



CONSULT-ADVANCE Study Summary of survey findings

Planning ahead for research participation: stakeholders' views about advance research planning

? Why did we do this study?

When someone with a condition that affects their memory or understanding is unable to decide about taking part in a research study, their families may be asked to decide on their behalf. However, some family members do not know what the person's wishes and preferences about research would be, and some find it difficult to decide.

Advance research planning is a process for people to express their wishes about being involved in research studies in the future. It might help families make decisions about research. It has already been introduced in some other countries. We wanted to know whether advance research planning is acceptable and feasible in the UK.

✓ What did we do?

We invited a wide group of people (members of the public including people living with capacity-affecting conditions, family members, researchers, clinicians, and other professionals) to complete an online questionnaire. We asked what they thought about the idea of advance research planning, what the barriers might be, and what could help support it. The survey was open November 2022 - March 2023.

Q What did we find?

A total of 327 people completed the survey. Participants were very supportive of introducing advance research planning in the UK. They identified a number of challenges, including how people will know about it, who should be involved, and how will their preferences be kept up to date. Participants suggested strategies to help raise awareness and improve uptake. The findings are [reported here](#) and summarised in Page 2.



Survey results



The survey was completed by 277 members of the public (including people living with conditions that affect their memory or understanding, and family members) and 50 professionals (including researchers, ethics committee members and healthcare practitioners).



Participants were from across the UK, with 64% from England, 21% Wales, 10% Scotland, 3% Northern Ireland, and 2% stating they were from elsewhere.

97%

Members of the public were interested in taking part in advance research planning

94%

Professionals thought it was important for public/patients to be able to undertake advance research planning



Members of the public thought it should be a formal (rather than informal or legal) process



Thought it should be directive (rather than legally binding or advisory) for decision-making



Thought a family member should also be involved in the process



There is a need for information and raising public awareness



Barriers include time, complexity, cost, and accessibility



Relationships and trust should underpin the process



Optimal timing will depend on life and illness trajectory



Embedding in current activities may improve uptake



Processes should include safeguards and allow for changes

We are now conducting interviews to explore these issues in more depth. Further work is needed to develop tools and resources to support the introduction of ARP in the UK.

