

**Kingston
University**
London

We are researchers at Kingston University

**Do you want to
talk with us?**



Assisted dying



**We want to talk
with people with
a learning
disability about:**

- What **assisted dying** is
- What **you think** about it
- Any **questions** you have

It doesn't matter
if you don't know
what assisted dying is.

We still want to
talk with you!

If you are interested, email Fred Inglis for more information

f.inglis@kingston.ac.uk

Assisted dying and people with a learning disability



What is the project about?

The Assisted Dying (AD) draft bill is currently being discussed in parliament. This law would allow some terminally ill adults to ask for help to end their life in certain situations. If the bill becomes law, people with a learning disability could have assisted dying if they have capacity. But concerns have been raised about what this means for people with a learning disability in practice. At the moment there is no research about how people with a learning disability understand assisted dying, or their views on it.

Kingston University (supported by the Down Syndrome Research Foundation and Mencap) are conducting a pilot study which will involve speaking to up to 20 people with a learning disability. We will speak to people in small focus groups (3-5 people) and individual interviews. These will be supportive conversations, and we welcome people who do not already know what assisted dying is.

Who can take part?

We are looking to speak with adults who:

- Have a learning disability
- Are aged 18 or over
- Are able to understand what the study involves and decide for themselves whether they want to take part
- Can understand and speak basic English
- Can share their views using single words or short sentences

People can take part in person or online

People can take part in person if they live within reasonable travelling distance of London

- Up to 1.5 hours' travel for one-to-one interviews
- Up to 3 hours' travel for focus groups

People can take part online if they

- Live in England or Wales
- Are willing and able to take part in an online one-to-one interview

What kind of questions will be asked?

We will ask people:

- What they think assisted dying is (it is okay if they don't know, we will explain it)
- What questions or worries they have about it
- What information or support people might need to understand assisted dying
- Where people find information about assisted dying
- Who or what influences people's views

There are no right or wrong answers.

How will people's information be used?

We will anonymise what people tell us by changing their names and taking out identifying information from our data. We will store audio recordings securely at Kingston University, and only the research team will have access to them. We comply with UK GDPR regulations.

Participants ask to access or change their data at any time, though some data may need to be kept for research purposes

How will participants be supported?

Interviews and focus groups will be led by experienced researchers who have worked with people with a learning disability about topics relating to death and dying. Researchers will pay close attention to participants' wellbeing and look out for signs of distress.

If a participant becomes upset, the researcher will pause or stop the conversation and offer support. A distress protocol is in place, which sets out what researchers will do in these situations. This includes providing emotional support, offering follow-up support, and sharing information about appropriate support services or helplines. Where appropriate, researchers may also encourage participants to involve someone from their support network.

Researchers will check in regularly with participants throughout the interview or group discussion, giving opportunities to take breaks, receive emotional support, or end the conversation.

Confidentiality will be explained to participants. Participants will be informed that if they share anything that makes us worried about their safety or the safety of others, the team may need to share this information with others to help keep people safe.

Who do I contact if I have any concerns?

You can contact Fred Inglis who is leading on the interviews and focus groups, or Prof Irene Tuffrey-Wijne (study lead).

Email: Fred f.inglis@kingston.ac.uk Irene i.tuffrey-wijne@kingston.ac.uk

Address: Kingston Hill Campus, Kingston Hill, Kingston upon Thames, Surrey, KT2 7LB *Please note that post may not be picked up regularly*

If you identify someone who might be interested in this study, please pass them the full participant information (Easy Read or video), or share our contact details so they can find out more.