

Written evidence submitted by NIHR Policy Research Unit in the Healthy Ageing (University of Manchester, Newcastle University, LSE) (ASC0022)

Health and Social Care Committee Inquiry
The Adult Social Care Reform: The Cost of Inaction
Response from the
NIHR Policy Research Unit in Healthy Ageing¹

Professor Jane McDermott, Strategic Lead Operations, Collaboration and Impact

Professor Barbara Hanratty, Director, Newcastle University

Professor Chris Todd, Deputy Director, University of Manchester

Professor Martin Knapp OBE, Deputy Director, London School of Economics and Political Science

the National Institute for Health and Care Research (NIHR) Policy Research Unit in Older People and Frailty (funding reference PR-PRU-1217-2150). As of 01.01.24, the unit has been renamed to the NIHR Policy Research Unit in Healthy Ageing (funding reference NIHR206119). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

The NIHR Policy Research Unit in Healthy Ageing Overview

The National Institute for Health and Care Research (NIHR) Policy Research Unit in Healthy Ageing (HAPRU - formerly Older People and Frailty) is funded by the NIHR to work directly with the Department of Health and Social Care (DHSC) and its arms-length bodies. Established in January 2019 HAPRU is a collaborative partnership between the University of Manchester, Newcastle University and the London School of Economics. HAPRU produces high quality evidence addressing the critical questions related to the health and social care needs of older people in England. Acting as a long-term resource for policy research and rapid-response service, we provide evidence for

¹ Formerly the NIHR Policy Research Unit in Older People and Frailty (2019-2024)

emerging policy and practice. The team also provides expert advice to policy makers, senior civil servants and analysts on the evidence base and options for policy development. For further information on the HAPRU see our website www.hapru.nihr.ac.uk

Response to the Health and Social Care Committee inquiry – what is the Adult Social Care Reform: Cost of Inaction

The following document provides a brief summary of a number of pieces of work the HAPRU has previously delivered for DHSC policy teams, alongside research which has recently been completed and which may be of interest and relevance to the committee. Not all reports are available and in the public domain, therefore please do contact HAPRU strategic lead operations, collaboration and impact should you require full copies of reports for more detailed insight into the work the HAPRU has and is undertaking.

The specific inquiry questions we are seeking to respond on:

- 1. Where in the system is the cost of inaction on adult social care reform being borne the most?**
- 2. What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?**

Projects of relevance and interest

- 1. Where in the system is the cost of inaction on adult social care reform being borne the most?**

The Policy Research Unit has undertaken a number of inter-related research projects which focussed on the role of unpaid carers, in particular older unpaid carers who play a critical role in the adult social care landscape and are currently carrying much of the inaction burden. These projects are listed sequentially here and include individual project webpage links, brief overviews of the projects, academic publication links alongside a you tube link to a webinar hosted by HAPRU presenting all projects.

[Characteristics of older unpaid carers in England: a study of social patterning from the English Longitudinal Study of Ageing](#)

This study aimed to describe the characteristics of older people who provide unpaid care and how these vary by socioeconomic position. We analysed cross-sectional data from the English Longitudinal Study of Ageing (ELSA) on 1,282 unpaid carers aged 50 years or older. Data on sociodemographics, health social wellbeing, care intensity and caregiver-recipients' relationships were extracted. Differences between the poorest and the richest groups were examined. Most older carers in the ELSA data were female and looking after another older person. Poor mental and physical health and social isolation were common and socially patterned. Our findings suggest that financially disadvantaged unpaid carers (and their households) may have the greatest needs for intervention and support. Focussing resources on this group has potential to address social inequalities.

Publication: Laurie E Davies, Gemma F Spiers, David R Sinclair, Andrew Kingston, Barbara Hanratty, Characteristics of older unpaid carers in England: a study of social patterning from the English Longitudinal Study of Ageing, *Age and Ageing*, Volume 53, Issue 3, March 2024, afae049, <https://doi.org/10.1093/ageing/afae049>

[Caring for older people as a social determinant of health: Findings from a scoping review of observational studies](#)

The provision of unpaid carer is critical to ensure source of support for people with health and social care needs. Unpaid carers are a group facing increasing demands, many of which are driven by the lack of adult social care reform, resulting in unpaid carers being at higher risk of adverse outcomes. This project examined the breadth of evidence on older carers/carers of older people in UK cohort studies. Findings highlighted specific gaps in evidence regarding the social, economic, health and quality of life outcomes for carers. Whilst a need to improve our understanding of care recipients, carers' trajectories, and those at the greatest risk of adverse outcomes were also highlighted as invaluable methodological considerations.

Publication: Stowell, M., Spiers, G.F., Kunonga, P., Beyer, F., Richmond, C., Craig, D. and Hanratty, B. (2024) 'Caring for Older People as a Social Determinant of Health: Findings from a Scoping Review of Observational Studies', *Journal of Long Term Care*, 0(), p. 28–41. Available at: <https://doi.org/10.31389/jltc.207>.

[What works to support carers of older people and older carers? An international evidence map of interventions and outcomes.](#)

Building on the earlier work (as above) we wanted to understand what works to support carers who experience a range of adverse outcomes, as a priority for public health. Our understanding of what works to support carers could be enhanced if future evaluations prioritise under-researched interventions and outcomes. In order to support this, we aimed to map evidence about what interventions to support carers had been evaluated to identify key gaps in current evidence. We found evidence of what works best to support carers is extensive but limited in scope. A disproportionate focus on mental health and burden outcomes neglects other important areas where carers may need support. Given the impact of caring on carers' physical health, financial and social wellbeing, future research could evaluate interventions that aimed to support these outcomes. Appraisal of whether interventions deliver equitable outcomes across diverse carer populations is also critical.

Publication: Spiers, G., Tan, M.M., Astbury, J.L. *et al.* What works to support carers of older people and older carers? an international evidence map of interventions and outcomes. *BMC Geriatr* **24**, 301 (2024). <https://doi.org/10.1186/s12877-024-04897-3>

A link to a webinar presentation of the three projects listed above alongside findings from a stakeholder workshop can also be viewed on the HAPRU you tube channel here: [The impact of unpaid caring on carers' health, quality of life and social and financial wellbeing: what's missing from current UK evidence?](#)

2. What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?

When thinking about the future and how people's lives may change with action, the PRU undertook a study which specifically focused on future preferences for models of care for older people with high care needs post COVID-19. This two-phase project delivers some valuable insights on individual preferences for care to inform future adult social care planning.

[New preferences for models of care for older people with high care needs.](#)

Phase one: scoping review and focus groups to discuss people's preferences regarding different components of the models of care.

This study, involving group interviews and a large-sample survey of people aged 50+, examined participants' preferences about components of care, covering housing, community assets, use of technology, provision of care, control and dignity, should they develop high care needs. New models of care emphasise the importance of providing services for individuals to build strong relationships, support independent living in a person's community, promote well-being and help older people maintain their dignity and autonomy. The main factor influencing people's choice is who provides support with the care task, followed (in order of importance) by receiving care from someone that respects their beliefs and values, housing setting, use of technology devices, cost, and access to community services. People are more likely to value living in their *own home* with appropriate adaptations if required (compared with other options); receiving care from family members or friends only (rather than other providers); and living closer to community services. Conversely, they attach less value to receiving care from someone that respects their beliefs and values. It is important to consider differences in preferences between demographic, socioeconomic and ethnic groups to ensure that care aligns with individual preferences, beliefs and values, and promotes equitable access to care and outcomes.

People value independence and having control over their lives and prioritise access to community resources and social connections. Consequently, they prefer models of care that allow them to stay living in their own home or moving to a community housing setting with their own space for as long as possible. Community assets are critical when planning for care along with a high priority to maintain social connections with neighbours, valuing community life and having access to local facilities. There are differences in preferences for some components of care between different ethnic and socio-economic groups, these highlight the need to ensure future care packages and options align with individual preferences, beliefs and values. There are differences in preferences for some components of care between different age, ethnic and socio-economic groups, which highlights the need to ensure future care packages and options align with individual preferences, beliefs and values. People also emphasise the importance of building a positive relationship with their care provider, respecting their sexual identity and personal beliefs to receive good quality care. Providing care packages that align with individual preferences may help to ensure that older people from diverse backgrounds receive high-quality care that promotes their independence and dignity and produces equitable care outcomes.

[Executive Summary](#)

Publication: Walbaum, M., Knapp, M., Wittenberg, R. and Mcdermott, J. (2024) 'Preferences of People 50 Years and Older when Thinking of their Future Care Needs', *Journal of Long Term Care*, 0(), p. 42–53. Available at: <https://doi.org/10.31389/jltc.200>.

Phase two: survey with people aged 50 years and over living in England to investigate preferences relating to care and support using a discrete choice experiment method.

Building on the first phase of this project, we sought to understand how preferences from different components of care are shaped by individual demographic, socioeconomic and needs-related factors. The survey included general questions about preferences relating to care and support. Specific questions formed a discrete choice experiment (DCE) to explore how participants would trade-off different features of social care arrangements when thinking about their own (current or future) circumstances, if they were to have high care needs.

Findings highlighted the importance of aligning care services with people's preferences, emphasising the value of independence, control, and accessible care. It reveals most individuals prefer receiving support from careers arranged by local authorities, suggesting a need to prioritise accessible and well-coordinated publicly funded care services. The strength of preferences varied by age, for example older people have stronger preferences than younger people in our sample, for continuing to live in their own homes with appropriate adaptations as required but for not using assistive technology – this would benefit from further investigation to ascertain if these differences were associated with an age effect (preferences as people age) or a cohort effect (generational differences). There were important differences in preferences for some components of care between sociodemographic groups, such as between males and females, and between participants from different ethnic and socioeconomic groups. These differences highlight a need for planning and commissioning of care services to ensure that a range of care models are available to accommodate different preferences. Additionally, information on care services needs to be more accessible to people from lower socioeconomic groups. Importantly, people with experience of care had a significant preference for having substantial choice over their care and support services. When people reach the stage of requiring care support, they value having flexibility in their choices of care, allowing them to maintain as much control and independence as possible over their lives.

[Executive Summary](#) (full report not in public domain/publication in draft)

A link to a webinar presentation of the projects listed above can also be viewed on the HAPRU YouTube channel here: [Preferences and willingness to pay for new models of social care for older people with high care needs in England](#).

Additional research undertaken by the Policy Research Unit which may be of interest to the taskforce – please also see our website www.hapru.nihr.ac.uk

Johnson E, Searle B, Green KL, Walbaum M, Barker R, Brotherhood K, Spiers GF, Craig D, Hanratty B. **Interventions to prevent hospital admissions in long-term care facilities: a rapid review of economic evidence.** Journal of the American Medical Directors Association (JAMDA) May 2024. <https://doi.org/10.1016/j.jamda.2024.105034>

Kingston A, Wittenberg R, Hu B, Jagger C. **Projections of dependency and associated social care expenditure for the older population in England to 2038: effect of varying disability progression.** Age and Ageing, Volume 51, Issue 7. July 2022. <https://doi.org/10.1093/ageing/afac158>

Maharani A, Sinclair DS, Chandola T, Bower P, Clegg A, Hanratty B, Nazroo J, Pendleton N, Tampubolon G, Todd C, Wittenberg R, O'Neill TW, Matthews FE. **Household wealth, neighbourhood deprivation and frailty amongst middle-aged and older adults in England: a longitudinal analysis over 15 years (2002–2017).** Age and Ageing, Volume 52, Issue 3. March 2023. <https://doi.org/10.1093/ageing/afad034>

Maharani A, Sinclair DR, Clegg A, Hanratty B, Nazroo J, Tampubolon G, Todd C, Wittenberg R, O'Neill T, Matthews FE. **The association between frailty, care receipt and unmet need for care with the risk of hospital admissions.** PLoS ONE 19(9): e0306858. September 2024. <https://doi.org/10.1371/journal.pone.0306858>

Spiers GF, Kunonga TP, Stow D, Hall A, Kingston A, Williams O, Beyer F, Bower P, Craig D, Todd C, Hanratty B. **Factors associated with unmet need for support to maintain independence in later life: a systematic review of quantitative and qualitative evidence.** Age and Ageing, Volume 51, Issue 10. October 2022. <https://doi.org/10.1093/ageing/afac228>

Boulton E, Kneale D, Stansfield C, Heron P, Sutcliffe K, Hayanga B, Hall A, Bower P, Case, D, Craig D, Gilbody S, Hanratty B, McMillan D, Thomas J, Todd C. **Rapid systematic review of systematic reviews: what befriending, social support and low intensity psychosocial interventions, delivered remotely, may reduce social isolation and loneliness among older adults and how?** F1000Research, 9:1368. April 2021. <https://doi.org/10.12688/f1000research.27076.2>

Work undertaken by researchers in our team but not as part of the policy research unit which may also be of interest to the taskforce.

G Spiers, F E Matthews, S Moffatt, R O Barker, H Jarvis, D Stow, A Kingston, B Hanratty, Impact of social care supply on healthcare utilisation by older adults: a systematic review and meta-analysis, *Age and Ageing*, Volume 48, Issue 1, January 2019, Pages 57–66, <https://doi.org/10.1093/ageing/afy147>

Spiers G, Matthews FE, Moffatt S, et al. Does older adults' use of social care influence their healthcare utilisation? A systematic review of international evidence. *Health Soc Care Community*. 2019; 27: e651–e662. <https://doi.org/10.1111/hsc.12798>

This submission was written on behalf of the NIHR Policy Research Unit in Healthy Ageing by Professor Jane McDermott, 02.12.24

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