

Engaging care home residents in research (ENGAGE study)

Health and Care Research Wales Social Care PhD Studentship Award

Supervisors: Prof Fiona Wood, Dr Victoria Shepherd, Prof Kerry Hood, Prof Carolyn Wallace

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Start date: January 2022

End date: January 2025

Background

- Older adults often live with medical conditions and require the most complex care and support
- Already an estimated 490,326 care home residents in the UK [1-3]
- Despite this growth, care home residents are often excluded from research that could potentially benefit their care [4]
- Study participants need to reflect the population to which the research is being applied
- Care homes are both health and social care facilities
- Aims:
 - To explore how care home residents can be better engaged in research, and the barriers and facilitators to their inclusion
 - Develop an intervention to support conversations about research with care home residents and facilitate advance planning for research participation

References:

[1] Office for National Statistics (2020). Care home and non-care home populations used in the Deaths involving COVID-19 in the care sector article, England and Wales. London: ONS.

[2] Public Health Scotland (2019). Care home census for adults in Scotland.

[3] Department of Health (2020). Statistics on community care for adults in Northern Ireland 2019/2020.

[4] Witham, M. D., & McMurdo, M. E. (2007). How to get older people included in clinical studies. *Drugs & aging*, 24(3), 187-196

Achievements

Stage 1


- Identifying barriers and facilitators to the inclusion of older adults living in UK care homes in research: a scoping review (published in BMC Geriatrics <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-023-04126-3>)

Stage 2

- Widening research participation: a survey exploring stakeholders' views about opportunities for older adults living in UK care homes to participate in research (submitted for publication)

Stage 3


- Exploring views about advance planning for research participation by UK care home residents (work in progress!)



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**OVERCOMING
BARRIERS AND FACILITATORS
TO INCLUDING CARE HOME
RESIDENTS IN RESEARCH**

Recommendations for researchers



RESEARCH METHODS

- Work with care home research organisations (e.g., ENRICH)
 - Be flexible, understanding and supportive
 - Use a collaborative working style to work with residents, their relatives and staff
 - Include residents who lack capacity to consent via use of a consultee
 - Embed public involvement at all stages of your project

COMMUNICATION

- Discuss and identify realistic research targets with the care home manager at the start
- Provide accessible, tailored communication tools (e.g., using large font or images) to ensure potential participants are fully informed
- Provide active appreciation through feedback

PREFERENCE-BASED DECISIONS

- Widen participation opportunities by utilising legal arrangements that enable staff to act as a nominated consultee
- Try to allay concerns about research motives faced by any of the stakeholders
- Work with care homes to raise residents' and their relatives' awareness of research opportunities

CARE HOME AND STAFF

- Recognise that staff have an invaluable role and can act as a bridge for communication
- Be flexible and understand the differences in each care home's culture
- Provide training so that staff can better understand how to support research
- Make allowance for staffing pressures and the unique environment of care homes may impact research




RELATIONSHIPS

- Demonstrate willingness to work with, and be guided by, staff
 - Be respectful and supportive to residents, relatives and staff
- Develop good and trusting relationships with residents, relatives, and care home staff and consider making them research partners
- Consider spending time in the care home before research begins

ELIGIBILITY CRITERIA

- Consider eligibility criteria carefully and avoid exclusion of potential participants because of age, multi-morbidity or frailty as these individuals are representative of the care home population

Authors: Silvana Boudali, Research Fellow, Professor Kerry Wood, Professor Caroline Walters, Professor Peter West
This study forms part of a PhD studentship project funded by the Welsh Government through Health and Care Research Wales

Achievements

Conferences

- International Clinical Trials Methodology Conference 2022 – poster presentation
- PRIME Centre Wales Conference 2022 – poster presentation
- South Wales SAPC Conference 2023 – poster presentation
- British Society of Gerontology Conference 2023 – oral presentation

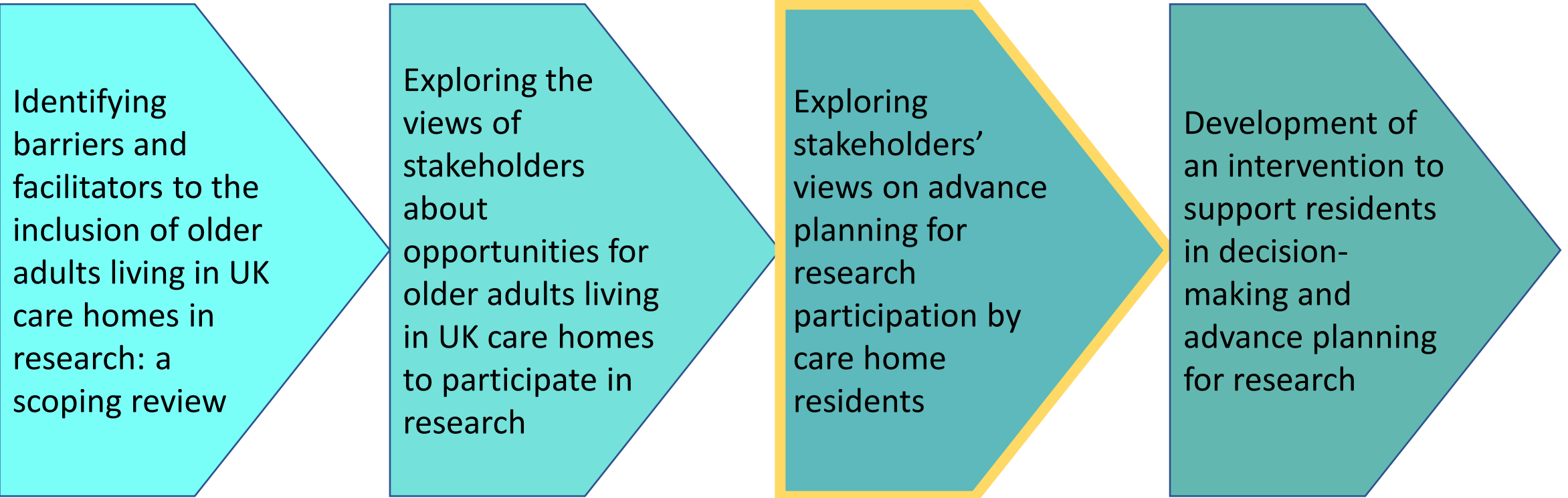
Blog posts and networking

- ENRICH Cymru, Centre for Trials Research, Cardiff University , PRIME Centre Wales, Age Alliance Wales

Other academic activities

- Teaching – Evidence Based Medicine case facilitation, Student Selected Component tutor, Dissertation Supervisor on Genetic and Genomic Counselling MSc
- Admin role in Division of Population Medicine – organising academic meetings
- Other projects: INCLUDE Impaired Capacity to Consent Framework, GW4 Mechanisms of Fatigue project
- SW SAPC 2024 conference organisation team
- Nominated PGR engagement award

Next Steps



Future Plans

- PhD thesis submission by end of 2024
- Continue taking opportunities for teaching and development as a researcher
- Other research methods I'd like to gain experience in
- Thoughts...
 - Apply for grant to further this – implementation of intervention
 - Developing research career – as a researcher – developing and evaluating interventions around inclusion – psychology background

Thank you!

- Supervisors
- Health and Care Research Wales as funder
- Participants
- PPI group

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