

Tammy Prescott Patient and Public Involvement Award 2025 winner

Project Title
The Victoria and Stuart Project: Co-designing a toolkit of approaches and resources for end-of-life care planning with people with learning disabilities within social care settings.
Person(s) nominated
Team nomination including a multi-centre research team and all the people with a learning disability, families, Support Workers, and professionals who were members of the co-design (All Together Group) and Research Advisory Groups who worked with us on The Victoria and Stuart Project (2022-2024).
Short summary of the project
<p>Learning disability services asked us for help in knowing how to get end-of-life care planning right for the people they support. Our study aimed to investigate what is likely to work best for whom and to produce a toolkit of end-of-life care planning resources and guidance that are welcomed by people with learning disabilities, families, and staff.</p> <p>To develop the end-of-life care planning toolkit we:</p> <ol style="list-style-type: none"> 1. Reviewed what is known about end-of-life care planning with people with learning disabilities, and what approaches and resources are already available. We found little evidence about what works well and a limited range of resources (mostly easy-read forms). 2. Held focus groups with 101 people with learning disabilities, families, and professionals, asking about their views and preferences. There was overwhelming support for end-of-life care planning, but we found differences in opinion about what end-of-life care planning involved, who should plan, and when it should be done. 3. Worked with a co-design group of nine people with learning disabilities, plus 17 family carers and professionals to develop a toolkit. They selected creative and pictorial resources; discarded all easy-read forms; and co-developed new resources and guidance. 4. Asked staff to test the end-of-life care planning toolkit with the people they support, gathered feedback, and finalised the toolkit and guidance. <p>The final toolkit is freely available online on the study website (https://www.victoriaandstuart.com/).</p>
Patient and Public involvement in project summary
<p>The aim was for the entire project to be user-led and truly co-produced. We wanted to ensure that the project had people with learning disabilities, families, carers, and Support Workers at the centre, so that the study and its outputs were relevant, welcomed and used. We included stakeholders from conception of the project. Learning disability service providers and two university-employed researchers with learning disabilities were co-applicants on the funding application. Co-applicants with a learning disability helped articulate the study in an accessible way. The study was supported by two research advisory groups that included people with learning disabilities, families, learning disability and palliative care organisations. Their meetings were inclusive and accessible to all members of the groups.</p> <p>The research team included four salaried researchers with learning disabilities and a research assistant to support them in their research role. Project leads from two major learning disability organisations were also employed and helped with conducting the research. Researchers with learning disabilities helped to plan focus groups with people with learning disabilities, tested innovative and inclusive data collection methods (such as washing lines, voting boxes, hats and dustbins); co-facilitated focus groups; helped analyse the findings; were part of the co-design group (which they named the “All Together Group” as</p>

“co-design” was deemed to be unacceptable jargon); helped analyse the results; and played an important role in dissemination, including co-chairing webinars.

The “All Together Group” was the most truly inclusive part of this study. The nine group members with learning disabilities (including our four researchers) worked hard at testing resources, developing new and inclusive methodologies to run meetings and ensure a safe enough space to talk about difficult subjects, and inspired the All Together Group of parents, health/social care workers and managers. These, too, contributed creatively to the project. This meant that the project went in unexpected directions, with standard procedures and end-of-life care planning resources quite literally binned, and new ones created. This truly helped us understand what works and what does not, and why.

We finished the project with a toolkit launch conference, which was chaired and led by people with learning disabilities. Feedback from 100+ delegates was overwhelming, with many indicating it was the best and most informative conference they had ever been to. See here:

<https://www.youtube.com/watch?v=1Q0czNG9F4k>.

People with learning disabilities, families and support workers were crucial to the success of this project. 195 people were actively involved in this project as contributors, including 36 people with learning disabilities (18.5%). The truly inclusive nature of the study was noted by stakeholders throughout, for example, through comments by the 1000+ delegates at our live webinars. We have demonstrated and described our learning from inclusive methodologies and co-production in presentations and academic papers. The final report to the funders also included an accessible final report video narrated by the researchers with a learning disability: <https://www.youtube.com/watch?v=FgKS1tnu-UU>.

Co-production has been a core value of the project and ensured that the end-of-life care planning toolkit is relevant and workable in practice. Following completion of the project, we have been approached multiple times regarding offering a free print service of the resources, translation of the resources into other languages, and doing workshops and training for staff. This is all due to the hard work of all the people involved in this project.

Who is the project lead?

Prof Irene Tuffrey-Wijne

Who was the funder for this project?

National Institute for Health and Care Research (NIHR202963)

Useful links/ resources

Project website: <https://www.victoriaandstuart.com/>

Published papers:

Bruun, A., Cresswell, A., Jeffrey, D., Jordan, L., Keagan-Bull, R., Giles, J., Swindells, S., Wilding, M., Payne, N., Gibson, S.L., Anderson-Kittow, R. and Tuffrey-Wijne, I. (2024), The All Together Group: Co-Designing a Toolkit of Approaches and Resources for End-of-Life Care Planning With People With Intellectual Disabilities in Social Care Settings. *Health Expectations*, 27: e14174. <https://doi.org/10.1111/hex.14174>

Bruun A, Cresswell A, Jordan L, et al. What are we planning, exactly? The perspectives of people with intellectual disabilities, their carers and professionals on end-of-life care planning: A focus group study. *Palliative Medicine*. 2024;38(6):669-678. [doi:10.1177/02692163241250218](https://doi.org/10.1177/02692163241250218)