

Developing a Measure of Outcomes of Social Care for Adults: Findings from a study testing people's understanding of quality of life questions and valuation tasks

PSSRU

RESEARCH
SUMMARY

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BACKGROUND

The importance of measuring social care outcomes is now recognised at all levels of government and across organisations. By social care outcomes, we mean the effect of social care on people's lives. If we can measure the impact of social care on people's lives we can make much stronger arguments about how much it benefits people and society more generally. It is therefore important to develop a way of measuring social care outcomes.

The Outcomes of Social Care for Adults (OSCA) project aims to develop a tool to measure social care outcomes. The project has two phases: a design phase and a main phase. In the design phase we are developing and testing the methods for collecting data about social care outcomes. In the main phase we will collect 'real' data using the tried and tested methods from the design phase. The data from the main phase will be used to put

together a tool that researchers and others can use to measure social care outcomes.

METHOD

We interviewed about thirty people from a range of backgrounds across England as part of the design phase, using cognitive testing (Willis, 2005). The aim is to make sure the questions make sense to people and capture the aspects intended by the research team. All of these people had some contact with social care services, although some arranged their own support. We tested the quality of life questionnaire, which forms the basis of the social care outcomes measure. We also asked people to value different quality of life states, using discrete choice experiments (DCE) and best-worst scaling (BWS).

As part of the development work for a measure of social care outcome, Juliette Malley, James Caiels and Diane Fox interviewed about thirty people across England. In the interviews they tested the wording of questions that asked people to rate their quality of life. They also tested two methods for capturing people's valuations of quality of life states, known as discrete choice experiments and best-worst scaling. This summary presents the findings from these interviews and discusses the implications for the measure of social care outcome.

Table 1. The aspects of quality of life in the social care outcome measure

Aspects of quality of life	Definition
Accommodation cleanliness and comfort	The service user feels their home environment, including all the rooms, is clean and comfortable
Control over daily life	The service user can choose what to do and when to do it, having control over his/her daily life and activities
Dignity	The negative and positive psychological impact of support and care on the service user's personal sense of significance
Meals and nutrition	The service user feels he/she has a nutritious, varied and culturally appropriate diet with meals he/she enjoys at regular and timely intervals
Occupation	The service user is sufficiently occupied in a range of meaningful activities whether it be formal employment, unpaid work, caring for others or leisure activities
Personal cleanliness and comfort	The service user feels he/she is personally clean and comfortable and looks presentable or, at best, is dressed and groomed in a way that reflects his/her personal preferences
Safety	The service user feels safe and secure. This means being free from fear of abuse, falling or other physical harm and fear of being attacked or robbed
Social participation and involvement	The service user is content with their social situation, where social situation is taken to mean the sustenance of meaningful relationships with friends, family and feeling involved or part of a community should this be important to the service user
Dignity	The negative and positive psychological impact of support and care on the service user's personal sense of significance

MEASUREMENT DOMAINS

Picking out the aspects of quality of life that matter most is an important part of developing the questionnaire. Since we are trying to measure social care outcomes, the most important aspects are those that are affected by social care. If we don't capture these aspects then the measure won't be sensitive to the impact of social care on people's lives.

The domains are shown in table 1. They are closely related to the activities of social care services. They also closely mirror the aspects that people who use social care services say are most important to them (Qureshi et al., 1998; Bamford et al., 1999; Miller et al., 2008). Everyone we interviewed agreed that these were important aspects of their quality of life.

WORDING OF QUESTIONS

For each domain we ask one question and each question has four answer options for people to choose from. Each option represents a different state, so, for example, the third option for each aspect of quality of life captures a state of low level needs. The meaning of the answer options is shown in Box 1.

Box 1. Meaning of the options for the answers

1. The preferred situation, where needs are met to the desired level
2. No needs, where needs are met but not to the desired level ('mustn't grumble')
3. Low level needs, where there are needs but these do not have an immediate or longer term health implication
4. High level needs, where there are needs and these have an immediate or longer term health implication

We tested the wording of the questions and the answer options to come up with wording to express each aspect of quality of life in everyday language. We also wanted to find words for the answer options that captured the states in Box 1.

For *accommodation cleanliness and comfort*, we used the wording 'my home is clean and comfortable'. Important aspects were having clean dust-free surface and hygienic kitchens and bathrooms, but people also mentioned the state of the décor, whether their home was neat and tidy, whether their

home had their own 'stuff' in it that they could get to easily and also whether they could get around their home easily. For example, a number of people mentioned the problems posed by stairs or mentioned how they had had their home adapted to make it easier for them to move around without help.

The term *control over daily life* was understood by the people we interviewed. They often distinguished between making decisions and carrying out those decisions. Most of the people we spoke to depended to some extent on help from others to see these decisions through. Having control over their daily life depended on them having someone and, importantly, the right someone to help them.

Dignity can mean many things to people, but 'the way I think and feel about myself' captured a person's sense of self and significance well. Including 'the way I'm helped and treated' forced people to consider the way their care and support packages impacted on their sense of self and significance. However, this was not the case for everyone. Some people felt negatively about themselves not because of how they were treated but because it was difficult for them to accept that they needed help. Some of these people chose the 'no needs' answer but others chose one of the 'low or high level needs' answer.

We used the term 'food and drink' for *meals and nutrition*. Including 'drink' was very important since people drink more often than they eat and many people discussed how they managed their lives to ensure they had the drink they needed. Initially the wording was 'I can get...the food and drink...', but we found that some people interpreted this too literally as being physically able to get food and drink without help. We changed the wording to 'I get...the food and drink...', which did not have the same problems.

'Doing things I value and enjoy' seemed to capture the type of things we intended for the *occupation* domain. People talked about voluntary work and paid work; activities they did with others, such as going out shopping or to eat; and activities they did on their own, such as reading, needlework or making cards; and caring for others. The answer options changed significantly from the first version of the question we tested to capture the frequency of doing things, the quality of the things done and the number of things people had to do. This is

important as for some people the problem was not that they didn't have enough to do or things they enjoyed doing, but not being able to do as many things as they would like to do because of health limitations.

'Clean and presentable' was used for *personal cleanliness and comfort*, which was understood well by people. People talked about how frequently they washed, showered or bathed and also about whether they were able to do their hair as they liked and wear the clothes they liked. Many of the women we interviewed talked about the difficulties they had with jewellery and make-up and how important it was for them to be able to wear them.

Feeling safe was understood by everyone, although some people questioned whether we meant did they feel safe outside or only inside their home. We have therefore recommended a prompt for interviewers to use or written guidance for self-completion versions to make it clear that we mean outside and inside the home.

We had some difficulty finding a good way of expressing *social participation and involvement*, but settled on the phrase 'social contact with people I like'. As with the *occupation* domain, it is important to reflect the quality of contact, the frequency of contact and the number of people known to the person being interviewed. However, it was not possible to reflect all three aspects throughout the question and the quality part, 'people I like' was dropped from the last three options. This did not seem to matter: people continued to talk about contact with friends and family. They also mentioned phone, email and letter contact as well as face-to-face contact.

The original answer options also included the phrase 'I feel lonely', but this was taken out as it was confusing. As one person explained, 'it depends on whether you mean personal or social life' as a person can be lonely because they don't have a special person in their life or lonely because they don't know many (or any) people. Given the areas over which social care can be expected to impact we felt it was important to focus the question on the social rather than personal side. We chose to use the term 'socially isolated' to denote social loneliness, which seemed to work well.

We also tested including a time frame in the answer options of 'the past couple of weeks'. We found however that it made the question difficult for people

to follow and because many people had conditions that fluctuated they tended to ignore the instruction even when it was pointed out to them. Most people preferred to answer according to an 'average' day. We decided to leave these instructions out.

THE IMPACT OF SERVICES ON QUALITY OF LIFE

To measure outcomes from services we ask people to assess what their quality of life within each domain would be like without services. For each domain there are therefore three questions: one question asks about the person's current quality of life; the second asks whether support and services help them in that domain; and the third asks what their life would be like without support and services.

This study confirmed the finding from previous studies that, for the most part, people could visualise the hypothetical situation in the absence of services. It was important to reiterate that they should consider the situation in which no-one else stepped in to compensate for the lack of those services.

Although what is to be included as 'support and services' depends on the purpose of the study, the interviews did reveal the importance of words chosen. People conceptualised 'support and services' very differently. For instance, few participants included equipment or adaptations when thinking about services. The researchers were only able to identify when people were making 'mistakes' because they had asked each service user what services they were receiving before asking these questions. We feel it is important to tailor instructions to the service user. Thus, although the precise nature of the wording will depend on the nature of the study, we have included detailed questions on service receipt which can be used to tailor the wording to each individual's situation.

ASKING PEOPLE TO VALUE QUALITY OF LIFE STATES

We also asked people we interviewed to value the quality of life states, using the DCE and BWS methods. Both DCE and BWS can be quite complicated as people need to hold a lot of information in their heads. The tasks are also very different to the types of questions normally asked in questionnaires, so they can seem strange at first. We wanted to find out how best to present

the tasks to people, whether they could do them and whether they made sense. Simplified examples for DCE and BWS tasks are shown in Boxes 2 and 3.

We found the testing particularly helpful for coming up with introductory wording that made it clear what participants were being asked to do. Since BWS and DCE are very different to the types of questions that are ordinarily asked in interviews it is very important that the tasks are explained clearly. We found that short and simple introductions helped people to understand what was being asked of them. In the DCE we also found formatting the options in a way that encouraged people to scan down, rather than across the page, helped.

The exercise provided a number of insights into the domains and their relationships. For example, it was common for people to choose control over daily life as the best option in the BWS experiment if it was at any of the levels except high level needs, because they felt that without control none of the other options were attainable. Similar results were found for DCE where people often choose the option with the most favourable control situation, arguing that if they had control over their daily life then they could improve all the other aspects.

We also gained valuable insights into the distinctiveness of the answer options. For the *dignity* and *safety* questions, it became clear during the

Box 2 Example of a Discrete Choice Experiment

From this point on I would like you to put yourself in a series of imaginary situations. I will show you a series of cards. Each card describes the lives of two imaginary people, person A and person B, in terms of their quality of life. I would like you to imagine how you would feel if you were person A and then how you would feel if you were person B. I'd then like you to tell me, which person you would prefer to be.

You'll notice each person's life has good and bad aspects and sometimes their lives are described in very similar terms. Please remember there are no right or wrong answers to these questions; we are only interested in your views.

Which person would you prefer to be, A or B?

	Person A	Person B
Personal care	I don't feel at all clean or presentable and...	I feel adequately clean and presentable and...
Safety	generally I feel adequately safe, but not as safe as I would like and...	I don't feel at all safe and...
Control over daily life	I have some control over my daily life but not enough and...	I have as much control over my daily life as I want and...
Choice	<input type="checkbox"/>	<input type="checkbox"/>
	mark 'X' in preferred option	

Box 3 Example of Best-Worst Scaling

From this point on I would like you to put yourself in a series of imaginary situations.

I will show you a series of cards, each containing a list of X statements. Each statement describes an aspect of quality of life sometimes negatively and sometimes positively.

I will ask you to read all the statements in the list and imagine how you would feel if you were in that situation. Then I would like you to choose which one of the statements you would consider to be the best, and which one you would consider to be the worst.

I'd just like to remind you there are no right or wrong answers to these questions; we are only interested in your views.

Which one of these four points would you rate as being the best? And which one would you rate as being the worst?

Best	Aspect of life	Worst
	I get food and drink adequate for my needs	
	I feel less than adequately clean or presentable	
	My home is adequately clean and comfortable	
	I have adequate control over my daily life	

interviews that there was not enough difference in meaning between some of the levels. For dignity the problem was for the bottom two levels, which were changed from 'sometimes undermines' and 'undermines' to 'sometimes undermines' and 'completely undermines'. The bottom two levels of safety were also seen as quite similar. These were changed to 'feel less than safe' and 'don't feel at all safe' from 'sometimes I don't feel safe enough' and 'most of the time I don't feel safe enough'. The top two levels of safety were also changed, with the second level changed to emphasise the sense of adequacy at the second level.

In some cases we were able to identify short cuts people used to make the tasks easier. For example, in the DCE, some people chose the person that had the best option for the first aspect of quality of life in the list. Similarly for BWS the length of the list seemed to make the task quite difficult and some people focussed on the options towards the top of the list. We plan to check for these effects in analyses of results in the main stage.

A number of people found it difficult to imagine themselves in someone else's shoes, and this was particularly the case for some of the aspects of quality of life. A typical comment was 'if someone treated me badly I'd tell the person to go away so I wouldn't be in that situation'. In a few instances people actually refused to do so, arguing that it was not possible to imagine what life would be like. One person drew on their experience of their own illness and how this affected their life saying 'since having my illness I'm a different person to who I was before'. Rather than missing out the questions,

people who found it difficult to imagine a change to their life circumstances often chose the option that corresponded most to their current state. Again this is something we can check for in the analyses for the main stage.

Another aspect of quality of life that we asked people to value in the DCE and BWS tasks was whether the person was *living in their own home* compared to not living in their own home. When people imagined not living in their own home, they tended to imagine living in a care home. When we asked people to describe what this was like they described it in terms of the other aspects of quality of life, such as control over daily life, social participation and involvement and so on. We felt that this made it confusing and there was the possibility of distorting choices and double counting so we have decided to leave it out of the measure.

IMPLICATIONS FOR THE MEASURE

The interviews helped us to refine the wording for the questions and make sure the language we used made sense to people. We made a number of changes to the wording to improve understanding and these seemed to help in subsequent interviews.

Because of problems with the living in own home aspect of quality of life we have omitted it from the measure. We have identified some problems with the dignity aspect, including the potential for misattribution of responses and people answering differently despite having similar circumstances. We plan to include an additional question in the interview asking about how having

help makes people feel about themselves. This should help people to focus on the way they are being helped in the dignity question and help us to interpret any problems.

An important finding is the need to capture detailed service receipt information to ensure the impact of services is captured accurately. It is only really possible to do this adequately in an interview situation as tailored instructions can easily be derived using computer-assisted personal interviewing (CAPI).

This work has also shown the importance of testing out the wording for introducing valuation tasks, since we needed to try out a number of variations before we found one that was widely understood. Once the introduction and layout were clear we found that most people were able to make choices that will allow us to reflect the relative importance of different aspects of social care-related quality of life when scoring our measure.

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