

Assisted Dying Public Engagement Project

24th November 2023 – Advisory Board Meeting Minutes

2 - 4:15pm, online via Microsoft Teams

Attendance – Advisory Board members:

Anne Kerr (Chair), Professor of Science and Technology Studies and Head of School of Social and Political Sciences, University of Glasgow; NCOB Council member

Clare Chambers, Professor of Political Philosophy, University of Cambridge; NCOB Council member

Sarah Cunningham-Burley, Professor of Medical and Family Sociology / Dean of Molecular, Genetic and Population Health Sciences, The University of Edinburgh; NCOB Chair-elect (January 2024)

Suzanne Hall, Director of Engagement, The Policy Institute, King's College London

Rachel Lopata, Freelance Researcher

Malcolm Oswald, Director, Citizen' Juries c.i.c; Honorary Research Fellow in Law, University of Manchester

Michael Reiss, Professor of Science Education, Institute of Education, University College London; NCOB Council member

Holly Rogers, Head of Engagement, Academy of Medical Sciences

Selena Stellman, General Practitioner; NCOB Council member

Nuffield Council on Bioethics:

Cris Cloyd, External Affairs Manager

Molly Gray, Project Manager

Rebecca Mussell, Associate Director, Research and Policy

Hopkins Van Mil/ M.E.L Research/ Independent evaluation:

Henrietta Hopkins, Director

Hally Ingram, Senior Associate

Kate Furber, Researcher

Kirsty Marshall, Associate Director, Research and Policy

Leah Holmes, Independent Evaluator

1. Welcome and introductions
2. Assisted Dying project background and context
 - NCOB gave an overview presentation that ran through the background of the project, roles and responsibilities, and the project timings.
3. Advisory Board draft Terms of Reference and membership
 - Board members were specifically asked to declare any conflicts of interest related to the project and their work. None were offered or recorded. (This

follows previously being asked to declare any real, potential, or perceived conflicts of interest related to the project ahead of the first meeting of the Advisory Board).

- Discussion of the draft Terms of Reference (circulated to Advisory Board members ahead of this meeting). It was **advised** that:
 - i. There needs to be a clearer distinction between the responsibilities of the Content Group and those of the Advisory Board, and that this needs to be modified to ensure a clear separation of roles.
 - ii. The draft Terms of Reference needs to be redrafted to add clarity on the role of the Advisory Board with respect to providing advice and/or decision-making.
 - iii. The language in parts of the draft Terms of Reference should be redrafted under 'role of the Advisory Board' to further emphasise providing advice on monitoring balance and integrity throughout the project.
- **Action (NCOB)** - redraft Terms of Reference taking into account Advisory Board feedback.

4. Citizens' Jury background and context

- HVM gave a brief overview presentation on the key features of a Citizens' Jury and the sortition process.

5. An overview of the methodology/plan

- HVM presented the methodology for the whole process including scoping and design, fieldwork, analysis and reporting
- M.E.L Research presented the plans for the two nationally representative surveys
- The independent evaluator spoke about the plans for the independent evaluation of the project, which includes both formative and summative processes.
- It was **clarified** that sortition invitations are sent to households instead of to individuals.
- It was **clarified** that participants will receive an incentive payment, which has been calculated in line with PPI rates used in healthcare. Reasonable expenses will also be paid when attending in person jury workshops.
- **Action (HVM)** – add the consequences of any delays to the sortition process to the live risk register document, as well as a contingency plan that will minimise disruption to project timeline.
- It was **clarified** that HVM will use various tools, including the online polling tool Mentimeter, to monitor changes in participant views over the course of the jury sessions.
- It was **clarified** that the purpose of the second survey is to compare the responses of a wider public group with what the Citizens Jury recommends in relation to assisted dying.

6. Group discussion on stakeholder engagement

- It was **clarified** that the purpose of the 12 stakeholder interviews conducted by HVM is to scope out potential evidence for the Jury, including expert witnesses, and to understand who might play the role of Jury Friend.
- It was **clarified** that the 12 stakeholders interviewed at this scoping stage are not the only stakeholders that will be involved in the research as expert witnesses or Jury Friends.
- It was **advised** that with 12 stakeholder interviews, it will be useful to prioritise interviewees that intersect topic themes, and reflect a balance of views.
- It was **advised** that the ethics dimension should be informed by both biomedical and philosophical evidence.
- It was **advised** that there is unlikely to be overlap between the 12 stakeholder interviews and the content group members, so as to include as wide a diversity in both.
- It was **agreed** that all 12 stakeholder interviews would be conducted by Christmas. The final stakeholder list will be shared at the next Advisory Board meeting in January.

7. Group discussion on surveys and Citizens' Jury design

- It was **advised** that it is important that the surveys capture the perspectives of those in older age categories.
- The **advantages** of including scenario and vignette based questions in the surveys was discussed.
- Draft jury questions were discussed. As a result of this discussion, it was **advised** that:
 - i. There needs to be clarity in the use of the terms “ethical, social and practical considerations”
 - ii. There needs to be clarity between the use of the terms - a circumstance or a constraint
- It was **agreed** that it is very important that the wording of the jury questions is right and this will mean several rounds of redrafting between now and the next Advisory Board meeting, as is standard with honing Citizens' Jury questions.
- **Action (HVM/NCOB)** – rework jury questions and circulate to Advisory Board members for next round of feedback.
- The Content Group was discussed.
 - i. It was **advised** that the group should be kept small in order to be able to work effectively and efficiently.
 - ii. It was **advised** that it would be good to have an individual with expertise on gathering/analysing empirical evidence as part of the Content Group.
 - iii. **Action (HVM/NCOB)** – work on Content Group shortlist considering Advisory Board feedback.
- Stimulus materials to be used in Jury workshops were discussed. The group made the following recommendations:

- i. It is important to ensure that stimulus materials are as accessible as possible for participants.
 - ii. It is crucial to clearly distinguish and explain to the Jury when the stimulus is objective fact or opinion.
 - iii. Quality checking expert witness presentations will be important to mitigate against unrelated aspects affecting participant views on the information received – for example, the quality of the delivery of the presentation.
8. Group discussion on horizon scanning/external factors
- Board members shared the following as things on the horizon which might impact on the delivery of the engagement project:
 - i. Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill
 - ii. Potential action by campaigning groups.
 - A risk register is being kept for the project and will be circulated to Advisory Board members for oversight.

It was confirmed that summary notes from this meeting would be made publicly available in line with the project's commitment to transparency and impartiality.

9. AOB
- The next meeting will take place in January.