

## Chapter 16

# Am I a Carer? Avoiding Research Fatigue and Labelling in Health and Social Care Research

*Charlotte Lucy Richardson<sup>a</sup>, Matthew Cooper<sup>b</sup> and David Black<sup>a,b</sup>*

<sup>a</sup>*School of Pharmacy, Newcastle University, Newcastle upon Tyne, UK*

<sup>b</sup>*Newcastle Patient Safety Research Collaborative, Newcastle University, Newcastle upon Tyne, UK*

### Abstract

This chapter examines the challenges of involving informal carers in patient and public involvement and engagement (PPIE) in health and social care research, particularly focussing on those who may not identify with the label of ‘carer’. A carer usually refers to any individual who provides unpaid care and support to family, friends, or community members. Many individuals will not see themselves as carers and perceive the support they offer as part of a moral duty. The lack of self-identification often makes the recruitment of carers challenging for research. Drawing on the author’s experience working with carers across research, we discuss the barriers to engagement with the carer population and how research could adapt to better ensure their meaningful involvement. We discuss the potential ethical dilemma of engaging with carers who may not consider themselves part of the ‘carer’ group, stressing the importance of recognising carers as individuals, not just as extensions of the patient. We advocate for avoiding imposing the label ‘carer’ on people who do not self-identify as such and instead use inclusive, experience-based language, thus respecting individuals’ journeys towards

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recognising their caregiving roles. We suggest researchers focus on authentic engagement and consider working with the right person, at the right time, for the right purpose. We outline practical strategies for meaningful engagement with carers and call for a shift in culture to better value these carers' unique perspectives and experiences.

*Keywords:* Caregivers; carers; family; ethics; participation; engagement

## **Introduction**

Part of our nature as social animals is to identify with those who are similar to us, and we seek to connect ourselves with those we feel mirror our own beliefs and values. However, within research, this can conflict with the realities of individualism, a central element of qualitative research. For example, we can use the visualisation of a rugby match where the referee has decided that a play was offside. The home fans and the away fans will have different opinions on whether it was offside or not; their opinion could also be affected by their view of the play from where they are sitting. Additional influences could also come from their knowledge of regulations or the opinions of those sitting nearby. In research, this is known as hermeneutics, and in qualitative work, we can look to ensure the individual voice is captured while grounding experiences about groups. If we consider the rugby match, we will accept that each individual might have a different opinion. However, if we spoke to a representative group of fans, we would find that there are some common experiences that we would interpret as representative of the event. When we are working with populations in research, we need to be comfortable that individuals will have their own beliefs and opinions about their experiences. What we must do as researchers is bring together experiences of the phenomena of enquiry and ensure we can triangulate common themes.

In health and care research, we default to grouping people into categories based on their conditions or experiences. We provide labels to these groups to help define who we are working with and what the population boundaries of our work are. Difficulties can arise when we apply a label that means different things to different people and can isolate those who do not all identify with it at all. Carer is a common term given to both those who provide informal/unpaid support and those who are carers by profession (social care-funded employment). As researchers, we are often interested in the 'other' and within our research, we wanted to speak and engage with the people who do not identify with the label of 'carer'. These 'carers' are a key part of the spectrum of carers and have an important voice that should be heard; however, for the reasons laid out below, they do not necessarily relate to the label, which causes challenges when trying to engage with them as part of PPIE in research. The term carer is used throughout this chapter to refer to informal (unpaid) carers, or:

anyone who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid. (NHS England, 2014)

Readers should be aware that the term ‘informal carer’ can be misrepresentative, and some carers report it minimises the importance and impact of their role (Wanless, 2006). Alternative terms commonly used can be unpaid carer, family carer, and non-professional carer. For this reason, we have simply used the term ‘carer’ and by this, we mean carers who provide support to friends, family or community members and are *not* employed as professional carers. We also use the terminology: PPIE, which refers to research which is ‘carried out “with” or “by” members of the public rather than “to”, “about”, or “for” them’ (INVOLVE, 2021). PPIE should take place throughout the research and can include contributions to identify a research question, right through to influencing policymakers and aiding in disseminating the results (NIHR Applied Research Collaboration East Midlands, 2019).

As part of a National Institute for Health and Care Research (NIHR), Research for Patient Benefit funded research grant, we set out to consider the involvement of carers in transitions from hospital to home relating to patient medicines use. Specifically, caregivers who are more likely to go unnoticed within the health and social care system. The desire to consider this as a focus for research came, as it does in many different contexts, from the first author’s personal experiences, whereby she witnessed her grandmother care for her grandfather as a doting life partner, sometimes to the detriment of her health and well-being. Had anyone asked Mrs Dodds if she was a carer for her husband, it would have been likely she would have been confused and responded along the lines of ‘it’s just what I do’.

Mrs Dodds is not alone; it is estimated that by 2037, there could be as many as 9 million carers in the UK (The Care Provider Alliance, 2020). Carers UK estimated this to be even higher at around one in five people (Carers UK, 2022). Part of the reason for differing estimations of the number of carers is due to the highly personal nature of this role and the inextricable link between caring responsibilities and familial and cultural responsibilities, which can result in carers feeling an obligation to care and thus not identifying with the term (Engster, 2005). Notably, self-identification as a carer is thought to occur over a prolonged period of time, with 51% of carers taking one year and 36% taking over three years to identify with their role as a carer (Carers UK, 2022). Other research has found that carers can be unsure about the norms associated with being a carer and that being a carer can be more obvious in extremes of ill health (Beatie et al., 2021).

When working with carers it is also important to acknowledge and respect the influence of culture within the role. Different cultures and norms will place different emphasis on the role of family and community in supporting individuals. Some may place more emphasis on the use of formal caregiving and some may feel caregiving is not a role but part of their moral duty to support community members. This is where language can be important and to work with the population of

carers to understand what beliefs and values systems underpin their perception of caregiving. An example of this is filial piety (traditionally a Chinese cultural value but commonly observed in many cultures), which is the value and respect held for parents, elders and ancestors. This is likely to influence a person's perception of their role as a caregiver and to suggest their role is beyond what they morally should be doing, which could be offensive to some. Researchers should always consider cultural norms and values when working with patients and public members, but particularly when engaging with carers ([NIHR School for Social Care Research, 2022](#)).

Carers who do not identify as caregivers are sometimes the ones most in need of support, including for their health and well-being, not least due to the emotional and physical burden that caregiving can cause ([Gérain & Zech, 2019](#)). As health and social care professionals and researchers, we need to better understand our own practices and positionality, as well as the implications of labelling, how people perceive themselves and the implications of this and why these carers do not see themselves as carers. Being more reflective and reflexive here, we will argue, will lead to a better understanding and allow us to better design services that these carers require and can access. The challenges of working with carers who do not see themselves as such, can leave a potential ethical dilemma for researchers working in this area when a notable proportion of the people we are trying to engage with do not see themselves as part of that group, and they may ask themselves 'but am I even a carer?'

In the following chapter, we will reflect on our experiences of working with carers and discuss several key considerations to facilitate more meaningful and authentic engagement with carers. The discussion will touch upon carer identity as complex and multi-faceted, the importance of carefully considering language when engaging with carers, the balance between professional PPIE contributors and those who are research naïve and what they can each bring to a project, and finally, we will hear direct reflections from a carer.

## **Being a Carer Is Not the Sum of Existence**

It is well-established that PPIE is a core element of health and social care research, but in high-level resources, such as the UK Standards for public involvement ([UK Public Involvement Standards Development Partnership group, 2019](#)), the 'who', 'why', and 'what' of PPIE can be vague, intended to leave room for flexibility for the individual research project but the risk is that there is confusion on what meaningful PPIE looks like. It is therefore important to first consider the value that including carers in research can offer. This is grounded in the principle of 'research with us not on us' ([NHS Health Research Authority, 2023](#)).

Understanding positionality here is key, and recognising that as researchers, we see the world in different ways. We each might have our own experiences of caregiving, for example and will hold our own biases as to how change could be made. By including carers in research from the beginning, we can gain insight into wider views and experiences *via* real-world stories and personal interpretations of caring. As researchers, we can work with people to connect the dots of individual

experiences against what is commonly experienced and use this to inform how we design and deliver research.

Carers might be the focus of the research question, like in our grant, and so that value is obvious as carers are central to the research question as opposed to other groups of patients or the broader public; conversely, other topics might warrant more obvious patient involvement, with carer input being secondary. It has been suggested that clarity about ‘why’ a project needs involvement can consequently direct ‘who’ to involve (Staley et al., 2021). ‘Why’ is not the focus of this chapter, and instead, we direct readers to resources that promote reflection as to the purpose and value of PPIE (Graffigna & Barello, 2022). Presuming you have asked yourself ‘why’ you are conducting PPIE and the answer has led you to recognise that carers are a group who can contribute to fulfilling your ‘why’, we will now discuss the ‘how’.

Carers are routinely involved in health and social care research in a similar way to patients and other people with lived experience relevant to a given research question, and as such, carers are also at risk of experiencing tokenistic PPIE, the same as other contributors (Bowness et al., 2024). From our experiences, however, we suggest that the risks of this tokenism are greater for carers than due to the manner in which they are considered by research teams and then involved. In 2023, the NIHR highlighted a need for more research involving carers and suggested that the benefits included that carers can (i) be a key part of the jigsaw of making services work, (ii) can support the person they care for to be involved to ensure their voice is heard, and (iii) can act as an advocate for those they care for if they are not able to do so themselves (Jarvis & Bowness, 2023). It should be noted that the latter two suggestions are not focussed on the value that the carer themselves can contribute, but are positioned to facilitate better patient input through utilising their carer as a proxy if you pause and imagine this from the perspective of a carer. This carer has its own experiences, thoughts, and opinions. What indication does it give to the carer of the value of their contribution?

In terms of carers’ experiences of health services (outside of research), it is acknowledged that carers are individuals and not merely an extension of the patient (Zavagli et al., 2019). Carers’ health and well-being are influenced by their caring role. Being a carer has been identified as a social determinant of health, and carers can experience poor physical and mental health and may have unmet care needs (Public Health England, 2020). It is important that carers are viewed as individuals and that the label of carer is not the extent of their identity (Eifert et al., 2015). This has been translated into the research space, whereby the NIHR is publishing a carer-facing and a researcher-facing set of recommendations for research involving carers (NIHR, 2023a, 2023b). These documents acknowledge the value carers can bring to research but fundamentally recognise the importance that researchers ‘recognise that carers are people first’.

## Treading Carefully Around Language

Not all carers will see themselves as part of the ‘carer’ group. Therefore, if we approached people by asking for ‘anyone who is a carer to get in touch’, we might

find ourselves with a certain demographic of carers. Particularly those who are well-established in their identity as a carer are particularly vocal about this and are potentially more aware of research. The concept of ‘hidden carers’ is documented within the literature and refers to carers who, for various reasons, do not identify as a carer and therefore are less likely to reach out for support; people not identifying as carer and thus being ‘hidden’ is suggested to be closely linked to cultural and familial roles and responsibilities (Knowles et al., 2016). Our project required a range of carers to contribute, which included hidden carers. Therefore, our reflections on how we approached and involved them are presented below.

Our research topic was broad and considered what works, for whom and in what contexts relating to the involvement of carers in hospital discharge relating to medicines use using a realist methodology (Cooper et al., 2024). In order to identify carers to contribute, we use broad reflective questions in recruitment documents and communication, including ‘Do you help someone with their medicines?’, ‘Have you helped someone during hospital discharge?’ and ‘Do you support or help a friend or family member with their health?’. The commonality here being – we did not necessarily use the term carer. This was intentional to expose a range of people to the research, people who might have relevant lived experience, even if they do not see themselves as a carer, just like Mrs Dodds. Similar methods have been documented in other projects using groups of participants where the participant identity is not clear-cut (Ibrahim & Sidani, 2014).

Apart from this approach seemingly being suitable to identify the range of people we were interested in working with, we also feel that ethically it is the right thing to do. As researchers, our perspective was that we did not want to engage with this group and, as part of the course of the research, enforce the label of carer upon them without them necessarily going through the personal journey of self-identification as a carer themselves. For this reason, we let the carer lead the use of language – if they described themselves as a carer, then we did too, if they were grainier on the terminology they used to describe themselves and their role, then we were too. This way, we felt we were not unduly accelerating or changing the course of the carer’s identity journey as part of the research. This approach is informed by insights from social theorists like Brewer (1991), who have identified that identities will be rejected (people disengage with services or research) if the identities available or imposed upon them are too restrictive.

## **When Do PPIE Members Become Professionals in Their Contributions?**

Some carers, just like patients and other public contributors, are well-versed in contributing to PPIE. This is recognised within the literature, as PPIE contributors can become professionalised in their role (Ives et al., 2013). Ives et al. (2013) summarised that ‘*the value of PPI[E] lies in the capacity of the agent to be an “outsider” who can reflect and comment, with relative objectivity, on the research process*’ and in such a way that it is informed by the person’s lived experience of the research topic. For our research, we wanted to avoid research weariness and to engage with a range of carers, including those who were more research naïve

to try and ensure that the PPIE was meaningful, to capture the lived experience, and to avoid carers who already had significant research experience contributing in a biased way based on what they expected the researchers to want rather than authentically. Those who choose to use a similar approach to us may find themselves having to ignore traditional approaches and organisations (which may seem counterintuitive) to get to carers who have not been so heavily involved in research in the past.

When planning our research and writing our funding application we identified, through an advert on VOICE-global.org.uk (a PPIE and research support to engaging with members of the public), a carer with a strong sense of identity in their role but with significant previous research experience as both a participant and as a co-applicant, and most notably with connections and relationships with local and national organisations, groups and panels. We took this approach as someone with more certainty in their carer role, and with connections to wider groups and organisations, was what we needed during the planning and running of the research (the involvement). This then allowed us to consider how we could identify carers who don't necessarily see themselves as such for the participation and engagement stages.

On reflection, this seems logical, but for a team of researchers who had never specifically worked with carers in the past, this was more like trial and error, but with a focus on situating authentic PPIE as central to the research project. To adapt an example from the health world where the lead author works as a pharmacist – students are taught to always consider the administration of medicines in terms of: *'the right patient, the right drug, the right time, the right dose, and the right route'* (Grissinger, 2010), is this not the same as considering PPIE in terms of the right person, the relevant lived experience, the right time and the right nature of contribution for the right purpose?

## Trying to Be Authentic with Carers

Local and national carer charities and support groups can be a useful starting point but as highlighted previously these will likely only identify people who already identify with the term carer. Awareness of this and the possible bias this brings is needed and we would suggest using a range of approaches from those discussed here, unless your research calls for working with a particular type of carer that is identifiable from only one or two methods. Additional, and more innovative, options could be engaging with other non-carer community and religious groups – any place or group that brings people together where that group could include a carer. It is possible that gatekeepers to communities might be needed to facilitate this, but where this approach is utilised, careful consideration is needed in working with a gatekeeper with who understands the nuances we have reflected on in this chapter regarding the labelling of carers and the varied nature of carers' previous involvement with research.

Other methods we have utilised include more general social media promotion and snowball techniques, and as discussed previously, a careful consideration of language and messaging about what the research is, involves and who it

relates to. In this case, a move away from referring to people as carers and instead focussing on the relevant experiences rather than the label. We have also worked with carers to identify their roles and responsibilities, which we have taken to an artist to make into a visual representation of what it means to be a carer. This artwork approach could be used to ask people who identify with an emotion, role, or visual image to take part, leaving the need to use the actual word ‘carer’ redundant (Fig. 16.1).

### Reflections From a Carer by David Black

I never sought to be a carer. One minute I was getting on with life, the next I was in the world of the carer through looking after my mum. My journey to identifying as a carer started when our GP suggested I apply for Lasting Power of Attorney for my mum. Acting as a carer I started to see at appointments, hospitals, care facilities, and interactions with public bodies the futility of doing what I had always done. Having worked in legal services and healthcare previously I thought that I understood the challenges, but I only really knew part of the story until it became my reality. Starting to navigate systems as a carer brought many new challenges and it changed my outlook on life.



Fig. 16.1. What Does It Mean to Be a Carer? Source: Co-produced with Carers. Cartoons Are Created by Sian McArthur from More Than Minutes, Published with Permission.

I am now a positive disruptor, an advocate for seldom heard voices and most importantly I discovered the role of public involvement in research. Through my research journey as a carer, I have experienced personal growth, fulfilment, and have developed a better understanding of my self-awareness as well as a self-acceptance in my approach to life. My contributions to research are wide ranging and are the most rewarding roles I have ever undertaken. No two research opportunities are alike, and I learn something new with each interaction with the research community. My involvement in research started by commenting on lay summaries, patient information sheets and research proposals at research support groups. It led me into getting involved as a co-applicant on individual research studies and helping to write the patient/public sections of applications. The most satisfying part of my work is being a co-author on several research papers.

A few years ago, I became an informal carer once again to multiple people in my local area. Whilst other people were caring for my mum in a local care home, I was involved in helping others around me. Identifying that in helping others you are a carer is not always apparent; it is more obvious when you have been a carer before. People can help others without really considering being a carer and this creates difficulties when researchers are trying to identify and engage with carers.

In reaching out to carer's it is important that researchers understand that caring activities are wide ranging, can take up a lot of time and are often unpredictable. Flexibility when designing the structure of a research project involving engagement with carers is an important consideration. As a carer the best experiences in engaging with researchers are those with built in flexibility around the needs of the carer. One way to try and focus comments from a carer is to have a clear and concise aim and question for their involvement. It may be necessary to steer the conversations with a carer to keep comments relevant to the research and it is the responsibility of the researcher to focus in on the carer's specific experiences relevant to the research question.

## **Conclusion**

Carers are a heterogenous group and as such flexibility and individualism are needed when engaging with them. Three considerations that appear more unique to carers that were raised as part of our research were as follows. Firstly, carers may need financial support to ensure a continuity of care for the care recipient while the carer contributes to the research, which is in addition to any remuneration. Secondly, carers may need flexibility in the timing and volume of input relative

to their caring responsibilities, which can fluctuate and flexibility in the nature of contribution, for example, in person, online, or asynchronously. Thirdly, carers themselves may have health and well-being concerns and may require adjustments in the same way other participants might. Creating a dialogue with carers and getting to know them as individuals can help to establish the need for adjustments to the PPIE to best allow carers to engage, in the same way as we would do for other participant groups.

There is an increasing interest in research focussed on carers, and as such, more research teams will be engaging and working with carers, which can be rewarding and insightful, but requires thoughtfulness to build meaningful relationships. It is important that research teams consider the nuances of the caring role and work towards sharing best practice that involves carers in a way that is of value to them, as well as to the research team, does not label them as something they do not identify with, and that carers are involved throughout the lifecycle of research.

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