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

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in association with  
**The Telegraph**

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# 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

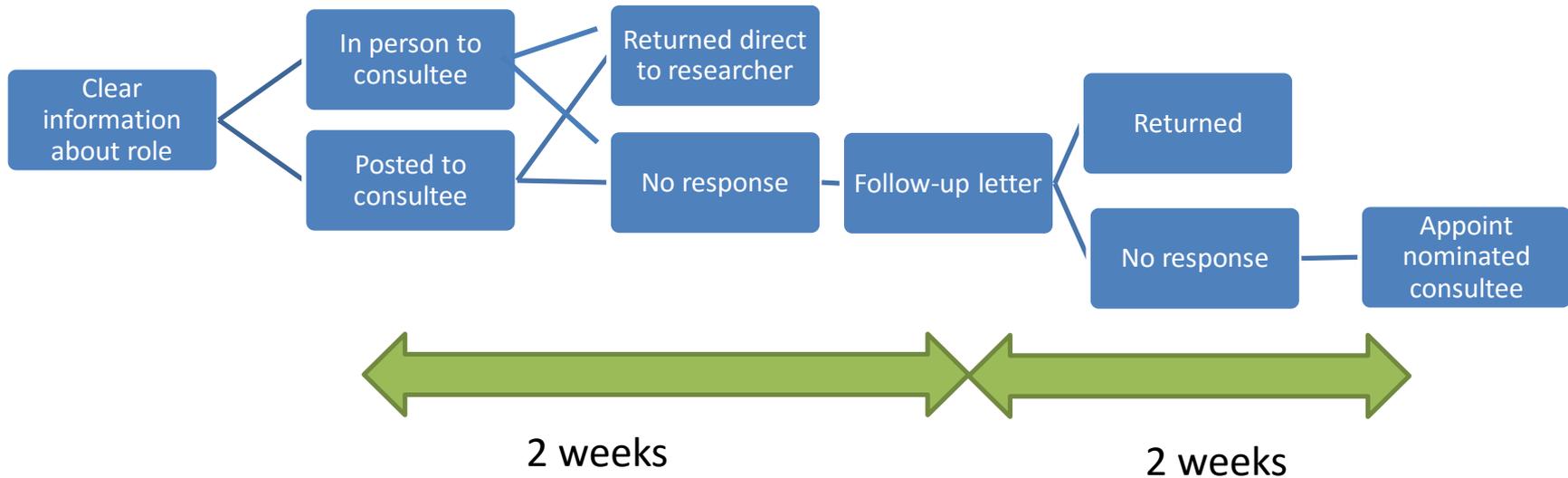


## EPIC trial challenges - approaching personal consultees



- 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



## 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

**Instructions:** Interviewer administers according to standard instructions. Circle participant responses.

1. Physical health	Poor	Fair	Good	Excellent
2. Energy	Poor	Fair	Good	Excellent
3. Mood	Poor	Fair	Good	Excellent
4. Living situation	Poor	Fair	Good	Excellent
5. Memory	Poor	Fair	Good	Excellent
6. Family	Poor	Fair	Good	Excellent
7. Marriage	Poor	Fair	Good	Excellent
8. Friends	Poor	Fair	Good	Excellent
9. Self as a whole	Poor	Fair	Good	Excellent
10. Ability to do chores around the house	Poor	Fair	Good	Excellent
11. Ability to do things for fun	Poor	Fair	Good	Excellent
12. Money	Poor	Fair	Good	Excellent
13. Life as a whole	Poor	Fair	Good	Excellent

The QOL-AD (Participant Version) from  
Logsdon et al (2002)

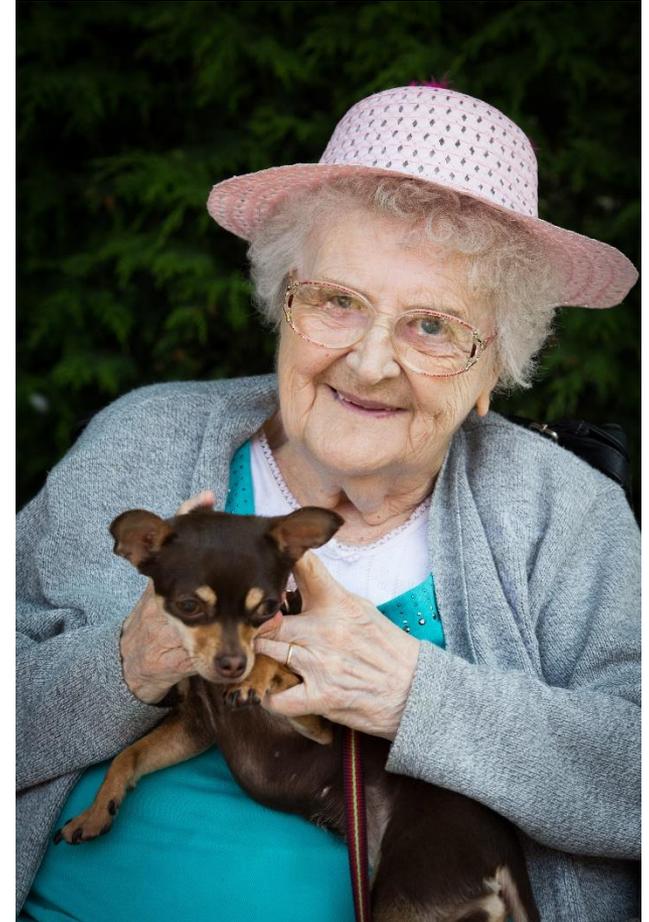
## QOL-AD-res (Edelman et al 2005)

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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