IPPOSI Outcome Report

Person-centred eHealth

Integrated Care, Electronic Health Record, Data Protection, Public Benefit, Data Sharing, Meaningful Use

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Irish Platform for Patients' Organisations, Science & Industry (IPPOSI)

Camden Business Centre, 12 Camden Row, Dublin 8, D08 R9CN

01 479 0552

Contact: Ken Rogan

info@ipposi.ie

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This Outcome Report arises from the Annual IPPOSI Round Table Meeting entitled ‘Person-centered eHealth’, which was held on 15th June 2016 in Farmleigh House, Phoenix Park, Dublin.

At this meeting, the listed speakers and contributors each took a turn to express their views, concerns and hopes for the development, design and implementation of eHealth strategies and solutions in Ireland.

A facilitated discussion then ensued which was widened to include the membership of IPPOSI as well as several senior members of State Agencies, the Health Service Executive, eHealth Ireland and the Council of Clinical Information Officers in attendance.

In all, and including IPPOSI staff and nominated contributors, over 90 people attended an interesting and positive meeting that incorporated views from right across the health sector – from policy-makers, clinicians, patients, academia and industry.

IPPOSI would like to thank everyone who took part in this meeting for their time and active contributions.

Dr Derick Mitchell
IPPOSI Chief Executive

“Emerging technologies have the power to transform healthcare from a centrally delivered model to one where the patient has more control and enhanced responsibility for their own health and wellbeing. The move towards such a system has inherent challenges in terms of data protection, ICT requirements, adequate resourcing, and staff training. There is also the need to focus on the end-user – the patient.”
1. **Derick Mitchell**
   - IPPOSI
   - @DerickOMisteal
   - *We need to ensure that the way that eHealth develops in Ireland is not driven by technologies, products or suppliers, but by the needs of the people.*

2. **Richard Corbridge**
   - Health Service Executive
   - @RichCorbridge
   - *Healthcare is the only business in the world that doesn’t ask its customers for their digital identity.*

3. **Muiris O’Connor**
   - Dept. of Health
   - *Are we doing enough to integrate care around people? It should be motivated by a patient-centred approach to health.*

4. **Brian O’Mahony**
   - Irish Haemophilia Society
   - @TheIHSS
   - *It’s not just resources & money that we need; it’s joined-up thinking & creativity, with patient input.*

5. **Scott Henderson**
   - Scottish Centre for Telehealth
   - @ScottIHSS
   - *Patients who are central in the measurement of their care and their health consume fewer resources and have much better outcomes.*

6. **Áine Carroll**
   - Health Service Executive
   - @AineCarroll
   - *There is confusion around integrated care; it is simply a delivery vehicle, not an outcome. The outcome is person-centred care.*

7. **Graham Love**
   - Health Research Board
   - @Graham_Love
   - *A model is needed in Ireland whereby linkage of datasets is achieved in a safe setting in order to understand the long-term impact of health decisions.*

8. **Martin G. Curley**
   - Intel
   - *We need to get used to the idea of personal responsibility and owning your own health.*

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**With thanks to Rachel Lynch, FibroIreland and EUPATI Patient Fellow**
Policies to support person-centred eHealth

The first session focused on the necessary policies that are required to support person-centred eHealth. Dr Derick Mitchell, Chief Executive of IPPOSI chaired the session and he began by explaining that 2016 is the right time to discuss the development of person-centred eHealth in Ireland.

The national electronic health record (EHR) business case, delivered by the office of the Chief Information Officer (CIO) in the HSE, is currently being considered by the Department of Health and while it is crucial that patient data and records are made available, these must also be used appropriately. Although the health system is not currently patient-centric, eHealth has the power to change this and be a facilitator of a more patient-centric approach to care, Dr Mitchell said.

eHealth will also facilitate the creation of an empowered patient, and patients and patient organisations need to have their say in how it develops and is designed.

“We want to create a situation where patients are the drivers of their own data; this will allow them to gain control of their health. We need to ensure that the way eHealth develops in Ireland is not driven by technologies, products or suppliers, but by the needs of the people,” he concluded.

NATIONAL POLICY

Mr Muiris O’Connor is Assistant Secretary for R&D and Health Analytics in the Department of Health and his role is to address the need for an adequate and comprehensive evidence base to inform health policy in Ireland. He discussed how the appropriate use of data will facilitate this.

The increased emphasis on integrated care within the health system is motivated by a person-centred approach to health and Ireland is embracing this wholeheartedly. However, he felt that integrated care programmes are often designed around illnesses and conditions, and he asked if we are doing enough to integrate care around people?

Since commencing his role within the Department, Mr O’Connor said he has been “blinded” by the sheer volume of data that exists within health. Often, he noted, the focus on the person and the citizen is lost. Unlocking the value of data is critical for the health research environment but there needs to be a “public value proposition” with a “clear-minded articulation of data as a public asset”.

According to Mr O’Connor, integrated care benefits hugely from eHealth and increased connectivity but he added that this is “much larger than an IT problem” and warned that “if you automate a mess, you get an automated mess”. Therefore, our use of information must be person-focused and this should form part of a broader and comprehensive change in the national approach to how health and social care services are delivered. Improved infrastructure and better relationships will enable this.

According to Mr. O’Connor, it is important to make it a necessity to share data with a clear articulation of “meaningful use”. He also advocated for the increased emphasis on “intentionality” as a core component of health policy in Ireland, using the example of current crime prevention approaches and how health can learn from this level of intentionality. Patient-centred approaches can “cut through the blizzard” and place increased emphasis on imperatives for the public and not those of service providers. The public value proposition is vital to determine whether this activity is valuable to the public, politically and legally possible, and ultimately “do-able”.

1
INTERNATIONAL POLICY

Scotland has had an eHealth strategy in place for a number of years, and Scott Henderson of the Scottish Centre for Telehealth spoke about the Scottish experience of telecare and telehealth. He has worked for a number of years with the Scottish authorities to accelerate the use of proven technology across health and across Scotland.

Focusing on the issue of home health monitoring, he explained some of the inherent challenges in delivering it, such as the practicalities of scaling its delivery. Home health monitoring has the potential to significantly reduce pressure on health services; “Patients who are active in the management of their health and healthcare have much better outcomes and consume fewer resources,” he said. The harsh reality of the resource-constrained healthcare environment is that introducing something new and innovative may mean difficult budgetary decisions have to be made; a strategic approach is therefore needed, where the long-term benefits to patients, carers and service providers, are realised along with early wins. He also emphasised the importance of staff and teams meeting regularly, in order to share experiences, stresses, and challenges. A first draft of a National Service Model for home health monitoring in Scotland is coming soon.

Henderson encouraged listening to patients and physicians when developing technology solutions and strategies so that they are truly person-centred and developed from the bottom up. The technology itself is not a treatment, rather it is an enabler and a tool that helps patients become more informed about their illness, and gives them the competence or confidence to take an active role in their health, he explained. It assists the delivery of more flexible solutions to enable shared learning.

RESEARCH POLICY

The recently-published “HRB Data Report” proposing an Enabling Data Environment for Health and Related Research in Ireland was circulated to attendees at the round-table, and Dr Love used his contribution to outline how the report proposes the utilisation of patient and health data in a safe and responsible way.

“Existing data is one of our most valuable national assets and while there is a complex mix of cultural, social and technical and governance issues associated with its utilisation, the potential is there to strike a balance between patient confidentiality, which is paramount, and public benefit”, he said.

Dr Love described the proposed “DASSL” model – Data, Access, Sharing, Storage, and Linkage – which the HRB believes would enable a robust data-sharing environment, facilitating and enabling health research and other data analysis for the betterment of Irish society. Key elements of this model include a health research data “hub”, trusted third-party data linkage services, a “safe haven” for storage, and a research support unit for outputs.

DASSL-like infrastructure has been used successfully in other jurisdictions and Dr Love used the opportunity to describe some successful stories arising from the benefits of the proposed “principled, proportionate risk-based approach”.
With a reference to the possible need for new legislation in this space, Dr Love said that building processes and structures around existing legislation is possible, and would allow this to happen in a sensible manner. This would not require a significant amount of additional investment but rather the alignment of interests in a bid to allow it to happen.

“We have the opportunity now to catch up in one big step.”

FEEDBACK

Mary Fitzsimons of Beaumont Hospital and the Epilepsy Lighthouse Electronic Health Record Project asked if we are “counting the things that count” when it comes to data collection in healthcare. She questioned if person-centred care means the same for all stakeholders, and suggested building a consensus on an agreed definition.

Parent advocate Olive O’Connor said that patients, in particular those with ‘lived experience’ should be involved in the design, development, and delivery of eHealth technologies. Patients and their carers can give input on exactly what data should be collected and what the end product should look like; patients are often only involved after the design has been finalised, she noted. Patient data needs to be actionable, and she expressed her own frustration at the amount of data going unused in the healthcare system. She added that there is also too much focus on individual illnesses, and not on the pathway of care.

Eibhlin Mulroe of Cancer Trials Ireland (formerly ICORG), echoed Olive's comments, explaining that different types of cancer may have the same treatments, depending on what genes are involved, for example. Linkage and sharing of data will thus become critically important in cancer treatment and research. Collaboration between policymakers, doctors, researchers, and patients will all be necessary, and the sharing of data and information will involve a culture change, she said, making comparisons with the Moonshot Initiative, endorsed by US Vice President Joe Biden to accelerate cancer research.

Cathal Ryan of the Office of the Data Protection Commissioner joined the conversation and told the audience that data protection essentially requires “starting on the right step” – it needs to be fully considered at the beginning of every project initiative involving the processing of personal data. Echoing Mr O’Connor’s comments on intentionality, he said it requires an intentional articulated approach, and the person must always be in the loop.

The EU General Data Protection Regulation (GDPR) will come into effect in May of 2018, and this will deal with, amongst other things, data anonymization and research activities, and how they can be brought within a legal framework and applied in a legal manner. Member states are being afforded some discretion as to how they can implement the regulation, he explained. The HRB Data Report has started the conversation, particularly in relation to secondary processing of data.

The meaningful and necessary use of data is key, and Mr Ryan said that data protection should be seen as “an enabler, and not an inhibitor”. He added that the Office of the Data Protection Commissioner is always open to discuss and engage with every organisation on these data protection issues; “we won't make our minds up in isolation”, he commented (i.e. we will consider all sides before making a determination on any issue). “The person should be the main driver of health research and as long as we bring that person along with us there should be no problem.”
The second session was chaired by Mr Richard Corbridge, CEO of eHealth Ireland and Chief Information Officer, HSE.

Mr Corbridge began the session by stating that as simplistic as it sounds, it must be remembered that the “H” in HSE stands for “health”, and not “ill”. He said the patient as a person is completely and absolutely at the centre of what is being done with the development of Electronic Health Records in Ireland. Utilising the vast amounts of health data in a meaningful way will be possible as long as the person continues to be our focus, he stressed. The health service, is aware that there should be a strong focus on, “engaging with patients digitally”, he added, which will enhance the adoption and delivery of eHealth initiatives; however how can we talk about integrated care, when we still use pens and paper?

“Healthcare is the only business in the world that doesn’t ask its customers for their digital identity,” which is something the HSE wants to address. This journey is beginning internally, HSE Director General, Mr. Tony O’Brien has tasked the Office of the Chief Information Officer to have all HSE staff digitally connected by the end of the year. This project will provide 45,000 staff with a digital identity and will also enable 10,000 staff members access to a digital device and the tools and support to use them in their work, by the end of 2016.

**PATIENT PERSPECTIVE**

Mr Brian O’Mahony of the Irish Haemophilia Society explained that in the case of Ireland’s 800+ haemophilia patients, the vast majority of treatment is carried out at home. This means that there is a very educated patient population, he explained.

The integrated haemophilia programme and national electronic system that links haemophilia treatment centres allows delivery of medication to patients’ homes and ensures patients receive the highest standard of care. Despite initial concerns about confidentiality, there is now significant buy-in from all stakeholders. The programme includes the development and use of a smartphone barcode scanning app that allows patients to personally ensure their medication is safe to take and records their medication usage.

Mr O’Mahony says the system works extremely well, and this is because it was developed with patient input from day one, which ensured that it was “accountable and workable and relevant”; “we weren’t faced with a coding solution that IT people came up with that we couldn’t understand and a device that nobody could use.” The system is continuously upgraded and the Society has worked closely with the HSE on this.

Exciting innovations are what is needed, he said; “It is not just a question of resources, it is joined-up thinking and organisation of care.” According to Mr O’Mahony, the current debate on ownership of patient medical records is “bizarre” and he believes patients will eventually be able to access their own records online.

Significant progress has been made, and the new electronic system has allowed patients with haemophilia take control of their condition. “Patient-centred care is what you need when you need it – patients need control, and you also need real engagement and partnership with health professionals.”
CLINICAL PERSPECTIVE

The dire need for electronic health records in Ireland was highlighted eloquently by Dr Áine Carroll; she spoke of referral letters being lost, of fax machines still being relied upon “which beggars belief”. Paper-based notes can often contain “utterly meaningless” information that is of no benefit to the person or patient. This wasted time and effort offers no value to the individual the system is supposed to be serving.

Various listening exercises have illustrated this disconnect between the design and implementation of healthcare. The continuum of care (from prevention to end-of-life care) will depend on three key enablers: ICT, Finance and Workforce. Getting the best value from resources, and appropriately valuing staff is key. Placing the person’s voice at the centre of all these efforts is crucial, but in the current system it is difficult to always get that voice heard, she noted.

Dr Carroll alluded to what she said was confusion around the concept of integrated care – explaining that it is a delivery vehicle, the outcome of which is person-centred care. The integrated care programmes in Ireland should be organic and constantly changing as we learn from experience, she explained, adding that eHealth underpins “everything that we do”.

“We want to create something sustainable that will be of benefit to citizens of this country.” She added that integrated care is not for everybody, as not everybody will need it, but stressed that “if we can get it right for the most vulnerable in our society, then we can get it right for everyone who does need it.”

INDUSTRY PERSPECTIVE

According to Professor Martin Curley, Intel and NUI Maynooth, healthcare is not about making sick people better but keeping well people well; “We need to get used to the idea of personal responsibility and owning your own health,” he said, adding that this will represent a marked shift from current thinking.

He echoed Mary Fitzsimon’s earlier point on the need for a shared vision for person-centred care, and also a shared value, which he described as “improved health outcomes helping to reduce the burden on the health service”. Now is the time for a healthcare transformation - wearable technologies and their pervasiveness are an example of how proactive wellness can be encouraged and enabled, he added.

According to Prof. Curley, “audacious” aims and goals are necessary for the shared vision of Healthy Ireland, such as every person in Ireland living five years longer. “It may sound ridiculous but I believe we should be even more audacious.” Customisation of healthcare delivery is critical, with a shift from a population-based model to a person-based model. While there may be scepticism around the Electronic Health Record, the business case proves itself; Professor Curley outlined an example whereby the introduction of EHR for a US healthcare insurer reduced medical error and hospitalisations by more than 50 per cent.

FEEDBACK

Mr Corbridge opened the Q&A by explaining to attendees that Ireland is the last developed country in the world to not have an Electronic Health Record, adding that in recent weeks Botswana went live with its EHR for every patient in that country. While it may be a “leap of faith”, the investment in monetary terms is minimal, he noted.

Dr Gerry Clarke, who works with the national clinical programme for surgery, explained the difficulties involved in counting data when faced with the twin issues of data protection, and the requirement to state intentionality when doing so. “The real research comes when joining together data from different sources, historically, and looking for the ‘unknown unknowns’ - those that we didn’t know we should know. How can we make that a reality in a world that requires data
protection to state intentionality when collecting the data?”

Mr Corbridge agreed, stating that we must move away from “counting beans” towards collecting information to provide care and other secondary uses. Dr Carroll reiterated the earlier point of questioning if we are actually “counting the things that count”? Designing eHealth initiatives with patient, carer and individual input will create the right data sets, she said.

Tony Heffernan of the Saoirse Foundation discussed the possibility of an “opt-out” clause when it comes to data sharing, saying he believes everyone should be automatically included. There are three health sectors in the country – the public, private, and the voluntary sector – and these should be working together. “Unless all of these three sectors are aligned, we cannot get to where everyone wants to be”, he said.

Bringing the session to a close, Dr Mitchell said that common themes from the proceedings centred around “the 3 C’s”: Competencies, Care, and Community. Clinical and patient competencies will be key to driving true person-centred care, and he noted that there appeared to be a lack of shared understanding on what exactly constitutes integrated care. The roundtable, and its broad range of participants and speakers, served to bring together this community to highlight the key issues that must be addressed as Ireland moves towards an eHealth-enabled system of person-centred care.
Conclusion

Key themes

- eHealth has the potential to be an enabler of more efficient and better quality systems of health care and health research in Ireland
- A consensus on what ‘person-centred care’ means, is needed among stakeholders
- Keeping the person at the centre of every and all eHealth initiatives is crucial for their ultimate success
- Integrated care is a delivery vehicle for person-centred care and eHealth will underpin these programmes
- Working within the realm of current data protection legislation is possible as we move to enable data linkage and secondary processing
- The meaningful use of data will be possible if the process is focused on the patient
- eHealth will allow for the further personalisation of healthcare, as the individual takes ownership of their own health and wellbeing
- The appropriate technology, as well as adequate funding and staffing will be required to ensure the success of eHealth initiatives and integrated care
- Ireland lags significantly behind other countries in terms of eHealth, particularly with reference to the electronic health record

Collaboration between clinicians, policymakers, health workers, organisations and patients and carers is absolutely necessary – a shared vision is needed.
SPEAKERS: Session 1

Muiris O’Connor took up the post of Head of R&D and Health Analytics in the Department of Health in November 2015. He moved to the Department of Health from the Higher Education Authority (HEA) where he served as Head of Policy and Strategic Planning since 2008. In that capacity he played a central role in the formulation of the ‘National Strategy for Higher Education to 2030’ and led the subsequent development of a new ‘Performance Evaluation Framework’ for Irish higher education. Before joining the HEA, Muiris spent five years as Statistician in the Department of Education and Science, prior to which he worked with the Conference of Religious of Ireland (CORI), the Economic and Social Research Institute (ESRI) and with the National University of Ireland, Galway (NUIG).

Scott Henderson is a Senior Manager at the Centre for Telehealth and Telecare which is a Division of Scotland’s national Telehealth services provider, NHS 24. He currently leads the roll-out of Home and Mobile Health Monitoring technologies across NHS Scotland as part of a wider Scottish Government initiative to expand Technology Enabled Care. A career-long change specialist, Scott led Scotland’s Pandemic Flu preparations programme and spent his earlier career leading change and transformation activities in the private sector.

Dr Graham Love is Chief Executive of the Health Research Board (HRB). The HRB manages a €100+ million investment portfolio spanning clinical, population and health services research. It also manages key health information systems and provides evidence-based policy support to the (Irish) Government’s Department of Health. Previously Graham worked in Science Foundation Ireland, where he filled senior roles such as Head of Strategy, Director of Policy and Interim Director General. Before entering the Public Service, Graham was in the private sector for many years working for management consulting firm Accenture. There he worked with international clients such as Microsoft, Vodafone and Norsk Hydro.

Dr Derick Mitchell is the Chief Executive of IPPOSI. Derick has over eight years’ experience of management, advocacy, scientific communications and patient/public engagement, through previous positions at both European and national level. From 2011-2015, Derick was Communications Manager with the EU Joint Programme – Neurodegenerative Disease Research (JPND), before taking up the position as IPPOSI CEO. Derick graduated with a BSc. in Biotechnology from NUI Galway and has completed a PhD in Molecular Medicine from University College Dublin.
Brian O'Mahony is the Chief Executive of the Irish Haemophilia Society and the President of the European Haemophilia Consortium. He represents the society on the statutory National Haemophilia Council and he is the Vice Chair of the Tender Commission established by the Irish Government for the Procurement of Factor Concentrates. He is a member of the Board of the Irish Blood Transfusion Service and of the Irish Government vCJD incident panel. He previously served as Chair of the Irish Haemophilia Society for 17 years and as President of the World Federation for Haemophilia (WFH) for 10 years from 1994 to 2004. A medical scientist by profession, he is a Fellow of the Institute of Biomedical Sciences (UK) and a Fellow of the Academy of Clinical Science and Laboratory medicine (Ireland).

Dr Áine Carroll was appointed National Director of Clinical Strategy and Programmes at the HSE in November 2012. The National Clinical Programmes were established to improve and standardise patient care. Dr Carroll is a Consultant in Rehabilitation Medicine and Senior Clinical Lecturer, University College Dublin. She is past Chair of the Medical Board of the National Rehabilitation Hospital, President of the Irish Association of Rehabilitation Medicine and National Clinical Lead for the National Clinical Programme for Rehabilitation Medicine. Dr Carroll has published on a wide variety of topics including life expectancy determination in disability, the use of botulinum toxin in spinal pain, osteoporosis in disability, whiplash injury and has presented at many national and international conferences.

Professor Martin G. Curley is Vice President of Intel Labs and Director of Intel Labs Europe and Senior Principal Engineer for Intel Corporation. Professor Curley leads Intel's research and innovation engagement with the European Commission and the broader European Union research ecosystem. Before assuming his current position in 2009, Curley was global director of IT innovation at Intel. Earlier in his Intel career, he held a number of senior positions for Intel in the United States and Europe. Martin is also co-founder of the Innovation Value Institute, a broad industry-academic open innovation research consortium and he is Professor of Innovation at the National University of Ireland, Maynooth. He is the chair of the EU Open Innovation and Strategy Policy group which is driving the further development and adoption of the Open Innovation paradigms in Europe.

Richard Corbridge is an expert in healthcare strategy and technology recognized by his industry globally. Since December 2014, Corbridge has been the Chief Information Officer for the Health Service Executive in Ireland and Chief Executive Officer for eHealth Ireland. He has been involved in the Health and Clinical Research Information sectors, leading various informatics delivery functions since the late 90s. Richard has a passion for business change and benefits management in health and very much insists on a focus on engagement and benefits being brought to technology implementation. He has led the delivery of a wide range of systems and process to aid the provision of healthcare and research.