Evaluation Report on the IPPOSI Citizens' Jury on Access to Health Information

By the DCU Institute of Future Media, Democracy and Society

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Executive Summary

This report evaluates the IPPOSI Citizens' Jury which was set up to deliberate on the topic of access to health information. By selecting a jury that is broadly representative of the Irish population and providing a selection of expert witnesses for jurors to hear and cross-examine, the IPPOSI Citizens' Jury has been able to generate recommendations which can inform policymakers. This report outlines the ways in which the jury process has been designed to facilitate deliberative democracy, providing credibility to the verdicts reached by the jury.

The design of the jury considered representativeness, bias, oversight and a broad range of partial and impartial witnesses while the self-reports from jurors indicate that overall, they experienced knowledge gains and attitude change as a result of their participation. Additionally, the feedback reported from jurors about the quality of deliberation was consistently high.

The IPPOSI Citizens' Jury has successfully laid the groundwork as a pilot for future Citizens' Juries, with the opportunity to incorporate the lessons learned to further strengthen the process in future iterations.

Introduction

The IPPOSI Citizens' Jury was created to deliberate on the issue of access to health information and to decide on a set of recommendations to be presented to policymakers.

The jury's mission was to discuss and deliver a verdict on the following questions:

> Who should be able to access, share, and use your health information (identifiable and non-identifiable) and for what purpose(s)?
>
> Are there provisions which would increase your trust and confidence in different stakeholders accessing, sharing, and using your health information?

The verdict and recommendations made by the jury are expected to inform the development of health information legislation and a national Electronic Health Record.

The jury itself took place over six two-hour online sessions running across three weeks in April, for a total of 12 hours. The first four sessions focused on witness testimony and the opportunity to ask questions of the witnesses and the final two sessions focused on in-depth juror deliberations and verdicts.

A team from Dublin City University's Institute for Future Media, Democracy and Society led by Professor Jane Suiter was contracted to provide evaluation of the deliberative quality of the jury process.

The evaluation is largely based on survey data in which jurors were asked a series of questions before participating in the jury and after each week's sessions. The response rate for the surveys varied a little with 76% (19) responding to the Pre-survey, 68% (17) in Week One, 64% (16) in Week Two and 68% (17) in the Post-survey. As such the analysis does not represent all jurors, but it does provide insight into how most jurors experienced this deliberative process.

Within this report we will address the design of the jury process, whether the jury process led to an increase in knowledge or an attitude change for the jurors and whether the process itself successfully facilitated a high level of deliberation.

Design

The jury consisted of 25 residents of Ireland who are broadly representative of the population with selection based on geographic location, gender, age, educational attainment, ethnic group, as well as their views on access to and sharing of health information. While an attitudinal question is not always part of the selection process for citizen juries, this was a useful way to ensure a balance of attitudes on the topic, particularly with a smaller jury size.

The recruitment process for the jury relied on volunteers to express interest through an application form, which received 1019 responses. Following additional requests for information and eligibility requirements this was then narrowed down to a pool of 555 eligible jurors. The 25 jury members (and 5 substitutes) were then selected through a random selection process overseen by Professor Mary Sharp from Trinity College Dublin and with the final selection approved by the Citizens' Jury Oversight Panel. Jurors received a €400 gratuity for their participation.

The Jury Oversight Panel featured a range of expertise across academia as well as those working with patients and within eHealth. The panel met online monthly and approved all jury materials in advance. In addition, there was also a bias panel to assess the impartiality of the evidence presented. While an oversight panel represents best practice, the addition of a bias panel validates the process with an additional level of transparency.

The selection of jurors initially had a one-to-one session with a facilitator to check their technical setup, answer any questions and brief them on the process. This was then followed up by an introductory session, which would not discuss the topic, with subsection of other jury members to allow introductions between members and to test out the breakout room functionality before the jury began. This dual approach of one-to-one followed by an informal group meeting is particularly important when a process is running entirely online as it allows jurors some opportunity to get used to the technology and the format.

Impartial witnesses were briefed that they should focus on issues of fact not values, while partial witnesses were encouraged to promote their particular point of view. In total there were 5 partial and 4 impartial witnesses who presented evidence. The topics covered in the first four sessions can be found in Table 1.

Table 1. Session topics by week

Session One	April 13 Week One	Intro to Health Information Regulation of Health Information
Session Two	April 14 Week One	Health Information for Public Service Improvement Researcher's Perspective on Access to Health Information
Session Three	April 20 Week Two	Civil Liberties Perspective on Citizen Rights Around Access to Health Information Industry Perspective on Access to Health Information
Session Four	April 21 Week Two	Ethical Arguments For and Against Access & Use of Health Information Arguments for Involving the Citizen in Access to Health Information Issues
Session 5	April 27 Week Two	In-depth Deliberations
Session 6	April 28 Week Two	In-depth Deliberations

Each witness was also briefed that their presentation should address some of the key questions required for understanding the topic. An example of one of these briefings is seen in Figure 1.

Figure 1. Sample witness briefing

The presentation does not have to be structured in a particular way but should include information to address the following questions:

- How does the health system (acute and primary care) currently collect & store health information?
- How does the health system currently share health information with public and private partners for secondary use (i.e., outside individual care)?
- How will this change in the future (e.g., with the EHR?)

While the witness briefing and weekly structure was clearly in place, this was not reflective in the materials given to jurors, and it would be useful to provide a clear structure of topics so jurors understand the relevance of the order of witnesses and the information they are providing.

Based on advice from the oversight panel, the jury deliberations made use of case studies (Figure 2) to help to contextualise the type of situation in which a stakeholder might request access to health information. Considering that the various categories of stakeholders and purposes was quite detailed, this was a useful way to ensure jurors could see the practical results of decisions made around access to health information.

Figure 2. Sample case study to assist jurors in deliberation

CITIZENS' JURY ON ACCESS TO HEALTH INFORMATION

CASE STUDY: MARGARET

NOTE: The example below is not real. Some of the situations described are currently in place in Ireland, others are not, but they could potentially be put in place in the future.

YOUR MISSION

WHO SHOULD BE ABLE TO ACCESS, SHARE AND USE YOUR HEALTH INFORMATION (IDENTIFIABLE AND NON-IDENTIFIABLE) AND FOR WHAT PURPOSE(S)?

STAKEHOLDER B:
Public servants in government departments and agencies (HIQA, HPRA) seeking to access health information to support legislative, policy or practice change

THE FACTS OF THE CASE

WHO: A PUBLIC SERVANT
WHAT: NATIONAL SUMMARY CARE RECORD OF PARTICIPATING INDIVIDUALS
WHY: TO PILOT A CHANGE IN POLICY AROUND PHARMACIST ACCESS TO RELEVANT HEALTH INFORMATION ABOUT THEIR CUSTOMERS

THE CASE: PUBLIC SERVANTS

Margaret is a Policy Manager in the Department of Health with responsibility for policy in the area of e-health/digital health. She is reviewing policy on pharmacist access to health information and is charged with developing policy options to improve the doctor-patient-pharmacist relationships using e-health.

Margaret believes that the best policy option is to give pharmacists access to a national summary care record for each of their customers. Each individual in Ireland is to have a national summary care record that contains specific pieces of information about their health (prescribed medications, allergies, recent laboratory tests). The records are to be managed by the patient's GP.

Margaret has received authorisation from the Department of Health senior management to implement a pilot project which grants 30 pharmacies from across Ireland (including high street pharmacies such as Boots, Lloyds and Hickeys) the right to approach customers to ask for their consent to share their summary care records. Only registered pharmacies are permitted to take part. If customers consent, data will only be accessible by the pharmacy through a secure, on-site network, with a log-in required for each access. The pharmacists are informed that the misuse of a patient's health information will result in severe penalties including having their license revoked.

The pilot project will act as a blueprint for a future nationwide rollout, which may or may not require the customer's consent. A potential approach to 'opt-in' all customers (with an option to permit individual opt-outs) will be explored. An Advisory Committee, including both patients and pharmacists, will monitor the pilot and, all going well, they will design the future nationwide rollout of the project.

The pilot hopes to provide patients with better health advice when filling prescriptions, as pharmacists may be able to spot prescription errors and offer personalised health advice based on their knowledge of the patient's condition. The pilot aims to also reduce delays for patients seeking to fill repeat prescriptions. In some instances, the pilot may lead to big pharmacy chains creating official sales targets for the sale of non-prescription products based on the health profile of their customers. There may be many other potential consequences – perceived as positive and/or negative.

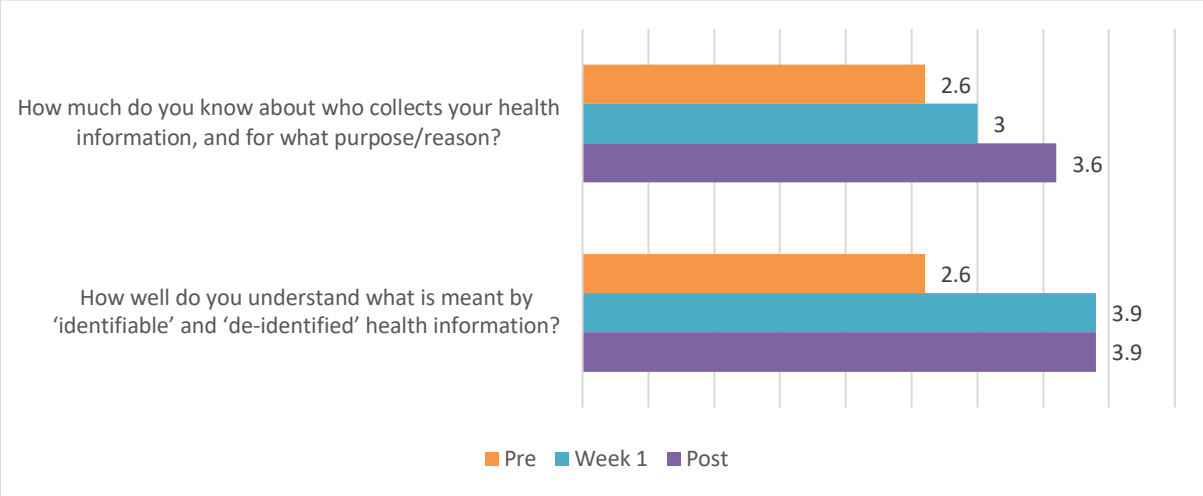
YOUR VERDICT

Knowledge Gains

One way of assessing the impact of a deliberative process is by measuring how much participants learn about information that is relevant to understanding the topic. To achieve knowledge gains we asked jurors a set of questions before the jury began.[1] We then asked these questions again after the topics were covered by witnesses and again once the jury concluded.

General knowledge about who collects information and for what purpose increased throughout the process. An understanding of the difference between identifiable health information and de-identified (anonymous) health information rose after week 1 and remained steady throughout (Figure 3).

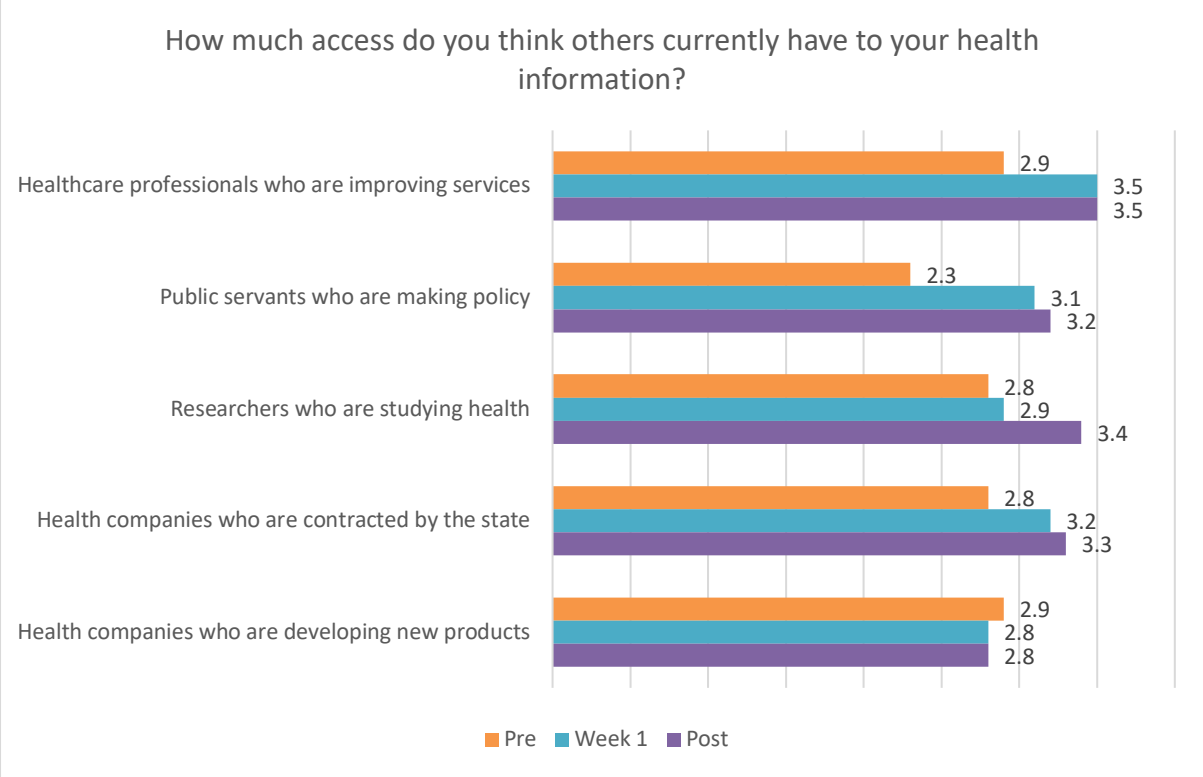
Figure 3. General knowledge gains



We asked jurors how much access they believe others have to their health information across a number of categories. In some categories jurors saw the situation differently from week one, believing that health care professionals who are improving services, public servants who are making policy, and health companies contracted by the state all had more access than the jurors had believed in the presurvey. However, in the category of researchers who are studying health, juror beliefs changed little after week one and then changed more substantially by the final survey. This suggests that either evidence in week 2 or the deliberations in week 3 made jurors feel that health researchers have more access than they had previously thought, even after hearing evidence in week 1. Health companies who are developing new products saw essentially no change, which may mean jurors did not learn anything new in this category or that their initial beliefs about access remained unchanged by the evidence presented.

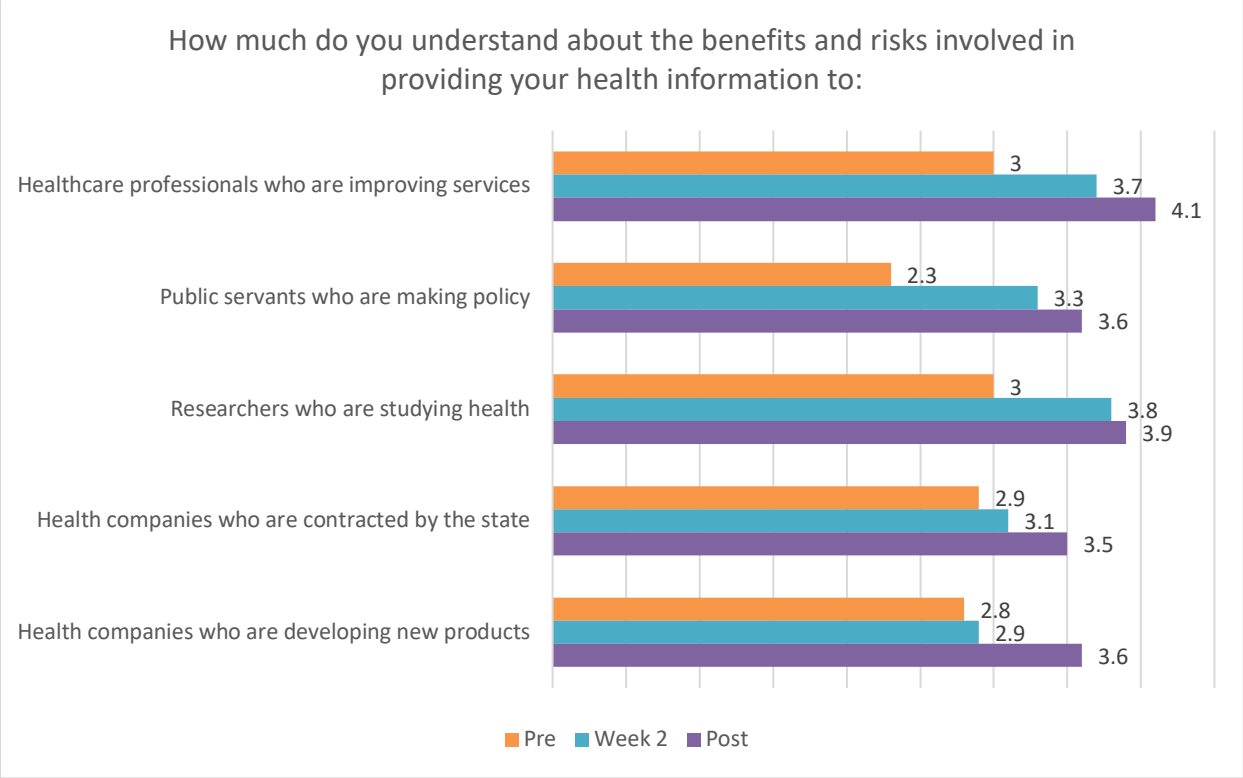
[1] All knowledge questions use a scale of 1 (None/Nothing) to 5 (A Great Deal) unless otherwise specified.

Figure 4. Beliefs about access to health information



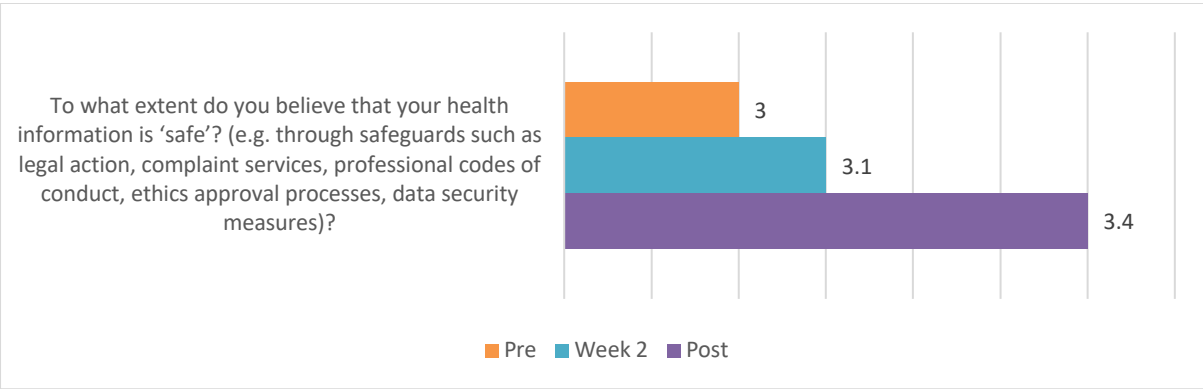
There was an increase in knowledge gains across all categories relating to benefits and risks of sharing personal health information (Figure 5), in both week 2, when the topic was addressed by witnesses, but also into the final week, suggesting that an understanding of benefits and risks was further developed in some of the discussions and deliberative work of the final week, particularly regarding the category of health companies who are developing new products.

Figure 5. Beliefs about benefits and risks



Similarly, jurors made some small gains in feeling that their health information is safe due to safeguards (Figure 6), but only by .3 points overall which suggests increased knowledge of various safeguards did not make a large impact on their level of confidence in the safety of their information.

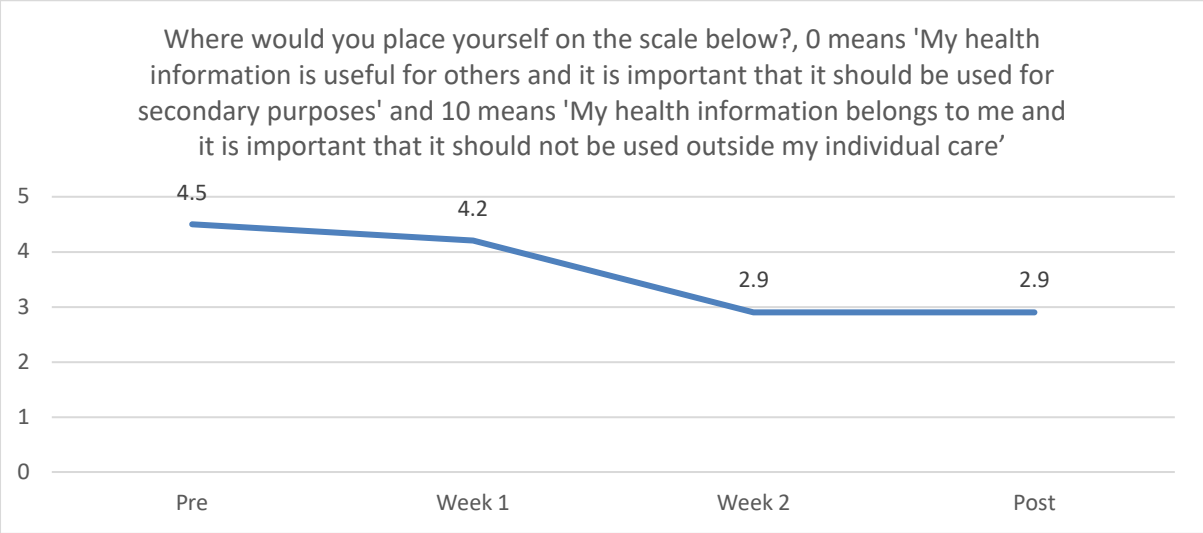
Figure 6. Belief about safety of health information due to safeguards



Attitude Change

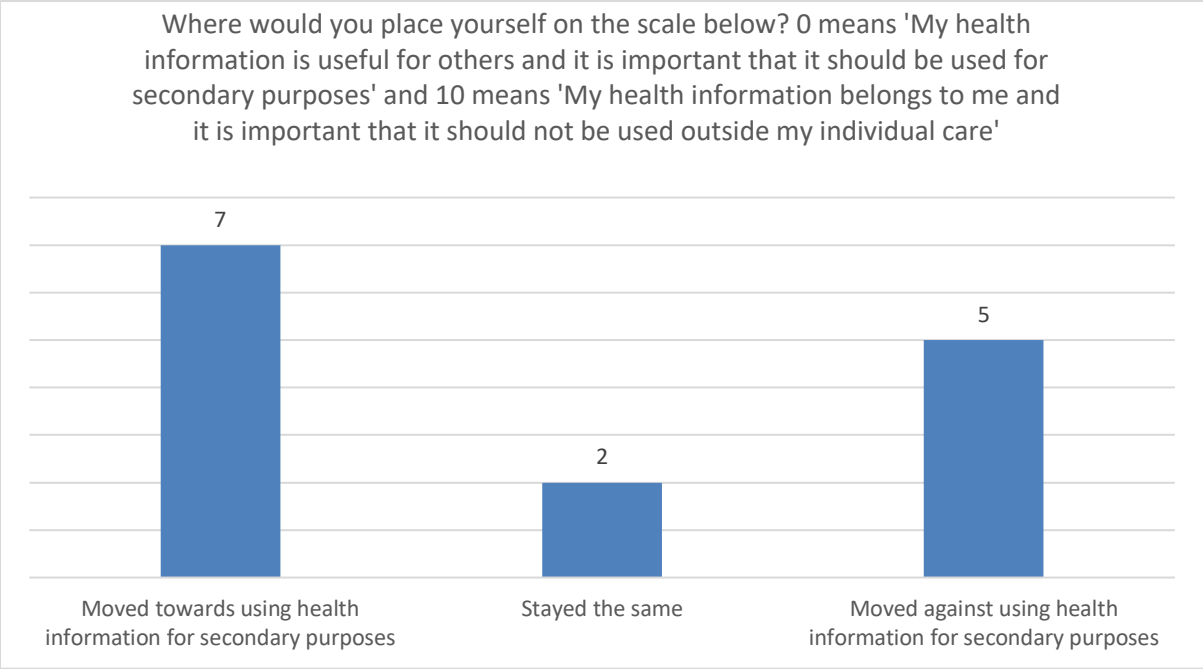
Another way to see the impact of a deliberative process on members is to examine whether jurors changed their minds or if their opinions shifted. During the jury process, overall attitudes about health information moved towards the position of using it for secondary purposes (Figure 7). This changed very slightly after week one and much more so after week two, with no further change identified in the post survey. The topics in week two included civil liberties and industry perspectives on access to health information as well as ethical arguments for and against access to health information and it seems that these subjects did make an impact on juror attitudes on this scale.

Figure 7. Attitude to health information



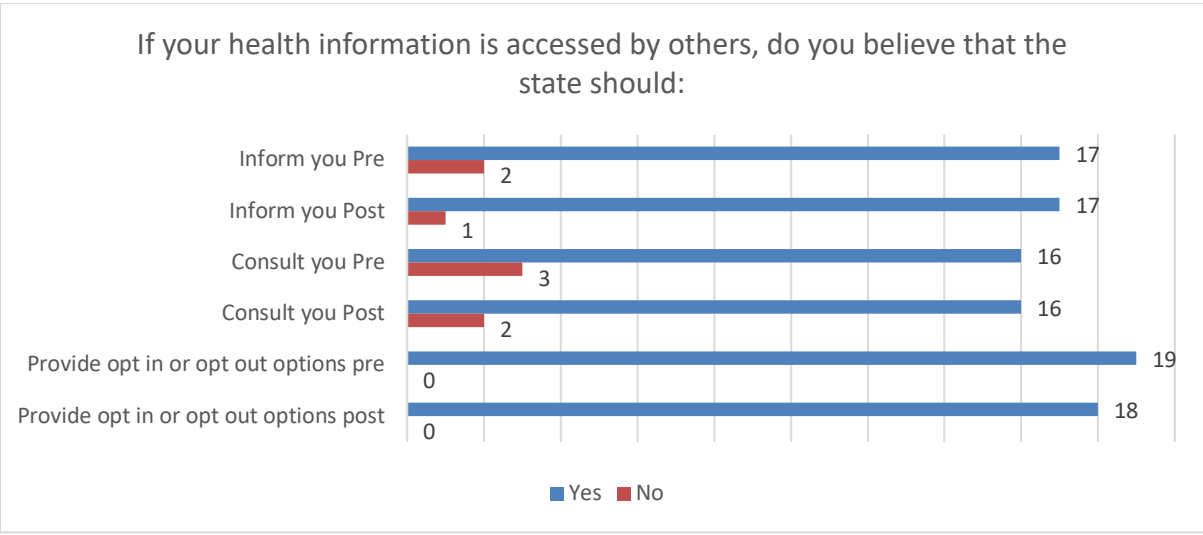
While overall, the average moved in a clear direction, when evaluating the 14 jurors who completed both the pre and post survey, the direction of change went both ways as seen in Figure 8. The individual level of change for each juror ranged anywhere from no change to 6 points, which would reflect a reversal of position. This is to be expected as deliberation does not imply attitude change is necessary but rather that people should feel more confident in. their beliefs and attitudes with greater levels of knowledge and so on.

Figure 8. Direction of change on attitudes to health information



In the presurvey there was a strong consensus that the state should inform, consult and provide opt in/out options if anyone's health information is accessed by others, and this consensus continued in the post-survey (Figure 9).

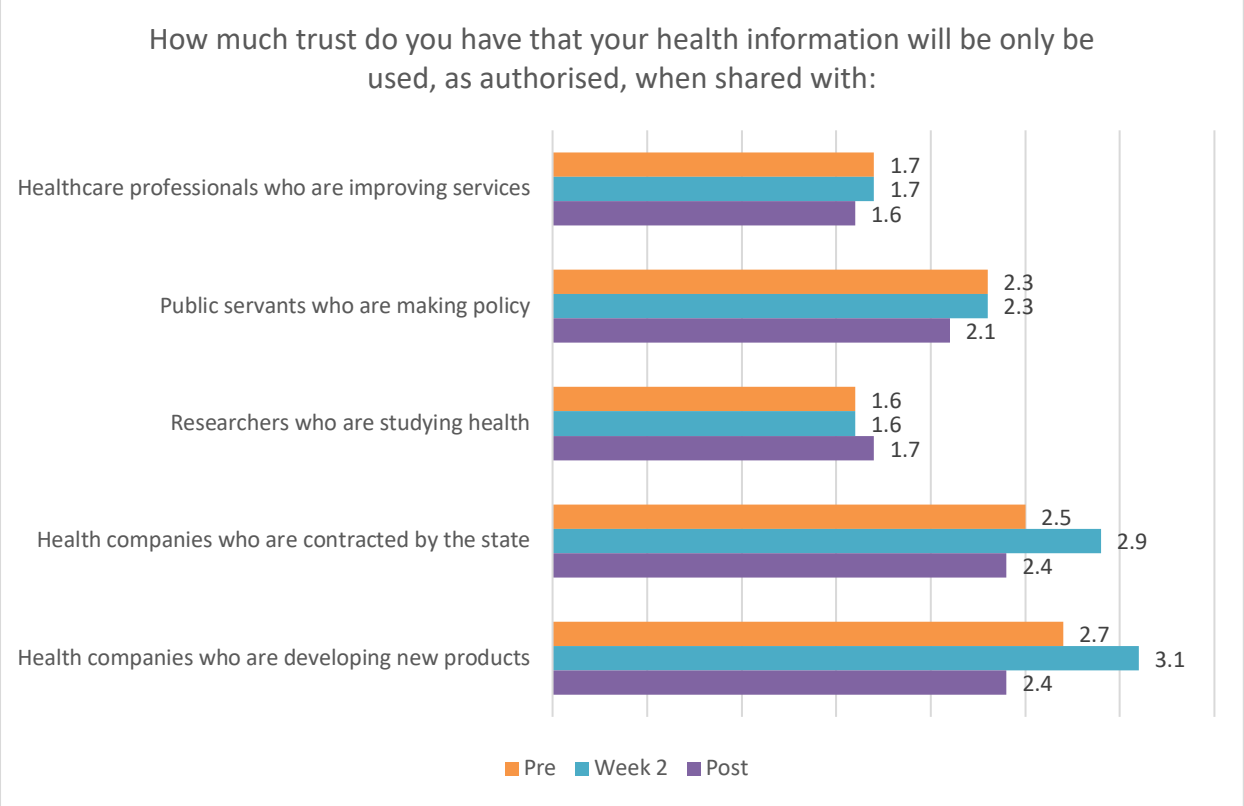
Figure 9. Beliefs about state responsibilities



Levels of trust in how secondary sources will use health information varied throughout the jury process and according to source. Levels remained almost static for health professionals improving service, public servants making policy and researchers studying health. However, trust in health companies who are contracted by the state and those developing new products jumped in the Week 2 survey and then fell below pre-survey levels by the post-survey, which would suggest that any gains in trust made via expert presentations and new

knowledge in the first two weeks was later countered by the deliberation process in the final week.

Figure 10. Levels of trust towards stakeholders

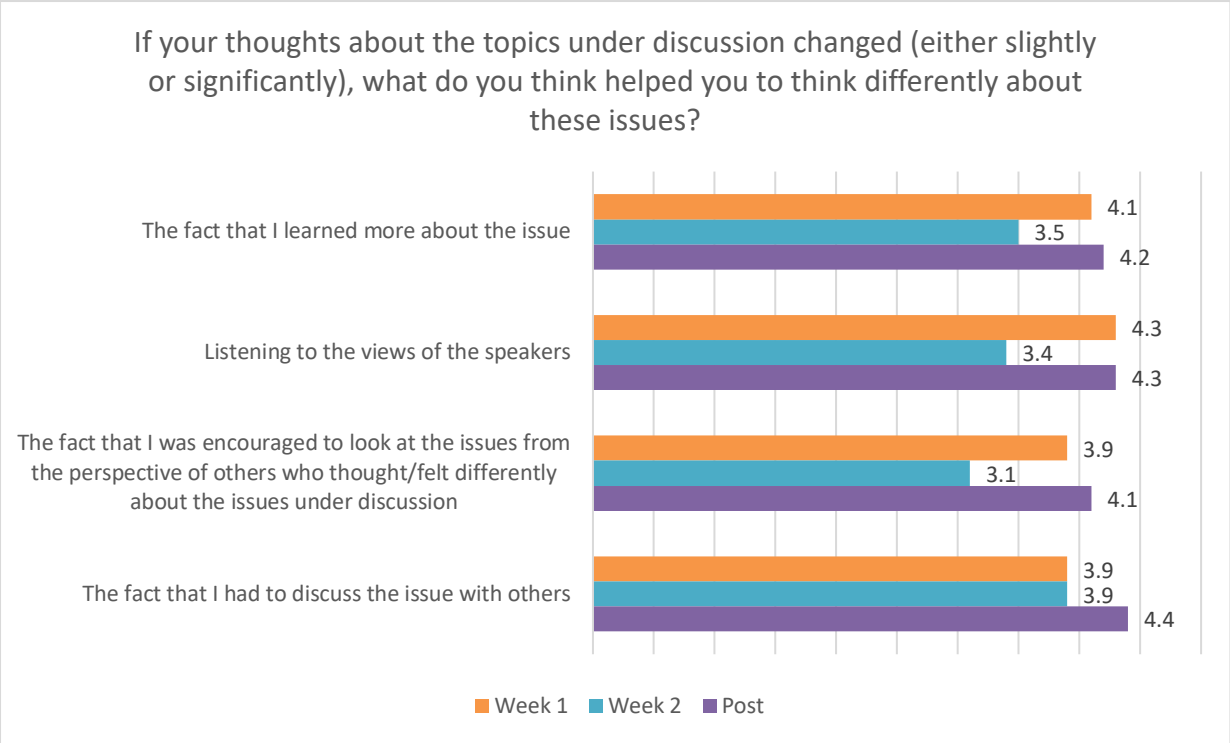


In the post-survey jurors were asked the following:

> On a scale of 1-10, with 1 representing no change and 10 representing a complete change, to what extent do you think you have changed your mind as a result of participating in the citizens' jury?

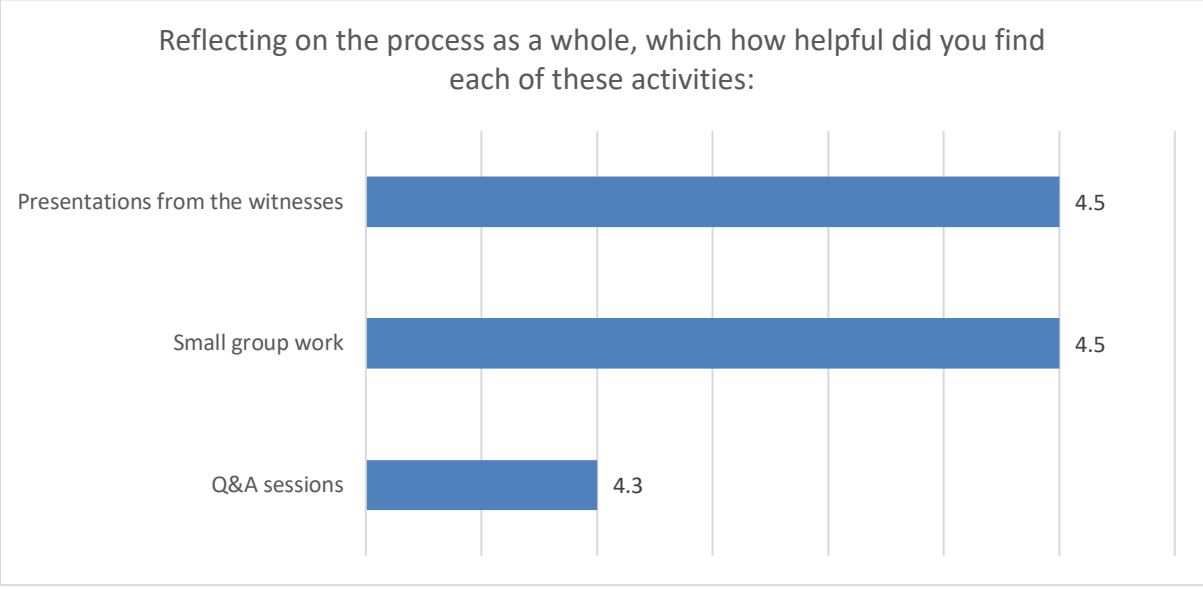
The average score was 6.3 with the lowest score reported being 3 and the highest score being 10, indicating that all jurors surveyed felt they had changed their minds, albeit some more so than others. When asked what they think helped in changing their thinking, answers varied somewhat across the weeks, but by the end of the jury process all participants rated each of the categories over 4 on a 5 point strongly disagree to strongly agree scale, indicating that a combination of learning, listening to speakers and deliberating with others all contributed towards any perceived change (Figure 11).

Figure 11. Reasons for change of mind



Similarly, after the jury ended, jurors reported finding the presentations, small group work and Q&A sessions very helpful overall (Figure 12).

Figure 12. Helpfulness of activities



When asked to reflect on how their thoughts may have changed, many jurors described how the process helped them to either change their minds or to embrace their pre-existing position more strongly. Three common themes within these answers were the importance

of learning new information, receiving reassurance on issues that may have been of concern and feeling a stronger sense that safeguards need to be enhanced.

Table 2. Juror reflections on how their thoughts have changed

Role of learning new information
I learned more from talking with the groups than I would have done looking up the information on my own.
Knowing that the benefits completely outweigh the potential risks
I found it useful to consider how the data subject and the state could obtain benefit from the sharing of patient data outside the traditional 'develop new drugs', and feel that any data sharing must include a direct stake in the revenue generated (particularly as the intended global company taxation policy will be detrimental to Ireland). I also felt considering data segmentation at governance and policy level was useful.
I know a lot more now in relation to the subject so have a more open mind now.
I had my doubts about sharing my information, George Orwell's 1984 came to mind. After listening and learning the benefits of how important my information is I feel it is a no brainer that we have to have an opt in system. If people want to opt out it can only slow the process up if they ever need treatment.
Reassurance on concerns leading to positive view of sharing health information
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 promise of safeguards being put in place that will provide a high level of security for the data.
I'm more open to secondary uses of data. I think that if robust safe guards and data processing agreements are in place then it's acceptable to me
I never realised people are so frightened of an issue that is controllable and manageable. That mistakes in the past and there have been many make them so afraid.
Feeling a need for stronger safeguards
That the strength of data control must be emphasized and that the Irish GDPR regulations need to be looked at again in relation to medical data.
I think my thoughts have generally stayed the same that health data should be used for secondary sources, however I would say that I feel more strongly that there needs to be a full-scale campaign on GDPR and health data so citizens can opt in with confidence. Right now there feels like there is a lot of mistrust, coupled with lack of knowledge about current safety mechanisms. I think as a group it was harder to pull out more nuanced ways of discussing how we view health systems and how they can be operated to the agency and benefit of Irish Citizens

Quality of Deliberation

Asking jurors about their own perceptions of the deliberation process allows us to evaluate the deliberative quality of the jury. Many of these questions were reported on in the weekly evaluation surveys provided to the IPPOSI jury organisers, but we present them again here to provide an overview of how well the process functioned, as assessed by the jurors themselves.

When it came to the facilitation of the process (Figure 13), jury satisfaction was high about having an equal chance to speak. Despite this there was a slight sense from some jurors that others dominated the discussions in their small groups, although the average score on this never moved into agreement overall. This issue was addressed by the research team within the weekly evaluation reports, but there was still not a strong sense from jurors that it was no longer an issue. For future juries we would recommend assessing this in more detail and revising scripts given to facilitators to strengthen their ability to manage equal speaking opportunities. Jurors also felt that facilitators did a good job of ensuring diverse views were considered, with an improvement showing throughout the process. While a number of feedback comments praised the facilitators, there was one which offered some constructive feedback to consider for future juries (Table 3).

Figure 13. Survey results on facilitation

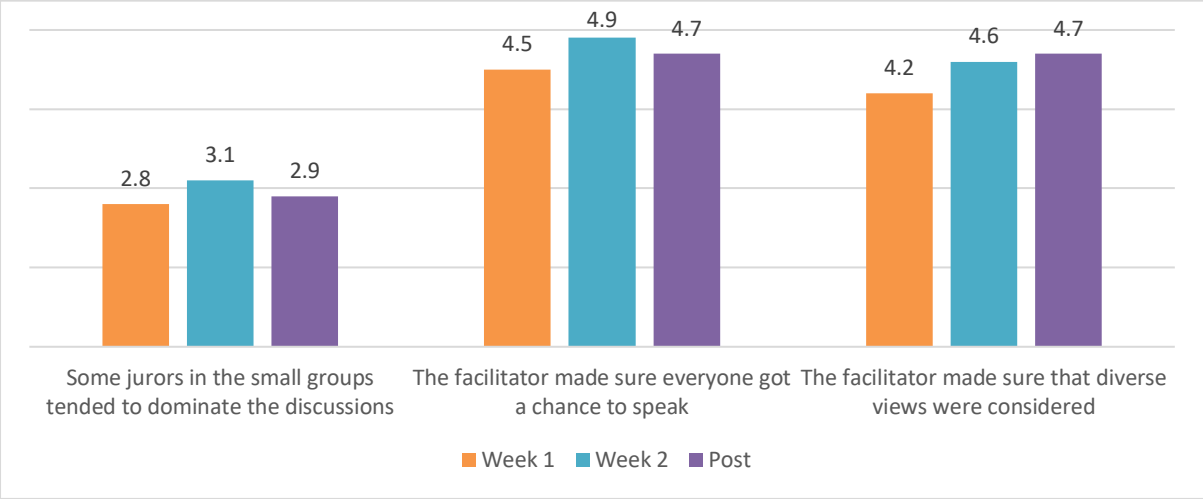
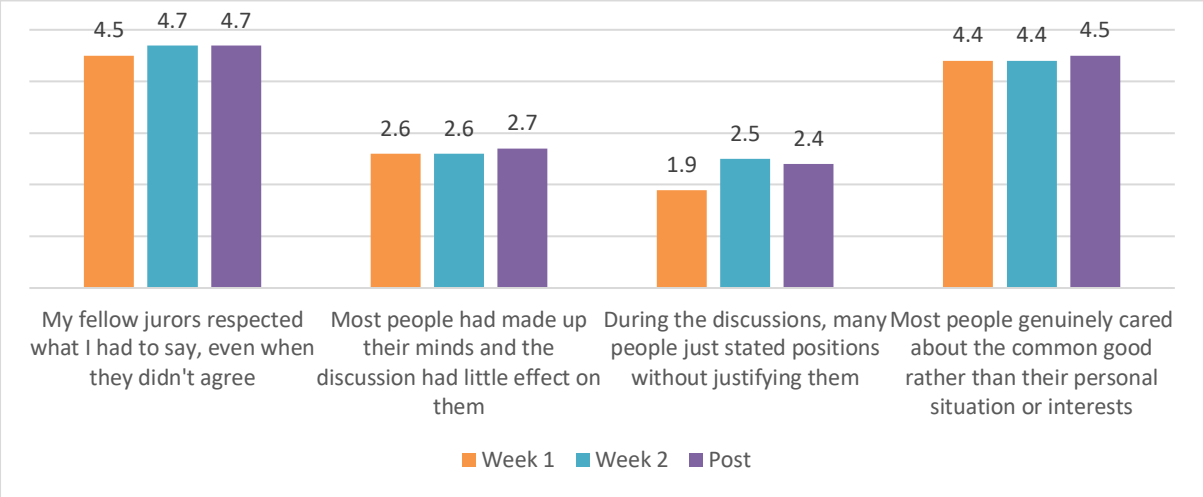


Table 3. Comment on facilitation

Comment on facilitation
I think that the facilitators need to be able to grapple with policy and strategic thinking - there were quite a few instances where I felt they didn't fully understand or engage with what I was saying as they were so focused on getting a point reduced to a few buzz words and the point was often lost.

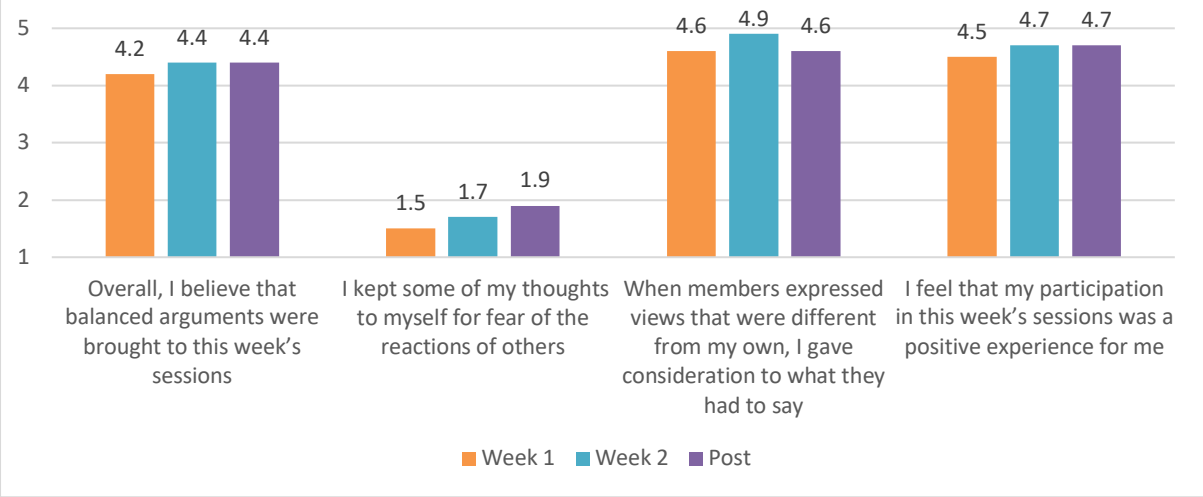
With respect to how the jurors viewed one another, there was a strong agreement that other jurors were respectful, even with dissenting opinions, and that most people genuinely cared about the common good (Figure 14). However, some jurors felt that others had already made up their minds and there was an increased belief that others were stating positions without justifying them, as seen by the low level of disagreement with the two statements. This may be partly reflective of the sampling and recruitment, as presumably jurors may have volunteered because they felt strongly about the topic, but it is something that can also be addressed within the facilitation by prompting facilitators to ask for justification and to encourage open mindedness.

Figure 14. Survey results on beliefs about other jurors



There was a strong consensus among jurors that balanced arguments were made, that they considered opposing views from other jurors, and that their participation each week was a positive experience (Figure 15). This is no doubt a reflection of the good work done by the bias review group, a very useful innovation in the process. The average score for not sharing thoughts due to fear of other jurors' reactions was low, but did increase a little each week, perhaps due to being more aware of others' opinions as the process progressed.

Figure 15. Juror beliefs about themselves



Jurors also had access to a website built on EngagementHQ, a community engagement platform. This website allowed jurors to interact with each other, post in discussion forums, ask questions, and review documents such as the jury mission and witness presentations. This was a useful way to ensure that jurors could feel part of the process, that they could see information about other jurors to help form a connection, and it acted as a central point of information. We consider this to be a positive addition to an online only deliberation process. In addition, the presentations themselves were uploaded to the general IPPOSI website so that they are available for the public to view, which is best practice to ensure transparency of the process.

When asked at the end whether they felt they had received enough information to make their decision, 15 answered yes and two answered that they did not know, which reflects well on jurors' levels of confidence in the information they received. Jurors were encouraged to be part of the process of drafting a jury report alongside an independent rapporteur as well as participating in the presentation of the results to policymakers, both of which facilitate ownership of the process by jurors. When asked 'how likely are you to encourage friends/family to participate in a future Citizens' Jury?', all survey respondents reported at least 4 on a 5-point scale, suggesting that they found the process a positive experience overall.

When offered the opportunity to provide any final feedback or thoughts on improvements, quite a few jurors offered expressions of thanks or their enjoyment of the process, as well as an appreciation of citizen juries as a concept, a sample of which can be found in Table 4.

Table 4. General feedback from jurors

Feedback from jurors
It was a very interesting experience, and one I am happy to have participated in. Thanks to everyone from IPPOSI, and all the facilitators, and Michael for being so great
A fantastic experience and I hope to see many more citizens juries as it gives us a voice. Empowering and enlightening experience.
It was helpful and I believe that there should be more juries to get our citizens more involved in issues that matter to all our lives
Yes the whole experience was very positive and afforded members of the public to have their say into the formation of Public Policy

While overall feedback was positive, jurors did offer some suggestions for improving the process. Five jurors mentioned that they think the process would be improved with more time, either for activities or extra sessions, with one suggesting that the need to complete the voting quickly made it feel, "*like a tick box exercise at the end*". One additional juror expressed that the sessions should not be held during mealtimes. A range of other suggestions and critiques can be found in Table 5 and should be reviewed as part of the planning for any future citizens' juries.

Table 5. Suggested improvements from jurors

Suggested improvements from jurors
Lengthen the initial break out beyond 5 mins slightly. Also reiterate the task each session to keep focus. Some time was wasted.
The voting in deliberation groups to be kept anonymous. Although I would still encourage discussion whilst in the groups.
Grounding/upskilling in GDPR would be really useful as a lot of the suggestions are already protected by law so I'm not sure what use it is reiterating them as potential safeguards. I think it would be great to have every speaker categorised by what kind of stakeholders they are (As in the same terms as is used in the case studies). I felt that it needed to be clearly stated/reiterated that we were voting on secondary use of data as there was some confusion over this.
A wider range of speakers, perhaps with an international link, to explore best practice on the topic from other countries. E.g. it would have been useful to have a speaker from Estonia.
On the technical side for the novice who isn't using computers a lot, checking in each session to see that we are managing it all.
I worried at times that we might have been concentrated too much on the concept of what health data is more so the uses and future risks. Perhaps a general brief on the state of (the topic for discussion) should be given to all members, and then when experts come in there is better general knowledge of the topic at hand as this would benefit for in-depth conversations despite the limited time.
More clarity - people in our group thought we were talking about de-identified data, even though the question was clearly written that it was both. The case studies seemed to give the impression we would be discussing de-identified data, so I strongly feel the case studies could have been more balanced and/or the facilitators could have made it clearer to the groups.
I think for future Juries maybe a more balanced view from Speakers who can find an argument against the positives of sharing our DATA.

Conclusion

Overall, we consider that this Citizens' Jury was very well organised and it functioned well in terms of deliberation.

When it came to design, the inclusion of both an oversight panel and a bias panel reflect positively on the validity of the process. The induction sessions for jurors also functioned well, particularly considering the Jury took place entirely online.

While there was a clear structure and rationale for each session behind the scenes, it may be useful to make the structure of the sessions a little clearer to jurors, with clearly defined topics and an understanding of why each witness has been chosen to present on that topic.

There was clear evidence of an increase in both knowledge gains and attitudinal changes as a result of the jury process, with learning new information forming an important part of how jurors changed their minds on any issues.

Juror satisfaction with the deliberation process was high with all surveyed reporting that they would likely recommend participation to friends or family. The addition of a juror engagement platform is also a useful addition to an online only process. We would recommend focusing on the training and instruction provided to facilitators for any future juries as while overall jurors felt positively about the facilitation, there was some room for improvement identified. Jurors also provided a number of suggestions for improving the process in the future, and these could be reviewed with a view to strengthening the quality of the jury process for the future.