



# CONSULT-ADVANCE Study: summary of interview findings

## Public and professional stakeholders' views about advance planning for research

### Why did we do this study?

When a person is not able to make their own decision about participating in research, someone else (usually a family member) is involved in deciding whether they take part or not which should be based on what they would have decided for themselves. However, this is often unknown. Advance research planning (ARP) is a process for people who anticipate periods of impaired capacity to express their preferences about research participation and identify who they wish to be involved in future decisions. ARP may help to extend peoples' autonomy by ensuring that research decisions are based on their actual wishes. Some countries have introduced processes for ARP, and in this study we wanted to explore stakeholders' views about the acceptability and feasibility of introducing ARP in the UK.

### What did we do?

We interviewed researchers, practitioners, and members of the public who had taken part in a previous survey and who said that they were happy to be contacted again. We selected people from different groups and backgrounds to try and gather a range of views. Participants were given information about the study and asked to confirm consent before the interview. Interviews were held by Zoom or phone between April - Nov 2023.

### What did we find?

We interviewed 27 researchers, practitioners, and members of the public including people with experience of living with a condition that affected their memory or understanding, and family members. Participants supported the concept of ARP, with differing levels of support for a range of possible ARP activities depending on the context (**see themes p.2-5**). Participants identified a number of challenges, and suggested strategies to overcome them.



## Planting a seed – creating opportunities to initiate or engage with advance planning for research

Whilst ARP was a new idea to almost all participants, there were strong levels of interest in enabling people to express their preferences about future research participation in order to maintain opportunities to be involved in research. Rather than being viewed as a one-off opportunity or a single event, participants thought it was important to consider how to maximise opportunities for people to have conversations about their research preferences, although participants recognised that it could be a potentially distressing topic for people to discuss. This highlighted the need for accessible information and guidance to support all those involved

Participants suggested that ARP could be embedded in advance care planning processes, legal processes like power of attorney or when making a will, or there might be opportunities when signing up to research or donating blood, if diagnosed with a condition, or could be signposted to by charities and support groups (see p5).

“ It just plants a seed there, and the seed may well come to fruition. It may not, but it gets the discussion going (family member) ”



## One part of the puzzle – using preferences expressed through ARP to inform decisions about participation

Participants expressed a range of views about how binding they thought preferences expressed through ARP should be. These were often shaped by the type of research, how general or specific the preferences were, and how recently they had been expressed. Some thought that preferences expressed through ARP could not be considered binding decisions as it would be impossible to foresee the potential range of circumstances that might apply, preferring ARP as a means to support people to discuss their general preferences. However, some clinicians saw greater utility in more specific documented preferences, particularly in emergency situations.

“ It’s a parallel process that would inform the consultee process, rather than replace it (researcher) ”

A dual layered approach was proposed in which people could express their general views, but also more specific preferences if they wished. Overall, ARP was viewed as supplementing the current process of consulting someone else on the person’s behalf. An advance research directive could help to guide the alternative decision-maker, informed by the person’s current circumstances, and involving them as much as possible.



## Finding the 'sweet spot' – optimising the timing of advance planning for research

One of the challenges identified by participants was how to align the opportunity for people to express their preferences about future research with their motivation to do so. Many participants recognised the challenge of people undertaking any form of future planning, like advance care planning, despite it being widely advocated. They also noted the difficult nature of these conversations and the challenge of getting the timing right.



**If you ask people too early, they're just going to be like 'what are you talking about I'm never going to get dementia', so it has to be at the sweet spot**  
*(researcher)*



**Although they may be distressed because of a life-threatening illness they would be able to make a decision ... but down the line you need to have already made the decision otherwise it's too late**  
*(member of public)*



## More than a piece of paper – finding the best modes for recording and documenting preferences

There were mixed views about the best way to record ARP conversations, and the preferences expressed. This often focused on whether a template 'advance research directive' document would be helpful in facilitating people to express their wishes, how detailed it should be with respect to specific conditions or types of research, and how it might align with other relevant documents that people might already complete and keep.

Some thought a template with various options to select would be helpful, others thought it could seem overly burdensome and might deter people from considering research all together. Some thought it would be too restrictive and preferred to have the ability to personalise their response. There were also mixed views about whether it would be more practical for it to be an electronic or paper document, with concerns about access and safe storage of both.



**Whatever documents that are finally agreed it is important to stress that you need to talk to your family about this**  
*(family member)*





## **Not shutting the door on an opportunity – minimising the risk of unintended consequences**

Whilst there were high levels of support for ARP, there was also recognition that introducing ARP is not without unintended consequences, particularly if peoples' preferences about participating in research or not were insufficiently informed. This was linked to the view that levels of awareness and understanding about research are relatively low in the general population. Participants were particularly concerned about the risk of exacerbating inequalities if having an advance research directive became a requirement before including someone in research in the future, as this would further reduce inclusivity and diversity in research.



**Potentially you're missing out on huge swathes of people that would not have signed something. People that tend to sign up or are in positions to make advance care plans, might just have less chaotic lifestyles .... it's all the social and economic drivers and determinants of health generally**  
*(researcher)*



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## **Navigating with a compass - principles underpinning ARP to ensure safeguarding and help address inequalities**

Trust plays a key role in advance planning for research, with some participants highlighting that it is important to take account of particular concerns around trust where that is impacted by cultural, historic, and other contextual factors. They suggested that communication aimed at raising awareness about ARP should include highlighting that there are existing safeguards in place and that its purpose is not to bypass or subvert these important protections. Despite the complex issues raised, introducing ARP was generally seen as an improvement on the current imperfect situation.

A number of strategies were suggested to enhance the opportunities for under-served populations to be able to engage with ARP. These included ensuring that the format of ARP and the information about it is accessible. This included information aimed at those in clinical roles who may be signposting or advising people about ARP but might themselves be less familiar with research.



**'I'd worry that if we were forcing stuff on people, whether that would worsen trust in healthcare ...**  
*(practitioner)*





## Opportunities for engaging with advance planning for research



## Conclusions

This study found high levels of support for enabling people to consider and express their preferences about being involved in research should they lose capacity to consent, with many participants viewing this as an important but currently missing step between people expressing their preferences about research and other expressions of future wishes.

Advance planning for research could enable people to prepare a trusted family member to make decisions about their research participation should they lose the ability to communicate their wishes. Recording those wishes in a (non-binding) document such as an advance research directive could act as a reminder for family members at a later point, but could also provide an insight into the person’s values, wishes and preferences where it may be the only available ‘evidence’ of their research preferences. People should have the ability to revisit and amend their preferences, and all those involved should have access to information and guidance that supports their role.

Future research should focus on developing interventions to support advance research planning, underpinned by accessibility and ethical principles such as trust. This will help to ensure that research is accessible to all and that in the future participation decisions are made more closely in line with peoples’ wishes and preference.

**Pre-print of the findings: ‘It’s not making a decision, it’s prompting the discussions’**

