



Scottish

Learning Disabilities

Observatory



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

Citizens' Jury Evaluation: Executive summary and recommendations

May 2021

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

Final Recommendations for future adapted Citizens' Juries

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.

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. 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.

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 in 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.

To read the full evaluation report in detail, please access the document [here](#).