



# Oxford Institute of Ageing

## Addressing Ethical and Person Centred Issues in Consent to Participate in Research

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## Aims

- Outline the research study that prompted this presentation!
- Establish the context for the approach to consent
- Outline the approach to consent being utilised
- Discuss initial insights in the application of the process





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## Grandparent / Grandchild Relationships, How are they affected by Alzheimer's disease and related dementias?

- How are young and preschool children affected by the experience of a grandparent with Alzheimer's disease or a related dementia?
- What is the impact of this disability upon the person's experience of being a grandparent?
- How do grandparents and grandchildren relate together where the grandparent is affected by this disability, (considering both the positive and negative aspects for both)?
- How do parents, grandparents and other family members experience the relationship between grandparent and grandchild?
- How do parents, grandparents and other family members support young and preschool aged children to cope with the effects of this disability?
- What implications does this have for the manner in which support is provided for families affected by this disability?





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## What the research study entails

- Recruitment of up to 20 families who have a grandparent with dementia and grandchildren aged 12 or below
- The research process includes:
  - **Conversational Interviews**
    - Person (Grandparent) with dementia
    - Young and preschool aged grandchildren (aged 12 or below)
    - Family members including parents, older children and grandparent without a diagnosis of dementia
  - Participant observation with grandparents affected by dementia and younger grandchildren in their familial context
  - Diaries recorded by families
  - Video recordings of interactions between grandparents affected by dementia and younger grandchildren, which will include an adaptation of interpersonal process recall
  - Researcher field diary





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## Issues Influencing Approach

- People with dementia have been excluded from research, often because they are not deemed competent or able to give a credible account of the issue under study
- Traditional assessments such as the MMSE are not reliable indicators of the capacity of the person to discuss their life, experiences and needs
- Proxy consent has been frequently and widely used as a replacement without considering the needs, abilities and wellbeing of the person with dementia
- Causing distress through inadvertent action e.g. diagnosis disclosure
- Changes in functioning mean that one off consent cannot be consent for the whole study
- It can be argued that it is only the person with dementia who can give an account of what it is really like for them





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## Mental Capacity Act 2005 (Implementation Oct 2007)

- Research with people who lack capacity may be carried out if approved by a research ethics committee **however:**
- Carers or nominated third parties must be consulted and agree that the person would want to join in an approved study
- If the person shows any sign of resistance or indication that they do not wish to take part, they must be withdrawn from the study





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## Procedures for addressing consent

- Recruitment through an organisation that works with and has an existing relationship with potential participants
- Use of the term memory difficulties until the family and particularly the person with dementia raises their diagnosis
- Consultation with **all** family members
- Gaining knowledge about the person with dementia and grandchildren to ascertain appropriate approach and developing a relationship





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## Procedures for gaining consent

- Meeting the person with dementia and the grandchildren individually to explain the research
- Use of proxy consent where necessary **but** this does not replace the need to gain agreement to participate from the person with dementia and their grandchildren
- Ongoing consent / assent (on each occasion that the researcher visits)
- Reflexivity

(approach adapted from Dewing, 2007 and Cocks, 2006)

