

# **'It's a tough decision': A qualitative study of proxy decision-making for research involving adults who lack capacity to consent in England and Wales**

Victoria Shepherd<sup>1,2</sup>, Kerenza Hood<sup>2</sup>, Mark Sheehan<sup>3</sup>, Richard Griffith<sup>4</sup>, Fiona Wood<sup>1</sup>

<sup>1</sup> Division of Population Medicine, Cardiff University, 5th floor, Neuadd Meirionnydd, Heath Park, Cardiff CF14 4YS UK

<sup>2</sup> Centre for Trials Research, Cardiff University, 7th floor, Neuadd Meirionnydd, Heath Park, Cardiff CF14 4YS UK

<sup>3</sup> Ethox Centre, University of Oxford, Big Data Institute, Li Ka Shing Centre for Health Information and Discovery, Old Road Campus, Oxford OX3 7LF UK

<sup>4</sup> College of Human and Health Sciences, Swansea University, Singleton Park Swansea SA2 8PP UK

## **Corresponding author:**

Victoria Shepherd

ShepherdVL1@cardiff.ac.uk

Division of Population Medicine, Cardiff University, 5th floor, Neuadd Meirionnydd, Heath Park, Cardiff CF14 4YS UK

+44 2920687641

## Abstract

**Background:** Research into dementia and other conditions connected with cognitive impairments is essential but conducting research with populations who lack capacity to provide consent involves a number of ethical, legal and practical challenges. In England and Wales, family members can act as a consultee or legal representative on behalf of someone who lacks capacity. However, there is a paucity of research about how family members make decisions concerning research participation.

**Objective:** To explore family members' experiences of proxy decision-making for research. Understanding how proxy decisions are made could lead to interventions to support greater inclusion of individuals in research who have impaired decision-making capacity.

**Methods:** Semi-structured interviews were conducted with a purposive sample of 17 family members who had experience as a proxy for making decisions about participation in research, including those who had agreed to participation and those who declined. Thematic analysis was used to examine experiences and generate findings for research practice and to develop future supportive interventions.

**Results:** Proxy decision-making is highly contextualised. Proxies balance a number of factors when deciding about research participation, including the person's values and preferences, within the specific context of the study, and the practicalities of being involved. Proxies use these factors to construct a decision that is authentic to the person they care for.

**Conclusions:** Proxy decision-making for research is a complex process with inter-woven layers of decision-making. Decisions can be problematic for some proxies who may benefit from decision support to make an informed decision about research participation on behalf of a family member.

## Introduction

Around 2 million people in the UK are thought to have significantly impaired decision-making abilities [1]. Cognitive impairment may be associated with neurodegenerative conditions such as dementia, follow acute events such as stroke, or develop towards the very end of life. With an ageing population, and an associated rise in conditions characterised by cognitive impairment, this number is expected to increase [2]. Mental capacity is considered one of the greatest ethical and legal dilemmas surrounding the care of people with dementia [3], and research involving those who lack capacity to provide informed consent is especially fraught with ethical and practical challenges [4]. Ethical practices which enable the inclusion of people with impaired capacity in research are essential for developing the best evidence-based practice care in conditions such as dementia [5].

Research governance requires special safeguards be in place to ensure that those considered 'vulnerable' are protected when they do participate in medical research [6]. For those who lack capacity to consent to research, their participation must be agreed by someone who is independent of the study in accordance with applicable legislation and guidance [6]. This may involve family members acting as a surrogate or proxy decision-maker on the person's behalf [4,6]. The legal frameworks in England and Wales permit a family member or friend to act as a research proxy without them having been nominated or legally authorised by the person while they have capacity [7,8]. Decisions about participating in research, which is intended to generate new knowledge, are different to those about medical treatment or care where the aim is to make a decision that will most benefit the person themselves. The UK law requires the family member acting as a 'legal representative' [7] or 'consultee' [8] to provide consent [7] or advice to the researchers [8] based on what the person lacking capacity would have wanted, had they the capacity to choose for themselves. However, in many cases the person's explicit wishes are not known to proxies [9] and few have previously discussed their preferences for research participation [10].

Previous studies identified that, whilst families were supportive of being involved in proxy decisions about research [11] it can be a difficult task [12]. Family members carry the responsibility for making a decision with potentially far-reaching consequences for the health and welfare of another person. Reportedly, nearly all proxies experience some degree of burden in making decisions regarding research [12]. However a systematic review we conducted found that much of the existing research involves hypothetical scenarios and has been conducted in North America [13], meaning little is known about how families actually negotiate these complex proxy decisions in practice, or under differing legal frameworks. Another recent systematic review which examined how ethical challenges, including proxy consent, are operationalised in research with people who have dementia also found that there is a current paucity of evidence, and concluded that this is a key area for future research [14].

The DECISION Study aimed to explore the experiences of family members of individuals who lack capacity and who have been approached to participate in a research study. The objective was to gain an understanding of how proxy decisions about research participation are made in practice in order to develop and tailor future supportive interventions.

## Methods

### Design

Semi-structured interviews were conducted with family members who had acted as a decision maker about research participation for a person who lacks capacity. The qualitative data were analysed using thematic analysis to identify and report patterns or themes within the data. Ethical approval for the study was provided by the School of Medicine Research Ethics Committee, Cardiff University (SMREC Reference Number 17/54).

### Sampling and recruitment

Research networks, community groups, and research registries such as Join Dementia Research [15] disseminated information about the study to their members, who then contacted the research team if they were eligible and interested in participating. Purposive sampling techniques were used to obtain a maximum variation sample. Participants included those who had experienced decision-making in different circumstances (e.g following a progressive loss of capacity or a sudden loss of capacity), relationships (e.g spouse, adult child), types of study, and decision outcomes (agreed or declined participation on behalf of the person). We anticipated that approximately 20 interviews would be required to meet the study's aims, however defining sample sizes *a priori* in qualitative research is not straight forward [16].

### Data collection

Following written informed consent, interviews were conducted either face-to-face at the participant's home or another place of their choice, or by telephone. Interviews were conducted by one researcher (VS) with a nursing background and experience in conducting research with adults who lack capacity. A topic guide was developed by three researchers (VS, FW, KH) which was informed by the relevant literature, findings from a recent systematic review [13], and in conjunction with a lay advisory panel. The lay panel supporting the project consisted of four members of the public with a range of experience of caring for family members with impaired capacity. They advised on the acceptability and clarity of the interview questions. The topic guide was further iteratively refined during the data collection period. Interviews were digitally audio-recorded and transcribed verbatim. The transcripts were checked for accuracy and completeness against the source data and anonymised.

### Data analysis

Data were thematically analysed using Braun and Clarke's approach involving familiarisation with the data and developing, analysing and reporting themes [17]. Data generation and analysis were undertaken concurrently to facilitate iterative coding and generation of themes, and exploration of candidate themes during subsequent interviews [18]. The first 11 interview transcripts were initially coded by one researcher (VS) and reviewed independently by the rest of the research team to review and establish the validity of the coding framework, prior to complete coding of the remaining data [18]. Qualitative Data Analysis software (NVivo 11, QRS International) was used to assist with data management. Developments in the analytical process were recorded through field notes, reflective discussions, and data analysis memos held in NVivo [19]. Adequate information power [20] was assessed as being reached following complete coding of 17 interviews with no new themes being identified.

## Results

### Participants

Interviews were conducted with 17 family members who had acted as a research proxy (either a consultee or legal representative) for a relative with impaired capacity. Participants were predominantly female (n=13, 76%), and were either an adult son or daughter (n=12, 70%), daughter-in-law (n=1), or spouse (n=3, 18%) of the person they represented, and one person was both a daughter and spouse.

Participants were family members of a person with dementia (n=16) or who had cognitive impairment following a stroke (n=1). Interviews were either conducted at the participant's home (n=8, 47%), other location (n=4, 24%) or by telephone (n=5, 29%). Interview duration was between 19-90 mins (mean 44 minutes).

Key themes were identified which captured the way proxies made decisions, viewed their authority as decision-maker, and experienced the challenges of making proxy decisions about research.

### Theme: taking all things into consideration

#### A balancing act

Proxies balanced a range of different factors to construct a decision, which included whether there were any advantages or benefits for their family member, balanced against any potential risks or harms. If the expected benefits outweighed any potential adverse effects then the proxy would agree to participation, or if there were no direct benefit then most proxies would agree to participation provided there was no detrimental effect. Benefits and harms were viewed as relational, where both the person and their proxy would be affected as part of their intertwined caring relationship, where they would either mutually benefit or both experience the negative impacts. Participating in research was viewed as a joint enterprise for both the patient and the proxy, however proxies primarily sought to promote the interests of the person they care for whilst protecting them from harm.

*"If I thought that there was something that was going to improve her, her wellbeing tremendously, then I'd jump at it but I have to look at the risks of even a little bit that she's less than what she is now. That's ... that is not going to be good for her, for her and us, you know, ultimately, it's not going to be good for us" [06, adult daughter]*

#### Weighing advantages and disadvantages of participation

The range of benefits or advantages considered by proxies went beyond those that might arise from the intervention or medication under investigation, or any additional monitoring and access to specialist expertise that may form part of the research activity. Benefits identified as important included social engagement with others, such as the opportunity for the person to meet and talk to new people.

*"Being able to talk to people, having different people to talk to.....lifts her mood you know..... and that's why I like to keep going to as many things as I can, and why I take part in as much research as we can" [12, male spouse]*

The value of participating in research was seen as something more than just a route to getting better care or treatment, but as something enriching - an opportunity to make a positive contribution and to 'do some good' or having an opportunity to 'tell their story', knowing that they were helping others and contributing to society.

*"If it helps her, great. If it helps other people probably even better because there'd be more than one person helped" [08, adult daughter]*

Potential harms that proxies were concerned about were related to any distress or upset caused to the person they cared for. The risk was weighed up against the benefits of participating by proxies.

*"He won't understand what you're saying. Well we could say you're having a scan and when you get there, he would get quite agitated, and it isn't worth it for dad" [10, adult daughter]*

Precarity and maintaining the status quo

Proxies saw their primary role as being to maintain the best quality of life for their family member for as long as possible, whilst doing what they could to make their life better. The person with cognitive impairment was viewed as being in a precarious situation, where they could not afford to be any worse off than they already are. Many proxies also provided direct care for the person they represented, but these care arrangements were seen as fragile where any deterioration in the persons' health could mean that the proxy would no longer be able to meet their care needs. This meant that proxies were reluctant to risk any complications that would jeopardise the status quo.

*"So it's tough because ... I mean she's quite happy over there at the minute. And we are on a ... you know ... we're okay. Don't get me wrong. There are still issues but we manage and we muddle along okay" [06, adult daughter]*

## Theme: knowing the big and the little things

Familiarity and similarity

Where proxies had not had explicit discussions with the person they cared for about their preferences for research participation, they were still comfortable making a decision as they used other things that they did know about the person to guide them. The closeness of their relationship may mean they have shared core values or held similar views about things, which helped the proxy to know what the person would have decided or would want.

*"I mean, I think of what my mum might have wanted when she was ... you know, what decisions she would have made prior to this disease taking over. My mum and I have always had a really very close relationship. You know we've always been close.... so I think pretty much we see things very similar" [06, adult daughter]*

Proxies sometimes discussed the issue with other family members, but more often just informed them if the person was going to be participating. For some proxies, once they had made a decision that the person would participate in research, they would involve the person themselves to check it was 'OK' as a form of assent rather than seeking any informed or active involvement in the decision itself. However, if the person they cared for strongly dissented then the proxy would respect it. Proxies felt that they knew the person well, and so knew the signs of dissent, even if they were not verbally expressed.

*"...it would depend how she said it, I think, because I know her, if there was enough feeling in it, no I wouldn't want to do that, no, then I'd be like well you know, she doesn't want to do that, it's just judging her at that, at that time" [16, adult daughter]*

#### Temporality of relationships

Proxies spoke about knowing the person through seeing them day in and day out; they were sensitive to how they reacted to situations where they may be unable to express their views or feelings. They also knew biographical aspects of the person's life such as their previous jobs and life-long interests, and what characteristics of the person were relevant to the particular decision context.

*"Say the possibility was that she would want to feel, that she would want to be sick a lot of the time. She [always] hated that feeling of being sick. I would most probably not let her be in any research that would have that.... knowing how mum hated feeling sick I would say no, don't do it whatever you know [laughter].... Knowing the person, you have to know the person don't you and silly little things like that you know" [04, adult daughter]*

Proxies also recognised that preferences may change over time, and that those who are no longer able to express their views should not necessarily be held to those prior preferences. Several proxies used examples from other types of decisions made for the person, such as food choices or financial investments, to show how they balanced the person's long-standing preferences against their current wishes, which were often perceived as intuitive or 'in the moment' rather than considered, and what the proxy themselves might consider to be the best option using their wider knowledge of the factors involved. Proxies also felt well placed to know whether they could comply with the practicalities of the research, such as undergoing an MRI scan.

#### Being good people

Proxies recognised that research is intended to benefit others in the future, which could include younger generations of their own family. Some proxies described how their closeness to the person they represented also included knowing their core or moral values. Proxies considered whether the person themselves would wish to help others or had altruistic character traits, described as being 'good people... in the depths of their real being' [14, adult daughter]. Proxies used examples of the person's previous willingness to help in other ways as indications of their altruistic nature, such as donating blood, volunteering, or registering as an organ donor.

*"He's quite altruistic, so I think he probably would help people if he could. I don't think he'd worry about it for himself, he wouldn't say "Oh I'll benefit from this"" [14, female spouse]*

### Theme: being trusted to do the right thing

#### Relationships, trust, and reciprocity

The proxies considered themselves to be trusted to make decisions in many areas of the person's life. The proxies reported that, because the person trusted them, they would also trust the decisions they made on their behalf.

*"Because she really trusted me bless her.....and then I wouldn't have made a bad decision for her. If I thought it was a bad decision, if I had any doubt whatsoever, or anything, then I wouldn't have done it" [02, daughter-in-law]*

Proxies described the reciprocal nature of trust within their relationships with those they represented. The caring roles may previously have been reversed, either as their parent or at times of illness during their marriage.

*“You have to have the trust don’t you, to make a decision for somebody, you, they have to trust you and you have to trust them, they know you’re doing the right thing for them” [02, daughter-in-law]*

However, not all family members were trusted equally by the person, with proxies describing how some relatives were considered unreliable or unlikely to faithfully represent the person’s wishes. One family member was usually considered to have the closest relationship with the person. Proxies universally reported that they were the one family member with the closest relationship and were the one most trusted by the person to make decisions on their behalf.

Making right and wrong decisions

Some proxies described knowing what to decide as a dilemma, as they were unsure what the ‘right’ decision was – which was usually linked to the decision outcome. They expressed concern about making a ‘wrong’ decision which they would later regret, which made it difficult to make a decision at times.

*“I thought well perhaps, I don’t know, have I done the right thing. It’s very, very difficult” [03, adult daughter]*

However, in comparison to other decisions that proxies had been involved in, or were responsible for, decisions about research were not the most problematic that some proxies had faced.

*“I mean I’m currently making a decision about whether to have him put in a home and I’d say that’s in the nine, ten level ..... but the decision about that particular bit of research was a three” [13, adult son]*

Comfort appeared to be increased when there was expected to be no negative impact on the person, when they felt supported by the researchers throughout the decision-making process without feeling pressured to agree to participation, or if the proxy knew the person’s views about research or that they had participated prior to losing capacity.

*“.....and that’s the way my mother has always thought, felt. Yeah, so it was easy, didn’t worry us at all” [11, adult daughter]*

**Theme: the need for support for proxy decision-makers**

Whilst some proxies reported that making a decision about research was straightforward which didn’t require great deliberation, others described it as a difficult and challenging decision.

*“It’s a tough ... it’s, it’s not an easy [clicks fingers] decision” [06, adult daughter]*

Improving the decision-making process was recognised as being much more than just ensuring the proxy had received adequate information. Proxies thought that greater decision support when considering research decisions would help in the future. This included orientating them towards considering the person’s own views and preferences.

*“Actually trying to write it in very simple English and saying if you’re making a decision for your loved one what [you] would be thinking about is what would they like to do ..... and prompting people so it helps them think actually it isn’t about me it’s about them and what they’d like” [08, adult daughter]*



Proxies suggested that this support could take the form of a different sort of information sheet which covered their role as proxy decision-maker, or other sources of advice and guidance. Some proxies reported that simply having an opportunity to discuss what they thought the person's views and wishes would be and reflect on whether they were making decision based on the person's preferences or their own, could have an impact on improving understanding about their role as proxy.

*"I looked at it, you know, whether mum should, I just thought, just said, no, you know, it was an instant thing, it wasn't really then, until after speaking to you, I actually thought about it and I was thinking well was that the right thing to do? I don't, you know, and it just starts you thinking about it doesn't it?" [16, adult daughter]*

## Discussion

Proxy decisions about research are complex and highly contextualised. Proxies were guided by their responsibilities and obligations to do what they thought was best for the person they cared for and viewed decisions about research as part of their wider caring responsibility. Proxies made a decision using what they thought the person would have decided through a 'constructed judgement' [21], whilst balancing the relational harms and benefits of participating, in order to make a decision that was in line with what they thought the proxy would want them to do. Thus, seeking a decision that was authentic to the person they represented, rather than attempting to accurately predict their preferences. The relational and constructivist nature of proxy decision-making identified in this study is supported by previous research which describes how choosing family members to act as a proxy is not solely based on their ability to predict the person's wishes [22]. A family member acts as proxy because strong family feelings of love, trust, and responsibility towards one another brings relational obligations and responsibilities, and with these comes some discretion about how these are fulfilled [23].

A recent Australian study explored how health proxies make decisions about treatment on behalf of a person living with dementia [24]. The DECISION Study adds to this evidence base by showing that research proxies also use the person's expressed wishes where available and, where these were not known, their in-depth knowledge of the person's values and preferences facilitated decision-making on their behalf. Another theme identified in both studies was proxies 'striking a balance' between respecting the wishes of the person and looking after their interests [24]. As reported by proxies in our study, the difficult balance between honouring the person's wishes and protecting their interests is more complex in practice than the rigid framework of proxy decision-making described in the bioethics literature [25].

Proxies' reasons for agreeing to participation in research on the person's behalf in our study closely matched self-reported reasons in a study of patients approached to participate in clinical trials [26]. The findings were also consistent with a previous study that explored how proxies made decisions about treatment and care (as opposed to research) which found that, while surrogates considered many factors, they focused more often on the person's well-being than simply on their preferences [27]. Similarly, both the previous research about treatment decisions and our study about research decisions found that prior conversations with the person about their preferences was not a significant factor in whether proxies prioritised well-being or preferences [27].

A previous study which explored experiences of proxy decision-making for treatment and care decisions also found that it can be difficult, and the uncertainty of decision-making can take its toll on proxies [28]. The participants in our study also identified the 'tough job' of being a proxy, which often involved acting as an advocate for the person, and sometimes there was a burden associated with decision-making, particularly when combined with day-to-day care for the person. There have been calls for future research to be directed towards understanding the difficulties people actually experience when serving in the proxy role by approaching the question of how surrogates contribute to the care of their loved ones in terms of the complexity and 'muddiness' observed in practice [29]. Our study has explored how decision-making for those with impaired capacity is contextualised within the wider care and decision-making paradigm and identified the need for decision-making support for those who experience difficulty when facing a decision about research participation on behalf of someone who lacks capacity to consent. This may take the form of a decision aid or tool (DA). DAs are known to be effective in supporting health-related decisions and are increasingly being used to support decisions about research participation [30] and by family members making difficult proxy decisions.

### **Strengths and limitations**

This study has explored research proxy decision-making in a variety of real-life situations with a range of family members who had acted as proxies, thereby providing rich first-hand accounts. This has enabled an understanding of proxy decision-making from the perspective of family carers for the first time in the UK. Limitations include the selection of proxies who all agreed to participate in the study and therefore necessarily have a positive attitude towards research generally. We attempted to include proxies for those who have had a lifelong impaired decision-making ability in order to incorporate a wider range of experiences but were not able to recruit these individuals. However, we did include those who had made decisions for the person to participate as well as those who declined, and a range of study types including clinical trials of medicines which have different legal provisions from other types of research [4].

### **Conclusions**

Proxy decision-making for research is a complex process with inter-woven layers of decision-making. Family members acting as proxies balance a number of different factors related to the person they care for and their values, preferences and interests, within the specific decision context of the potential harms and benefits of the study, and the practicalities of being involved. They use the person's biographical narrative alongside the information about the specific study in question as building blocks to construct a decision that is authentic to the person and their life, and one that they think will lead to the best outcome for the person and, at times, for themselves as the person's carer. However, decisions can be problematic for some proxies who are concerned about making the 'right' decision, and some proxies may benefit from decision support in order to make an informed decision about research participation. Ethical research which enables the appropriate participation of people with impaired capacity is essential in order to develop the evidence-base for conditions such as dementia.

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## Competing interests

None declared.

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