

Nuffield Council on Bioethics

Terms of Reference for the Assisted Dying Advisory Board

Project title: Exploring public views on assisted dying

1. Introduction

The Nuffield Council on Bioethics (NCOB) has begun a new project exploring public views on assisted dying and the associated social, ethical, and practical considerations that the public considers important in forming their views and in their deliberations. The project will deliver:

- Two quantitative surveys on the public's views towards assisted dying.
- A Citizens' Jury with members of the English public to explore views about the current law on assisted dying; the circumstances and conditions where assisted dying should, or should not, be permissible; and the associated social, ethical, and practical considerations raised by assisted dying that the public considers important in forming their views and their deliberations.

The project will publish the findings from the public engagement work, including the recommendations from the Citizens' Jury. It will not give a NCOB view, position, or recommendations on assisted dying or the ethics of assisted dying.

NCOB has commissioned Hopkins Van Mil (HVM) and their partners M.E.L. Research and the Sortition Foundation to carry out the assisted dying public engagement project.

2. Aims and objectives

Project aim

To deliver credible, well-informed, evidence of public views about assisted dying in England, with the goal of generating an informed national conversation on the issue and embedding the findings of the public engagement with key decision-makers.

Specific project aims

- To explore public attitudes towards assisted dying in England and the circumstances and conditions where assisted dying should and should not be permissible; and to understand the associated social, ethical, and practical considerations that the public considers important in forming their views and deliberations.
- To identify the most up-to-date evidence and analysis of a diverse range of ethical views on assisted dying in order to inform the public engagement process.
- To inform future debates in this area and embed the findings of the public engagement with key decision-makers to inform any future policy and practice related to assisted dying.

Primary project objectives

- To deliver two quantitative surveys and a Citizens' Jury with members of the public to explore public attitudes towards assisted dying in England – the circumstances where and constraints under which assisted dying should and should not be permissible, and to understand the associated social, ethical, and practical considerations that the public consider important in forming their views and deliberations.
- To produce a series of authoritative and accessible opinion pieces on the range of ethical views on assisted dying.
- To engage government, media, and decision-makers (including professional bodies) on the findings of our report and public engagement, with the intention of informing future debates in this area.

Specific objectives of the public engagement activities

- To conduct a nationally representative quantitative survey of the English population to explore and capture current attitudes towards assisted dying.
- To use these initial survey results to inform the recruitment stratification criteria for the Citizens' Jury.
- To use the deliberative public engagement exercise to explore the views and deliberations of an informed Citizens' Jury regarding the current law of assisted dying in England; the circumstances and constraints where assisted dying should or should not be permissible; and the associated ethical, social, and practical considerations raised by assisted dying that the public considers important in forming their views and their deliberations.
- To conduct a second nationally representative quantitative survey of the English population to gather views on the recommendations and views of the Citizens' Jury.
- To produce a report suitable for sharing that will contribute and inform current and future debates related to assisted dying.

3. The role of the Advisory Board

The role of the Advisory Board is to oversee the assisted dying public engagement project and aim to give impartial and informed advice overall, constructive challenge, and feedback to the NCOB and HVM (and partners) project team on the project process and planning. The Advisory Board is established to:

- Oversee the design and process of the surveys and Citizens' Jury to help ensure the robustness, rigour, and integrity of the process and outcome.
- Monitor the impartiality of the project teams and help ensure the process is balanced overall.
- Support impact generating activities and act as an ambassador for the project.

The Advisory Board will be expected to advise on:

Balance and impartiality

- Oversee that the project process, including the surveys and Citizens' Jury design, process, so that evidence remains balanced and robust.
- Monitor the impartiality of the project teams.

- Support the process and oversee that suitable questions have been asked at the optimal times and that the people with the necessary expertise are part of the public engagement activities.

Support for the project process

- Act as a sounding board for potential activities or decisions about the project process or content.
- Give advice to the NCOB project team and HVM and partners in challenging situations (if they arise), including dealing with uncertainties and giving advice on contacting people with appropriate expertise quickly.

Ambassador role

- Provide advice and feedback on the public engagement activities from the set-up stage through to the dissemination of findings, impact, and follow-up.
- Disseminate and promote the findings through their own professional networks.
- Provide a credible independent voice for the project process, and if needed and where appropriate, provide quotations explaining the role of the Advisory Board, representing the project in media interviews, posting on social media, and presenting at events.

It is expected that the Advisory Board members will be asked to provide feedback on key aspects of the surveys and Citizens' Jury, including:

- The membership and appointment of the Content Group.
- The entities and people we consult.
- The overarching designs of the surveys and Citizens' Jury process.
- The key question(s) which Jury members are asked to deliberate on.
- The recruitment methodology.
- The process of speaker and evidence selection for the Citizens' Jury.
- The Citizens' Jury specifications and design documentations including the written briefings created for Jury members.
- The balance of who is invited to give evidence at the Citizens' Jury.
- Communications and engagement strategies.
- Outputs from the public engagement exercises, including written reports and films.

Members of the Advisory Board will be independent from the project teams. The NCOB and HVM project team commit to reporting back on how they have responded and acted on the advice of the Board.

4. Membership

The Board will be comprised of NCOB Council members and external experts representing a range of backgrounds and technical expertise/knowledge in public engagement, qualitative and quantitative methods, and diversity, equity, and inclusion (DEI).

The Advisory Board will be chaired by Professor Anne Kerr, Professor of Science and Technology Studies and Head of School of Social and Political Sciences, University of Glasgow.

Members should be committed to open dialogue, mutual respect and tolerance of other views, and be willing to see their own and others' opinions reviewed and discussed on merits.

Observers will attend Advisory Board meetings from the NCOB and HVM and partners to keep a record of the Board's advice.

5. Time commitment

We expect the Advisory Board to meet around 4 times between November 2023 and July 2024. This will be decided according to the needs of the project. Meetings are likely to be no more than 3 hours in duration.

Every effort will be made to find dates when all Advisory Board members can attend meetings. For key items of business where the group's opinion is sought, those not attending meetings will be invited to submit comments and views in advance. These will be presented to the rest of the Board.

We expect to hold the meetings in person (at the Nuffield Foundation's Offices in Farringdon, London), remotely via video conference or hybrid to enable maximum attendance.

For each meeting, pre-reading will be provided (likely to require approximately 2 hours). These materials will be discussed during the upcoming meeting. Board members will receive these materials 7 or more days before the meeting.

6. Conflicts of interest

Participants are required to declare any potential conflicts of interest that might compromise their participation in the Advisory Board, prior to taking up the role. A register of interests will be kept for the duration of the project and members will be asked to complete a form to declare any necessary interests when appointed.

7. Confidentiality

All Advisory Board members must treat as confidential any discussions at Advisory Board meetings, emails, and any papers that are tabled, including pre-publication copies of outputs/materials/reports.

8. Compensation

Advisory Board members will be offered an honorarium of **£160** for attending each meeting and reasonable travel expenses will be paid.

9. Transparency

Minutes will be taken at the Advisory Board meetings and kept on record.

A summary note, which is not attributed, that details the contents of the meetings, suggestions, advice, challenges raised, and questions asked during each meeting will be made publicly available.

Members, including those who were unable to attend the meeting, will have 5 working days to comment on meeting notes once received before they are circulated more widely.

Notes will be stored securely in accordance with Data Protection Arrangements at the NCOB and will not be shared beyond the immediate membership of the Advisory Board and the NCOB, although summary action points will be conveyed to the wider research team as appropriate.

Membership of the Advisory Board, along with their organisations and roles will be indicated on the NCOB's website, though members will be marked as attending in a personal capacity. The contribution of the Advisory Board will also be acknowledged in project outputs, such as reports, press releases, blog, as appropriate.