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# Removing the 'gag': involving people with dementia in research as advisers and participants

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## Abstract

People with dementia are often excluded from taking part in research because of perceived difficulties in consent, capacity and communication. We argue that involving people with dementia in research is important, and describe how we involved people with dementia as both advisers and participants in research about the use of life story work.

Researchers worked in partnership with Innovations in Dementia, who supported a network of advisers with dementia. Focus groups were arranged to ensure meaningful contributions by people with dementia. It was difficult to use standardised quality-of-life measures, and we describe the challenges faced with capacity and consent, recruitment and selection, and data collection.

We suggest there is a need for (a) new tools for measuring quality of life of people with dementia which do not require participants to respond in prescribed ways, and (b) ethics and consent processes which are appropriate for non-medical research and which facilitate the involvement of people with dementia.

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## Introduction

In the past, people with dementia have often been excluded from shaping and taking part in research, either because they were considered to be incapable of verbally communicating their thoughts and feelings, or because those thoughts and feelings were considered to be of questionable validity (Hubbard et al, 2003). Instead, carers were asked to rate people's quality of life using proxy measures (for example the Alzheimer Disease Related Quality of Life measure, Rabins et al, 1999), which collected information **about** people with dementia, rather than **from** them.

However, research has demonstrated that there are often discrepancies between carers' views on what is important for people with dementia, and what people with dementia themselves consider to be important (see for example Dröes et al, 2006). Moreover, care-giver ratings of quality of life consistently under-estimate people with

dementia's own perceptions of their quality of life (Logsdon et al, 2002; Moyle et al, 2012). Indeed, Trigg et al (2011) suggested that self-reported and proxy assessments of quality of life of people with dementia may measure two very different things. This means that proxy measures are not necessarily an appropriate or accurate way of incorporating the perspectives of people with dementia into research. (For further discussion about quality-of-life measures for people with dementia see Ready and Ott (2003), and for a review of the challenges of using proxy measures see Rand and Caiels (2015)).

Since Kitwood (1997a, 1997b), the view that people with dementia do not have an internal reality worthy of attention has been strongly challenged. However, the assumption that they may not be able to communicate that reality in a meaningful way has lingered. Moreover, the ethics processes around research are complex and can be time consuming, and this may discourage researchers from involving people with dementia. If people with dementia are included in research, their participation is usually limited to those in the early stages of dementia who are able to give informed consent to join the research project themselves. However, the experiences of people with early and later-stage dementia differ greatly.

In this paper, we describe how our research team worked in partnership with Innovations in Dementia<sup>1</sup> to ensure people with dementia were involved in meaningful ways, both as advisers shaping the project, and as participants. The research referred to in this paper was a three-year study, funded by the National Institute for Health Research (NIHR), which explored the use of life story work in dementia care. The full report of the study is available (Gridley et al, 2016).

## Life story work

Life story work involves both **recording** aspects of a person's past life, present interests, and future plans and wishes, and **using** that information to improve their care or for their pleasure. It can involve elements of reminiscence (Woods et al, 2005) and life review (Morgan and Woods, 2010), but both reminiscence and life review focus on the past, whereas life story work seeks to include aspects of current preferences and future wishes and plans. Also, unlike reminiscence and life review, the aim of life story work is to create a tangible product, such as a life story book or box which could be shared with others.

Life story work has been used in health and social care for three decades, with children (Ryan and Walker, 1985), people with learning disabilities (Hewitt, 2000) and older people (Clarke et al, 2003). There has been a growing interest in its potential to improve care for people with dementia (Gibson, 1991; Murphy, 1994).

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<sup>1</sup> Innovations in Dementia is a Community Interest Company that works collaboratively with people with dementia, and on projects to enhance the lives of people living with dementia and showcase living well with dementia. It also facilitates the Dementia Engagement and Empowerment Project (DEEP).

However, at the start of this project, there was limited research evidence on the outcomes or costs of doing life story work with people with dementia (Russell and Timmons, 2009; McKeown et al, 2010).

## The study

The purpose of the research was to carry out the development and initial feasibility stages of an evaluation of life story work for people with dementia. The research was carried out between July 2012 and March 2015.

People with dementia were involved in several stages of the project:

Stage	Involvement of people with dementia	
	As advisers	As participants
Systematic review of the existing literature to produce a narrative synthesis of good practice and theories of change	Gave views and talked about experiences of life story work which informed the search and data extraction	n/a
Qualitative focus groups with people with dementia, family carers and professionals who use life story work	Advised on ethical issues involved in running focus groups with people with dementia  Advised on the development of information sheets and consent forms  Validated focus group findings	25 people with dementia (and others) took part in focus groups to explore good practice
Feasibility study to test data-gathering processes and instruments	Advised on the development of information sheets and consent forms	39 people with dementia took part by completing quality-of-life measures at several time points  10 people gave qualitative feedback about their life story books

Findings from the research are reported elsewhere (Gridley et al., 2016). This paper considers the involvement of people with dementia both in an advisory capacity, and as participants in the qualitative study and the feasibility study.

## Involving people with dementia in research

Involving people in research that is about them has become an important principle in health research. Guidance from INVOLVE, an advisory group funded by NIHR that supports active public involvement in health and social care research, advises that:

*'It is a core democratic principle that people who are affected by research have a right to have a say in what and how publicly-funded research is undertaken. Public involvement is an intrinsic part of citizenship, public*

*accountability and transparency. In addition, public involvement in research can lead to empowering people who use health and social care services, providing a route to influencing change and improvement in issues which concern people most'*

INVOLVE (2012, p8)

Public involvement in research can both improve the research and also lead to empowerment of those involved. This is particularly important for groups which have traditionally lacked power and voice, such as people with dementia. Assuming that people with dementia cannot contribute to research perpetuates negative stereotypes of incapability (Wilkinson, 2002). There is also a risk that, by not including the voices of people with lived experience, we may lack understanding and, therefore, fail to deliver adequate care (Cohen, 1991).

However, traditional user involvement is done in such a way that it can exclude people with dementia. Service-user involvement in research design and delivery is often in the form of an advisory group. This can exclude people with dementia from taking part, as they may be unwilling or unable to travel; may have decreased confidence; or need support to take part in formal meetings. Because of the nature of dementia as a deteriorating condition, there can be problems with the same people continuing to be involved over a longer-term project.

Ethics procedures designed to ensure that participants are treated well and are not exploited may exacerbate the exclusion of people with dementia from research. For example, the process of gaining consent may cause confusion, and there can be anxiety about 'official' forms (see for example Dewing, 2008).

We were concerned that traditional research processes could effectively 'gag' people with dementia and prevent their voices from being heard. We therefore began our study with the underlying conviction that people at all stages of dementia have a key part to play in research into services or interventions which are designed to help them (Downs, 1997). We had three motives:

- To actively work to include as many people with dementia in our research as possible
- To take a broader, more flexible attitude towards consent, including exploring the concept of assent and the use of consultees
- To use a wide range of ways of engaging with people with dementia throughout the research

We tried to work creatively to ensure that people with dementia could contribute to the research in positive and meaningful ways suited to their abilities; were able to understand, consent and assent to take part in research activities; and were able to withdraw from research activities when they wanted to.

## Involving people with dementia as advisers

The project had traditional advisory and steering groups, consisting of representatives of partner organisations (steering group) and other organisations including specialist academics (advisory group). But, as outlined above, we considered that there were more appropriate ways of involving people with dementia in shaping the research (see Corner, 2002).

Innovations in Dementia recruited six advisers with dementia who contributed to the project through individual meetings with members of the Innovations in Dementia team. The research team produced easy-to-read documents at various stages explaining aspects of the research and asking questions. Innovations in Dementia staff then visited each adviser individually, collated their comments and fed back to the research team.

By meeting with people in their own homes, people with different abilities, needs and interests were supported to give advice to the project. Throughout the research, the research team produced feedback telling people how their comments had been used.

Using this format, our advisers with dementia were able to shape crucial aspects of the research:

- **Outcomes of life story work:** advisers told us what they would expect life story work to achieve, which gave us an idea of what to look for in our literature review
- **Ethical issues involved in doing focus groups:** we listened to advisers' comments about how they would feel about being involved in focus groups, and fed these into our research design and application for ethical approval from the Social Care Research Ethics Committee. For example, our advisers told us that it would be best for people with dementia to meet in a familiar place and with people they knew
- **Information sheets and consent forms:** advisers helped us make our information sheets and consent forms for people with dementia clear and easy to understand
- **Validating focus group findings:** the research team met with advisers to discuss and refine the findings from the first stage of the project
- **Style of film for dissemination:** advisers watched several short films and told us about their preferences, for example for real people rather than animations, and to avoid voiceovers. This informed the brief and will help us to choose a film-maker

The partnership between the research team and Innovations in Dementia to set up a network of advisers in this way ensured that people with dementia were able to contribute in a real and valuable way to this research. This also made for a better experience for those who took part in the research itself as participants, which we describe in the following two sections.

## Involving people with dementia in the qualitative research

We conducted focus groups with 25 people with dementia, 21 family carers and 27 professionals (a total of 73 people). The aim of these was to find out:

- The different ways life story work was done
- What people perceived as good practice in life story work
- Challenges faced

In order to make sure that people with dementia could contribute, we conducted the focus groups in an inclusive way (see Bamford and Bruce, 2002 for further discussion of the successes and challenges of involving people with dementia in focus groups). Following advice from our network of advisers and advisory group, we held informal meetings in small groups, at familiar venues where people felt safe and confident, and at times to suit group members. Where appropriate, there was extra support from friends, family or professionals. People were given easily accessible information sheets, and time to read these, and we explained the research in person too.

Researchers took examples of life story books, a memory box, and a tablet with photographs to the focus group sessions. Participants brought in memorabilia, and discussed memories and meanings, and their feelings and wishes about recording and sharing their stories. In general, the focus groups with people with dementia had fewer participants than those with carers and professionals in order to allow and encourage people to take part, especially those with communication impairments.

All these sessions were held in familiar settings such as their day centre, and known and trusted group facilitators were on hand. In the group sessions, we gave people the opportunity to ask questions, and reflected back opinions and statements to make sure people were happy that their views were understood.

These group sessions provided useful information about the way life story work is done and what people consider to be good practice, and also fed directly into the next stage of the research by influencing our decisions on which outcome measures to use (for more details see Gridley, 2016).

## Involving people with dementia in the quantitative research

We also involved people with dementia as participants in the feasibility-study phase of the research. Participants for this phase were in care homes or hospitals, and likely to be at a later stage of dementia than the advisers or participants in the qualitative work described above. There were, therefore, different considerations to facilitate their involvement.

This phase of the research had two strands: (1) a study in six care homes, using a stepped wedge<sup>2</sup> design (comparing quality of life and relationships before and after life story work was introduced); and (2) a pre-test, post-test design<sup>3</sup> in in-patient mental health assessment units across two hospital trusts (comparing outcomes in wards where life story work was done with those where it was not).

Participants with dementia were asked to take part at three time points (in hospitals) or four time points (in care homes) over six months. At each point, they were asked to complete three separate questionnaires to measure outcomes, discussed below.

The next sections outline the challenges at the assessing capacity to consent, selection of participants, and data collection stages of the feasibility study.

## **Capacity and consent**

The Mental Capacity Act (2005, Section 2(1)) states:

'For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.'

(Department of Health (DH), 2005)

Dementia is listed in the Code of Practice accompanying the Act as an example of 'an impairment or disturbance in the functioning of the mind or brain' that could affect their ability to make a decision (Department for Constitutional Affairs, 2007, p44). This may have been seen by some as sufficient justification for excluding all people with dementia from research on the grounds of lack of capacity. However, while such impairment is necessary for an assessment that a person lacks capacity under the Act, it is not sufficient. The act states that:

'a person is unable to make a decision for himself if he is unable -

- (a) to understand the information relevant to the decision
- (b) to retain that information
- (c) to use or weigh that information as part of the process of making the decision or
- (d) to communicate his decision (whether by talking, using sign language or any other means)'

(DH, 2005 section 3(1))

Even if a person has dementia, they may still be able to meet these conditions, especially as the Act requires that people be given 'all practical and appropriate

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<sup>2</sup> In a stepped wedge design, each setting receives the intervention (life story work training and implementation) at some point during the period of the study (ensuring equity), but roll out is staggered, rendering implementation across multiple sites more straightforward than attempting a simultaneous start (Brown and Lilford, 2006).

<sup>3</sup> In a pre-test post-test design, the sites receiving the intervention (in this case the hospital wards already doing life story work) are compared with a control group (a hospital ward not doing life story work).



support to help them make the decision for themselves' (Department for Constitutional Affairs, 2007, p45). Moreover, assessments of capacity are decision-specific. People with later-stage dementia may not have the capacity to understand all the details of a complex research project in order to give informed consent to become a long-term participant, but they may be capable of deciding to answer some straightforward questions that they know will be used for research purposes, and they may want the opportunity to do so.

Life story work is widely used with people in both the early and later stages of dementia, and therefore, we considered it important to measure outcomes for people at all stages of the disease.

There are already established mechanisms for including people in research who do not have the capacity to give informed consent through the use of consultees (DH, 2008). Consultees can come in two forms.

A 'personal consultee', usually a family member, is:

'someone who knows the person who lacks capacity in a personal capacity who is able to advise the researcher about the person who lacks capacity's wishes and feelings in relation to the project and whether they should join the research'

(DH, 2008, p3)

If such a person is not available, researchers must nominate another person, a 'nominated consultee', who may be a paid professional, providing they have no connection with the research project.

For people without capacity to give informed consent we took the combined approach of seeking the advice of a consultee about whether to include the person with dementia in the study as a whole, while also seeking the **assent** of the person with dementia to ask them questions for specific outcome measures at each time point. With advice from the consultee, we were thus able to include people without the capacity to consent in the project, enabling us to collect information from their care records and approach them for their assent to complete the outcome measures.

Assent in research with people with dementia:

*'includes an affirmative agreement to participate as expressed verbally (i.e. orally) or a non-verbal indication of willingness to cooperate with study procedures, both at the time of enrolment and over the course of the study'*

(Black et al, 2010)

At the start of the research, and at each time point we asked the person if they would like to answer a few questions for our research project (the outcome measures). They were free to say yes or no, or just answer a few of them. For a wider discussion of consent processes for involving people with dementia in research, including the idea of process consent, see Dewing, 2002, 2007; and McKeown et al, 2010.

## Recruitment and selection

Recruitment and selection were approached slightly differently in hospitals and care homes. In hospitals, diagnosis of dementia was recorded in medical records, but in care homes it was not always clear which residents had dementia.

Diagnosis rates for dementia were below 50% in England (DH, 2013) and diagnosis was not routinely recorded in care records in our care homes. We therefore relied instead on the judgement of the care home managers, who were asked to produce an anonymised list of all residents with dementia from which 10 in each care home were randomly selected to be approached (directly or through a consultee).

Contacting consultees was not always straightforward, as, for data protection reasons, initial contact had to be made by care home staff to ask if they would mind being contacted by a researcher. This was obviously not a priority for staff, and the research team had to remind staff several times before contact was made in many cases (staff 'gatekeeping': Hellstrom et al, 2007).

This proved to be a critical barrier to recruitment, as it transpired that the majority of people with dementia (43 out of 59) who were selected for the study did not have the capacity to give informed consent, and without agreement from the potential consultee for us to make contact with them we could not progress, effectively excluding the person with dementia from the study. Because of the indirect nature of first contact, we will never know the reasons for refusal or non-response from those who did not agree to a researcher making contact.

In each care home, we randomly selected ten residents to take part – a total of 59 were invited, and 39 eventually recruited. Out of the 16 people with dementia we approached who had capacity to consent for themselves, 14 chose to take part (87.5%) and two refused (12.5%). Of the 43 people without capacity, 25 consultees advised us to include their relatives (58%), seven were excluded on consultee advice (16%) and a further 11 (26%) were effectively excluded because potential consultees did not agree to the researchers contacting them in the first place. Clearly, the people with dementia who had capacity were more likely to give a positive response than consultees. However, further research would be required to ascertain whether this difference reflects true differences in the preferences of people with dementia at different stages of progression, or differences in the perspectives of consultees on the one hand and people with dementia on the other.

Recruitment was slightly different in hospitals – this was not a stable population so people were recruited on admission. Hospital recruitment remained open for six months, and our target was to recruit 60 new patients in total. However, there were only 50 new admissions across all sites during the recruitment period. Of these, 43 were eligible to take part, but none were assessed to have capacity and only 27 consultees were approached by staff. We finally recruited a total of just 12 people with dementia across all hospital sites (44% of those approached, 28% of all those eligible). Here, the combination of staff gatekeeping and consultees advising against inclusion made recruitment doubly difficult.

## Data collection

We used three standardised measures to collect data about the quality of life of people with dementia and their relationships with their family carers. To measure quality of life we used two tools designed specifically for use with people with dementia: DEMQOL (Smith et al, 2007) and the Quality of Life in Dementia – Alzheimer's Disease measure (QOL-AD) (Logsdon et al, 2002). We also used The Scale for the Quality of the Current Relationship (Spruyette et al, 2002) to measure the quality of relationships between people with dementia and their carers.

Both QOL-AD and DEMQOL have been shown to be reliable and valid measures of quality of life for people with mild to moderate dementia (Bowling et al, 2015) but there is less evidence of successful use for people with severe dementia. Both consist of a series of questions with a choice of four answers for each question. The Scale for the Quality of Current Relationship consists of 14 statements with answers given on an agree/disagree scale.

In care homes, people with dementia found QOL-AD the easiest of the three sets of questions to answer, and 64% (24/39) of people were able to complete this at baseline (in a face-to-face interview). This was substantially more than were able to give informed consent themselves (36%, 14/39), demonstrating the importance of including people who do not have capacity to give informed consent in research. DEMQOL fared slightly less well, with 31% (12/39) of participants able to complete this at baseline. However, we used a visual aid for QOL-AD (each question printed in large print on coloured paper, with the answer options underneath). It was also the shortest, and often delivered first, which may have influenced the successful response rate. We alternated the order of the measures at the final follow up but this did not appear to influence response rates.

In hospital wards, where participants had more severe dementia, none were able to give consent to take part themselves, and four out of the 12 consultees did not give permission for us to approach their family member directly. Of the eight participants we did approach, at baseline only two were able to complete QOL-AD and one to DEMQOL.

The Scale for the Quality of the Current Relationship was the least successful measure in this study. It consists of a series of statements to be read out by the researcher, and an agree/disagree scale ranging from 'strongly agree' to 'strongly disagree'<sup>4</sup>. Agree/disagree scales are cognitively difficult for anyone as they mix attitudes (whether you agree or disagree with a statement) with strength of feeling (how much you agree or disagree) (Fowler, 1995). The subject matter compounded difficulties, as the questions ask how well the person gets on with their family carer. Asking participants to clarify a response by saying to what degree they 'agreed' or 'disagreed' was inevitably confusing. However, many participants understood the questions and gave an appropriate verbal response, but could not pick a point on the

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<sup>4</sup> The items in this measure are translated for use in English from a validated Dutch measurement tool. The language in the answer scale was particularly difficult for our first set of participants to understand, spanning from '1 = totally not agree' to '5 = totally agree'. After piloting we amended the answer scale to the more conventional '1 = strongly disagree' to '5 = strongly agree'.

scale, so we recorded verbatim answers (which a member of the research team coded later) to ensure as many people as possible could participate.

We found that some questions in all of the measures could be emotional for some people, and often people wanted to give longer, more detailed answers than was required by the tick-box format. It felt unethical to rush people, particularly bearing in mind we might be their only visitor that day or even that week.

Data collection for this stage of the study was particularly resource-intensive. It takes time to build relationships and trust with people with dementia, and with staff in care homes and hospital wards.

Conducting research in care homes and hospital ward environments is difficult and time consuming. Researchers had to fit data collection around the priorities and activities of the site, and residents, of course, had their own preferences. Data collection had to stop for residents' scheduled meal times, activities or medical appointments, and we arrived for one pre-arranged visit to find many of the residents in the study were out on a day trip.

We could collect data from several people with dementia in a care home or hospital ward on the same day. But if someone had moved, for example, from a hospital ward to a non-study care home, it could take an entire day to visit and collect information from that one person. Although some measures were designed for self-completion, this was not possible for people with later stages of dementia, so it could take a researcher anything up to two hours to get through the three measures (including the consent process at the start, and general chatting about what the resident wanted to talk about). This is not feasible for off-site researchers in a larger-scale trial, and in such studies, it may instead be more appropriate to have on-site staff administering outcome measures.

## Conclusion

Early in this paper, we raised concerns about excluding the voices of people with dementia from research. Processes designed to protect potential research participants from harm can sometimes lead to them being excluded from research altogether. Researchers may be discouraged from including people with dementia as participants, particularly those who cannot themselves consent to take part by lengthy ethics processes largely designed for medical research and sometimes ill-adapted for qualitative work. Involving people with dementia in the design and management of research projects in a meaningful way is also time consuming and can be expensive. Previously, researchers have either neglected to do this or have resorted to tokenistic involvement such as inviting a single individual to join an advisory group.

In this paper, we have described how we were able to involve people with dementia as advisers and participants in this research project through a partnership between the research team and Innovations in Dementia. By planning this partnership in advance, we ensured Innovations in Dementia had enough resources, and were able to spend adequate time involving people in a meaningful way. In addition, through

the use of consultees, we were able to include people with more advanced dementia as participants, particularly in the feasibility-study stage of the research. As this is a group which is often excluded from research, we felt it extremely important that we were able to collect information about quality of life and relationships from this group directly, rather than relying on proxy measures. Our completion rates showed that more people were able to complete the outcome measures than were capable of giving consent to take part, demonstrating that people with more advanced dementia can give useful information even when not able to complete a complex consent process. This is particularly important in light of research demonstrating that there are often differences between how people with dementia and carers rate the quality of life of people with dementia, with carers relying on functional performance, and people with dementia on current mood (Trigg et al, 2011).

However, there were still aspects of involving people with dementia which did not work as well as we had hoped. The process of using consultees, while it allowed some people with dementia to be involved when they otherwise may not have been, was lengthy and complex. We relied heavily on busy care home and hospital staff to contact potential consultees initially, and this was often unsuccessful, meaning several people were not given the opportunity to participate at all.

Outcome measurement tools, while widely recognised standards for measuring quality of life, did not necessarily work for all participants. People with the later stages of dementia in particular could find prescribed 'tick box' answers restrictive and unsuitable, even when they were able to understand the questions being asked. If outcome measures are being used, we would recommend a more flexible approach of recording verbatim answers and, if necessary, coding these later.

We encourage the wider research community to:

- Include as many people with dementia in research as possible
- Take a broader, more flexible attitude towards consent, including exploring the concept of assent and the use of consultees
- Use a wide range of ways of engaging people with dementia throughout the research process

In order for this to happen, there is an urgent need to develop: (a) new tools for measuring quality of life for people with dementia which do not require participants to respond in prescribed ways, but which are still acceptable for use in cost-effectiveness studies; and (b) ethics and consent processes which are more appropriate for non-medical research to facilitate involvement of people with dementia.

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