



Deposited via The University of York.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/id/eprint/242830/>

Version: Published Version

Conference or Workshop Item:

GRIDLEY, KATE (2026) What next?: Accessing support and navigating social care after a diagnosis of dementia. In: Centre for Dementia webinar, 10 Jun 2026.

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

What next?

Accessing support and navigating social
care after a diagnosis of dementia

Presented 10th June 2026 to the University of Nottingham
Centre for Dementia webinar

Kate Gridley

University of York kate.gridley@york.ac.uk



UNIVERSITY
of York



DETERMIND

FINDING A FAIRER PATH TO DEMENTIA CARE

Study

People

Leadership team

Postgraduate researchers

Research

Engagement and impact

About us

Contact us

Current staff and students

KATE GRIDLEY RESEARCH FELLOW

Visit [Kate Gridley's profile on the York Research Database](#) to:

- See a full list of **publications**
- Browse **activities and projects**
- Explore **connections, collaborators, related work** and more.



View my profile in the
York Research Database



Contact details

Kate Gridley
Research Fellow
Social Policy Research U
Church Lane Building
University of York
YO10 5ZF

Tel: +44 (0)1904 321988

kate.gridley@york.ac.uk

Profile **Research** External activity

Biography

Kate Gridley is a social care Research Fellow at the University of York specialising in dementia care research for the [Older Adults' Social Care Research \(OSCAR\) group](#). She joined the University of York in 2006 and has worked on and led numerous multi-site NIHR funded research projects. Much of Kate's work focuses on the intersection between health and social care services, and the experience of navigating these complex systems from the perspectives of people using services and their carers, using the concept of navigation capital. Projects include [Care Confidence in Action](#) designed to support and evaluate the implementation of a decision aid for older social care self-funders; the [Good Life with Dementia](#) research evaluating a peer-led course for people recently diagnosed with dementia; and [DETERMIND](#). Kate is public involvement lead for the University of York's [NIHR School for Social](#)

NIHR | Research
Support Service

Request Advice

[Home](#) > [Log In](#)

NIHR Research Support Service (RSS)
Specialist Centre for Social Care
delivered by University of York and Partners

NIHR | School for Social
Care Research

SCHOOL FOR SOCIAL CARE RESEARCH

The national home of research excellence for social care.



DETERMIND

Determinants of quality of life, care and costs, and consequences of inequalities in people with dementia and their carers

NIHR | National Institute for Health and Care Research



Qualitative DETERMIND strands:

- Social care self-funders
- Experiences of care and support during COVID



SUPPORTING SELF-FUNDERS TO MAKE CONFIDENT CARE DECISIONS: 'CARE CONFIDENCE IN ACTION'

NIHR | School for Social Care Research

20 Years

[Home](#) [About](#) [Research](#) [Career Development](#) [Impact](#) [Involvement](#) [News & Events](#) [Dementia Rese](#)

Researching The Good Life with Dementia Course: A Feasibility Study

Addressing uncertainties for a randomised controlled trial of a post-diagnostic peer-led dementia course 'The Good Life with Dementia'

What is DETERMIND?

DETERMIND is an ambitious research project that aims to find out how we can make dementia care and outcomes in the UK more equal. The project is a collaboration of researchers at 10 UK research institutes and is funded by the Economic and Social Research Council (ESRC).

- 940 people with dementia
- 698 of their carers
- Recruited within 6 months of diagnosis
- Annual quantitative data
- Interviews for qualitative strands
- York led the qualitative strand on social care self-funding

Latest News





Question

In the context of living with dementia:

- *What are self-funders' experiences of navigating social care systems and arranging care after a diagnosis of dementia?*

Our vision

To strengthen the evidence base for adult social care practice, building capacity and driving the development of a research system in practice which can support, mobilise, and deliver impact on practice and for the benefit of the public as service users, carers and the workforce.



Our research themes



Our strategies

#SocialCareFuture [About](#) [Noticeboard](#) [Changing the Story](#) [Glimpses of the Future](#) [Resources](#) [Do your bit](#)

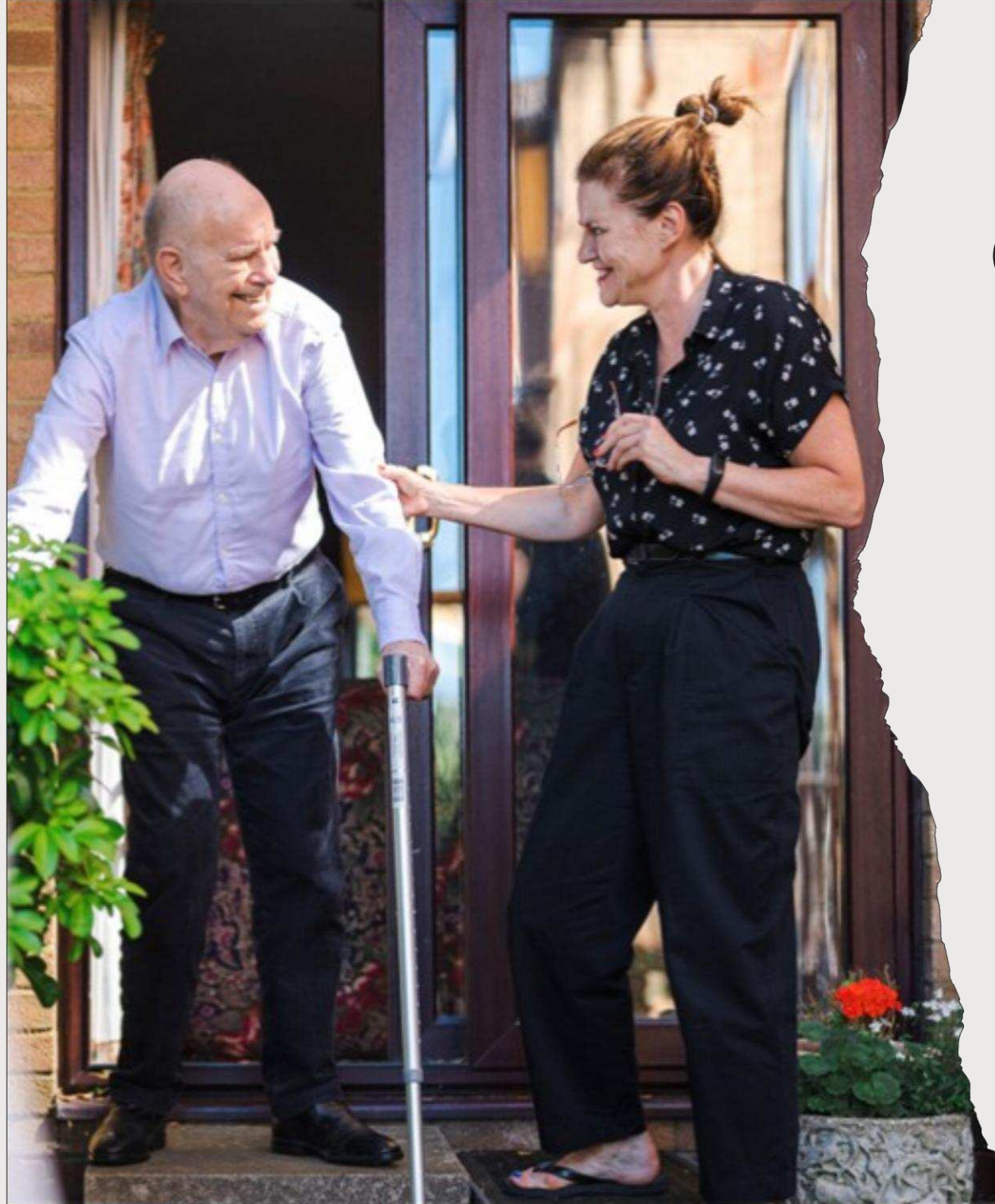
About us

Social Care Future is a growing, people-powered movement for change, born of frustration but powered by hope. Together we are growing a future where we can all live in the place we call home, with the people and things that we love, in communities where we look out for one another, doing the things that matter to us.

#SocialCareFuture <https://socialcarefuture.org.uk/>

What do we mean by social care?

Help to live life the way you want to

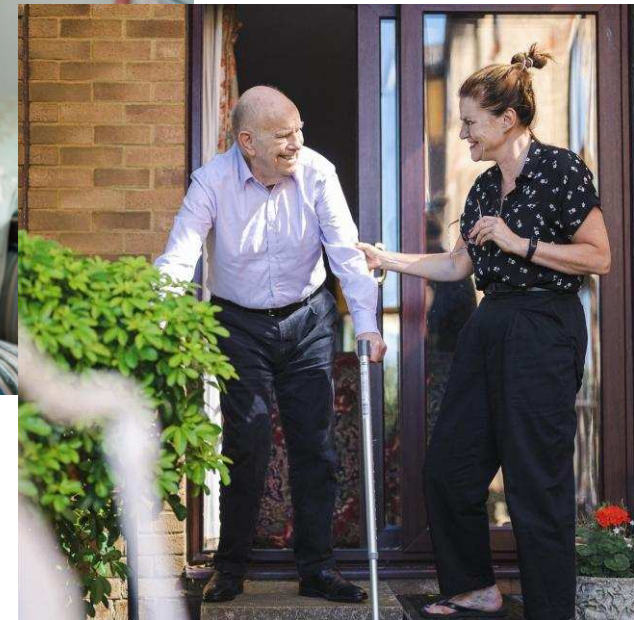


In practice in England, social care tends to refer to:

- Social work
- Occupational therapy
- Equipment and home adaptations
- Home care (practical and personal)
- Groups and activities
- Support for family carers
- Respite (day services and residential)
- Care homes

Background

- In England, health services are free at the point of use, but **social care is means tested** and has tight eligibility criteria
- Most social care service users pay something towards the costs of their care
- Those who pay the full cost of social care are often referred to as ‘self-funders’
- **Most self-funders are older people** (and most older social care service users **live with dementia**)



Statutory responsibilities:

Under the Care Act, councils have a responsibility to help self-funders via:

- Assessment of need
- Information and advice



Very little proactive social care

Usually, a crisis triggers a request for social care

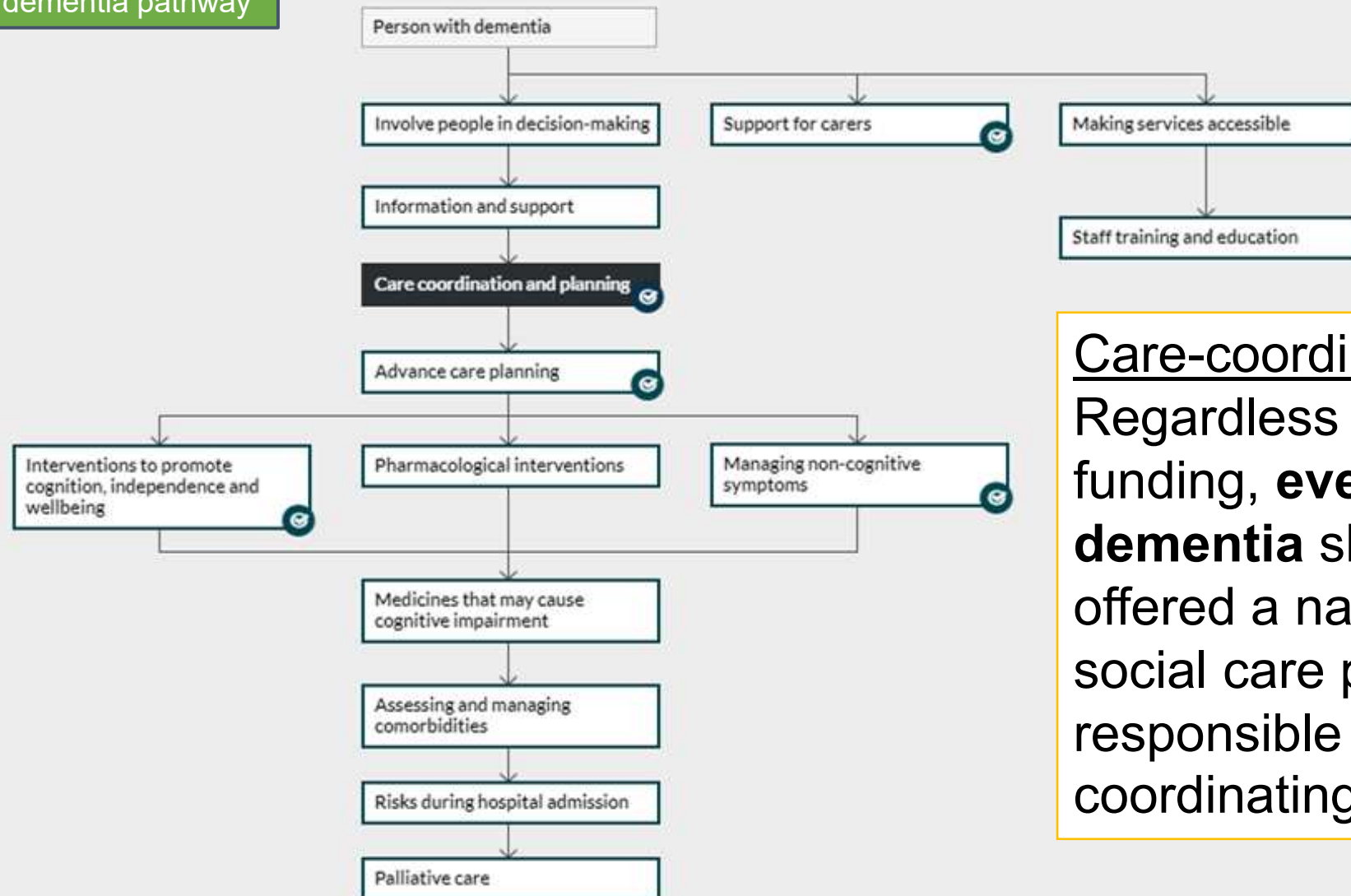
Eg:

- A fall/hospital admission leading to reduced independence
- Family carer stretched too thin/reaches crisis



NICE guidance

NICE dementia pathway



Care-coordination:
Regardless of social care funding, **everyone with dementia** should be offered a named health or social care professional responsible for coordinating their care

From the DETERMIND baseline:

Assessment of need:

- Only 25% (26/103) of those self-funding homecare reported having had a social care assessment (this should be available regardless of financial situation)

Care Coordination:

- 12.5% of self-funders had a named care coordinator (compared to 33% using LA funded homecare)

A social worker:

- Just 8.8% had a social worker (compared to 39% of those using LA funded homecare)

Self-funders less likely to report receiving formal support to navigate services than people who receive council funded social care



Self-funding can be challenging

*'...an older person might be relatively affluent but severely disabled, confined to the home and have **no knowledge of care services** or how to purchase them.'*

Tanner et al., 2018

In-depth interviews

67 interviews 2020-2023:

- 46 different participants (people with dementia and family members)
- Some people were interviewed twice or three times

Topics included experiences of:

- Finding care and support
- Using social care and support
- Planning for future care



Absence of formal support...

*...when you're self-funding, from a carer's point of view **you're a little bit left on your own basically** to, to navigate your own way through and, you know, make the decisions, **there's no sort of person there saying, "well yes, you've got to fund it but this would be a good route to take"**, or "that would be an ideal way to go". So **it's tricky...***



Gate D: Daughter of self-funding mum with dementia (interview 1 of 3)

Heavy reliance on family and friends

In the absence of state support

- **Family and friends are often the people doing the day-to-day work to navigate the system** (researching and liaising with providers, arranging payment, etc.)



Knowing **someone with relevant experience and knowledge** gives you an advantage...



*I think if you, if you're supported by family that are quite clued up, you're in a much stronger position. I mean if you, I mean my, **my husband used to be a social worker so**, you know, we are aware of the support that's out there...*

SUSS E: Daughter of self-funding mum with dementia
(interview 1 of 2)

A row of wooden figures, one red and many white, on a white surface. The figures are arranged in a line, with the red figure in the center. The background is a light blue gradient.

**Where does this leave people
without well informed contacts?**

Potential for inequity

Links to social capital theory?

- Strong *bonds* (family/close friends) may be instrumental in accessing social care (Bonding social capital?)
- Assumes the family member/friend will feel inclined/have the time and wherewithal to help them to access social care (Predispositions to help?)



It's a big ask:

*...you kind of take one step forward, ...and then it all kinda falls apart again, or **I have to do so much in order to make something happen**, you know. So I then have to fill in all of these financial forms, you know, so, and somebody has to contact me about that and then someone else has to do something else and then it all goes off for, for, for ages and ages and ages.*

Wife of self-funding man with dementia (trying to access a day service) interviewed together for DETERMIND (SUSS I)

Not all contacts will be predisposed to help...

*I think everybody had come to that conclusion that he needed more help, but **we weren't really sure how to go about it** and, well **whose responsibility it was really** to, obviously [person with dementia] couldn't do this himself, he probably realised he needed help [but] he wasn't in the right part of the system*

Niece of person with dementia living alone, interview 2 of 3

- This participant had no close family
- But reported that he was well supported by friends (in interview 1)



- By interview 2 he had deteriorated and moved to a care home
- Niece said no-one had acted as crisis approached... (she had a young family and busy job – whose responsibility was it?)

—
Bridging* social capital
may also play a role

*Links between *different* groups with different
knowledge/experience

*...we were both very lucky, **one of my husband's friends used to be a bank manager ...[he] had sort of an independent chat with mum, with the financial advisor, just so they could sort of explain about the situation, I made sure that she was, you know, getting Attendance Allowance and things.***

SUSS E: Daughter of self-funding mum with dementia

And social capital may mobilize other types of capital...

- Cultural capital?
 - Cultural knowledge
 - Relevant skills
 - Confidence speaking to professionals
 - Language style
- In social care, this is sometimes referred to as knowing '*the phrase that pays*'



Combination of **personal experience/skills** (cultural capital)...

...we're very informed, she's a counsellor, I'm a teacher, and we just know about... We've got this information, and a lot of it we've got it in our heads...

...combined with **social capital?**

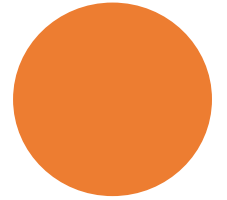
....or we know people who've got access to things, we're of an age where we've got friends with parents who are doing similar things.

SUSS B: Daughter of self-funding mum with dementia

Navigation capital

Navigation capital:

- The potential for people with **close bonds** (typically family) to have better access to social care:
 - **Particularly if family and friends have prior experience/knowledge of the social care system** (or comparable systems – financial services, health or education systems)
 - *And* a **predisposition** to use this to help the person access/arrange care
- *And/or* the **bridging** potential of wider social connections (of either the person needing care or their family) to other people who have further relevant knowledge/experience and **can inform or act as advocates/help to leverage care**



Low navigation capital

- The 'stock' of navigation capital that different people have will differ
- Those who are low in navigation capital describe **struggling to access** the range of services that should be available to them
- Some describe **reaching crisis** before sufficient care is secured
- In that sense, navigation capital could be a **potential source of inequality**:
 - If you have low social and cultural capital (and/or your social contacts do) you have low navigation capital
 - The result may be poorer access to care...



Read more here...



[Link to Navigation Capital blog](#)

The screenshot shows the website for 'Social work with Older People research'. The logo features a green diamond with a white magnifying glass over a tree. The main title is 'Social work with Older People research'. The navigation menu includes 'Home', 'Blog', 'Research findings', 'SWOP Resources', 'About us', 'Useful reading and links', and 'Contact us'. The subtitle is 'Exploring the contribution of social workers to older people's well-being'. The featured article title is 'Navigation capital: How social workers can guide older people with dementia through the social care maze'. At the bottom, it says 'In this guest blog, [Kate Gridley](#) shares learning from the [DETERMIND project](#) about the'. There are also 'Comment' and 'Share' icons.

Social work with Older People research

Social Work with Older People Research
Exploring the contribution of social workers to older people's well-being

Home Blog Research findings SWOP Resources
About us Useful reading and links Contact us

Navigation capital: How social workers can guide older people with dementia through the social care maze

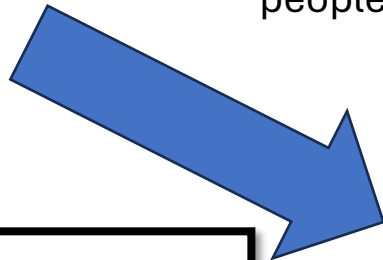
In this guest blog, [Kate Gridley](#) shares learning from the [DETERMIND project](#) about the

Comment ↗

Our findings (on the cliff edge and limited support to navigate the system) tallied with previous research on self-funding...



...and living with dementia



- Baxter, K., Heavey, E., & Birks, Y. (2019). Choice and control in social care: Experiences of older self-funders in England. *Social Policy and Administration*, (June), 1–15. <https://doi.org/10.1111/spol.12534>
- Baxter, K., Heavey, E., and Birks Y. (2017). Older Self Funders and their information needs. <http://eprints.whiterose.ac.uk/119213/1/RF62.pdf>
- Baxter K., and Glendinning C. (2015). People who fund their own social care: A scoping review. London: School for Social Care Research
- Heavey, E., Baxter, K., & Birks, Y. (2024). Care chronicles: needing, seeking and getting self-funded social care as biographical disruptions among older people and their families. *Ageing & Society*, 44(4), 916-938.

Health and Social Care in the community

ORIGINAL ARTICLE | Open Access |

Specialist nursing case management support for carers of people with dementia: A qualitative study comparing experiences of carers with and without Admiral Nursing

Kate Gridley BA(Hons), MRes Social Policy | Gillian Parker BA (Hons), PGDip, PhD

First published: 24 May 2021 | <https://doi.org/10.1111/hsc.13437> | VIEW METRICS

Accessibility issue? [Request accessibility update.](#)

Funding information:
This paper presents findings from research funded by the National Institute for Health Research Health Services and Delivery Research Programme (project number 14/154/07). The views and opinions expressed are those of the research team and do not necessarily reflect those of the HSRP Programme



DEMENTIA IN YOUNGER AGES MAPPING IDEAL CARE (DYNAMIC)

Social care planning and provision for people with young onset dementia and their families: current practice and resources for improvement.

<https://www.youngdementianetwork.org/research-evidence/dynamic/>



What else did we learn from the DETERMIND interviews?



DETERMIND started during COVID:

- Can't ignore the huge impact of COVID restrictions on the experiences of people using social care and support
- We collaborated with PriDem to understand more...



UK/Europe and the rest of the world

The Importance of the Social Environment for People Living With Dementia and Their Carers: Qualitative Evidence From DETERMIND and PriDem on the Impact of COVID-19 Service Changes and Restrictions in England and Wales

Dementia
2025, Vol. 0(0) 1–23
© The Author(s) 2025

Article reuse guidelines:
sagepub.com/journals-permissions
DOI: [10.1177/14713012251361189](https://doi.org/10.1177/14713012251361189)
journals.sagepub.com/home/dem


Kate Gridley¹, Marie Poole², Yvonne Birks¹, Ben Hicks³,
Josie Dixon⁴, Alison Wheatley⁵, Louise Robinson⁵ and
Sube Banerjee⁶

Abstract

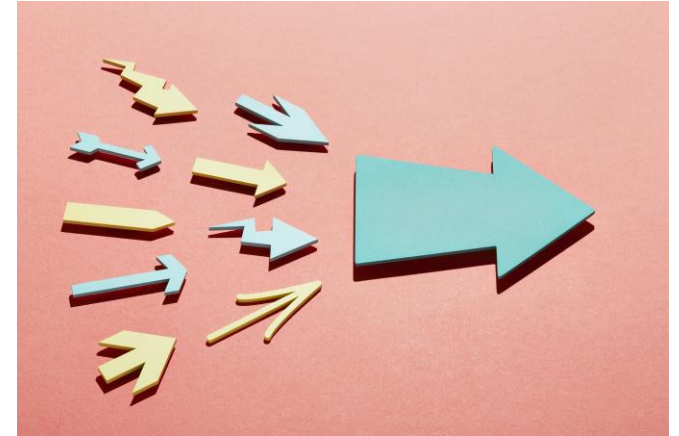
This paper presents evidence from multiple perspectives on the impact of changes to health and social care service delivery, and the related social environment, for people living with dementia and their carers during the COVID-19 pandemic. Qualitative interview data from 130 people living with dementia, family carers and health and social care professionals in England and Wales were collected for the DETERMIND and PriDem studies during the height of the COVID-19 pandemic (2020–2021). These were analysed abductively by members of both teams, applying the lens of person-centred dementia theory. The lack of in-person social and professional contact was of great concern during the pandemic to people living with



We brought together findings from 130 interviews

Data from

- 16 people living with dementia and 30 carers interviewed for DETERMIND self-funders work
- 21 people living with dementia and 42 carers interviewed for the DETERMIND COVID study
- 21 health and social care professionals (GP, dementia specialist nurses, occupational therapists, dementia support workers) interviewed for PriDem (Newcastle University <https://research.ncl.ac.uk/pridem/>)



Service changes during COVID impaired the social worlds of people living with dementia

- Services stopped seeing people face-to-face
- Groups stopped running
- People felt lost/in limbo
- Family carers were often the only people who could
 - Facilitate access to support
 - Provide social contact



Social support not prioritised

- Government rules did not recognise the importance of the social environment for people living with dementia
- Dementia services and groups were not considered 'essential'
- The lack of opportunities to socialise and take part in valued activities had a negative impact on wellbeing, skills and confidence
- Infrequent social contact is a risk factor for dementia and can make symptoms worse



The Lancet Commissions

 **Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission**

Gill Livingston, Jonathan Huntley, Kathy Y Liu, Sergi G Costa-Jorda, Geir Selbaek, Suvarna Alladi, David Ames, Sube Banejee, Alistair Burns, Carol Brayne, Nick C Fox, Cleusa P Ferri, Laura N Gitlin, Robert Howard, Helen C Kales, Mika Kivimäki, Eric B Larson, Noeline Nakasujja, Kersneth Rockwood, Quincy Samus, Kokoro Shirai, Archana Singh-Manoux, Lon S Schneider, Sebastian Walsh, Yao Yao, Andrew Sommerlad*, Naasheed Mukadam*

Lancet 2024; 404: 572-628
Published Online
July 31, 2024
[https://doi.org/10.1016/S0140-6736\(24\)01266-9](https://doi.org/10.1016/S0140-6736(24)01266-9)

Executive summary
The 2024 update of the Lancet Commission on dementia provides new hopeful evidence about dementia prevention, intervention, and care. As people live longer, majority populations within them, so dementia is more likely to develop at an earlier age. Evidence for specific risk factors suggests that all children should be educated, and a long duration of

*'Prioritise age-friendly and supportive community environments and housing and **reduce social isolation by facilitating participation in activities and living with others**'*

[Link to Lancet Commission article - social isolation is a risk](#)

Impact on family carers

Dementia support worker, PriDem, February 2021

Well I've been pretty much doing everything, it's the relentlessness of COVID that's made it more difficult, not my mother...

Carer, WS4, June 2021

The singing for the brain group is still running, you know, with [charity], they are quite good. But that they can only reach people who are tech savvy and have got a computer, or maybe they have got a family member that can set up.

Double disadvantage?

Suggestion that people who were already disadvantaged were most affected by service changes:

- People living alone without a carer
- People less able to engage in remote provision

No, I'm not online, I'm not on the computer... I just can't, can't fathom out... I've been shown but I just forget each time. So, I just leave it.



Sheffield Hallam University UCL id Innovations in Dementia NHS West Yorkshire Integrated Care Board NHS NIHR National Institute for Health and Care Research

<https://livingalonewithdementia.co.uk/>

The Importance of the Social Environment for People Living With Dementia and Their Carers: Qualitative Evidence From DETERMIND and PriDem on the Impact of COVID-19 Service Changes and Restrictions in England and Wales

Kate Gridley¹, Marie Poole², Yvonne Birks¹, Ben Hicks³, Josie Dixon⁴, Alison Wheatley⁵, Louise Robinson⁵ and Sube Banerjee⁶

Abstract
This paper presents evidence from multiple perspectives on the impact of changes to health and social care service delivery, and the related social environment, for people living with dementia and their carers during the COVID-19 pandemic. Qualitative interview data from 130 people living with dementia, family carers and health and social care professionals in England and Wales were collected for the DETERMIND and PriDem studies during the height of the COVID-19 pandemic (2020–2021). These were analysed abductively by members of both teams, applying the lens of person-centred dementia theory. The lack of in-person social and professional contact was of great concern during the pandemic to people living with

Dementia
2025, Vol. 0(0) 1–23
© The Author(s) 2025
Article reuse guidelines:
sagepub.com/journalsPermissions
DOI: [10.1177/14713012251361189](https://doi.org/10.1177/14713012251361189)
journals.sagepub.com/home/dem
Sage




Key messages:

- Person-centred delivery *is* possible even in the most challenging of circumstances
- Social wellbeing should be prioritised alongside medical need

Gridley, K., Poole, M., Birks, Y., Hicks, B., Dixon, J., Wheatley, A., Robinson, L. and Banerjee, S., (2025). The Importance of the Social Environment for People Living With Dementia and Their Carers: Qualitative Evidence From DETERMIND and PriDem on the Impact of COVID-19 Service Changes and Restrictions in England and Wales. *Dementia* <https://journals.sagepub.com/doi/full/10.1177/14713012251361189> (open access)

Findings on planning for social care (and why people don't):



AGEING & SOCIETY
VOLUME 45 PART 3 2025




A & S

CAMBRIDGE UNIVERSITY PRESS

Ageing & Society





The role of uncertainty in planning for self-funded social care for older people with a diagnosis of dementia


Published online by Cambridge University Press: 02 October 2023

Kate Baxter , Kate Gridley  and Yvonne Birks 

Show author details ▾

Article Figures Metrics

 Save PDF  Share  Cite  Rights & Permissions



Baxter K, Gridley K, Birks Y. The role of uncertainty in planning for self-funded social care for older people with a diagnosis of dementia. Ageing and Society. 2025;45(3):514-534. doi:10.1017/S0144686X23000594 [Link to published paper \(open access\)](#)

Not everyone makes a plan



- Whilst people do recognise that they may need to pay for care in the future
- This does not necessarily mean they have made a plan. The reason given was....

Uncertainty:

- Don't know what care I will need
- Or when I will need it
- And things will change over time
- I'm/we're ok now and I just want to enjoy that
- And besides, I don't know where to start...

People found the system difficult to understand



Person with dementia

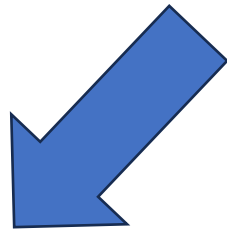
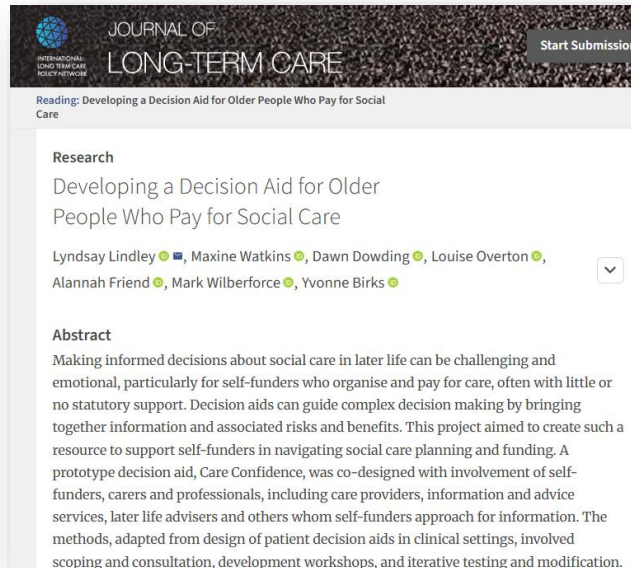
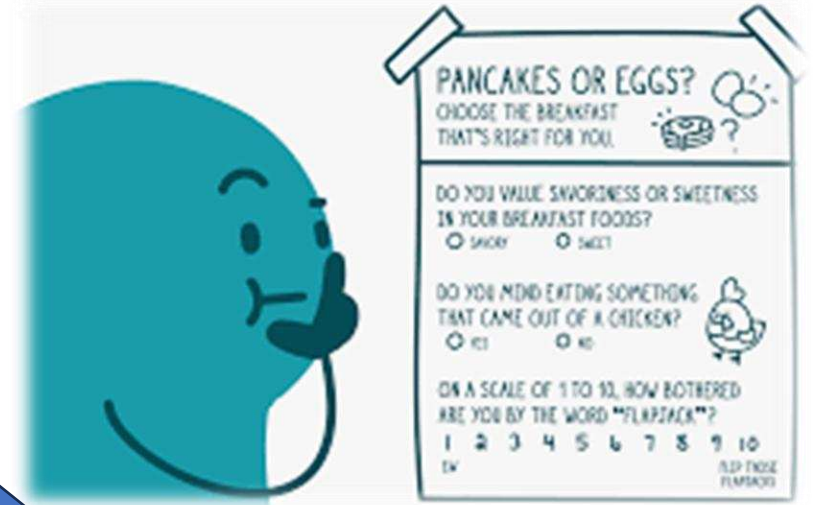
[Paying for care is] the one bit I've not properly engaged with and I don't feel like doing it, first of all cos part of me thinks well we'll deal with it when we get there, and the other bit is that I've never understood all that stuff anyway. I'm not very comfortable with all that kinda stuff, my talents lie elsewhere.

A 3D-rendered yellow puzzle piece is centered on a dark gray background. The piece is slightly raised and casts a soft shadow. The word "Solutions?" is written in a clean, white, sans-serif font across the middle of the puzzle piece. The background features faint, dark, wavy lines that suggest the shape of other puzzle pieces.

Solutions?

Learning from health care

- In health care there are decision aids to help people make life changing decisions
- There is nothing like this in social care [Baxter et al. 2021](#)
- So, York and partners pooled their evidence and collaborated with people with lived experience to develop one



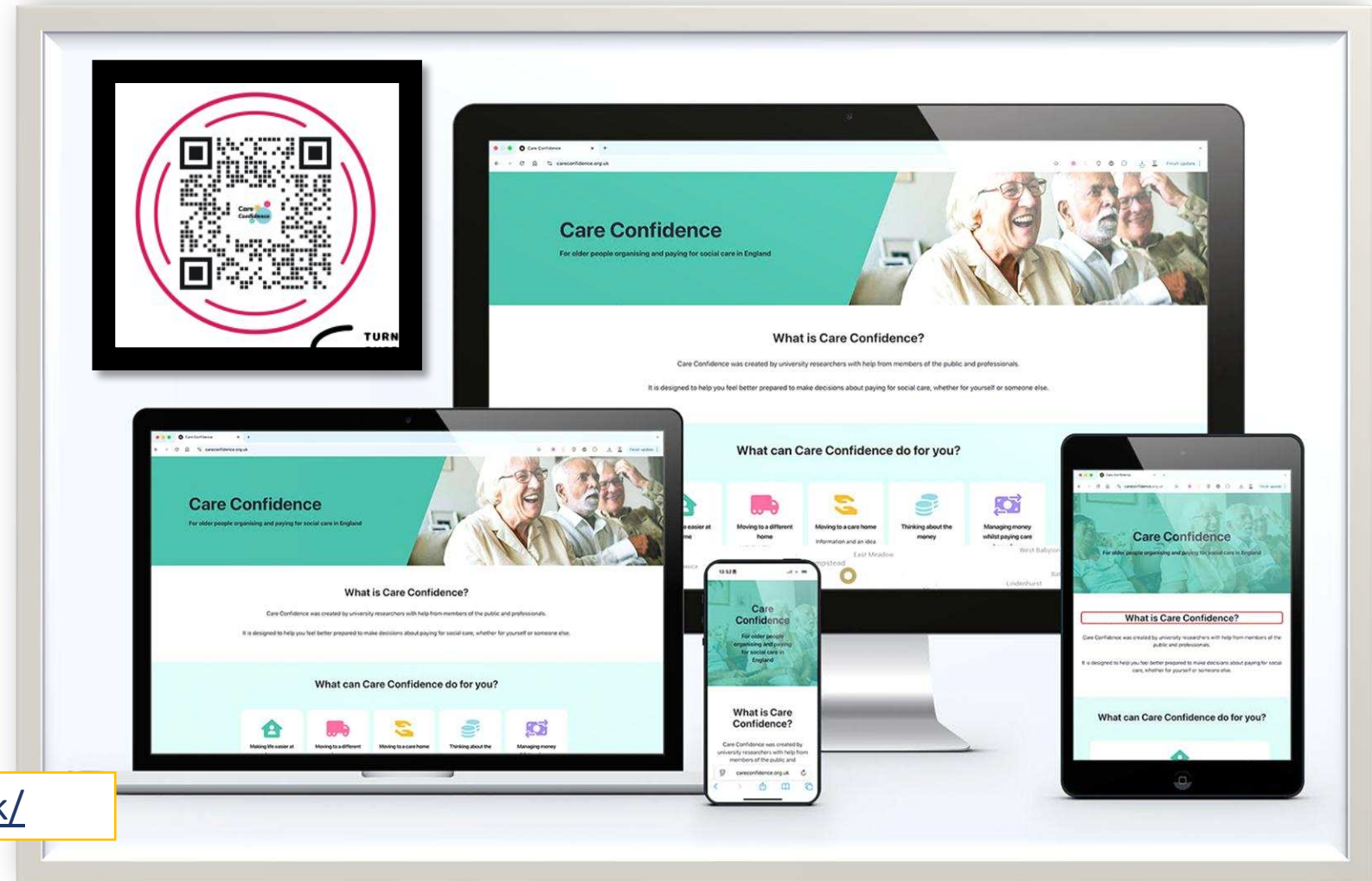
[Lindley et al. 2025](#)

Lindley, L. M., Watkins, M., Dowding, D., Overton, L., Friend, A. E., Wilberforce, M. R., & Birks, Y. F. (2025). Developing a Decision Support Tool for Older People Who Pay for Social Care. *Journal of Long-Term Care*, 142-153.



Care Confidence – a social care decision aid

- Sets out different types of care, what they can cost and what options there are for paying
- Helps you to make an action plan



<https://www.careconfidence.org.uk/>

SUPPORTING SELF-FUNDERS TO MAKE CONFIDENT CARE DECISIONS: 'CARE CONFIDENCE IN ACTION'

This study will support and evaluate the use of [Care Confidence](#) within service pathways for older social care self-funders.



[Link to Care Confidence SSCR research webpage](#)

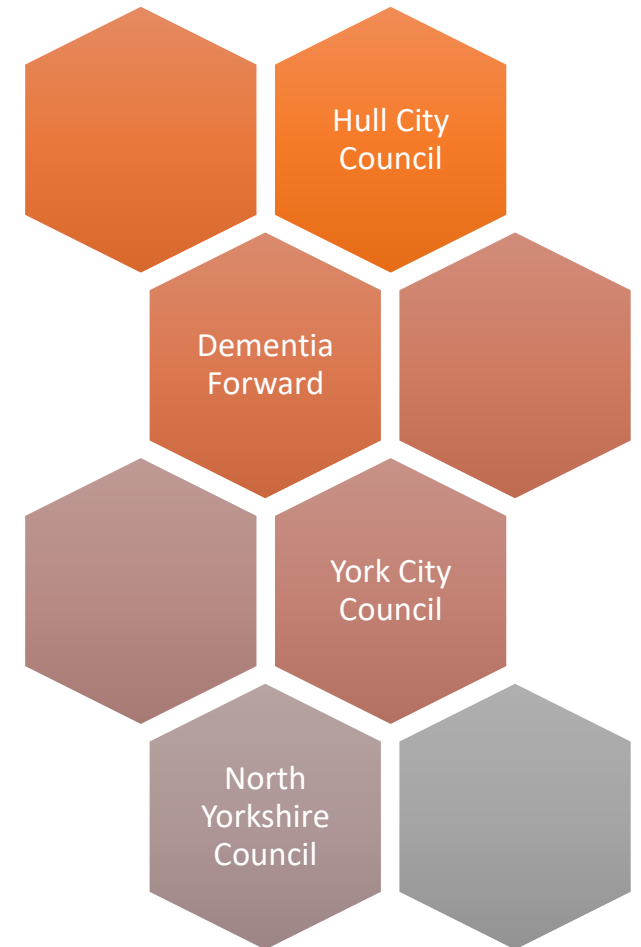
[Link to Care Confidence York webpage](#)

[Link to Care Confidence training resources for staff](#)

<https://www.careconfidence.org.uk/>



Four Implementation Sites (3 councils and a regional charity)



Care Confidence

For older people organising and paying for social care in England



What is Care Confidence?

Care Confidence was created by university researchers with help from members of the public and professionals.

It is designed to help you feel better prepared to make decisions about paying for social care, whether for yourself or someone else.



Care Confidence

For older people organising and paying for social care in England



What is Care Confidence?

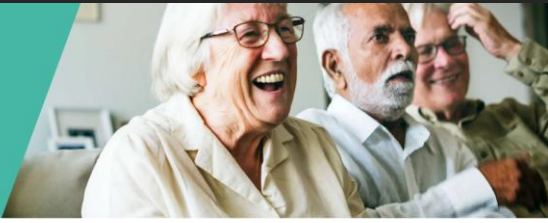
Care Confidence was created by university researchers with help from members of the public and professionals.

It is designed to help you feel better prepared to make decisions about paying for social care, whether for yourself or someone else.



Care Confidence

For older people organising and paying for social care in England



What is Care Confidence?

Care Confidence was created by university researchers with help from members of the public and professionals.

It is designed to help you feel better prepared to make decisions about paying for social care, whether for yourself or someone else.



Care Confidence

For older people organising and paying for social care in England



What is Care Confidence?

Care Confidence was created by university researchers with help from members of the public and professionals.

It is designed to help you feel better prepared to make decisions about paying for social care, whether for yourself or someone else.

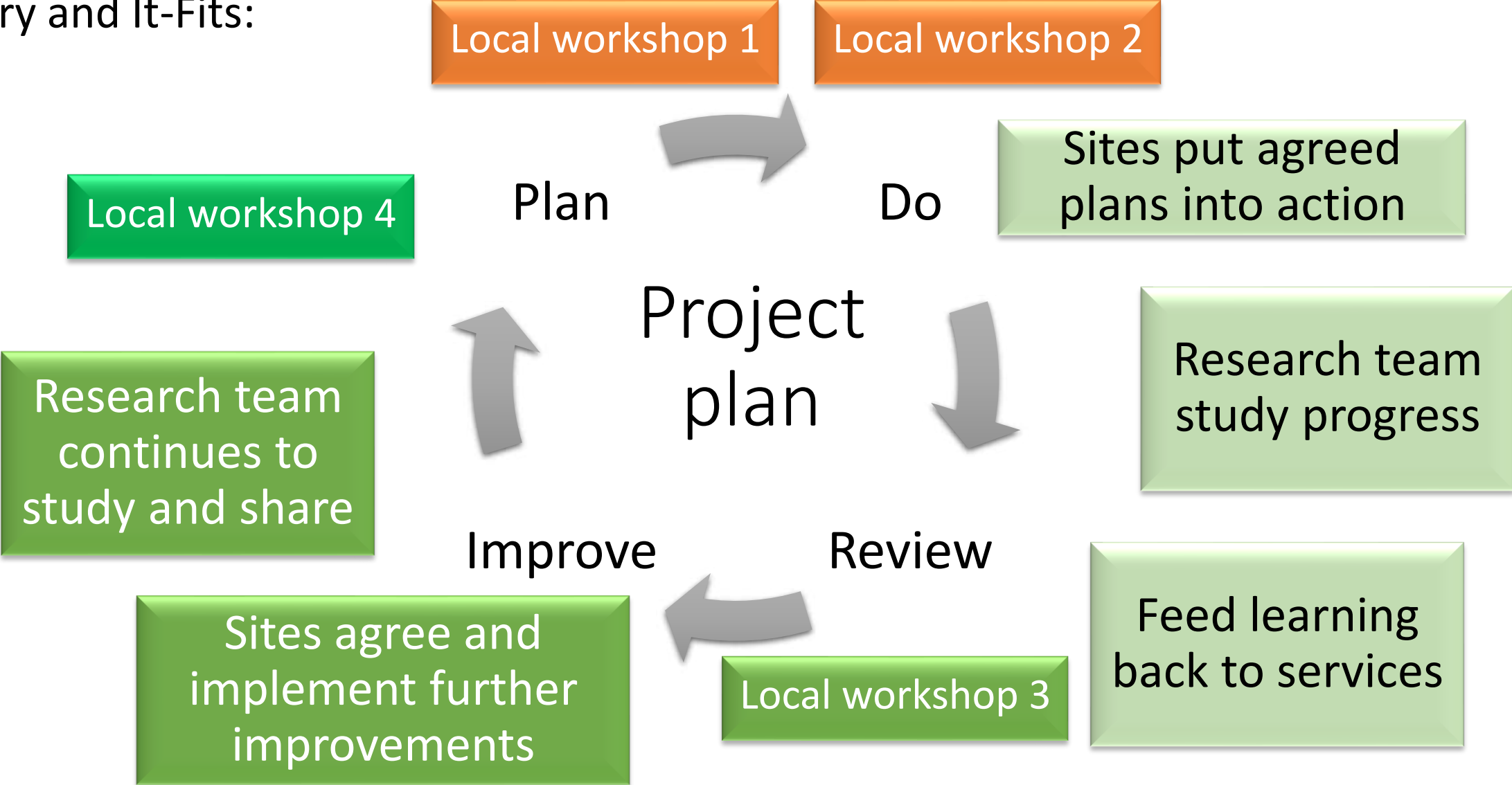


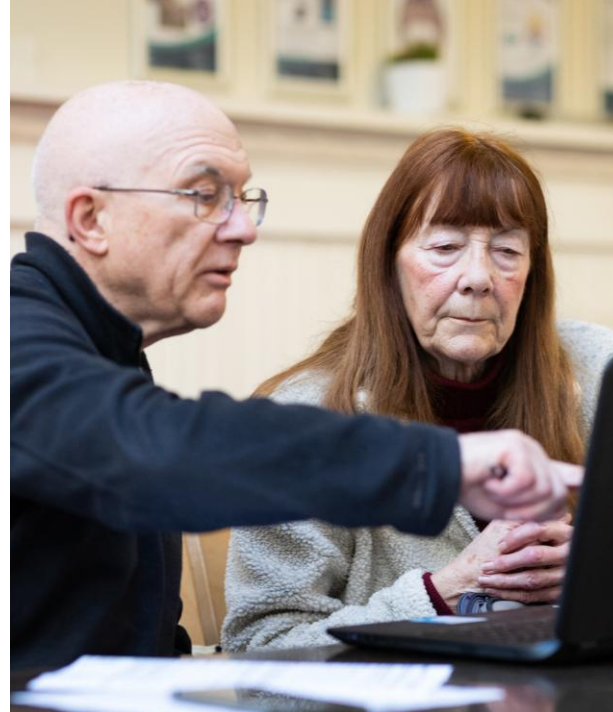


Co-producing ways to embed the decision aid into practice



Informed by normalization process theory and It-Fits:





Potential for learning about:

- A) How councils can better meet their Care Act responsibilities to self-funders using Care Confidence
- B) How the voluntary sector can use Care Confidence to support people living with dementia and their families
- C) The application of implementation science in social care settings


[Watch this space...](#)

But social care should be more than a response to crisis/deterioration

Thinking back to what we learnt about the importance of the social environment...

What about the need for social connection and support to live well from the outset?



A group of five diverse elderly people are shown from the chest up, laughing joyfully outdoors. They are arranged in a line, with a woman on the far left, a man in a cap behind her, a man with glasses in the center, a man in a light blue shirt to his right, and a woman on the far right. The background is a soft-focus outdoor setting with green foliage. The entire image has a semi-transparent dark overlay.

The Good Life with Dementia

A peer-support intervention

The Good Life course



- A 6-week course about living well with dementia
- Co-produced *by* and *for* people with dementia
- Attended by 8-12 people recently diagnosed
- Peer-tutors and the facilitator tailor each course in pre-course co-production sessions
- Sessions are run by peer-tutors with dementia, with professional support and expert speakers
- Emphasis on next steps (and beyond)



Developed in Yorkshire, but is spreading...

York

Beverley

Bridlington

Cottingham

Goole

Market
Weighton

Thorngumbald

Hornsea

Hammersmith
and Fulham

Hounslow

Ealing

Fife



The screenshot shows the top section of the website. On the left is the 'id' logo (Innovations in Dementia) with the tagline 'Inspiring Different Conversations'. To the right is a search bar labeled 'Search term'. Below this is a navigation menu with links for 'Home', 'About our work', 'What we do', 'Resources', and 'Contact us'. A large photograph of four women sitting together is featured. On the right side, there are green buttons for 'Latest News from ID' and 'ID Blogs', a 'twitter feed' section with a 'follow us on twitter' link, and a 'site map' link at the bottom.



A GOOD LIFE WITH DEMENTIA

A post diagnostic course for people living
with dementia

People with dementia as
course designers

People with dementia as
course tutors



ted Kinadam\



<https://www.youtube.com/watch?v=XRS4Aha068Y>

Good Life with Dementia

Understanding the Role of 'Peer Tutors' in Post-Diagnostic Support for People with Dementia



Funded by the [NIHR Three Schools Dementia Research Programme](#)



UK-wide policy states that post-diagnostic support should include peer support by people who share 'lived experiences' of dementia to promote social inclusion. However, existing approaches are often unstructured, lacking clear objectives or conceptual foundations. Additionally, existing evidence-based approaches to peer support are often led by a professional or are defined as 'therapy'; lacking an explicit focus on facilitating peer support, which misses essential elements of co-production and empowerment necessary to ensuring peer-based post-diagnostic approaches are meaningful and inclusive.

An alternative approach is through peer led formats, in which people with lived experiences actively provide structured support, for example, by acting as 'tutors' to newly diagnosed individuals. However, evidence-gaps exist around peer led post-diagnostic support in dementia, especially in the early post-diagnostic phase. We need to know more about underpinning theories, outcomes and implementation, including how this approach is best delivered in different communities, such as those from South Asian communities who can face barriers to accessing services and information.

Study 1: Complete

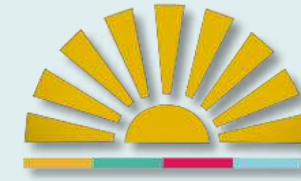
- 15-month qualitative study
- Asked: *How does the Good Life course work?*
- Finished April 2024

Key findings



- The Good Life course helped people living with dementia to **feel valued, gain confidence, build connections and face challenges.**
- The course creates a safe space in which to **share experiences, learning from each other (the experts!) and share resources**
- A safe space could **look different for people in different communities**

Paper in press: Gridley et al. (2026) The Good Life with Dementia Approach: A realist-informed qualitative study of a peer-tutored course, co-produced with and for people living with dementia. PLoS One



Researching
**THE GOOD LIFE WITH
DEMENTIA COURSE**
A Feasibility Study

Next steps

An inclusive feasibility study asking:

- What happens when different organisations facilitate the course with different communities?
- Can we measure outcomes in a randomised controlled trial?

FUNDED BY

NIHR | National Institute for
Health and Care Research

June 2025 – August 2027

Three areas: Sheffield, Bristol... and
Manchester



FEASIBILITY STUDY OF A POST- DIAGNOSTIC PEER-LED DEMENTIA COURSE: ADDRESSING UNCERTAINTIES FOR A RANDOMISED CONTROLLED TRIAL OF THE GOOD LIFE COURSE

This study will explore the feasibility of evaluating the Good Life with Dementia peer-led course, focusing on inclusive research practices.

RESEARCH

[Accounting, finance and actuarial science](#)
[People, Work and Employment](#)
[Management and Organisation Studies](#)
[Marketing, International Business and Entrepreneurship](#)
[Social policy](#)
[Comparative and Global Social Policy](#)
[Welfare, Employment and Conditionality](#)
[Social work](#)
[Operations, strategy and governance](#)

CONTACT US

Mandy Willcox

Research Associate

✉ mandy.willcox@york.ac.uk

📍 Church Lane Building, University
of York, Heslington, York YO10 5ZF

RELATED LINKS

[Realist evaluation of the Good Life](#)

Good Life Feasibility Study

The aim is to address key uncertainties before an RCT can be done:



Can the Good Life course be manualised and consistently delivered across settings

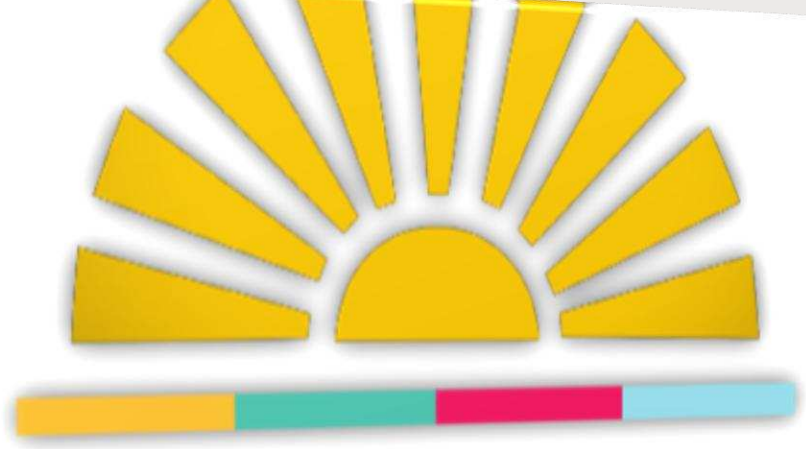


Is it feasible to evaluate this? Will there be any issues with participant recruitment or data collection?



How can we make sure that research methods are culturally inclusive?





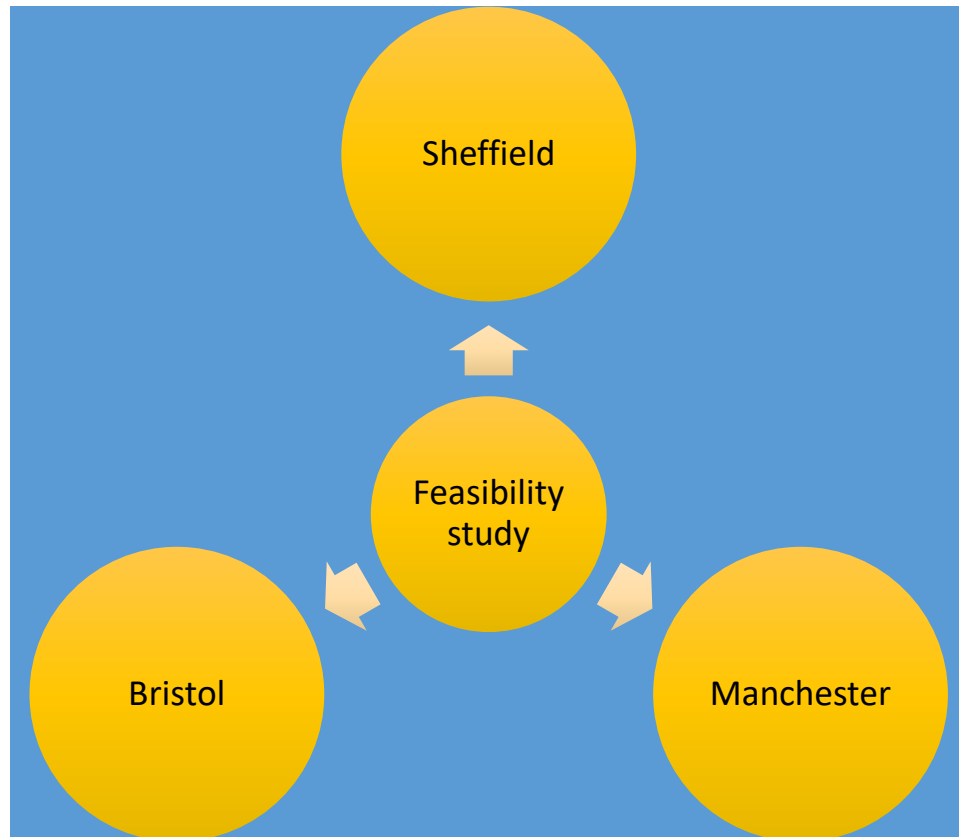
A GOOD LIFE WITH DEMENTIA

Programme manual Version 1 (For use in the Good Life feasibility study) February 2026



A manual has been co-produced, and training has been run for new facilitators

Trained facilitators in three community organisations will co-deliver the Good Life course this autumn with local peer-tutors:

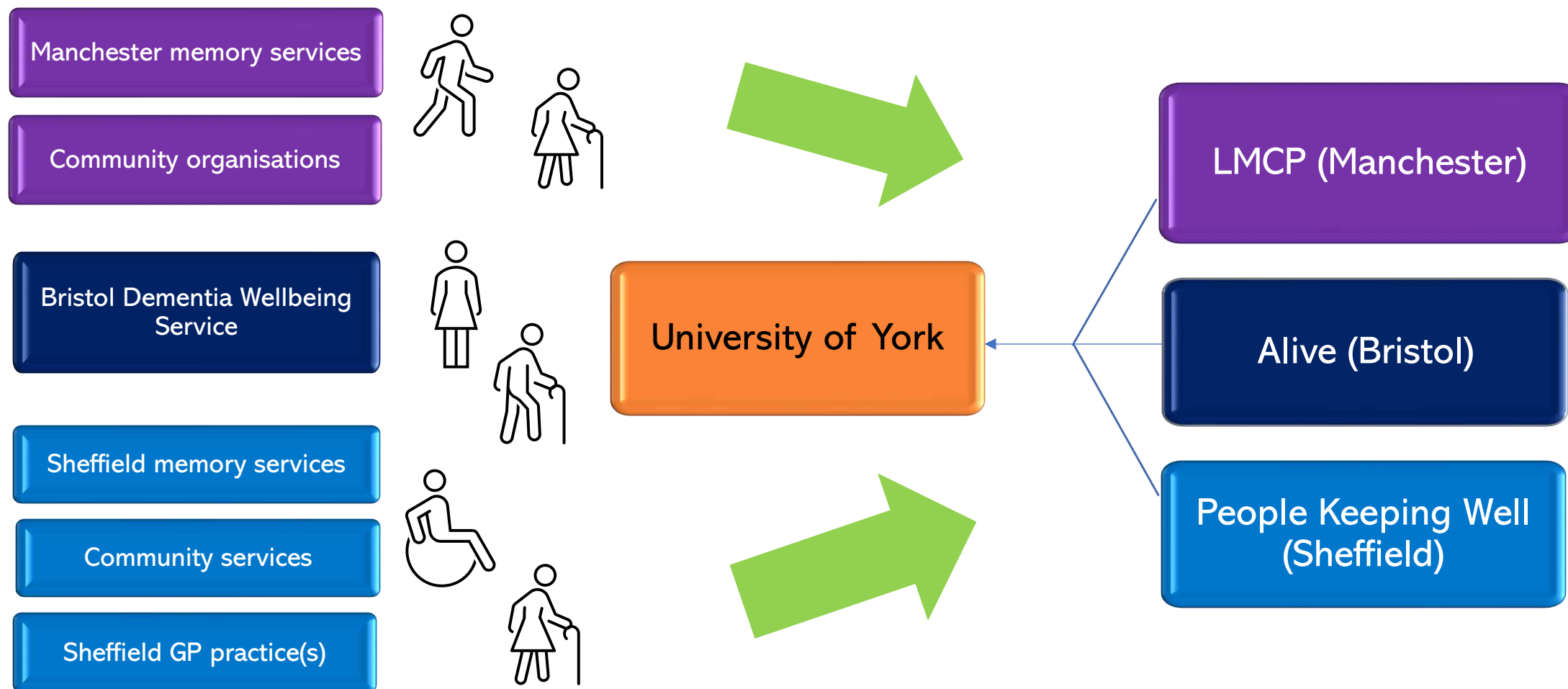


The study has a focus on developing inclusive research processes, with the support of LMCP in Manchester

<https://lmcp.co.uk/>



NHS and community services to recruit participants for the research



Aiming to recruit 18 people per area: 12 to attend the course, 6 to tell us about usual care



Researching The Good Life with Dementia Course: A Feasibility Study

Addressing uncertainties for a randomised controlled trial of a post-diagnostic peer-led dementia course 'The Good Life with Dementia'



This work is ongoing, see [Link to feasibility study webpage](#)



In summary

- Qualitative research gives us a picture of fragmented support - gaps and cliff edges
- But it doesn't have to be like this...

Meet the dementia rebels!



Tue 9 Jun 2026

Features [Link to Dementia Rebels Guardian article](#)



Dementia

'You're treated like this is the end': Meet the dementia rebels – diagnosed and determined to change people's minds

“Every person with a diagnosis of dementia is supposed to have an annual dementia review with someone who knows about dementia in their GP practice,” says Rook. “Most people don’t get that and, when it does happen, it’s rarely actually seen as useful because the GP knows a lot less about it than I do, by their own admission.” More useful are **schemes** where people living with dementia act as “peer tutors”, as Rook has, to the newly diagnosed.



[Links to the Good Life findings](#)



‘The advice was absurd’ ... George Rook. Photograph: Dementia UK

NIHR | School for Social
Care Research



It's a process...

For more information
contact kate.gridley@york.ac.uk



Acknowledgements and disclaimer

NIHR SSCR/Three Schools

This independent research was funded by the National Institute for Health and Care Research (NIHR) on behalf of the NIHR SSCR and Three Schools' Dementia Research Programmes. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

DETERMIND:

These slides present independent research funded by the Economic and Social Research Council (ESRC) and the National Institute for Health and Care Research (NIHR), under Grant Award number ES/S010351/1.

The views expressed in these slides are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.