





- Working in social care research (older people) since 2003
- Housing with care, care homes, domiciliary care
- Quality of Life: measurement, impact of services.
 - Adult Social Care Outcomes Toolkit (ASCOT): social carerelated quality of life (www.Pssru.ac.uk/ascot/)
 - Designed as an outcome tool, sensitive to the impact of social care and preference-weighted for use in economic evaluations.
- But measurement alone does not change practice and many residents cannot 'self-report' using conventional methods.
 - How do we capture residents' QoL in a way that can inform direct care?







Case Study 1 (2016-2019)

Whiddon Group in NSW, Australia

- Co-produced an approach to using ASCOT care planning conversations
- 'Circle of Care' approach (resident, family, care worker and RN/care planning lead).

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Case Study 2 (2020-2021)

ARC project with care homes in England.

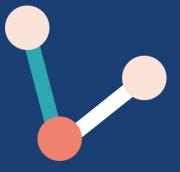
- Trained four homes from one chain, flexible approach to fit their systems.
- Winter and COVID-19 pressures stopped the pilot.



Case Study 3 (2021-2023)

Attendo in Sweden

- Pilot 3 NHs, 10 staff, 55 QoL care plans
- First implementation 2022: 12 NHs, 60 staff, 190 QoL care plans
- Wider roll-out 2023: 28 homes, 22 'trainers', just started







Feedback from Attendo:

- ✓ Positive feedback from residents and families who really appreciated the conversations
- ✓ **Tool** for resident-centred care capturing every individuals needs and preferences
- ✓ Complementing individual care planning: clear goals & activities supporting quality
 of life in day-to-day care
- ✓ Measurable Quality of life (QoL) outcome for providers/organisations to use to demonstrate the impact of the service they are providing.
- ✓ https://dreambroker.com/channel/tonr6e1c/1q47mlj2 (video with English subtitles)

Challenge: how to replicate in the UK? Cannot be research-led, has to be provider-led.









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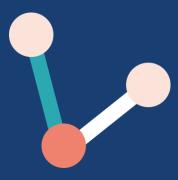


- Care Homes are complex settings to implement randomised controlled trial research designs
- Between 2007-14 NIHR awarded over £8.5m for five Care Home randomised controlled trials
 - All reported neutral findings
- Are there alternative explanations for these results?
- What if we were to look at the Process Evaluations of the trials?





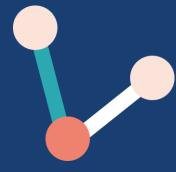






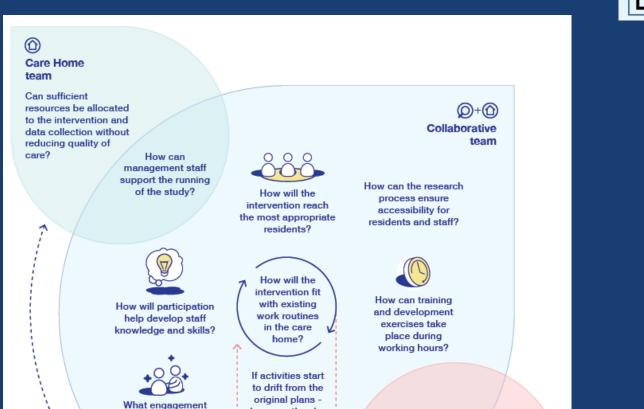


- Research Load Primary Barrier
- "The new routines were seldom accompanied by suggestions as to what routines should be replaced"
- "There was a lot of negative feedback from the staff; they thought it was a stupid project"



Ensuring trial interventions in Care Homes have their best chance of success





how can they be

adjusted in line

with shared

objectives?

How can the care

home be seen as a

Learning Partner?

Do the researchers understand the care home's motivation for participating?

Research

team

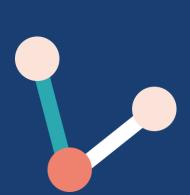
activities will support

a positive working

relationship?

What is the best way to keep in touch in

between meetings to address problems early?

















- There are many gaps between the activities of university researchers and the needs of people who work, live in, and care for others in care homes.
- We established the ExCHANGE (the University of Exeter and Care Homes Knowledge) Collaboration as a pilot innovative model of bringing together researchers and care home stakeholders.
- We aim to improve mutual understanding of research and evidence-use in care homes and to generate applied research that directly addresses care home practice-needs.
- Our collaboration is made up of care home owners, family members of care home residents and university researchers.







...co-designing

...shared interests

project activities

...involving people from all walks of care home life

...maintaining equality between collaborators

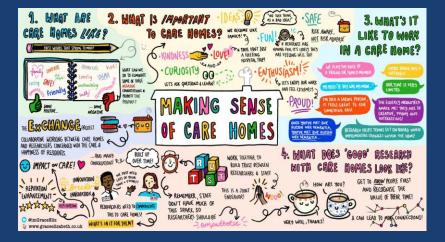
...being flexible

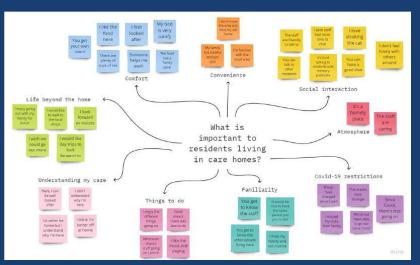
...regular communication ...incentives for all collaborators

...using accessible language

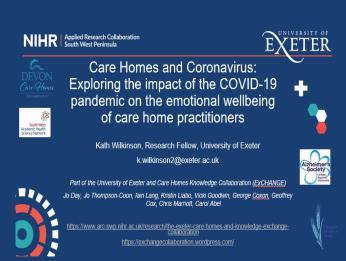
..our shared **passion &** enthusiasm to improve care home life

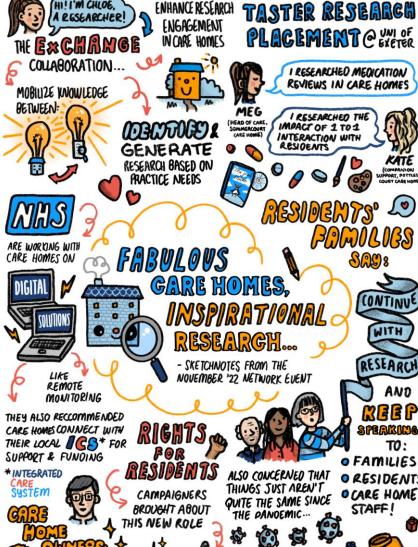
..strong facilitation











ALSO CONCERNED THAT THINGS JUST AREN'T QUITE THE SAME SINCE

o FAMILIES · RESIDENTS O CARE HOME

CONTINUE

WITH

RESEARC

Keep

TO:

SPEAKING



WHAT MAKES







· CARE HOME STAFF HAVE

. WE NEED TO SHARE OUR

A MAGIC! NO GATE KEEPING!



















https://www.arc-swp.nihr.ac.uk/research/the-exeter-care-homes-and-knowledge-exchange-collaboration

https://exchangecollaboration.wordpress.com













- Associate professor occupational therapy, researching long term care for 15 years
- Began with care home research on sensitive topic of abuse, in which participatory approach important for empowerment
- Care home research typically hasn't involved older people living in care homes in 'public involvement' roles
- CLAHRC East of England study found residents wanted to be involved but research coming to them
- DACHA study planned to facilitate 2 resident involvement groups in residents' homes – COVID intervened
- DACHA collaborated with National Activity Provider Association (NAPA) – with activity providers facilitating research involvement activities



- The voice, priorities and perspectives of care home residents are key
- Residents likely to have limited energy, range of needs for support to engage
- Activity providers know residents' needs
- Activity providers have a relationship of trust with residents
- Researchers and activity providers develop involvement activities together
- Series of involvement activities regular input of residents' voices to the research project
- CAHPPI will research this approach to residents' involvement



- People living in care homes active as citizens
- Research that keeps the priorities and perspectives of care home residents at the centre
- A meaningful activity for residents
- Activity providers recognised for their skills, with professional development opportunities













