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# A Citizen's Approach to National Electronic Health Records

Derick Mitchell, PhD

Irish Hospital Consultants Association Conference

Sept 30, 2023

[www.ipposi.ie](http://www.ipposi.ie)

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**We are a *patient-led organisation*  
that works with *patients, science & industry*  
to *put patients at the heart of health innovation***

*Irish Platform for Patient Organisations, Science and Industry*

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# What do we do, and how?

EDUCATION

ADVOCACY

INFORMATION

## Our Patient-led, Public Private Partnership

- 111** patient organisations\*
- 137** individual patients
- 228** individual scientists/researchers
- 25** healthcare companies

\*represents the largest network of patient organisations in the country

## IPPOSI ANNUAL REPORT 2022



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## IPPOSI Pillars



EDUCATE



INVOLVE



IMPACT

## Priority Areas



ACCESS TO  
INNOVATION



PATIENT & PUBLIC  
INVOLVEMENT



DIGITAL HEALTH +  
INFORMATION

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## What is a National Electronic Health Record (EHR)?

A long-term digital record of a patient's medical history, across different health services



A digital version of a patient's paper chart?

# Benefits of integrated, national EHRs

Supports safer, more efficient care and more timely patient care

Facilitates the use of data to improve services and support research



Access to all of your relevant health information

• Comprehensive view of patient records

streamlined pathways

reduces medical errors

streamlined

patients will have fewer forms to fill out

data used to inform health strategy

analytics and aggregated patient data

efficiency and cost savings

*'A national EHR is a key requirement for the efficient enablement of integrated care.'*

*It provides us with a North Star, or an ultimate destination for the digital transformation of our health service.*

*Existing strategic investments and individual point solutions must be integrated into an electronic health record'*



**Fran Thompson, HSE Chief Information Officer**

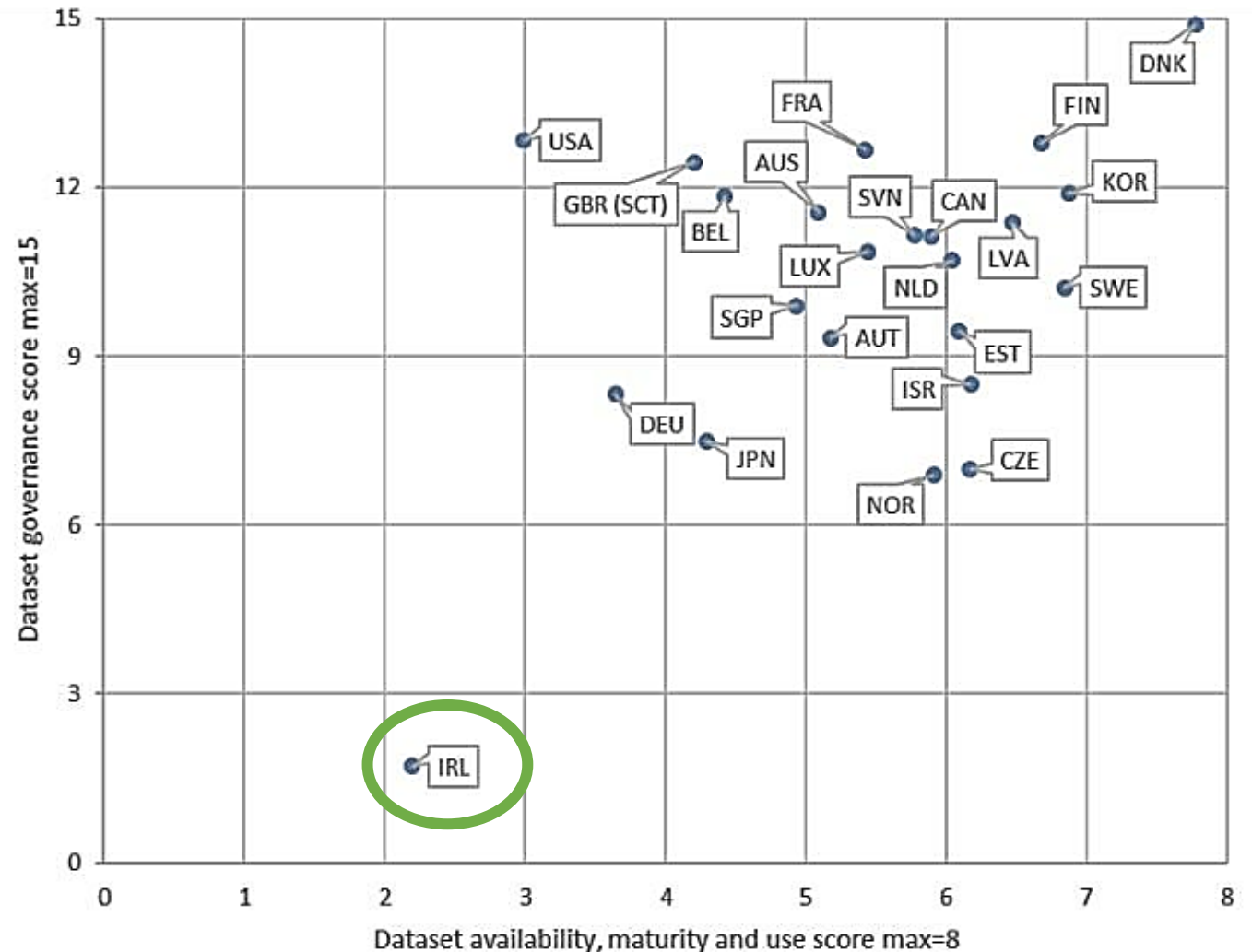
# Big issue: Current state of Irish Health Data

COVID-19 shone a stark light on the siloed nature of Irish health data

2022 OECD report **ranked Ireland way last for availability of health datasets and secondary use**

Ireland is one of only two countries not regularly linking datasets for research, statistics, and monitoring

Ireland is one of 4 EU member states who have not implemented EHRs

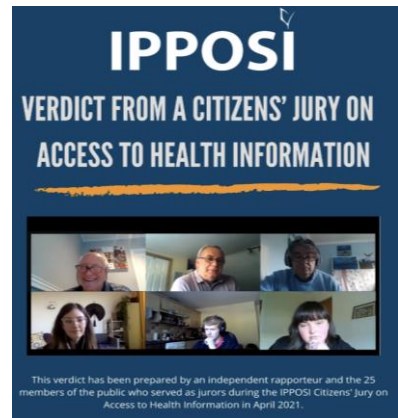
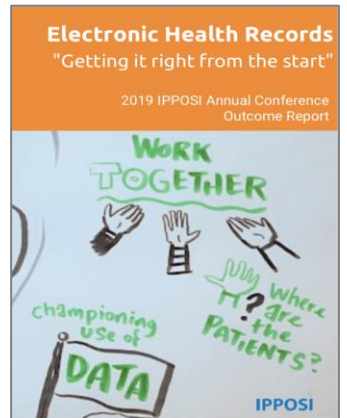
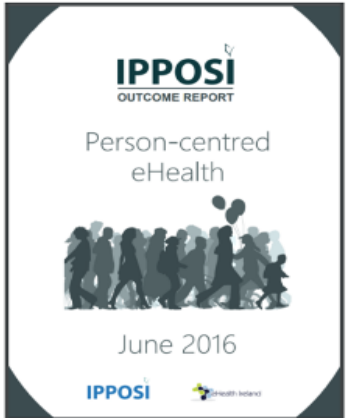
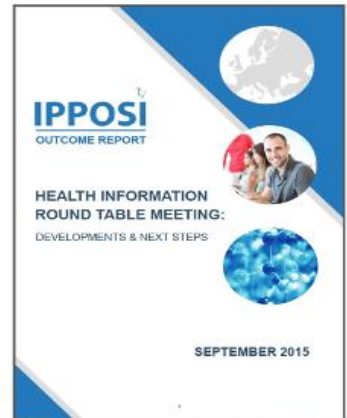




# What we are keeping an eye on...



2013 2023



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# Focus: IPPOSI Citizens' Jury

## HOW DO YOU FEEL ABOUT YOUR INFORMATION BEING COLLECTED, SHARED AND USED?

**1000+** APPLICANTS  
**25** JURORS  
**6** ONLINE SESSIONS  
**3** WEEKS OF DELIBERATIONS  
**1** VERDICT



-  WE NEED A CONNECTED, QUALITY DIGITAL HEALTH INFORMATION SYSTEM
-  WE NEED CITIZENS TO BE THE OWNERS OF THEIR OWN INFORMATION
-  WE HAVE A COLLECTIVE RESPONSIBILITY TO DO THE RIGHT THING
-  WE NEED TO BE SUPPORTED TO GROW TRUST AND CONFIDENCE IN THE STATE
-  WE NEED INDEPENDENT OVERSIGHT OF OUR HEALTH INFORMATION
-  WE NEED ACCOUNTABILITY
-  WE NEED TO PARTNER WITH CITIZENS TO DESIGN OUR HEALTH INFORMATION FUTURE
-  WE NEED TO TREAT DATA AS A NATIONAL RESOURCE
-  WE NEED CONSENT TO BE THE CORNERSTONE OF EVERYTHING WE DO

## 2023 - Where are we now?

- **January** – Joint Oireachtas Health Committee Meeting
  - Health Research Charities Ireland
- **May** – (Heads of) Health Information Bill published
  - Provisions on Summary Care Records, Shared Care Record and EHRs
- (Due in **Oct**) DOH Digital Health & Social Care Framework
  - A ‘roadmap for Digital Health 2023-2030’
- (Due in **Dec**)- HSE Digital Health Strategic Implementation Plan

# Implementing a National EHR

- Need clinically led, clinically-delivered programmes of work
- Need associated enabling governance and Patient/Public Involvement
- Need to foster & scale up digital innovation in the HSE
- Need Joint Advocacy + Joint Action
- Need Political appetite

**A clinician's perspective:**


**"There is nobody more interested in the patient's health, than the patient themselves, and I would not have any reticence at all about patients having access to their own records, I would say bring it on!"**



**DR GRAINNE COURTNEY**  
Former Chief Clinical Information Officer at St James' Hospital, Dublin

Listen to the podcast episode at <https://bit.ly/3FGbBO1>

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**MY NAME IS Mark Byrne**

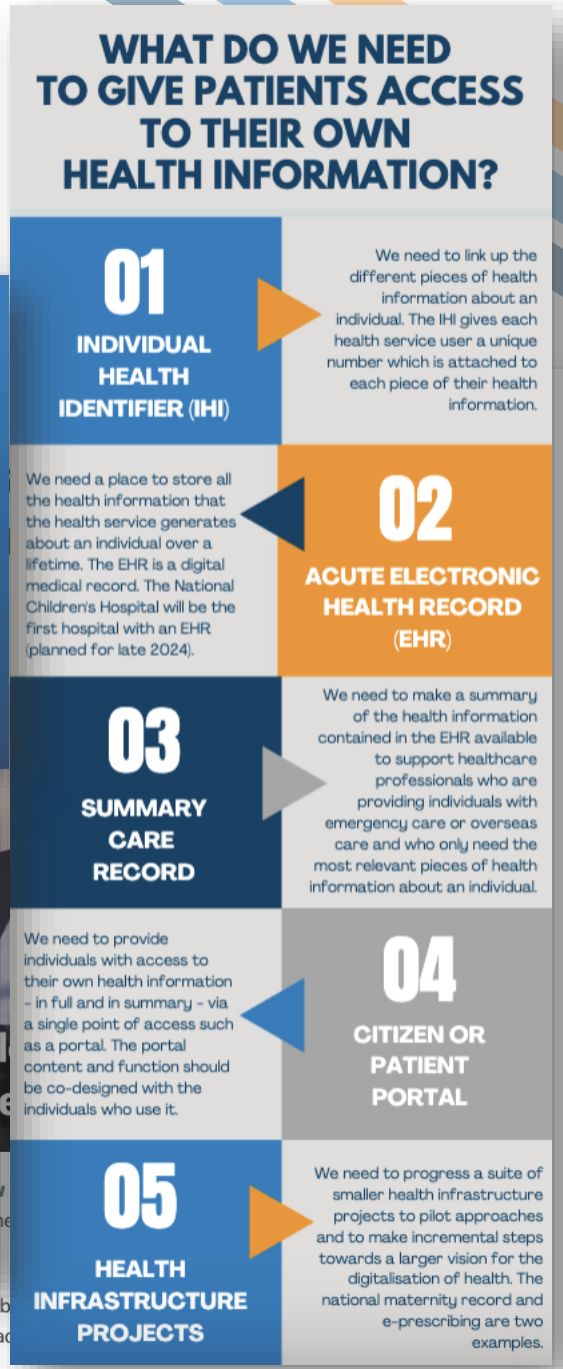
**I LIVE WITH Stage 4 Male Breast Cancer**

**IN THE PAST, I OBTAINED ACCESS TO MY HEALTH INFORMATION BY Ringing my Oncologist, and by following up on scans and appointments with my GP**

**IN THE FUTURE, I WANT ACCESS TO MY HEALTH INFORMATION VIA A secure patient database where I can access my own personal information from anywhere in the European Union.**

**HEALTH INFORMATION IS PATIENT INFORMATION**

**#MyHealthMyData**



[https://issuu.com/ipposi/docs/health\\_information\\_campaign\\_graphics](https://issuu.com/ipposi/docs/health_information_campaign_graphics)

The president gave a surprisingly frank assessment of something his administration has tried,

# Challenges + Opportunities



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## How one Irish hospital has turned its performance around in quite a dramatic way

Dr Muiris Houston: A patient experience confirms the absolute transformation of Beaumont's emergency department

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Fáilte go dtí  
Ospidéal Beaumont  
Welcome to  
Beaumont Hospital

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Apart from the excellent and timely treatment of the patient, **what absolutely blew me away in this case was the provision of a detailed printed summary of their care as they left the emergency department.** This detailed all the person's test results and clinical findings – a rare occurrence in a system that usually limps along with a dismissive and unfulfilled promise that “we will be in touch with your GP”. But the Beaumont experience was of seamless care of the highest standard.



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**Thank you!**

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