Repurposing trial data in care homes and identifying new research priorities for care home staff and residents

Lisa Irvine, Senior Research Fellow
University of Hertfordshire

DACHA
Developing resources And minimum data set for Care Homes' Adoption

University of Hertfordshire UH

NIHR | National Institute for Health Research

Making better use of **existing** data in care homes

Administrative - Census

Care home factors - CQC

Cohort studies – CFAS/ELSA

Randomised controlled trials

What is a Randomised Controlled Trial (RCT)?

Randomly assign participants to one of two or more treatment groups, and then **comparing** the outcomes of the groups

Most reliable way to assess the **effectiveness** of a treatment

Can provide **a lot of information** with a relatively small number of participants

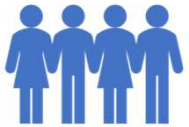
Care Home RCTs – a year in the life of a care home resident…

Challenges with conducting RCTs in care homes

Recruiting participants

Obtaining informed consent

Maintaining confidentiality



Managing the care of participants

TIME CONSUMING FOR RESEARCHERS

TIME CONSUMING FOR STAFF

EXPENSIVE

Examples of RCTs in care homes

Falls in Care Homes

1650 residents
84 homes
12 months
Checklist completed by CH staff
Falls, Quality of life, resource use and medications

Person-centred dementia management

1000 residents
50 homes
16 months
Dementia-related outcomes, quality of life, resource use & medications

Medication review by pharmacists

900 residents
44 homes
6 months
Falls, Quality of life, resource use and medications

Repurposing RCT data

Process of using data that has already been collected for one purpose (RCTs) to answer new questions

Can be a more efficient and cost-effective way to conduct research than conducting new RCTs

Can answer questions that would be difficult or impossible to answer with new RCTs

Requires researchers to have a good understanding of the data that has been collected

Difficult to get access to data that has been collected by other researchers

What is VICHTA?

- Virtual Trials Archive (University of Glasgow) provides a platform for researchers to share and access data from care home trials worldwide
  - VI**CH**TA – Virtual International **Care Homes** Trials Archive
- INCLUSION criteria: Any RCT conducted in UK care homes, published since 2010. At least 100 participants
- Request full trial IPD and other study documentation eg data dictionary, protocols, evidence of consent/assent
- Includes detailed data on residents' demographics, outcomes, and contextual information captured in RCTs

How does VICHTA work?

- Data must be **fully anonymized** before it is added to the repository - Minimise risk of re-identification
- Electronic data **stored securely** on University of Glasgow server and will not be transferred or copied to any other location
- Original trialists = **Trialist Steering Committee** - Gatekeepers to their own data – oversee sharing, can block research proposals or join them
- **Data sharing agreement** between original trial sponsor, Herts and Glasgow

RCTs pooled in VICHTA so far

	Challenge DemCare	CAREMED	FINCH	CHIPPS	DCM-EPIC	ELECTRIC
Recruitment period	2011-12	2011-12	2016-18	2017-19	2014-16	2018-19
Budget (2023 prices)	£3,219,996	£378,054	£2,554,408	£2,510,418	£2,992,957	£1,498,605
Location	England	England	England	England, Scotland & Northern Ireland	England	England & Scotland
N Resident participants	832	826	1698*	WP6: 882 WP5 (Pilot): 41	Cohort 1: 726 Cohort 2: 261	408
N Care homes	63	30	84	44	50	37
Follow up (months)	4	12	12	6	16	4
Intervention type	Dementia, Challenging behaviour	Medication management	Falls prevention	Pharmacist review	Dementia, Person centred care	Incontinence

Data availability

- **Variables with complete data** (n=5669)
  - Age : range 23 – 106 Mean 85
  - Sex - 72% female
  - Duration follow-up
  - Death status at study end (DeathYN)
  - Capacity / Ability to consent
  - Year of follow-up
  - Country, Region
  - Timepoints

- Other factors collected in some trials
  - Education level, Previous residence
  - Care home mix, funding
  - Staffing, occupancy

- **Outcome measures**
  - Quality of Life: EQ5D, DEMQoL,
  - Cognitive: MMSE, QUALID, QUALIDEM, DEMQoL
  - Physical: Barthel, Clinical Frailty Score, PAM-RC
  - Disease specific: Minnesota toilet, Waterlow

- **Co-morbidities – varying denominator**
  - Dementia diagnosis
  - Stroke, Diabetes, CHD, Parkinsons
  - Charlson index
  - Later – try to map to medications?

DACHA
Developing resources And minimum data sets for Care Homes' Adoption

Virtual International Care Homes Trial Archive

Potential future uses for VICHTA

Benchmarking across homes / regions / resident groups

Identifying **subgroups** of residents

Relationship between X symptom and Y outcomes (e.g. pain and dementia)

Mapping outcome measures (esp. Quality of life)

Focus on health resource use / **medications** data

Workforce issues (inked with resident outcomes

Impact of **funding** mix?

“**A year in the life** of a care home resident”

Next steps: Gathering new research ideas

Public involvement – care home residents and staff

Consultation – what type of research should we be doing? Is there data already available in VICHTA to help answer?

Facilitated through Activity Co-ordinators working in care homes around the country

NAPA
National Activity Providers Association

CHAPPI
Care Home Activity Providers facilitating Public Involvement in research

Process to identify new research priorities from residents

Public engagement exercise – Explain VICHTA & data avail

Identify potential research question

Has it been researched before? Collate evidence

Assess whether there is data in VICHTA to help answer

- Yes – publish research idea on VICHTA website
- No – list research idea as ‘other priorities’

Conclusion

- Data repurposing is a valuable tool for researchers who are interested in improving the care of older adults
- Can be a more efficient and cost-effective way to conduct research than conducting new RCTs
- Can answer questions that would be difficult or impossible to answer with new RCTs
- VICHTA will be available for use from early 2024
- Priority setting among care home staff and residents will continue into 2024

DACHA

Developing resources And minimum data set for Care Homes' Adoption

More information in our protocol paper:

More information on the DACHA study is also available at:
www.dachastudy.com

Contact me at:
l.Irvine@herts.ac.uk
@lisirv

Irvine *et al. Trials* (2021) 22:157
https://doi.org/10.1186/s13063-021-05107-w

Trials

STUDY PROTOCOL Open Access

Protocol for the development of a repository of individual participant data from randomised controlled trials conducted in adult care homes (the Virtual International Care Homes Trials Archive (VICHTA))

Lisa Irvine[1*], Jennifer Kirsty Burton[2], Myzoon Ali[2], Terence J. Quinn[2] and Claire Goodman[1,3]

Abstract

Background: Approximately 418,000 people live in care homes in the UK, yet accessible, robust data on care home populations and organisation are lacking. This hampers our ability to plan, allocate resources or prevent risk. Large randomised controlled trials (RCTs) conducted in care homes offer a potential solution. The value of detailed data on residents' demographics, outcomes and contextual information captured in RCTs has yet to be fully realised

This study is funded by the National Institute for Health and Care Research (NIHR) Health Service Research and Delivery programme (HS&DR NIHR127234) and supported by the NIHR Applied Research Collaboration (ARC) East of England.
The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.