Workshop Participants

• 75 participants incl. 20 invited IPPOSI patient member contributors

• 4 Guest Speakers - Ingrid Brindle, Amir Hannan (both Haughton Thornley Medical Centres), Tony Shannon (Ripple OSI), Ros Moran (Health Research Board)

• 6 Chairs - Michelle Kearns (CCIO), Dmitri Wall (Irish Skin Foundation), Ingrid Brindle, Amir Hannan, Tony Shannon, Ros Moran

• 6 Facilitators - Harriet Doig (MS Ireland), Olive O Connor (Medistori), Avril Kennan (Debra Ireland), Rachel Lynch (FibrolIreland), Rita Darcy (OOCIO), Hannah Fitzgerald (Trinity College Dublin)

• Organisers - Derick Mitchell (IPPOSI), Gaye Stephens (Trinity College Dublin)
Background
What is an Electronic Health Record?

The Healthcare Information and Management Systems Society (HIMSS) defines an EHR as

...a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting.

[An] electronic version of a patient’s medical history, that is maintained by the provider over time, and may include all of the key administrative clinical data relevant to that person’s care under a particular provider, including demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data and radiology reports (CMS.gov).

The International Standards Organization (ISO) defines EHR as

...a repository of patient data in digital form, stored and exchanged securely, and accessible by multiple authorized users (Hayrinen et al. 2008).
To Ensure Quality, Safety and Value

Consent
Identification
Data Definitions
Use Cases
Community Of Stakeholders
What do Irish people think?

What does Patient Engagement mean to you?

- Patient Portal Access
- User-Generated Data, Tracking & Logging
- Communication Via EHR
- Self-efficacy
- Condition-Specific Educational Content
- Shared Decision Making

https://ayogo.com/blog/patient-engagement-definition/
Building trust between patients / service users + other stakeholders in the development of EHRs in Ireland

Themes

1. Data sharing & use
2. Patient-clinician relationships

What contributions do patients want to make?
General Question: What are the benefits for patients?

• From having your health data stored in one place?

• From sharing your information and data?
  • for research
  • for evaluating and improving health, social care services?

• From how it affects the relationship with your clinician?
Overview of outputs
Wordcloud

Common Themes

- Trust
- Patient Experience
- Education and Training
- Collaboration
- Communication
- Timing
- Sharing
- Community
- Access
- Consent
- Data Quality
Opportunities identified that EHRs will bring for patients

• Involvement in our own care
• Empower ourselves and our families
• Improves ability to collect better / good data
• Management of prescriptions by Pharmacist
• Complete the information in the EHR
• Apps to manage complex medications and multi-medications
• Timeliness of care
• Management of care as disease progresses + through transitions of care
• Potentially improving access to clinical trials
OPPORTUNITIES FOR PATIENT INVOLVEMENT

National Education / Training on EHRs
For clinicians, nurses and Patients
By clinicians, nurses and Patients
Capacity Building / Empowerment of patients
Link to self-management programmes

EHR Design + Roll-out
Patient Portal
Other building blocks
Decision-making boards

Public Trust + Confidence
Who, When, Why?
Consent – How?
Special Considerations for individual groups
Data Linkage & Sharing

Advocating for essential building blocks
Real-Time information
Informed Consent
Bi-directional flow of information
Tracking patient outcomes

Promoting Partnerships with Clinicians, Nurses
Communication
Openness & Transparency

TO ADDRESS THE FOLLOWING CHALLENGES

Trust
Patient Experience
Education and Training
Collaboration
Communication
Timing
Sharing
Community
Access
Consent
Data Quality

Development of Electronic Health Records (10 years)
A ‘flavour’ of discussions
Theme A - Data Sharing and Use

Common Themes:
- Trust
- Patient Experience
- Education and Training
- Collaboration
- Communication
- Timing
- Sharing
- Community
- Access
- Consent
- Data Quality
Theme A - Data Sharing and Use

Flavour of Trust

- Concerns expressed on who is accessing the record
- Increased transparency is required on the use of data, the benefits to patients and the consequences for any breach in confidentiality
- A national data protection oversight body or Trust would be very valuable
- Need to communicate patient concerns to the general population prior to roll out - use clear language and use images or story boards
- There are some good examples of relationships with pharmaceutical companies and how data from registries can be shared with them, but not for commercial / marketing purposes – e.g. Cystic Fibrosis
- Security Issues need to be acknowledged and addressed
Theme A - Data Sharing and Use Flavour of Community

- Acknowledged that there are cultural challenges around partnerships between HCPs and patients (e.g. who has ownership and control of information)

- Opportunity for patient and community organisations to be linked in to the EHR in order for patients and health professionals to find each other

- There is a need for a co-designed EHR; one for acute settings, one for primary care - and at the centre, one for patients – of which summary care reports or correspondence can feed in to. The patient is the only common denominator between all of their health professionals.

- Huge passion in the eHealth industry and belief in their products – they want to work with the HSE

- Technical challenges around getting IT systems operational (e.g. there is currently no ‘basic’ platform in Ireland that ehealth companies coming in can use to ‘plug and play’)

- The EHR should work to reduce, not increase the workload of nurses, doctors, etc.

- Support for data controllers is required

- Patients and professionals need to work in partnership to make this happen

- All stakeholders involved should be in the same room when designing the EHR – not separate working groups e.g. CCIO should have patients in its group
Theme A - Data Sharing and Use

Flavour of Sharing

• Most patients are happy for their data to be shared if there is transparency around how it will be used and they have confidence that it will bring genuine benefit to them and others with their condition.

• Acknowledged that there is also variable willingness to share patient data depending on disease, context and life situation.

• Development of rules and codes of conduct for data sharing + linkage will be important.
Theme A - Data Sharing and Use Flavour of Timing

- The opportunity for the EHR is that it is for all people, from birth to end-of-life, and that it would need to cater just as much for the healthy as the unwell (e.g. at any time in life people can become unwell)
- Real time information is required to facilitate health professionals when making accurate decisions with their patients.
- Issues arose concerning monitoring and evaluation the progression of conditions
- If patients and health professionals could track outcomes and feed into the EHR this would improve patient’s future health and be useful for research.
- Patients should have a portal with relevant medical clinical information for which emergency services or family members can access.
- Allow up to date information regarding specific rare conditions to be easily accessed by health care professionals at the point of care for shared decision making.
- For out-of-hours services, information should be shared between GPs, with the consent of patients.
Theme A - Data Sharing and Use

Flavour of Data Quality

• There is a lot of data and data systems out there, but how do we identify what data is good or useful?
• There were concerns that certain cohorts of patients or age groups would be the only ones used for research
• There is an opportunity for information to be in the EHR for ethics boards
• Opportunity to capture qualitative data e.g. patient experiences, concerns, symptoms
• It was deemed important that information from the EHR could be population-based, in line with other areas (e.g. pollution and its impact to health and wellness)
• Opportunity to combine data sets with patient representative groups and the EHR
• The EHR needs to be free from technical jargon, and possibly approved by NALA
• Standardisation of IT systems across the healthcare system is a good place to start
Theme A - Data Sharing and Use

Flavour of Access

• The question arose about concerns the public may have in relation to “When, Why and Where” a patient’s personal information is used.

• There is an opportunity to discuss this at the policy level and through education (i.e. inform the public via PR and workshops) that a health professional will need to know the person whom they are dealing with, and therefore require personal information, but researchers should not need to know the person’s personal information and so this information should be anonymised.

• Concerns expressed regarding patients accessing & using record.
Theme A - Data Sharing and Use

Flavour of Consent

• A need for explicit consent to be built into the EHR policy and that this should be reviewed at different stages (maybe build an algorithm into it if certain criteria arises)

• Legislation needs to facilitate data sharing between legal entities e.g. GP and hospitals, with patient consent

• Anxiety on the part of patients around disclosure and how their information will be used – particular mention was made about fears of data being passed to pharmaceutical companies for use for commercial purposes
Theme A - Data Sharing and Use
Flavour of Education and Training

• There is an opportunity to gain insights into patients’ own knowledge

• Education for health care professionals on what information patient’s need and are able to retain needs to be part of the implementation of EHR

• Opportunity for education on what “consent” is

• National education programmes relating to health data and EHRs would also be valuable
Theme B - Patient Clinician Relationships

Common Themes:

Trust
Patient Experience
Education and Training
Collaboration
Communication
Timing
Sharing
Community
Access
Consent
Data Quality
Theme B - Patient Clinician Relationships
Flavour of Patient Experience

EHR has the potential to improve:
• Time efficiencies and continuity of care
• Communication of plans – e.g. End-of-life care
• Transition from child to adult services
• Integrated care – inclusion of parents in care
• Inequality of services
• Lack of repetition and replication of tests, and also patients having to constantly give same information when visiting healthcare professionals
Theme B - Patient Clinician Relationships
Flavour of Trust

• Definition of ‘Trust’ – What?, Who?, Why?

• The EHR can lead to the building of ‘trust in oneself’ to manage ones own health and healthcare

• Fear of litigation apparent in many relationships
Theme B - Patient Clinician Relationships

Flavour of Collaboration

• Promote integration of care across different settings, in particular for complex conditions
• Burden on HCPs needs to be addressed – often there is too much information in EHRs
• ‘System’ interference: i.e. the system that interferes between the clinician and patient. There is not enough information in this system, and the ability to use the system is not equal
• People who experience difficulties accessing services should be a key focus
• Rare diseases – need clearly identified pathways – a relatively straight forward to process map
• Management of patients with multiple symptoms is a challenge
Theme B - Patient Clinician Relationships
Flavour of Communication

• Openness is a key principle:
  • It starts a conversation towards being able to view information together
  • It allows patients to view information before appointments – to know what questions to ask
  • After appointments, patients will be able to refer back to see what was discussed / recommended

• Fear was expressed in relation to:
  • Diagnosis – finding out from the EHR instead of from a clinician
  • Breaking news to the patient

• Needs to be a standardization of terminology between clinician and patient

• Empower the family and the patient together
Theme B - Patient Clinician Relationships

Flavour of Data Quality

- EHR improves ability to collect better / good / more up-to-date data

- How to document and communicate with a patient-focus in mind is a challenge for doctors, nurses, etc.

- Making sure the information in an EHR is complete and updated is essential
Theme B - Patient Clinician Relationships
Flavour of Consent

• Concerns were expressed regarding consent for data being inputted and being shared
  • i.e. children cannot consent and there are instances where a person in the first instance did consent, but at later stages may be in situations where it makes it more difficult to make decisions to give consent (e.g. in labour, cognitive impairment etc.)

• Bringing families on board in relation to the EHR may improve their willingness to consent to access and use child record