Research involving adults lacking capacity to consent – health and social care professionals' knowledge and understanding of the legal frameworks

Background

Approx. 2 million people in the UK unable to make own decisions – e.g. as a result of dementia, critical illness, LD

Research essential but challenging → under-represented

Health and social care professionals involved in identification, provision of information, and recruitment

Limited knowledge of the legislation, may impact on their confidence and competence

Canolfan PRIME **Cymru**
Wales PRIME Centre

Research study portfolio

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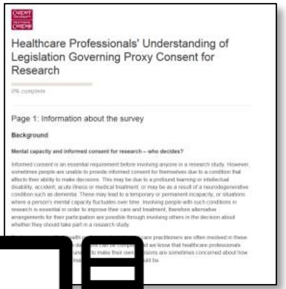
Methods

Online cross-sectional survey – vignette-based

Examine knowledge and understanding of legislation governing research involving adults lacking capacity in England and Wales



Healthcare Professionals' Understanding of Legislation Governing Proxy Consent for Research

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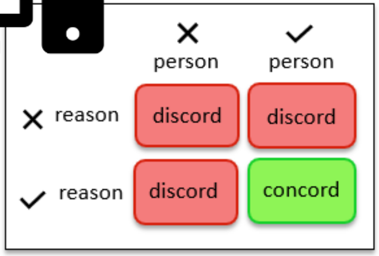
Page 1: Information about the survey

Background

Mental capacity and informed consent for research – who decides?

Informed consent is an essential requirement before involving anyone in a research study. However, sometimes people are unable to provide informed consent for themselves due to a condition that affects their ability to make decisions. This may be due to a profound learning or intellectual disability, accident, acute illness or medical treatment, or may be as a result of a neurodegenerative condition such as dementia. These may lead to a temporary or permanent incapacity, or situations where a person's mental capacity fluctuates over time. Involving people with such conditions in research is essential in order to improve their care and treatment, therefore alternative arrangements for their participation are possible through involving others in the decision about whether they should take part in a research study.



	✗ person	✓ person
✗ reason	discord	discord
✓ reason	discord	concord

Results

Participants n = 127

56% based in Wales

80% female

34% nursing background*

82% had been in profession 8+ years

63% involvement in research

55% recruiting participants*

*participants could select more than one response

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Results

Category n=127 (%)	Scenario 1	Scenario 2	Scenario 3	Scenario 4	Scenario 5
Discord	104 (82%)	96 (76%)	96 (76%)	104 (82%)	94 (74%)
Concord	12 (9%)	15 (12%)	10 (8%)	10 (8%)	23 (18%)
- wholly	5	6	5	1	5
- partially	7	9	5	9	18
Uncertain	5 (4%)	7 (6%)	12 (9%)	7 (6%)	4 (3%)
Unclear	6 (5%)	9 (7%)	9 (7%)	6 (5%)	7 (6%)

Conclusions

Demonstrated low level of knowledge and understanding

Further in-depth exploration and interventions may be warranted

Victoria Shepherd
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