

Inclusive Practices around Mental Capacity & Consent in Palliative Care Research

Workshop report

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Background

When someone is approaching the end of life, their ability to make informed choices may become impaired. Yet, knowing their values, preferences, and wishes remains vital—not just for medical decisions, but also to ensure that research is conducted in an ethically and inclusive way.

There can be several barriers to conducting research in a palliative care setting, and navigating challenges in communication and consent can present additional complexity. Informed consent processes in research studies are often not designed to be accessible to those with additional communication and/or decision-making needs and can lead to those people being excluded from research.

With the right support, people with additional communication and/or decision-making can be included in research, ensuring that the evidence underpinning their care and treatment is representative of the population. This protects their right to make their own decisions, and ensures their views are heard.

The CAPER Project (Consent, Advocacy and Proxies in End of Life Research) was established to explore challenges around consent, understand the role of advocacy and proxies in supporting decision making and understanding the right participatory approaches to promote ethically sound and inclusive end of life research. We aim to develop resources, training and advocacy opportunities to involve people meaningfully in research, often through the support of proxy decision-makers or accessible communication strategies.

Aims of the CAPER project

The aim of the [CAPER project](#) is to improve the accessibility and inclusivity of research for people with additional communication and/or decision-making needs towards the end of life. There are three stages to the project, which has been supported by the NHS England Research Engagement Network:

1. Understanding the structural barriers to research participation for adults with challenges in communication and cognition towards the end of life.

2. Implementing two key recommendations from stage 1 of the project:

- Recommendation 1: Guidance on how proxies might support involvement in research of people with decision-making challenges towards the end of life.

People who lack capacity are recognised as an under-served group in many aspects of research. We presented some of the systemic, structural and methodological challenges and solutions seen across the lifecycle of different areas of health and social care research. We discussed the OPTIMISE (recommendations for designing inclusive consent in trials) project as one way in which inclusive consent can be ‘designed into’ studies.

After a brief presentation of the CAPER work to date, we used a participatory method called the ‘Sailboat’ exercise to explore the question:

How can we improve inclusivity, representation and accessibility in research for those with communication and/or decision-making challenges towards the end of life?

This report summarises discussions around this question and the draft recommendations identified for future work.

Workshop Discussion: Sailboat Exercise

I. Winds (What Helps Us Move Forward)

Participants identified *enablers* already supporting inclusion in palliative care research:

Inclusive Practices & Tools

- Use of inclusive research methods and simplified consent procedures
- Accessible patient information
- Standardised, clear, and stock phrases to support understanding
- Standardisation of inclusion processes

Culture & Communication

- Greater cultural awareness
- Clear communication of vision and benefits of inclusive research
- Raising voices of advocacy bodies
- Public involvement throughout projects

Major opportunities recognised:

- Growing interest in inclusive, person-centred research across health services
- Potential to standardise accessible approaches nationally
- Increased collaboration across the multidisciplinary workforce
- Momentum around equity, diversity, and inclusion in research funding

Capacity & Capability

- Increasing the quality of research protocols
- Improving internal buy-in, training, and organisational knowledge
- Building evidence that supports inclusive approaches
- Peer support groups for writing and dissemination



2. Anchors (What Holds Us Back)

Key barriers *slowing* progress:

Systemic & Ethical Barriers

- Ethical barriers and gatekeeping
- Over-protection of “vulnerable” groups
- Lack of co-production or tokenistic involvement
- Rigid or exclusionary protocol structures

Practical Barriers

- Limited skills or resources for inclusive practices
- Challenges in adapting methods for people with communication or capacity needs
- Inflexible timelines and workloads
- Lack of standardised processes for accessible communication



3. Rocks (Threats Ahead)

Risks the group felt could *derail* progress if not addressed:

Structural Threats

- Increasing complexity of regulatory/ethical requirements
- Organisational inertia or lack of prioritisation
- Limited funding specifically supporting inclusive research

Operational Threats

- Failure to adapt methods meaningfully (i.e., “tick-box” approaches)
- Inconsistency across services in communication or accessibility
- Poorly understood or under-supported adaptations leading to unreliable data

4. The Boat (Who must move together)

A. Regulatory and Governance Bodies

Groups responsible for oversight, approval, and governance of research:

- Research Ethics Committees (RECs)
- R&D offices / research departments/ Sponsors
- Funders
- Regional delivery networks

B. Health and Social Care Providers

Organisations delivering palliative care and supporting research access:

- Hospices
- NHS services
- Care homes
- Multidisciplinary team (MDT), including speech and language/ learning disability specialists



C. People With Lived Experience & Their Communities

Those who are central to participation and shaping inclusive approaches:

- Patients
- Families and carers
- People around the person
- PPI experts (public and patient involvement)
- Lay people
- People with communication/capacity needs
- Community groups
- General public

Role: Provide insight, participate in studies, co-design processes, and ensure research remains person-centred.

D. Supporting Organisations & Systems

Infrastructure and partners that influence research processes:

- Charitable organisations
- Voluntary sector organisations (VSCO)
- Universities
- IT systems

Role: Provide resources, technology, collaboration, and institutional frameworks for research.



5. The ‘Desert Island’ (where are we trying to get to?) This is our *Call to Action*.

We identified five core aims:

1. Research that is Equitable and Right for Everyone

- Research is accessible and appropriate for all, including those with communication or capacity challenges.
- People are not treated as “guinea pigs”, but as respected partners.

2. Research Embedded in Routine Practice

- Palliative care services routinely integrate research into care.
- Asking for consent to research becomes a natural part of care pathways.

3. Ethical Processes that Support Inclusion

- Research Ethics Committees (RECs) make decisions informed by cultural differences, modern practice, and inclusivity principles.
- REC policies reflect a modern, person-centred society.
- RECs improve their understanding of practical realities in palliative care and inclusive research.

4. Supportive Structures and Tools

- Guidance for involving people with communication/capacity challenges.
- Encouraging and recognising research-active, inclusive palliative care organisations

5. Values-Led Research Culture

- Research is undertaken for the right reasons, with genuine benefit to participants and communities.
- Organisations are encouraged to embrace research culture and recognise its value.

To achieve our aims, we considered several recommendations for next steps, to be refined with a follow up poll of participants and future online workshop:

Recommendations

1. Getting hospices to have an 'opt in' to data sharing /hearing about research involvement for people who may go onto develop impaired capacity
2. Development of research 'kite mark' accreditation programme to indicate knowledge, experience and skills of working with adults with impaired capacity
3. Encouraging hospices and palliative care teams to be health learning organisations – promoting a culture of collecting, collating, reflecting and learning from data and patient experience
4. Creating a 'how to' booklet for palliative care research involving adults with impaired capacity including helpful resources, and practice examples.
5. Ongoing partnership working, collaboration and discussion

Key Takeaway Points

There was strong momentum, support and motivation for making palliative care research more inclusive of people with communication and cognitive challenges. Whilst many **helpful tools** exist (simplified consent, accessible communication, public involvement), a more **consistent approach** and **structural support** is needed in palliative care settings. The biggest barriers are **ethical constraints**, **resource limitations**, and **organisational** cultures. The team is keen to focus on simple, achievable steps to achieve change in this area, and are keen to maintain a collaborative and inclusive approach in the future.

Next steps

The next step of the project is to agree a workplan for the recommendations identified, and to explore and secure funding opportunities to do so. A further workshop will be planned in spring 2026.

See the Palliative Care section of this website for updates:

<https://www.capacityconsentresearch.com/palliativecare>

If you have any questions, please contact:

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