



Citizen Science as a Framework for Improving the Science-Society Interface in Long-Term Care Research

PERSPECTIVE

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ABSTRACT

Context: Engaging with and involving the public in research has become a widespread consideration in many research fields, including long-term (social) and health care.

Perspective: Citizen science (CS) is an umbrella concept that has grown rapidly in many scientific areas and has been noted as increasing in health research. Its root is the need to work at the science-society interface and its place in societal development. This interface is understood to operate in several ways, and the overarching CS goal is to strengthen it through a variety of practices. We seek to encourage a dialogue across long-term care research and CS to the benefit of both sides.

Implications: We argue that using CS as an overarching concept for engaging with the public in long-term care research would provide a variety of benefits to that scientific field. These would include opportunities to examine the state of citizen involvement across the field, employing the most appropriate modes of involvement and engagement in specific contexts. It would also open opportunities to develop the methodological imagination by examining examples of CS in other research areas. CS could also benefit from the experience of public involvement in long-term care research, including its extensive consideration of power, payments, and including people with additional support needs. There is a need generally for greater dialogue about being more inclusive and addressing inequalities.

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INTRODUCTION

Engaging and involving members of the public who are not professional researchers more widely in research is an international concern spanning diverse social issues and research fields (Silvertown, 2009; Bonney et al., 2014; Bonney et al., 2016; Heckler et al., 2018; Vohland et al., 2021). In this Perspectives article, we draw on our experience of the developments and debates in public involvement and engagement in long-term (social) care research in England to consider the application of the concept of citizen science (CS) in that field.

We begin with a discussion of the background to this article, namely movements towards greater public involvement in long-term and health care research. Next, we examine the development of CS. We then consider some advantages to long-term care research of using the umbrella concept of CS, before finally examining the experience that long-term care researchers can offer to inform developing CS research.

We are not seeking to provide a detailed overview of approaches to public involvement and engagement in research in this article, a systematic task that would be helpful but is beyond the scope of this work. Rather, we are endeavouring to stimulate thought and discussion amongst different stakeholders (e.g., researchers, guardians of research systems, members of the public, research funders) in the field of long-term care research about the potential for CS to help us collectively move forward and develop the science-society interface. It is our view, as expressed in the following, that there is mutual benefit to be achieved by more dialogue about involvement and engagement across long-term care research and CS.

BACKGROUND

The concern with greater public involvement and engagement in research has been growing internationally, arising from many sources of motivation, including an interest to build and sustain public understanding of and support for science (e.g., Bonney et al., 2016; Brossard, Lewenstein & Bonney, 2005). A further drive has been to ensure that members of the public can actively contribute to shaping research, rather than only as passive participants in research led by professional researchers. A rationale for this is that many of the public can contribute experience and ideas to improve the quality and relevance of research by diversifying its underpinning knowledge base. Ultimately, the intention is to thereby strengthen the impact that research has on improving society and people's lives.

Many funders of health and long-term care research in the UK promote extensive public involvement and

engagement in research, including statutory funders such as the National Institute for Health and Care Research (NIHR) and Research Councils, as well as charitable funders, such as the Alzheimer's Society (e.g., NIHR, 2021). Expectations often include involvement in planning and operationalising projects, as well as the need for public contributions to identifying research priorities. An example of the latter is the extensive work of the James Lind Alliance Priority Setting Partnerships (<https://www.jla.nihr.ac.uk/>). In long-term care in the UK, there is a rich history of public involvement in research, including participatory research approaches, emancipatory research, and research led by people living with disabilities, and often this work has been ahead of involvement in health care research (NIHR, 2021).

The result of these drives to increase involvement is a complex conceptual and practice landscape for public involvement and engagement. The concept of engagement usually conveys nurturing general public interest in, understanding of and support for research. Involvement denotes directly contributing to specific research projects and programmes. Involvement practices include convening advisory and steering groups which include public contributors; co-design and co-production as means of involving people in forming and undertaking research projects; participatory research directly working with groups of people with a stake in a research area; service user or peer researchers as individuals with experience of the subject working as researchers; and user-led/controlled research in which people with lived experiences of conditions such as mental health problems lead research. It is beyond the scope of this perspective article to comprehensively discuss this complex landscape. Rather, here we acknowledge that there is an extensive and often blurred landscape of involvement approaches.

'Co-production', as an example concept, is currently a popular term for developing public involvement in research in the UK. It is, though, a word that is potentially being overused, rendering it a buzzword, not always clearly defined and often stretched in meaning (Farr, 2018; Locock & Boaz, 2019; Williams, Robert et al., 2020; Beresford et al., 2021; Bandola-Gill, Arthur & Leng, 2022; Masterson et al., 2022). The fuzziness of the concept can result in questions about who owns it and what the practice is for (Carr, 2018). There is a plurality of practices under the label of 'co-production' (Farr et al., 2020; Williams et al., 2021), meaning there can be different experiences of and outcomes from processes that are similarly labelled (Farr, 2018). Across the different understandings of co-production identified by Bandola-Gill, Arthur and Leng (2022), for example, tensions include those involving people in existing ways of working and those seeking to change relationships more fundamentally.

Co-production's flexibility as a concept has arguably helped its rise (Bandola-Gill, Arthur & Leng, 2022), but it may also mean that it can be co-opted to describe processes which do not significantly alter researcher-public relationships. Hence, a critical perspective is required when assessing any claim to have taken a co-production approach (Williams, Robert et al., 2020). More reflective debate about the nature and impact of co-production is required, such as the dialogue between Oliver, Kothari and Mays (2019) and Williams, Sarre et al. (2020).

In this blurred and congested involvement space, there is a risk of reducing debate to an unhelpful competition in which approaches not using the preferred language are dismissed as inadequate irrespective of the context and the claims being made (Locock & Boaz, 2019) and ignoring the potentially political and unclear nature of even the preferred language. Such antagonism could mean losing involvement and engagement approaches that are helpful but which do not fit the dominant narrative. Each approach to involvement has positive and negative aspects in relation to different individuals and communities, and there needs to be space to carefully consider these. To be inclusive, we need to avoid the risk of becoming over-reliant on one label, such as the somewhat vague term 'co-production', and thereby ignore a rich history, philosophical depth and diversity of practices for research collaboration with the public (Facer & Enright, 2016, Masterson et al., 2022).

CS offers an opportunity to consider these issues within a wider framework of understanding the science-society interface beyond an individual project or approach to involvement. Next, we discuss the concept of CS and the potential for adopting it as an umbrella concept for involvement in long-term care research.

WHAT IS CITIZEN SCIENCE?

CS is an overarching concept aimed at improving the science-society interface. The concept evolved separately in the 1990s to convey both top-down (professional researchers engaging citizens, e.g., as volunteer scientists collecting data) and bottom-up (citizens being more involved in directing research agendas) developments (Woolley et al., 2016; Strasser et al., 2019). Both directions sought greater consideration about the science-society interface, improving public engagement in, understanding of and support for science and the place of science in societal development. The emergence of both bottom-up and top-down perspectives reflects the complex, multifaceted nature of the science-society interface and the need to manage it in many ways. Consequently, CS work has evolved to be inclusive of both perspectives.

CS is seen as having the potential to help with addressing the complex questions faced in many fields of research by widening the knowledge and resources bases to address them (Bonn et al., 2018). Whilst better known in other areas of science than long-term care, including ecology and physics, CS has been noted as on the rise in health research (Dickinson et al., 2012; Wiggins & Wilbanks, 2019).

CS is fundamentally about the relationship between citizens and professional research communities. It contains an epistemological belief that greater sharing of resources and better dialogue across the science-society interface is beneficial. To this end, there ought to be more and better engagement between professional scientists and members of the public with a stake in a shared research area/social issue.

Beyond involvement in projects, CS has also extended engagement with the public to shape research environments, including setting research priorities, commissioning research and being involved with research funders and on research ethics committees. CS does not prescribe any one mode of engagement or involvement. Rather, its concern is to adopt a system-wide view of a research field and whether CS principles are being advanced to help develop it and its science-society interface, rather than a purely project-by-project focus on what form of involvement is being used in each. CS is a broad social change with ongoing dialogue across all aspects of a research field and its systems.

Three broad modes of engagement and involvement for CS have been defined (Bonney et al., 2009; Rowbotham et al. 2019):

1. **Contributory:** Where professional scientists define research questions and methods and citizens are asked to contribute to the research through being active in data collection, but with the goal that this stimulates a wider interest in that field of knowledge.
2. **Collaborative:** Where scientists design the overarching research project and citizens are engaged in refining questions, methods, data collection and/or analyses.
3. **Co-created:** Where professional and citizen scientists work together across the whole research process, from defining the project through detailed planning and operationalisation.

An example of the first mode, contributory, is when citizens are asked to send data as part of mass census days for local wildlife, such as birds or insects in gardens. Note that this is asking citizens to provide data and to be very active as field researchers collecting it. A broader goal is to engage citizens in a wider interest in the scientific topic. Lessons from this mode of CS are the public reach that projects can have, the resultant scale of data collection that can be achieved and the level of public interest in a topic that can be generated.

The second mode, collaborative, is a well-established experience in long-term care research in England where citizens (sometimes in roles labelled as service user, person with lived experience, carer, family member and/or practitioner) contribute to defining research projects. This may include, for example, informing details of methods, such as what outcome measures will be used; helping refine interview schedules; or potentially sense checking analyses and outputs from projects.

The third mode, co-created (or co-produced), requires more citizen commitment to shape research projects during the whole process, potentially from initial decisions about the focus of the research and certainly through planning details, operationalisation and reporting of the project. This mode is likely to be more resource intensive and requires more ongoing engagement and time commitment from all parties relative to the previous two.

These three modes were expanded to five modes of CS (contractual, contributory, collaborative, co-created and collegial), but still without any implication of a hierarchy of better approaches (Shirk et al., 2012). The modes are not mutually exclusive, and different combinations may run through research projects and programmes. The key consideration is the underlying intention, that is, better public engagement across a scientific field to positively shape the science-society interface and the degree to which this is improving. Each mode of engagement has strengths for CS, which ought to be the basis for choosing which mode(s) to use in any project or programme.

To assist with operationalising the concept, 10 principles of CS have been developed (European Citizen Science Association, 2015; Robinson et al., 2018):

1. CS projects actively involve citizens in scientific endeavours that generate new knowledge or understanding.
2. CS projects have a genuine science outcome.
3. Both professional scientists and the citizen scientists benefit from taking part.
4. Citizen scientists may, if they wish, participate in multiple stages of the scientific process.
5. Citizen scientists receive feedback from the project.
6. CS is considered a research approach like any other, with limitations and biases that should be considered and controlled for.
7. CS project data and meta-data are made publicly available, and where possible, results are published in an open-access format.
8. Citizen scientists are acknowledged in project results and publications.
9. CS projects and programmes are evaluated for their scientific output, data quality, participant experience and wider societal or policy impact.
10. The leaders of CS projects take into consideration legal and ethical issues surrounding copyright,

intellectual property, data sharing agreements, confidentiality, attribution and the environmental impact of any activities.

These principles would operate at the levels of individual projects, such as points 7, 8 and 10, and across research programmes and systems, such as 4 and 10. The principles express a definition of 'research' as an activity generating new knowledge (2) that is scientific in nature and robust (1, 7 and 9). They combine this with scientific reflexivity to encourage reflection on the nature of CS and its impact (principles 6 and 10). Reciprocity across the science-society interface underlies the approach (3 and 5).

The CS programme is far from complete across any field of science (Bonn et al., 2018). There is a need, for example, to develop more robust evidence for the modes of engagement in CS in different fields and criteria for evaluating CS work generally. Ways of understanding and managing the ethical issues in CS research are developing (e.g., Resnik, Elliott & Miller, 2015) but require further testing and evolution. The frameworks of modes and principles above provide a start in structuring that work and the evolution of CS.

WHAT ARE THE POTENTIAL BENEFITS FOR LONG-TERM CARE RESEARCH OF ADOPTING CITIZEN SCIENCE?

Long-term care represents a highly complex field of research to which CS could add value. The diversity of people and communities connected with long-term care and their strengths and needs, combined with multifaceted care and support and complex service interfaces, present a mosaic of research questions. Many of these are known to professional scientists, whilst others are potentially only experienced by the public and yet to be fully articulated. Some may be particular to communities. Some may need an array of data to answer that current research methods and infrastructure will struggle to capture. Bridging the divides between research and practice/policy requires another set of complex relationships to nurture in long-term care.

To address these issues, we need to include in the scientific endeavour those people directly affected by them: citizens in various guises, including those with lived experience of conditions; family carers; and practitioners. Drawing on CS experience in other areas of science (e.g., Hecker et al., 2018; Moedas, 2018), we suggest that bringing CS experience into long-term care research would help energise and nurture the long-term care research science-society interface. It would constructively evolve this interface across the field beyond the positive engagement and inclusion developments we

have already achieved. This, as we discuss later, would not be a monologue from CS to long-term care, as there is strength to be gained for all by a dialogue across the fields.

Drawing lessons from the wider science-society interface view of CS, we should recognise the need to increase the general interest in and support for long-term research amongst the public. New alliances and social movements could be invigorating for all. Engagement with more members of the public and new communities can help overcome the potential risk in public engagement of overly relying on individuals with similar characteristics. The COVID-19 pandemic has highlighted issues of inequality in health and long-term care, and these need to be addressed in public engagement in research across those fields (Clark, van Vliet & Collins, 2021). CS has the potential to increase diversity in science (Bonn et al., 2018), and in some fields, a CS commitment to work with local communities has resulted in community-led projects, also called 'community science' (Bonney et al., 2016).

This can be developed in to programmes of linked local CS projects addressing concerns with communities, connecting people and projects in a virtual laboratory. This has been an experience in, for example, environmental research (Silvertown, 2009). Such sustained involvement may enable better mutual understanding across science and communities and enable creative thinking in long-term care research, including with marginalised communities.

With CS as an overarching ethos, involvement practices that may be presented as competing, such as researcher-led, peer-led and co-production, can all be employed without competition in an overarching understanding of how the science-society interface needs to evolve for a field. Rather than seeing the 'contributory' mode of engagement as lesser than or in antagonism to 'co-created', we can consider the strengths and weaknesses of each across the whole field of research. The former mode might, for example, be most suited to a project that is seeking a large number of people to be active to collect data and build their general interest in a topic. Collaborative and co-created modes may be more suited to working with specific communities but can only engage a relatively modest number of people at any one time. The intensive level of involvement needed for co-creation may not be suitable for some people, who nevertheless could have valuable contributions to make on an advisory group. Overemphasising co-creation as a preferred mode of engagement risks losing such contributions; we ought to be looking to strike a balance across a research field, and this can be accommodated within an overarching CS ethos.

An additional potential benefit is that CS experience from other fields could stimulate methodological

imaginings and encourage innovation in long-term care research. For example, what might be the equivalent in that context of asking citizens to undertake a census of local wildlife? Perhaps it could be a census of people's use of long-term care, how they feel at that moment, what needs are not being met and the status of their community engagement and relationships network. This may develop into longitudinal studies akin to annual CS wildlife surveys, resulting in a stronger long-term care science-society interface by mobilising more public interest and engagement. In such a programme, long-term care research could draw lessons from other fields regarding assuring the quality of data from citizen scientists (Bonney et al., 2014).

Similarly, how might consideration of the diverse uses of technology to develop CS programmes in other areas of science (Woolley et al., 2016) stimulate developments in long-term care research? What would be the long-term care research equivalent of 'community science' working with communities to research their local concerns about their environment (e.g., Bonney et al., 2016; Brooks et al., 2019). The potential of learning from the history of CS to stimulate methodological development in long-term care seems considerable.

WHAT CONTRIBUTIONS TO CITIZEN SCIENCE CAN LONG-TERM CARE RESEARCHERS MAKE?

By encouraging a dialogue between long-term care and CS researchers and the cross-fertilisation of ideas between the fields, we also see that long-term care research can contribute to the development of CS. Long-term care research has, for example, experience in some modes of public involvement in research, including co-production and peer researchers, and this could helpfully inform CS more generally.

A further example is that many CS programmes work with the public as volunteers, such as when they collect data within their neighbourhoods. Long-term care research has less experience of this but has extensive experience of working with the public in paid roles in research. This experience of payments and different power relations could also contribute to developing CS practices.

Similarly, long-term care researchers have experience of involving and working with people with a diversity of health and social care needs. Knowledge about how best to work with, for example, people living with communication or cognitive difficulties or fluctuating conditions would be invaluable to widening engagement in other CS programmes. Dialogue across disciplines on ethical issues within a CS framework could also be productive.

In collaborative working between citizens and professional scientists across the science-society interface, questions remain, including understanding power relationships, and the degree of transformation to science and society that can be achieved (Farr, 2018). There would be strength in greater dialogue across CS and different fields of research to address these.

CONCLUSION

In this article, we have set out a case for developing citizen science (CS) as an umbrella concept for engaging and involving the public in long-term care research. Experiences of and reflections on involvement in long-term care research and in CS are too far removed from each other, hindering a potentially helpful dialogue (Heyen et al., 2022). Our view from a long-term care research perspective is that CS could provide an overarching framework within which to integrate involvement and engagement practices and lessons, to bring in new evidence from other fields and to stimulate the methodological imagination within long-term care. This ought to be a mutually beneficial dialogue between long-term care research and CS, as we have argued. There is growing interest and experience in working with members of the public and communities in developing research across many academic fields, and if we are to avoid lessons becoming siloed, we need more dialogue about them. We see CS as an umbrella to facilitate this. Sharing developments in making research involvement and engagement more inclusive and addressing inequalities would seem to be a pressing need in all fields.

The opportunity to share and learn with a wider community committed to CS across disciplines has increased enormously. CS is rapidly evolving, including continuing development in conceptual definitions and methods, the use of technology, understanding of impact and growing networks of those committed to developing CS practice (Heigl et al., 2019; Den Broeder et al., 2018). Similarly, long-term care research has its own rich history of widening involvement in many ways, the evidence from which would enrich the field of CS.

It is our perspective that engaging in a dialogue with CS can helpfully improve the social contract underpinning long-term care research and improve our understanding of the science-society interface. Ultimately, this is likely to help in addressing the highly complex and long-standing issues facing long-term care and the individuals and communities connected to it.

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The authors have no competing interests to declare.

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