ISPA
Intersectional Stigma of Place-based Ageing

A Volunteer's Perspective

A call to underpin the volunteering of "lived experiences", so the 'voice of the people' can help to stem emergency call on health and social care services

September 2025

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BLOG: A VOLUNTEER'S PERSPECTIVE: A CALL TO UNDERPIN THE VOLUNTEERING OF "LIVED EXPERIENCES", SO THE 'VOICE OF THE PEOPLE' CAN HELP TO STEM EMERGENCY CALL ON HEALTH AND SOCIAL CARE SERVICES

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Introduction

Deeper collaboration of university social scientists and NHS is strongly encouraged so that citizens may see greater positive impact from volunteering their informed views. This call comes as NHS and universities already seek collaborating citizens who will volunteer their lived experience. The capacity of unpaid caring friends and family is under immense pressure. Think, for instance, of unpaid, older carers of partners or adult offspring with special needs; the reduction in respite and drop-in options; and shortage of housekeepers and support workers. This capacity shrinkage will in turn likely raise demand for health and care services, as services designed without the input of volunteers with lived experience will result in a decline in overall quality. This blog outlines the challenges facing volunteers in offering their experiences and views, the damage the failure to include this input has for the quality of services and how universities can play a part in creating solutions.

I have shared views since 1990 as an unpaid citizen, initially in co-production on work-related standards with University of Lancaster, and as a member of the Health of the Nation workplace taskforce when the UK organised 'care in the community'. I have volunteered as a community researcher with the University of Stirling since 2015 and as a public partner with NHS since 2019. I have noted that success of initiatives to ease local economies and pressure on health services depend upon co-production which involves meaningful collaboration across disciplines and policy areas, and knowledge of problematic aspects[1]. Citizens' motivations for volunteering views were notably wide-ranging, sometimes changing over time: a purpose to get up for in the morning, and feel in the swim of things; the interest in meeting new people different from oneself. There might be a particular passion for the subject being researched, deriving from direct personal experience or the experience of a loved family member, friend or partner. A volunteer might want to share their views after a negative experience, in the hope that this might prevent others from suffering in the same way.

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[1] Healthcare Improvement Scotland (2023). *Gathering Views.* Accessible from: www.hisengage.scot/informing-policy/gathering-views/. Last access date:12/09/2025.

For instance, volunteering one's lived experience to the NHS comes from a whole range of experiences. Many volunteers see patients' loss of confidence and muscle power when in hospital, even when they subsequently head back home. Delays occur while transport, medicines and paperwork are sorted; and agencies, perhaps involving social services and providers of housing, residential or home care, arrange a discharge plan suiting 'the needs and preferences of patients, their families and carers'[2]. Delays may also happen when overworked staff cannot complete tasks[3], with recruitment failing due to a lack of feasible relocation or travel to work options[4]. Poor enabling of self-management[5] will have contributed to Scotland's 666,190 hospital days lost to delayed discharge in the year ending March 2024[6]; and England's 14 percent of around 143,000 hospital beds lost during Winter 2023-24[7].

[2] NHS England (2023). *Guidance: The NHS Constitution.* Accessible from:
https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england Last access date:12/09/2025

[3] Institute of Fiscal Studies (2025). *Can the Government Achieve its 18-week elective waiting time target?* Accessible from:
https://ifs.org.uk/publications/can-government-achieve-its-18-week-elective-waiting-time-target. Last access date:12/09/2025

[4] See for example: BBC Scotland (2022) *Hundreds of Skye jobs vacant due to homes shortage.* Accessible from:
https://www.bbc.co.uk/news/uk-scotland-highlands-islands-62162956.

[5] Pengelly, R. (2022) *Keeping Going...by sharing ways in which to be happily home-based. ScotSectorLink.* Accessible from:
www.scotsectorlink.org.uk/resources/KeepingGoing.pdf.
Last access date:12/09/2025

[6] Public Health Scotland (2024). Delayed Discharges in NHS Scotland: Annual summary of occupied bed days and census figures: Data to March 2024. Accessible from: https://publichealthscotland.scot/media/30972/2024_12_10-delayeddischarges-annual-summary_final.pdf Last access date:12/09/2025

[7] The King's Fund (2024). *Data and Charts: The number of hospital beds.* Available from:
https://www.kingsfund.org.uk/insight-and-analysis/data-and-charts/number-hospital-beds Last access date:12/09/2025

Barriers to effective volunteering

Despite this wealth of knowledge, there are many factors which demotivate people from volunteering their knowledge. Volunteers might ask themselves what the point in contributing is when:

- national measures are lacking, concerning, for example, the declining health of the working-age population since the pandemic, rising health-related benefit claims[8] or the ways in which poor health curbs the participation in paid work[9].

- collaborating partners may discard volunteered lived experience as contradicting peer-reviewed publications, thereby doubling volunteers' frustration by also stifling essential adaptation to clear trends.

- organizations delay the implementation of obvious solutions, such as the informing and enabling of 'self-management' of health conditions, so that people can see how to remain safely home-based, away from making crisis calls.

- collaborating partners fail to ensure that service users know the anticipated benefits of initiatives or proposed solutions. Benefits may be described, for example in restored self-management and independence, or avoided further treatment. In some cases, collaborating partners are not trusted even to have duly considered proposed solutions in terms relevant to wider contexts, such as user age, cost effective alternatives[10], or relevant case studies or test trials.

- inspection regimes fail to capture where one inspected area adds to the workload of another. For example, where prescription of new medication by primary care ignores a known intolerance, this can trigger unscheduled calls on ambulance and hospital emergency services.

The above indicates areas where services could be eased by the constructive input of volunteered lived experiences. However, NHS can find great difficulty in accepting the constructive suggestions of critical friends. NHS can also be in almost perpetual reform, so lacking in the capacity to spot trends. And NHS is not positioned by governments to raise aspects which add to its work, but which are not within either the health nor social care remit. One such aspect, for example, is a lack of housing relocation options,

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[8] The Institute for Fiscal Studies (2025) *The role of changing health in rising health-related benefit claims.* Available from: https://ifs.org.uk/publications/role-changing-health-rising-health-related-benefit-claims. Last access date:12/09/2025

[9] Randolph, H (2024). *Economic inactivity and ill health in Scotland.* Scottish Parliament. Available from: https://digitalpublications.parliament.scot/ResearchBriefings/Report/2024/7/26/e76632ef-84a0-465c-9594-9c2f07f29153

[10] National Institute for Health and Care Research (2023). *7 findings that could save the NHS money and improve care.* Available from: https://evidence.nihr.ac.uk/collection/7-findings-could-save-nhs-money-improve-care/ Last access date:12/09/2025

which undermines the recruitment of support staff and also the downsizing of increasingly needy people into safer dwellings, closer to facilities or support options.

Encouraging university-led solutions

Universities are well-placed to lead on reforms as they can approach this complex interplay of factors influencing organizations' service delivery holistically. They can work collaboratively across sectors and disciplines[11], while also involving citizens and key parties including NHS. Strengths lie in being positioned to consider factors which are external to NHS, but which trigger work for NHS. For instance, university research may look at underlying preventable reasons for crisis calls to public services, from survivors, as well as from long-standing caring friends of those who have since died due to these crises.

Universities are also well-placed to gauge potential savings in public resources. For example, to stem emergency calls on health and care services, university research could explore practical solutions, such as: greater citizen access to practical self-management tips, from public libraries, community-based pharmacists, district nurses and allied health workers, Alternatively, should a locality's highest priority be to: upgrade sub-standard homes; build homes with room for house-keepers or support workers; or build relocation options, as houses become increasingly unsafe as unfeasible to adapt to occupants' rising needs?

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[11] Theakstone et al. (2024). *Thinking about Stigma in Housing, Health and Social Care Delivery Implications from the Intersectional Stigma of Place-Based Ageing (ISPA) Project Evidence Review.* Housing LIN. Available from: https://www.housinglin.org.uk/_assets/Resources/Housng/OtherOrganisation/Thinking-about-Stigma-in-Housing-Health-and-Social-Care-FINAL-13.02.24.pdf. Last access date:12/09/2025

Bowes, A & Pengelly, R. (2024) *Designing homes for healthy cognitive ageing: a co-productive approach*. Healthcare Improvement Scotland. Available from: https://www.hisengage.scot/events-list/17-april-2024-webinar/. Last access date:12/09/2025

DesHCA (2022) Engaging Communities in Research: A Volunteer's Perspective. University of Stirling. Available from: https://www.deshca.co.uk/blog/engaging-communities-in-research-a-volunteers-perspective/. Last access date:12/09/2025

University research would still need to address and be alive to issues concerning the value of volunteers' lived experience. However, universities could well lead on establishing a UK-wide, publicly-available, well-promoted and succinct co-production guide[16], as none can be found which focuses on the clarity needed to retain motivation for collaboration. Clarity should combat the use of ill-defined terms and acronyms; and poor reasonable adjustments, including on meeting timings and accessibility. Clarity stems confusion on the part of volunteers concerning the aims and commitment sought, likely deadlines and travelling, arrangements for reimbursements of subsistence and out of pocket expenses, and any freely-provided kit. Clarity on safety aspects can cover: products, declarations of interests including conflicting ones, confidentiality stipulations, and service integrity, including the management ethos to safeguard employees and outsiders, thereby maintain public indemnity and employers liability insurance cover, with intention to hear whistleblowers as a backstop. Clarity on limitations can be crucial where: a part-time secretariat may leave some volunteers feeling disconnected; or an initiative may not produce ongoing publicly-available resources. Lastly, clarity on tokens of appreciation eases sensitive handling of vouchers which can counter volunteers' welfare rulings, or be seen as another patronising curb on freedom of choice. Some volunteers refuse token payments so to retain independence or avoid need to submit a self-assessment tax return. Involving paid workers as volunteers during work hours can be challenging, where they have to take leave or lose pay. But a bonus can be for tokens to enable volunteers to attend gatherings or away days.

University-led collaboration which feels overdue

University-led collaboration could now effectively pick up on NHS leaders who state that a think tank of some sort would ease progress. This is strongly encouraged as a key way forward, to assist in the gathering, packaging and presentation of the constructive suggestions of critical friends, especially those relating to "non-health" aspects which add to the work of NHS, so also social care. It is called for with urgency, as NHS and social care are unlikely to be positioned soon by governments to undertake such work. Meanwhile, wider trends are likely to be in rising costs, from fuel through to infrastructure maintenance, and in rising demand on health and social care services.

Intersectional Stigma of Place-Based Ageing (ISPA) Project

The ISPA project is an ambitious 5-year participatory mixed method study that will explore and understand how the stigma attached to where people live can intersect with experiences of disability and ageing. This will provide nuanced insights into the structures and systems that drive exclusion and allow us to tackle the inequalities experienced by older disabled adults. Do visit https://www.youtube.com/@ispaproject for an audio and visual overview.

We aim to develop interventions related to home and environmental modifications that encourage interventions for inclusive approaches within housing, health and social care delivery. This in turn supports people to age well within homes and communities across England, Scotland, and Wales. The project is funded by the Economic and Social Research Council (Ref: ES/W012677/1) and runs from September 2022 to September 2027.

The Intersectional Stigma of Place-Based Ageing (ISPA) Project is a collaboration between the University of Stirling and the University of St Andrews, Newcastle University and University of Bristol. We are also partnered with the Housing Learning and Improvement Network (Housing LIN) and Scottish Federation of Housing Associations (SFHA).

Author Biography

Ro Pengelly, Community Peer-researcher for ISPA can be contacted via Professor Vikki McCall, Faculty of Social Sciences, University of Stirling and Principal Investigator on the Intersectional Stigma of Place-based Ageing (ISPA) project. Vikki and Ro worked on the Designing homes for Healthy Cognitive Ageing (DesHCA) project, which co-produced community engagement functions, including the Serious Game 'Our House' and the 'Power of Co-Production' video.

Ro has volunteered as a public partner with NHS since 2019, and between 1992-3. DesHCA lead, Professor Alison Bowes, and Ro jointly presented a well-received, well-attended housing-related webinar to Healthcare Improvement Scotland in April 2024.

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