



University of
BRISTOL



Balancing Best Interests in Healthcare Ethics and Law (BABEL)

Information for Participants

Helping you decide whether or not
to join our research

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.

Invitation to take part in research

You are invited to take part in research to find out what you think about 'best interests' decisions. 'Best interests' guides decisions made for people who can't make decisions for themselves because they are too young (referred to as 'immaturity' in law) or unwell.

The research is being done by the Centre for Ethics in Medicine at the University of Bristol. Before you decide if you want to take part in it, we want you to know why the research is being done and what you would be asked to do.

Please read this booklet carefully and talk about it with other people if you want to.

Part 1 of this booklet tells you what the research is for and what will happen if you take part.

Part 2 gives you more detail about the research.

Part 1

1. What is the research study called?

- The research study is called: “Balancing Best Interests in Healthcare, Ethics and Law”. This is shortened to “BABEL”.

2. What’s the research about?

- Children or adults who can’t make a health or care decision for themselves have decisions made in their ‘best interests’.
- ‘Best interests’ guides a huge range of decisions. For example, best interests might be used to decide about...
 - The food someone eats
 - The sort of medicines someone receives
 - The type of treatment someone has
 - Whether treatment continues or stops
 - What happens to their body after a person dies

- These decisions may be taken about adults or children by professionals, carers, parents or people close to the patient.
- How ‘best interests’ is understood and used by people who make these decisions has not been looked at closely.

3. What are ‘ethics’?

- ‘Ethics’ is the study of what is good or bad. The research investigates the ethics of ‘best interests’ decisions and how the law reflects these ethics.

4. What does the research aim to do?

- The research aims to show people who make policy how health professionals, families and carers can make good decisions for someone else.
- The research will help patients, families, carers and professionals have a voice in working out

how these sorts of decisions should be made in the future.

5. Who is taking part?

- Up to one hundred patients, families, carers and professionals will take part.
- We need to speak to people like you who have seen how healthcare decisions are made in hospitals, care or residential homes, hospices and people's homes.
- We would like to talk to:
 - People who could not make a healthcare decision for themselves
 - Young people who were not allowed to make a healthcare decision for themselves
 - Families, parents, friends and carers, whose loved ones could not, or were not allowed to, make healthcare decisions for themselves.
 - Doctors, nurses and other health professionals who have seen or made

decisions in the 'best interests' of their patients.

- The person who the decision was about may now be well or may have since died.

6. What would taking part involve?

- The research involves talking to a researcher, either on your own or in a group. You will be able to choose how you wish to take part.
- You could take part in:
 - A research interview
 - A focus group
 - A series of three 'ethics discussion groups'.
- If you agree, the interview or group will be sound recorded so the researcher can study it later.
- You will talk on a computer or telephone, using 'Microsoft Teams', a computer program (app). Your access will be arranged by the researcher, and if you need help accessing a computer we will do our best to help you.

- Whether you take part in a research interview, focus group or ethics discussion group will depend partly on what you prefer, and partly on the stage of the research.
- In some cases, it will be possible to take part in an interview, a focus group **and** an ethics discussion group if you would like to.

7. What does a ‘research interview’ or ‘focus group’ involve?

- In a ‘research interview’, a researcher will ask you about your experiences of health care. You and the researcher will talk on your own. You are welcome to invite a friend or family member to accompany you if you wish.
- In ‘Focus groups’, two researchers will talk to you as part of a group of about 6 people, who will chat about experiences that you might have in common and how your experiences might be different.

- In both cases, the researchers will ask about how you have seen decisions being made, including what ‘best interests’ means to you.
- For interviews and focus groups, you will meet the researcher once. Interviews will take about an hour, focus groups will take up to an hour and a half.

8. What does an ‘ethics discussion group’ involve?

- In ‘ethics discussion groups’, two researchers will talk to you as part of a group of people, who will chat about the things the research has found so far. You will be asked about how ‘best interests’ decision-making should work in the future.
- Ethics discussion groups will involve three meetings with some of the same people.
- Ethics discussion groups will happen after all the interviews and focus groups have finished.

- Ethics discussion groups will take up to two hours. You'd be involved in three of these (six hours in total).

9. Are there benefits in taking part?

- There are no direct benefits to taking part, although you may enjoy sharing your views and experiences.
- Participants will be thanked for taking part with a gift of £20 of “Love to Shop” vouchers. These will be sent after the interview, focus group or ethics discussion group, even if the interview is interrupted for any reason.
- You may also enjoy knowing that you have taken part in research that will hopefully benefit other people.

10. Are there risks in taking part?

- Depending on your experiences, you may find talking about them upsetting. It could remind you of stressful or painful experiences.

- The situations the interviewer mentions, or that others discuss in focus groups or ethics discussion groups, could remind you of difficult experiences and talking about them could be hard.
- If you find any part of it distressing or upsetting, you will be able to stop or leave 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 take part, please continue to read Part 2 before deciding.

Part 2

10. What if I want to complain?

- If you are upset by anything in our research or you want to complain, please contact University of Bristol Research Governance team at:

University of Bristol
Research and Enterprise Development
One Cathedral Square
Bristol, BS1 5DD
Telephone: 0117 428 3065

Email: research-governance@bristol.ac.uk.

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

- If you decide to take part, you can stop at any time without giving a reason.

- If you decide to stop, we will keep any records of what you said up to the point that you stopped, and use this in the research. Nothing that could be recognised about you personally will be used.

12a. Will my personal information be kept private?

- Personal information is anything that might be recognised about you, like your name and contact details. This information will be kept private. No private things that can be linked to you personally will be shared with anyone outside of the research team.
- The only reason any private things could be shared is if a court orders it to be released because it relates to a possible crime: this is very unlikely to happen.
- We will not mention your name, or things which will be recognised by other people as being about you, in any results from the research.

12b. Will my research information be shared?

- Your ‘research information’ is the things you tell the interviewer about your experiences. These things will be ‘anonymised’, which means they can’t be recognised as being about you personally.
- Written reports from the research may include some examples of things people said in interviews or groups. Nothing that could be recognised about you personally will be quoted.
- Anonymised data (data where private things have been taken out) may be shared with other researchers doing research in this area. Any requests from other researchers to look at the data we gather will be carefully checked and will need approval by the University of Bristol.
- Anonymised data may also be used in training and teaching within the University of Bristol.

12c. How will my information be stored?

- Private things about you (like your name and contact details) will be stored securely, in either locked cabinets or on password protected areas of computers. We will follow the University of Bristol's 'research governance policy'.

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

- When it is safe to hold public events, we will publicly share our work and gain advice from interested groups. Public events will give you a chance to hear how the research is going, if you want to attend.
- When the research has finished, you will be sent a written report of the results, if you wish.
- The research results will also be published in medical and scientific journals.
- The research results will also be presented at scientific conferences in order to circulate them as widely as possible.

14. Who is organising and funding this research?

- The research is being led by Richard Huxtable, a professor of medical ethics and law who directs the Centre for Ethics in Medicine at the University of Bristol.



- A team of experienced university researchers will run the interviews, focus groups and ethics discussion groups.
- The research is being funded by the Wellcome Trust, a charity that aims to improve health and wellbeing.

15. Who has been involved in designing this research?

- The research protocol and materials have been prepared with the advice of patient support charities and similar organisations.

16. Who has reviewed this research?

- This research has been given a favourable opinion by the University of Bristol Health Sciences Research Ethics Committee [REF: 118590]

17. Can I get further details about this research?

- Giving your contact information to our research team using our online form will allow a researcher to contact you in order to answer any questions you might have.

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

- If you would like to take part please leave your details on the [online form](#). Please visit our website at: www/bristol.ac.uk/babel-take-part
- If you have difficulties accessing our online form, please email us at babel-project@bristol.ac.uk with your details
- Once we have your contact details, a university researcher will contact you. They will answer any questions you may have about the research, talk about how you can take part, and arrange a date for a meeting.
- You will have more time to decide if you want to take part or not before the researcher gets in touch again.
- When you meet with the researcher online or talk to them on the telephone, you will have another chance to ask questions about the research. If you are still happy to take part, they will ask for your written consent. A copy of the

consent form will be sent to you, and you will be asked to send or email the original to the researcher for safekeeping.

**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, please
contact Dr. Giles Birchley:
giles.birchley@bristol.ac.uk