Engaging people who have dementia in research: The experience of the Whare Aroha Care transition study.

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Background

- Whare Aroha Care aged residential care facility in Rotorua, New Zealand must move to new premises due to expiry of their current lease
- Opportunity to move to a different model of care
- Currently building a new facility where residents will be housed with others from similar backgrounds, based on the Hogeweyk model
- Aim is to give residents a more normal life in more normal surroundings, maximise remaining abilities and increase enjoyment of life
- Research will explain the process of the transition and the effects of the transition on the lives of the residents
Data

Interviews with:
Management, board members, other stakeholders, staff, residents, family members

Examination of documents relevant to the process and outcomes of the transition

Observation of resident life at the current facility and the new village
The presentation will cover

• Ethical considerations when working with research participants who have dementia in New Zealand

• Experience and lessons learnt from engaging Whare Aroha Care residents who have dementia in the research about the transition.
Ethical considerations

• Compliance with legislation
• Decision-making capacity
• For those who are unable to provide informed consent participation must directly benefit them
• Respect for the individual’s right to contribute
• Attending the ethics committee meeting is recommended
Key factors for successful data collection

• Organisational culture
• Relationship building
• Having practice experience helps
Interviews with people who have dementia

• Consent
• Support from staff and family
• Choice of sit down or walk along interview offered
• Adapt to the individual – interviews generally short
• The value of leaving space
Observation of people who have dementia

• Consent
• Support from staff and family
• Theoretically driven protocol used
• Observation times arranged collaboratively
• Staff provided information about the participant’s usual demeanour and ways of expressing themselves
Thank you. Discussion.


