

CITIZENS' JURY ON ACCESS TO HEALTH INFORMATION

The IPPOSI Citizens' Jury on Access to Health Information published its verdict in September 2021, setting out six recommendations for policy-makers and expressing a strong preference for greater access to health information in Ireland.

After more than 12 hours of online deliberations, the 25 jurors concluded that citizens must be the owners of their own health data and that practices, processes, and policies developed to manage or share health information must be made in partnership with them. The jurors also underlined that health information must not only be easily accessible to every citizen who wants to view their information, but that citizens must also be able to actively manage and consent to the use of their information on an ongoing basis.

The jurors expressed a lack of trust in the State because of its past failings in relation to the collection and use of health information. They also discussed the potential for data breaches and they called for robust cybersecurity solutions, safeguards to protect health information, and a zero-tolerance approach to the misuse of health data.

The jury presents their recommendations and they invite health policy-makers and decision-makers to continue the national conversation on the future of Ireland's health information infrastructure.

”

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

- Juror, IPPOSI Citizens' Jury, April 2021

Citizens must be the owners of their own health data and that practices, processes, and policies developed to manage or share health information must be made in partnership with them.

THE JURY MISSION

The IPPOSI Citizens' Jury on Access to Health Information was tasked with responding to two questions:

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

- A** **Healthcare professionals in public or private settings** (hospitals, GP, community health, social care) seeking to access health information to support service improvement, change, innovation
- B** **Public servants in government departments and agencies** (e.g. HIQA, HPRA) seeking to access health information to support legislative, policy or practice change
- C** **Researchers (academic or clinical)** seeking to access health information to complete health research, with the appropriate ethics approval (publicly or commercially sponsored)
- D** **Professionals from private health companies, contracted by the public sector**, seeking to access health information to conduct health research or develop health innovation
- E** **Professionals from private health companies** seeking to access health information to conduct health research or develop health innovation (medicine, device, vaccine)

2 Are there provisions which would increase your trust and confidence in different stakeholders accessing, sharing and using your health 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

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

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

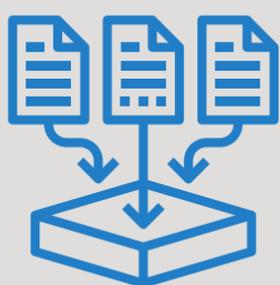
INFORMATION

INVOLVEMENT

REGULATION

COMMON THEMES

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



**WE NEED A CONNECTED,
QUALITY DIGITAL HEALTH
INFORMATION SYSTEM**

**WE NEED CITIZENS TO BE THE
OWNERS OF THEIR OWN
INFORMATION**



**WE HAVE A COLLECTIVE
RESPONSIBILITY TO DO THE
RIGHT THING**

**WE NEED TO BE SUPPORTED
TO GROW TRUST AND
CONFIDENCE IN THE STATE**



**WE NEED INDEPENDENT
OVERSIGHT OF OUR HEALTH
INFORMATION**

**WE NEED
ACCOUNTABILITY**

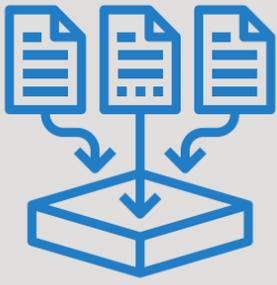


**WE NEED TO PARTNER WITH
CITIZENS TO DESIGN OUR
HEALTH INFORMATION FUTURE**

**WE NEED TO TREAT DATA AS
A NATIONAL RESOURCE**



**WE NEED CONSENT TO BE
THE CORNERSTONE OF
EVERYTHING WE DO**



WE NEED A CONNECTED, QUALITY DIGITAL HEALTH INFORMATION SYSTEM

RECOMMENDATION #1:

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 (closed 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 sharing 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

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

”

Having suffered from the lack of linked up records before and having remembered the neighbour of mine who was a diabetic and he collapsed, and his family would be shouting at the ambulance man 'make sure they bring him to Beaumont' because that's where his records were. For me, it was a no-brainer that the record should be available across the service.

- Juror, IPPOSI Citizens' Jury, April 2021



WE NEED INDEPENDENT OVERSIGHT OF OUR HEALTH INFORMATION

WE NEED TO PARTNER WITH CITIZENS TO DESIGN OUR HEALTH INFORMATION FUTURE



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.



**WE NEED CITIZENS TO BE
THE OWNERS OF THEIR
OWN INFORMATION**

**WE NEED CONSENT TO BE
THE CORNERSTONE OF
EVERYTHING WE DO**



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

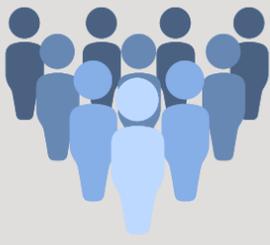
- Health information should not be shared on the basis of consent obtained via a 'once-in-a-lifetime' occurrence; individuals must have control over access to their own health information on an ongoing basis. Provision must be made for the withdrawal of consent and the deletion of data.

”

I saw information in my file that I had never seen before, but I wasn't allowed to photograph it for my own knowledge.

- Juror, IPPOSI Citizens' Jury,
April 2021

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?



**WE HAVE A COLLECTIVE
RESPONSIBILITY TO DO THE
RIGHT THING**

**WE NEED TO TREAT DATA
AS A NATIONAL RESOURCE**



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.

”

I do believe there's an obligation that our data should be (used) for the benefit of our citizens.

- Juror, IPPOSI Citizens' Jury,
April 2021

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.



WE NEED ACCOUNTABILITY

WE NEED TO BE SUPPORTED TO GROW TRUST AND CONFIDENCE IN THE STATE



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.

”

Trust has to be built up again.

- Juror, IPPOSI Citizens' Jury,
April 2021

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.

THE JURY PROCESS

1000⁺ APPLICANTS

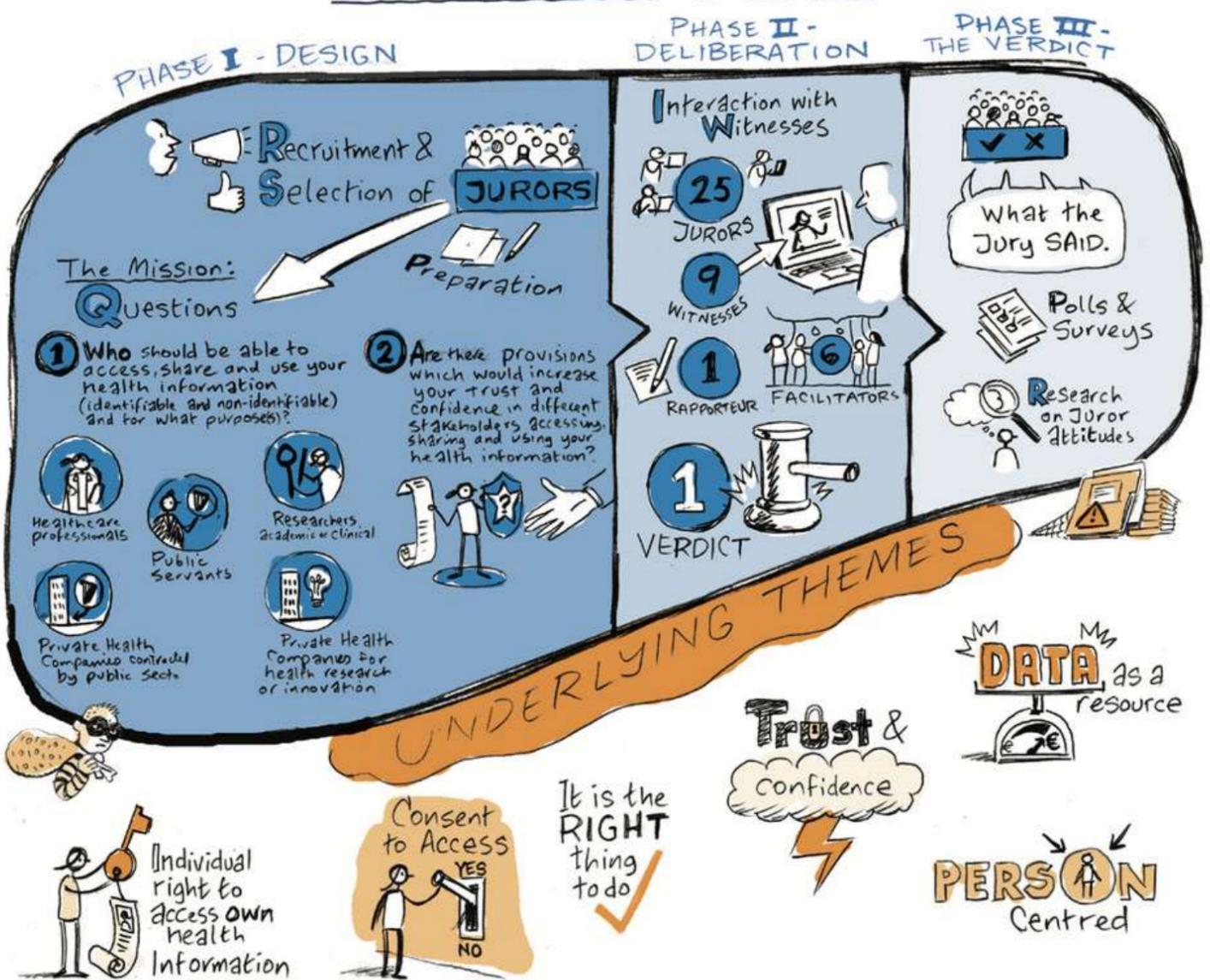
25 JURORS

6 ONLINE SESSIONS

3 WEEKS OF DELIBERATIONS

1 VERDICT

CITIZENS JURY - PROCESS



Cartoon created by Philip Barrett

”

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

- Juror, IPPOSI Citizens' Jury, April 2021

88%

of post-jury survey respondents would recommend getting involved in a jury to their friends or family

THE JURY PROFILE

Following the launch of 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.

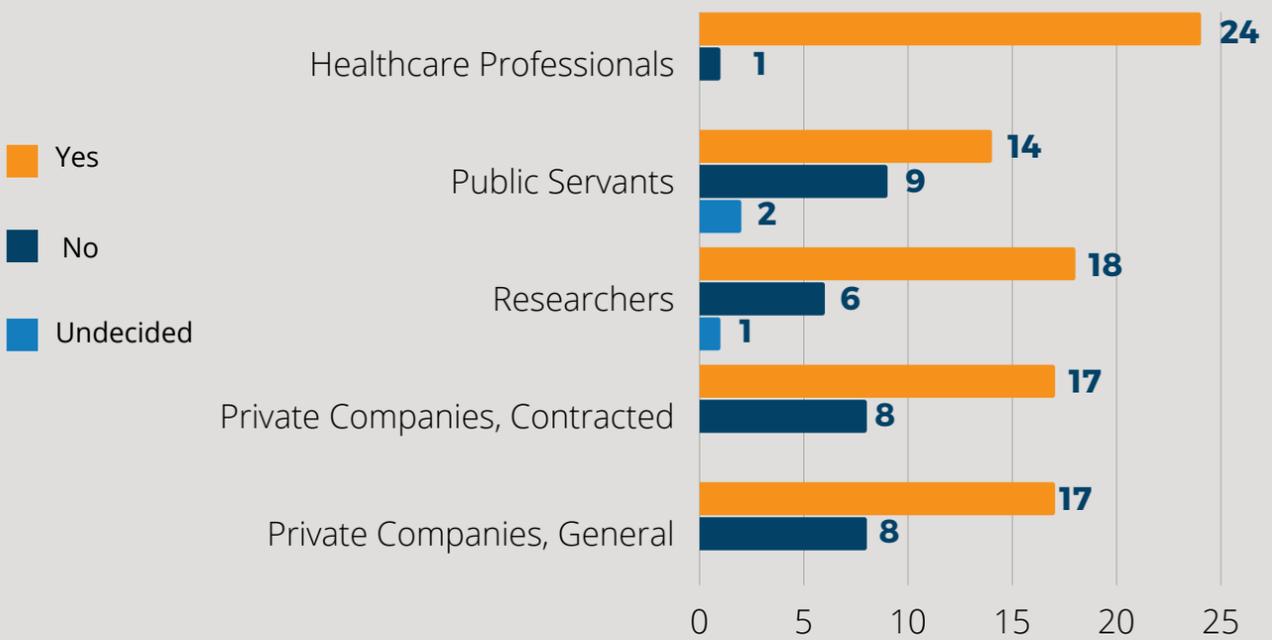
GENDER	MALE	11
	FEMALE	14
AGE	18-29	5
	30-44	8
	45-59	7
	60+	5
LOCATION	LEINSTER	12
	MUNSTER	6
	ULSTER	3
	CONNACHT	4
ETHNICITY	WHITE	24
	NON-WHITE	1
EDUCATION	PRIMARY	2
	JUNIOR CERT	3
	LEAVING CERT	9
	THIRD-LEVEL	11
TOTAL		25

THE WITNESSES

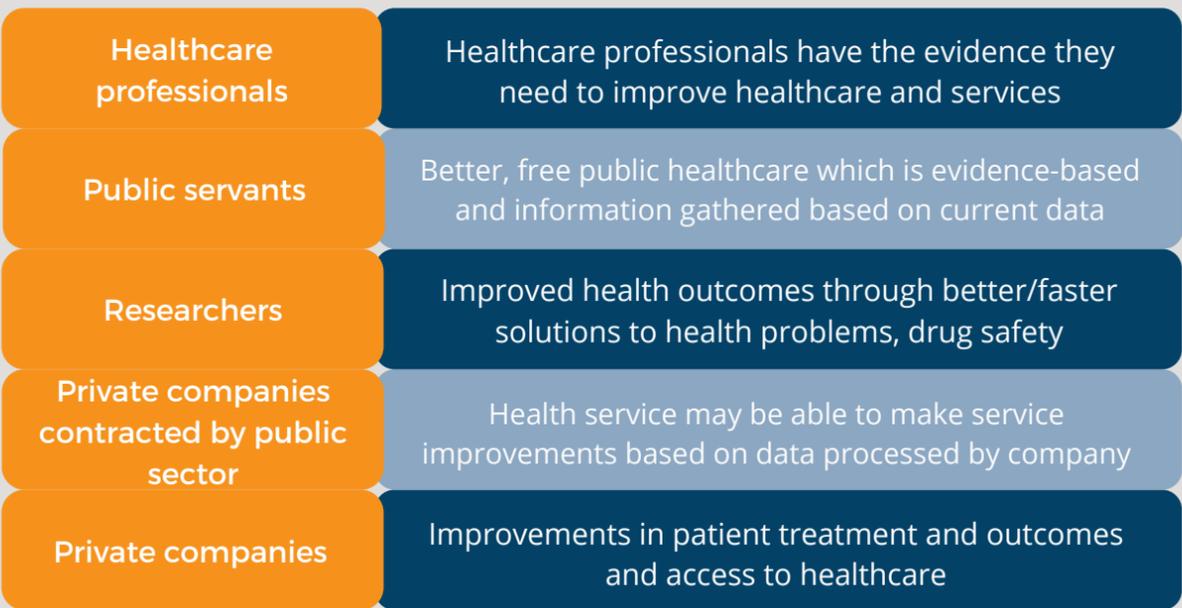
Session 1	<p>Prof Neil O'Hare Chief Information Officer at Children's Health Ireland</p>	<p>"You can build in (to digital solutions) who can see your data, and you can control that, and that's how it should be, and who has seen that data can be logged, and we can give you access to see who has looked at your data – because it is YOUR data!"</p>
	<p>Cathy Duggan Programme Lead at the Health Information & Quality Authority (HIQA)</p>	<p>"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."</p>
Session 2	<p>Louise Brent Audit Manager with the National Office of Clinical Audit (NOCA)</p>	<p>"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-compliant – everything we do is with keeping patient data safe."</p>
	<p>Dr. Dmitri Wall Consultant Dermatologist at Hair Restoration Blackrock, and Assistant Clinical Professor at University College Dublin</p>	<p>"Health 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."</p>
Session 3	<p>Simon McGarr & Olga Cronin Irish Council for Civil Liberties</p>	<p>"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 deidentified data or pseudonymized data...it's still personal data."</p>
	<p>Richard Corbridge Chief Information Officer at Boots UK & Ireland; and former CIO at the HSE</p>	<p>"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."</p>
Session 4	<p>Prof David Smith Associate Professor of Healthcare Ethics at the Royal College of Surgeons in Ireland (RCSI)</p>	<p>"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. "</p>
	<p>Dr. Natalie Banner Understanding Patient Data at the Wellcome Trust, UK</p>	<p>"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."</p>
Session 5	<p>Eamonn Costello CEO at patientMpower</p>	<p>"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."</p>

THE VOTES

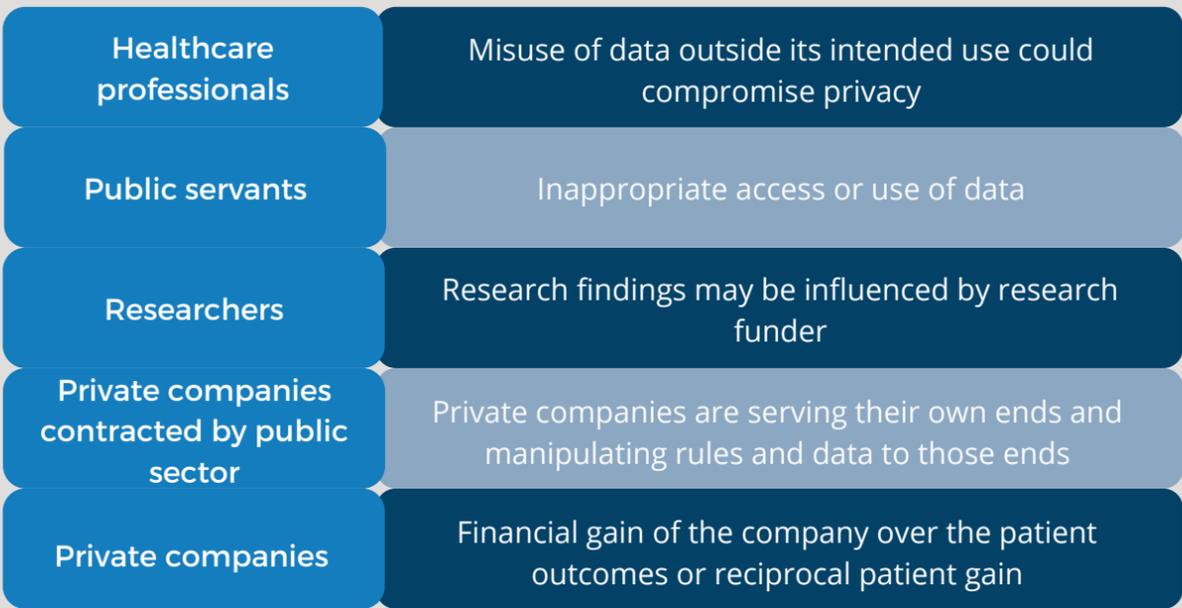
FIRST JUROR VOTE ON 'ACCESS'



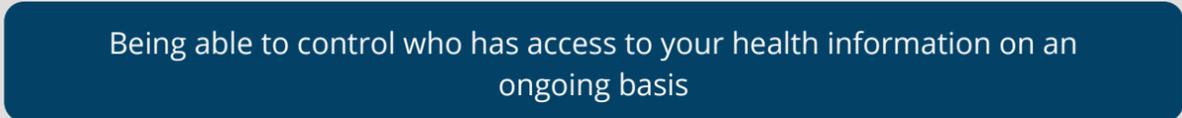
VOTE ON TOP BENEFITS OF SHARING HEALTH INFORMATION WITH:



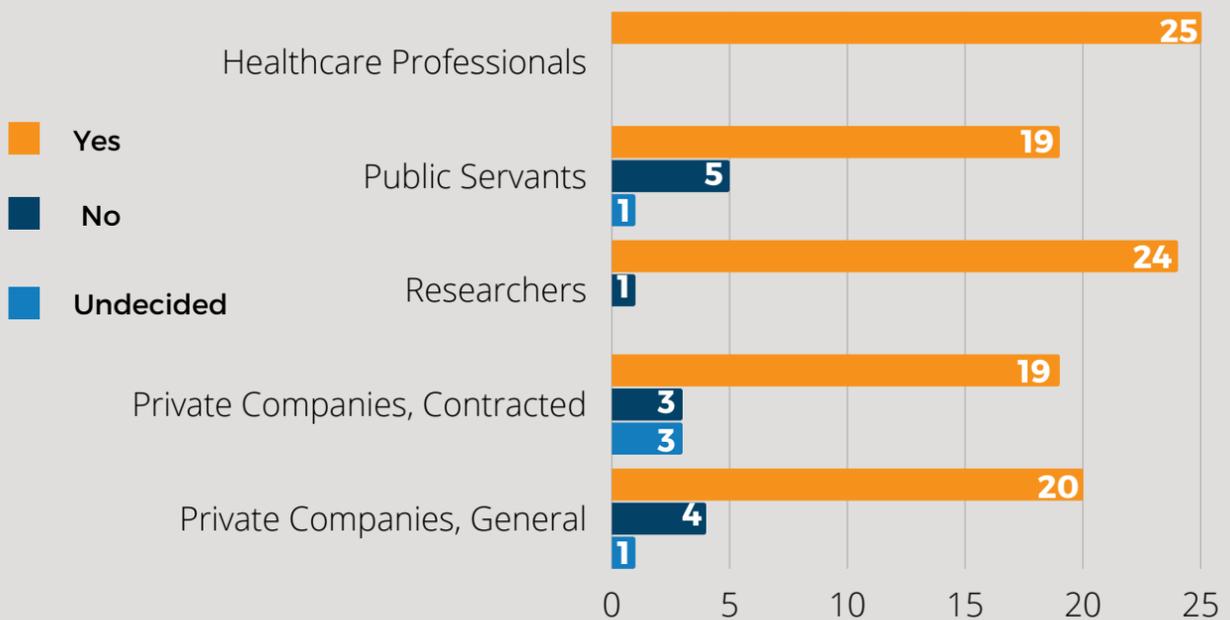
VOTE ON TOP RISKS OF SHARING HEALTH INFORMATION WITH:



VOTE ON TOP SAFEGUARD FOR SHARING HEALTH INFORMATION



SECOND JUROR VOTE ON ACCESS, THIS TIME WITH SAFEGUARDS IN PLACE



To read the full report, visit www.bit.ly/ipposicizensjury

THE VOTES

While the voting results from question 1A in the jury mission 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.

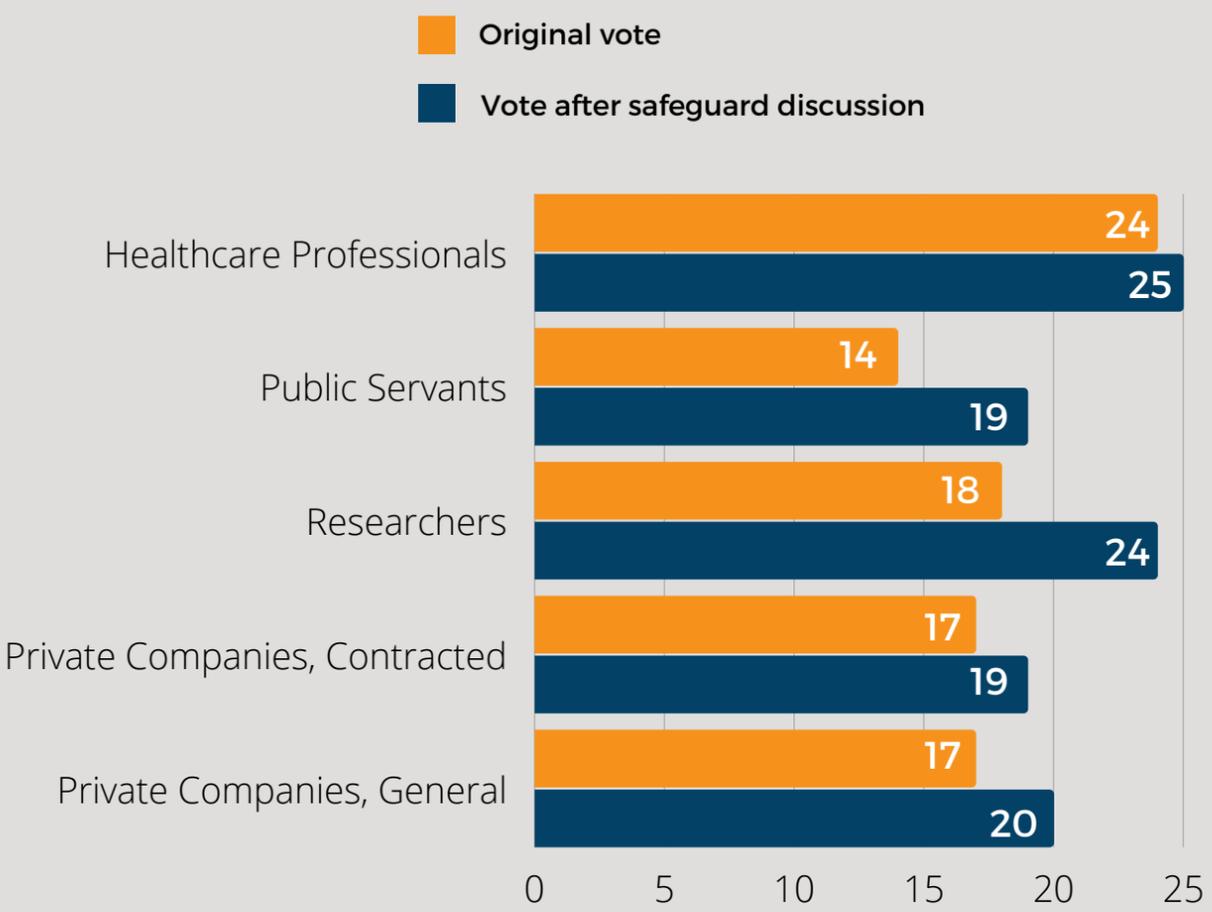
Across the board, the universal request from all jurors was for the citizen to be able to control how their health information is accessed, shared and used. Many jurors started by requesting sight of their own health information, but as the discussion developed, it became clear that being able to view 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.

CHANGE IN 'YES' VOTES, COMPARING CONFIDENCE WITHOUT SAFEGUARDS



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.

FOR THE FULL JURY VERDICT REPORT, VISIT THE PAGE BELOW:

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

IPPOSI

Irish Platform for Patient Organisations, Science and Industry

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