

Institution: University of Hertfordshire		
Unit of Assessment: 3 – Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Enhancing health in care homes and communities.		
Period when the underpinning research was undertaken: 2004 – 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor Claire Goodman	Professor in Health Care Research	2005 – present
Professor Frances Bunn	Professor in Health & Complex Conditions	2002 – present
Dr Elspeth Mathie	Senior Research Fellow	2005 – present
Dr Daksha Trivedi	Senior Research Fellow	2006 – present
Dr Andrea Mayrhofer	Research Fellow	2013 – present
Dr Melanie Handley	Research Fellow	2009 – present
Dr Jennifer Lynch	Research Fellow	2016 – present
Dr Anne-Marie Burn	Research Fellow	2012 – 2018
Dr Sarah Amador	Research Fellow	2011 – 2014
Period when the claimed impact occurred: 1 August 2013 – 31 December 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words)		
<p>Research led by Goodman and Bunn at the University of Hertfordshire (UH) underpinned a new programme of work to fundamentally change the working relationship between care homes and the NHS. These changes shaped NHS England initiatives to improve integrated working between the NHS and care homes that led to the national Framework for Enhanced Health in Care Homes, covering around 11,300 care homes and 410,000 care home residents in the period 2013-20. The work has also shaped guidance from the National Institute for Health and Care Excellence (NICE) and Social Care Institute for Excellence (SCIE), and professional training, along with work by policy makers in government and the third sector. The research has directly influenced work by the Alzheimer's Society on Dementia Friendly Communities; this is now being extended to other organisations such as Dementia Friendly America (DFA). The group have contributed to the COVID-19 response in care homes at both a government level and through partnership with care homes and their representative organisations.</p>		
2. Underpinning research (indicative maximum 500 words)		
<p>The Older People's Health and Complex Conditions research group at UH is a leading centre for care homes and dementia care research, with a focus on the interface between social care and health care. The group is led by Professor Claire Goodman, with projects led by Goodman, Professor Frances Bunn, and key researchers as listed above. The impact described stems from a 15-year programme of cumulative research with external grant funding from the National Institute for Health Research (NIHR) and Alzheimer's Society totalling over £12.8m.</p> <p>The Optimal study [G.3], funded by NIHR and led by Goodman, built on earlier work that had found residents' access to healthcare provision was 'erratic and inequitable' (APPROACH [G.1] and FINCH [G.2] studies 3.1, 3.2). Optimal studied all the different ways that the NHS in England works with care homes, identified common elements within the different approaches likely to lead to improved outcomes and tested this by tracking what happened to 242 residents living in 12 care homes distributed across England. The study concluded that there was not a single 'right' way of delivering healthcare to care homes; there were however core elements within services that should be addressed, and key was when NHS decision-makers recognised care homes as partners, rather than as a problem or a drain on NHS resources. It called for more time to be given to NHS staff to learn how to work with care home staff to discuss, plan and review care and strengthen ties with existing health care services. It identified that activities that supported working more closely together provided the best evidence for improved healthcare. It also argued for the need to ensure that both NHS and care home staff had access to and support from dementia specialist services. This led to recommendations about how NHS services should work with care homes (3.3).</p>		

The CoDem [G.4] and DIAMOND [G.5] studies were among the first studies to consider healthcare organisation and delivery for people living with dementia who have comorbidities. The work demonstrated that systems or environments can unintentionally block access to care for people living with dementia and that staff often lack the skills and confidence to tailor care to the needs of this group (3.4, 3.5). There is a need for strategies to raise clinician awareness and account for the additional needs of this patient group (e.g. longer consultation times, monitoring). The research also showed that this patient group relies more on unpaid care compared to equivalent people without dementia. The involvement of family carers in decision making requires formal recognition and support.

The DEMCOM study [G.7] undertook a national evaluation of dementia friendly communities (DFCs) and developed a tool to enable DFCs to capture the impact of their work at different stages of development (early, developing, and embedding). It has also led to the development of a theory of change that supports the impact and sustainability of this initiative for the benefit of people affected by dementia (3.6) Ongoing work using this evaluation framework has been funded to evaluate how people affected by dementia access and engage with physical activity within DFCs and a Global Challenge Research Fund networking grant with Vietnam has been awarded to build expertise in community engagement for people affected by dementia.

These studies have also generated an NIHR (£2.2 million) grant to exploit existing data on residents and develop systems of data integration across a heterogeneous and rapidly changing independent care sector to establish a minimum data set for care homes [G.8]. Led by Goodman, it is a unique collaboration between national leaders in care home research, charities, provider representatives and residents' representatives.

3. References to the research (indicative maximum of six references)

- 3.1** Gage H, Dickinson A, Victor C, Williams P, Cheynel J, Davies SL, Iliffe S, Froggatt K, Martin W, Goodman C. Integrated working between residential care homes and primary care: a survey of care homes in England. *BMC Geriatr*. 2012 Nov 14;12:71. <https://doi.org/gbcf3t>
- 3.2** Buswell M, Goodman C, Roe B, Russell B, Norton C, Harwood R, Fader M, Harari D, Drennan VM, Malone JR, Madden M, Bunn F. What Works to Improve and Manage Fecal Incontinence in Care Home Residents Living With Dementia? A Realist Synthesis of the Evidence. *J Am Med Dir Assoc*. 2017 Sep 1;18(9):752-760.e1. <https://doi.org/gbwvpv5>
- 3.3** Goodman C, Davies SL, Gordon AL, Denning T, Gage H, Meyer J, Schneider J, Bell B, Jordan J, Martin F, Iliffe S, Bowman C, Gladman JRF, Victor C, Mayrhofer A, Handley M, Zubair M. 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. Southampton (UK): NIHR Journals Library; 2017 Oct. <https://doi.org/fhdm>
- 3.4** Bunn F, Burn AM, Goodman C, Robinson L, Rait G, Norton S, Bennett H, Poole M, Schoeman J, Brayne C. Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem). Southampton (UK): NIHR Journals Library; 2016 Feb. <https://doi.org/fhdk>
- 3.5** Bunn F, Burn AM, Robinson L, Poole M, Rait G, Brayne C, Schoeman J, Norton S, Goodman C. Healthcare organisation and delivery for people with dementia and comorbidity: a qualitative study exploring the views of patients, carers and professionals. *BMJ Open*. 2017 Jan 18;7(1):e013067. <https://doi.org/f9mij4>
- 3.6** Buckner S, Darlington N, Woodward M, Buswell M, Mathie E, Arthur A, Lafortune L, Killett A, Mayrhofer A, Thurman J, Goodman C. Dementia Friendly Communities in England: A scoping study. *Int J Geriatr Psychiatry*. 2019 Aug;34(8):1235-1243. <https://doi.org/fhdi>

Peer-reviewed funding:

- G.1** NIHR. 2009-11. APPROACH study. £432,711. Award ID: 08/1809/231.
- G.2** NIHR. 2014-16. FINCH study. £203,298. Award ID: 13/75/01.
- G.3** NIHR. 2013-16. OPTIMAL study. £397,000. Award ID: 11/1021/02.
- G.4** NIHR. 2012-15. CoDem study. £336,252. Award ID: 11/1017/07.
- G.5** NIHR. 2015-17. DIAMOND study. £237,895. Award ID: 13/138/03.

G.6 Alzheimer's Society. 2014-17. A realist evaluation of interventions that support the creation of dementia friendly environments in health care. £79,240.

G.7 NIHR. 2017-20. DEMCOM study. £458,814. Project number: PR-R15-0116-21003

G.8 NIHR. 2019-2023. DACHA study. £2,261,598. Award ID: NIHR127234

Collaborators

The research was developed and led by researchers at UH in collaboration with the following academic and clinical partners: Universities of Bangor, Cambridge, Cardiff, East Anglia, Nottingham, Surrey, Liverpool, Lancaster, Sheffield, Newcastle, Glasgow Caledonian, Kingston, Leiden (Netherlands), Vrije Universiteit Brussel (VUB), the University of Technology Sydney, Kings College London, University College London, City University of London, South Essex NHS Trust, Diabetes Frail, My Home Life, CLAHRC East of England, East and North Hertfordshire Clinical Commissioning Group, WE-THRIVE consortium (funded by Duke University USA with members from China, Hong Kong), Alzheimer's Society.

4. Details of the impact (indicative maximum 750 words)

Impact on health and care services: the Enhanced Health in Care Homes programme

The care home research described above has directly influenced the way care homes and the NHS work together. In 2014, as part of its plan to implement the Five Year Forward View, NHS England set up a series of "vanguards" to pioneer new systems of joined up care. One of the areas chosen was Enhanced Health in Care Homes (EHCH) which aimed to offer older people better, joined up health, care and rehabilitation services. Goodman briefed the Department of Health leads (David Foster and Jean Christensen) on the nursing workforce in care homes and spoke at the NHS England Vanguard summit. The findings from the Optimal study were critical in determining how these sites operated. The National Care Homes Lead at NHS England wrote in 2017 that "*The emerging evidence from Optimal both supported and shaped the work NHS England has done to develop a model of care for Enhanced Health in Care Homes*" and that "*the Optimal study has both shaped and supported transformation of care at a large scale across England*" [5.1]. Implementation of the EHCH framework has now become national policy for the NHS in England, applicable to over 11,300 care homes and 410,000 care home residents.

The former National Clinical Director for Older People and Person Centred Integrated Care at NHS England, who was responsible for taking forward the findings from the care homes Vanguards initiative into national NHS policy and developing the EHCH programme in England, has said: "*The evidence from your care home research not only fed directly into our utilisation of outputs from the care homes Vanguards but also the subsequent development of national care homes policy and the approach to national implementation of the NHS EHCH service offer. The findings and recommendations from the Optimal study about the need for the NHS to provide wraparound care for care homes are reflected in the EHCH framework. It has been a hugely rewarding experience to directly utilise evidence from your and others' programme of care home research to help directly address some of the current and most pressing challenges facing social care. It has provided much needed and robust evidence for policy reform that aims to redress inequalities of access to health care experienced by care home residents*" [5.2].

The findings from Optimal and other studies were also disseminated widely to care home professionals and healthcare decision-makers through a policy briefing paper and accompanying YouTube video which the research team created in 2017. Findings from the Optimal Study and a link to the video were disseminated to 18,000 care homes by the My Home Life Charity. The bulletin, which was badged "for the staff room" said in its introduction "*Great news! A new piece of research - The Optimal Study - shows how the NHS and care homes can work better together to improve the lives of those who live in them... the study provides helpful evidence of how the NHS needs to work in better partnership with care homes*" [5.3]. Notably, the briefing received over 200 referrals linked from the My Home Life website, showing that the target audience valued the information and wanted to learn more. The video has been viewed over 1,000 times to date [5.4].

Impact on policy making and professional practice: dementia and co-morbidities

In 2016, Bunn was invited by the Alzheimer's Society to be an expert witness to the All-Party Parliamentary Group (APPG) on Dementia's inquiry into care for people living with both dementia and other chronic conditions. She gave oral evidence (based on the findings from CoDem and DIAMOND) to the inquiry. For example, she outlined how people with dementia and diabetes may find it difficult to manage their medication and must rely on help from family carers. This point was picked up in the APPG report published later that year titled: *Dementia Rarely Travels Alone: living with dementia and other conditions* [5.5].

The same year, the CoDem team created an animated infographic video to disseminate the findings of the study to healthcare professionals and service users. This was conceived in direct response to feedback from busy specialists who did not have enough time to read and digest academic papers. The film was uploaded onto the University's YouTube channel and sent directly to key stakeholders including clinicians, policy makers, voluntary groups, organisations involved in the care of people with dementia, academics and members of the public. An evaluation of impact the following year found that the film had disseminated the study's findings well, and that people found this an effective alternative to academic publications. Many recipients reported that they had passed it onto other colleagues. Highlights included: the film was included in the training of GPs by the Wessex Academic Health Science Network and was used in training of over 300 people (doctors, nurses and other surgery staff); the Alzheimer's Society put the film on their staff pages; Vision 2020 UK disseminated the film in their newsletter sent to about 45 member organisations including: RNIB, Association of Optometrists, Association of Health Professionals in Ophthalmology, Action for Blind People; the RNIB produced and distributed an accessible version of the film for visually impaired people [5.6].

Impact on health and social care guidance

NICE Guidance 97 "Dementia: assessment, management and support for people living with dementia and their carers," (published June 2018) for the first time included recommendations about dementia and comorbidity, citing the CoDem study and rating this evidence as "very valuable" [5.7]. Research on interprofessional working was used in NICE Guidance 22 on "Older people with social care needs and multiple long-term conditions" (published November 2015) [5.7]. Work on end of life care was cited in NICE Guidance 86 on "People's experience in adult social care services: improving the experience of care and support for people using adult social care services" (published June 2018) [5.7]. A briefing issued by SCIE on "End of life care for people with dementia living in care homes" (published in 2012 and valid throughout the current REF period) cited six papers from the group, and Goodman also assisted the authors of the briefing. SCIE have confirmed that there have been around 330,000 visits to the end of life pages which are based on the briefing, and over 500 downloads of the full briefing from 2018-20 (data not available prior to 2018) [5.8]. Alzheimer's Disease International (the international federation of Alzheimer associations around the world) cited CoDem four times in its 2016 World Alzheimer's Report [5.9].

Impact on dementia-friendly initiatives

The Dementia Friendly Communities programme, led by Alzheimer's Society, encourages everyone in England, Wales and Northern Ireland to share responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community. The national evaluation of Dementia Friendly Communities (DEMCOM, 3.6) has directly influenced the planning and delivery and support of the programme by the Alzheimer's Society. It will be used to inform the next five years work to normalise the experience of living with dementia. Specifically, findings have been used to structure how local authorities are involved, how data is collected and how effectiveness is measured. Alzheimer's Society wrote in 2019 that "the research... on community engagement for people affected by dementia has informed Alzheimer's Society's current and future work and support for Dementia Friendly Communities by providing evidence to secure their sustainability" and that "this evidence... has helped

Alzheimer's Society's planning for extending, evaluating and monitoring the work of Dementia Friendly Communities across England, Wales and Northern Ireland" [5.10].

The impact of this research is also starting to spread internationally. Alzheimer's Society used the findings to brief the World Dementia Council on the impact of meaningful Dementia Friendly initiatives and guidance for the global evaluation of DFCs. The World Dementia Council cited the research in their global advocacy on Dementia Friendly Initiatives, and Goodman advised directly on this work. The DEMCOM findings also provided the basis for the launch event of the first dementia friendly community in Spain and a stakeholder event in Vietnam on dementia and mental health. We have also provided assistance to Dementia Friendly America who are using our research to work on evaluation approaches [5.11].

COVID-19: 'Top Tips for Care Homes' and advice to government

When Covid-19 hit care homes in early 2020 there was no specific evidence-based guidance to help. To fill this information vacuum the UH team worked to support a network of care home managers via a WhatsApp group. The team worked iteratively with the WhatsApp group to identify eight topics that might help address some of the key questions. A series of rapid reviews were conducted and research-based 'Top Tips' were produced, which drew directly on all the team's care homes studies, to complement emerging COVID-19 policy and practice guidelines. Feedback was largely positive especially as a resource for new and inexperienced staff. Some were reassured that they weren't missing something, others appreciated that it gave them space to reflect. The Top Tips were downloaded from the NIHR East of England ARC website 333 times by 269 different users between March and December 2020 and have been translated into Spanish. They have been disseminated in Wales and promoted by SCIE, the End of Life Care Partnership, Association of Directors of Public Health, and the National Care Forum [5.12].

During the first part of the COVID pandemic in 2020 Goodman briefed the Foreign and Commonwealth Office and Cabinet Office (Health Minister Helen Whatley) on the care home data and evidence of what supports improvement and also briefed (with supporting report) members of the SAGE Social Care Working Group on visiting in care homes [5.13].

5. Sources to corroborate the impact (indicative maximum of 10 references)

5.1 Letter from National Care Homes Lead, NHS England. 26 Jan 2017.

5.2 Email from former National Clinical Director for Older People and Person Centred Integrated Care, NHS England. 3 Feb 2021.

5.3 My Home Life issue #20. <https://myhomelife.org.uk/wp-content/uploads/2014/11/ID861-MHL-Bulletin-ISSUE-20-SING.pdf>

5.4 Policy briefing: <https://medium.com/policyherts-reports/towards-better-healthcare-in-care-homes-2cf383dd7e4d>; Video: <https://www.youtube.com/channel/UCZS-4-JBIIA87www1npKoDg>

5.5 APPG report <https://www.alzheimers.org.uk/about-us/policy-and-influencing/2016-appg-report>.

5.6 Report into the dissemination and impact of the CODEM video.

5.7 Collated citations of the work in NICE guidance (97, 22 and 86).

5.8 Full briefing: <https://www.scie.org.uk/publications/briefings/briefing40/>; End of life pages: <https://www.scie.org.uk/dementia/advanced-dementia-and-end-of-life-care/end-of-life-care/>; email from Senior Research Analyst at SCIE provides download figures.

5.9 <https://www.alzint.org/resource/world-alzheimer-report-2016/>

5.10 Letter from Chief Policy and Research Officer, Alzheimer's Society. 30 October 2019.

5.11 Impacts of DEMCOM study corroborated here: <https://arc-eeo.nihr.ac.uk/research-implementation/research-themes/ageing-and-multi-morbidity/amm08-demcom-study-national>; email from Dementia Friendly America also provided.

5.12 <https://arc-eeo.nihr.ac.uk/covid-19-projects-innovations-and-information/covid-19-resources-training-information/top-tips>

5.13 Email exchange with Cabinet Office.