

NIHR Dissemination Centre
THEMED REVIEW

ADVANCING CARE

Research with care homes



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FOREWORD

Every day, there are more than twice as many people living in care homes in England and Wales than staying in hospital. And yet historically there has been much less health care research in care homes. We know far more about effective treatments in hospitals and less about what works most effectively to improve care and experience for older people living in care homes.

But this is changing. In this report, we can see examples of different kinds of research supported by the NIHR in and with care homes. These include some of the most vulnerable people in our community with complex health and care needs. Research can help care homes to support residents to live well, age well and to achieve a comfortable and dignified death. We also need to work well together, joining up the services of NHS and other professionals with staff working day and night in care homes. There is more to be done, but this report shows how research is addressing some of the real challenges for those working and living in care homes.

Professor Martin J Vernon

National Clinical Director for Older People and Person Centred Integrated Care,
NHS England



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EXECUTIVE SUMMARY

Over 400,000 older people live in 19,000 independently owned care homes in the UK. In recent years, the number of care home residents living with severe frailty has risen and the care needs of individuals have become greater. Many now live longer with multiple conditions, including long-term physical and mental health problems.

Meeting these care needs is the responsibility of a great number of professionals, including care home staff and a range of visiting NHS professionals. Finding the most effective ways to organise care, so that it genuinely meets the needs of care home residents, is the focus of much of the current research in this field.

This review of research funded by the National Institute for Health Research (NIHR) reports on three main themes relating to the care of care home residents:

- » Living Well – maintaining good health and quality of life
- » Ageing Well – managing long-term conditions associated with ageing
- » Dying Well – ensuring a good quality end of life

The NIHR research related to Living Well includes studies that aim to improve nutrition, improve the quality of life of residents and to find better ways to reduce depression and pain and manage incontinence. It includes studies that aim to increase residents' access to routine health checks and to support approaches to prevent health problems from occurring in the first place.

In order to support residents in Ageing Well, NIHR research is aiming to find ways to improve the care of people living with dementia. This includes finding better ways of managing residents' distress and behaviour that challenges. Studies are also identifying the needs of ageing residents with multiple serious conditions, looking at strategies to

reduce the number of medication errors, optimise medication and avoid hospital admissions where appropriate.

Research that aims to improve end of life care for care home residents and to ensure a good quality death is included in the theme of Dying Well. This ranges from work on preferred place of death, through to supporting the very old at the end of life. There is also growing interest in research around the care of people with dementia at this stage, given there is still uncertainty as to what are the best kinds of support for these residents.

Across all of these areas of research activity, it is clear supporting partnership working between care homes and the NHS, at individual, organisational and system levels, is the key to achieving the outcomes that matter most to residents and their relatives. Related NIHR research has helped to explain why such partnerships sometimes work well or sometimes fail. It has started to explore the pivotal role of the care home manager in creating a culture in homes that enables change. New studies are addressing the important question of what kind of workforce is required to deliver the best quality care. These issues are discussed under the theme of Working Well.

Finally, the experience of carrying out research to improve care has led some researchers to recognise a deep understanding of the care home context is essential to a project's success, and that research works best when informed by the expertise, values and priorities of residents, relatives and front-line staff. The most successful research projects involve a partnership approach to their work, taking steps to ensure everyone involved is enabled and supported to make their contribution. This includes ensuring residents have their say, care homes benefit from their participation, and the researchers themselves have the support they need to work in this setting. The research on these issues is discussed in relation to the theme of Researching Well.



Improving the lives of older people living in care homes is a key focus of all who work in the sector. Care homes are places where people are enabled to live and die well. The skills and expertise of staff, and the need for services to be person-led, not just person-centred, should encourage researchers to consider wider and more inclusive approaches to how they conduct research programmes. Practice is enriched when it is underpinned by research and evidence. This research should be shaped and informed by the voices of people who use services and be of genuine relevance to the care homes.

Sharon Blackburn, Policy and Communications Director, National Care Forum



INTRODUCTION

THE CARE OF CARE HOME RESIDENTS

Over 400,000 older people live in 19,000 independently owned care homes in the UK. Care homes are very mixed, and include care homes with nursing (the minority, where nursing staff work in the home) and care homes without nursing (residential only). Some are privately owned and others are run by charities or councils. Some are based in adapted housing, while others will be based in large communal centres. The majority have 35 beds or fewer.

The population of care home residents has changed dramatically over the last five to ten years, to include people living with severe frailty and illness. The average care home resident is likely to be female, aged 85, and have a life expectancy of 12-30 months. He or she may have six or more diagnoses, may be taking seven or more medications, and live with physical disabilities and mental health problems. The majority live with dementia and many experience incontinence, depression and pain. Some residents with severe and complex health care needs are wholly funded by the NHS. Others are self-funding or have their care paid for by the local authority or a mix of both. Meeting the health and care needs of this very vulnerable group of older people is a significant challenge for both NHS and care home staff.

This recent change in the care home population has partly arisen because of a policy shift towards maintaining older people's independence for as long as possible and improving the care provided to people in their own homes. Therefore entry into a care home is being delayed until older people's health problems have become difficult to manage at home. People whose care is paid by a local authority or trust may go into a care home at a later stage than those who self-fund. At the same time, the long-term management of conditions that affect older people, including heart disease and dementia, has improved. So, for example, the people who may not have survived a heart attack ten years ago are now much more likely to survive and to live with the effects

of long-term cardiovascular disease. These people have multiple and complex healthcare needs, so that the nature of the care and support provided in care homes has had to change in response (see next page).

Ensuring older people living and dying in care homes have access to appropriate health care is the job of a great number of people. GPs play a central role in providing and coordinating medical care to care home residents, and are increasingly supported by community based geriatricians. Equally, a host of community healthcare professionals including community nurses, podiatrists, speech and language therapists, pharmacists, physiotherapists, opticians and dentists, provide health care alongside the staff who work in care homes. All of these professionals have valuable expertise to offer. Their input will vary over time, as residents' health needs are likely to fluctuate. At times of rapid and serious decline, the input of specialists from hospital settings or palliative care teams may also be required. The central aim of much current research and development is to coordinate the contributions from health and social care professionals to ensure the care provided is person-centred: timely, appropriate and reflecting what each individual resident wants.

Partners and relatives have an important role to play here too. They often support their loved one to communicate with professionals to ensure a clear understanding of the individual's needs. This is particularly important when residents are unable to speak for themselves. Finding out what matters to care home residents and their families is fundamental to shaping the care that is provided and assessing its quality. This is true both for the individual and for the home, since the care of any one resident will affect the quality of life of other residents. At a strategic level, the interests and concerns of residents and relatives need to inform policy and practice as well as future research. Understanding and meeting residents' needs provides a unifying agenda for everyone involved.

WHAT DOES THIS REVIEW COVER?

ENHANCED HEALTH IN CARE HOMES – DEVELOPING NATIONAL POLICY AND PRACTICE

Recognising the importance of improving the quality of care in care homes, NHS England has established six vanguard areas, where care homes are working closely with the NHS, local authorities, the voluntary sector, carers and families to optimise the health of their residents (NHS England, 2016). The model being used to develop practice has been informed by the research evidence available to date. The NIHR has also funded a rapid review of research findings to support this work with a focus on: the use of technology; the care home workforce; collaborations between care homes and external organisations; and evaluating changes in care. Each vanguard is working on achieving core objectives as well as developing other initiatives to reflect their local strengths and interests. All the work will be evaluated and the lessons shared through care home chains and associations, to ensure the spread of best practice across England.

 [READ MORE \(Study 1\)](#) 

Newly funded NIHR research will also explore links between the UK care home workforce and its influence on the quality of care. This evidence will be used to inform national workforce policy and care home level decisions about staffing, as well as finding the best ways to develop, support and organise staff within homes in order to optimise care.

 [READ MORE \(Studies 2 & 3\)](#) 

This themed review provides an overview of recent research on improving the health and care of care home residents. It is not a comprehensive review of all research in this area; it focuses on studies funded by the NIHR. Set up in 2006 as the research arm of the NHS, the NIHR aims to provide a health research system focused on the needs of patients and the public. Over the last ten years, it has funded a number of programmes, projects, research centres and staff working on research in care homes. There has been a deliberate investment by the NIHR in this area in recent years, following concerns care home residents were under-represented in dementia and other research (Department of Health 2011). This includes setting up a dedicated network to support better research in care homes (www.enrich.nihr.ac.uk – see page 28), as well as a range of national and regional research activities. There has also been particular targeted support for dementia research, including a national exercise to set research priorities.

Research in care homes is a relatively new and emerging field. Care homes are also calling for more research to be done, as they want a better

understanding of how best to provide care and what ‘good’ looks like, as well as obtaining evidence to support the good quality care already being provided.

Many of the projects discussed in this review are ongoing, and the evidence to inform practice is still limited. By highlighting current research, and exploring how new approaches are being developed to better meet the challenges ahead, we hope this review will be of interest to the health and social care professionals providing care, the residents and relatives who will benefit, and to researchers interested in working on this important topic.

The review includes research based in care homes for older people living with frailty and does not include research relating to care homes for other groups of people with physical or learning disabilities. It includes studies relating to care for care home residents, but not other related clinical studies (such as treatments for dementia), or those relating to care for older people in their own homes, or ways to prevent people moving into care homes. The focus is on the care of the oldest old, recognising



the complexity and challenges of supporting these individuals are distinct - interventions that work in other contexts might not always be transferable to a care home setting.

To find out about other NIHR research on related topics, including a range of clinical effectiveness studies on topics from pressure ulcers to falls prevention, visit <https://www.journalslibrary.nihr.ac.uk>

Relevant studies were identified by searching online databases and websites where NIHR research is registered or published. A total of 44 studies were then selected for this review, which included NIHR and Department of Health funded research carried out in care homes where the findings had been published (in the case of completed studies) or where researchers were able to discuss their ongoing work (in studies that were still underway). The focus was mainly on large-scale national studies funded through a range of NIHR sources. Other applied research with care homes taking place in different parts of the country will be reported separately – see <https://www.clahrcprojects.co.uk/>.

The current terms used to describe different types of care homes include ‘care homes with nursing’, where residents receive on-site nursing as well as social care, and ‘care homes without nursing’, where residents receive personal care and support in activities of daily living. Some of the studies in this review involved more than one type of care home or did not specify the type of home they involved. Where the study has focused on a particular type of

care home this has been made clear in the text.

The review reports on three main themes relating to the care of the oldest old:

- » Living Well – maintaining good health and quality of life
- » Ageing Well – managing long-term conditions associated with ageing
- » Dying Well – ensuring a good quality end of life

One of the important ways of achieving these outcomes is to promote good practice both within care homes and across the wider NHS, supporting partnership working between these sectors at the individual, organisational and system level. These cross-cutting issues are discussed in relation to the theme of Working Well.

Identifying, supporting and developing good practice relies on research that is informed by the expertise, values and priorities of all stakeholders – residents, relatives, care home staff and NHS health professionals – to focus on the outcomes that matter most to residents and are relevant and practical. These cross-cutting issues are discussed in relation to the theme of Researching Well.

All research discussed in this review has been wholly or partly funded by the NIHR, unless otherwise stated.

Summaries of all NIHR studies are available at the end of the review.

LIVING WELL



PERCENTAGE OF POPULATION AGED
65 YEARS AND OVER LIVING IN CARE
HOMES

4%

PERCENTAGE OF POPULATION AGED
85 YEARS AND OVER LIVING IN CARE
HOMES

16%

Source: ENRICH – Laing and Buisson survey 2016

Enabling care home residents to live well means taking action to maintain their current state of health, to ensure the best possible quality of life, and being proactive and preventative in their care. For health and care professionals, this means providing routine health checks to detect problems early, prevent avoidable health problems such as falls, and quickly treat any acute illness to avoid potentially serious consequences. If secondary care is required for serious symptoms, then access to hospital needs to be timely and appropriate and genuinely in the interests of the patient.

It also means taking a person-centred approach, recognising older people as individuals with very different experiences of life, as well as different needs, concerns, likes and dislikes. Any care and support needs to be tailored to each person, to prioritise the health outcomes and home life that they want most. The interests and concerns of the oldest old are likely to be different from those of other groups.

Since it is estimated that 70% of care home residents in England experience dementia, an important part of tailoring care is recognising some residents may need additional support to access routine health care and to communicate their needs.

This section covers:

- » Maintaining good health
- » Ensuring the best possible quality of life
- » Routine health checks
- » Preventing avoidable health problems.

MAINTAINING GOOD HEALTH

For this most vulnerable group of people, maintaining good health often simply means keeping well-nourished, staying hydrated, being active and continuing to socialise with others. Even achieving these simple goals is complicated by the physical and mental health problems the oldest old commonly experience. This means some approaches used to maintain the health of older people at home, such

as exercise programmes, may be difficult to transfer directly to a care home setting (see *Researching Well*, page 11).

Agitated behaviour at mealtimes can stop people in care homes from eating enough. One study aimed to identify ways of improving nutrition amongst care home residents with dementia, by reviewing all the published research on how to reduce residents' stress and anxiety around mealtimes.



RESEARCHING WELL - WORKING TOWARDS A BETTER UNDERSTANDING OF CARE HOME RESIDENTS' NEEDS

The Occupational Therapy in Care Homes trial tested whether rehabilitation for people affected by stroke in care homes could help them become more mobile and increase their physical activity. The trial found no evidence of benefit from a three-month course of occupational therapy that included setting goals with the patients, educating staff and adapting the care home environment. These findings prompted the researchers to raise an important question: "Do we expect too much from this predominantly frail population...?" Because care home residents have high levels of disability, dementia and depression, it may be unrealistic to expect them to engage in and benefit from the type of physical therapy that might work for other groups of older people. A different approach is required. The researchers concluded that greater attention should be given to care home residents' specific needs when researching and developing future interventions.

 [READ MORE \(Study 4\)](#) 

Similar conclusions were reached by researchers investigating the use of an exercise programme to reduce falls amongst care home residents. They found even under research conditions, residents weren't able to achieve the amount of exercise required to bring about an improvement in balance.

 [READ MORE \(Study 5\)](#) 

One of the most effective ways to understand and respond to residents' needs, and to assess their interest and capacity to engage, is to work with them, and with their relatives and carers, in developing and designing care home research. Only in this way can they be involved in prioritising what research needs to be done and identifying the outcomes of care that they would find most beneficial (see Researching well, page 13).

The evidence to date suggests playing music during lunch and/or the evening meal may be effective, particularly relaxing music such as bird and whale songs, or quiet classical piano pieces. These need to be played at a volume that can just be heard over the background noise. Other helpful changes included: replacing pre-plated meals with family-style meals, placing food on the table and

serving people individually; promoting conversation during the meal; and increasing the lighting and maximising the contrast of the place settings, for example by using black placemats on a white tablecloth. All had a positive impact on behaviour, but music was the most effective.

 [READ MORE \(Study 6\)](#) 

Although research shows playing music at mealtimes might be helpful, in practice these kinds of interventions won't work for everyone. While music might calm one person down, it might equally disturb someone else, for example, if that piece of music brings back unhappy memories. The challenge for us is finding a way to meet everyone's needs at the same time. Research needs to recognise that every resident is different.

Joyce Pinfield, Care home owner

POSITIVE INTERVENTIONS TO IMPROVE WELL-BEING

One NIHR study has looked at using Life Story Work to improve the quality of life for care home residents with dementia, as well as how best to evaluate this approach. Life Story Work involves recording aspects of a person's past life, as well as their current interests and future plans and wishes. Individuals often produce a life story book or a box that can be shared with others. The information is used to improve people's care or simply to provide them with pleasure. This study was the first to discuss the benefits and outcomes of such an approach with people with dementia.

The researchers also worked with advisers with dementia to shape the research design, which made

it easier for people with dementia to take part (see *Researching Well*, page 13). Early results from this pilot study showed a positive change in staff attitudes towards dementia, and an improvement in the quality of life for residents, for relatively little cost. This suggests a large-scale trial of this approach would be worthwhile in the future. However, the researchers also highlighted that new tools are needed to measure quality of life for people with dementia in ways they can engage with and understand, rather than asking others to make this assessment. The lack of relevant measures of quality of life in this context is a problem raised by a number of NIHR researchers.

 [READ MORE \(Study 7\)](#) 

The sooner Life Story Work starts with a person with dementia and their families, the richer the outcome. Although there is value in the 1-1 process of producing the Life Story, this work should start way before someone goes into permanent care, so that staff are supported to engage with the person, and see beyond their dementia.

Newcastle University Care Home Interest Group Member

The Adult Social Care Outcomes Toolkit (ASCOT) is one such measure. It looks at aspects of people's lives that are affected by social care including having control over daily life and activities, feeling clean and comfortable, having choices about food and drink, feeling safe, taking part in social activities, feeling occupied, living in clean and comfortable accommodation and living with dignity.

Researchers tested the use of this toolkit in care homes. The researchers observed residents' behaviour in order to complete the measure, and then worked with staff to give feedback about their practice and how well this was meeting residents' needs. The staff found it useful to identify the challenges (such as too few staff) and in finding alternative approaches (for instance, employing an agency with expertise in creating activities for people with dementia).

Despite such changes, the researchers did not find any evidence that the residents' quality of life had improved during the 12-week interval between assessments. This may be because some residents were becoming increasingly frail, or because the health of care home residents tends to vary - people

often have good and bad days. The researchers conclude any measure that just takes a snapshot of residents' lives is going to be limited. A better way to use the tool might be to decide the outcomes for care for each individual in a person-centred way, and then use the tool to assess whether the care put in place achieves what each person wants and needs.

 [READ MORE \(Study 8\)](#) 

The researchers are also working on another project with a local authority to see whether the tool could be useful in routine quality monitoring.

 [READ MORE \(Study 9\)](#) 

A recent review looked at evidence on improving eating and drinking for people with dementia in care homes. Although there were no conclusive findings, some strategies like family-style meals with caregivers did appear promising.

 [READ MORE \(Study 10\)](#) 

Changing the care home environment is another potentially important way to improve residents' quality of life, for example, by enabling residents to enjoy nature in a garden.

 [READ MORE \(Study 11\)](#) 

A small-scale project is reviewing the evidence on whether allowing pets or having animals visit homes might contribute to residents' well-being and their physical and mental health.

 [READ MORE \(Study 12\)](#) 

RESEARCHING WELL – INVOLVING RESIDENTS AND RELATIVES IN CARE HOME RESEARCH

Researchers working on a project to evaluate Life Story Work developed new approaches to involving people with dementia in their research project, to allow for the fact that people varied in their ability to engage and some had difficulty in communicating. The researchers went out to meet people with dementia and ensured individuals were supported by family members, friends or care workers to contribute their views. The patient advisers shaped crucial aspects of the research project, including:

- » Identifying what outcomes they would want the life story work to achieve
- » Helping to plan focus groups with people with dementia to maximise their participation and minimise any distress
- » Making information sheets and consent forms easy to understand
- » Validating the findings from the research
- » Deciding on the format of a film to disseminate the results.

 [READ MORE \(Study 7\)](#) 

Another group of researchers reviewed all the evidence relating to involving care home residents in research. They found although there can be multiple barriers to this involvement, it has been successful and made a difference to several studies, particularly studies involving qualitative research.

 [READ MORE \(Study 13\)](#) 

MINIMISING THE IMPACT OF NEGATIVE SYMPTOMS

Treating depression

Up to 40% of care home residents may experience depression. Treatment with antidepressants may not be appropriate because of potential drug interactions and toxicity, which can lead, for example, to an increased risk of falls. A large NIHR study in this area investigated whether exercise, in the form of physiotherapist-led sessions and increased general activity, would reduce depression amongst care home residents. The exercise intervention was well-received in all 78 care homes that participated, and uptake was good. However, no effect was found on residents' depression. The study did not measure whether other areas, such as resident well-being, were improved by exercise.

 [READ MORE \(Study 14\)](#) 

A more recent study is looking at ways to enhance routine activities (such as walking to the dining room), to increase residents' activity. The researchers will assess whether this impacts on the residents' physical and psychological well-being. They are working with groups of residents and staff to develop their approach, which they hope will make it practical and widely applicable.

 [READ MORE \(Study 15\)](#) 

Managing pain

Around 80% of people in care homes experience regular pain, caused by conditions like arthritis or pressure sores. Besides causing great discomfort and distress, untreated pain limits movement and is a major cause of behavioural problems. Researchers in one study found pain management in people with dementia is particularly difficult because these

patients are often unable to describe their pain in words. Care workers and relatives play an important role because they can tell whether the person with dementia is in pain and whether any treatment is working. 'Knowing the person' becomes essential to providing the most suitable treatment and care.

 [READ MORE \(Study 16\)](#)

The study also highlighted the limitations of current pain treatment. Care professionals tend to favour drug treatments, typically paracetamol in the first instance, followed by opioid patches in cases of severe pain. Other drug treatments are available but have not yet been tested in this setting. Relatives tend to favour non-drug approaches, such as the use of hot and cold, massage, aromatherapy and music, recognising that what sometimes helps is getting the person moving - but these approaches are rarely used in practice.

Overall, the findings suggested a need for guidance for all stakeholders, supported by training to promote an understanding of the common types and causes of pain and ways of locating and recognising the severity of pain, as well as broadening the treatment responses.

Managing incontinence

Many people living with dementia in care homes experience faecal incontinence (FI). NIHR researchers

have reviewed the published research evidence to explain what works and why in terms of managing FI. They found although studies recognised that dementia was a risk factor, they had rarely considered how the symptoms of dementia might affect whether a care home resident would benefit from the different kinds of interventions being tested. Nor has it been widely recognised that there are practical, dementia-specific skills which staff need, in order to support continence care for people living with dementia.

The researchers have concluded that improving the management of FI requires involving clinicians in assessing the causes and possible treatment of FI, increasing staff knowledge and skills in tailoring continence care to the individual person with dementia, and greater recognition of the valuable role of care workers in delivering this personal and intimate care. The researchers also concluded an exclusive focus on FI was possibly unhelpful, as the majority of residents with FI would also be incontinent of urine. Staff attitudes and awareness are also important - only if staff are convinced they are 'doing the right thing' in persevering with regular toileting and ongoing assessment and review of an individual's care, will there be successful management of FI.

 [READ MORE \(Study 17\)](#)



ROUTINE HEALTH CHECKS

It is well established that residents in care homes may not have such good access to health services as other older people (Ilfiffe et al, 2016). A recent study asked whether people with dementia in care homes are receiving regular sight tests to make sure prescriptions for their glasses are up to date and to identify people who might benefit from cataract surgery.

The researchers found residents with dementia are more likely to have eyesight problems compared with other people of the same age. 50% of the residents who took part in the study had a visual impairment. Just under half of those people had their vision corrected by glasses, and more would have had their vision corrected by cataract surgery. Good vision is important, for example in preventing other health problems such as falls. But it seems that relatives and care staff, as well as optometrists themselves, may be assuming incorrectly that people with dementia are unable to complete a sight test.

 [READ MORE \(Study 18\)](#) 

The study showed that more than 80% of the people living with dementia who took part in the study could complete the important parts of an eye examination. If these residents are supported by carers and given a longer period of time for the sight test, they were more able to engage with and complete the process. The researchers concluded routine sight tests for people with dementia might be increased by developing a care pathway and increasing optometrists' skills in providing care to older people with dementia.

Additionally, focus groups with care home staff and residents provided valuable insights into the needs and concerns of the people they care for. They described how people with dementia sometimes refuse to wear their glasses, and frequently break or lose them, or often end up wearing someone else's glasses. The challenges around improving vision for people with dementia, therefore, aren't only about access to sight tests and glasses, but also about understanding people's choices and behaviour and the practical challenges that arise from living with people with dementia in a communal environment.

PREVENTING AVOIDABLE HEALTH PROBLEMS

Falls are one of the most common avoidable health problems amongst the oldest old. One recently completed study looked at whether a new approach to medication review could reduce the

number of falls amongst care home residents. An earlier study suggested there might be an effect. The new approach involved bringing together a GP, a pharmacist and a resident or their representative (often a member of staff from the care home) to review the individual's prescriptions. The review was done on two separate occasions six months apart, and the impact assessed six months later (12 months after the first review).

The researchers found the review process made no difference to the number of falls, the number of hospital admissions or the number of deaths amongst care home residents, although there was a measurable improvement in prescribing. They conclude a more holistic approach may be needed to see a significant effect, one that also looks at other aspects of medication management, such as how medicines are stored and administered in care homes. The medication review might have also impacted on other aspects of residents' lives: for example, their quality of life may have been improved if side-effects were reduced, but this wasn't measured in this study.

 [READ MORE \(Study 19\)](#) 

Another study that is still underway will assess whether a novel falls prevention intervention reduces the number of falls amongst care home residents. The intervention, called the Guide to Action Care Home (GtACH) intervention, involves bringing in falls prevention experts to train care home staff, first to help them assess residents' risk of falling, and secondly to take action to reduce any risks.

 [READ MORE \(Study 20\)](#) 

Preventing falls, together with medication errors, are often identified as important patient safety priorities. One new study is looking at improving the safety culture in care homes by developing and evaluating a training and improvement initiative in 35 care homes.

 [READ MORE \(Study 21\)](#) 

Other research still ongoing will look at another preventable problem of managing infection in care homes, given the need to minimise antimicrobial prescribing.

 [READ MORE \(Study 22\)](#) 

WORKING WELL – HOW CARE HOME STAFF AND NHS STAFF IN THE COMMUNITY CAN WORK TOGETHER TO PREVENT HEALTH PROBLEMS

Supporting care home residents to live well often means providing healthcare that aims to be proactive, preventing problems occurring in the first place. Coordinating health services to achieve this goal is a serious challenge, since up to 26 different NHS services can be involved in residents' care, and all need to work closely with care home staff. A large-scale study assessed how care home staff and community health professionals were working together.

Over the first six months, the researchers found on average, the care homes in their study accessed between 14 and 15 different professionals or services, most often district nurses, opticians, chiropodists, podiatrists, community psychiatric nurses and continence services. However, there was no single, recognisable way in which homes and primary care services worked together. The arrangements seemed to be on an ad hoc basis, and largely dependent on individual relationships between care home staff and NHS professionals.

 [READ MORE \(Study 23\)](#) 

One approach to joining up care is to understand the key characteristics of different models of care that will trigger ways of working that benefit residents' access to healthcare. Another project, the Optimal study, has looked at different approaches to support effective working between NHS and care home staff. Organised in two phases, it mapped the current range of provision and then tested what kind of service provision works when and in what circumstances.

A review of published evidence showed variation in generalist and specialist health services to care homes could not be adequately explained by resident need or care home type. The research also suggested that there is no need for more descriptive research on health care delivery to care homes, rather studies that address what kind of interventions will work in what kind of circumstances.

The second stage of research suggested two main factors that make a difference to effective working between the NHS and care homes: what happens at an organisational level and what takes place between individual staff. For example, it asked what needs to be in place in terms of GP incentives and investment in NHS professionals to improve outcomes in care homes.

It found this was more likely to be effective if practitioners had been able to develop how they worked together over a sustained period of time, if the care home work was valued by the practitioners and the organisation they worked for and if the care homes were linked to a network of NHS support. Access to dementia specialist care for both NHS and care home staff was also important in addressing situations of uncertainty about how to support a resident in the care home.

 [READ MORE \(Study 24\)](#) 

A newly funded project is looking at all the different ways GPs work with care homes, and assessing their cost-effectiveness and impact on residents' care.

 [READ MORE \(Study 25\)](#) 



For effective partnership working, NHS organisations need to value and invest in working with care homes, so that NHS input is seen as legitimate and important work. When care homes are recognised as working 'with' the NHS it is easier to find workable solutions that support residents' access to appropriate health care.

Prof Claire Goodman, Care Home Researcher

There might be tensions between medicalising and normalising the care home environment. Some practitioners can forget that care homes are homes first, and places where disability and illness are managed second. The visiting GP may want the care home to run with the clinical efficiency of a hospital ward, whilst the care home staff want to maximise residents' comfort and foster warm relationships.

Professor Steve Iliffe, Researcher in Primary Care for Older People

AGEING WELL

PERCENTAGE OF PEOPLE IN CARE HOMES WITH DEMENTIA OR SEVERE MEMORY PROBLEMS

70%

Source: Alzheimer's Society

Many care home residents have multiple long-term health conditions (known as multi-morbidity) which are likely to progress or flare up occasionally, presenting different and complex problems at different times. Supporting care home residents to age well means managing these conditions successfully, and dealing with new symptoms promptly to minimise the impact on people's quality of life.

One of the most common long-term conditions amongst care home residents is dementia, which may also be complicated by episodes of delirium and depression. Therefore managing these mental health symptoms is one of the most common challenges for care home staff. All care homes, not only those specialising in dementia care, are now expected to provide quality care for people with this condition.

For residents with two or more long-term health conditions, current policy and practice are focused on providing person-centred care, as described in recent NICE guidance (NICE, 2016), and supported by NHS England. The goal is to improve the individual's quality of life by promoting shared decisions on treatment and care, based on what's important to each person. This care-tailoring approach means supporting individuals to make informed choices, weighing up the potential burdens of care – from multiple medications, multiple appointments and unnecessary admission to hospital - against the likely benefits. The aim is to create a better experience of care for the individual.

This section covers:

- » Improving care for residents with dementia
- » Reducing the number of medication errors
- » Reducing hospital admissions.

IMPROVING CARE FOR RESIDENTS WITH DEMENTIA

Find out about a range of published NIHR studies relating to dementia via the NIHR Journals Library collection on Dementia:

www.journalslibrary.nihr.ac.uk/collections/dementia/#/

Reducing the use of anti-psychotics

As well as loss of memory and intellect, people with dementia often experience neuropsychiatric symptoms (such as wandering, agitation, aggressive behaviours, depression, anxiety, and delusions). Anti-psychotic drugs are often used to treat these symptoms, but there are concerns about their side effects which can be serious. One large study aimed to develop a way of managing these behavioural problems, while reducing anti-psychotic use in care homes. The researchers tested an approach that combined a review of anti-psychotic prescriptions with increased exercise and social interaction (both involved 60 minutes of activity each week).

They found residents who only reduced their anti-psychotic medication had worse neuropsychiatric symptoms than those whose medication stayed the same. But importantly, if the reduced medication was combined with an increase in social interaction, then the person's symptoms did not get any worse. This combination also resulted in the greatest reduction in

the number of deaths. Exercise also proved effective in reducing neuropsychiatric symptoms. These results suggest a medications review that aims to reduce anti-psychotic use must be carried out at the same time as other non-drug interventions in order to achieve a positive outcome.

 [READ MORE \(Study 26\)](#)

Another group of NIHR researchers are building on current evidence to look in more depth at the medication review process and training needs for care home staff. Recognising the complex needs of people in care homes with dementia, these researchers suggest the review might be better conducted by a specialist pharmacist with experience in dementia care. The clinical pharmacist will review all medicines used to treat the behavioural and psychological symptoms of dementia, rather than focussing on a single class of medication (anti-psychotics). This review will be combined with training for care home staff so that they are better equipped to manage these symptoms without the need for medication.

 [READ MORE \(Study 27\)](#)

Managing agitated behaviour

Agitation is common in dementia and typically involves shouting, moving about or even violence without an obvious cause. It's distressing for everyone and can cause care to break down or increase care



costs. Drug treatments can have serious side effects and are often ineffective, so researchers have investigated which non-drug approaches might work to manage agitation.

They found teaching staff in care homes to communicate and consider the person with dementia's needs rather than focus on completing tasks with them was helpful for severe agitation, as were touch therapies. Pleasant activities and structured music therapy also helped to decrease agitation. Neither aromatherapy nor light therapy was effective. Further research is required to know whether these interventions also offer good value for money.

 [READ MORE \(Study 28\)](#) 

A new study is assessing whether a practice development tool called Dementia Care Mapping (DCM) helps to reduce agitation amongst people with dementia. DCM is a technique used in the NHS and care homes to help staff develop person-centred care. It involves observing the experience of care from the

point of view of people with dementia and feeding this back to staff, who then use this information to develop their practice. The review takes place every four to six months to reflect on and implement changes when needed.

DCM has been in use for many years, but there haven't been any studies in England to assess how well it works. This trial is the first large-scale assessment of whether it improves health outcomes for residents of care homes, as well as whether it reduces hospital admissions and improves residents' quality of life.

 [READ MORE \(Study 29\)](#) 

One distinct problem linked with agitation is delirium. This is common and distressing, but there have not always been reliable ways of detecting this in care home residents. One new study will test a new tool for use in routine care.

 [READ MORE \(Study 30\)](#) 

Another project has tested the feasibility of a trial to evaluate a complex intervention to try to reduce rates of delirium in fourteen care homes. The intervention included a delirium practitioner (mental health nurse) leading interactive training and education around delirium risk factors with delirium champions in each care home.

 [READ MORE \(Study 31\)](#) 

The NIHR has also jointly funded a major study with the Economic and Social Research Council which aims to improve the management of agitation and raise the quality of life for people with dementia living in care homes (the MARQUE Study). The project consists of six different work streams, which together will provide a greater understanding of agitation and dementia.

 [READ MORE \(Study 32\)](#) 

Identifying the causes of behavioural problems to find the right ways to respond

Although people **with** dementia might often behave in ways that are difficult to manage and cause distress to caregivers, the reasons why an individual behaves in a way that is challenging will vary from person to person and in different situations. The most appropriate response will depend on the individual's needs at the time when it occurs. For example, if the person with dementia is violent because they are in pain which isn't being treated, then the best response is likely to be pain relief and supportive personal

care. If the cause is a problem with staff skills, then an intervention that helps staff to improve their interactions with the person might be more useful. Delivering behaviour management programmes usually requires a combination of responses to deliver care in a way that is acceptable to the individual. This means addressing the causes as well as adjusting the way care is given, to match it to the individual's own personality style and preference.

One large-scale project aimed to address this issue by enabling staff to identify what might be causing an individual to behave in ways that are challenging. It was hoped this approach, supported by a review of evidence, would help staff to tailor their responses to the person with dementia and the specific context. The research team therefore developed an online training package and a computer-based decision-support tool to assist staff in detecting the causes of behaviour and respond appropriately, including in their interactions with the individual. This is being tested in a multi-centre study reporting soon.

 [READ MORE \(Study 33\)](#) 

Many researchers have noted the importance of context in care home research. Indeed, there is a call for new approaches to applied research in this area. This includes recent thinking on the challenges around psychosocial interventions in dementia care (Vernooij-Dassen and Moniz-Cook, 2014) and insights from other researchers working in and around care homes research (see *Researching Well*, page 22).

In developing and testing interventions which will be effective in care homes, we as researchers need to work closely with care home staff. Our experience for instance suggests online training may be less used and useful than expected and different kinds of support and supervision may be needed. We need to think about this from the start.

Professor Esme Moniz-Cook, dementia researcher

RESEARCHING WELL – A REALITY CHECK FOR COMPLEX INTERVENTIONS

Many of the approaches to dealing with the complex problems of ageing care home residents involve combining several components. These typically aim to increase stakeholders' knowledge and awareness of the problem, to develop new skills amongst care staff, to measure a difference in outcomes that matter to residents and to tackle cultural barriers by engaging all stakeholders. It can sometimes be assumed that putting these complex interventions in place is like giving a drug – a uniform, technical fix. But any such approach that aims to improve the quality of healthcare is going to be hugely influenced by the context.

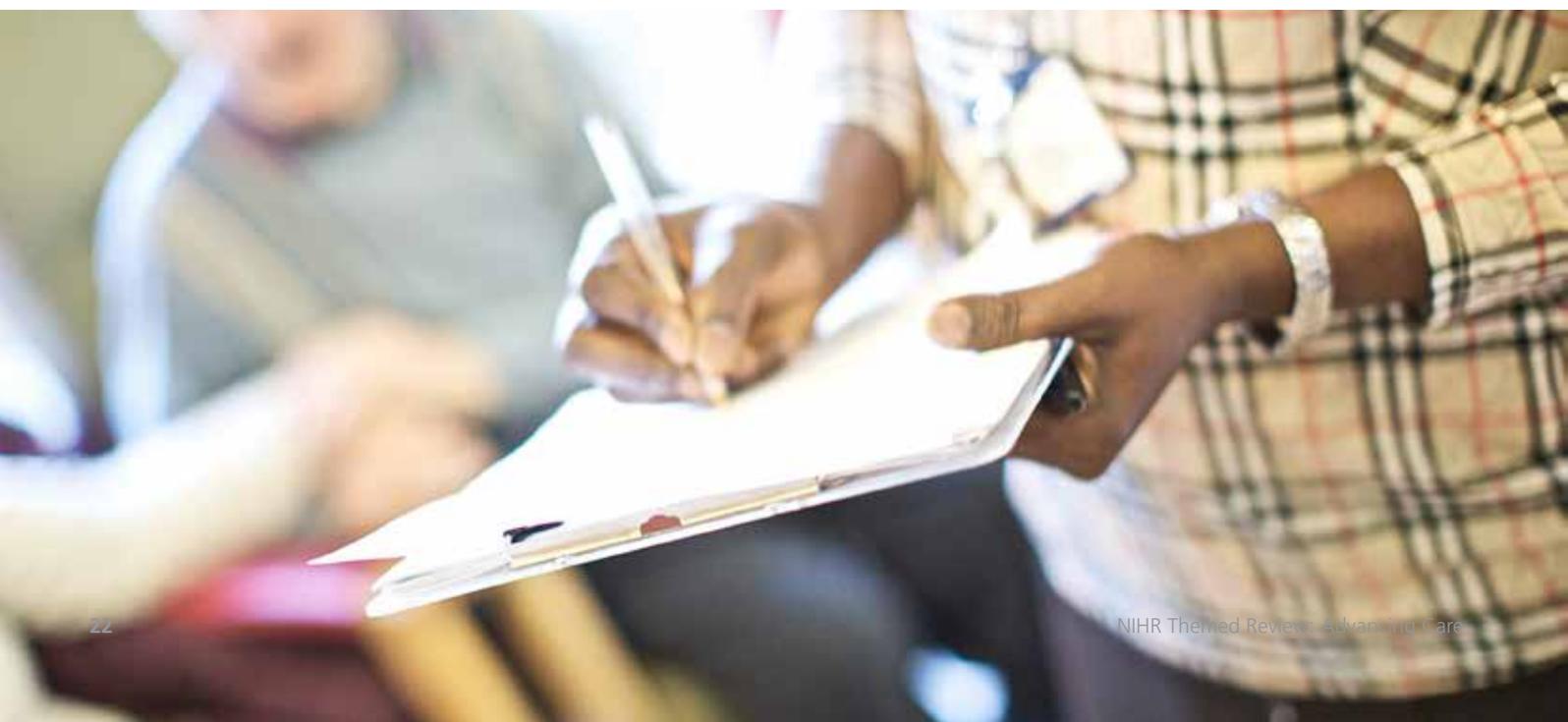
One group of researchers (not funded by the NIHR) designed such an intervention to improve the safety of people living in care homes (Marshall et al, 2016). By improving care of pressure ulcers, urinary tract infections and following a fall, they aimed to reduce the number of hospital admissions and reduce costs. When they evaluated their approach they found only three of the original nine parts of their complex intervention could be implemented in the way they originally planned. Furthermore the results showed no change in residents' health problems or rates of hospital admissions. They concluded: 'As a project team, we thought that we had designed the original intervention thoughtfully and carefully, but the findings of our evaluation suggested that we could have done a lot better'.

Thinking about what they would do differently next time, the researchers stated they would put more effort into:

- » Defining the problem in a way that reflects the reality of life in care homes
- » Thinking about how the intervention might need to be designed in different ways to make it practical and workable in different contexts
- » Piloting the intervention during a longer run-in period, to test and refine its design
- » Seeking a wide range of views from frontline staff and care home residents, continually throughout the project
- » Being aware of the resource constraints under which the improvement team and care homes are operating.

In summary, this modified approach to turning any theory into practice requires a more extensive 'reality check' throughout a project, as well as building in more scope for learning and reflection. NIHR funded researchers have reached similar conclusions.

 [READ MORE \(Study 33\)](#) 



Another study is also focused on individual needs of residents. Using a human rights framework to support care planning has been found to encourage care home staff to think about what's in the individual's best interests, rather than just making decisions based on clinical criteria. Researchers developed a training package to support staff in making this change in their practice. They gave the training to one set of care homes and then compared their residents' care plans with those from other

homes who hadn't received the training. The results of the evaluation in 20 care homes are expected shortly.

 [READ MORE \(Study 34\)](#) 

Many of these initiatives highlight the importance of organisational culture and the role of the care home manager is central in this (see Working Well, below).

WORKING WELL - CARE HOME MANAGERS AND THEIR ROLE IN CHANGING PRACTICE

NIHR-funded researchers in the School of Social Care reviewed all the published research on the role of care home managers. They found very little is known about the practice, experiences and skills of care home managers, even though they are responsible for everything that happens in their homes. Care home managers are often an overlooked group when it comes to research, although many are involved in studies about life or work in care homes.

 [READ MORE \(Study 35\)](#) 

The manager remains a hidden figure in the research, even though their impact on the culture of care is often commented upon. For example, a study funded by the Department of Health Policy Research Programme concluded the managers' role is central to creating a culture within a care home that ensures residents with complex needs receive high-quality care.

 [READ MORE \(Study 36\)](#) 

Another study has concluded managers with an open attitude and a willingness to engage in research and service improvement are key to the success of any attempt to bring about change in practice.

 [READ MORE \(Study 33\)](#) 

Research evidence to date shows care home managers face a variety of challenges in their role including: a lack of professional recognition and support, a heavy workload, financial and staffing pressures, responsibilities for developing relationships and networks, keeping up to date with regulations and policies, facing and addressing negativity from the outside world, creating a homely environment, and responding to the increasing complexities of residents' needs. Further research is much needed to understand how best to develop and support people in this role.

REDUCING THE NUMBER OF MEDICATION ERRORS

Care home residents typically take several different drugs at the same time for different long-term conditions, increasing the risk of drug interactions and serious side effects. One of the most common medication errors is continuing with medication that is no longer required (Furniss et al, 2000). Much of the current research aims to find ways to prevent this happening.

One study is investigating whether a pharmacist who can prescribe drugs (rather than a GP) might be the best person to do this for all of the residents in a care home. The study will explore how this could work, define what successful outcomes would look like, and develop training and guidance for pharmacists in this role. They will test this new approach in a clinical trial to see how well it works and whether it is cost-effective.

 [READ MORE \(Study 37\)](#) 

REDUCING HOSPITAL ADMISSIONS

People with chronic conditions such as chronic obstructive pulmonary disease or congestive cardiac failure often experience relapses or sudden worsening of their health. If such problems are detected early, they can often be treated in the care home, rather than a hospital. This is best for everyone – hospitalisation is costly to the NHS and distressing for the older person, their family and nursing home staff.

One part of a larger study aimed to describe the health and healthcare resource use of a representative sample of UK care home residents to estimate their needs and the services required to meet these needs. They found high levels of dependency, cognitive and behavioural problems, multiple conditions requiring multiple drug prescriptions and frequent use of NHS resources in care homes both with and without nursing. The most expensive care outside of the care home resulted from hospital inpatient stays.

The findings suggest the most cost-effective model for providing healthcare for care home residents would need to focus on preventing admissions to hospital, and that this might be more cost-effective if targeted at nursing home residents. However, the total savings to the NHS may be relatively small, given other studies suggest care home residents do not use hospital services as much as other older people in the general population (Smith et al 2015).

 [READ MORE \(Study 38\)](#) 

Another study is developing an approach to reducing hospital admissions that combines several interventions. These aim to: enhance the knowledge and skills of nursing home staff; improve clinical guidance and decision-support tools; engage with families; and provide support to care homes to implement these changes.

 [READ MORE \(Study 39\)](#) 



DYING WELL

PERCENTAGE OF PEOPLE DYING IN ENGLAND EACH YEAR WHO DIE IN A CARE HOME

18%

Source: ONS 2008-10

After hospitals, care homes are the most likely place of death for people aged over 65. This number is set to increase as the population ages and inappropriate admissions to hospital from care homes are reduced. Therefore care homes play a significant role in end of life care provision, and are only likely to expand this role in future. Current research is exploring how to improve this care and ways of ensuring a comfortable and dignified death for care home residents. This is not only important for older people and their relatives, but also for the staff who experience the emotional impact of a resident's end of life experience (see page 26).

 [READ MORE \(Study 40\)](#)

Dying well is everybody's business; from the care residents themselves to their families and friends, staff, researchers and other providers. Dying well is concerned with an approach to care which is constantly curious about what matters to and supports people as they live and die. In order to die well, we need to not only understand and act upon what works best but to also value care homes as a significant provider of end of life care.

Dr Sarah Russell: Head of Research, Hospice UK

Recent policy developments have aimed to improve the quality of end of life care for all dying people, including the five Priorities for Care (Wise, 2014) from the Leadership Alliance for the Care of Dying People, and the development of a national framework for local action, by The National Palliative and End of Life Care Partnership.

An earlier NIHR Dissemination Centre Themed Review featured research on end of life care under the themes of right care, right place, right time. This ranged from large studies of variation in place of death to research looking at care from different professionals in the last year of life. The review, 'Better Endings', can be downloaded here www.dc.nihr.ac.uk/themed-reviews/better-endings_2.htm

PRIORITIES FOR END OF LIFE CARE IN CARE HOMES – THE VIEWS OF RESIDENTS, RELATIVES AND STAFF

A recent non-NIHR study of the views of residents, relatives and staff identified six priorities for end of life care (Percival & Johnson, 2013):

- » Personalised care – maintaining relationships and having personal items to hand.
- » Dignity and respect – paying attention to cleanliness, explaining while carrying out personal tasks, thoughtfulness on the part of staff, culturally relevant care.
- » Making time – sitting with residents, listening, touch, patience, reorganising the workload to enable this.
- » Talking about end of life issues (and death) – staff can feel they are protecting residents by not talking about it, while most residents want to talk about it (especially the practical aspects).
- » Relatives' roles and collaboration – relatives are often willing to work with staff and residents are reassured if staff and relatives collaborate. Relatives help by staying overnight and providing care, and there are benefits to staff of having a 'bond' with relatives.
- » Staff support and training – staff readily admit the need for emotional support for themselves, which is more likely to be informal. They like to attend the funerals of the people they cared for. They also recognise the importance of ongoing education and training.

This section covers:

- Choosing the place of end of life care and death
- The quality of end of life care in care homes
- End of life care for people with dementia



CHOOSING THE PLACE OF END OF LIFE CARE AND DEATH

One study examined people's choices around the place of end of life care and death, amongst people dying from a health condition other than cancer. They found older people's preferences for their place of death change over time and will depend on their individual circumstances. It is often influenced by a desire not to place a burden on the family or carer. People with long-term neurological conditions often wish to plan ahead. Such advance care planning requires specialist skills and an ability to revisit decisions sensitively in response to a significant change in a person's condition. The researchers concluded that greater resources are needed to support a better quality of death in care homes.

 [READ MORE \(Study 41\)](#)

THE QUALITY OF END OF LIFE CARE IN CARE HOMES

Another study observed the deaths of a number of the 'oldest old' in care homes with nursing, to identify the issues around embedding good practice in end of life care. They found staff were skilled in identifying when a patient was close to death, particularly if they had been caring for that person for some time.

In this study, some nursing staff reported difficulties in securing a visit from a GP, particularly out of hours, because some GPs seemed to be reluctant to be involved in diagnosing someone as dying when they had no previous knowledge of the patient. This led to problems with prescriptions for drugs, for example, to treat pain. However, there was also some reluctance around use of these drugs, as nursing staff were worried about the under- or over-use of this medication being interpreted as hastening the death of any individual.

 [READ MORE \(Study 40\)](#)

During the last days and hours of life, nursing staff were observed to make routine visits to patients. Some continued regularly turning patients and trying to feed them, when relatives questioned whether this was strictly necessary. The staff reported that they were again concerned about being criticised for being neglectful. There seem to be conflicting messages around what constitutes best practice. The researchers concluded training in this area might need to be improved, to promote a deeper understanding of the complexities and challenges in

caring for people who are dying.

END OF LIFE CARE FOR PEOPLE WITH DEMENTIA

The Evidence-based Interventions in Dementia – End of Life study assessed the quality of end of life care for people with dementia and enabled care home and NHS staff to work together to develop new ways to improve care. The first part of the study followed 133 older people with dementia, and in particular focused on the end of life experiences of those that died during the 18-month observation period.

The researchers found even with access to end of life care tools, providing end of life care to people with dementia was problematic because there was so much uncertainty. Firstly, the staff were uncertain as to when someone could be said to be actively dying and were also unsure how to interpret and manage key events and symptoms. Secondly, the people involved (care home and NHS staff and relatives), were unclear about their respective roles, responsibilities and working relationships. Finally, the care home and NHS staff were unclear if they had the capacity or expertise to provide end of life care to people with dementia.

 [READ MORE \(Study 42\)](#)

In the second phase of the study, care home staff and visiting NHS staff worked together to identify what was working well in terms of end of life care for people with dementia, and then used this understanding to plan and implement change. They co-designed new tools to address the uncertainties which emerged in phase 1. These included: a script for discussing end of life wishes with relatives; a tool to support discussions with emergency and out of hours services; and a GP-led implementation and audit of advanced care planning.

These were evaluated by the research team, who found this approach supported a shift in care home culture that addressed the uncertainties and helped to embed different ways of working between NHS and care home staff. It did not come with any extra cost as the demand on resources was the same, and there was also a reduction in hospital costs.

 [READ MORE \(Study 42\)](#)

A new study is assessing the Namaste Care Intervention, which aims to improve the quality of dying for people with advanced dementia living in

care homes. It takes place in a prepared group space, where people receive daily individualised comfort assessment and care. A structured approach to this care, provided by the usual staff (four hours a day, seven days a week), engages the individual's senses, offering meaningful activities that reflect their particular interests.

The project will establish whether it is possible to

deliver the Namaste programme in care homes, and also find the best way to measure the outcomes. Carers linked with the Alzheimer's society were involved in developing this research proposal and care home staff and relatives will be involved in designing the resources used to deliver the new programme.

 [READ MORE \(Study 43\)](#) 

RESEARCHING WELL – ENSURING THE WELL-BEING OF PARTICIPANTS AND THE RESEARCHERS

An NIHR-funded group produced guidance for researchers working in care homes, highlighting the challenges of working in this complex setting. They found research in care homes can be difficult for researchers, even for those with a health or social care background. Researchers report being surprised by the rapid decline of some residents, and sometimes saddened by collecting data from residents who have died during the study. The work is emotionally as well as ethically demanding. Researchers, therefore, need to be supported to undertake research sensitively, to a high standard and without risk of burnout or emotional fatigue. As such, non-academic support and supervision needs to be built into a project from the start.

 [READ MORE \(Study 44\)](#) 

The importance of the skills which researchers bring to work in care homes needs to be recognised. These include an ability to relate to others, to communicate effectively, to empathise, to make ethical judgements, to remain flexible, be patient and, importantly, to ensure the wellbeing of the residents, relatives and staff at all times. Inter-personal and emotional skills may be as important as an understanding of research methods.

Many care homes have already provided an enormous amount of support to facilitate the research that has taken place to date, and many more will need to be engaged in the future. It is important to recognise research work may also challenge the people working in care homes, as it adds yet another pressure on an already heavily-burdened sector. Many care home staff and managers may, understandably, not give research and development high priority. The onus is therefore on the researcher to minimise disruption or added work within the care home, make clear the potential benefits to that particular care home and/or the care home sector, and work with the care home, either as a research partner, or at the very least to fit in with the rhythm and norms of the home.

Recognising these particular challenges for care home research, the NIHR has also funded the production of an online toolkit for researchers and their care home partners called ENRICH – ENhancing Research In Care Homes. ENRICH provides advice and guidance to everyone involved to ensure care home research is carried out to a high standard <http://enrich.nihr.ac.uk/>

 *The researcher in a care home needs to remember that residents and staff are doing them a favour that they are privileged to receive.*

Professor Steve Iliffe, Researcher in Primary Care for Older People



LOOKING FORWARD - WHERE NEXT FOR CARE HOME RESEARCH?

This review shows an encouraging and growing number of studies aiming to support improvements in the lives of people resident in care homes. But the research base is still new and relatively undeveloped. NIHR and other funders want to support more high quality research in this area. There is an opportunity for future research to build on what we have learnt to date, in particular aiming to:

- » Address the issues that are most important to those directly affected by the findings – residents, relatives, carers and care home staff
- » Support partnership working between health professionals, staff, residents and relatives in designing and delivering new approaches to care
- » Achieve the outcomes that matter to residents, relatives, carers and care home staff
- » Support partnership working between care home staff, residents and relatives to design, deliver and disseminate research
- » Recognise and address the specific needs and concerns of care home residents that are distinct from other groups of older people
- » Agree what works, for whom and when – approaches such as participatory action research can help promote practice development that reflects local contexts
- » Develop approaches to care that reflect the specific needs of people with dementia
- » Reflect and build on the learning that has come out of the research that has gone before.
- » Develop interventions that are grounded in the reality of care home life

Over fifteen years of research on service provision to care homes has found that patterns of NHS service delivery are ad hoc and very variable. We need to move on from repeating this kind of descriptive work to do more intervention studies that are informed by the knowledge, priorities and values of those living and working in care homes.

Professor Claire Goodman, Care Home Researcher



“

What this review highlights so well is the importance of the need for a multi-disciplinary approach to the care of our service users and this is still something that is so very lacking. It would help to develop more positive attitudes to the ‘front line’ care staff in homes, because they are the ones who are providing the care and will often know the person best. It’s the staff who have the know-how and experience to help researchers find new ways to improve care.

Stacey Armstrong, Care Home Manager

”

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- » **Steve Iliffe** Emeritus Professor of Primary Care for Older People - University College London
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- » **Stacey Armstrong** Care Home Manager
- » **Joyce Pinfield** Care Home Owner

STUDY SUMMARIES AND REFERENCES

STUDY SUMMARIES

LIVING WELL

STUDY 1 ONGOING

Innovation to enhance health in care homes: Rapid evidence synthesis

Due to publish 2017, Hanratty

The aim of this research is to review evidence on new ways of working to promote health in care homes. Four factors will be evaluated, which include the use of technology, the workforce, communication and engagement between care homes and external bodies, and the evaluation of changes in care and how care is received. These factors have been taken from the vanguard programme, which was set up to develop new ways of working to meet complex needs. The evidence will be reviewed in a short timescale, and summaries will be provided in an easily accessible format.

<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/157705/#/>

STUDY 2 ONGOING

Relationship between care home staffing and quality of care: a mixed methods approach

Due to publish 2020, Spilsbury

The aim of this study is to explore the relationship between the mix of staffing in the care home workforce and how this affects quality of care. Outcomes for residents, relatives and staff will be assessed. The research will examine how care is paid for and how this affects quality. It will involve a review of the literature and discussions with care home managers and staff. Information from key organisations (such as Skills for Care, Care Quality Commission and BUPA) will provide insight into UK-wide care homes. Six care homes will be selected to assess the relationship between staffing mix and levels and quality of care. Ultimately, the research aims to provide decision-makers, including care home managers and commissions, with important information about staffing and care quality.

<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1514429/#/summary-of-research>

STUDY 3 ONGOING

Improving the quality of care in care homes by care home staff

Due to start summer 2017, Cassell

This study aims to develop new outcome measures for pain and anxiety/depression that can be used with care home residents. It will look at the care home staff mix and evaluate potential ways of improving quality of life in care homes. The study is due to start in summer 2017, when the project page will go live.

<https://www.journalslibrary.nihr.ac.uk/#/>

STUDY 4 PUBLISHED

A cluster randomised controlled trial of an occupational therapy intervention for residents with stroke living in UK care homes

Published, 2016, Sackley

This study evaluated the clinical effectiveness and cost effectiveness of a targeted course of occupational therapy (OT) in maintaining functional activity and reducing further health risks from inactivity for care home residents living with stroke-related disabilities. The study included care home residents who had a history of stroke or transient ischaemic attack. The intervention consisted of a personalised three month course of OT delivered by qualified therapists. Care workers also participated in training workshops to support personal activities of daily living. The control condition was usual care. Overall, 568 residents from 114 care homes were allocated to the intervention arm and 474 residents

from another 114 care homes were allocated to the control arm. After the intervention, there were no significant differences between groups on a measure of Activities of Daily Living. There was also no difference between the groups in measures of depression, mobility and quality of life. Mean incremental cost of the OT intervention was £438.78. Whilst the authors caution that a large proportion of participants with very severe activity-based limitations and cognitive impairment may have limited capacity to engage in therapy, they concluded that the intervention showed no benefit in maintaining functional ability.

Health Technology Assessment 2016. DOI: 10.3310/hta20150

BMJ 2015. doi: 10.1136/bmj.h468

STUDY 5 PUBLISHED

Prevention Of Falls in COGNitively impaired older adults living in residential care (PROF-COG): A pilot multi-factorial intervention to prevent falls in older people living in care homes tailored towards risk factors related to cognitive impairment

Published, 2015, Whitney

This study evaluated an exercise programme to reduce falls in older people living in care homes. Twenty-nine participants from four different care homes (two nursing and two residential) involved in a falls prevention study had their twice-weekly exercise sessions timed over three months. 265 sessions were timed individually including session duration and time challenging balance whilst standing. Mean exercise session duration was 22.8 minutes with a mean standing time of 11.0 minutes. Those living in residential homes had longer session and standing times compared to nursing home residents. It is recommended that effective exercise programmes should be of high dose (at least 120 minutes weekly over six months) and include highly challenging balance training. The authors concluded that even in a research context the recommended exercise dose could not be achieved by care home residents. The dose of exercise achieved was 74 minutes shorter per week than that recommended.

Age Ageing 2015. Doi: 10.1093/ageing/afv032.06

STUDY 6 PUBLISHED

Effectiveness of mealtime interventions on behaviour symptoms of people with dementia living in care homes: A systematic review

Published, 2014, Whear

This systematic review examined the effectiveness of mealtime interventions aimed at improving behavioural symptoms in people living with dementia (aged 65 or over) in residential care. Eleven studies, involving 265 individuals, were included. Studies that investigated the use of oral nutritional supplementation, or vitamin and mineral supplements were excluded. The studies were based mainly in the USA, with none in UK. Mealtime interventions were categorized into four types: music, changes to food service, dining environment alteration and group conversation. Although all studies showed a positive trend in favour of the intervention, only six reported a statistically significant improvement in behavioural symptoms. However, the authors caution that the study quality was poor, limiting the generalisability of the conclusions. They concluded that well-designed studies are needed to evaluate the effectiveness of mealtime interventions for individuals with dementia in care homes.

Journal of the American Medical Directors Association 2014. http://dx.doi.org/10.1016/j.jamda.2013.10.016

STUDY 7 PUBLISHED

Improving Care for People with Dementia: Development and initial feasibility study for evaluation of Life Story Work in Dementia care

Published, 2016, Gridley

Life Story Work (LSW) is an intervention that aims to improve individual outcomes and care for people with dementia and their

carers. It involves collecting information and artefacts about the individual to produce their life story. This study was designed to evaluate whether a large trial of LSW was feasible. It involved a review of the literature, interviews with dementia care staff, individuals with dementia and their families, and a focus on six care homes to measure the costs and outcomes of LSW, and to see how feasible LSW was to introduce. Whilst LSW was identifiable in the care homes and two different models emerged, practice varied between settings and did not always follow "good practice". However, they did find positive changes in staff attitudes towards dementia, and improvements in quality of life for people with dementia. The cost of delivering LSW was relatively small. The study found that it would be possible to evaluate LSW in a larger trial, and would require researchers to work very closely with the care setting to achieve high quality data collection.

Health Service Delivery Research 2016. https://www.ncbi.nlm.nih.gov/books/NBK379598/pdf/Bookshelf_NBK379598.pdf

STUDY 8 PUBLISHED

The acceptability and feasibility of using the Adult Social Care Outcomes Toolkit (ASCOT) to inform practice in care homes

Published, 2016, Towers

This study evaluated the use of the Adult Social Care Outcomes Toolkit (ASCOT), which is used to measure social care related quality of life (SCRQoL) across different social care settings. Data was collected in four care homes, although the participation rate in each care home was low, and many individuals lacked the capacity to consent. The reliability of the tool over time was assessed to be good. Managers also reported implementing changes due to the results yielded by the toolkit. The authors therefore concluded that ASCOT is an appropriate measure of social care that can be utilised by care homes.

BMC Health Service Research 2016. DOI: 10.1186/s12913-016-1763-1

STUDY 9 ONGOING

Measuring Outcomes of Care Homes (MOOCH)

Ongoing, Towers

This study builds on previous work around ASCOT (Adult Social Care Outcomes Toolkit), which measures the quality of life most affected by social care services. There are measures available for service users and carers. The aim of the present study is to investigate the social care-related quality of life of older people living in care homes and the family and friends who care for them (unpaid). The review will include the impact of the care home on quality of life, and the types of support care homes provide. A newly adapted toolkit will be piloted with a local authority quality monitoring team.

<http://www.hra.nhs.uk/news/research-summaries/measuring-outcomes-of-care-homes/>

BMC Health Services Research 2015. doi: 10.1186/s12913-015-0942-9.

STUDY 10 PUBLISHED

Eating and Drinking Well IN dementia (EDWINA)

Published, 2016, Hooper

The aim of this review was to develop a better understanding of the complexities around eating and drinking well in dementia. A comprehensive review evaluated 56 interventions that aimed to either maintain, improve or facilitate food or drink intake of more than 2200 people with dementia. Studies were often small and of a short duration. Most studies were based in North America (29), with 16 based in Europe. The majority of interventions were assessed in institutional settings (such as dementia units, nursing homes and long-term care). Although no particular intervention was found to be highly effective, promising interventions included:

eating family-style meals with care givers, playing music, and engaging with multisensory exercise. The authors concluded that high-quality trials are needed to evaluate these promising interventions to provide more definitive results.

BMC Geriatrics 2016. DOI: 10.1186/s12877-016-0256-8

STUDY 11 PUBLISHED

What Is the Impact of Using Outdoor Spaces Such as Gardens on the Physical and Mental Well-Being of Those With Dementia? A Systematic Review of Quantitative and Qualitative Evidence

Published, 2014, Whear

This review looked at studies focusing on the impact of gardens and outdoor spaces on the mental and physical well-being of people with dementia living in care homes. Seventeen studies, a mixture of quantitative and qualitative, were included. Outdoor activities included walking, playing games such as golf, gardening and doing tasks, as well as passive enjoyment such as sitting, eating, sunbathing and looking around the garden. The qualitative findings suggested that such visits in the garden raised both staff and residents' spirits. Although the nine quantitative studies were of poor quality, they indicated that decreased levels of agitation were associated with garden use. The researchers argued that there is early evidence that gardens may have positive impact on individuals with dementia living in care homes, and so the issue would benefit from high quality research studies with key outcome measures.

Journal of the American Medical Directors Association, 2014. DOI: <http://dx.doi.org/10.1016/j.jamda.2014.05.013>

STUDY 12 ONGOING

Effects of animals on the health and wellbeing of residents in care homes

Due to publish 2018, Orr

This mixed methods study will examine the short and long term impact of animals on the physical and mental health, social well-being, medication use, and quality of life of older people living in care homes. It will explore different types of interventions (for example resident pets, pet visitation programmes, group or individual format, spontaneous or guided interaction) and assess the evidence around human-animal interactions. The project will also explore the challenges of involving animals in care homes for staff, relatives and residents.

<http://clahrc-peninsula.nihr.ac.uk/research/effects-of-animals-on-the-health-and-wellbeing-of-residents-in-care-homes>

STUDY 13 PUBLISHED

Older care-home residents as collaborators or advisors in research: a systematic review

Published, 2015, Killeth, Backhouse

This systematic review looked at how care home residents have been involved in research as collaborators or advisors. A systematic search found 11 different studies where care home residents had been involved in the research process. It was found that residents were involved as collaborators and partners in small-scale studies, where as they took on advisory roles in larger scale projects. Barriers and facilitators to involvement centred around social factors such as the development of trust, communication and cognitive skills, the availability of resources such as time and money, the care home environment and the organisation of research. The authors concluded that care home residents could be successfully included in the research process to have meaningful impact.

Age and Ageing 2016. DOI: 10.1093/ageing/afv201.

STUDY 14 PUBLISHED

Older People's Exercise intervention in Residential and nursing Accommodation (OPERA)

Published, 2013, Underwood

This randomised controlled trial evaluated the impact of a 'whole-home' intervention on depressive symptoms in care home residents. The intervention consisted of training care home staff along with twice-weekly, physiotherapist-led exercise classes for residents. The study took place in 78 care homes. Some care homes received the intervention and the rest received the control condition of a depression awareness training programme. From 765 residents, 374 residents were identified as having depression. Over the 12 months, 3191 group exercise sessions were run, with an average group size of 10 (5.3 study participants and 4.6 non-study participants). On average, study participants attended around half of the possible sessions. The intervention was well received by both staff and residents. No adverse effects were recorded. There was no evidence of the intervention significantly reducing depression symptoms in the depressed residents after 12 months. The additional NHS cost of the OPERA intervention was estimated at £374 per participant. As the intervention was not clinically or cost-effective, the authors concluded that OPERA cannot be recommended as a means of reducing the burden of depression in care home residents.

Health Technology Assessment 2013. DOI: [10.3310/hta17180](https://doi.org/10.3310/hta17180)

STUDY 15 ONGOING

Development and preliminary testing of strategies to enhance routine physical activity in care homes

Due to publish 2018, Forster

This research programme will work with care home staff and residents to develop and test methods to enhance routine activity in care homes. Barriers and facilitators to activity will be assessed through observations and interviews with staff, residents and relatives. The results will be used to inform a programme of activities and methods to enhance activity, which will be trialled in four care homes. This will be followed by an evaluation of the programme, comparing the intervention (delivered in six care homes) with usual care (another six care homes). Outcomes measures will include levels of physical activity, mood, quality of life and number of hospital admissions.

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22Forster+A%22&gid:%22RP-PG-1210-12017%22>

STUDY 16 PUBLISHED

Management of pain in people with dementia living in care homes: Programme and intervention development

Published, 2016, Corbett

This programme of research will provide preparatory work for an evidence-based pain management intervention for care homes. Consultations with care home staff and family carers have already taken place. Six major themes in current pain management in dementia were identified: importance of person-centredness, current lack of pain awareness in staff, communication as a core element, disparities in staff responsibility and confidence, the need for consistency of care and current lack of staff training. This information will be used to develop a preliminary algorithm for decision-making around assessment and treatment (pharmacological and non-pharmacological) of pain for individuals living with dementia. A small study will be undertaken in three care homes to evaluate the new algorithm. It is hoped that results will inform a larger trial and the development of a pain care pathway.

International Journal of Geriatric Psychiatry 2016. DOI: [10.1002/gps.4445](https://doi.org/10.1002/gps.4445)

STUDY 17 ONGOING

Managing Faecal Incontinence in people with advanced dementia resident in Care Homes (FINCH study)

Due to publish 2017, Goodman

This study will review what is known about faecal incontinence (FI) including the different interventions that have been developed to manage it. The project aims to provide better strategies for managing FI for individuals with dementia living in care homes to ensure their well-being. The research will involve a series of literature reviews and workshops, to facilitate the development of a set of recommendations about what works, for whom and in what context.

<https://www.journalslibrary.nihr.ac.uk/programmes/hta/137501/#/>

STUDY 18 PUBLISHED

The prevalence of visual impairment in people with dementia

Published, 2016, Bowen

This study aimed to measure the prevalence of eye conditions causing visual impairment (VI) in people with dementia. The study included 708 participants with dementia (aged 60–89 years): 389 lived in the community and 319 lived in care homes. A further 119 participants participated in interviews and focus groups (people with dementia, care workers, optometrists, and family carers). VI was defined by visual acuity worse than 6/12 or worse than 6/18 measured before and after refraction. Overall, the study found a high prevalence of all types of VI, which was disproportionately higher in people with dementia living in care homes. Almost 50% of presenting VI was correctable with spectacles, and more with cataract surgery. A third of VI was associated with macular degeneration. The researchers also found that carers and care workers underestimated how much could be achieved in an eye examination, and thus awareness needs to increase about the purpose, scope and limitations of examinations to encourage greater uptake for those with dementia. The authors indicated that improved communication is needed between optometrists and carers, and the diagnosis of dementia should be known. Developing an eye-care pathway for people with dementia would be beneficial.

Health Service Delivery Research 2016. <https://www.journalslibrary.nihr.ac.uk/hsdr/hsdr04210#/abstract>

STUDY 19 ONGOING

Multi-professional clinical medication reviews in care homes for the elderly. A randomised controlled trial with cost-effectiveness study

Protocol published, 2011, Desborough

The aim of this study is to determine the clinical effectiveness of a novel model of multi-professional medication review to improve the administration of medicines in care homes. Thirty care homes will be recruited and allocated to the intervention or control. The intervention homes will receive a multi-professional medication review at baseline and at six months, with follow-up at 12 months. The control homes will receive usual care. The researchers will assess the number of falls of care home residents and potentially inappropriate prescribing, as well as medication and resource costs, hospitalisations and mortality. Cost effectiveness will also be calculated.

Trials 2011. DOI: [10.1186/1745-6215-12-218](https://doi.org/10.1186/1745-6215-12-218)

STUDY 20 ONGOING

A multi-centre cluster randomised controlled trial to evaluate the Guide to Action Care Home fall prevention programme in care homes for older people (FinCH)

Due to publish 2019, Logan

This trial will compare falls rates in care homes where staff have received a novel fall prevention intervention with homes that are

providing usual care. The Guide to Action Care Home (GtACH) intervention involves falls prevention experts, training care home staff in small groups to assess residents fall risk and then providing actions to reduce fall risk. Sixty-six care homes and 1308 residents will be recruited across the UK. Each care home will be randomly assigned to receive the intervention or usual care. Care home staff in the GtACH intervention will attend the training and residents will be offered the assessment and actions. At three, six, nine and 12 months data will be collected on falls and fractures, changes in medication and equipment use, quality of life, activity and mortality. Interviews and observations will also be conducted.

<https://www.journalslibrary.nihr.ac.uk/programmes/hta/1311529/#/>

STUDY 21 ONGOING

Improving Safety in Care Homes: Evaluating the Walsall and Wolverhampton Care Home Improvement Programme

Protocol published, 2017, Damery

This study aims to evaluate a safety programme, funded by West Midlands Patient Safety Collaborative, implemented in 30 care homes with an estimated 1500 staff. The safety programme intends to reduce the incidence of harm, and to promote a culture of safety in care homes. The programme consists of training and workshop sessions for care home staff and requires groups of staff to undertake local improvement projects. The mixed-methods evaluation will take place over two years and will include quantitative assessment of changes in safety culture, hospital admissions, qualitative staff interviews, focus groups and case studies of four care homes. Results are expected in 2018/19.

BMC Health Services Research 2017. DOI: 10.1186/s12913-017-2013-x

STUDY 22 ONGOING

An evaluation of a multifaceted intervention to reduce antimicrobial prescribing in care home residents [REducing Antimicrobials in Care Homes (REACH)]: a non-randomised feasibility study and process evaluation

Due to publish 2018/19, Hughes

This two year study will examine the management of infection in care homes, specifically the use of antimicrobials (antibiotic, antifungal and antiviral medicines). A training package will be developed to train care home staff and GPs about how to manage infections in residents. The package will be evaluated in six care homes to assess its feasibility. A high use of antimicrobials can lead to resistance, where by the drugs are no longer effective. This study will therefore determine whether a training intervention can assist staff in managing and treating infections appropriately, thus reducing the risk of antimicrobial resistance.

<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/139712/#/>

STUDY 23 PUBLISHED

A study to develop integrated working between primary health care services and care homes

Published, 2013, Goodman

The aim of this research was to understand how care homes and healthcare services achieve integrated working. A systematic review was initially conducted, followed by a national survey to assess how integrated working was achieved for care homes that do not have on site nursing. Case studies were then used to examine integrated working in different contexts by following six care homes over 12 months. The three different settings included care homes with NHS funded beds and multidisciplinary teams, care homes in receipt of specialist service support, and care homes reliant on primary care services. The researchers looked at the use of services, how needs were met and conducted interviews with residents, relatives and staff. Overall, it was found that integrated working was often informally negotiated and based on staff

confidence. No particular service model was more superior. Primary care services were often reliant on how care home staff interpreted the health status of the residents. Results indicated that investment in the development and creation of good working relationships between NHS and care home staff could improve service delivery and integrated working.

NIHR Service Delivery and Organisation programme; 2013. <https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/081809231/#/summary-of-research>

Journal of the American Medical Directors Association 2015. DOI: 10.1016/j.jamda.2015.01.072.

STUDY 24 PUBLISHED

Optimal NHS service delivery to care homes: a realist evaluation of the features and mechanisms that support effective working for the continuing care of older people in residential settings

Published, 2017, Goodman

This study aimed to explore how different service delivery models for care home residents support and/or improve wellbeing and health-related outcomes in older people residing in care homes. The study took part in two stages. The first stage aimed to develop theory and explanations through review of range of evidence and interviews with NHS and Local Authority commissions, providers of care home services, care home managers, residents and families. Findings were tested out with these stakeholders. The second stage tested out some of this emerging theory through in-depth case study research over time with 12 care homes in three different parts of the country. Through these mixed methods, the researchers concluded that there was no single service model which worked best. However, their research suggested that NHS services were likely to work better with care homes when payments and role specifications supported staff at an institutional level as well as with individual residents.

First-look summary published, full report later in 2017

<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/11102102/#/>

Published realist review - BMC Health Services Research 2016. DOI: 10.1186/s12913-016-1493-4

STUDY 25 ONGOING

Organising general practice for care homes: A multi-method study

Due to publish 2018/19, Hanratty

This study aims to identify ways of organising GP services for care homes that produce good health outcomes at lowest cost. Three areas across England will be studied, two of which will have introduced a new way for GPs to work with care homes. Anonymised GP patient records will be accessed, looking at factors such as how GPs manage chronic illness, how often residents are admitted to hospital for conditions that could be looked after in the community, and the quality of prescribing. Interviews will be conducted with GPs, care home staff, residents and relatives. The cost of each model will also be calculated.

<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1419605/#/>

AGEING WELL

STUDY 26 PUBLISHED

An Optimized Person Centred Intervention to Improve Mental Health and Reduce Antipsychotics amongst People with Dementia in Care Homes (WHELD)

Published, 2016, Ballard, Whitaker

This study evaluated the impact of anti-psychotic review, social interaction, and exercise, in conjunction with person-centred care, on anti-psychotic use and agitation in people with dementia living

in nursing homes. Participants were recruited from 16 UK nursing homes. All homes received training in person-centred care, and eight were randomly assigned to receive 1 of 3 interventions: antipsychotic review, social interaction with activities or exercise, for 9 months. Most homes received more than one intervention. Interventions were delivered by a therapist who had attended an intensive training programme, with support from nursing home staff. Overall, anti-psychotic review significantly reduced anti-psychotic use by 50%. Antipsychotic review plus the social interaction intervention significantly reduced mortality compared with the group receiving neither intervention. The group receiving anti-psychotic review but not the social intervention showed significantly worse outcome in neuropsychiatric symptoms compared with the group receiving neither. The exercise intervention significantly improved neuropsychiatric symptoms but not depression. Agitation symptoms were not affected by any intervention. The authors concluded that the study demonstrated the feasibility of implementing an intervention to reduce anti-psychotic use in people with dementia, and further highlights the needs to review current practice and the evidence base.

American Journal of Psychiatry 2016. <http://dx.doi.org/10.1176/appi.ajp.2015.15010130>

Trials 2014. DOI: 10.1186/1745-6215-15-284

STUDY 27 ONGOING

Introduction of a pharmacy and psychosocial intervention in residential and nursing homes to limit the use of psychotropic medication to treat Behavioural and Psychological Symptoms of Dementia (BPSD) – a feasibility study

Due to publish 2017/18, Maidment

This research aims to test the feasibility of a pharmacy-psychosocial intervention to limit the use of psychotropics to treat Behavioural and Psychological Symptoms of Dementia (BPSD) in residential and nursing home residents. Up to six care homes will be recruited. Staff will be trained and supported in the use of behavioural change techniques to support the management of challenging behaviours. A specialist pharmacist, in collaboration with the GP, person with dementia and/or carer, will undertake a review of medication used to treat challenging behaviour. The reviews will be followed up to see if the recommendations were implemented. An embedded qualitative study will aim to understand barriers and facilitators to the intervention. Ultimately, the results will be used to inform the design of a larger trial to evaluate whether the intervention improves quality of life and health outcomes by reducing the inappropriate use of psychotropics.

BMJ Open 2016. Doi:10.1136/bmjopen-2015-010279.

STUDY 28 PUBLISHED

A systematic review of the effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia

Published, 2014, Livingston

This project reviewed the literature of non-pharmacological interventions for reducing agitation in individuals with dementia. The review took into account a range of factors including dementia severity, the setting and cost-effectiveness. A total of 160 papers were included, mainly from USA, Australia, the UK (13 papers) and Canada. The review found that supervised person-centred care, communication skills and dementia care mapping, as well as sensory therapy activities and structured music therapies, reduced agitation in individuals with dementia who lived in care homes. However, training family carers in behavioural or cognitive interventions did not decrease severe agitation. Health and social care costs were between £7,000 over three months in people without clinically significant agitation symptoms to around £15,000 for severe agitation. The authors cautioned that although

there were some high quality studies, only 33 had more than 45 participants. Future research also needs to investigate the use of interventions for agitation for individuals with dementia who live at home.

Health Technology Assessment 2014. DOI: 10.3310/hta18390.

STUDY 29 ONGOING

Evaluating the effectiveness and cost effectiveness of Dementia Care Mapping (DCM) to enable person-centred Care for people with dementia and their carers: A UK cluster randomised controlled trial in care homes (DCM EPIC trial)

Due to publish 2017/18, Surr

Dementia Care Mapping (DCM) is a technique used in the NHS and care homes to help staff apply person-centred care. It involves observing the experience of care from the point of view of people with dementia and feeding this back to staff. Review takes place every four to six months to reflect on and implement changes when needed. This study is evaluating the use of DCM in UK care homes. Fifty care homes across West Yorkshire, London and Oxfordshire have been recruited and over 950 individuals with dementia. Nineteen homes continued with usual care, and 31 homes were randomly selected to deliver DCM in addition to usual care. Staff at these homes received appropriate training in DCM and were asked to use it three times at four month intervals. Measures were taken again at six and 16 months, looking at changes in behaviour and quality of life.

<https://www.journalslibrary.nihr.ac.uk/programmes/hta/111513/#/>

Trials 2016. DOI: 10.1186/s13063-016-1416-z IF 1.859

STUDY 30 ONGOING

Investigation of the Delirium Observation Screening Scale for the routine detection of delirium in care homes by care home staff

Protocol published, 2016, Teale

This study will evaluate the use of a delirium screening tool. Current methods to detect delirium in care homes are varied, and measures are often too long and require specific training. Staff from four care homes will administer the 25 item Delirium Observation Screening Scale (DOSS) compared to a standard measure. Measures will be used to assess the reliability and validity of the DOSS, as well as the feasibility of using this measure in routine care. Routine screening with an appropriate measure would help timely detection and enable future systematic research into delirium in care homes.

BMJ Open 2016. DOI: 10.1136/bmjopen-2015-009615.

STUDY 31 PUBLISHED

Pilot trial of Stop Delirium! A complex intervention to prevent delirium in care homes for older people

Published, 2016, Siddiqi

'Stop Delirium!' is a tailored delirium intervention for care homes, which also aims to improve quality of care for residents. The 'PiTSTOP study' aimed to address key aspects of trial design for the particular circumstances of care homes in order to prepare for a full cluster randomised trial of Stop Delirium! This feasibility study took place in 14 care homes, comparing Stop Delirium! with usual care. Control homes were offered the intervention package at the end of the study. The intervention is a 16 month enhanced educational package to support care home staff to address key delirium risk factors, incorporating multiple strategies to change practice. The intervention was delivered by a specialist Delirium Practitioner. A process evaluation was also carried out. Two-thirds (215) of eligible care home residents were recruited. One-month delirium prevalence was 4% in the intervention homes and 7.1% in control homes. The authors concluded that a full trial of the intervention packaged was feasible with further design modifications. They indicated that their measures may have underestimated delirium.

STUDY 32 ONGOING

The MARQUE Project: Managing agitation and raising quality of life to improve agitation for people with dementia in care homes

Due to publish 2019, Livingstone

This research project involves interviewing and observing a wide range of individuals, including staff, managers and care home residents with dementia. The overall aim of the study is to evaluate the effectiveness of new training practices in care homes to deal with agitated patients and improve their quality of life. Staff from care homes will be interviewed to determine the barriers and facilitators to changes in policies. This will feed into the development of a manual for care homes. Paid carers will then be trained with the aim of reducing agitation in patients with dementia. After eight months, the levels of agitation in the residents will be assessed using a standardised questionnaire. It is hoped that this study will develop both theoretical and practical understanding of dealing with agitation in dementia, as well as provide greater insight into the experiences of agitation for residents, carers and staff.

<http://gtr.rcuk.ac.uk/project/317B9AB0-77BE-46E6-834A-3021A62873F6>

<https://ukctg.nihr.ac.uk/trials/trial-details/trial-details?trialNumber=ISRCTN96745365>

STUDY 33 ONGOING

Management of challenging behaviour in dementia at home and in care homes

Review published, 2012, Moniz-Cook

This programme grant is evaluating whether providing family and staff carers with training and support in behaviour management for dementia symptoms, enables them to improve their coping strategies as well as increase the wellbeing of people with dementia. This research has multiple components, including the development of a training package for staff and family carers. A systematic review was also undertaken to assess the effects of functional analysis-based interventions for people with dementia (and their caregivers). Functional analysis (FA) is a behavioural intervention for challenging behaviour. It is based on individually tailored strategies to relieve distress for the individual. Eighteen trials were included. The majority were in family care settings. Three studies were based in care homes, and a further two smaller studies in an assisted living and a hospital setting. For 14 studies, FA was just one aspect of a broad multi-component programme of care. Overall, positive effects were found after the intervention for the frequency of reported challenging behaviour (but not for incidence or severity) and for caregiver reaction (but not burden or depression). These effects were not evident at follow-up. The authors cautioned that poorly described intervention protocols made it difficult to establish the real effect of FA components. They indicated that there are emerging beneficial effects of multi-component psychosocial interventions that incorporate FA. However, there is limited data to evaluate its efficacy. Further robust trials are needed in both the family and care home setting. Full results from the programme grant are expected in late 2017.

Cochrane Database of Systematic Reviews 2012. DOI: 10.1002/14651858.CD006929.pub2.

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22Moniz-Cook+E%22+gid:%22RP-PG-0606-1067%22+ga:%22DH/NIHR%22>

STUDY 34 ONGOING

Embedding a Human Rights Based Approach to Dementia Care

Due to publish 2017, Kinderman

This study will evaluate a Human Rights Based Approach to

dementia care, comparing 10 dementia inpatient wards/care homes with 10 other sites where the intervention has not been implemented. This approach brings together the Human Rights Act and care provision by providing staff with practical strategies to assist them in delivering care that is both person centred and mindful of human rights. The "Getting it Right Assessment Tool" will allow staff to complete a person-centred assessment whilst capturing an individual's basic human rights. Staff will also attend a one day staff training package to explore how human rights and dementia are linked and training in the use of the assessment tool. Measurements will include quality of life for individuals with dementia, carers and staff members. It is hoped that this study will improve quality of care and empower staff to make difficult clinical decisions.

<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1220953/#/summary-of-research>

STUDY 35 PUBLISHED

Care Home Managers: A scoping review of the evidence

Published, 2014, Orellana

This review explored evidence about the role of Care Home Manager, through reviewing a variety of resources such as primary research studies, secondary analysis of published data and policy documents. The review looks at who care home managers are, their skills and experience, their practice and the support they receive from their managers and the care home. It also looks at the challenges faced by care home managers in their practice. The authors concluded that this group is often overlooked and there remain many unanswered questions and evidence gaps.

<http://www.sscr.nihr.ac.uk/PDF/ScopingReviews/SR8.pdf>

STUDY 36 PUBLISHED

CHOICE (Care Home Organisations Implementing Cultures of Excellence)

Published, 2013, Killeff

The study aimed to analyse positive and negative care experiences through understanding residents' experiences, organisational cultures and practices and developed the recording of measurable indicators of quality. The research project was part of the Preventing Abuse and Neglect in the Care of Older Adults (PANICOA) programme. Using a case study approach, 11 care homes across the UK were observed. There were several key findings from this study. First, a shared purpose in a care home impacts on quality of care. A shared vision amongst staff and management that highlights person-centred care was associated with positive care experiences. Second, a strong sense of community in the care home led to a positive experience of care. Third, managers who were sensitive to staff needs and prevented negative impact from external factors such as families and owner organisations helped to ensure a good quality of care was delivered. Care experiences also benefited when staff felt empowered to take responsibility for the care they delivered and when they were open to changes that would benefit the residents. The authors concluded that the in-depth observations revealed how organisational cultures impact upon care, comprised of a number of dynamic and evolving elements.

Final report DoH Policy Research Programme 025/0064: http://www.worcester.ac.uk/documents/CHOICE_final_report.pdf

STUDY 37 ONGOING

Care Homes Independent Pharmacist Prescribing Service (CHIPPS): Development and delivery of a cluster randomised controlled trial to determine both its effectiveness and cost-effectiveness

Due to publish 2020, Wright

This study aims to determine the effectiveness of pharmacist independent prescribing in care homes. The research comprises of

six work packages, which will be carried out in England, Scotland and Northern Ireland. The work packages include a review of the evidence around prescribing practices in care homes, focus groups and interviews with key stakeholders to discuss best practice for pharmacist independent prescribing and an analysis of the most effective way to measure outcomes. This research will be used to inform the design and implementation of a pharmacist independent prescriber (PIP) training package, which will first be evaluated in four care homes before a larger trial of 900 residents in 90 care homes is conducted. PIPs will be recruited to deliver the service to intervention homes over six months

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22Wright+DJ%22+gid:%22RP-PG-0613-20007%22>

STUDY 38 PUBLISHED

Medical Crises in Older People

Published, 2015, Gladman

This programme of research explored the care of three different groups of older patients: patients discharged from acute medical units, patients with dementia and delirium admitted to general hospitals, and care home residents. For the work on care homes, the researchers conducted a literature review, a cohort study of care home residents and an interview study of the delivery of healthcare to care home residents. The cohort study included 227 residents across 11 UK care homes (including residential and nursing homes). A range of measures were used to describe the health, functional status and healthcare resource use of residents over 180 days. Overall, 30% of residents were malnourished, 66% had behavioural disturbance and 16% died. Almost half of residents used secondary care services and from 209 participants 181 used either primary or secondary care services. Over the 180 day follow-up period there were 41 hospital admissions that resulted in an overnight stay. The authors concluded that this study demonstrated high dependency, mild frequent behavioural symptoms, multi-morbidity, polypharmacy and frequent use of NHS resources. In the qualitative study, interviews were conducted with care home managers, nurses and assistants, a variety of nurse specialists and an occupational therapist. Overall, interviews highlighted that the health care of residents was difficult due to their complex needs. Often a lack of time or resources prevented these needs from being fully met.

Programme Grants for Applied Research 2015. <https://www.journalslibrary.nihr.ac.uk/pgfar/pgfar03040#/abstract>

STUDY 39 ONGOING

Reducing rates of avoidable hospital admissions: Optimising an evidence-based intervention to improve care for Ambulatory Care Sensitive conditions in nursing homes

Due to publish 2017/18, Downs

This research will evaluate an intervention to reduce rates of hospital admissions from nursing homes for Ambulatory Care Sensitive (ACS) conditions. ACS is defined as conditions, which, if not detected early and actively managed in the care home, can lead to unplanned hospital admissions. First, a literature review will be conducted to identify effective ways of managing ACS conditions in care homes. This will be used to inform the development of an intervention, which will be implemented in two nursing homes. A pilot evolution of the intervention will be then conducted in 14 nursing homes, assessing the impact on avoidable hospital admissions and on a range of resident, staff, family and system-related secondary outcomes. If positive results are obtained, funding for a larger trial will be sought.

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22Downs+M%22+gid:%22RP-PG-0612-20010%22>

DYING WELL

STUDY 40 PUBLISHED

The Care of Dying People in Nursing Homes and Intensive Care Units: a qualitative mixed methods

Published, 2016, Ellershaw, Perkins

The original aim of the study was to assess the impact of the Liverpool Care Pathway (LCP) on care in two settings: nursing homes and intensive care units (ICUs). However, a robust comparison of the LCP could not be conducted due to site recruitment issues. The LCP was interpreted and used differently across sites, with the greatest variation in ICUs. There were no real differences between nursing homes that operated the LCP and those that did not. The majority of nursing homes had implemented some kind of 'pathway' for dying patients. In nursing homes, training was often minimal, ranging from watching a DVD to attendance on a one day course. However, there was a common desire for a natural and peaceful death, and the goals of care usually matched the wishes of the relatives for a dignified death. This study has provided new insight into end of life care in two different settings. The authors concluded that the study has revealed the complexity of end of life care, and point to a need for more research into how organisational culture can promote principles of good practice.

Health Service Delivery Research 2016. <https://www.journalslibrary.nihr.ac.uk/hsdr/hsdr04200#/scientific-summary>

STUDY 41 PUBLISHED

Understanding place of death for patients with non-malignant disease: a systematic literature review.

Published, 2012, Murtagh

This systematic review considered evidence on place of death, preferences and transitions of care for conditions other than cancer. The authors identified 290 relevant papers and both quantitative and qualitative evidence was assessed. A narrative synthesis and conceptual model was developed to provide better understanding of the factors influencing place of care and death in advanced non-malignant conditions. Three main factors were identified, including personal and demographic, disease-related and environmental factors. The authors found some important differences in preferences and care for those at end of life with conditions other than cancer. This included lower rates of preference for home death overall in non-cancer patients. There were also marked differences in the trajectory of disease, for instance those with chronic heart failure or COPD having less predictable patterns of illness. This made planning end of life services more challenging. Dementia was associated with a greater chance of a nursing home death. The authors cautioned that the majority of evidence came from the US with a different healthcare system and context, thus generalising results to the UK system may be limited.

NIHR Service Delivery and Organisation programme 2012. <https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/081813257/#/>

STUDY 42 PUBLISHED

Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to end of life (EVIDEM)

Published, 2015, Iliffe

The EVIDEM (Evidence-based Interventions in Dementia) research programme was designed to address issues around dementia and end of life care for people with dementia and their carers. The programme included an evaluation of an educational package to enhance GP diagnostic and management skills; an evaluation of an exercise therapy for dementia; a toolkit for managing incontinence for people with dementia living at home; a toolkit for palliative

care; and the development of practice guidance on the use of the Mental Capacity Act 2005. A mixed methods approach was used, including case studies, interviews, longitudinal surveys, RCTs, and database analysis, and involved participation from a range of individuals including people with dementia, carers, care home staff, GPs, community mental health teams, local authority and third sector staff. The educational intervention did not change GP practice. The exercise therapy did not affect dementia symptoms but it did have a significant positive effect on carer burden. Incontinence was found to be a common but poorly understood issue. The authors concluded that more research is needed on the potential benefit of exercise therapy for dementia and future work could address developing optimal working relationships between care homes and NHS staff.

Programme Grants for Applied Research 2015. <https://www.journalslibrary.nihr.ac.uk/pgfar/pgfar03030/#/abstract>

STUDY 43 ONGOING

The Namaste Care intervention to improve the quality of dying for people with advanced dementia living in care homes: A realist review and feasibility study for a cluster randomised controlled trial

Due to publish 2019, Froggatt

This feasibility study will determine whether it is feasible for care home staff to deliver the Namaste Care programme and also collect data on relevant outcome measures to then undertake a full randomised controlled trial. The aim is to establish an evidence base for Namaste Care as an appropriate intervention to improve end of life care for individuals with advanced dementia living in care homes. Namaste Care involves individualised assessment and care, provided by staff for four hours a day, seven days a week. It aims to engage the individual's senses, offering meaningful activities. This feasibility trial will be undertaken in eight care homes and eight people with advanced dementia will be recruited in each home. Six care homes will deliver Namaste care and two will continue to deliver their usual care. Data will be collected over four weeks, and then for up to six months or until the individual dies.

<https://www.journalslibrary.nihr.ac.uk/programmes/hta/151011/#/>

STUDY 44 PUBLISHED

Care Homes

Published, 2012, Luff

This guide was published to assist researchers who undertake projects in care homes. It brings together a range of case studies and real-life experiences. It also highlights specific issues relating to researching in care homes and reflects on a variety of research methodologies.

School for Social Care Research: http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/SSCR_Methods_Review_8_web.pdf

Other research relevant to care homes is underway in different parts of the country supported by NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRCs). More details of these projects will be available from autumn 2017 <https://www.clahrcprojects.co.uk/> of relevant projects including:

Preventing pressure ulcers in nursing homes

<http://www.clahrcprojects.co.uk/impact/projects/preventing-pressure-ulcers-nursing-homes>

Residents Research Active in Care Homes (RREACH)

<http://www.clahrcprojects.co.uk/impact/projects/residents-research-active-care-homes-rreach-0>

The Care Home Implementation and Knowledge Mobilisation Project (CHIK-P)

[http://www.clahrcprojects.co.uk/impact/projects/care-home-](http://www.clahrcprojects.co.uk/impact/projects/care-home-implementation-and-knowledge-mobilisation-project-chik-p)

[implementation-and-knowledge-mobilisation-project-chik-p](http://www.clahrcprojects.co.uk/impact/projects/evaluation-proactive-care-care-homes-project)

Evaluation of the Proactive Care in Care Homes project

<http://www.clahrcprojects.co.uk/impact/projects/evaluation-proactive-care-care-homes-project>

Effectiveness of integrated physical and mental healthcare in-reach teams in care homes

<http://www.clahrcprojects.co.uk/impact/projects/effectiveness-integrated-physical-and-mental-healthcare-reach-teams-care-homes>

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