



Balancing Best Interests in Healthcare Ethics and Law (BABEL)

Information for Participants

Helping you to decide whether or not
to take part in our study

We would like to invite you to join our research,
and want you to know what is involved
before you decide.

Please read this booklet carefully.

Balancing Best Interests in Healthcare Ethics and Law (BABEL)
University of Bristol. Participant information booklet
October 2021

Invitation and brief summary

You are invited to participate in a research study about your views on how decisions are made in the 'best interests' of persons who are deemed to be unable to make decisions for themselves. The study is being conducted by researchers in the Law School at the University of Bristol. Before you decide whether to take part, it is important that you understand why the research is being done and what it will involve. Please read this booklet carefully and discuss it with others if you wish.

Part 1 of this booklet tells you the purpose of the study and what will happen if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Part 1

1. What is the study title?

- The study is called: “[Balancing Best Interests in Healthcare Ethics and Law \(BABEL\)](#)”.

2. What’s the study about?

- When a person is unconscious or is considered to be unable to make a healthcare decision for themselves, either permanently or for a limited time, a decision is made in their ‘best interests’ under the Mental Capacity Act 2005 or where the healthcare decision concerns a child, in accordance with Children Act 1989.
- ‘Best interests’ guides decisions about people of all ages and abilities who cannot make a decision for themselves.
- How ‘best interests’ is understood in healthcare and law, and how and when it is used has not been studied very closely.

3. Who is taking part?

- About 20-30 (legal and allied) professionals who have experience of working with the Mental Capacity Act 2005 and/or the Children Act 1989, or experience with the law on best interests decision making for adults and/or children, will be invited to take part in the interviews.
- The group sessions (witness seminars) will involve a group (10-12 people) consisting of different professionals (from law/health and/or social work) as well as other people who have been involved with key events relating to best interests decision making.
- We need participants who have worked closely with the law and have relevant knowledge/experience of how best interests decisions have been and are being made in legal contexts.
- We would like to talk to: legal and allied professionals who have professional experience

of how best interests is interpreted in a legal context, as well as

other professionals who have been involved with healthcare decisions or in legal developments relating to how best interests are interpreted by the courts.

4. What would taking part involve?

- The study involves talking to a researcher about your knowledge and experience of best interests decision making.
- You may take part in:
 - A research interview; and/or
 - A witness seminar (this is a type of focus/small group discussion)
- If you agree, the interview or group session will be audio recorded for later analysis by the researcher.
- The interview will take place in person or on a suitable online platform, and the group

seminars will be held in person – venue and timing TBC.

5. What does a research interview involve?

- Interviews will involve a researcher talking to you about your professional experience and knowledge.
- The interviewer will ask about your experiences of best interest decision making and what you understand by the concept of ‘best interests’.
- Interviews will involve one meeting with the researcher. Interviews will usually take about an hour.

6. What does a witness seminar involve?

- Witness seminars are similar to focus groups – and involve discussing in a small group (of approx. 10-12 participants) your views and experiences of a particular legal context of best interests. This may relate to a particular

case with which you were involved, or a consultation on the law, or a significant legal development or event that relates to best interests decision making that you were directly involved in.

- The project researchers will send you some information about the focus of the seminar in advance and a list of other participants who will be attending.
- The researchers will facilitate the group discussion and the invited participants will have been directly involved in the particular legal case/event.
- Witness seminars will take between 2-3 hours.

7. What are the study aims?

- The study aims to uncover how best interests has been conceptualised and operationalised in a legal context, with a view to influencing future law and policies that guide a range of

professionals, families and carers in making decisions for others.

- The results of the study will help the views and experiences of patients, families, carers and professionals play a part in these framing future laws and policies.

8. What are the possible benefits of taking part?

- There may be no direct benefits to taking part, although you may find talking about your views and experiences interesting, or that it gives an outlet for your feelings.
- The main benefit of the study will be to give you some influence in national discussions about the way healthcare decisions should be made.

9. What are the possible disadvantages and risks of taking part?

- Depending on your experiences, you may find the interview topic upsetting. It may remind

you of stressful episodes you have personally experienced. The situations discussed within the interview may remind you of your own experiences and you may find discussing these difficult. Should you find the interview or group distressing you will be able to stop taking part at any time.

This completes Part 1 of the information sheet. If the information in Part 1 has interested you and you think you may wish to participate, please continue to read the additional information in Part 2 before making a final decision.

Part 2

10. What if something goes wrong?

- If something has gone wrong or you wish to make a complaint, please contact:

University of Bristol
Research and Enterprise Development
One Cathedral Square
Bristol, BS1 5DD
Telephone: 0117 428 3065
Email: red-office@bristol.ac.uk

11. What will happen if I don't want to carry on with the study?

- Your participation is voluntary and if you decide to take part you will be free to withdraw at any time without giving a reason.
- If you decide to withdraw, we will retain use of the information you give us during your interview before your withdrawal.

12a. How will my personal data be kept confidential?

- All of your identifiable personal data (your name, contact details etc.) will be kept confidential, and will not be disclosed to anyone outside of the study.
- The only exception to this is if a court orders it to be released.
- Neither your name nor any identifiable details will be reported in any research papers or other outputs from the study.

12b. Will my study data be kept anonymous?

- Your study data (i.e. the information you give us during your interview) will be anonymised, which means it cannot be traced back to you personally.
- Written reports and research papers from the study may include some quotations from interviews and seminars. These will be

anonymous and any identifying features will be removed.

12c. How will my data be stored?

- Identifiable personal data, and anonymised study data will be stored securely, in either locked cabinets or on password protected computers in accordance with the University of Bristol's research governance policy and in line with the General Data Protection Regulations.
- Anonymised data may be shared with other researchers conducting research in this area in the future. Any requests for data sharing will be carefully screened and subject to approval by the university.

13. What will happen to the results of the study?

- If conditions allow, public events will take place during the study period to share our work and gain advice from interested groups.

These will give you an opportunity to hear how the study is going or give feedback from your participation, should you wish to attend.

- When the study has concluded, you will be provided with a report of the results, if you wish.
- The study results will also be published in legal and medical/scientific journals.
- The study results will also be presented at legal and medical conferences in order to circulate them as widely as possible.

14. Who is organising and funding this study?

- The study is being led by researchers in the Law School and Centre for Ethics in Medicine at the University of Bristol.
- A team of experienced university researchers will conduct the interviews and facilitate the groups.

- The study is being funded by the [Wellcome Trust](#), a charity that aims to improve health and wellbeing.

15. Who has reviewed this study?

- This study has been given a favourable opinion by the University of Bristol Law School Research Ethics Committee.

16. I would like to take part. What should I do?

- If you would like to take part or want further details about the study, please contact our Senior Researcher, Aoife Finnerty via email at: aoife.finnerty@bristol.ac.uk
- The researcher will be able to answer any further questions you may have about the study, decide how you can take part, and arrange a date for a meeting.
- You will have further time to think about whether you want to take part or not before the researcher contacts you again.

- When you meet with the researcher, they will give you a further opportunity to ask questions about the study. If you are happy to take part they will ask for your written consent. A copy of the consent form will be given to you and the original paperwork will be kept by the researcher.

**Thank you very much for taking the time to read
this information booklet**

Please keep this copy

If you there is anything that you don't understand
or if you would like more information or in a
different format, please contact the project
researcher: Dr Aoife Finnerty:

Email: aoife.finnerty@bristol.ac.uk