IPPOSI SUMMARY REPORT

THE EUROPEAN UNION HEALTH DATA AGENDA AND IRELAND'S PREPAREDNESS TO MEET ITS EUROPEAN COMMITMENTS

IPPOSI Digital Discussion - 2 November 2021

Key Messages

- While the EU General Data Protection Regulation (GDPR) provides a solid foundation, Ireland must enact specific legislation around the primary and secondary use of health data - taking inspiration from others, like Finland.

- Irish patients and their advocates must be involved in policy development and decision-making around health data at the European level to ensure the perspective of patients is heard and to promote policy alignment across the European Union (EU).

- Irish policy makers must respond to emerging evidence of a willingness among the public to share their health data to benefit public health goals (with the appropriate safeguards in place). Digital health solutions are needed to improve care and deliver research and innovation.

- Discussions about digital health and health data must not be simply left to the technologists, but progress must be led by a partnership of citizens, clinicians, health care professionals, patients, and technologists together. We need more dialogue, more transparency, and more involvement to identify the digital health solutions needed for Ireland.

- The recent cyberattack exposed weaknesses in Ireland's health system, but it has also underlined the importance of moving towards a modern, quality, digital system. It is important to now act - to improve security, ensure quality data, and enact appropriate safeguards.

- Ireland should explore the potential role that a data permit authority could play in facilitating timely researcher access to data, along with the model of Finland's one-stop-shop, FinData - the Finnish Social and Health Data Permit Authority.

Saara Malkamäki
Specialist, Health Data 2030, SITRA Finland

Avril Daly
CEO, Retina International

Dr Teresa Maguire
Director of Research Strategy & Funding, Health Research Board
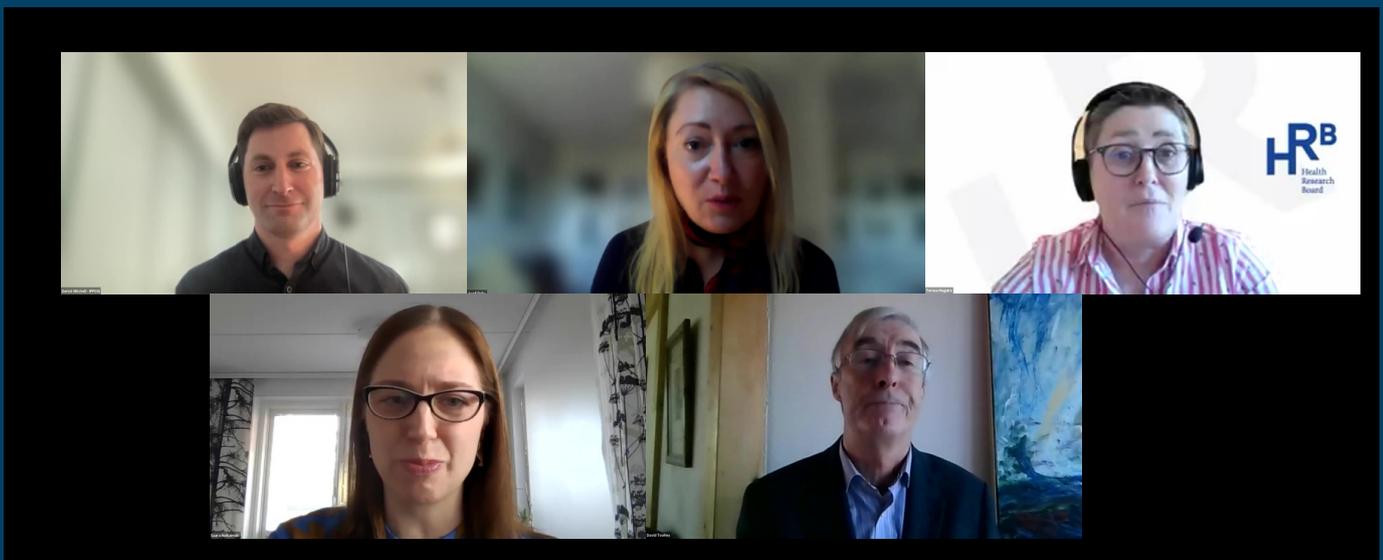
David Toohey
CEO and Co-founder, Syncrophi

Dr Derick Mitchell
CEO, IPPOSI

Speaking at the IPPOSI digital discussion, Saara Malkamäki of SITRA Finland introduced The European Health Data Space (EHDAS) and the Joint Action - Towards The European Health Data Space (TEHDAS).

- The European Strategy for Data seeks to create a common European data space where data can flow within the EU and across sectors while utilizing fair, practical, and clear rules for access and use.
- The European Health Data Space (EHDAS) is about the primary use of health data and the secondary re-use of health data. The aim of EHDAS is to improve healthcare, policy-making, research, and innovation under the four pillars of **legal/governance, quality of data, infrastructure, and capacity building.**
- The Joint Action - Towards The European Health Data Space (TEHDAS) is a voluntary initiative involving 25 European countries and focusing on **the secondary use of health data.** TEHDAS helps the EU Member States and the European Commission develop and promote approaches to sharing data for the purposes of citizens' health, public health, health research and innovation in Europe.

Saara highlighted the progress of Ireland, Finland, and other countries in preparing for the secondary use of health data:

- In a recent Open Data Institute report scruitising the progress made by European countries in providing a policy framework for the secondary use of health data, Ireland ranks behind Finland and 18 others, with a score of 55.1%.
- Saara also referenced the Organisation for Economic Co-operation and Development (OECD) report which shows that Ireland is well behind other European Member States in terms of the quality & availability of our health data and our preparedness to progress a European health agenda.

Top L-R: Dr Derick Mitchell, IPPOSI CEO and moderator of the discussion; Avril Daly, CEO of Retina International; Dr Teresa Maguire, Health Research Board. Bottom L-R: Saara Malkamäki, Health Data 2030, SITRA Finland; David Toohey, CEO Syncrophi

PANELLIST RESPONSES

The panellists were asked to respond to Saara's presentation from their own perspectives and to provide insights on where and how the EU agenda will influence their work.

Avril Daly
CEO, **Retina International**

Avril emphasised the need for Irish patients to be involved in legislation at the European level to ensure alignment across the EU. Health requires its very own particular legislation and she believes it is critical for patients and patient advocates to understand that there is a broad body of legislation relevant to secondary health data that still need to be developed. Avril said that while patients and stakeholders understand the need to safeguard health data and to share data effectively and appropriately, patients' experiences with GDPR tend to be negative. She explained that this experience might put patients off from engaging in other frameworks, so there needs to be more structured and positive engagement from Irish patients in this type of action at the EU level. Avril concluded by emphasising that the structures, the willingness, and the multistakeholder approach exist, but the lack of alignment needs to be addressed so that patients will participate in these discussions.

Dr Teresa Maguire
Director of Research, Strategy, & Funding, Health Research Board

Teresa stated that a range of issues exist in our health system which affect our approach and our ability to effectively collect, store and use health data – not least the complication of a mix of public and private healthcare providers. She acknowledged that pockets of activity exist and pointed to the fact that we already spend quite a lot on our health system. She referenced high levels of trust in health research, and emerging evidence of a willingness among the public to share their health data further (with the appropriate safeguards in place). She spoke about the verdict of the IPPOSI Citizens' Jury, and she looked back to the DASSL report of 2016. She called for an updated framework for moving forward, given that the latest health information strategy dates back to 2004, and that the need for legislation and policy in this space is being more and more evident. She noted the constraints of working within the CSO and public sector data legislation, and the challenges encountered around health data use during the recent pandemic.

David Toohey
CEO and Co-Founder, Syncrophi

David emphasised how urgently Ireland needs to implement a health data system to treat patients most effectively. He highlighted the Health Innovation Hub and the National Centre for Digital Health Innovation as two initiatives that have displayed how effective health data can be for research and innovation. He mentioned a piece in Fortune Magaine entitled *Death by a Thousand Clicks: Where Electronic Health Records Went Wrong*, which looks at the many issues in healthcare that persist in spite of Electronic Health Records in the United States of America. David concluded by explaining that successfully deploying digital health in Ireland would lead to a "virtuous circle" because Ireland would be improving both primary and secondary use and the secondary use for research would feed back into the primary use of patient care.

QUOTES FROM THE DISCUSSION & SOCIAL MEDIA

> The general public doesn't fully understand secondary data and how useful it is. More public discussions are needed on this.

Super discussion @IPPOSI and some great takeaways. 'Death by 1,000 clicks' report referred to by David Toohey - what can go wrong if implement #ehealth too fast without incorporating #interoperabilty and #standards

We are in danger of sitting back and thinking that TEDHAS is going to do all the thinking for us, but it cant do our member state actions for us – we still need to make sure that we have a policy position, that we enact legislation, and that we have an investment plan"

Dr Teresa Maguire

Garbage in, garbage out. We need quality data. Researchers cannot work with poor quality data.

David Toohey

> If there is anything positive that can be said about Covid-19, it has pushed the need to have different aspects of our health system talking to each other which is definitely a step in the right direction.

Patients are not 'against' the sharing of health data, but we need to be 'across' it.

Avril Daly

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