

Electronic Health Records

"Getting it right from the start"

2019 IPPOSI Annual Conference
Outcome Report





Patients want to be able to rely on an EHR (Electronic Health Record) to provide a complete, accurate, real-time picture of their health and many ask, where are we now when it comes to the creation of a national EHR in Ireland?

This outcome report is a record of the observations, concerns and recommendations raised by the 200+ patients, clinicians, researchers, regulators and government representatives who attended our conference on the 7th October, 2019. IPPOSI members, and in particular, IPPOSI patient members will have heard us discuss EHRs at a number of events in recent years initially, with optimism, but more recently with frustration.

We selected EHRs for the 2019 IPPOSI Annual Conference to reignite conversation around an often complex topic which has seemed to stagnate somewhat, despite broad consensus of its importance and immediacy and work ongoing behind the scenes. It is clear that Irish patients eagerly await the day when they can let an EHR do the heavy lifting around their personal health care management. Several people openly shared the harsh reality and enormous psychological and administrative burden of filling copy books full of medical notes for their children or of carting printed copies of their own self-made records around from consultation to consultation.

We heard patients describe how they recounted their medical history repeatedly within a single hospital visit or appointment and how they were worried that this onerous task could lead to inevitable inaccuracies and omissions.

Derick Mitchell
CEO
IPPOSI

Click here for the full range of conference outputs including live stream recording, official photos, graphic artist representation, presentation slides and more .



A "Terminology Explained" section is available on our website here



Where are we now with an EHR?

Vincent Jordan, Director for ICT Services for Acute Hospitals in the Office of the Chief Information Officer at the HSE, stated that the term 'eHealth' first appeared within the 2012-2015 Strategic Framework for the Reform of the Health Service. He attributed the development of a more comprehensive policy framework to two milestone documents:

- The **2013 E-Health Strategy for Ireland** which acknowledged EHRs as a cornerstone of any future transformation in care delivery.
- The **2017 Slaintecare Report** which called for "necessary funding for the timely roll-out of the EHR system."

Executive Director of the Slaintecare Programme Implementation office, Laura Magahy, announced that a "shared care record" will be procured next year and that a demonstration patient portal is due for imminent release to start the public conversation around questions of collection, storage, management and use of health data. She stated that the Individual Health Identifiers (IHI) Office has been established and it is currently looking for good project proposals to make use of the IHI data. She confirmed the current Government's commitment to progress eHealth solutions, including a national EHR, which she described as "a critical enabler for integrated care that can also facilitate research and future service planning". She referred to the 2019 Slaintecare Action Plan which reflects this position in greater detail.

TIMELINE - MILESTONE DOCUMENTS IN EHEALTH STRATEGY, IRELAND

2013: eHealth Strategy for Ireland

2015: eHealth Strategy for Ireland's vision and direction document

2016: eHealth Strategy for Ireland's business case

2017: Slaintecare report

2018: Slaintecare Implementation Strategy

2019: 2019 Slaintecare Action Plan



"For many of our investments, it takes a long time to yield the benefits, because the benefits only come when we change the way we receive and deliver care".

Vincent Jordan
Director ICT Services
Office of Chief information officer, HSE

"We know that an electronic health record is a critical enabler for integrated care and that it can also facilitate research and future service planning. That's why it has been prioritised as part of eHealth development plans for 2019 and beyond. I look forward to continued engagement with citizens as we move forward with these plans."

Laura Magahy
Executive Director
Sláintecare Programme Implementation Office



When will we have an EHR in place?

Eilish Hardiman, Chief Executive Officer of the new Children's Hospital, stated that it is the Government's ambition for the new Children's Hospital to be **"born digital"** and confirmed that a tender for the hospital's EHR opened in November 2019. Mindful that it is likely to be some time before this major infrastructure project is completed, Vincent Jordan (HSE CIO Office) offered examples of new technology platforms already underway which can be built upon and used to inform future and more widespread eHealth solutions:



The National Ambulance Service have introduced a new technology platform to handle emergency calls and patient care. Ambulances have a data terminal for routing and contact with the call handlers. All emergency medicine technicians also use a tablet which contains an electronic patient record to document care. The country-wide roll-out is 90% complete and will finish by year end (2019).



In blood donation, a new technology platform has been created to host an electronic blood tracking system (EBTS). This enables blood products to be traced from donor to end user and it allows for a whole host of safety checks to be included along the way.



In x-rays, a new technology platform established by the National Integrated Medical Imaging System (NIMIS) project allows health care professionals across the country to access and view the results of a patient's x-ray. This means improved care for patients, as expert radiologists are able to remotely input into diagnosis and treatment.

In the coming months and years the building blocks for a national EHR will be put in place, including the roll out of Individual Health Identifiers (IHIs), the development of an EHR for acute hospitals and an EHR for community care, as well as the creation of a data dictionary. The digitisation of our health service will not happen overnight, its progression will need careful, continued and concerted action.

Why do we not have EHRs now?

In part an expression of frustration and in part a willingness to troubleshoot, some patients asked: why do we not already have EHRs? And while explanations were forthcoming, there was some shared impatience from the speakers.

Laura Magahy (Slaintecare) described most of the issues in this area as “two-legged problems” and she quoted the old adage “perfection can be the enemy of the good”; leading the rally to “get on, and do it”, to break down barriers between data collectors, and to promote true collaboration around data sharing. **Declan Noone (European Haemophilia Consortium)** alluded to the culture of data guarding within clinical research communities.

He proposed incentivising registries to put data in correctly which means funding for database managers, as well as to code it correctly which allows for the sharing of anonymized data.

Vincent Jordan (HSE CIO office) noted the relative under-funding of digital solutions in Ireland compared to European and international peers. Choosing to fund digital solutions is difficult when other areas of health are also seeking resources.

Eilish Hardiman (Children’s Hospital) questioned whether the benefits should always be monetised “are we investing, or are we doing a return on investment?”.

She added bureaucracy as a key obstacle, citing the absence of an agile approvals process for designing, procuring and introducing new infrastructure which allows us to keep up with emerging technology. **Darrin Morrissey (Chief Executive, Health Research Board)** pointed to the highly specialized nature of the decisions required and the challenge of equipping politicians and public officials with the necessary understanding.

“Traditionally around 0.9% of the health budget has been spent on ICT, Information Communication and Technology.

In the last three years this has increased to 1.1%, which while welcome, still falls behind the European average of 2-3% and the US investment of 4% plus.

Vincent Jordan
Director ICT Services,
Office of CIO, HSE

Where is the patient voice ?



"Patients are citizens, and citizens own their record."

Laura Magahy
Executive Director
Sláintecare Programme Implementation Office



"There is an absolute need to keep patient considerations front of mind when developing EHR and the potential research outputs".

Darrin Morrissey
CEO
Health Research Board



"We have more in common than we don't have in common"

Jacqui Browne
Patient Advocate



Watch the Panel Debate: "Digital/eHealth - looking to the future in Ireland."

Patient involvement in EHRs

A recent workshop with the HSE Public Involvement Panel on the topic of the clinical portal established support for ensuring that patients have direct access to health records and that data can be shared appropriately with health care providers. Further workshops are planned in 2020 on a range of topics including data privacy expectations, the shared care record, the acute EHR patient portal, and the community EHR.

**Vincent Jordan, Director
ICT Services, Office of
CIO, HSE**

The importance of patient involvement quickly centered around if or how patients are being involved in the EHR agenda? **Eilish Hardiman (Children’s Hospital)** referenced their long-established Youth Advisory Committee (YAC) and the National Family Forum as important consultation resources, but highlighted the desire to identify new or alternative voices. **Laura Magahy (Slaintecare)** cited plans for greater citizen engagement around eHealth related topics in 2020, assuring attendees that more detail would soon follow. **Darrin Morrissey (HRB)** reminded delegates that patients are involved as reviewers in some of the HRB funding calls, with intentions to expand this further in upcoming calls. **Vincent Jordan (HSE CIO office)** shared the work undertaken by the 18-member Public Involvement Panel whose intention is “to make sure that what we progress with what aligns with everybody’s expectations – we need to keep the enablement, the legislation, and the patient demand working together.”

Regrettably, few other tangible examples were offered, leaving many patients in the room querying if there was real meaningful patient engagement around the EHR agenda in Ireland?

Are patients meaningfully involved around the EHR agenda in Ireland?

Jacqui Browne, independent patient advocate and a member of the HSE Public Involvement Panel described being approached on only one occasion for input in the last year. Patient advocate, **Sheila Fitzgerald**, raised concerns about the ‘representativeness’ of the patient voice within the health sector, which because of lack of appropriate supports was largely middle-class, geographically centred on Dublin and involved older and wealthier retired people because only they could afford to do this unpaid work. Describing the patient community as fragmented, **John Dowling (Men Against Cancer)** called on patients to use organisations like IPPOSI or other umbrella groups to ensure that the patient voice can be united.

Lightning Presentations

In Northern Ireland, the Electronic Care Record “Encompass” is changing how care is delivered. The record allows data to be shared across the acute and community health system (not the primary....yet). The data collection is standardised across the region. Patients and health care professionals work in partnership, using patient portals and other tools, and operating within a system of dynamic consent.

“We need to talk to each other.”



Shane McKee, consultant in genetic medicine, Belfast HSC Trust



Watch Presentation



Loretto Grogan, National Clinical Information Officer for Nursing and Midwifery in the HSE



Watch Presentation

Nurses and midwives in Ireland have a roadmap for going digital. A key component is the empowerment of citizens. Patients, families and carers are invited to identify the digital solutions – the goal being to use data in a way that patients can have a comprehensive picture of their health and can play a role in shared decision-making. Information follows the patient.

“There is a remarkable potential for digital healthcare technologies to positively impact care if we get it right.”

Lightning Presentations

The epilepsy ePortal makes patients the 'author' of their health destiny - accessing patient summary records, completing quality of life questionnaires, and reading pre-appointment material. The national epilepsy electronic patient record (EPR) shares genetic data with health care professionals to help present a complete clinical picture. These digital solutions have taken time, patience, lateral thinking and close collaboration between patients and clinicians.

"It's very little to do with technology, and all about people."



Mary Fitzsimons,
Epilepsy Lighthouse Project/Future Neuro



Watch Presentation



Declan Noone, European
Haemophilia Consortium/Haemophilia
Patient Record



Watch Presentation

The Haemophilia EHR app is designed to allow patients to go into any hospital in Ireland and receive treatment without being on the system of that hospital. The app collects health data from the patient, for instance the frequency of bleeds and where they occur, meaning that treatment can be tailored accordingly. A warning system is incorporated to remind patients to take their medication. The app gives patients important peace of mind and contributes towards better health outcomes.

"It changes the conversation with the clinicians, and it creates information that is useful in my daily life."

Life without EHRs



"Young adults are busy getting on with life – often while managing life-long or chronic illnesses – they do not have the interest, time or energy to maintain personal medical records the way their parents may have to that point

Caroline Murphy
Mother of teenage son with epilepsy



"..the design must be right and patients must be involved from the start."

Jacqui Browne
Patient Advocate

Asked to share their personal patient perspectives on how the absence of EHR's impacts on their lives, patient representatives, **Sheila Fitzgerald, Jacqui Browne and Caroline Murphy**, did not shy away from some harsh home truths on how the absence of an EHR impacts on the patient experience. Using travel as a metaphor, they described the journey as long, the pace as slow and they highlighted the fact that some of the stakeholders are still reluctant travellers. They called for immediate and concerted action. Caroline, the mother of a teenage son with epilepsy, stated that the absence of an EHR makes the transition from child to adult services particularly difficult. She explained how, "young adults are busy getting on with life – often while managing life-long or chronic illnesses – they do not have the interest, time or energy to maintain personal medical records the way their parents may have to that point." Caroline suggested that "An EHR has the potential to accurately capture and share the information, so a clinician can quickly drill into his/her records". Jacqui, a patient with many co-morbidities, stated that the absence of an EHR has required her to prepare her own eight-page summary medical record. This summary contains her treatments at home and abroad and her adverse reactions to drugs. She considered a shared medical record as essential, but she highlighted that "the design must be right and patients must be involved from the start."

Life without EHRs



"Technology itself will not transform care, a cultural change must take place: The Irish healthcare system needs to build trust."

Sheila Fitzgerald
MS Patient Advocate



Derick Mitchell, CEO
IPPOSI, speaking at the
conference.

Sheila Fitzgerald, an MS patient and former Assistant Director of Nursing, emphasised that there is both a business case and a human rights case for greater patient engagement in healthcare. Patients need open access to their medical records. Technology itself will not transform care, a cultural change must take place: "The Irish healthcare system needs to build trust." Caroline, Jacqui and Sheila all shared the hope that the experience of involving patients in the development of an EHR would facilitate further cultural changes within the health system, including to the traditional patient-clinician relationship. **Anne Lawlor (22q11)**, a mother of a rare disease patient with learning difficulties, reiterated the appeal for an EHR and shared an example of positive clinician-patient collaboration around the co-production of the care pathway for 22q11 children transitioning to adult services in Crumlin. Some patients raised privacy concerns and enquired about whether a future EHR would mean that non-clinically relevant patient data would be accessible to healthcare professionals. **Declan Noone, President of the European Haemophilia Consortium (EHC)**, described "the fine balance" between improving care and protecting privacy. **Loretta Grogan, National Clinical Information Officer for Nursing and Midwifery in the HSE**, stated that the patients should be able to have some degree of control over their information. She emphasised the importance of patient consent and that EHR functionality (currently in development) should allow patients to deny access to certain personal data. **Derick Mitchell (IPPOSI)** raised the importance of developing standards for collecting data, to ensure that patients are not collecting data which cannot be linked into the system.

Declan Noone (EHC) emphasised the value of pairing people with the technology – apps supported by interactions with nurses, doctors and other professionals are game changers. Darrin Morrissey (HRB) described the inability to look at data in a joined up way as the greatest gap in the system. He referred to "band aid solutions" to support research using databases which are "just sitting there".

Watch Fireside Chat with patient
representatives



Benefits of Patient Data in Research

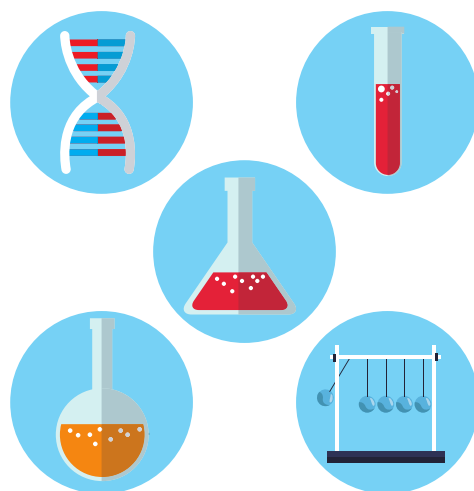
Professor Dipak Kalra, President of the European Institute for Innovation through Health Data (i~HD), stated that the two traditionally distinct worlds of clinical research and health care are slowly starting to converge, presenting an unique opportunity to collaborate and share access to health data from multiple sources. Professor Kalra said , "we cannot have silos of research and silos of care. We need to use (and share!) our health care data to inform this clinical research, and we can then in turn use this research to transform how we deliver care. Our current knowledge relies largely on research completed in single disease areas.

However, as patients start to live longer and longer, and as a consequence, start to develop more than one disease across their lifetime; we need new research spanning across multiple disease areas. Providing researchers with access to 'big data' (1 million+ patients) allows for the detection of patterns. As Ireland's population continues to age, failing to integrate data systems will mean that patients lose out, especially those with multiple chronic diseases"



Watch Presentation

Professor Dipak Kalra (i~HD) believes that an EHR has the potential to transform the quality of Irish health data. He suggested that the Irish health system has swathes of data but he described it as 'poor quality', notoriously "scrappy and incomplete", and collected in a 'non-standardised fashion'. This is currently limiting our ability to share health data in order to inform research, deliver care, and improve patient outcomes. He emphasised the importance of not just sharing the data, but of establishing a 'learning ecosystem' where we learn from the data and improve the outcomes for patients. The identification of high quality reusable EHR data is a critical success factor for the future. His belief is that when done in a GDPR-compliant, aggregate data way, patients are positive about use of their data in EHRs.



"It needs buy in from all stakeholders on a grand scale. We can't have silos of research and we can't have silos of care. Small amounts of data are useful, but when you get beyond a million participants, you can really begin to transform people's lives using data."

Professor Dipak Kalra

John Dowling (Men Against Cancer) stated that the opportunities for patients to meaningfully communicate their experience to their clinicians can be augmented by digital tools. He expressed his hope that an EHR would allow greater emphasis to be placed on patient-centred outcomes over clinical outcomes, and he called for the development of patient-mediated quality of life questionnaires.



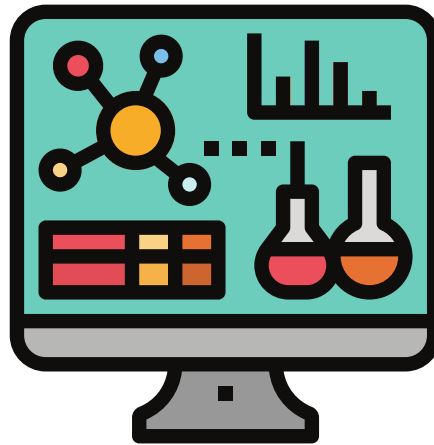
Orla Hardiman (Consultant Neurologist, HSE National Clinical Lead for Neurology) noted that while discussions tend to center around data sharing with consultants (at the secondary and tertiary levels), GPs are the primary holders of health data. GPs need therefore to be able to access any future EHR. This presents a challenge as the majority of our primary care providers are private businesses in Ireland.

Dipak Kalra (i~HD) cautioned against throwing large amounts of data at GPs, without supplying the digital tools needed to correctly filter and profile information and to provide charts and trends. He suggested that the patients should also be in receipt of these digital tools, as they are frequently very well versed in their own conditions compared to non-specialist GPs.



Declan Noone, European Haemophilia Consortium (EHC), emphasised the need for an EHR to capture qualitative as well as quantitative data in order to share a true picture of the patient experience, for instance, when faced with two drugs that are performing equally well against clinical outcomes we need to be able to capture the quality of life improvements of benefit to the patient.

Good Practice in Health Data Capture, Cooperation and Re-use



The rate at which technology is travelling, vastly outpaces the speed at which the health system is able to make policy and to implement solutions. We need to improve the understanding of the digitisation of health care and the process by which decisions are made to be able to even have a fighting chance of keeping up to date. Patients and the public must increase their awareness, and the awareness of others, around these issues. Only collective buy-in and concerted advocacy will deliver the digital solutions that we need to meet the health challenges of the future, and deliver the EHR which we all so urgently want and need.

