Recruitment, consent and data collection in research involving care home residents with dementia – lessons from the EPIC trial

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Research Team of the Year
Background

• Over 16,000 care homes (nursing and residential) in England (CQC 2016)

• Resident population of over 460,000 (CQC 2016)

• One-third of people with dementia live in a care home (Knapp et al 2007)

• Estimated that c.70% of care home residents have dementia (Alzheimer’s Society 2016)

• Issues with care quality and meeting of resident needs
Conducting trials in care homes

• Significant need for research in this setting
• Comparatively few RCTs conducted in care homes
• Care homes therefore not ‘research ready’
• Poor understanding of research and its processes and procedures
• Many see value in being research active
EPIC trial (Surr et al 2016) recruitment of care home residents with dementia to research

- Follows standard process for assessment of capacity
  - Individual informed consent OR appointment of personal or nominated consultee
- 145/726 (20.0%) personal consent
- 263/726 (36.2%) personal consultee
- 318/726 (43.8%) nominated consultee
EPIC trial challenges - approaching personal consultees

- Access to personal details – data protection
- May not visit frequently/live at a distance
- May not respond to correspondence
- Can be left with ‘unknown’ status of invited participants
- Personal views rather than participant’s wishes
EPIC trial solutions – personal consultees

- Clear information about role
- In person to consultee
- Returned direct to researcher
- No response
- Follow-up letter
- Returned
- No response
- Appoint nominated consultee

Timeline:
- 2 weeks
- 2 weeks
EPIC trial challenges - approaching nominated consultees

• Finding suitable individual
• Concerns about role and providing advice on residents wishes
• Concerns about family views if personal consultee did not respond
• Staff turnover and finding replacement consultee
EPIC trial solutions – nominated consultees

- Where possible one consultee for multiple residents
- Spend time explaining role and discussing concerns
- Emphasise right of residents to take part in research if they would wish to – not be excluded due to non-response of family
- Emphasise ability to withdraw later if relatives make contact and advise differently
Resident outcomes QoL - challenges

- Consistent person to report/complete measure (self vs proxy)
- Discrepancy between self vs proxy reports (Arons et al 2013; Buckley et al 2012)
- Sensitivity in moderate/severe dementia
- Residents
  - Suitable measure for moderate to severe dementia
  - Items relevant to care home residents
  - Burden/time
  - Enjoyable and not cause distress
- Staff
  - Turnover and availability
- Relatives
  - Engagement
  - Frequency of visiting
Resident outcomes - solutions

• DEMQOL
  – MMSE 10+
  – 28 items

• QOL-AD
  – MMSE 3+
  – 13 items
But .... QOL-AD

<table>
<thead>
<tr>
<th>Instructions: Interviewer administers according to standard instructions. Circle participant responses.</th>
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</thead>
<tbody>
<tr>
<td>1. Physical health</td>
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<tr>
<td>2. Energy</td>
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<td>3. Mood</td>
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<td>4. Living situation</td>
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<td>5. Memory</td>
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<td>6. Family</td>
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<td>7. Marriage</td>
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<td>8. Friends</td>
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<td>9. Self as a whole</td>
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<td>10. Ability to do chores around the house</td>
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<tr>
<td>11. Ability to do things for fun</td>
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<tr>
<td>12. Money</td>
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<tr>
<td>13. Life as a whole</td>
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</tbody>
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The QOL-AD (Participant Version) from Logsdon et al (2002)

QOL-AD-res (Edelman et al 2005)

Removes two items and adds four new ones:
- people who work here,
- ability to take care of oneself,
- ability to live with others, and
- ability to make choices in one’s life
Summary

• Conducting trials in care homes with people with dementia can be challenging
• Lack of/no consistent, direct access to relatives
• CH staff not used to research roles and processes
• Lack of suitable measures for use in this population
• Be pragmatic and do things differently/push boundaries
EPIC trial team

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References


