Scottish Learning Disabilities Observatory

Research Voices: Including the voices of people with learning disabilities in health research

Citizens' Jury Evaluation Report

May 2021

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Citizens' Jury Evaluation

Contents

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Executive Summary

About the Research Voices Citizens' Jury

People with learning disabilities face significant health inequalities but are under-represented in health research designed to address these inequalities. The Scottish Learning Disabilities Observatory produces research on the health and healthcare of people with learning disabilities and autistic people in Scotland.

The Research Voices Project is a partnership between the Scottish Learning Disabilities Observatory and Talking Mats and was funded by the Wellcome Trust in 2018. The Research Voices project brought together a group of people with learning disabilities to form a Citizens' Jury to discuss and challenge existing practices around health research. This adapted Citizens' Jury was the first of its kind and aimed to find out more about the views of people with learning disabilities on health research as well as pioneer this approach to deliberative democracy with a seldom-heard population. The jury addressed this key question:

How can people with learning disabilities influence health research? Including influencing:

- What research is done to help people with learning disabilities
- How this research is done

The group met for 5 preparatory workshops in advance of the Citizens' Jury itself, to build trust and relationships as well as develop key deliberation skills. The final Citizens' Jury took place over 5 full days. Eight expert witnesses provided accessible, good quality evidence to support deliberation and the Citizens' Jury produced 10 well-considered recommendations for health research.

Overarching findings

- People with learning disabilities are capable of deliberating on complex issues when given the appropriate resources and specialised communication support
- Some jurors struggled with elements of deliberation including challenging different perspectives and finding consensus in the moment
- Jury members reported increased confidence in communication and increased knowledge of health research following their involvement, particularly for skills that were explored in capacity-building workshops
- An accessibility-first approach to project design enabled participation, but some jurors may have benefited from increased one to one support
- Expert witnesses reported positive experiences from being involved, but adapting complex information to be more accessible was time-intensive

Considerations for future projects

Future work with people with learning disabilities or other marginalised groups with communication support needs should consider:

- The addition of capacity building workshops on challenging other perspectives and finding consensus
- Committing additional resources to the emotional wellbeing of participants exploring sensitive issues
- Recognising the importance of connection and relationships as an outcome for participants who may be otherwise socially isolated
- Building in additional time at key pressure points to allow for more one to one work with jurors who may need additional support to interpret information
- The need for thoughtful planning in digital processes for people with learning disabilities

1. Introduction

People with learning disabilities experience major health inequalities and face barriers to engagement in research that seek to understand and improve their health. The Research Voices project was established by The Scottish Learning Disabilities Observatory and Talking Mats to engage people with learning disabilities in a rigorous and in-depth discussion about inclusive health research.

To achieve this, the project developed an adapted Citizens' Jury; a form of deliberative democracy where groups of 12-24 people from different backgrounds come together to explore challenging issues and present recommendations. This approach was adapted to be accessible and meaningful for citizens with learning disabilities. The aims of this ambitious project were to:

- Provide insight into the views of people with learning disabilities on health research
- Challenge attitudinal barriers to involvement of people with learning disabilities in research as participants, subjects and collaborators
- Challenge structural barriers that limit opportunities for inclusion in research
- Develop, evaluate and share project resources
- Generate recommendations supporting inclusive public engagement in health research

The Research Voices Citizens' Jury published 10 recommendations for the health research community which outlined how people with learning disabilities can influence research development, delivery and dissemination. These recommendations are available online. A key aim of this project was to evaluate the viability of an adapted Citizens' Jury method for engagement and to share the learning from this approach, which we hope will be of interest to a range of stakeholders including:

- The health research community, including those who focus on learning disabilities health research
- Community and civic engagement teams who want to know how to adapt Citizens assemblies, Citizens juries and wider deliberative democracy to involve people with learning disabilities
- Public and patient involvement and engagement practitioners who work with marginalised groups

1.1. Project Outcomes

The project had ambitious outcomes for people with learning disabilities and stakeholders in health research, listed below:

For people with Learning Disabilities

- To have the opportunity to participate meaningfully in an engagement process adapted to their needs

- To feel more confident speaking up about what matters to them and expressing their views
- To express their opinions on health research and feel their voice has been heard
- To know more about health research and how it relates to them
- To develop their communication/deliberation/questioning skills

For stakeholders involved in health research

- To be more informed about barriers to engagement for people with learning disabilities and how best to overcome these
- To understand the benefits of meaningful participation of people with learning disabilities in health research and have access to tools that support them to achieve this
- To be more informed of the skills and values required to facilitate effective engagement with people with learning disabilities in a research setting
- To have access to good practice examples of accessible health research information
- To better understand and value the research priorities identified by people with learning disabilities

The full logic model for this project is available in Appendix A.

1.2 Scope of this evaluation

The evaluation data collected through the project lends itself best to an evaluation of three key categories from the projects proposed outcomes:

1. The effectiveness of the Citizens' Jury approach in supporting jury members to deliberate on health research and have their voice heard
2. The impact of the Citizens' Jury on jury members' knowledge and confidence
3. The impact of the Citizens' Jury on professionals and stakeholders in health research who were directly involved

There is still insufficient data to effectively evaluate the impact of the Jury recommendations report at this time. However, the project team will publish an impact report at a later date.

1.3 Data sources and methods

The project adopted a mixed-methods approach to evaluation using data from various sources. Evaluation methods were aligned to individual evaluation questions relating to project outcomes, and included:

- Talking Mat individual interviews on knowledge of health research and confidence in communication
- Emotional touchpoint process evaluation
- Ethnographers/observers notes
- Expert witness evaluation surveys
- Group evaluation Talking Mats
- Research Voices team reflections

A full overview of data sources, time collection and corresponding evaluation can be found in Appendix B.

1.4 Project planning and design

The project team had considerable experience of working on a range of engagement projects with people with learning disabilities but had never planned or delivered a Citizens' Jury before. The design of this project relied on evidence of best practice in Citizens' Juries, including the Scottish Health Council literature review and Roberts and Escobar's (2015) study of 3 Citizens' Juries. However, the Research Voices Citizens' Jury faced unique methodological challenge as this method needed to be adapted to maximise the contribution of people with learning disabilities. The project team also met with People First to discuss their 2011 Citizens' Grand Jury of people with learning disabilities to influence the process design and discuss issues of power and ownership.

Although there is consensus that the Citizens' Jury method has evolved considerably and different models have been developed, this particular project best fits within the Wakeford et al (2015) definition of:

> *'Twelve or more members of the general public (the 'jurors') participate in a process of dialogue under the guidance of a chair or 'facilitator'. They interrogate specialist commentators (sometimes called witnesses) chosen because of their knowledge of a particular subject… Jurors then draw up and publish their conclusions.'*

However, this project aimed to deliver an adapted Citizens' Jury which was accessible for people with mild and moderate learning disabilities. This meant a range of adaptations and supports were put in place to support deliberative democracy for a group of adults with different support and communication needs.

Key adaptations included:

- Delivering 5 preparatory workshops to build skills, confidence and knowledge, as well as develop trust within the group
- Reduced length of meetings with shorter activities and breaks
- Use of additional communication supports such as Talking Mats and 'I want to speak' cards as well as easy read materials
- Accessible expert witness presentations adapted to the required pace and learning style of the group
- Welcoming of supporting staff (a support worker and a transcriber)
- The group setting their own question and agenda
- Use of graphic facilitation to summarise information and prompt discussion

Setting the Jury question

One of the key adaptations made to this Jury was the decision to allow the group to develop their own Jury question. This decision was made because it was important for people with learning disabilities to set their own agenda and pursue a discussion that they felt was important for their community.

The final focus of the Citizens' Jury was:

How can people with learning disabilities influence health research? Including influencing:

- What research is done to help people with learning disabilities
- How this research is done

Inclusive Project Planning

The project team took an inclusive approach to project planning from the outset of this work. This included the interview of the project lead, which was designed and conducted with input from a member of the National Involvement Network (NIN) with learning disabilities, who had training in Talking Mats. This interviewer had a clear, independent role in the design of interview questions and was supported to express preferences in selecting a candidate.

Project recruitment resources, including information sheets and interview protocols were also tested with a person with learning disabilities, who gave valuable feedback to the process. Where external presentations or updates were made about the project, jurors were invited to contribute or participate to share their own voices. The group also co-authored their Jury Recommendations report and led on the design of their Video Jury Recommendations report.

All Citizens' Juries require careful planning, however it is important to note that the project team had additional responsibilities to ensure that the project was as inclusive as possible, including:

- The development of all jury facing materials (information sheet, consent form, meeting minutes, group rules) in easy read formats
- The development of a targeted accessible recruitment strategy through community groups and 'Gatekeepers'
- The development of bespoke Talking Mats to support Jury processes
- Additional support for expert witnesses to adapt their presentations to be accessible
- Coordination with support organisations and personal assistants
- Managing travel and transport for some Jurors
- Supporting Jurors with planning and diary management

This project drew on a range of resources to deliver the adapted jury, see Appendix C.

Jury oversight

This jury did not have an external oversight panel. However, the group that organised and delivered the jury was composed of 5 key members from the Scottish Learning Disabilities Observatory and Talking Mats who met every 6 weeks for planning and decision-making. This group also drew on external experience through meetings with other stakeholders in learning disability services, deliberative democracy and public and patient engagement and allowed for the project to be more responsive to frequent changes. However, jury oversight

panels are an important element of a Citizens' Jury, and future projects may wish to constitute this group at the outset of their work.

Project activities

Recruitment consisted of at least one informal meeting or phone call with potential jurors, followed by an interview supported by Talking Mats. Twelve adults with learning disabilities from across Glasgow were recruited for the project.

Following recruitment, the project team delivered 5 preparatory workshops on the following topics:

1. What is a Citizens' Jury?
2. What is health research?
3. Developing communication and questioning skills
4. Choosing a Jury question
5. Preparing for the Citizens' Jury

These workshops were followed by the Citizens' Jury itself. The Citizens' Jury met for 5 days spaced across a period of two weeks. Four of these days focused on presenting evidence, asking questions and distilling important learning and the final day focused on deliberation and proposing recommendations.

Following the jury, the team delivered 4 additional workshops focused on evaluation and co-producing outputs for the project including.

Recruitment limitations

The recruitment of the Citizens' Jury aimed to be demographically representative, and to reflect the age, sex and health needs of people with learning disabilities as outlined in Scotland's 2011 census. While this could not be achieved completely, recruitment focused on diversity and the value of lived experience. Twelve people were initially recruited, the final group of 9 included five men and four women aged 16 to 66 years old with different experiences of health and inequality. Recruitment of people with learning disabilities to research is a known challenge (Cleaver et al, 2010) and this project was no exception. The project struggled to find representation in the 45-54 age group (projected n=2, achieved n=0). Recruitment focused on adults with mild and moderate learning disabilities but did not require that candidates present evidence of a diagnosis of learning disabilities. A more comprehensive review of the approaches taken to recruitment and challenges faced is available on the Research Voices blog.

Jury Design

The Jury itself took place over 5 full days (10am – 3pm), spread across two weeks. The project team reflected that there was benefit in compressing meetings into two weeks, but that the final deliberation session on day 5 should have been extended to allow more reflection and consensus building for the team. An additional post-jury workshop was

arranged to allow for reflection and sense-check the group's consensus given the demands of this final day.

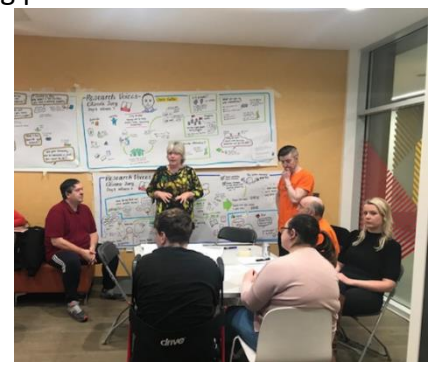
The pre-Jury workshop and jury sessions all followed a similar structure. Each meeting had clear stated aims, a mix of activities and discussions and an opportunity for evaluation. Workshops were a mix of small group discussions, wider discussion and individual contribution. Smaller groups and sub-groups were always allocated in advance rather than free formed to promote socialisation and skill sharing. These smaller group discussions often facilitated more in-depth engagement and sharing of ideas, a benefit recorded in other Citizens' Juries (Smith, 2009). However, it is important to note that each sub-group needed an individual skilled facilitator to support discussion.

A sample programme outlining how jurors engaged with Expert Witnesses is available in Appendix D.

Tools used in the jury

There were a number of tools to support engagement and debate used in the Citizens' Jury including:

- The use of a 'car-park' to redirect irrelevant talking points
- 'Stop' and 'I want to speak cards'
- Graphic facilitation
- Question starter cards with powerful question starters (Why? How?) to prompt question asking
- Accessible PowerPoint presentations using photosymbols
- Jury Packs which included group rules, 'What is a Citizens' Jury?' handout and slides for each Expert Witness presentation
- Adapted presentations from Expert Witnesses



1: A small group using Graphic Facilitation visuals to explain their ideas

Payment for participants

This project did not pay its participants to take part, a departure from a typical Citizens' jury in which many offer payment (Street et al 2014). The project team explored this in depth at the outset of the project and raised issues including challenges in University payment systems and the potential impact on benefits. For this project, all travel expenses for jurors were paid, and refreshments were available as well as opportunities for social activities.

However, there is also evidence that remuneration is 'crucial for successful recruitment and inclusive participation' (Roberts and Escobar 2015). Reflections from ethnographers in attendance at the Jury was that it was a demanding process and may have been legitimised if payment was offered. The challenges of paying people on benefits are well-recorded, but not insurmountable. Future projects should seek to explore every avenue to pay participants with learning disabilities if it is what individual participants want.

2. Evaluating the impact of the Citizens' Jury

2.1. The wider context of impact

This process aimed to address the attitudinal and practical barriers that exclude people with learning disabilities from health research by harnessing the principles of deliberative democracy. People with learning disabilities remain under-represented in democratic processes in Scotland, including processes of deliberative democracy, where the image of 'ordinary' citizens frequently excludes disabled people from social debate (Raisio et al, 2014). Adults with learning disabilities continue to face challenges asserting individual choices in their social and political lives (Dowse, 2009), despite the successes of self-advocacy movements across the UK. This project aimed to create an inclusive space where people with learning disabilities could actively engage in deliberation on health research. However, discussion will also acknowledge the wider context of power and exclusion members of the Citizens' Jury experienced in their daily lives which shaped their experience of involvement.

Project Impact Summary

The effectiveness of the Citizens' Jury approach in supporting jury members to deliberate on health research and have their voice heard

- Jury members reported positive experiences in the Citizens' Jury and emphasised the importance of peer support and feeling included
- Skilled facilitation and specialist communication support were vital in supporting participation
- The jury used various decision-making and consensus-finding mechanisms, but ultimately some jury members needed additional time and support to find consensus
- For some jury members, challenging other perspectives was difficult and future adapted processes should consider focusing on these skills

The impact of the Citizens' Jury on jury members' knowledge and confidence

- Overall, pre- and post-project evaluation showed an improvement in jury members' self reported confidence in communication and knowledge of health research
- There are limitations to self-reporting with people with learning disabilities
- External influences including the communication environment may have an impact on these results

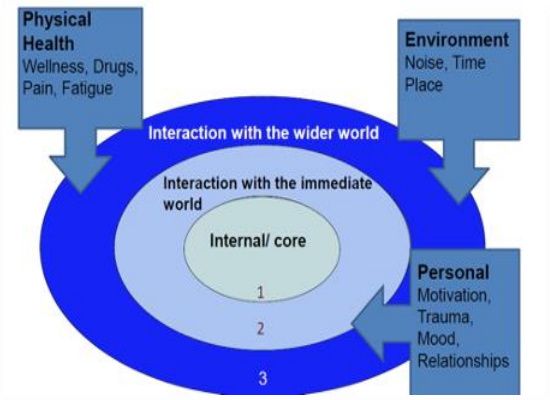
The impact of the Citizens' Jury on professionals and stakeholders in health research who were directly involved

- Expert witnesses reported positive experiences in giving evidence to the Citizens' Jury
- Expert witnesses came from different backgrounds and some witnesses needed more time and support to contribute

2.2. The effectiveness of the Citizens' Jury approach in supporting jury members to deliberate on health research and have their voice heard

Planning for this project drew on the project team and project facilitators' expertise in working with people with learning disabilities, as well as literature on Citizens' Juries. When developing a facilitation approach for the jury itself, the team drew on Roberts and Escobar's (2015) work to define principles of deliberative democracy in practice. The project aimed to support deliberation that was **"un-coerced, other regarding, reasoned, inclusive and equal debate"** (Chappell, 2012, pp. 7-10; see also Dryzek 2000, 2010).

Quality of deliberation



The concept of equal and inclusive debate was interesting for this group, who each had different communication styles and support needs. Ultimately, as with all groups, some jurors were more confident in their communication than others. Using the Talking Mats circle model, one facilitator reflected on the different communication strengths of the group and how this impacted on participation:

"Most of our jury members operate in level 3 of the model. This means they can think about things outside their immediate world and that means they can engage with aspects of the jury … There is at least one group member whose availability is always in terms of [their] immediate world and therefore accessing information about concepts like research will always be a challenge no matter what communication supports we put in…I think we need some honest reporting of this rather than assuming we can get over all barriers by inclusive communication – we can get over a lot but not all" – Facilitator notes

As noted in this facilitator reflection, not all barriers to participation can be addressed through inclusive communication. However, ethnographers in attendance noticed that peer support played a strong role in supporting good quality deliberation, and ethnographers' notes outlined several examples of supported deliberation in practice including:

- Jurors asking other jurors to read out their questions for them or ask questions on their behalf (*"I could be your voice for you"* – Juror)
- Support workers finding opportunities for engagement (e.g. one juror found it hard to connect with a more abstract concept presented by an expert witness. Their support worker went through the presentation slides with them and pointed out similarities in their employment history which sparked an interest in the juror to formulate a question)
- Jurors celebrating each other's successes, encouraging other people to participate and offering to sit with them to build their confidence

Some jurors initially struggled to show consideration of and response to each other's different views, and particularly struggled with challenging each other, as a Citizens' Jury

should. One group member reflected on why challenging other people and being challenged was difficult:

"I was OK once it went on but at first, I felt nervous. I'm not used to saying…really challenging people's point of view - I'm always one that just agreed even if I'm not happy"
- Juror

On the final day of the Citizens' Jury when the jury was tasked with forming their final recommendations, facilitators decided to introduce the role of the 'challenger', where one facilitator moved from group to group to challenge recommendations to make them more robust. This facilitator wore a 'challenger' scarf while in this role so that it was clear to the group that it was a role and not a personal challenge.

There was a mixed response to the role of challenger. Some jurors reported positively about the impact and were able to engage with the challenger constructively to better their ideas.

One ethnographer commented that response to these challenges may be determined by how confident and communicative each individual juror was, and for some jurors they observed a dip in confidence or a perceived lower mood as a result of the challenge. This view was supported by jurors during evaluation, with 3 of the 9 jurors sharing negative experiences of the challenger:

"Some of it was like oh man I don't know what to say" – Juror
"Annoying" - Juror

In future, there could be value in keeping the 'challenger' role, but it is important that this challenger has a clear and understood role. Perhaps introducing the challenger role in earlier workshops would have normalised the practice and limited the negative impact on juror confidence.

Interestingly, ethnographers and facilitators all reflected on what participation *looks like* in an adapted Citizens' Jury for people with learning disabilities. Some jurors learned and engaged differently, choosing, for example, to fidget to help them focus or to take frequent breaks to stay engaged. One juror was mentioned in all of the ethnographers' notes, as they appeared to be asleep for periods of Expert Witness testimony. However, this juror also asked poignant and well-reasoned questions to experts and was able to reflect in their group on key learning points. Conversely, another juror who seemed much more engaged (taking notes and leaning in to indicate listening) told facilitators they were tired and had missed whole sections of presentations. Perhaps the performance of engagement does not always indicate engagement, and future adapted Juries should normalise and accept different styles of listening and learning.

The Citizens' Jury was demanding for jurors. There was a recorded dip in attention and engagement for jurors in the afternoon sessions, with some feeling keen to head home or feeling sleepy. In addition, facilitators reflected that while everyone had an equal opportunity to contribute, the pace of the process meant there was no additional time to work individually with jurors to gage their understanding or reinforce learning.

Feeling heard

It is challenging to measure how 'heard' the group felt, but throughout the process the group was overwhelmingly positive about their experience. One juror reflected that they enjoyed the debate element of the project:

"You get to share your side. I felt happy when I heard other points of view" - Juror

For many Jurors, the social aspect of the group was the most important change for them, and for some members the group was one of their only opportunities to meet up with other people;

"It's good getting to know other people and getting friendly new friends" – Juror

"It was good. Felt part a team or a group, because I don't go out to work... I felt really part of a team - all are together. It did good for my self confidence." - Juror

In addition to social impact, some jurors also felt invested in the impact of the work and hoped it could change the world of health research:

"It may improve on how the research has done" - Juror

In a blog post about his experience, one group member wrote:

"We feel left out speechless voiceless never feeling part or important feeling alone is never good for anyone but with a disability it's scary harder to put your trust in people to do right things by you and be let down now I personally am now a better person better speaker talker never feeling alone"

KEY LEARNING:
Key learning from this project was that it was important to respond to what motivated the group to participate. The project team invested in the social aspect of the group (with shared birthdays, longer lunches and group celebrations) and believe this fostered trust and peer support as well as kept the group engaged in the process. Future adapted Citizens' Juries may benefit from recognising the impact of social isolation on participation and confidence explore whether brokering stronger community relationships should be an explicit aim of deliberative democracy for marginalised groups.

The role of facilitation

In the analysis of Citizens' Juries, "the process of facilitation itself has been largely ignored" (Wakeford and Pimbert, 2013). Facilitation was a particularly important part of the process for this adapted Citizens' Jury as the project was working with people with a wide range of support and communication needs, some of whom had never taken part in group work before.

Throughout the project, facilitator to juror ratios never fell below 1:6, and most sessions aimed to have at least 3 facilitators. It is important to note that a reflection from one ethnographer who attended the Citizens' Jury was that the number of facilitators may have been overwhelming at times and raised the question of whether facilitators could have clearer individual roles. This is a potential planning challenge for adapted Citizens' Juries, where fluctuating needs of the group may mean differing facilitation ratios are needed at late notice. For example, on days where one juror was unable to secure support with transcription, facilitator roles needed to change to respond to these needs. Jurors were consistently positive in their feedback on the facilitation of the project.

Facilitation was tight and task-focused. However, where possible, jurors were encouraged to take on a leadership role and facilitators were committed to limiting their input only where they felt necessary. The role of facilitator included:

- Balancing the contribution between group members
- Supporting and encouraging group members to express views, ask questions and contribute
- Fostering opportunities for peer support and cooperation
- Clarifying the task and adapting the task where it was not achievable
- Refocusing on task
- Supporting recording i.e. through note taking or assisting the graphic facilitator to capture details of discussion

In their first workshop, the group negotiated their group rules and agreed a working together agreement. Facilitators referred to rules throughout, and usually a reminder and redirection was all that the group needed to get back on track.

Facilitators sometimes had to closely mediate debate between jurors to ensure both jurors understood each other's perspectives and had a chance to share their views. Facilitators also used a range of group consensus-finding techniques, including votes, Talking Mats, 'thumbs up' or 'thumbs down' and individual agreement to make sure individual decisions were un-coerced and everyone had the opportunity to express independent views. Sometimes this presented a challenge in group settings where individual jurors did not have the confidence to challenge what they perceived to be consensus:

> *"It was frustrating. You didn't want anyone to be annoyed with you. I just did thumbs up to all them, like 'go with the flow'"* – Juror

As a response to this feedback, facilitators decided to dedicate an additional post-jury workshop to confirming final recommendations and giving more opportunities for smaller group conversation to refine, challenge or change recommendations.

A final reflection on facilitation was that our relationship-focused facilitation should have prioritised thoughtful endings between participants and facilitators, particularly for facilitators who joined the process for short periods of time. Another confounding factor for these endings was COVID-19, which shifted communications online and meant that vital opportunities to celebrate successes and plan a transition for this group were missed.

LEARNING POINT:
A key learning point for facilitators reflecting on the process was that personal experience was a lens through which jurors analysed evidence and related to the democratic process. This is not unique to deliberative processes including people with learning disabilities and Escobar (2011) notes that deliberation requires emotional engagement. Facilitators allowed space for personal stories where possible, particularly in smaller groups, and then looked for opportunities to connect these narratives with expert witness testimony. For example, one juror told the story of a family member enduring bullying and harassment and the impact of this on their wellbeing and facilitators supported her to form this story into a question about the impact of bullying on the health of people with learning disabilities.

A reflection of the project team was that the jurors were at times emotionally vulnerable because of what they were sharing and while facilitators could offer support in the moment, there was no longer-term strategy to support the group. However, future projects should consider having more structures of support in place which may include counselling services or group support.

Ultimately it was this personal storytelling that brought depth to the discussion and differentiated the discussion from one led by professionals to a discussion that was led by people with learning disabilities.

Addressing barriers to deliberation

Memory was a key barrier to reflection and deliberation for some Jurors, and a challenge that facilitators had to address in process design. Jurors reported a fear of forgetting throughout the project, often highlighting how poor memory could impact on confidence:

"I'm not good at remembering. I was scared I could get into trouble" – Juror

Facilitators took an active role in supporting memory and recall throughout the process and provided:

- Recaps of previous workshops at the beginning of each meeting
- A jury pack which contained presentations from each expert witness which could be accessed at any time
- Recorded presentations from expert witnesses which could be re-watched
- Photos of expert witnesses which could be used in place of names

However, the most effective tool for supporting memory was graphic facilitation. The team hired an experienced graphic facilitator who had worked with people with learning disabilities before. The graphic facilitator used simplified language and illustrations to capture the key points made in presentations, and then recorded questions and answers using easy to understand language and drawings. These were used in real time by jurors:

"See you did not get a question... [the graphic facilitator] wrote it down and you read it. She might even write it in easy words" - Juror

On the final day the Citizens' Jury used these graphic summaries to aid their deliberation. Another interesting benefit of graphic facilitation is that the process set a pace for expert witnesses. If the presenter was speaking too quickly to be graphically captured, it was very likely they were speaking too quickly for the group to engage. This was a useful pacing tool for the group, as pace and speakers talking too quickly was an ongoing communication barrier.

KEY LEARNING:

A key learning point was that smaller details in planning the Jury had meaningful impact. An example of this was team t-shirts developed for the Jury. In the final planning workshop before the Citizens' Jury began, jurors were invited to share concerns. A common concern was about what to wear, accompanied by an anxiety that they would not look professional enough given the calibre of expert witnesses. The workshop facilitator tried to reassure the group that they were not expected to dress professionally and that expert witnesses could be asked to dress casually, but instead the group asked for matching team t-shirts. The team ordered these for a small cost and presented them on the first day of the Jury. The jurors wore these throughout, and they brought a cohesiveness to the group. This is a small example of how anxieties can be addressed by listening to the needs of marginalised groups, and understanding the power dynamics that underpin them.

Juror 5*: "[the facilitator] doesn't just say she's listening, she shows she is"*
Juror 8*: "Yeah I can't believe we actually got them [the t-shirts]"*

Conclusions:

Facilitation was the most important component for achieving key principles of deliberative democracy. At key points in the jury, jurors showed evidence of thoughtful, open and balanced debate. However, the different support needs and communication demands of this group made measuring equal contribution challenging, as everyone's contribution was very different. Throughout the Citizens' Jury, acknowledging and responding to different perspectives and challenging one another was difficult for the group and may be an area for future development.

2.3. The impact of the Citizens' Jury on Jury Members' knowledge and confidence

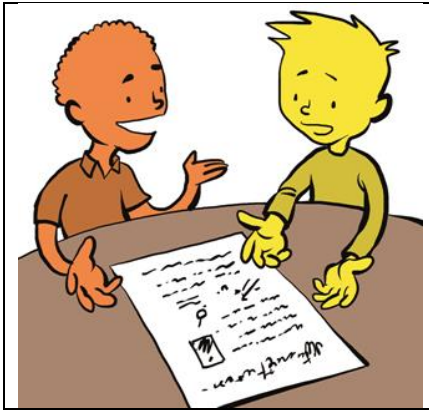
An aim of this project was to evidence whether this approach would have a demonstrable impact on the knowledge and confidence of participants.
The project team had to develop novel methods to measure knowledge and confidence before and after the project. The group chose to use Talking Mats, a form of augmentative and alternative communication (AAC) that facilitate conversations. Using this method, participants communicate their opinions and preferences by placing symbols representing words or concepts on a scale.

The benefits of using Talking Mats include:

- Successful adaptation as a communication approach for people with learning disabilities (Betty-Jean et al, 2020)
- The ability to deconstruct complex ideas and concepts into smaller, more focused ones
- The ability to structure conversation and avoid open ended questions
- Flexibility in adding vocabulary and symbols
- The ability to confirm results (Bunning and Steel, 2006) and allow opportunities for redress and clarification

Participants were interviewed once at the beginning of the project, as part of their project recruitment and then again after the Citizens' Jury had concluded. These interviews were conducted in different settings. However, because some of the options that were being discussed were abstract and potentially unfamiliar to the participants, the Talking Mat was combined with an easy read document that allowed those options to be explained e.g. ethics, consent, risk so that there was a common language that related to the participants and supported their participation

For example, the word 'Consent' was explained as:

	If you are a research participant it is your right to say 'yes, I want to take part' or 'No, I don't want to take part' If you change your mind you can stop being involved **This is called Consent**

In the interviews, participants were presented with one symbol at a time and then asked to place the symbols using a topscale (i.e. 'I know a lot about that' or 'I don't know about that'). The conversations were structured to allow people to place their symbols wherever they felt was right for them. Some jurors had more positive engagement in the interview process than others. Based on work from Cameron and Murphy (2007), good engagement was measured in terms of eye contact, body language, and additional comments.

Limitations to this method

Some jurors chose to have these interviews at home, others asked for a neutral location. There were clear instances where the physical aspect of the communication environment (Bradshaw, 1998) was not ideal. Some participants chose to have a supporter with them, either a paid support worker or family member. There were times where the presence was helpful and added clarifying information and put participants at ease, and occasionally other times where the supporters' involvement made it difficult to confirm independent contribution.

Self-reporting is a challenge in all interviews, but particularly for people with learning disabilities. Tourangeau et al (2000) suggest that self-reporting requires four cognitive tasks:

1. accurate interpretation of the question
2. retrieval of information
3. judgement of retrieved information
4. formatting a response

The use of Talking Mats aimed to add a framework to support these processes, but there were points in the interview process for all participants where at least one of these steps was challenging. Three in-depth case studies available here outline the challenges that emerge from self-reporting and explore how individual jurors engaged in the process of self-reporting in very different ways.

Health research

The 'Knowledge of health research' mat explored how much each juror knew about some key concepts in health research before the Citizens' Jury and after. Jurors were invited to report on their knowledge using a 3-star system:

3 stars	I know a lot about that
2 stars	I know a little about that
1 star	I don't know about that
Middle ground	Jurors were invited to shift symbols between star ratings where they felt it was most appropriate

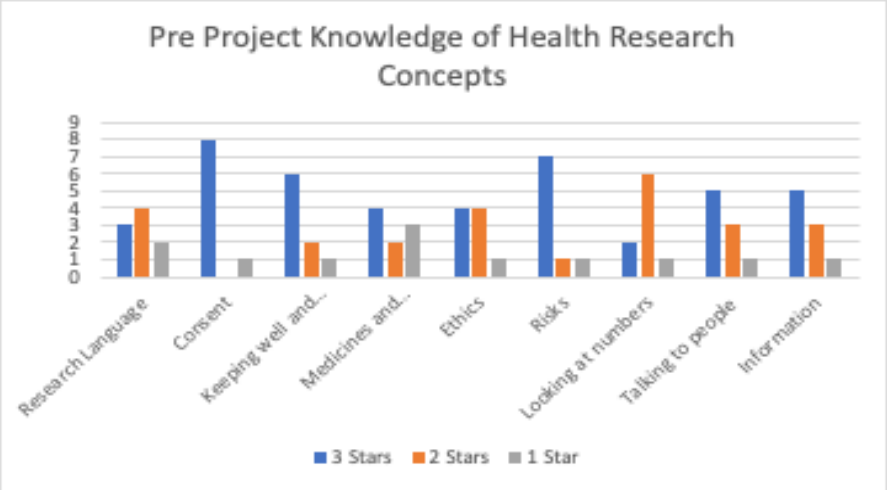
The Talking Mat explored 9 topics under two headings:

Heading 1: Things research looks at	**Heading 2: How research is done**
Keeping well and healthy Medicines and treatments Risks (health risks such as smoking or eating unhealthy foods)	Looking at numbers (statistics) Talking to people (interviews) Ethics Research language (jargon and language used in research) Information (accessible information about research) Consent (informed consent in research)

This Talking Mat was unique because it was accompanied by an easy read information sheet. The purpose of this information sheet was to explain key concepts in accessible language before asking people to rate their knowledge so that participants could accurately interpret our questions. This was a novel approach in Talking Mats methodology.

KEY LEARNING:
Overall, an analysis of pre and post project 'Knowledge of health research' Talking Mats showed an improvement in knowledge of health research, most notably a 58% reduction in jurors placing symbols in the 'I don't know about that' category.

In pre-project interviews, the concepts that jurors thought they knew most about were **Consent** (n=8 'I know a lot') followed by **Risks** (n=7 'I know a lot') and **Keeping Well and Healthy** (n=6 'I know a lot').

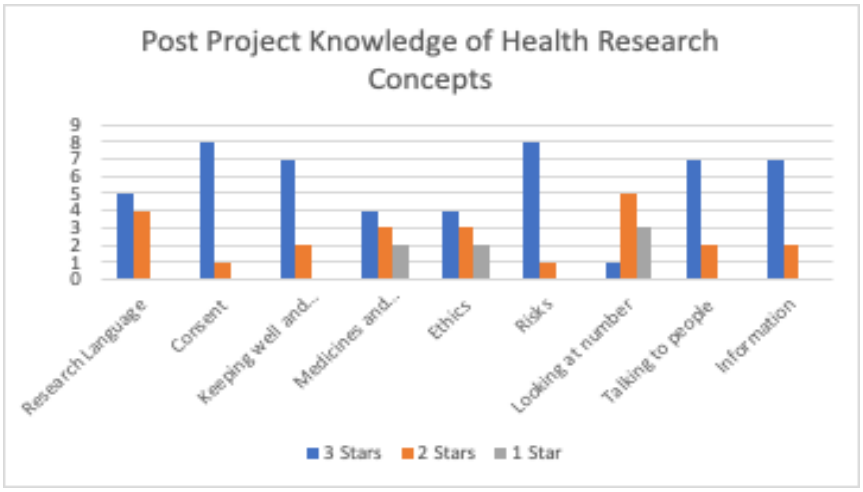


In the pre-project interviews, exploring specific examples was helpful for Jurors discussing **Risks**. Juror 3 initially responded *"I'm not very sure"* and gave a 1 star ('I don't know about that') for their knowledge of Risks. But using examples of health risks (such as drinking too much alcohol) meant they better understood the question and went on to discuss the risks of having sex without using a condom, before moving their symbol to 3 stars ('I know a lot').

In addition, knowledge of **Consent** was rated highly at the start of the project. The illustration of the symbol was also very concrete, and showed a person signing a consent form. Some jurors were able to recognise the consent form and use this as a talking point: Juror 5: *"if this was a real letter and this is me and I wouldn't know what I was signing."*

It is interesting to note that Juror 5 gave the same 3 star rating to **Consent** in their post project Talking Mat, but gave an indication of a more nuanced understanding of consent in a health research context: *"They [research people] cannae force you to do it"* – Juror 5

After the project, the concepts best known by jurors were **Consent** (n=7 'I know a lot'), **Keeping well and healthy** (n=7 'I know a lot'), **Talking to People** (n=7 'I know a lot'), **Information** (n=7 'I know a lot') and **Risks** (n=7 'I know a lot'). Knowledge of more concrete topics such as **Keeping well and healthy, Risks and Consent** remained strong following the project, but there was a significant increase in self-reported knowledge of some of the more abstract concepts related to research.



The biggest increase in self-reported knowledge was for **Information**, the symbol used to discuss research information. Jurors were able to express their preferences for accessible information about research and added more depth of comment in post-project interviews.
"I like pictures" (Juror 4)
"I want colour, not too many writing" (Juror 9)

Interestingly self-reported knowledge of **Medicine and treatments** reduced in post-project interviews. Medication and knowledge of available treatment was a theme in the Citizens' Jury, and many group members recognised how difficult it was to access easy to understand information and advice.

Self-reported knowledge of **Ethics** also decreased following the project. This is interesting because there was a focus on Ethics committees in the Citizens' Jury. However, the comments in post-project interviews do evidence more nuanced understanding of **Ethics** for some jurors, with one juror giving the example of putting poison in water without telling people, and another giving an example of having to ask if a student nurse or doctor could join a patient appointment. The complexity of jurors learning more about topics and

recognising that they are more complex than they initially assumed is explored in more depth in these case studies. Again, this may have been an issue of complex terminology leading to challenges in retrieving information.

Simplified language such as **Talking to people** and **Looking at numbers** were used in place of 'interviews' and 'statistics' respectively. From the comments in both pre and post interviews, it is clear that participants were not always accurately interpreting the question. Sometimes, trying to adapt complex language to be more accessible can mean that meaning is lost, and this is a consideration for future adapted Citizens' Juries.

Overall, self-reported knowledge was rated lowest for the symbol **Looking at numbers** (statistics). Participants rated low self-knowledge for the concept at in pre-project interviews, and an additional 2 jurors decided to place it at 1 star for knowledge after the project ended. However, an analysis of the notes from these interviews also suggests that this symbol was the most consistently misunderstood, as it depicts a person doing maths on a board. Some jurors wondered if this was asking about their knowledge of abilities in maths:

"Adding up or something...aye" (Juror 5)

This demonstrates that whilst symbols can support meaning there is a risk that they inadvertently narrow or confuse meaning. In this case, the association with maths triggered an immediate emotional response in some jurors that limited further discussion of what statistics really meant.

Confidence in communication

The 'Confidence in Communication' Talking mat explores how confident participants felt engaging in different types of communication and learning before and after the Citizens' Jury. Jurors were invited to choose from three options:

Thumbs up	I feel really confident about that
Shoulder shrug	Somewhere in the middle
Thumbs down	I don't feel confident about that
Middle ground	Jurors were invited to shift symbols between ratings where they felt it was most appropriate

While evidence suggests that questions about emotions can be more challenging to answer than concrete questions (see Argus et al., 2004; Finlay & Lyons, 2001; Marshall & Willoughby-Booth, 2007; Ruddick & Oliver, 2005), this topscale allowed for more reflection than simply asking about skills or knowledge.

The topics selected for this interview reflected key communication skills we thought would be practiced during the Citizens' Jury. Some of the questions (watching videos for

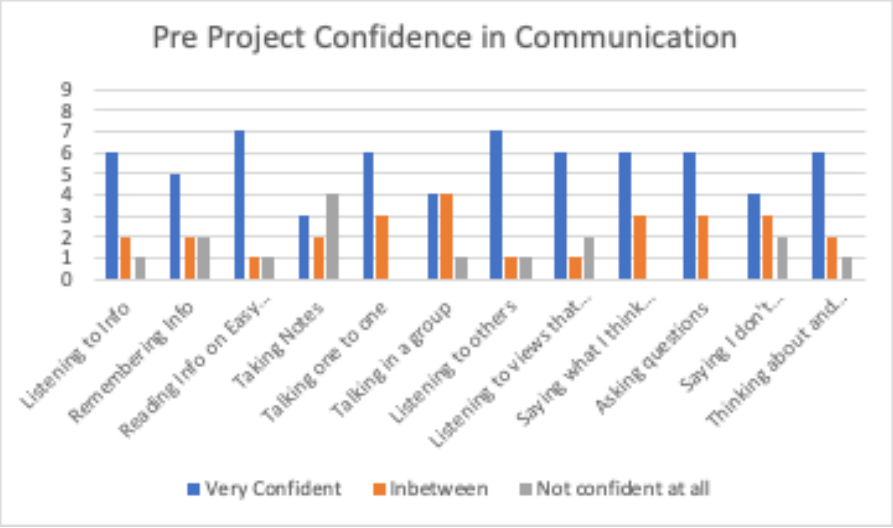
information and reading in easy read) also served to help the project team plan for accessibility through the process.

Topics:

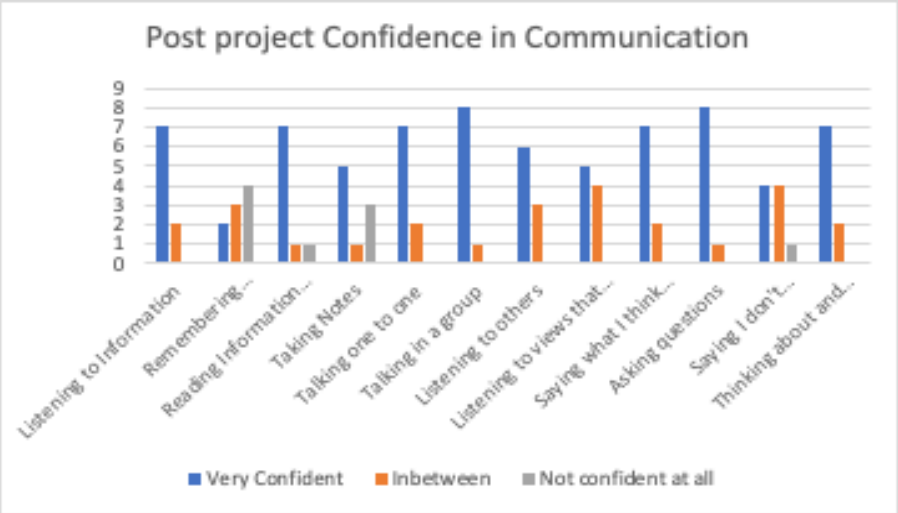
- Listening to information
- Remembering information in easy read
- Watching videos to get information
- Taking notes
- Talking one to one
- Talking in a group
- Listening to others
- Listening to views that are different from yours
- Saying what I think about something
- Asking questions
- Saying I don't understand
- Thinking about and learning new things

KEY LEARNING:
Overall, self-reported confidence in communication increased following the Citizens' Jury. The biggest shifts in this Talking Mat was that fewer people rated themselves as 'not confident at all' across all communication skills following the project.

Before the project, jurors said they were most confident in: **Reading information in easy read** and **Listening to others** ('very confident' n=7). However, jurors also rated **Listening to information**, **Remembering information, Talking one to one**, **Saying what I think about something** and **Thinking about and learning new things** as skills they felt very confident about (n=6). Some jurors offered a qualifying statement, for example asserting that they felt more comfortable talking one to one to certain people. Some jurors were particularly firm on **Reading in easy read**, stating that other formats such as long letters would not be possible for them to understand: *"Not gobbledegook [jargon]!"* (Juror 8)



The lowest self-reported confidence was in **Taking notes** ('not confident at all' n=4) and **Saying I don't understand** ('in between' n=3 and 'not confident at all' n = 2). Low confidence in note-taking may reflect challenges in literacy in people with learning disabilities. Jurors struggled to explain why they lacked confidence in **Saying I don't understand**, perhaps because of the complex reasoning behind this.



The three concepts that showed most improvement following the project were **Asking questions, Listening to views that are different to your own** and **Talking in a group**. These three concepts are the key skills that the project's pre-jury workshops focused on, so this improvement suggests that this skills development work had a positive impact on confidence.

Asking questions improved with almost all jurors rating themselves as very confident following the project (n=6 'very confident' to n=8 'very confident')

"I was quite good at [asking questions], that just surprised me - they kept popping into my head!" – Juror 1

Listening to views that are different to yours had no increase in participants saying they were 'very confident', but a decrease in people saying they were 'not confident at all (n=2 to n=0). One participant reflected on heated conversations as part of the jury:

"I was nearly arguing with [other juror]!" – Juror 2

Interestingly, **Saying what I think about something** did not have an increase in 'very confident' responses, but more participants moved their symbols from 'in between' to the space between 'in between' and 'very confident', showing improvement. One juror said they felt less confident in this, but attributed this to a change in their personal family life.

Jurors also showed an increase in self-reported confidence when **Talking in a group** (from n=5 to n=7 'very confident').

There was also a slight increase in confidence in **Watching videos to get information** ('very confident' rose from n=5 to n=6), although there were potential comprehension issues on

this question as the responses included references to watching sport, or films. However, one juror who moved from 'not confident at all' to 'very confident' in watching videos spoke about their experience of watching a video of a presentation they missed in the Citizens' Jury and being able to ask questions based on that video and felt they were very good at picking up information in this medium.

One symbol, **Reading information in easy read**, saw no changes after the project. This is likely because improving literacy was not an aim in the work. However, it is interesting to note that there was an increase in confidence in **Taking notes** (from n=3 'very confident' to n=5 following the project). We noticed in the course of the project that some jurors were copying down notes or using doodles to capture thinking and had the opportunity to practice these skills.

One concept that showed a decrease in confidence was **Remembering information** (n=6 'very confident' to n=3 'very confident' following the project). The issue of memory and confidence also emerged in the evaluation workshop of the group, with the group noting that memory was a difficult skill to master.

In these interviews, self-reported confidence was often impacted by elements outside of the project itself. For example, Juror 8 discussed the impact of communication aides on their confidence:

"My hearing is better" [due to hearing aid] - Juror

Discussions about confidence in communication were broader than conversations about health research knowledge, because they encompassed feelings drawn from day-to-day life outside of the project

Conclusions:

Despite methodological challenges in self-reporting, evidence from pre and post interviews shows noticeable improvement in self-reported knowledge of health research and confidence in communication following the project. These changes in confidence were also noted by the Research Voices project team in their evaluation reflection session, where each team member could name clear examples of changes in behaviour that supported these shifts in confidence.

2.4. The impact of the Citizens' Jury on professionals and stakeholders in health research who were directly involved

Expert witnesses play a key role within Citizens' Juries and other mini publics by ensuring that Juries have access to a "range of relevant opinions and evidence, which they can then scrutinise and synthesise with their own views to form collective recommendations." (Roberts et al, 2020).

In a preparatory workshop before the Jury, the group was invited to share their ideas for who they felt should join the Jury as an expert witness, with the aim of promoting more agency and avoid recreating power relations (Roberts et al, 2020). The group's suggestions were taken on as guidance for the organisers, who honoured many of the suggestions with adaptations, but also made some independent choices - for example, the choice to include an expert in ethics committees, as ethics is a known barrier to participation in research which the group did not know about. The result of this process was that the Citizen's Jury invited 7 expert witnesses to give testimony, listed in Appendix E.

There were difficult timelines for recruitment of expert witnesses in the project and a key learning point is that more time may be needed to give organising teams to recruit key witnesses. However, we were ultimately fortunate enough that through the links of the University of Glasgow, a competent panel with a wide range of specialities were recruited.

Before their contribution, expert witnesses were given guidance with the background of the group, key communication guidelines developed by the group and samples of accessible presentations. Each expert witness was also offered individual support from the project lead to develop presentations and were given feedback on presentations when asked. Not all experts chose to take up the offer of support, but most had at least one check in before their presentation. Some expert witnesses had extensive experience of working with groups of people with learning disabilities, others found the task more challenging:

"Quite a daunting task to take lots of health research and decide what was most important for our group" - Expert Witness

Each expert witness was asked to complete an evaluation following their input, and 5 of the 7 returned this evaluation. Expert witnesses reported an overall positive experience, and all agreed or strongly agreed that they were given time, information and support to develop materials.

"I found taking part in the Citizens Jury to be one of my most positive experiences of 2019"
- Expert Witness

All expert witnesses who responded said they agreed that jurors were able to engage on some level with their evidence. Experts reported taking between 4 and 16 hours to prepare and deliver their input to the group. It is important to note that for expert witnesses without experience in learning disabilities or accessible presenting, this may take more time. There is also an innate challenge in developing accessible information, which is how to make information simple without diluting its meaning. One ethnographer who attended the Jury shared their own frustration at feeling like the shorter input from witnesses meant they were not able to properly address the complex power dynamics that underpinned health inequalities.

Almost all expert witnesses commented on the quality of questions from the Jury, which had a personal and professional impact:

"They were insightful questions, ones with emotion and personal experience reflected in

the wording and thoughts. I spent the entire journey home considering some of their reflections… They made me consider areas that I hadn't really focused on …"
- Expert Witness

Jurors engaged with expert witnesses differently, often on an individual level. This is typical in Citizens' Juries, where "the expert is more trusted than the expertise they provide." (Aitken et al, 2016 in Roberts, 2020) Almost all jury members had a 'favourite' expert witness, and common feedback showed that friendly, informal presentations were well received:

"[Expert Witness] was good, so funny, excellent. The rest were kinda [makes motion of buttoning up his shirt and adjusting tie to suggest 'buttoned up' or serious]." - Juror

However, some jurors also responded to the high calibre and professionalism of expert witnesses. One juror was impressed that an expert witness had been on the news, as this meant they were an expert not just to the group but to the media.

Jurors sometimes had a critical perspective to offer on expert testimony, particularly group members with experience of self-advocacy. For example, one juror felt that an expert touched too briefly on the issue of participation of people with learning disabilities in their line of work and suggested to a facilitator that maybe that expert did not want to get into trouble with their boss, before deciding to ask a question pressing them for more information. This critical perspective was helpful for the wider group, but perhaps could have been fostered more if there was time to dedicate a preparatory workshop on bias and questioning the role of experts.

Conclusions:

Expert Witnesses reported mainly positive experiences of taking part in the Jury, and jurors had positive interactions with expert witnesses. However, the time taken to prepare for the Jury varied widely, and it should be taken into consideration for future adapted juries that experts may need support to make their input accessible without losing its depth. A reflection of facilitators was that the range of well-researched and substantial evidence presented by witnesses was key to the quality of group deliberation.

3. Final Recommendations for future adapted Citizens' Juries

3.1. Accessibility

- An accessibility-first approach to process design was vital to this project's success. We believe that future projects adapting deliberative approaches for people with learning disabilities would benefit from this same approach.

- Prioritising communication allows for equal contribution. Inclusive communication approaches including specifically designed Talking Mats were invaluable in

supporting communication in this project. However, in seeking a representative group of jurors and a complex topic for discussion not every barrier can be overcome with inclusive communication.

- In future adapted juries, we recommend planning one to one sessions with jurors who need additional support to navigate evidence, or more time to express themselves.

3.2. Resources

- We recommend that future projects should consider having more structures of emotional support in place which may include counselling services or group support.

3.3. Facilitation

- The success of this project in achieving its aims rested largely on the mix of skills and experience of the facilitators involved. Projects that seek to involve people with learning disabilities should work with experienced facilitators in that field and include people with learning disabilities themselves in planning and recruitment.

- Future adapted Citizens' Juries should consider the importance of socialisation and relationships to socially isolated participants and should plan appropriate transitions at the end of the project to reduce the impact of staff or peers no longer seeing each other.

- Engagement looks different for different people, and facilitators should be aware that in demanding processes, people with learning disabilities may not 'appear' engaged but are still able to make a meaningful contribution.

3.4. Planning

- The inclusion of capacity-building workshops with this group was vital to the project's outcomes and had a direct link to changes in knowledge and confidence. However, future projects might also want to consider building capacity in additional concepts including expert bias, constructive challenge and managing differences in opinion.

- In planning an accessible engagement process, time is often the most valuable resource. While this project had the benefit of 18 months to achieve its outcomes, there were particular pressure points in the project that perhaps required additional time including: the recruitment of jurors and the recruitment of expert witnesses.

- COVID-19 impacted on the final stages of delivery of this project, and many jurors experience digital exclusion. There was a commitment from the project team to continue to offer support and opportunities to participate to the group for as long as possible. Contingency planning, including access to equipment and internet connection, should be planned and budgeted for in future projects.

Sources

Betty-Jean M Dee-Price, Lorna Hallahan, Diane Nelson Bryen & Joanne M Watson (2020) Every voice counts: exploring communication accessible research methods, Disability & Society, DOI: 10.1080/09687599.2020.1715924

Braye S. (2000) The language of participation. In *User involvement and participation in social care*, eds H Kemshall and R Littlechild. London: Jessica Kingsley Publishers.

Bunning, Karen & Steel, Gabriela. (2006). Self-concept in young adults with a learning disability from the Jewish community. British Journal of Learning Disabilities. 35. 43 - 49. 10.1111/j.1468-3156.2006.00388.x.

Cameron, L. and Murphy, J. (2007), Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. British Journal of Learning Disabilities, 35: 113-120. doi:10.1111/j.1468-3156.2006.00404.x

Carson, L., Hartz-Karp, C. (2005). 'Adapting and Combining Deliberative Designs.' IN The Deliberative Democracy Handbook. Gastil, J., Levine, C. (eds). San Fransisco, CA: Jossey-Bass.

Cleaver, S. , Ouellette-Kuntz, H. and Sakar, A. (2010), Participation in intellectual disability research: a review of 20 years of studies. Journal of Intellectual Disability Research, 54: 187-193. doi:10.1111/j.1365-2788.2010.01256.x

Dee-Price, Betty-Jean & Hallahan, Lorna & Bryen, Diane & Watson, Jo. (2020). Every voice counts: exploring communication accessible research methods. Disability & Society. 10.1080/09687599.2020.1715924.

Dowse, L. (2009) 'Some people are never going to be able to do that': Challenges for people with intellectual disability in the 21st century. Disability & Society. 24:5, 571-584. 10.1080/09687590903010933

Duffy, J. (2006). Participating and Learning: Citizen Involvement in Social Work Education in the Northern Ireland Context. A Good Practice Guide. London: Social Care Institute for Excellence/Social Work and Social Policy (SWAP)/Northern Ireland Social Care Council (NISCC).

Escobar, O. (2011) Public Dialogue and Deliberation. A communication perspective for public engagement practitioners, Edinburgh: Edinburgh Beltane -UK Beacons for Public Engagement.

Hall, E. (2004). Social Geographies of Learning Disability: Narratives of Exclusion and Inclusion. *Area, 36*(3), 298-306. Retrieved August 10, 2020, from www.jstor.org/stable/20004395

Laws and Radford, (1998) in R. Kearns, W. Gesler (Eds.), (Eds), Putting Health into Place: Landscape, Identity and Well-Being, Syracuse University Press, Syracuse (1998), pp. 77-101

Morris, J. (2005). Citizenship and disabled people: a scoping paper prepared for the Disability Rights Commission. London: Disability Rights Commission.

Smith, G. (2009) Designing Institutions for Citizen Participation. Cambridge University Press.

Street, Jackie & Duszynski, Katherine & Krawczyk, Stephanie & Braunack-Mayer, Annette. (2014). The use of citizens' juries in health policy decision-making: A systematic review. Social Science & Medicine. 109. 1–9. 10.1016/j.socscimed.2014.03.005.

Raisio, H., Valkama, K. and Peltola, E. (2014). Disability and deliberative democracy: towards involving the whole human spectrum in public deliberation. Scandinavian Journal of Disability Research, 16(1), pp.77–97. DOI: doi.org/10.1080/15017419.2013.781957

Roberts, J.J., & Escobar, O. (2015). Involving Communities in Deliberation: A Study of Three Citizens' Juries on Onshore Wind Farms in Scotland.

Roberts, J.J., Lightbody, R., Low, R. *et al.* Experts and evidence in deliberation: scrutinising the role of witnesses and evidence in mini-publics, a case study. *Policy Sci* 53, 3–32 (2020). doi.org/10.1007/s11077-019-09367

Wakeford T., Pimbert M., (2013) 'Opening participatory democracy's black box: facilitation as creative bricolage' IN problems of participation: reflections on authority, democracy, and the struggle for common life. Noorani, T., Blencowe, C., Brigstocke, J. (eds). Authority Research Network

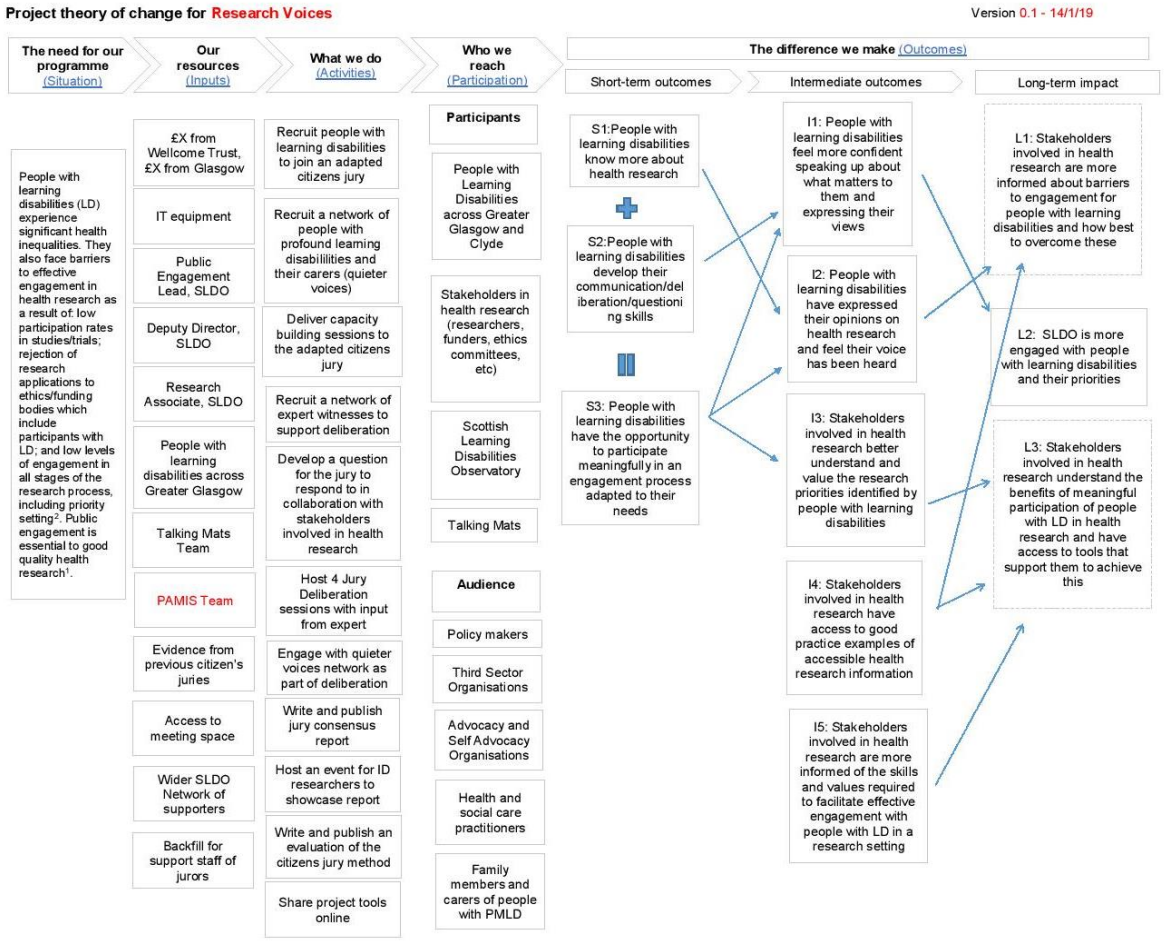
Walmsley, J. (2004), Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research. Nursing Inquiry, 11: 54-64. doi:10.1111/j.1440-1800.2004.00197.x

Wakeford T., Pimbert M., Walcon E. (2015) Refashioning citizens' juries: Participatory democracy in action. In: Bradbury-Huang H. (ed.) The Sage handbook of action research, 3rd ed. New York, NY: SAGE, (pp. 229–245).

Willis, D., McGlade, I., Gallagher, M., Menabney, C. (2016) Voting and the Scottish referendum: perspectives of people with intellectual disabilities and their family and paid carers. Disability & Society, 31:7, 914-928, DOI: 10.1080/09687599.2016.1211002

Appendices

Appendix A: Logic Model



Appendix B: Data Sources

Data Sources

Data source	**Time collected**	**Evaluation theme**
Talking Mats Interviews on: Knowledge of Health Research Confidence in Communication	At point of recruitment (pre-project) After the completion of the Citizens' Jury (post-project)	The impact of the Citizens' Jury on jury members' knowledge and confidence
Emotional Touchpoints process evaluation	Evaluation workshop after the completion of the Citizens' Jury	The effectiveness of the Citizens' Jury approach in supporting jury members to deliberate on health research and have their voice heard
Ethnographer/ observer feedback	Throughout the Citizens' Jury	The impact of the Citizens' Jury on jury members' knowledge and confidence The effectiveness of the Citizens' Jury approach in supporting jury members to deliberate on health research and have their voice heard
Talking mats 'Opinion mat' to judge changes in opinion before and after the mat	Day 1 Jury and evaluation workshop	The effectiveness of the Citizens' Jury approach in supporting jury members to deliberate on health research and have their voice heard
Expert Witness Evaluation surveys	Throughout Citizens' Jury	The impact of the Citizens' Jury on professionals and stakeholders in health research who were directly involved
Group evaluation Talking Mats	After first 3 workshops	The effectiveness of the Citizens' Jury approach in supporting jury members to deliberate on health research and have their voice heard
Research Voices team reflections	Throughout the project with a final	The impact of the Citizens' Jury on jury members' knowledge and confidence

	formal meeting April 2020	The effectiveness of the Citizens' Jury approach in supporting jury members to deliberate on health research and have their voice heard The impact of the Citizens' Jury on professionals and stakeholders in health research who were directly involved

Appendix C: Project Resources

This project was funded by the Wellcome trust, but also drew on partnership and community resources to achieve its outcomes. Project resources are listed below:

Core staffing	The project was delivered by a core team of people from the Scottish Learning Disabilities Observatory and Talking Mats, including 1 part time dedicated project lead.
Support staff	1 support worker (not funded by the project) 1 support worker with transcription responsibilities (not funded by project) 4 volunteer ethnographers/observers 1 volunteer note taker for the Citizens' Jury 1 student on placement to support data analysis
Expert Witnesses	7 Expert Witnesses volunteered their time (between 4-16 hours each) to attend the jury
Materials	Specialist materials including custom-designed Talking Mats
Expenses	Travel expenses for Jury members
Equipment	IT equipment including laptops, projectors and recording equipment
Venue	Accessible venue used for 13 full days Catering included

Appendix D: Jury Planning

Sample Expert Witness testimony schedule

Activity	Timing
Introduction in the morning and recap of group rules	15 minutes
Context for expert witness, who they are, what they will speak to the group about	5 minutes
Expert witness is welcomed to the group and introduces themselves	5 minutes
Expert witness is given 15 minutes for presentation, which can be paused if a person on the Jury does not understand but not for questions until the end (support is given to help jurors 'hold' a question)	15 minutes
First question round for 'burning questions' - these questions are urgent questions that will help the group process the presentation	5 minutes
Supported questions development - small groups work with a facilitator to share ideas, develop questions and consider which questions are most important	15 - 20 minutes
Second question round for 'powerful' questions - these questions dig deeper into the subject and can include constructive challenges. Each juror is given a chance to ask at least one question if they wish, and take turns asking questions in a clockwise order	up to 45 minutes
Final reflection on key learning - each juror is supported to record the key piece of information they took from the expert witness	5 minutes

Appendix E: Expert Witness List

Expert Witnesses who attended the Research Voices Citizens' Jury

Speaker	**Job role and Organisation**	**Presentation topic**
Laura Hughes McCormack	Research Associate, Scottish Learning Disabilities Observatory, The University of Glasgow	The physical and mental health of people with learning disabilities
Gillian Smith	Research Assistant, Scottish Learning Disabilities Observatory, The University of Glasgow	The physical and mental health of people with learning disabilities
Dr Thomas Kabir	Head of Public Involvement, The McPin Foundation	Research ethics and ethics committees
Professor Craig Melville	Professor of Intellectual Disabilities Psychiatry and Director of the Scottish Learning Disabilities Observatory, The University of Glasgow	Research funding – how projects get money
Ian Davies	Independent Self Advocate and Researcher (Northhamptonshire People First, The Open University)	My life as a researcher
Jenny Miller	Chief Executive, PAMIS	Including people with profound and multiple learning disabilities in health research
Professor Andrew Jahoda	Professor of Learning Disabilities, The University of Glasgow	How research can help people with learning disabilities get the right help for their problems
Professor Chris Hatton	Professor of Public Health, Disability Co-Director of Improving Health and Lives, the Public Health England Specialist Learning Disabilities Public Health Observatory, and Regional Co-Director of the NIHR Research Design Service North West, Lancaster University	Using information that health services collect about people with learning disabilities