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ENRICH Scotland: A research network ENabling Research In Care

Homes in Scotland

Abstract

There is a need to understand the lives of people who live in care homes and how care should

be delivered in this setting. Enabling Research in Care Homes (ENRICH) was funded by NIHR

in 2012 in England to increase research awareness and participation for people who live and

work in care homes. A similar model was developed for Scotland, but without funding this

proved difficult. In 2021, the Chief Scientist Office funded an expansion of the existing model

for Scottish care homes. This paper describes the components of ENRICH Scotland and the

research infrastructure the team are developing to enable more research, including clinical

trials, to be carried out in Scottish care homes, and how this will benefit the residents, families

and staff of care homes.

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Keywords

Care home, residential care, older adults, frailty, research network, enrich

Key Points

- There is a need for more research, including clinical trials, to be carried out in care homes.
- 2. The benefits that research participation and involvement can create should be accessible to care home staff, residents and their families.
- Research carried out in care homes can have additional barriers that often require specialist knowledge and expertise to be overcome.
- 4. The Enabling Research in Care Homes (ENRICH) research network has effectively increased research participation for care homes in England and Wales and a similar model is proving successful for Scotland.
- 5. Co-production should be fundamental to research being developed for care homes.

Reflective Questions

What areas of care that are commonly delivered in care homes could be shared through research participation to enable mutual learning between the care home sector and wider health and social care services?

What areas of care that are commonly delivered in care homes could be improved on through research?

What role should or could a registered nurse working in a care home have in a clinical trial being carried out in a care home?

Background

A care home is where people live in homely surroundings, when they are no longer able to live at home or in supported housing. Care homes may also be referred to using a wide range of other terms, such as residential care, nursing homes, retirement homes or residential care homes, long term care facilities and homes for the aged. Scotland currently has 1069 care homes for adults. These care homes provide care for a variety of reasons, including alcohol-related and brain injuries, learning disabilities and mental health problems, with a mixture of short- and long-term stays. However, the majority (91%) of care is provided to older adults (aged 65 and over), with or without onsite nursing (Public Health Scotland, 2021). There are around 33000 adults living in care homes out of the approximately 40000 available places (Public Health Scotland, 2021). Compared to 2011, there has been a 20% reduction in number of care homes and 11% reduction in occupancy of available beds (Public Health Scotland, 2021).

The people who live in care homes are increasingly diverse due to ageing populations and variations in service provision (Burton et al., 2019, Goodman et al., 2016). Most care home residents (71%) are female, and the average age a person moves into a care home is 82 (Public Health Scotland, 2021). Life expectancy once a person moves into a Scottish care home is typically between 1.6 and 2.7 years (Burton et al., 2019). Sixty-four percent of care home residents live with dementia (medically diagnosed and not) (Public Health Scotland, 2021). Therefore, care home residents account for around 23% of the 90,000 people in Scotland who live with dementia (Scottish Government, 2017). The COVID-19 pandemic has accelerated a change in care homes towards shorter term, palliative, and end of life care (Burton et al., 2021, Oluyase et al., 2021, Bone et al., 2018). Changes within care homes because of the pandemic have not just been limited to length and approaches to care. Care home staff,

residents and their families have dealt with significant visiting restrictions and environmental alterations that have caused deep psychological distress for many (Bloomer and Walshe, 2021). As a result, understanding the population who live and work in care homes, as well as appropriate care to benefit residents, which includes drug therapies and interventions, and living with dementia, has never been more important.

Benefits and Challenges to Research Participation

Research is the keystone to understanding the needs of care home residents and their carers to identify appropriate support and treatment. However, care homes have been historically underserved by researchers, which contributed to their disproportionate impact from the pandemic (Toms et al., 2020). A survey of Scottish care homes in 2014 found as few as 7% had been involved in research (Law et al., 2021). Reasons for this relate to the perceived complexity of undertaking research in the care home environment. Researchers anticipate challenges that include ethical barriers around capacity and consent for people with dementia and high staff turnover (Robinson et al., 2020). These are further compounded by variations in service provision and record keeping, and researchers who often do not understand care home culture (Bunn et al., 2020, Musa et al., 2020). Interviews with care home staff found poor relationships, alienating research communication, and limited time and space were all barriers to their participation (Law et al., 2021).

Care home staff and residents can have significant positive effects from research not just from the findings of the research itself. Involving care home staff and residents in the research process can be mutually beneficial for care homes and research teams (Backhouse et al., 2016). Co-production can ensure that questions are asked that are relevant to care home residents and staff, and elicit deeper understandings of tested interventions, including identification of aspects that require further attention (Hall et al., 2017). Collaboration

between research teams and care homes can also improve study retention (Froggatt et al., 2016, Millar et al., 2017). Researchers working in this environment must have good communication and interpersonal skills, develop accessible information, and plan adequate time to build positive relationships with care homes, especially when a study involves people with dementia (Backhouse et al., 2016, Law et al., 2021). It is imperative that the identified challenges are overcome so care home staff, residents and their families have equitable access to research opportunities in-line with wider society.

Enabling Research in Care Homes

In 2012, to address some of the identified challenges, the National Institute for Health Research (NIHR) developed a specific care home research network in England and Wales. It was hoped that a specialist research network could act as a support and co-ordinating service that would streamline the processes around such a complex but necessary area of health and social care research. The Enabling Research in Care Homes (ENRICH) networks in England and Wales have successfully promoted and supported care home staff, residents, and their families to participate in research (Goodman and Davies, 2012). A mixed-methods analysis of ENRICH evidenced that the care home research network encouraged more research in care homes and increased participation among care home staff (Davies et al., 2014).

Adult Social Care Reform in Scotland

The Independent Review of Adult Social Care in Scotland (Scottish Government, 2021) highlighted the need for such an entity as ENRICH, to provide essential support to researchers from both health and social care sectors. The framework set by the Public Bodies (Joint Working) (Scotland) Act 2014 (operative from April 2016) has an advisory and regulatory approach to the format of integration, suggesting that a similar approach should be applied to research. Integrating ENRICH into Scotland would provide an opportunity to deliver on the

long-established plans for reforming and integrating health and social care, and to deliver ethical and accountable research practices (Scottish Government, 2015).

ENRICH Scotland

Although there was an identified need for a similar model to ENRICH in Scotland, developing it proved difficult without funding. Despite this, the then Scottish Dementia Clinical Research Network (SDCRN) — now Neuroprogressive and Dementia Network (NDN) - remained active within NIHR ENRICH and recruited 54 care homes to the ENRICH national database between 2012-2021. During this period, approximately six studies were supported with recruitment. However, in the absence of dedicated staff, these data were not routinely collected.

The manager of the NDN (EL) and the Speciality Lead for NRS Ageing Network (SDS) established regular meetings for academics and other stakeholders interested in care home research. This coupled with the potential for rapid recruitment to studies for COVID-19 (e.g. PROTECT-CH (www.protect-trial.net)) led to successful bid to the Chief Scientist Office (CSO) for funding for ENRICH Scotland. ENRICH Scotland now has a dedicated full time national coordinator and part time Clinical Studies Officers (0.4WTE) based in the four large teaching boards of Greater Glasgow and Clyde, Tayside, Lothian and Grampian plus administration support, and a Patient and Public Involvement (PPI) lead. Funding for 2022-2023 has been secured from the Chief Scientist Office to expand the team into the remaining Scottish Health Boards.

The team are developing various branches of activity to improve research infrastructure around care homes in Scotland (Figure 1).

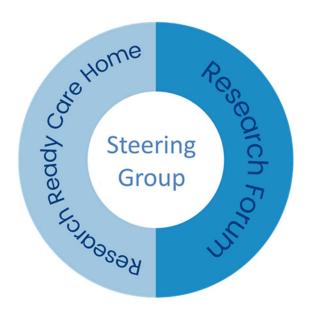


Figure 1: Primary branches of ENRICH Scotland activity.

Research Ready Care Homes

A Research Ready care home registered with ENRICH Scotland is a care home that has agreed to participate in research and has provided basic information that includes but is not limited to its location, number of beds, types of care provided, and number of staff employed to work in the care home. They agree to be contacted by researchers who are looking for 'Research Ready' care homes. They will consider participating in studies that may be of interest to them depending on their expressed interests and any previous research experience but there is no formal participatory obligation. Each care home in the network is supported by an ENRICH Clinical Studies Officer. All 'Research Ready' care homes receive a regular newsletter that details studies open to recruitment. They also receive a certificate, which is endorsed by the Care Inspectorate: this does not indicate any level of research training or experience, but a willingness to engage in this.

Current Challenges to Engaging with Care Homes

The main challenge to recruiting care homes as 'Research Ready' is the significant impact of COVID-19 on the care home sector. Changes to practice and priorities in response to the pandemic, staff vacancies and burn-out of remaining staff have significant effects on

wellbeing and mental health, and staff's ability to participate in additional activities, although staff acknowledge that there is an important opportunity for learning and new practices. Staff availability and capacity for change are important influencers for success (Bunn et al., 2020), but these are currently significantly reduced. Therefore, new ways of supporting care homes to embrace change are required at a time when staff shortages and burnout increase (Watson et al., 2021).

Research Forum

The ENRICH Scotland Research Forum is made up of academics, researchers and clinicians from a wide range of backgrounds based in Scotland with an interest in care home research. The Forum aims to support integrated, multi-disciplinary research. Members of the Forum are encouraged to share their expertise and collaborate on studies to enhance the existing creativity and vibrancy within the Scottish care home research community.

ENRICH Steering Group

ENRICH Scotland steering group includes representatives from the Care Inspectorate, Scottish Social Services Council (SSSC), Scottish Care and The Institute for Research and Innovation in Social Services (IRISS). The steering group also includes staff members from several care homes.

Partners in Research

Partners in Research captures 'patient and public involvement' in the Neuroprogressive and Dementia network. The group's ethos centres on positioning people with dementia and neuroprogressive conditions as 'experts by experience'. Group members are offered a range of research-related activities including but not limited to, reviewing research documents e.g., Information sheets and consent forms; participating in group meetings; setting research priorities and areas of interest; and co-leading in research and funding applications. Partners

in Research collaborate with ENRICH Scotland through their advisory panel of PPI volunteers and we are now developing a specific PPI group for ENRICH learning lessons from the NDN Partners in Research.

Care Home Innovation Partnership

The Care Home Innovation Partnership (CHiP) is a group of six care home managers based in Lothian that have been working together for several years (https://services.nhslothian.scot/CareHomes/Research/Pages/Care-Home-Innovation-Partnership-.aspx). The group develop tests of change with academics and other key partners, co-designing projects of importance to them and their residents. This enables them to be an integral part of co-production and more connected to the research that is being carried out. This is part of a larger vision towards a "Teaching and Research Based Care Home in Scotland" (https://www.ed.ac.uk/usher/primary-palliative-care/recent-grants/care-homes-project).

The CHiP group is now supported within the ENRICH framework to ensure its achievements can continue with plans to replicate the model in other areas in Scotland.

How to Get Involved

Anyone who is based in Scotland and lives or works in a care home - including within a care home support team within an NHS Board - or anyone who supports a family member or friend who lives in a care home, or researchers interested in improving the health and care of care home residents or staff, can get involved. Contact can be made by emailing tay.enrichscotland@nhs.scot with a short introduction.

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