

IPPOSI SUMMARY REPORT

LEARNING FROM THE PANDEMIC RESPONSE: IMPLICATIONS FOR HEALTH INFORMATION IN IRELAND

A summary of contributions & comments from an IPPOSI discussion on 20 September 2021

Speaking at the IPPOSI digital discussion '*Learning from the pandemic response: Implications for health information in Ireland*', Muiris O'Connor from the Department of Health highlighted several lessons learned throughout the past 18 months, including:

- There is a critical need for comprehensive and accurate health information at a national level.
- People have a desire to access their health information and to have access to reliable, up-to-date sources of information about health.
- Public sector collaboration and innovation is incredibly valuable. For example, the Central Statistics Office was instrumental in establishing the COVID-19 data hub alongside the Health Research Board.
- Unique identifiers are and will continue to be important for linking information and authenticating the identity of citizens engaging with the health service. For example, understanding the profiles of people who had benefited from the COVID-19 vaccination programme would require unique IDs.
- There is a need to build up and invest in the statistical capability and data management capacity of the health service, learning from the lessons of the HSE vaccine programme and contact tracing databases.
- The recent cyberattack highlighted the fragility of the IT and data management infrastructure in the health service.

Looking forward, Muiris highlighted the following:

- Ireland is behind other EU countries in developing electronic health records and a bottom-up approach that originates with the citizens is now needed.
- Ireland can build upon and benefit from the health information approaches that have been implemented across Europe.
- The State needs to build trust with the public and ensure data security.
- The development of health information systems may require legislation.



Muiris O'Connor
Assistant Secretary
Department of Health



Loretto Grogan
National Clinical
Information Officer
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Head of Research
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Sara Hurley
Juror
IPPOSI Citizens' Jury on
Access to Health
Information

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PARTICIPANTS

PANELLIST RESPONSES

The panellists were asked to respond to the presentation by the Department of Health and provide insights on where and how health information has played a role in their work over the past 18 months. Specifically, they were asked to consider the influence that policy can have on the future of the health system in Ireland.



Loretto Grogan

National Clinical Information Officer, HSE

In her response, Loretto highlighted the development of systems such as the COVID care tracker and CoVax and the national implementation of telehealth. She also pointed out that healthcare data is complex and is currently stored in many different places throughout Ireland with a gap in standards in terms of formats, definitions, etc. Loretto explained that Ireland needs to get the fundamentals of digital health right, such as having a good individual health identifier programme to be able to identify patients. Finally, she stressed that digital health has to be about the people first, then process and technology.



Dr. Robert O'Connor

Head of Research, Irish Cancer Society

Dr. O'Connor emphasised the fact that the COVID-19 pandemic has illuminated many issues and future challenges regarding the Irish health system and health data infrastructure. He also discussed how Ireland, as a community, needs to address the challenge head-on in the coming decades. Dr. O'Connor expressed that a 'team approach', like what was seen during the pandemic, needs to be utilized to improve the health system. Finally, he addressed the common theme of trust and confidence, highlighting that the public needs trust and confidence in the State for improvements to be made.



Sara Hurley

Juror, IPPOSI Citizens' Jury on Access to Health Information

In her response, Sara highlighted the main themes from [the verdict of the Citizens' Jury on Access to Health Information](#), including the need for a connected, quality digital health information system, independent oversight of citizens' health information, and citizen ownership of their health information. Sara also highlighted that the jury's verdict and recommendations provide a way of including citizens and patients in the development of a health information system and a starting point for the bottom-up approach that Muiris O'Connor mentioned. Sara emphasised that patients and citizens need to be the owners and controllers of their data and they need to engage with care providers and researchers to help create quality health services.

QUESTIONS & ANSWERS

Q: What are the key value propositions that we can be communicating around health information right now to decision makers?



The resolution of challenges like access and accountability are impossible to solve without a resolution of some of the fundamental issues. Simplification of the whole system and digitalisation of health records in an electronic approach does offer a way forward which is most critical currently. Every Irish citizen should be promised that some core data (blood type, medicines, allergies, etc.) will be recorded. Simplification and allowing health services to focus on the core mission at the people level, and in terms of population and health outcomes will give better insight into the health and well-being of people in Ireland.



Communication seems to be the problem. Policymakers don't seem to understand the value and impact of data, systems, and organisation. People can relate to being sick, the fear of sickness and having to wait for x-rays, results, consultations, then treatment. Communicating some of the truly shocking realities of healthcare in Ireland in terms of wait times, etc., and making these issues more personal could be a more effective way to communicate the importance of a health data system.



We need to simplify and get our fundamentals right. To simplify we need to break things down further in terms of where things are stored, how it's stored, what the regulations are around this, etc. We need to define what a citizen centred approach looks like and connected care requires connected teams and we just don't have that yet.



A patient-centric and citizen-centric model is vital. It needs to be an inclusive model, something that is easy for citizens to understand what information is held on them, how that information is shared and accessed. Having an understanding of what is happening with patient data is caregiving as well.

Q: What is the role of patient registries in health data strategies going forward?



Registries are really important, some of the registries in Ireland are key strengths in health services. Registries are generally disease or condition-specific and there is some competition in medicine around registries. They are a critical building block, but I'd rather build from the centre out to get a holistic view of the health and well-being of each citizen. My ideal would be a national citizen-centred database that could be the core platform for a whole range of registries, but these registries could just be extracted from that comprehensive health database. I support registries, but I don't think registries are the path to a national approach. I think there's something at the centre that has to be built.



Registries have to be resourced appropriately in line with international standards. The Scandinavian approaches show us workable models where every interaction is recorded allowing a lot of analysis across different health dimensions. People who get cancer also get cardiovascular disease, or they have various other health conditions, and you can't look at health as a set of different silos, so I think there's benefit in having various registries, but you have to start from a basis of having a trusted and safe way to capture all of the relevant health information.

QUESTIONS & ANSWERS

Q: How ready is our system right now for pulling information from various sectors to address public concerns?



We're very poorly equipped at the moment to draw inferences across different specialities. We didn't succeed at a national level to secure investment to phase out technological capability across all services. The Irish health and social care system is so complex. The legacies of voluntary, public, private, etc. even the public system is totally disconnected from itself in terms of social care, community care, respite care. That's why the health services need to assign responsibilities for population health and that's how you get the teams because people must work together because they share responsibility for the health outcomes of a known population.

I think we need to turn to the citizens because it hasn't worked to go top-down and people don't have the patience for this to be figured out. We could start slow with core health data and then get into the fancier stuff, like advanced care notices.



We are in a hurry here. Patients want to manage their own health and many are using unregulated apps to track their own information. If we don't get a handle on this there will be other private companies like Amazon, that will take over and then this will be out of the control of the government, health agencies, and health services.



We need something that has a grand scope, that can be preemptive about future technologies coming in. Electronic health will be the entire future of generations of citizens and we need to ensure that there is a capable system in place.

Q: Is there a roadmap of what the department's intentions are in this space?



There's a growing appreciation of how vital some of these fundamental issues are, but Ireland has never made the effort to make a transformative change until Sláintecare. There has been some anxiety about the pace and momentum behind Sláintecare, but I do hope the pandemic crisis is giving us that scale of ambition because it shows us the vital importance of information in a health service, the vital importance of coherent national approaches, and how health is a communal thing in more ways than we realize.

The department is going to be restructured, a core number of issues will be pursued, and hopefully, it won't take as long as before when we were meandering through the complexities. If we get the green light, I'd be looking to head a bill alongside doing data strategy, because we have enough strategy.

QUESTIONS & ANSWERS

Q: From a research perspective, are there other initiatives that we can be harnessing?



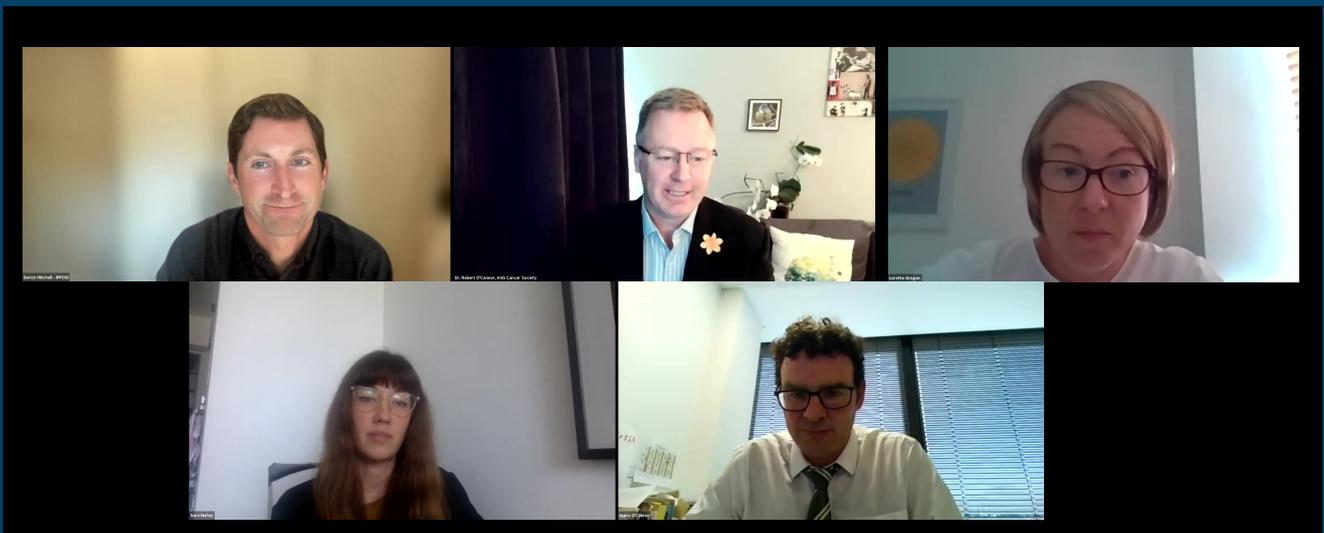
A lot of systems are trying to connect in the background. I worry that we need to have the right mindsets before going into this. We have an awful lot of reports of scandals that took place in our health system, there's an urgency now around action. We need to start moving forward, the urgency that came from COVID needs to be brought into this issue. We're talking about individual elements, but we need to recognize the urgency around the bigger picture. We can do an awful lot of talking around this, but the larger problem is recognizing that we need to get going. The cyberattack is an example, because this is something that had been brought up before, but wasn't addressed and has now made people more nervous about these systems.



My whole motivation for getting health information moving correctly on a clear legal basis is to support research and the DASSL model. The IPPOSI Citizens' Jury had a strong endorsement for the DASSL model which is about addressing the flow of health information in the delivery of service and then using information generated in the delivery of service, de-identifying it and having population-based services that correspond to known populations in Ireland. There are ways where the whole Irish population could become the subject of research. Research is not a next phase, it is almost resolved in the same legislation and strategy and approach as our first steps.



We need to be honest about where we are and about what is crippling the country and everyone in the country. We need to use the collective intelligence of the good people that we already have in our system. We need to better communicate and use what we already have. We also have gaps in terms of capabilities, so we need to call out those and start moving forward.



L-R: Dr Derick Mitchell, IPPOSI CEO and moderator of the discussion; Sara Hurley, IPPOSI Citizens Jury representative; Dr Robert O'Connor, Irish Cancer Society, Muiris O'Connor, Dept of Health, Loretto Grogan, HSE