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Better care at the end of life

WHO Collaborating Centre for Palliative Care and Rehabilitation

KING'S College LONDON

BETTER-B

Better Treatments for Breathlessness in Palliative and End of Life Care

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BETTER-B: The ethical journey



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DISCLOSURE

- Name: Bobbie Farsides
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- Relationships with for-profit and not-for-profit interests: member of ethics advisory board of Our Future Health
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The role of ethics in BETTER-B

- Permissions and Governance
- Research Culture
- Relationships
- Support
- Ambition

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Embedding Ethics

- Ethics Advisor
- Ethics Advisory Committee
- Researchers as moral agents

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Ethical questions

- Should we be doing this work?
- How should we do this work?
- How do we deal with unexpected issues or challenges?
- How do we report the findings of our work?
- How do we secure the legacy of the project?

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The ethical importance of process

- The sharing of equipoise
- Scientific robustness
- Fair and appropriate recruitment
- Open and transparent reporting

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A few examples

- Research involving terminally ill patients
- Meeting the challenge of Brexit and Covid
- Preparing to share study results

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Who matters? Who counts?

- For an ethicist the focus is primarily upon the people recruited to a trial, but other people matter as well.
- A delicate balancing act between the good of the participant and the good of the trial
- Final piece of work is to demonstrate that everybody mattered, everybody counted, and everybody contributed

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