians move together there is a couple of seconds of a break in the tune and then it restarts often in a different key and tempo.
Considering this scenario from a computer science perspective for a moment, the following slides identify critical factors that are required to getting the “harmony right” in integrated care. These examples span a number of years 30 plus and are by no means exhaustive. Rather they are purposefully selected to drive home a key point, the challenges we encounter in integrated care persist and global policy suggests we are not making the expected progress we anticipated. RM-ODP and its viewpoints provide the transition breaks just as the musicians shift so too does the project team between the viewpoints.

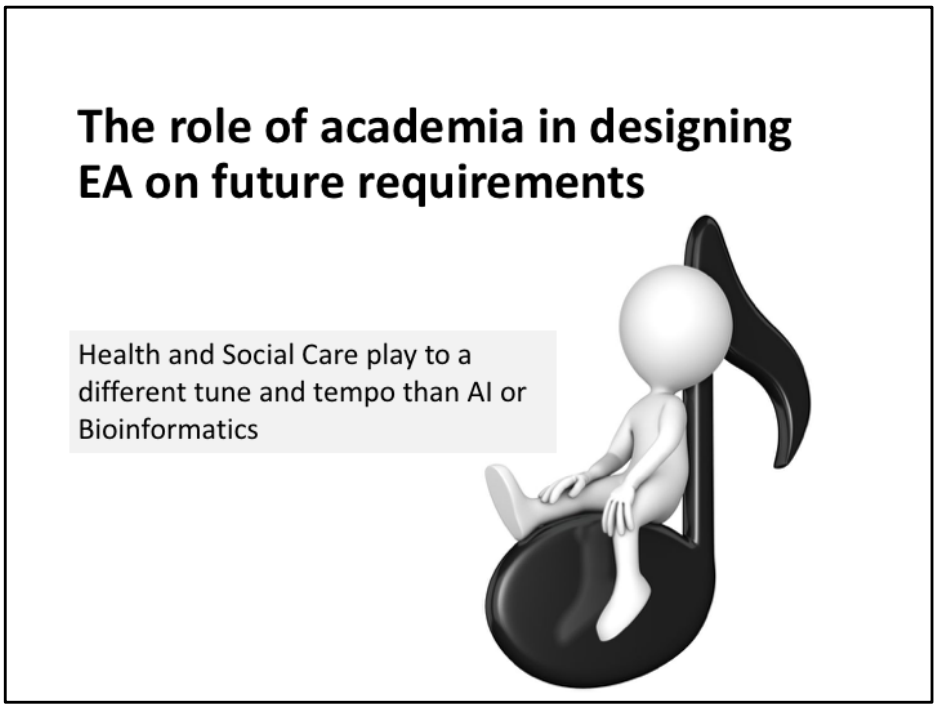


http://www.ehealthireland.ie/Our-Team/Enterprise-Architecture/HSE-National-Data-Dictionary-Briefing-Paper.pdf

Example 1 is firmly located in bridge building between the information and computational viewpoints as identified in RM-ODP. Defining infrastructure with associated concepts and syntax with pre-defined templates (e.g CDA), listed transactions and pathways delivers vital ground work for interoperability to be achieved. In 2017 , Mr Martin Tully (also a Celtic musician!) and I published a high level paper to demonstrate the need for a metadata registry framework we provide a link here to this publication http://www.ehealthireland.ie/Our-Team/Enterprise-Architecture/HSE-National-Data-Dictionary-Briefing-Paper.pdf that may be of interest to some.



Just as the musicians know or have access to the sheet music of the tunes they play and the key they play in , so too does the computer use the identity services to distinguish between organisations, people, assets, and locations. In Ireland we are working on development of infrastructure to deliver the first step in building safe interfaces between delivery of information beyond the boundaries of any one organisation. Figure 1 provides an example of a service and its associated constructs embedded in the data dictionary with associated properties.

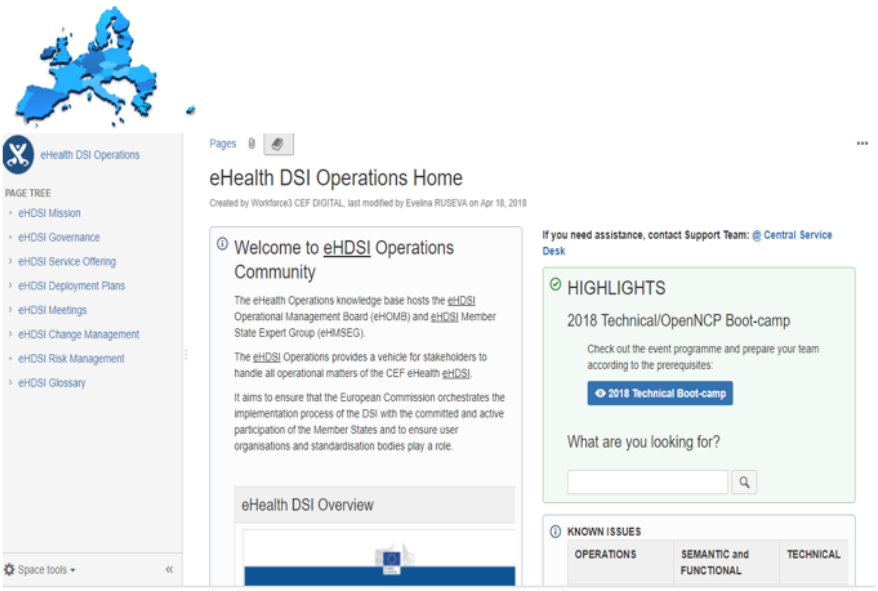


Every musician knows the groups skills expertise and role in delivering the tune. For example, certain tunes require specific musicians to lead out or do solo pieces with a fiddle or wooden flute at specific points in the tune. In Ireland we are rethinking our national data dictionaries for optimal use. Providing the specific metadata for stakeholders engaged in delivery of integrated care could be compared to providing sheet music to achieve a musical score. There is no doubt that Computer science is progressing at a rapid pace e.g. AI, Robotics, Bioinformatics, but it's useful to remember that health and social care play to a different tune and operate at a different tempo. From Celtic music perspective we would be classified as a reel rather than a gig! Factors impacting on this pace are multifaceted and beyond the scope of this talk but patient safety plays a key role.

Value proposition rethinking the role of data dictionaries

Considering the value proposition on how data dictionaries can provide much needed detail to one to many stakeholders is an evolving process. Initial steps include rethinking the role of data dictionaries in advancing integrated care not just considering data dictionaries as holding spaces for descriptive data. There is opportunities for signposting core infrastructural requirements e.g. identifiers, essential syntax pathways, core value sets and versioned terminology services ICD10, ICNP, Snomed International.

When it comes to considering integrated care the issue of clinical risk and patient safety cannot be under stated. Poor transition in a Ceili would not result in a well-played out tune. In the domain of ICT conformance testing to ensure wire to wire transmissions are 100% accurate and defining cardinality of data transactions i.e if they are mandatory or optional provides much needed detail for conformance testing and certification. The process of development evolves as the technology does.

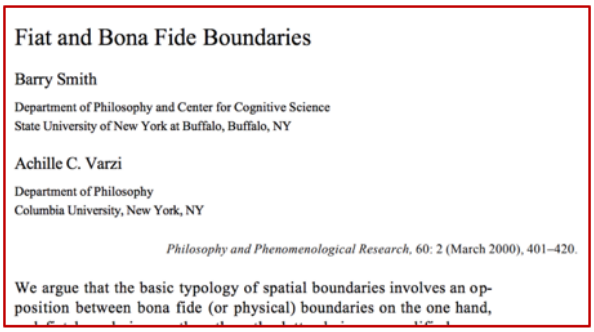


https://ec.europa.eu/cefdigital/wiki/display/EHOPERATIONS/eHealth+DSI+Operations+Home

The Digital Agenda for Europe is providing vital infrastructure to engage in testing. The European Union is investing in Digital Services Infrastructure and providing connectathans for testing conformance of EU Digital Services in process. Further information is available from https://ec.europa.eu/cefdigital/wiki/display/EHOPERATIONS/eHealth+DSI+Operations+Home

This approach builds both national and EU capacity thus providing a ROI to tax payers, avoiding the advancement of black box and vendor lock in.

The role of the academic community in EA viewpoint



Fiat and Bona Fide Boundaries

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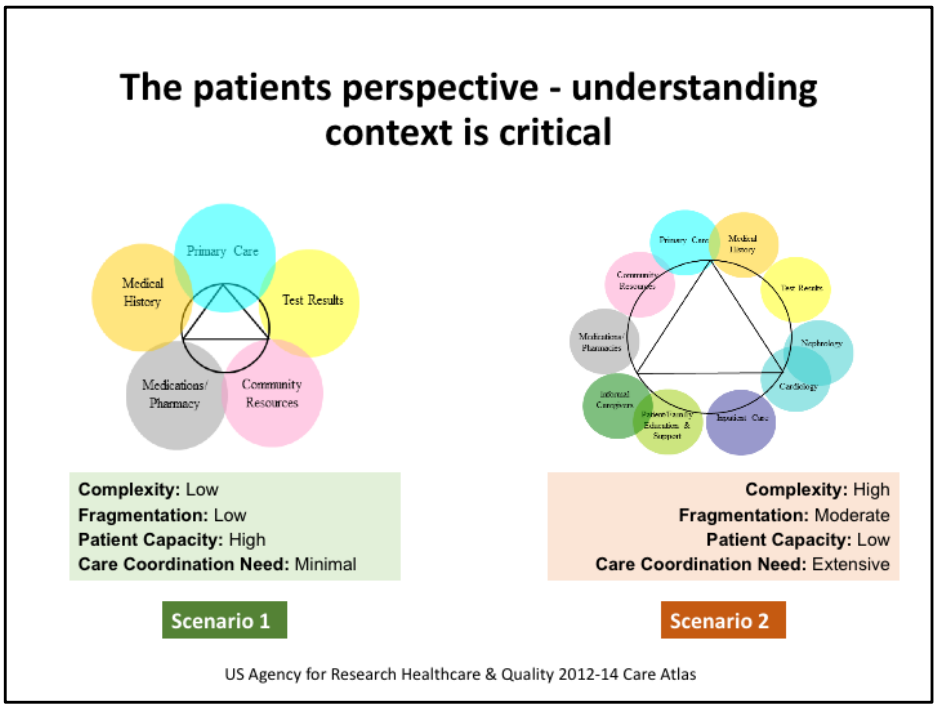
Philosophy and Phenomenological Research, 60: 2 (March 2000), 401–420.

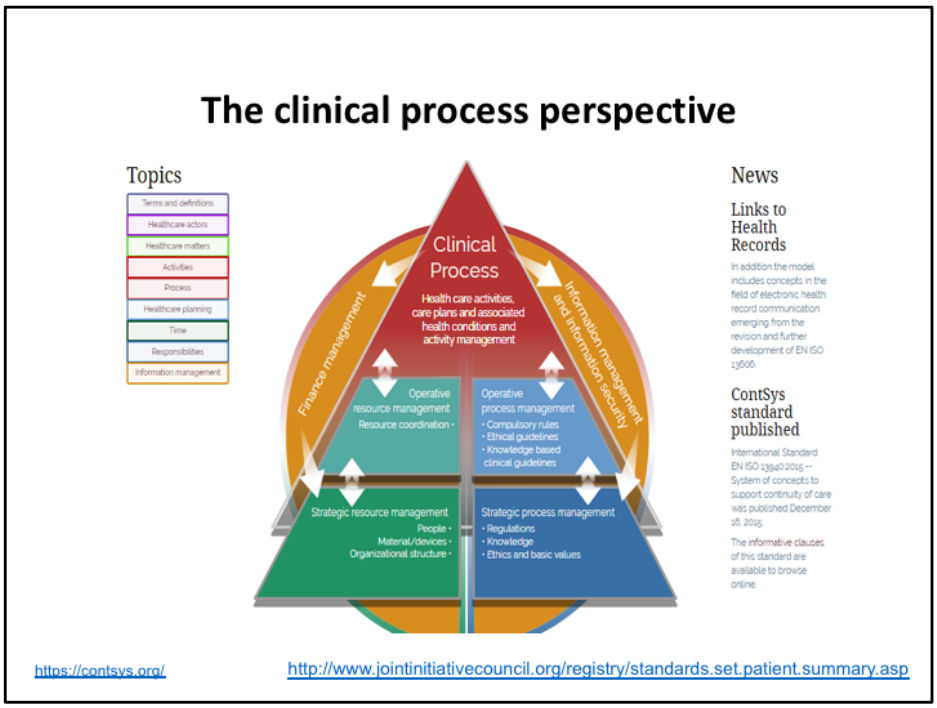
We argue that the basic typology of spatial boundaries involves an opposition between bona fide (or physical) boundaries on the one hand,

http://ontology.buffalo.edu/smith/articles/fiat-boundaries.pdf

I have mentioned boundaries and specifically social boundaries a few times in this talk. Understanding the notion of social fiat Boundaries and their dependencies is a critical factor when defining semantic interoperability. For those interested in this space I include a link to Barry Smiths work on ontology and boundaries http://ontology.buffalo.edu/smith/articles/fiat-boundaries.pdf

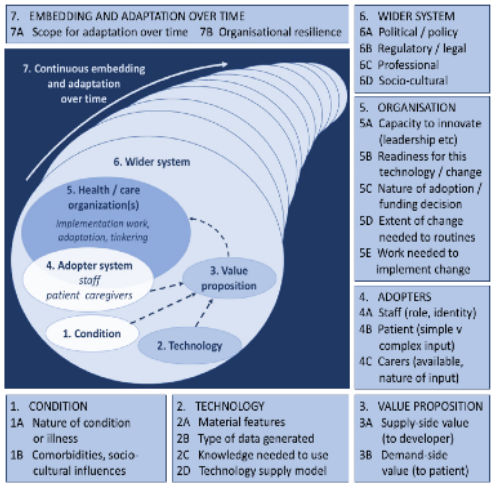


Connecting health information across the continuum of care is often diluted with an alternative competing single organisation agendas. The broader systemic issues such self-management support and care co-ordination are considered less of a priority. The US Agency for Research Healthcare and Quality (ARHQ) developed some interesting work in 2012 /14 which demonstrates the complexity of care co-ordination and an associated care atlas using scenarios of individual client's needs.



Progressing the celtic music notion additional core factors influencing a good ceili session , in addition to musicians is that the instruments used by the musicians are to a good standard and are fit for purpose. The health informatics standards community provide consistent standards to support integrated care. One standard that I invested time in was a standards entitled System of Concepts for Continuity of Care. Now an ISO standard the development of which was led by Mr Nicholas Outbridge this resource provides a model and suite of resources worth reviewing. The concepts and overarching care flows for shared care are available from the link provided here. The recently published Joint Initiative Council report is also worthy of mention and the url is also listed here for access of use
http://www.jointinitiativecouncil.org/registry/standards.set.patient.summary.asp

Practice makes perfect



https://thehealthcareleadership.academy/nasss/

As someone who comes from a family of traditional music musicians I can vouch that much practice is needed consistently and over many years to learn the tunes played in celli music sessions. We will avoid talking about what a novice fiddler sounds like when practicing.

Recent publications on a Systems adoption framework by Prof Trisha Greenhalgh and her colleagues provide us with vital insight into systems failing to deliver over time. Suggesting that applying what we are learning in practice is key.

The NASSS Framework published in 2017 considers how systems and technologies are characterized by non -adoption or abandonment by individuals at an organization or system level. NASSS as a framework depicted in the figure has seven domains – the condition or illness, the technology, the value proposition (that is, the initial assessment of whether the technology is worth developing), the actual or intended adopters (staff, patients, caregivers), the organisation, the wider system (especially the policy, legal and regulatory context), and the process of adaptation over time.

Of interest In this study is the key finding that across all of the case studies critiqued it was demonstrated that only a fraction of potential end users were assessed by their clinicians as “suitable” for the technology. In the majority, the condition was considered clinically high risk, unpredictable, or atypical (e.g. complicated by comorbidities or sociocultural factors, especially cognitive or health literacy.

Harmonization is a primary step in service delivery. And yet from the service user's perspective we fail iteratively because we try to achieve our goals in a siloed and fragmented fashion. It's easy to become despondent. I selected music today as it has a way of crossing boundaries, Derek's engagement like my family's engagement in traditional music provides an opportunity to come together to create something lyrical , which when brought together is greater than the sum of the individual parts. Session musicians are experts in their activity knowing the tunes they provide a natural rhythm and predictable sound with well-rehearsed tunes. They join in and leave with ease and with minimal impact on the group cohesion and the associated sound of the tune being played.

Yet each rendition of the songs creates a unique sound that collectively creates more than the one solitary attempt to replicate the notes on a sheet of music. The sound creates its own unique identity and with it provides synergy to lift the most lowly of individual spirits.

The musician picks up his instrument and plays that well-rehearsed tune with a pace and style unique to his personhood. From observing Derek in his teaching when we shared a joint session I sat back and listened with ease and admiration at his style of

delivery. For me this transition from music to education was like a performance that translated in his working life, he lectured in a purposeful but steady way. The topic for students whose main preoccupation was delivery of health care and who found computers an alien topic was eased The students assimilated and learned.

Derek would draw them in to the world of possibilities perhaps given the students the time and space to reflect on his stories this quiet passion wrapped in humour to keep their interest sustained.
Innovation in healthcare may seem a bit dull. Just as a Derek could light up a room with some tunes, we need to manage transitions, simplify messages and stimulate an individual's participation and imagination. Explaining its value by blending his stories of experience can give us something concrete on how is it going to make individual lives better
I think there is much work to be done on delivering Integrated care, harmonizing design, and delivering the tune. To act decisively in the absence of certainty as Bertrand Russell suggests. This is why I have invested my time establishing a Centre for eIntegrated Care in DCU. This centre will be launched formally on the 14th May and your all welcome to attend. Global predictions (published by the lancet and supported by WHO), provide a very stark picture of chronic disease projections for the next twenty years. As WHO and UN promote the adoption uptake and use of interventions to support the Sustainable Development Goals, there is need for the health informatics community to provide leadership to create clinically pragmatic design solutions to address health and social care issues. Derek's vision of what we could do with Snowcloud clinical templates and ICNP provide insights for next steps and this new centre is investing time in delivering this vision.

The A4 paper Derek and I wrote on many years ago has I believe longevity. Projects we invest in provide key insights to others in future work that is yet to be created or delivered. Just as Derek said to me I am careful with what I spend my time on I ask everyone to *act decisively in the absence of certainty be careful what you invest your time in and* consider devoting energy to making integrated care in your work and our digital health services become a reality. The rewards would be great and our quiet contribution valued.

Thanks to Sharon and BCS for their kind invitation to deliver this lecture.