

Addressing the barriers to research involving adults with impaired capacity to consent

Background to CONSULT

Informed consent is a fundamental principle in research. People with conditions or disabilities that affect their ability to communicate and/or make decisions may require additional support to make a decision about whether to take part in a research study. Some people, even with support, may lack capacity to consent for themselves.

People with impaired communication and/or decision-making are frequently excluded from research, including clinical trials, due to concerns about their ability to provide consent, or the ethical, legal and practical issues that arise if they lack capacity to consent.

Routinely excluding populations from research can result in healthcare not being designed for the people who most need support, leading to poorer outcomes. As a result, improving inclusivity in research is a priority area for research funders, regulatory bodies, and research organisations.



Aim of CONSULT



CONSULT aimed to support ethical inclusion of adults with impaired capacity to consent in research through identifying and addressing the barriers to inclusion.

It involved a series of mixed-methods studies and the development and implementation of methodological interventions to target barriers at different systems levels.

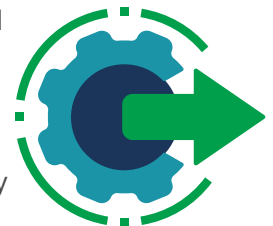
The findings will help researchers, research funders, regulatory bodies, and other organisations to ensure research is more inclusive of people with impaired capacity to consent.

Members of the public helped to ensure that the findings are relevant to people with conditions or disabilities that can affect communication and/or decision-making and those caring for them.

Findings and outputs

CONSULT identified a number of challenges which act as barrier to research involving people with impaired capacity to consent, and ways that they could be addressed.

We also developed a range of resources and tools to support researchers, funders, regulatory bodies, as well as people living with conditions or disabilities and their families.



See the diagram on page 2 for a summary and links to more information.



Next steps for this research

We are working with researchers, research funders, regulatory bodies, and research organisations to ensure the findings from CONSULT lead to changes in guidance and practice.

Following on from CONSULT, a new project (ACCORD) will explore the ethical and legal uncertainties surrounding research involving adults with impaired capacity to consent and develop behaviour-informed interventions to improve inclusion.

<https://www.cardiff.ac.uk/centre-for-trials-research/research/studies-and-trials/view/accord>



Click on a circle
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out more.



For more information

Visit **CONSULT** website:
www.capacityconsentresearch.com

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Llywodraeth Cymru
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