This verdict has been prepared by an independent rapporteur together with the 25 members of the public who served as jurors during the IPPOSI Citizens' Jury on Access to Health Information in April 2021.
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*written by IPPOSI  written by Rapporteur
FOREWORD

‘NEVER DOUBT THAT A SMALL GROUP OF THOUGHTFUL, COMMITTED, CITIZENS CAN CHANGE THE WORLD. INDEED, IT IS THE ONLY THING THAT EVER HAS.’

MARGARET MEAD

Rarely have I ever been so proud of a report such as this one. It has captured the essence of a fantastic effort from IPPOSI staff, members, collaborators, advisors and not least of all, the 25 jurors who all came together to make this pilot jury happen.

This 2021 jury is aimed at starting a public debate on the benefits and the risks of sharing, or of not sharing, health information. Indeed, a Citizens’ Jury on this topic is very relevant in light of the recent cyberattack on our national health system.

For me, it also reflects Ireland’s growing reputation for delivering impactful citizen engagement at the national level. This has led to pressure on policymakers and public agencies to find ways to meaningfully engage in a dynamic way with the public, and to respond to citizens’ calls for action on ‘tricky’ topics.

We in IPPOSI, and more importantly the jurors, want their recommendations to be listened to and acted upon. So over to you, agencies and policy makers!

Our small (and mighty!) team in IPPOSI, together with our broad membership, led this effort. But we want other teams to conduct similar deliberative democracy-based initiatives in Ireland and internationally.

That’s why we are accompanying this report with an analysis of how we conducted the jury. It is self-reflective in nature but also contains an analysis by an independent research team who studied the deliberative quality and outcomes of the jury, including any knowledge gains, opinion shifts and empathy building.

Of the many people and organisations who came together to make this happen (see overleaf), I wish to personally thank all the jurors for their commitment as well as the other members of the IPPOSI project team. Particular thanks go to Laura Kavanagh, Jennifer Moran and Shannon Karpinski for their excellent work in bringing this initiative to fruition.

We hope you enjoy reading the verdict!
ACKNOWLEDGEMENTS

This jury is a first for IPPOSI and took the relentless support of many partners to complete. We wish to thank them all.

The first mention is to the IPPOSI members who provided financial support in the form of unrestricted grants. These include Abbvie, Alexion, Biomarin, GSK, Pfizer and the Trinity College Dublin HRB-IRC-PPI Ignite project. We are also grateful for the in-kind contributions made by a number of our academic partners, in particular the TCD PPI-Ignite office.

Without the advice of our Oversight Panel members, it would have been impossible for the project team to progress through the various stages of the jury process in a meaningful way. The Panel members showed commitment, flexibility, and good humour in meeting our repeated requests for guidance - we thank Prof. Jane Suiter (DCU), Rachel Flynn (HIQA), Prof. Mark Little (TCD), Vicky McGrath (RDI), Kate Morris (Campus Engage), Dr. Pamela Hussey (DCU), Robert Joyce (EUPATI fellow), Dr. Avril Kennan (HRCI), Prof. Jane Grimson, Michelle Kearns (formerly of CareDoc), and Prof. Gaye Stephens (ADAPT-TCD).

Our facilitator, Michael Foley (TCD PPI Ignite office) deserves special recognition for his role in the jury success. He is not only responsible for the jury design, but he managed to set a positive and focused tone throughout the proceedings, carrying everyone through a new and challenging process with ease!

Similar acclaim is reserved for June Shannon, our independent rapporteur and author of this jury verdict report. June kept the public record on track with her updates and has delivered an insightful, balanced, and comprehensive commentary of the deliberations.

Numerous others supported us along the way – a team of independent facilitators (Jennifer, Catherine, Scott, Anne-Marie, Martine and Emily) chaired our small group sessions; an expert public participation team led by Prof. Jane Suiter (DCU) coordinated an invaluable piece of research around the jurors’ experiences and jury process, and an expert health informatics team led by Prof. Mary Sharp (TCD) performed the all-important juror selection (thanks Oisin!). We also thank our expert witnesses for their time and effort. Thanks also to Anna for initiating the report design, and Philip for the graphics.

Finally, we thank our jurors – they made the jury! We learned so much from you, and we shared laughs and banter during the Zoom sessions. An extra thank you to jurors who volunteered to work with June to prepare this report (Elaine and Daniel), and to the jurors who are presenting the findings to policy-makers (Elijah, Kevin and Sara).
## GLOSSARY OF TERMS

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td><strong>Citizens’ Jury</strong></td>
<td>A Citizens’ Jury is a small group of randomly selected citizens, representative of the demographics in the area, that come together to reach a collective decision or recommendation on a policy issue through informed deliberation.</td>
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<td><strong>Deliberation</strong></td>
<td>The act of thinking about or discussing something and deciding carefully.</td>
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<td><strong>Health Information</strong></td>
<td>‘Health Information’ generally means ‘information about an individual person which may be relevant to decisions about current or future health or illness’. For the purposes of the IPPOSI Citizens’ Jury initiative, we are focusing on information collected as part of clinical care and treatment, that is held in health records (e.g. GP records, hospital records, other provider records), which could be used for purposes beyond individual care (e.g. for service improvement, policy change, health research or innovation).</td>
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<tr>
<td><strong>Electronic Health Record</strong></td>
<td>An electronic record is a ‘digital filing cabinet’ containing all of the health information about an individual/patient, including personal details, medical notes, diagnoses, medications, medical history, immunizations, laboratory data, and radiology reports. The electronic record has the ability to generate a complete record of a patient’s interaction with the health system. Also known as an electronic medical record, or EMR.</td>
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<tr>
<td><strong>National patient summary care record</strong></td>
<td>A national patient summary care record is a “summary version” of the electronic health record. The national patient summary care record is intended for use by doctors called to the scene of an accident, or staff treating a patient at A&amp;E.</td>
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<tr>
<td><strong>Identifiable Data</strong></td>
<td>“Personal identifiable data” refers to information that can identify a specific individual. This can include – but is not limited to – names, dates of birth, addresses, telephone numbers, occupation information, photographs, and fingerprints. This information exists in paper and digital records, and so it must be carefully managed, regardless of the format or medium in which it is held.</td>
</tr>
<tr>
<td><strong>De-identifiable Data</strong></td>
<td>“De-identifiable data” refers to information where the “personal identifiable data” (such as names, dates of birth, addresses, telephone numbers, occupation information, photographs, and fingerprints) have been removed.</td>
</tr>
<tr>
<td><strong>Facilitator</strong></td>
<td>An independent person appointed to guide the discussion during a meeting.</td>
</tr>
<tr>
<td><strong>Rapporteur</strong></td>
<td>An independent person appointed to report on the proceedings of a meeting.</td>
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EXECUTIVE SUMMARY

“They assume that you as the patient know nothing and they know everything because they have the information.”

Juror, IPPOSI Citizens’ Jury, April 2021

The IPPOSI Citizens’ Jury on access to health information presented the Irish public with an unprecedented opportunity to share their perspective on who they would be comfortable with accessing their health information and for what purpose.

During six online sessions, 25 randomly selected jurors – ‘the jury’ – were provided with ‘testimony’ from ‘witnesses’ with expertise in health service management, health policy development, health research, health innovation, ethics, and public and patient involvement in order to reach their ‘verdict’.

Due to the COVID-19 pandemic, the whole process took place online. Over a three-week period in April 2021, jurors joined in via Zoom to listen and cross-examine witnesses, deliberate and ultimately, vote on the verdict.

The jurors tackled the challenge with enthusiasm, and a rich discussion took place. It is not possible to capture the full breadth of opinions and suggestions shared in this report alone, but we have attempted to describe a number of the common themes emerging from the citizens’ jury process. These themes included arriving at the conclusion that the sharing of health data for the improvement of patient care is a collective responsibility, and ultimately ‘the right thing to do’.

Jurors agreed that, fundamentally, citizens are the owners of their health data and that any decisions, processes or systems developed to manage or share health information must be made in partnership with them.

As owners and partners, health information must first be easily accessible by each and every citizen who wants to view (and potentially manage) access to their health information. A system such as a ‘locked box’ in a patient’s file should be introduced to confidentially store highly sensitive information, such as sexual and mental health data, and that access to this box should only be permitted in the case of an emergency or in line with the appropriate protocols.
Jurors agreed that healthcare professionals involved in their care should have access to a complete, real-time record of the patient’s information and that information should be made available in a seamless, joined-up manner across the health service (both public and private) to ensure quality care.

Access to health information for secondary purposes, including for health research or policy, should be allowed, but with certain conditions, and authorisation should be guided, first and foremost, by the specific purposes for which the information is being sought, which must always be in the public interest.

The point was made that health information sharing must accrue benefits for the citizen (as the owner) and that benefits accrued must be channelled back to the state. Citizens who are less versed in the benefits of sharing health information must be supported to make autonomous but informed decisions, and no citizen or community should be left behind from a health equity point of view.

One of the challenges related to sharing health information that arose throughout the process was the lack of trust members of the public had in the State as a result of past failings (with frequent citings of the Mother and Baby Homes and Cervical Screening programmes) and there was agreement that this legacy needs to be addressed. Jurors also expressed real concern around data breaches and called for robust security solutions to protect health information and a zero-tolerance approach to the misuse of health data.

Overall jurors underlined the importance of transparency and trust in everything from the technology to the process to the reasons for collecting health information. Key elements of the process, such as the use of consent models, must be designed with the public’s input and must be explained in writing using clear and concise language (not medical or legal terminology).

Finally, jurors underlined the need for increased public awareness around health information access issues. They called for any legislation, regulation, policy or practice that informs how we manage our health information in the future to be developed in partnership with the citizen.
We expect healthcare professionals to be able to access the health information they need to provide quality, evidence-based, real-time care to individual patients.

CONDITIONS

- Health information should contain up-to-date, complete, joined-up data which provides an accurate and comprehensive account of the individual’s history of contacts with the health service and his/her health record.

- Information sharing should be limited, both in terms of what information can be viewed (locked box) and in terms of who can view the information (audit trail).

- Professional codes of conduct should guide healthcare professionals in the best practice around the ethics and legislation associated with the use of health data.

- Information sharing should be via a portal that is equally accessible to both the patient and the healthcare professionals engaged in their care.

RED LINES

- Health information must be first shared with every citizen who wants to view (and potentially control access to) their own health information.

- Health information portals and decisions over who should have access to this information should be co-designed with members of the public, and agreement should be reached on who should have access to which pieces of data.

- Health information should never be shared with employers, banks, or insurance, pension, and marketing companies.
RECOMMENDATION #2:

We recognise that decisions about service delivery, policy, research, and innovation priorities are best made when they are based on real-life evidence and that health information provides invaluable data for healthcare managers, health policy-makers, health researchers and healthcare companies.

CONDITIONS

- Health information sharing should be conditional, broad access is not appropriate, and access should not be granted for purposes other than those which have demonstrable public interest. De-identified and anonymised information should be shared.

- Information sharing should contribute to public interest goals, not just commercial ventures, and requests to access information should have to demonstrate their social value.

- The role of research ethics committees is key in approving health research projects therefore citizens should be made more aware of and become more involved in the work and oversight of these committees.

RED LINES

- The sharing of health information should not leave certain communities behind or result in increasing health inequalities - health information equity issues must be prioritized and specific communities at risk should be supported to understand health information access issues.

- Health information management must never violate public health ethics principles.
RECOMMENDATION #3:
We believe that the state has a poor record when it comes to (health-related) information management, and mistakes of the past, as well as the resulting cultural legacies, must be publicly addressed. The duty of care around the management of health information must be given extensive reconsideration and must at all times be guided by the voice of the citizen.

CONDITIONS

● Health information sharing needs to be guided by an independent, state-mandated, public champion who acts in the interest of the citizen, and who is responsible for informing, educating, empowering, and protecting the public.

● Health information misuse should be approached from a position of zero tolerance, especially misuse from within the system, in particular by public servants outside of healthcare professionals.

● We believe that a robust, multi-faceted, practical suite of safeguards are needed to promote public confidence in health information sharing. A simple data sharing agreement is not sufficient. There must be dialogue, enforcement, deterrence, and regulation.

● Health information recipients must store and secure data to agreed standards. These standards need to be co-designed with citizens.

RED LINES

● Health information management should not be passive. Prevention is a priority. Silence in the face of mismanagement is not acceptable.
The sharing of health information requires a model of consent that is co-designed with the citizen, and one that puts the citizen in control of the management of their health information.

**RECOMMENDATION #4:**
We believe that health information belongs to the citizen, and it is up to citizens to individually and regularly consent to how their information is accessed, shared and used.

**CONDITIONS**

- The sharing of health information requires a model of consent that is co-designed with the citizen, and one that puts the citizen in control of the management of their health information.

**RED LINES**

- Health information should not be shared on the basis of consent obtained via a 'once-in-a-lifetime' occurrence; individuals must have control over access to their own health information on an ongoing basis. Provision must be made for the withdrawal of consent and the deletion of data.

**RECOMMENDATION #5:**
We acknowledge the potential health information has to influence how our health sector performs, and so we must also attribute a value to its acquisition. The philosophy informing the future of health information sharing must be co-determined with the citizen, as part of the modern social contract.

**CONDITIONS**

- Health information must be quality data. It must be as complete as possible and as interoperable as possible - only then does it have value.

- Health information must be appropriately secured by the State, and sufficient resources dedicated towards its security.

- Health information should generate income for the State and this income should be channelled back to the health system.

**RED LINES**

- Health information should not be given away 'for free'. It is a modern-day 'national resource'. Society must accrue a tangible, financial benefit (or in-kind benefit) for sharing its information.
RECOMMENDATION #6:

We maintain that transparency, accountability and public participation are the key principles that must guide any decisions around health information management.

CONDITIONS

- The management of health information must be the focus of a national conversation. The system for health information management must be co-designed with the citizen. A citizen advisory committee could be a meaningful mechanism to guide future public involvement around this topic.

RED LINES

- Health information decisions cannot be imposed on the individual from the top down.
INTRODUCTION

- How does the public feel about their health information being viewed, shared, and used by others?

- Are there certain sectors or individuals such as healthcare professionals, researchers, or state bodies that we are more comfortable sharing our health information with?

- What safeguards need to be in place to protect citizens from the misuse of the data if that occurs?

- What are the benefits and risks, both for the individual and society as a whole, of sharing health information?

- Are there specific pieces of health information that should never be shared, or given additional protections, such as the status of an individual’s mental or sexual health?

To answer some of these questions, the Irish Platform for Patient Organisations, Science, and Industry (IPPOSI) organised a first citizens’ jury on the topic of access to health information in Ireland in April 2021.

Citizens’ Juries are an example of a deliberative approach to decision-making or solution development, developed in the 1970s by the Jefferson Centre in the USA.

IPPOSI is piloting the use of such approaches, to gain meaningful insight into current public perceptions around questions of health information access, but also to explore the potential for greater (virtual) public participation around important health topics in the future, using the citizens’ jury approach.

According to IPPOSI, “a successful citizens’ jury will deliver considered recommendations for decision-makers, but also and perhaps more importantly, highlight the need for a broader public debate around the topic, as well as model a method for greater public involvement in health decision-making.”

This report focuses on delivering the verdict of the IPPOSI Citizens’ Jury on Access to Health Information. It sets out the key themes emerging from three weeks of deliberations together, and it includes the concerns and expectations expressed as well as the recommendations and conditions proposed.
Information is collected about the health of every citizen in Ireland – in different settings, by different institutions, from different healthcare professionals. This information is amassed both by the health system and by individuals through medical devices, self-management apps & lifestyle wearables.

It is clear that we urgently need an agreed set of rules around how this digital data is collected, stored and used by information owners, information gatekeepers, and potential information recipients (researchers, companies). Legislators, regulators, & policy-makers from all over the world grapple with this challenge.

In 2018, the European Union legislated to ensure greater protections for the personal data (including health data) of all European citizens (the General Data Protection Regulation (GDPR). This is probably the most (in)famous piece of legislation affecting health information, but much work preceded and follows this. The creation of a European Data Space - one of the priorities of the European Commission for 2019-2025 - includes a European Health Data Space to promote the exchange of health information between Member States and provide access to health information for a range of purposes, including research and innovation. Work on the eHealth Digital Service Infrastructure and European Reference Networks support the vision for a common Health Data Space.

Ireland recognised the need for a national strategy to manage health information as far back as 2000, but in the 20 years since, successive governments have only succeeded in advancing this agenda in fits and starts. The creation of the Health Information and Quality Authority (HIQA) in 2007, the publication of the eHealth Ireland Strategy in 2013, and the passing of the Individual Health Identifiers Act in 2014 showed signs of promise. But these have been tempered by the failure to approve the business case for a national electronic health record (submitted in 2016), the limited health data uses provided for in the 2018 Health Research Regulations (amended early 2021), and the delayed publication of a national health information systems strategy.

The experience of COVID-19, as well as the recent cyberattack on the health service, underline the need for a renewal of major efforts in this area. However, to ensure that health information is managed effectively, securely & meaningfully in the future, both Irish and European authorities will have to find answers to difficult questions – ‘who owns health information’, ‘who decides who should have access to it’, and ‘who can use it and for what (secondary) purpose’. And perhaps, most challenging of all, they will have to do this based on the express wishes of the citizens of Ireland and of the broader European Union area.
PUBLIC ATTITUDES

For many, the experience of living with COVID-19 has necessitated a move to a more digital lifestyle, including the management of their health & care. As things return to a ‘new normal’, which measures are to be maintained & whether there is support for a broader programme to bring about the digitalisation of healthcare, are interesting questions.

Digitalisation makes it possible to collect, share, and use health information at unprecedented levels. There appears to be a general feeling among the public that ‘access’ to this health information, when used to inform individual care, is a good thing. What is less clear is how people feel about access to their health information for purposes beyond their own care, for research and innovation for example.

In an effort to gauge the public appetite for broader health information sharing, a number of recent initiatives are attempting to explore public attitudes in Ireland.

In 2020, a national survey by the Health Information and Quality Authority (HIQA) invited over 1200 individuals and groups to share their views on the collection, use and sharing of health information.

Also in 2020, a research study by PRIVATT (a DCU-led project supported by ADAPT and LERO and funded by Science Foundation Ireland) began to assess attitudes to privacy in response to digital solutions identified to address COVID. The pilot study suggests a marked increase in the willingness of individuals to share their personal data.

IPPOSI first contributed to this space via a public attitudes survey in 2009, and now via our Citizens’ Jury - a public participation tool which invites 25 individuals, representative of the broader population (‘the jury’) to reach an informed decision (‘the verdict’) after hearing from experts (‘the witnesses’) and after deliberating as a group of peers over several days and weeks (‘the sessions’).

As with any social group, each juror brings a different perspective to the table depending on their life experience, including their own interaction with the health system, their political beliefs, their philosophy around privacy, their digital literacy, and even their perception of academic institutes and commercial entities. As part of the jury process, the jurors are invited to challenge their own beliefs based on the evidence presented to them and on discussions with fellow jurors. As such, the IPPOSI Citizens’ Jury represents an example of what public attitudes might look like after information and debate have been added into the mix.
In January 2021, following a national and local media campaign, over 1000 residents of the Republic of Ireland expressed an interest in joining the IPPOSI Citizens’ Jury.

A team of independent academic experts were engaged to randomly select 25 jurors who were broadly representative of the population in terms of gender, age, location, ethnicity, educational attainment, and public attitudes toward health information access.

For three weeks in April, the 25 jurors selected became the ‘jury’ and they heard ‘testimony’ from nine witnesses who presented both partial and impartial perspectives.

During six sessions, jurors cross-examined the evidence and they deliberated together to arrive at a ‘verdict’ on who should have access to their health information and for what purposes.

The jury presents this verdict to Irish health policy-makers for their consideration in deciding the direction of travel for legislation, policy and practice in this area.
To download IPPOSI's analysis on the full jury process, visit www.bit.ly/ipposicitizensjury
In session 1, jurors were introduced to the health information landscape in Ireland, and in particular the regulations in place around the collection, access and sharing of health information, both for individual care and for secondary purposes.

The two expert witnesses at this session were:
- Professor Neil O’Hare, Chief Information Officer at Children’s Health Ireland
- Cathy Duggan, Programme Lead, Health Information & Quality Authority (HIQA)

In his presentation, Neil provided an overview of health information and the ways in which it is stored which includes more traditional paper and electronic patient records. He explained the challenges of paper records as they degrade over time and may not be complete due to missing files. He said that electronic patient records had huge benefits over paper records, but noted that they too have their challenges.

He discussed the wide range of health data sources and the various ways they are used, and he also spoke about GDPR, which he said has its challenges.

He introduced the idea of a patient portal where patients can keep track of all their health information in one place and he pointed to the importance of built-in privacy controls. He spoke about the challenges in storing patient data such as how and when it could be deleted, and how to use it safely for research or education.

Neil also discussed Artificial Intelligence (AI) and its role in healthcare. He also compared the data on the Public Service Card which contains 16 fields of data to the data the public willingly give online retail sites such as Amazon – albeit he acknowledged that the information the public gave these retail giants was less sensitive.
Cathy Duggan, Programme Lead at the Health Information and Quality Authority (HIQA)

In her presentation Cathy discussed the secondary use of health information and she underlined that in using secondary health information there was a need to strike a delicate balance between privacy concerns and data sharing.

She discussed the question of who owns health information and outlined the various roles in relation to health information (i.e. data subject/data controller and data processor).

She discussed the legislation that currently exists in relation to patient data in Ireland and she mentioned that there was no specific legislation in place for the secondary use of health information.

Looking at how other countries access health information, she said some were more advanced in terms of the development and use of electronic health records (EHR). She described the opt-in opt-out systems in Australia in relation to EHR and explained that there was increased patient engagement when an opt-out system was used.

“You can build in (to digital solutions) who can see your data, and you can control that, and that’s how it should be, and who has seen that data can be logged, and we can give you access to see who has looked at your data – because it is YOUR data!”

Neil O’Hare, IPPOSI Citizens’ Jury, April 2021

“Secondary use of health information requires a balance (to be struck) between people's privacy and confidentiality and the need to share data in order to improve healthcare.”

Cathy Duggan, IPPOSI Citizens’ Jury, April 2021
Jurors’ Questions and Reaction to Session 1 Testimony

Jurors were highly engaged with the testimony and asked a number of questions of the witnesses. These questions and discussions in small groups after the testimony included the following topics:

- Whether or not Ireland would look at developing an opt-in or opt-out system of sharing personal health data?
- How a patient portal would work in a practical sense?
- Concerns raised about safety of personal health information and vulnerability to hacking/breaches etc.
- The importance of learning from other countries that are more advanced in this area

Jurors expressed concern about private companies such as banks and insurance companies, employers, pension companies having access to personal health data and the reasons for which they may be accessing it.

Jurors also agreed that easier access to health information was needed, for patients and for healthcare professionals to avoid patients having to repeat their health history at every visit.

There was therefore an expectation that care should already be joined up, for example, between primary and secondary care.

A number of jurors were unhappy with the comparison between data given by consumers to Amazon and health data as personal medical data would contain a lot more sensitive information than that given to a shopping channel. These discussions resulted in the following final questions from Session One:

1. Will health insurance companies and other third parties have access to health information stored by the agencies?
2. Will Ireland be an opt-in or an opt-out country?
3. How much can we learn from others who are further down the line?
Using the Irish Hip Fracture Database as an example Louise outlined the entire process of how a clinical audit is carried out.

By measuring the process of care, NOCA can provide the health service with information on how the whole service is working to care for older people and fracture patients. Louise explained that there were many benefits of having information from the audit available and these included: improved patient care and outcomes.

Louise said that NOCA worked very closely with patients who are involved in the clinical audits and that all processes of the audit were always done with patient privacy and data protection in mind.

“We only collect the minimum amount of data – any patient sensitive data is not shared with NOCA, it is kept at the hospital, and all the audits are GDPR-compliance – everything we do is with keeping patient data safe.”

Louise Brent, IPPOSI Citizens’ Jury, April 2021
In his presentation, Dmitri made the analogy of Irish health information as an overstuffed large paper patient chart bulging with bits of loose paper and elastic bands. A combination of health data that is partially organised, partially randomised, stuffed together in a way that makes it un-useable.

According to Dmitri, doing nothing at the moment costs lives. Separating research from clinical data costs lives, having health information in its current format wastes time. It is random, it is often duplicated - this is data and time that should be used to care for patients.

Dmitri then outlined his experience in health informatics, which includes involvement in the development of patient registries.

Dmitri described patient registries as organised systems that collect defined, real world information to outline outcomes for groups of patients with similar conditions or those on similar medications. They are also network-building projects that bring together healthcare professionals, scientists, regulators, industry, and patients. They also directly involve people who can benefit from the collection and organisation of the data and who closely govern its use.

He explained that patient registries produce relevant and organised data, which can generate research questions - the answers to which, ultimately improves care.

He outlined the problems with patient registries which he said included funding, ethics, legislation, planning, and politics and he stated that registries had traditionally been detached from direct patient care.

Dmitri proposed a potential solution, which was to have health records grown out of patient registries. 

“Heath information is like a junk room, it’s the type of room that you need to tidy up before you let the neighbours in, that way you can display what is appropriate, and hide what is not.”

Dr. Dmitri Wall, IPPOSI Citizens’ Jury, April 2021
Jurors’ Questions and Reaction to Session 2 Testimony

Jurors were highly engaged with the testimony and asked a number of questions of the witnesses. These questions and discussions in small groups after the testimony included the following topics:

**Juror Questions:**

Patient registries – who oversees them, what level of trust can the public have in them and who has access to the data?

What happens when health information is leaked?

What supports are there for patients/individuals whose health information has been compromised?

How do we address issues of inequality of access to digital health information for people who are not digitally literate?

How can patients be involved in deciding who gets access to health information?

What are the issues around consent, including the ability to remove/delete data?

Who would oversee a registry?

Would there be different levels of access to health information on that registry depending on who is accessing?

How do we manage the conflict of interest e.g., a doctor passing information onto a third party?
In session 3, jurors heard about the legislative framework in relation to medical data, the laws that currently exist both in Ireland and the EU in this area and the issue of consent.

The expert witnesses at this session were:
- Simon McGarr, Solicitor and Olga Cronin from the Irish Council for Civil Liberties
- Richard Corbridge Chief Information Officer (CIO) of Boots UK and Ireland, and former CIO of the HSE

Simon McGarr, a solicitor, speaking on behalf of Digital Rights Ireland, set out the legislative framework in relation to medical data by explaining that in Ireland we follow EU law in relation to data processing (GDPR), we also have local rules (The Data Protection Act) (EU law is superior) and we have the Irish Constitution and the Charter of Fundamental Rights, which he said places respect for people’s privacy and their data at a constitutional level. He said that this legal framework ensures that the individual (i.e. data subject) is put at the heart of decision-making and that their individual rights are not lost sight of at any stage.

He said that while GDPR was frequently viewed as a catchall excuse for institutions not to do something they didn’t want to do, in reality, there were lots of ways in which GDPR not only permits health research, but also specifically accounts for it because health research is recognised as a matter of public good.

He said that contrary to what some may believe, consent was just one of the legal bases under which you can process personal data and therefore was not always required for general processing e.g., for reasons of public interest (Article 9.1 GDPR). However, Ireland’s Health Regulations have made clear that consent - from the data subject or from the Government’s appointed board on their behalf - must be obtained for Health research. Finally, he said that anything that is not fully anonymised was still personal data. Pseudonymised data is not anonymous.

“There is anonymized data and there is personal data and anything that isn’t fully anonymized no matter what kind of usage of language that it uses whether they call it the identified data or pseudonymized data…it’s still personal data.”

Simon McGarr, IPPOSI Citizens’ Jury, April 2021
Olga Cronin said that one of the questions the citizen’s jury was being asked was ‘who should be able to access, share and use your health information both identifiable and non-identifiable and for what purpose? She suggested that the jury flip this question and answer the second part first i.e., the purpose of the data. Because she explained that by ascertaining this (the purpose), the jury should then be able to ascertain who should be able to access and share that data and when that sharing should occur.

She explained that the legal basis for accessing data was purpose rather than identity based. It was important to ask if the data that is collected is the minimum required to meet the purpose, if it is more than what is required for that purpose, and to consider the principles of necessity and proportionality.

Olga said, this should not be about who you are in terms of who gets to access other people’s data, but what is the purpose, what do you want to do with that data and what is the purpose of the processing.

She added that trust and confidence could only come from valid and informed consent and that transparency was also key.

“Trust and confidence can really only come from valid informed consent.”

Olga Cronin, IPPOSI Citizens’ Jury, April 2021
Richard Corbridge, Chief Information Officer at Boots UK & Ireland; and former CIO at the HSE

Richard Corbridge said that data and the way it is currently stored (in paper format) doesn’t make it easy to share, get consent, or do good clinical governance.

He said that in Ireland the information key is the individual health identifier - a small set of data linked to an identifier that allows information to be found. According to Richard, successful consent models are those that ensure co-designed communication, assure healthcare need, provide clarity on who can access after consent, consent for consent, ensure a clinical understanding of ‘break glass’, assumed consent, was condition led, and was explicit + transparent.

"We have to find the easiest possible way for those people that do want to have information shared, for it to be shared in appropriate circumstances with appropriate checks and measures."

Jurors were highly engaged with the testimony and asked a number of questions of the witnesses. These questions and discussions in small groups after the testimony included the following topics:

Some jurors suggested that a cooperative of patients could act as data controllers of their own health information.

There was agreement that the success of the HSE’s COVID-19 app should be built on particularly with regard to its connectivity, anonymity of the data, and the feelings of trust garnered from its use.
There was concern that creating a centralised database of patient information was an impossible task. Jurors asked how data was going to get into the system, what about historical data and how would this be dealt with? How is the data going to follow you and how do you fill in the gaps in patient data?

Jurors asked about ethics and training needed to ensure that patient public health rights are protected?

Jurors agreed that there was a great benefit to sharing health data both for individual patients but also for the greater society.

Jurors also expressed concerns about the ability of people being able to access their own digital records given poor IT literacy, broadband issues etc.

They suggested looking to other countries that have implemented a way of sharing and accessing health data successfully and adapt those successes for Ireland. Concern was raised about the possibility of data breaches. Jurors agreed on the importance of layered consent processes. However, they said that for the public to understand and agree to informed consent the language used to explain the consent process needed to be user friendly and not overly complex.

"It's going to be difficult no matter what we do because, as was said, nobody's got it right. Estonia seemingly has a good system. Canada has a good system. Denmark has a good system. I'm told Finland have a good system. So we really need to be working on that side."

"I think it's a good idea to build on the success of the COVID app."

"I'm in favour of data sharing. Certainly. There are huge benefits, of course, but, you know, the breaches have happened."
The two expert witnesses at this session were:

- Prof David Smith, Associate Professor of Healthcare Ethics at the Royal College of Surgeons in Ireland (RCSI)
- Dr Natalie Banner, Understanding Patient Data, Wellcome Trust in the UK.

David Smith spoke on the ethical and legal perspectives of using personal data in research and Natalie Banner addressed the jury on ‘What we know about citizen views on health data.’

In his presentation David addressed the ethical arguments for citizens controlling access to health information, the ethical arguments for facilitating greater third-party (public and or private) access to health information, the law, and rights of citizens to control how their health information is accessed.

David explained that confidentiality and the rights of citizens to control how their health information is accessed dated back to the Hippocratic oath and was also ingrained in the Declaration of Geneva, as well as in the various medical and nursing codes of conduct. He added that the right to privacy was a fundamental human right and medical confidentiality was a practical expression of that right. Confidentiality is also protected under article 40 of the Irish Constitution, which covers personal rights, he added.

Citizens also have rights to control how their health information is accessed under Human Rights Law, Common Law, GDPR and Professional Regulation. David explained that confidentiality was not an absolute right, and it involved the balancing of rights. Therefore, he said that the right to privacy of personal information was protected by law and upheld in the ethical guidelines for healthcare professionals. Except in exceptional circumstances can information be given to a third party without the consent of a person (the patient).

He also highlighted the introduction of GDPR and outlined where GDPR covers consent. David outlined reasons why explicit consent was a big challenge for the research community and why concerns were raised. David also explained that in response to these concerns an amendment to the Data Protection Act was made in 2021, which gave explicit consent exemption for the purposes of retrospective chart reviews under certain conditions.
In conclusion, David said that the ethical principles of respect of autonomy are the major principle when considering a person's rights to control access to their personal data. The Law and Ethics is clear that this is their data, and a person has a right to determine who can access it and how it can be used.

"Citizens have a responsibility to their fellow citizens and if their data can be used to enhance the future healthcare of their fellow citizens then this should be permitted. However, (research should ensure) equal respect for the dignity of the people involved in that openness and transparency so people know what is going on."

David Smith, IPPOSI Citizens’ Jury, April 2021

Understanding Patient Data is based in the UK and aims to help inform people about how health data is used, understand their views, and ensure these are channeled into how the rules for data use are set up and managed.

Natalie went on to provide an overview of previous research carried out in the UK on people's view of health data in the UK. One example of such research was The One London dialogue on shared care records.

She summarised the things that mattered to people when asked about how their health care data can be used. These she said included: Public benefit driving use of data, equity of benefits (and risks), the importance of clear public communication and involvement, as well as transparency, accountability, and good governance.

In relation to consent, Natalie said that basing data use on consent would mean individuals would make a choice over every type or instance of the use of data from their records. Although people often prefer the idea of consent initially, they have had to weigh up: On one hand that it could be really empowering, you would have full control over data about you and could demand more information to inform your decisions each time. While on the other hand, consent puts a lot of burden on you as an individual, requires time and energy to learn about all the options, and many people wouldn't actively consent, so the health system wouldn't have representative data about the whole population. Finally, Natalie outlined the things that made people feel more positive or negative about the use of health data.

"People are very concerned to ensure that the benefits of using data and the risks attached to it are shared equitably right across the population."

Dr. Natalie Banner, IPPOSI Citizens’ Jury, April 2021
Jurors were highly engaged with the testimony and asked a number of questions of the witnesses. These questions and discussions in small groups after the testimony included the following topics:

Jurors felt that health information should be viewed as a national resource – access to which must be paid for and citizens must not pay twice - once by providing access to their health data and twice by paying for a new therapy developed as a result of that access to their data.

Jurors felt that society or the health service should benefit/reap financial rewards from any commercial success of treatments developed as a result of using patient data.

The idea was discussed that there needed to be a clear framework for what access to health data for commercial entities would entail, and there also needed to be a demonstrable benefit for patients for that access to take place.

There was also a need for agreements to be put in place between the state and any commercial entities that provides for the sharing of the benefits (and profits) of having access to patient data. The distinction was made between health service and commercial research and if they could be considered separately.

Concern was raised about the possibility of ethics clashing with commercial benefit.

There was strong agreement with the principle of solidarity – we have a duty as citizens to share our health information to help others for secondary use – but there is caution around public-private partnership for research – and there is the need for more safeguards to prevent potential breaches or problems.

Patients and the public should be involved in decisions around who can access health information. Communication should be open and transparent trust is paramount.

Currently the information provided in relation to consent processes is too long and too complex.

Jurors expressed concerns about the clash between commercial and ethical principles.
Jurors were of the view that there is trust in the medical profession but mistrust in commercial entities.

It was agreed that patients and the public should be involved in decisions around who can access health information. Communication should be open and transparent, and trust were seen as paramount.

**JUROR QUESTIONS:**

How can we reduce tensions between commercial and health service research?

Would the burden of consent be made easier if a patient body explained the level of risk to a patient/participant in a research study?

"Why can't they just put everything in plain language that you understand?"

"I firmly believe in sharing the data if it's for helping, for instance like in COVID when information was used, but if it's for profit for a drugs company, then I'm not overly keen on that."

"Have there ever been any leaks and has anybody ever been prosecuted for the leak...what were the penalties?"
For this session the citizen’s jury heard from one last expert witness before they entered deliberation.

Eamonn Costello, CEO at patientMpower

patientMpower is a private digital healthcare company that provides technology solutions such as remote patient monitoring for people living with long-term illnesses.

Eamonn spoke about how healthcare systems have responded to the global COVID-19 pandemic and said that included rolling out solutions like those provided by patientMpower (patientMpower provides home oxygen measurement and automated alerting to the healthcare provider).

Eamonn said this allowed the HSE to expand their capacity effectively providing a high level of care in people’s homes.

He explained that the system allowed acute hospitals that were managing patients at home to identify which patients needed to be brought back into the hospital. Often patients who were ill with COVID could be managed remotely because the hospital had access to the data to understand their current health status, he said.

Eamonn said that COVID has demonstrated that hospitals can manage patients in a different way, and that the HSE and other hospitals abroad had started to accelerate the remote home management of patients.

He explained that patientMpower deployed their remote home oxygen monitoring solution in the midst of a rapidly evolving COVID-19 situation and despite the urgency the company followed all the necessary data protection processes.

Moving on to discuss the use of patient data for research purposes, Eamonn explained that they had gathered patient consent for secondary or research purposes and this allowed clinicians to publish research papers that found that the patientMpower COVID solution was safe and effective.

"Patients who were severely ill with COVID, they (doctors) could manage them effectively at home because they had access to the data to understand their current health status."

Eamonn Costello, IPPOSI Citizens’ Jury, April 2021
Having heard testimony from all nine witnesses, the attention of the jury then turned to its deliberations, and the task of responding to two key questions.

As a first step in their deliberative process, during session 5, jurors were asked to agree what health information can be used for, and who might need access to it. Jurors were asked to consider questions of access in relation to five main stakeholder groups, and they were provided with five case studies detailing examples of how these different stakeholders might seek to use health information.

**Question 1A:**
Who should be able to access, share and use your health information (identifiable and non-identifiable) and for what purpose(s)?

- **Healthcare professionals in public or private settings** (hospitals, GP, community health, social care) seeking to access health information to support service improvement, change, innovation
- **Public servants in government departments and agencies** (e.g. HIQA, HPRA) seeking to access health information to support legislative, policy or practice change
- **Researchers (academic or clinical)** seeking to access health information to complete health research, with the appropriate ethics approval (publicly or commercially sponsored)
- **Professionals from private health companies, contracted by the public sector**, seeking to access health information to conduct health research or develop health innovation
- **Professionals from private health companies** seeking to access health information to conduct health research or develop health innovation (medicine, device, vaccine)
Jurors almost unanimously recognised improved healthcare, and more importantly, improved health outcomes as the upshot of greater health information sharing. It was broadly acknowledged that healthcare professionals, health service managers, and health researchers need access to health information to improve the care they deliver, the services they offer, and the health solutions they create.

In equal measure, jurors were in agreement that the greatest risk around health information sharing was the potential for the misuse of data, either as a consequence of inappropriate data sharing or of a data breach. The ethical practices of different health partners were also questioned, in particular, concerns were raised about researchers being influenced by the interests of funders and about companies manipulating information to suit their commercial interests.

When asked to vote whether they would provide healthcare professionals (outside those managing their direct care) with access to their health information, 24 jurors responded positively with only one juror declining to share their information. When asked about allowing public servants to view their information, the jury was more divided with 14 agreeing to provide access and 9 opting to withhold their information and two undecided.

The jury was again somewhat more aligned when it came to sharing information with researchers, and 18 voted to authorise access to their health information, 6 voted against and 1 had no opinion. In deciding about the contentious question of allowing health information to be shared with private health companies, 17 jurors believed that companies should be given access (regardless of whether they had been contracted by the state to perform a particular function) while 8 jurors stated that they would not be in favour of sharing information with companies under any circumstances.

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**FIRST JUROR VOTE ON ‘ACCESS’**

<table>
<thead>
<tr>
<th>Category</th>
<th>Yes</th>
<th>No</th>
<th>Undecided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare Professionals</td>
<td>24</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public Servants</td>
<td>9</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Researchers</td>
<td>14</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Private Companies, Contracted</td>
<td>17</td>
<td>8</td>
<td></td>
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<tr>
<td>Private Companies, General</td>
<td>17</td>
<td>8</td>
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Session 6: Wed. 28 April: Deliberative session and vote

Having reached a verdict on who should have access to health information and for what purposes in session 5, during the sixth and final session of the jury, focus centred on identifying what safeguards need to be in place to confidently and comfortably permit access to health information in the future.

Jurors were provided with a list of 11 potential safeguards and were asked to nominate the safeguards of most importance when considering access for each of the five stakeholders discussed in session 5. Jurors were invited to focus on the particular role played by citizens, or patients, in managing access to health information.

Question 1B:
Are there provisions, which would increase your trust and confidence in different stakeholders accessing, sharing, and using your health information?

These provisions were separated into three themes:

INFORMATION | INVOLVEMENT | REGULATION

Jurors John T Quinn, Kevin Molloy, and Barry Clohessy deliberating for the jury’s final verdict
INFORMATION

A. Being able to view what health information is available about you (i.e., see your own health data)
B. Being able to view who has accessed your health information
C. Being informed about how your health information is kept secure
D. Having more information about the benefits of sharing health information
E. Having more information about the potential future uses of sharing health information

INVolVEMENT

F. Being able to withdraw from/opt out of sharing your health information (once-off)
G. Being able to consent to/opt in to sharing your health information (once-off)
H. Being able to control who accesses your health information (ongoing)
I. Being able to request the destruction of your health information after use

REGULATION

J. Having more public and patient involvement where decisions are being made around who can use health information and why
K. Being confident that sanctions exist and will be applied where health information is misused
While the voting results from question 1A indicate that jurors are not completely averse to sharing their health information to contribute to health service improvement, policy development, research, and innovation, from the discussion during session 6 of the jury, it is also clear that jurors are keen to have a robust suite of safeguards in place.

**Second juror vote on access, this time with safeguards in place**

<table>
<thead>
<tr>
<th></th>
<th>Healthcare Professionals</th>
<th>Public Servants</th>
<th>Researchers</th>
<th>Private Companies, Contracted</th>
<th>Private Companies, General</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>25</td>
<td>19</td>
<td>24</td>
<td>19</td>
<td>20</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Undecided</td>
<td>1</td>
<td>1</td>
<td>1</td>
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</table>

Across the board, the universal request from all jurors was for the citizen to be able to control how their health information is accessed, shared and used. Many jurors started by requesting sight of their own health information, but as the discussion developed, it became clear that being able to view their information was not sufficient, they wanted to be involved in managing their information.

Along a similar vein, an appeal was repeatedly made for citizens to be involved in broader, strategic-level decision-making around health information management (i.e., outside their involvement in the management of their own information). There were specific calls for patient involvement in governance, oversight, and advisory mechanisms.

Another safeguard that came strongly to the forefront related to sharing more information about health information management with the public. Citizens want to know what information is held about them, they want to know how secure their information is, they want to know what it might be used for in the future.

The calls for sanctions to be applied when health information had been misused were heard loud and clear, as was the need for a mechanism to be established to allow for a person’s health information to be withdrawn or deleted from circulation.
When asked to vote again whether they would provide healthcare professionals (outside those managing their direct care) with access to their health information, with safeguards in place, all 25 jurors responded positively.

A marked improvement in the numbers willing to share their health information with public servants was observed, the number agreeing to provide access changing from 14 to 19, with only 5 still reluctant to share and 1 undecided.

A large shift was also seen in those opting to share their health information with researchers, with an additional 6 voters joining the original 18 consenting jurors, bringing the total number willing to share to 24 jurors with only 1 juror declining to grant access.

In determining whether companies contracted by the state should obtain health information, 19 jurors now demonstrated an interest in sharing health information, 3 declared themselves undecided with 3 opposed.

When considering the sharing of health information with companies more generally, 20 jurors consented, 1 moved to a position of uncertainty and four remained reluctant to share.
## VOTE RESULTS ON TOP BENEFITS, RISKS, SAFEGUARDS

### TOP BENEFITS OF SHARING HEALTH INFORMATION WITH:

<table>
<thead>
<tr>
<th>Healthcare professionals</th>
<th>Healthcare professionals have the evidence they need to improve healthcare and services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public servants</td>
<td>Better, free public healthcare which is evidence-based and information gathered based on current data</td>
</tr>
<tr>
<td>Researchers</td>
<td>Improved health outcomes through better/faster solutions to health problems, drug safety</td>
</tr>
<tr>
<td>Private companies contracted by public sector</td>
<td>Health service may be able to make service improvements based on data processed by company</td>
</tr>
<tr>
<td>Private companies</td>
<td>Improvements in patient treatment and outcomes and access to healthcare</td>
</tr>
</tbody>
</table>

### TOP RISKS OF SHARING HEALTH INFORMATION WITH:

<table>
<thead>
<tr>
<th>Healthcare professionals</th>
<th>Misuse of data outside its intended use could compromise privacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public servants</td>
<td>Inappropriate access or use of data</td>
</tr>
<tr>
<td>Researchers</td>
<td>Research findings may be influenced by research funder</td>
</tr>
<tr>
<td>Private companies contracted by public sector</td>
<td>Private companies are serving their own ends and manipulating rules and data to those ends</td>
</tr>
<tr>
<td>Private companies</td>
<td>Financial gain of the company over the patient outcomes or reciprocal patient gain</td>
</tr>
</tbody>
</table>

### TOP SAFEGUARD TO ALL SHARING OF HEALTH INFORMATION

Being able to control who has access to your health information on an ongoing basis
COMMON THEMES

When it comes to the question of who should be able to access health information for secondary purposes, a number of common themes emerged over the three-week process.

WE NEED A CONNECTED, QUALITY, DIGITAL HEALTH INFORMATION SYSTEM

All jurors agreed on the importance of health information and the many benefits of sharing that data can have for individual patient care and the overall health service. They also agreed that a connected health service could make the patient journey a lot easier.

It was clear from jurors’ comments and examples that it was easier for them to see the benefits of connected health information (at least initially) through the lens of individual care.

For the initial jury sessions, there was some confusion around the term ‘secondary health data’. This was evident from small group discussions and topics debated in the larger sessions where jury members discussed their own experiences of accessing and using their own health data for individual care needs i.e., primary use of health data.

While the final questions put to the jury for deliberation focused on the secondary use of health data, the consensus from jurors on the need for an electronic health record accessible to all those providing healthcare to patients is important to note. The general consensus was that the current system where patients had to “tell their story” each and every time they accessed healthcare was frustrating and time-consuming.

The point was made that currently, hospitals do not have a way of sharing information with one another, which is frustrating for patients who nowadays have an expectation of joined-up seamless health care.
The jurors agreed that there is a need for digital health infrastructure, including a single number to identify individuals so that there is interoperability across the health service. The point was also made that at times digital files can be as unwieldy as paper files. However, some jurors also expressed some doubt over Ireland’s ability to provide a truly patient-centred integrated healthcare system with connectivity between private and public hospitals in a safe manner.

Stories and Quotes

“The idea of it to me, in principle is good. To see how the actual implementation of it will be the hard part. That’s what I’m most interested in that, like they’ve implemented it with hip fractures and with strokes. And they’re building up just for how well they implement the whole thing across the entire HSE and hospital network that’s what’s worrying me, because they don’t normally do that very well.”

“If they were able to go in and bring up my files electronically and know this, it will tell them. Instead of me spending half an hour or an hour talking to a doctor, then talking to another doctor then explaining to consultant and explaining it to registrar. I could see the logic behind it”
Jurors also expressed frustration around the ability of patients to access their own health data.

Most jurors believed that as the owners of the health information, patients or individuals should have access to their own health information as a priority.

However, the point was also made that the idea that the patient is the primary owner of the data does not seem to be shared by all healthcare professionals.

It was agreed that the current process for accessing personal health information e.g., applications under the Freedom of Information Act was not fit for purpose and other alternatives should be pursued.

The GDPR legislation, which came into effect in Ireland in 2018, was discussed at numerous times by the Citizens’ Jury. While jurors were aware that they had the right to access their own personal information under GDPR and were thankful for the protection offered by this legislation, many also felt that at times, GDPR could be used as an excuse by healthcare organisations not to provide patients access to their own health information. Therefore, while the majority of jurors were aware of the many benefits of GDPR in relation to protecting their personal data, there was also acknowledgement that it could also act as a barrier for individuals seeking access to their own health data.

One of the points to come out of the small group discussions underlined the frustration felt by patients at not having easy access to their own health information. The group felt it was unfair that health professionals, maybe even those not directly involved in the treatment of a patient can access that patient’s health information but the patient themselves, family members and carers may not have the same ease of access.

Without sight of their own health information – and by extension a greater understanding of the health information that is collected about them – it was hard for jurors to make a determination around how others might use their health data. Several jurors pointed to the general public lack of awareness around access to health information while also pointing to the perception of a common interest in and recognition of the value of health information among the public. There would be value in raising awareness of these issues among the general public.
We are being told that we have the right to access our health data but why then is the process of accessing it so difficult?

They assume that you as the patient know nothing and they know everything because they have got the information.

“I picked up my husband’s medical chart and started reading it to him and was given out to by a nurse.”

“We are being told that we have the right to access our health data but why then is the process of accessing it so difficult?”

One juror said they saw information on their file that they had never seen before but wasn’t allowed to photograph it.
There was general consensus among jurors that the principle of solidarity required members to think about and come to an agreement on how health information can be accessed, shared and used for the benefit of others and for society as a whole.

The majority of jurors agreed that as citizens they had a duty to allow certain groups to access their secondary health data in circumstances where access to this data would help others i.e. for research leading to improved treatments or clinical audits that would enhance patient care.

Therefore, the jury was in agreement that the sharing of healthcare data for the improvement of patient care either for themselves or others was the right thing to do.

The group also felt that the sharing of health data for the betterment of society needed to be equitable so all sections of society can benefit.

However, they also agreed that strict conditions had to be in place before this could be allowed and that the patient had to be central to the process.

In its deliberations, one group of jurors agreed that there already is a sufficiently robust system in place to protect personal data (GDPR, etc.) and there could be a danger that a preoccupation with enhancing this or introducing any further laws may get in the way of the overall process of sharing useful patient data. The group felt that personal health data within the provisions, which currently existed, could be shared, and put to good use.

Jurors agreed that patients and the public should be involved in decisions around who can access health information, that communication should be open and transparent, and trust was paramount.

The point was made that if people understood the greater benefits of sharing health data, then they may be more likely to give their consent.

A number of jurors felt that other countries already had successful processes in place around the sharing of health data and Ireland could learn from these and adapt and tailor these practices in an appropriate manner for the Irish system.
"I would understand that what I am doing is for my own good and for the greater good also."

“There is an overwhelming benefit to society to have good quality data for research purposes. And of course, that means that the more data you have, the better."

“I do believe there’s an obligation that our data should be for the benefit of our citizens.”
A recurring theme throughout the citizens’ jury was one of trust and the sense that historical failings in health policy have created significant public distrust.

**Post-jury survey: How much trust do you have that your health information will only be used, as authorised, when shared with:**

- **Healthcare Professionals**
  - Completely Trust: 44%
  - Somewhat Trust: 56%

- **Public Servants**
  - Completely Trust: 11%
  - Somewhat Trust: 67%
  - Don’t Trust: 22%

- **Researchers**
  - Completely Trust: 33%
  - Somewhat Trust: 67%

- **Private Companies, Contracted**
  - Completely Trust: 5%
  - Somewhat Trust: 50%
  - Don’t Trust: 28%
  - Don’t Know: 17%

- **Private Companies, General**
  - Completely Trust: 56%
  - Somewhat Trust: 33%
  - Don’t Trust: 11%
  - Don’t Know: 11%

Personal health data is incredibly sensitive and while allowing healthcare professionals, medical researchers, and scientists access to personal healthcare data for the benefit of individuals and society at large was seen as the right thing to do, jurors also expressed concern as to whether all those that may have access to their data could be trusted.

Jurors pointed to recent examples such as the Cervical Check controversy as an example of where trust had been badly broken and raised the question of whether state bodies can be trusted with personal health data.
Conversely despite the general feeling of mistrust of government bodies, there was also a call for a state-appointed independent body to be charged with the protection of health information.

Therefore, while jurors agreed that the state had a duty of care to protect an individual's personal health information there was also concern that the state may not be up to the task.

Jurors were also concerned about allowing commercial organisations such as banks and health insurance companies access to their personal health information. Overall while jurors were happy to provide access to their health data to healthcare providers or researchers they were not as comfortable sharing this information with commercial entities although their comfort levels increased when appropriate safeguards were in place.

**Pre- and post-jury surveys:**

*To what extent do you believe that health information is safe?*

- **Pre-jury**
  - Not at all: 6%
  - A lot: 35%
  - A little: 24%
  - A moderate amount: 35%
The sense from jurors was that people were mistrusting statutory agencies due to historical failings and this was a challenge to the sharing of health data in general.

To rebuild this trust, the jury stated that patients needed reassurance that any process where their personal data may be accessed needed to be transparent and patient-centred.

Concern was also expressed around the ability of the Department of Health and the HSE to store data and keep records safe, and jurors stated that there needed to be punitive consequences for those found to be mishandling data.

The point was made that patients needed to know how their information would be stored and who would have access to it. There were calls for a system that would allow for data auditing which would allow patients to see every person who has accessed an individual’s health information and the reasons for that access and what the data was used for.

Concern was also expressed around the possibility of data being shared or sold to private companies such as insurance companies or research companies. What protections do people have when their health data may be used against them e.g., denied a mortgage due to health conditions?

Jurors called for complete transparency around breaches of health information, and around how their health information would be collected, stored, shared, and accessed.

There were calls for strong robust controls over access to sensitive patient information and the need for strong repercussions if a leak or data breach occurred.
Jurors also said there was a need for all those accessing their health data to be held accountable for any mismanagement of that information including assurances/evidence of sanctions being applied when there is evidence of mismanagement or breaches. The question was raised as to the ethics and training needed for healthcare professionals and all those who access personal healthcare data to ensure that the patient rights are protected. This would be particularly important if there was a conflict of interest e.g. if organisations/hospitals were given monetary rewards for participating in research would that be a conflict of interest?

In relation to the role of research ethics committees, some jurors questioned how they are held to account, and if ethics committees monitored or had oversight over whether or not the health information is used in the manner in which it was approved.

There was a general sense from jurors that it was people rather than technology that were the problem. If a data leak occurs this was usually due to human actions or inactions rather than technology.

Stories and Quotes

“I don’t mind giving information if its medical information, but I would be very concerned if it was going to come back and bite me in a court of law.”

“Trust has to be built up again.”

“The trust issue is always and ever present in my mind. You have to think about it in the context of Ireland. Not just it’s not just this abstract concept. It’s in Ireland and what is our typical history with these things.”

“I think actually that ethics should be written into the law.”
WE NEED TO PARTNER WITH CITIZENS TO DESIGN OUR HEALTH INFORMATION FUTURE

A central theme running through the IPPOSI citizens’ jury was the importance of public and patient involvement in the decisions around who or what institutions could access their health information and what data they should have access to.

There was also support for models that would allow individuals to control/manage access to their own health information directly.

Jurors agreed that innovations such as a patient portal or health passport where individuals could access and, more importantly, control who accesses their health data would be helpful in empowering patients in this regard.

There was overall support for providing different levels of access to health information. Jurors welcomed the option of having particularly sensitive information (mental/sexual health details) put away in a “locked box” within the patient file or portal.

Post-jury survey:
If your health information is accessed by others, do you believe the State should:

- Yes: 94%
- No: 89%
This would be information that would be kept completely confidential except in the case of a medical emergency and would never be shared with any outside agency or body for secondary use.

The point was made that a patient is not “just data”. In the debate over access to health information and its use and storage, the patient’s identity should not be lost. At times some jurors felt that patients were just seen as data to be processed and this was not right.

Overall jurors agreed on the importance of patient involvement in all of the processes involved in collecting, accessing, using and sharing their health information.

They agreed that citizens should be involved in all aspects of decision making around access to health information including the technology solutions pursued, the ethical decisions reached and the access granted.

They also agreed that communication must be open and transparent, and that trust was paramount.

**Stories and Quotes**

“I don’t want to see who has access to my data. I want to decide who I give access to my data.”

“It’s ours, not theirs.”
Jurors felt that health information was a national resource, a resource which needs to be remunerated if it is to be shared and that the benefits from this remuneration must accrue directly to the citizen and to the health system – citizens should not ‘pay twice’ by providing their health information for free and then by having to pay for the product developed on the back of that health information.

Therefore, the suggestion was made that patients should collectively benefit from any profit/new treatments that arose as a result of sharing their information.

In its deliberations, one group felt that there needed to be a clear framework for what access to health data for commercial entities would entail and there needed to be a demonstrable benefit for patients for that access to take place. There needed to be agreements in place between the state and the commercial entities that provide for the sharing of the benefits (and profits) of having access to patient data. The distinction was made between health service and commercial research and if they could be considered separately.

Jurors understood once explained that due to the nature of clinical research in the development of a new treatment there might not be any guarantee of success. The suggestion was made that perhaps a condition could be inserted into contracts that if an entity were successful in developing treatments, then these benefits would be shared with patients/the health service.

One group suggested the creation of a patient co-operative or patient representative body that would have a role in advising and informing patients and possibly acting as a broker between healthcare professionals and patients in relation to the access of health information.

The overall view of jurors was that society or the health service should benefit/reap financial rewards from any commercial success of treatments developed as a result of using patient data.
But I think it is unethical for, you know, massive pharmaceutical companies or insurance companies to take our data and use that to generate more profit for them, which actually might, you know, hinder some services for people. So, I would like to see you know, a possibility of there being further, like social benefit from third party commercial sources."

"I would also want to see a direct benefit to patients for commercial use of their data...I think there's, you know, a huge amount of profit that is derived from patient data"

"If we're going to be sharing our data with private research companies, then I would expect a very big payback to the Irish government and then, in terms of our plan to taxpayers."

Stories and Quotes
WE HAVE TO MAKE CONSENT THE CORNERSTONE OF EVERYTHING WE DO

A number of expert witnesses to the citizens’ jury discussed the issue of consent and how it was collected to allow for the secondary use of health data under current legislation.

Overall the jury agreed on the need for a strong consent model, with provision for regular, layered, informed and dynamic consent when asked to share their health information.

Some jurors felt there was little confidence that people will be asked to consent for their health information to be used, or that the processes involved will be explained to them.

The jury agreed that in order for the public to be in a position to agree to informed consent the language used to explain processes to them needed to be user friendly and not overly complex and mindful of the different levels of health/digital literacy among the general population.

Jurors expressed concerns around how people who were not digitally literate could be supported in a world of dynamic consent and that supports needed to be in place so that people with poor literacy skills could understand complex consent processes.

Several jurors mentioned the issue of health equity and that any model that sought to access health information needed to ensure that it collated information from all sections of society to allow for health equity analysis.

It was agreed that the easier it was made for patients to understand the process of consent with the use of clear and concise language and the more practical the process could be made for the patient, the better. In its deliberations, one group pointed out that if people understood the benefits of sharing data, they might be more willing to give their consent for their data to be used.

Jurors agreed that currently, the information provided in relation to consent was too long and complex.

The suggestion was made that perhaps donor cards or a registry could help with gaining consent and with this register it would be possible for consent to be considered ongoing, once updated occasionally with a provision to opt-out on ethical or moral grounds.
I think when giving consent. There has to be clarity about what you’re consenting to ...

Consent has to be easy to understand. Easy to give and easy to remove. Honestly, I think sometimes people give consent without really understanding what gets it into.

I don’t ever remember being asked to sign anything that would allow my data to be shared” (that would help myself or others.)

“I think when giving consent. There has to be clarity about what you’re consenting to ...”
Our main motivation for hosting a Citizens’ Jury in 2021 was to start a conversation (outside of our immediate patient community) about access to health information – the benefits, the risks, the safeguards. Little did we realise that the timing of our jury would be book-ended by two important national news stories: in March 2021 a whistle-blower made allegations against the Department of Health concerning the use of medical records to prepare dossiers on children with autism with dormant legal actions against the state, and in May 2021 an attack by cybercriminals on the health service threatened to publish the personal data of thousands of patients on the internet.

Whereas such incidents will not be the last of their kind, they serve as timely reminders of why this discussion is so important. What data is collected, how it is secured, who can access it, and why, are questions that need to be asked in light of the ongoing digitalisation of all aspects of our lives, including our health. If people are to be asked to share increasing amounts of personal information, then it is only right that the answers to these questions are arrived at democratically, through a national conversation of the evidence and its implications.

Reflected in the outcomes of the jury process are a willingness, an ability, and an expectation among citizens that public involvement in navigating the digitalisation of health be prioritised. We at IPPOSI conclude, that the sooner this consultative approach is adopted, the better. Left unaddressed, the potential for growing frustration and misinformation is huge.

Pre-jury surveys of jurors reveal that only 30% of respondents believe their health information is currently very safe. Only 11% completely trust public servants to use it for the purposes for which it is intended. 24% think researchers and 33% think industry are already granted a lot of access to health information.

At a 2015 IPPOSI event, a patient member made an impassioned plea to the Secretary General of the Dept. of Health on the topic of health information.

Describing progress in legislation and infrastructure as “groundhog day”, he called for action, and most importantly, for citizen involvement.

“You (health officials) are looking at the macro picture, and you have to, but out there are all these microchips (patients): we make the picture”.

These words have stayed with us and were the inspiration for this Jury.
Despite this open and welcoming environment and despite having six evenings of discussions, it actually felt like we only started to scratch the surface.

“I learned more from talking with the groups than I would have done looking up the information on my own.”

“There should be more juries to get our citizens more involved in issues that matter to all our lives.”

“The whole experience was very positive and afforded members of the public to have their say into the formation of public policy.”

“A fantastic experience and I hope to see many more citizens juries as it gives us a voice.”

Indeed, jurors took a unanimous view on involvement around access to health information. During deliberations, for each of the five categories of stakeholders (healthcare professionals, public servants, researchers, companies contracted by the State, and companies in general), ‘being able to control who accesses your health information’ was agreed as the most desirable safeguard (although over a dozen other options were presented and discussed). This position was supported by those individuals completing pre- and post-jury surveys, with 100% of respondents calling on the State to design an opt-in or opt-out system that allows individual citizens to choose whether or not to share health information.

The key finding from the Citizens’ Jury is that we need to have more conversations, more consultations, more citizen engagement. Jurors approached the process with wonderful enthusiasm, and on many occasions, surprised us with their pre-existing understanding of, and/or interest in, high-level health information issues.

Despite this open and welcoming environment and despite having six evenings of discussions, it actually felt like we only started to scratch the surface.

We could have hosted a dedicated citizens’ jury around any one of several topics emerging from deliberations: who actually owns health information?; what does citizen control over information look like?; how can we meaningfully invite citizens to consent to the use of their information; what about genetic/genomic health information? There is a demonstrable public appetite to explore health information issues and there appears to be a consensus that now (especially given recent global, European, and national developments) is an opportune time to prioritise this.
Within IPPOSI we fully support the findings of the Citizens’ Jury. As a platform, we believe that if timely and considered action around how we manage our health information is not taken, our ability to respond to the next crisis will be limited, our promise to keep pace with our counterparts in the EU will be undermined, and our duty to provide quality health care to our citizens will be compromised.

Observing the Citizens’ Jury process in its entirety has been a thought-provoking experience and one which will inform and improve IPPOSI initiatives going forward. We thank all jurors for taking the time to share their perspectives. We fully support their experience, and we believe that many of the individuals involved will become their own advocates, make their voices heard, and take ownership of their own health information futures. We would fully support similar initiatives (from both government and civil society partners) to advance citizen participation around these key (but complex) issues, and we plan to use the findings from this experience to refine the IPPOSI approach for public and patient involvement activities in the future.

“It solidified my belief that the vast majority of people who would be involved in utilizing my data would be doing it to advance healthcare within ethical standards and individual safeguards are respected.”

“I became more open towards the idea of my health data being used for secondary purposes. This is because I was able to hear a balanced presentation from the speakers concerning the benefits and risks involved, and also because there is the promise of safeguards being put in place that will provide a high level of security for the data.”
ANNEX 1 - THE JURY PROFILE

Following a nationwide recruitment campaign in January 2021, over 1,000 applications were received by IPPOSI from members of the public.

A random selection process was completed by an independent team of academics (Trinity College Dublin) to identify 25 jurors (and five reserve jurors). The selection was based on a Central Statistics Office (CSO)-based priority criteria (gender, age, location, ethnicity, education) agreed upon by the Citizens’ Jury Oversight Panel and designed to ensure that the jury would reflect a cross-section of the wider population of Ireland.

Randomly selected jurors were invited by IPPOSI to consent to join the jury. They were made aware of the commitment involved and the different stages of the process. Click here to view an infographic designed by IPPOSI.

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ANNEX I - THE JURY PROFILE

Our recruitment and selection process sought to ensure the diversity of voices on the final jury.

We share our brief analysis of how individual jurors voted during the IPPOSI Citizens' Jury.

**MALE JURORS WERE MARGINALLY MORE CONFIDENT PROVIDING ACCESS TO THEIR HEALTH INFORMATION THAN FEMALE JURORS.**

**FEMALE JURORS WERE LESS TRUSTING OF SHARING THEIR HEALTH INFORMATION WITH PRIVATE COMPANIES, WITH ONLY 71% VOTING IN FAVOUR COMPARED TO 100% OF MALE JURORS.**

**THERE WERE NO DEMONSTRABLE DIFFERENCES IN VOTING PATTERNS BASED ON LOCATION. JURORS IN THE DUBLIN AREA EXPRESSED A RANGE OF VIEWS ON HEALTH INFORMATION.**

**YOUNG JURORS (18-29 YEARS OLD) WERE THE MOST COMFORTABLE SHARING THEIR HEALTH INFORMATION, WITH ALL VOTING TO SHARE WITH ALL STAKEHOLDERS, INCLUDING PRIVATE HEALTH COMPANIES.**

**MIDDLE-AGED JURORS (45-59 YEARS OLD) WERE VERY UNSURE ABOUT SHARING THEIR HEALTH INFORMATION WITH PUBLIC SERVANTS, WITH ONLY 43% VOTING IN FAVOUR COMPARED TO 100% OF 18-29, 75% OF 30-44, & 80% OF 60+.**

**JURORS IDENTIFYING AS GAY AND LESBIAN, VOTED IN FAVOUR OF SHARING THEIR HEALTH INFORMATION WITH ALL STAKEHOLDERS.**

**JURORS FROM NON-IRISH COMMUNITIES WERE LARGELY IN FAVOUR OF SHARING THEIR HEALTH INFORMATION, VOTED MORE FAVOURABLY THAN THEIR IRISH COUNTERPARTS FOR EACH STAKEHOLDER.**

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More focused research into how special interest groups feel about sharing access to their health information would be needed to confirm these jury observations.
The IPPOSI Citizens’ Jury formally concluded its deliberations on 28 April 2021. Just over two weeks later, on 14 May, the Irish health system was the target of a cyberattack. Given the focus of our jury, we wanted to know what (if any) impact this event had on our jurors and their perspectives on health information access.

We waited to approach our jurors until the full details of the attack were known, and until much of the media attention had subsided. On 11 August, we sent a survey to 22 of our 25 jurors (three were unresponsive to previous requests to consent to remain in contact with the project). Over the next two weeks, 19 of the 22 jurors got in touch to share their views.

**Question 1:**
To what extent has the recent cyber-attack on the Irish health system changed your opinions around providing access to health information for secondary purposes (service improvement, policy development, research and innovation)?

Over 50% of jurors responding indicated that the cyber-attack had not changed (37%) their opinions around health information access issues, or had only changed their opinion a little bit (21%). Just 16% suggested that the cyber-attack had changed their opinion a lot (11%) or a great deal (5%). Approximately one-quarter of jurors (26%) believed their opinions on health information access had been moderately affected by the cyber-attack.
Question 2:
In your opinion, what is the appropriate response to future cyber-attacks on the Irish health system?

Almost 60% of jurors (58%) suggested that increased funding for cyber-security be the appropriate response to the cyberattack. Further 26% proposed improving cybersecurity awareness through education and training, and a final 16% called for the development and testing of cyberattack response plans. Not one juror recommended that all digital health projects be halted and a return to a paper-based system be implemented.
When invited to build upon their responses, several jurors voiced the belief that “if it's going to happen, it's going to happen”, as “these attacks happen from time to time in other areas of our society” with most acknowledging that “nothing is unhackable”.

One juror stated “the cyber-attack did not surprise me at all - even with regulation, information and involvement (safeguards), sensitive information is always at risk of being leaked”, adding that “this should not stop progress in this whole area”. Another summarised “The solicitor put it well when it came to data leaks. In order for a better health system, we must provide data and be aware of the fact that all data will eventually leak”. One juror appeared to buck against this trend suggesting that “if a secure system was in place with appropriate safeguards and training for all those using it, an attack like this wouldn’t happen”.

The sense of inevitability expressed by many was also accompanied by repeated calls from jurors for “a more robust and secured system to protect the health data of residents” and for the HSE to “install better safeguards”. One juror put it plainly “I am very concerned that the HSE won’t invest in adequate and future-thinking cybersecurity”, another described the cyberattack as “my personal nightmare, that my health history could be publicised and known by random strangers or friends, colleagues, or family members”.

Interestingly, some jurors suggested that building a system where individuals control and manage their health information might mitigate future cyberattacks, “The key to (managing) detailed data is the patient. I control my data, this also protects the HSE”. Others elaborated further “separate patient information from health information and only match it in a secure way – preferably with the involvement of the patient or the carer”.

The jurors displayed a range of reactions to the cyberattack, but these reactions do not seem to have significantly impacted their views on health information access. Our experience of the jury, and our discussions with jurors, all indicate that health information is deeply personal. We need a national conversation around how we – as a society – plan to use the health information of individuals to inform our health future. We hope the IPPOSI Citizens’ Jury makes some small contribution to this discussion.
TO DOWNLOAD IPPOSI’S ANALYSIS ON THE FULL JURY PROCESS AS WELL AS ALL OTHER JURY OUTPUTS, VISIT

WWW.BIT.LY/IPPOSICITIZENSJURY

THIS CITIZENS’ JURY WAS SUPPORTED BY IPPOSI RESOURCES IN ADDITION TO A NUMBER OF UNRESTRICTED GRANTS FROM THE FOLLOWING IPPOSI MEMBERS:

ABBVIE, ALEXION, BIOMARIN, GSK, PFIZER
AND THE TRINITY COLLEGE DUBLIN HRB-IRC-PPI IGNITE PROJECT

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