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Outcomes of Social Care for Adults (OSCA)

Interim Findings

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the authors**

Ann Netten, Peter Burge, Juliette Malley, Dimitris
Potoglou, John Brazier, Terry Flynn and Julien
Forder

PSSRU Discussion Paper 2648
August 2009

PERSONAL SOCIAL SERVICES RESEARCH UNIT

University of Kent

University of Kent
Cornwallis Building
Canterbury
Kent
CT2 7NF
Tel: 01227 823963/823862
PSSRU@kent.ac.uk

London School of Economics

London School of Economics
LSE Health & Social Care
Houghton Street
London
WC2A 2AE
Tel: 020 7955 6238
PSSRU@lse.ac.uk

University of Manchester

University of Manchester
Dover Street Building
Oxford Road
Manchester
M13 9PL
Tel: 0161 275 5250
PSSRU@man.ac.uk

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Acknowledgements

We are very grateful to all those who participated in the research both in the consultation and fieldwork stages; to Accent, which undertook the fieldwork with the general population; and to James Caiels and Diane Fox who undertook many of the cognitive interviews.

Summary

- The paper summarises interim findings from initial development stage of the Outcomes of Social Care for Adults (OSCA) project which is developing a gold standard preference weighted measure of social care outcome. There are two strands to the work:
 - Developing the instrument
 - Estimating and attaching preference weights.
- The project is building on previous work including the Adult Social Care Outcome Toolkit (ASCOT) measure which is designed to capture information about an individual's social care-related quality of life (SCRQOL). The aim is for the measure to be applicable across as wide a range of user groups and care and support settings as possible.
- Analysis of datasets that have used ASCOT in previous projects identified good psychometric properties for a measure based on seven of the proposed domains of outcome. Areas for improvement identified were the domains of occupation, social participation and involvement and safety. Conceptual work had also identified the need to add a domain reflecting 'dignity': the impact of the way services and support affected people's sense of personal worth.
- One item reflects the outcome for each domain with four levels reflecting capabilities (whether people are where they would like to be) at the top two levels and functionings (what people are actually doing) where any needs are identified.
- Cognitive testing with 29 service users confirmed the relevance and scope of the domains and that the final wording reflected the intended meaning in terms of levels of capabilities and functioning. The final version of the measure is shown in Appendix A.
- People who have problems in coming to terms with receiving help from others were not entirely consistent in their responses to the dignity question, which is intended to reflect the impact on people of the way they are helped. An additional question has been included in the interview with service users to allow us to explore the impact of this at the next stage of testing the measure.
- Cognitive testing of the approaches tested to eliciting preferences allowed a more in depth understanding of the meanings and relationship between the domains of outcome.
- Once introductory wording and layout had been clarified most service users were able to undertake both the discrete choice experiment (DCE) and best worst scaling (BWS) tasks.
- The results of the cognitive testing suggested that people were thinking of our other domains when considering the domain 'living in own home', which had been proposed to be included to reflect the separate effect on well being of moving into a care home setting. We felt that this could lead to confusion and that there was the potential for distorting choices and double counting so have decided to leave it out of the measure.
- Interviews were undertaken with 300 members of the general population to compare the results of the well established DCE and emerging BWS approaches to identifying preferences. The results were broadly comparable, and as BWS is

both less demanding on respondents and allows all our domains to be considered at once we have decided to use this in the main study.

- The next step in developing the measure is to test its psychometric properties on a sample of 300 service users recruited through the older home care user experience survey.
- The next steps in establishing preference weights are to:
 - Use BWS in a preference study being conducted as part of the Quality Measurement Framework project. This will compare a previous three level version of ASCOT with the version developed as part of this work
 - Undertake cognitive testing of the time- trade off technique (TTO) with a small population sample. If successful, TTO conducted with a population sample will allow us to estimate quality adjusted life year (QALY) equivalents allowing wider applicability of the measure.

Introduction

Measuring outcomes is increasingly important at all levels of policy and practice in social care. We are developing a measure of social care outcome that is intended to capture all domains relevant to social care interventions, have credibility in the social care community, and to demonstrate good psychometric properties (be valid, reliable and sensitive to differences between individuals, interventions and changes over time). In scoring the measure the aim is to reflect the relative importance of different aspects of outcome, ideally distinguishing the difference between service user views and the general population.

The work that we report on below is being undertaken as part of the Outcomes of Social Care for Adults (OSCA) project, which is building on work that has been undertaken on outcome measurement over a number of years, including, as we describe below the Individual Budget pilot evaluation (Glendinning et al., 2008). The measure being developed is part of the Adult Social Care Outcome Toolkit (ASCOT) and is referred to as the ASCOT measure throughout. The toolkit is being developed as part of the Quality Measurement Framework (QMF) project, which is led by ONS and is developing techniques for measuring and monitoring outcome in care homes and for low-level interventions. The QMF project also encompasses a planned preference elicitation study (see below). The work has also drawn on and fed into national service User Experience Surveys (UES) including the planned new survey to reflect the Putting People First agenda. This paper summarises the findings of the project to date. Full details are available in the interim report of the project (Netten et al., 2009).

We start by outlining the methods we employed in this initial developmental stage of the project. The concepts underlying the measure and its structure are described before summarising the results of the analysis of data from previous studies that had used earlier versions of the measure. We describe the key issues that arose when testing the wording and concepts with service users. The results of the work on the feasibility of establishing service user and population preferences are summarised before we describe the next steps of the project. The instrument that is to be taken forward to the next stage of testing is shown in Appendix A.

Methods

The first phase of the study focused on development of the instrument itself and testing approaches to identifying preference weights to allow the relative importance of the different domains of outcome to be reflected. An important first step was defining the theoretical underpinnings of the measure and ensuring that it had face validity in reflecting the objectives of social care. We drew on datasets that had used previous versions of the measure to identify psychometric properties to date and where development work was needed. We consulted with service users and carers on what we were proposing to test and with a reference group of key stakeholders including policy makers, local councils, regulators and other observers before undertaking cognitive testing of the questions and concepts with 29 service users reflecting a variety of user groups and living circumstances. We considered a variety of approaches to eliciting

preferences and anchoring the measure to increase its value. We then tested the main approaches to eliciting preferences through the cognitive testing with service users and a pilot population study that compared two principal techniques: discrete choice experiments (DCE) and best-worst scaling (BWS).

Conceptual basis of the measure

Scope

The ASCOT measure is designed to capture information about an individual's social care-related quality of life (SCRQOL). The aim is for the measure to be applicable across as wide a range of user groups and care and support settings as possible. In identifying and defining the domains (see Table 1) the aim was to ensure the measure is sensitive to outcomes of social care activities. Evidence from consultation with service users, experts and policy-makers, as well as focus group work and interviews with service users indicated that the measure captures aspects of SCRQOL that are valued by service users (and policy-makers) (Qureshi et al., 1998; Bamford et al., 1999; Netten et al., 2002; Harris et al., 2005; Netten et al., 2005; Malley et al., 2006; Miller et al., 2008)

Capabilities and functioning

For people with impairments, quality of life is often limited by their ability to pursue the different aspects of SCRQOL, often due to environmental and sometime financial barriers. Aligning itself with the social model of disability which foregrounds the contextual barriers over individual impairments, the focus of much policy has been on broadening opportunities for people with disabilities and developing 'independence', 'choice' and 'control' (Cabinet Office, 2005; Department of Health, 2005; Department of Health, 2006). It is argued that it is this flexibility and freedom that people want most and value from services.

This focus on choice and control is consistent with the capabilities framework, put forward by Sen (see e.g. Sen, 1985) as an alternative to standard welfare economics (Burchardt, 2004). Sen argues that utility is not the sole object of value; it is rather capability, understood as the substantive opportunities an individual has to be, or to do, a range of things, that is the object of value. Capabilities are contrasted to functionings, which are understood to be states of being (for example being well-fed or being safe) or activities (for example shopping). Most health outcome measures, for example the EQ-5D (EuroQol Group, 1990), capture functionings and ask people to value these functioning states. However, if it is capabilities and not functionings that are valued then each domain should be designed to capture the individual's capability rather than functioning state.

The distinction between capabilities and functionings is of central importance to the development of a measure of social care outcome. On the one hand, evidence from user movements and research implies that it is opportunities or capabilities that are valued. But from another perspective functionings are important. For some aspects of SCRQOL, it could be argued that a low level of functioning is indicative of need, whether a person

recognises that need or otherwise. For example someone who is anorexic may choose to have poor nutritional intake, but as a society we deem the level of functioning poor enough to require some form of intervention. Similar issues exist for people with disabilities as they may adapt to their circumstances (for example, in a poor quality care home), adjust their expectations and judge their opportunities within an aspect of their life to be quite good. However, an external observer might identify the potential for much better opportunities for that individual in another care environment. If it is the case that for each SCRQOL aspect of people's lives there is a level of functioning that we as a society judge to be unacceptable our measure should reflect this.

Earlier versions of the measure used three levels of need in each domain and language that focused on functioning. In order to ensure the measure could reflect the increased policy emphasis on capabilities an additional level has been included for each domain in our current measure with the domains phrased in the language of capabilities at the high quality of life end of the spectrum and in terms of functionings when reflecting low quality of life.

Value and attribution of social care interventions to outcome

A major problem in measuring outcomes in social care is reflecting the full value of what has been provided. Most social care is for people with long term conditions where 'before' and 'after' only reflect the marginal impact of an intervention. For those where the underlying health state deteriorates a before and after measure might reflect no change where in practice there has been considerable increase over the period in the contribution of the intervention to people's well being. It is also difficult to distinguish the effect of changes that are attributable to interventions from other factors, such as life events in the absence of specific research designs such as randomised control trials. People who use services and support know themselves the contribution that services make and their likely (or occasionally actual) situation in the absence of those services. In order to reflect this in face to face interviews, in addition to a question asking about a person's current status within each domain, there is also a 'hypothetical' question that asks people to rate what their quality of life would be like in the absence of services, or their 'expected needs'. These questions can be combined with those asking about current status to provide a measure of the contribution of social care services to SCRQOL.

Evidence from previous use of the measure

Previous versions of the ASCOT measure have been used in a number of studies, most notably in the Individual Budget's evaluation (IBSEN) where it successfully identified the impact of personalisation both in the overall measure and the domain of control (Glendinning et al., 2008). Versions have also been used in User Experience Surveys (UES) for younger adults and older home care service users. These datasets allowed an analysis of how the measure has behaved when used across a variety of service user groups in the past and where there was room for improvement. Netten et al. (2009a) describes how the measure has developed over time. Here we summarise the results of an analysis of the psychometric properties of the items and measure in the IBSEN (which was conducted through interview and included the hypothetical questions) and younger

adults (YA) UES datasets (which was based on a self-completion questionnaire).

Item response rates

In both datasets a number of the items had non-response rates which were greater than 5 per cent, suggesting room for improvement in the wording of these items. In particular, the employment and occupation item was missed out by a number of respondents in both the YA UES and IBSEN datasets, suggesting that there was some element of the question that respondents did not like and the social participation and involvement item was omitted for a number of respondents in the IBSEN questionnaire suggesting some problem with the wording. In these datasets a separate question was included about role support, which was intended to identify the degree to which services supported people in their caring responsibilities for others. This was judged as not applicable by such a large proportion of people that it was excluded from subsequent analysis. This aspect of quality of life is now covered by the occupation domain. In general the items were more problematic for the mental health and learning disabled client groups in the IBSEN study, which may reflect the fact that at this point cognitive testing on the questions used had been undertaken only with the physically and sensorily impaired people. Some testing, but not of the employment and occupation and social participation and involvement domains, had also been undertaken with the older people. Not surprisingly, these items tended to be answered poorly by older people.

Scalability

Using a variety of approaches one scale was extracted indicating that the questions were reflecting a single construct. The analysis suggested that in these datasets the items formed a weak scale but performed well in terms of appearing to consistently reflect an underlying latent construct. Since current SCRQOL is affected by a number of factors, we would not expect a strong scale to emerge. The employment and occupation item was dropped from the scale in the IBSEN dataset in one analysis and appeared to cause the most problems in the YA UES dataset. In one analysis of the IBSEN dataset, when the personal safety domain item was not included the resulting scale had very few violations. This suggested that this item required rephrasing.

Reliability

In virtually all cases the estimates of reliability of the scale were greater than 0.7¹. This indicated that the scale had good reliability. Coefficient rho and Cronbach's alpha were very similar despite the differences in the methodology lending support to the conclusion. A coefficient of reliability greater than .8 is desirable for a widely used scale, but given that there are multiple factors influencing current needs in each domain we would not expect the reliability to be very high. It is interesting that much higher reliability (>0.8) was achieved for the hypothetical SCRQOL scale which is based on the individual's assessment of their need state within each domain in the absence of services. In this scale it is mainly impairment and residual sources of help that are influencing SCRQOL and we would expect the scale to be more reliable.

¹ The only exception was in the current status scale derived from the IBSEN dataset when the employment and occupation item was dropped.

Discrimination

Responses to the current status items were clustered towards the all needs met levels. This means that these versions of the scale (based more closely on needs and functionings) were not very good at discriminating between people who score highly on the scale. The clustering of the responses at the high end of the current status scale is probably the (desirable) result of the effect of services. As we would expect, the responses to the hypothetical status scale had a much better distribution and were more evenly spread throughout the length of the scale.

The instrument

The evidence from these analyses, conceptual development and results of the consultation with stakeholders and service users and carers (Netten et al., 2009b) fed into the draft instrument that was then cognitively tested with 29 service users from a variety of user groups. In addition to testing the questions, the interviews tested out the preference elicitation techniques, which drew out important insights both into what was important to people and these aspects of their lives. Table 1 describes the domains included in the measure and Appendix A provides the individual question wording. Here we draw out the key issues that arose during the testing of the measure.

Table 1: Domains of outcome

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
Food and nutrition	The service user feels he/she has a nutritious, varied and culturally appropriate diet with enough food and drink 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

Question wording

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.

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.

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 affected

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. In order to investigate the impact of this on the measure and its interpretation, an additional question asking about the impact of having help at all on how people feel about themselves will be included in the interviews with service users in the next stage.

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. 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. The term 'poor personal hygiene' had been used in earlier versions and had been disliked by many who were consulted. We found that the revised version reflected this type of situation without using this term.

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.

Differences between answer options

For the *dignity* and *safety* questions, it was clear that there was not enough difference in meaning between some of the levels. These findings were confirmed by the pilot study of the DCE and BWS approach to attaching value that was conducted with members of the general population described below. 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.

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 services help them in that domain; and the third asks what their life would be like without services. Previous studies and the cognitive testing with service users identified that, for the most part, people could visualise the hypothetical situation in the absence of services. It was important to clarify what services they were receiving prior to asking the questions and to reiterate that no one else stepped in to compensate for the lack of those services. What was included as ‘services’ and the precise wording and guidance for interviewers would depend on the purpose of the study.

Preference elicitation

Techniques for eliciting preferences

In addition to developing the instrument itself we tested approaches to preference elicitation in order to identify weights that allow us to reflect the relative importance of different aspects of outcome when the measure itself is calculated. As we identified above, the focus was on discrete choice experiments (DCEs) and Best-Worst scaling

(BWS). , DCE and BWS overcome theoretical problems associated with other approaches including standard gamble (SG), time trade-off (TTO) and the visual analogue (VG) (Ryan et al., 2006). Moreover, DCE and BWS methods are best suited to the comparison of vignettes that consider each of the domains within them in some detail.

Discrete choice experiments and Best-Worst scaling experiments share the same theoretical basis, experimental design and modelling approaches. However, their difference lies in the way DCEs and BWS experiments are presented to respondents and the preference elicitation task itself. In the case of DCE, participants choose the most (or least) preferred option between two alternative situations defined by a list of attributes (in this case domains) at different levels, in effect they are asked to weigh up the pros and cons of each alternative and then choose the package they prefer. A BWS task presents a single card of domains at different levels and respondents choose two domains within that list; one they consider being the "best" and another being the "worst", In effect, respondents indicate the two domain levels from the list that they consider to be at the extremes.

One of the main concerns about preference elicitation methods is respondents' fatigue. Theoretically, the risk of respondent fatigue is higher in the DCEs than the BWS approach because DCEs become more complex and difficult for respondents to evaluate as the number of domains involved in the experiment increases. One way to overcome this issue in DCE would be to split the total number domains in this study into two groups and design two separate experiments.

BWS is an emerging approach and offers an alternative option in covering some limitations of DCEs in preference elicitation studies. BWS is an "information-efficient" approach compared to the "pick-one" task of DCEs where respondents are not permitted to like or dislike domains. A BWS scenario allows participants to choose a "most" and a "least" preferred domain whereas. DCEs do not offer flexibility (at least, for the number of questions typically asked) in capturing respondents who focus on and make choices based on a single domain only while they are presented with a set of domains. Therefore, modelling of BWS data estimates all domains' levels on the same scale, while DCE estimates are specific to individual domains (Flynn et al., 2007). However, as BWS is a relatively new method, there is lack of empirical evidence that demonstrates the superiority of BWS over DCEs in terms of practical considerations in the field (e.g. respondents fatigue) and the robustness of the modelling estimates.

In the next stage of the study the aim is to identify preferences of the general population and of service users to identify whether service user views differ from those of the general population. In this feasibility stage we tested the approach with service users in the cognitive interviews and with the general public through a survey. In the cognitive interviews with service users we tested the acceptability and validity of the approaches in terms of how well people understood the presentation and the tasks. In a survey of the general population we tested how the results of the two methods of preference elicitation compared.

Service user preferences

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 1 and 2.

We tried a number of explanatory wordings for the tasks before we found ones that seemed to work well (see Box 1 for DCE and Box 2 for BWS). Short introductions seemed to work best and we found it helpful to describe the choice in terms of imaginary people rather than as different situations. In the DCE, formatting the options in a way that encouraged people to scan down, rather than across the page, also helped with understanding.

Once initial introduction and presentation were simplified and clarified, service users found both DCE and BWS tasks acceptable and feasible. In order to help in the process of making decisions people used a variety of strategies to choose which person they preferred to be. Some of these were short cuts to help make the decision. In the DCE tasks this sometimes took the form of choosing the person that had the best option for the first aspect of quality of life in the list. Others approached the problem by counting up the number of negatives and positives for each person and choosing the person that had the fewest negatives: it should be noted that such behavior cannot be represented using the statistical models commonly used to implement DCEs. In the BWS task the length of the list seemed to make the task quite difficult and some people focused on the options towards the top of the list.

One common approach was to try to order the different aspects of quality of life logically, and applied this logic consistently to each question. For example, it was common for people to choose control over daily life as a key domain. In the DCE tasks this could result in people preferring the situation of the person for whom the control over daily life aspect was rated most highly, even if the other aspects were extremely negative. In the BWS task, control was sometimes selected as the best option if it was at any of the levels except high level needs. A common argument for this choice was that if they had control over their daily life then they could improve all the other aspects. While it is feasible to identify situations with low control and higher levels of SCRQOL in other domains (for example, residents of care homes could find themselves in such situations) these could be seen as logically inconsistent. Some people stated this explicitly, saying "If I had control over my life then I wouldn't be in the position of X".

Box 1: 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?

Which of these two situations would you consider to be the worst?

	Situation A	Situation B
Food and Nutrition	I can't always get all the food and drink I need, and I think there is a risk to my health	I can't always get all the food and drink I need, but I don't think there is a risk to my health
Personal Care	I do not feel adequately clean or presentable	I feel adequately clean and presentable
Safety	Generally I feel as safe as I want	Most of the time I don't feel safe enough
Control over daily life	I have as much control over my daily life as I want	I have as much control over my daily life as I want
The way I am helped	The way I'm helped undermines the way I think and feel about myself	The way I'm helped sometimes undermines the way I think and feel about myself
Choice (mark "X" in worst option)	<input type="checkbox"/>	<input type="checkbox"/>

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 make a choice, 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 in the DCE task that corresponded most to their current state. In the BWS task people would sometimes ignore that domain. For example one service user stated "I would never have nothing to do because I'd make sure I found something to do". This person then went on to choose something else as the worst option, despite commenting that having nothing to do would be terrible and really depressing.

Box 2: 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 can't always get all the food and drink I need, but I don't think there is a risk to my health	
	I feel adequately clean and presentable	
	My home is as clean and comfortable as I want	
	Sometimes I don't feel safe enough	
	I have as much contact as I want with people I like	
	I don't have enough things I value or enjoy to do with my time	
	I have some control over my daily life but not enough	
	The way I'm helped makes me think and feel better about myself	
	And I am not living in my own home	

One aspect of quality of life that was not included in the instrument but we asked people to value in the DCE and BWS tasks, as we hypothesised that there may be well-being effects over and above the other domains, was whether the person was *living in their own home* compared with not living in their own home. When service users imagined not living in their own home, they tended to imagine living in a care home. When we asked them to describe what this was like they described it in terms of the other aspects of quality of life that we already included in the measure, such as control over daily life, social participation and involvement and so on. We felt that this could lead to confusion and that there was the potential for distorting choices and double counting so have decided to leave it out of the measure.

General population preferences

The number of domains (nine) meant that the respondents needed to absorb a lot of information for each task. For DCE, therefore, we asked each individual to undertake two separate discrete choice experiments, each with a sub-set of domains. We refer to these two experiments as DCE1 and DCE2, respectively. The principles of grouping the domains into the two experiments were the following:

- Control over daily life and dignity should appear in both experiments,
- Safety, personal care and food and nutrition should appear in the same experiment as social services tend to see these domains as the core outcomes of services,
- Employment and occupation and social participation and involvement should also appear in the same experiment.

The logic of this allocation of domains between the two experiments was first that people may make trade-offs between personal care and safety. An example from earlier cognitive interviews was a lady who would prefer to be clean and put herself at some risk getting into the bath rather than be safe and unclean. The other reason is because safety, personal care and food and nutrition can be represented as the core outcomes of social services. Cleaning the house, social participation and being active/occupied can be seen as at a less fundamental level in terms such as Maslov's hierarchy of needs. At this stage, it was acknowledged that by splitting the attributes across two experiments, it would not be possible to cover all possible interactions. Specifically, we would not be able to estimate any interactions in preferences for domains that are in different experiments. Therefore, it was necessary to make a priori assumptions about which interactions were likely to be most important when grouping the domains. The final allocation of the domains between the two choice experiments is shown in Table 2. (See Box 1 for an example of the way DCE1 choices were presented.)

For purposes of clarity and in order to avoid wording that may lead to some domains dominating the choices, the *dignity* is presented with the term *the way I am helped* and *employment and occupation* is presented with the term *use of my time*.

Table 2: Grouping of domains between the two choice experiments

DCE1	DCE2
1 Food and nutrition	4 Accommodation, cleanliness and comfort
2 Personal care	5 Social participation and involvement
3 Safety	6 Use of my time (employment and occupation)
7 Control over daily life	7 Control over daily life
8 The way I am helped (dignity)	8 The way I am helped (dignity)
	9 Living in own home

The best-worst scaling experiment contained exactly the same attributes as the discrete choice experiments, but rather than splitting them in two groups, all nine were presented in a single situation (see Box 2). The respondent was asked to choose the best and then conditional on this, the worst of the domains presented.

All respondents saw both the DCEs and the BWS tasks with the order of these randomised between respondents so we could check whether finding the task easier or more difficult was associated with fatigue. Interviews were undertaken with 300 members of the general population located in Birmingham and the Southeast of England. From this dataset the utility weights placed on different levels of social care outcomes were estimated using mixed logit models.

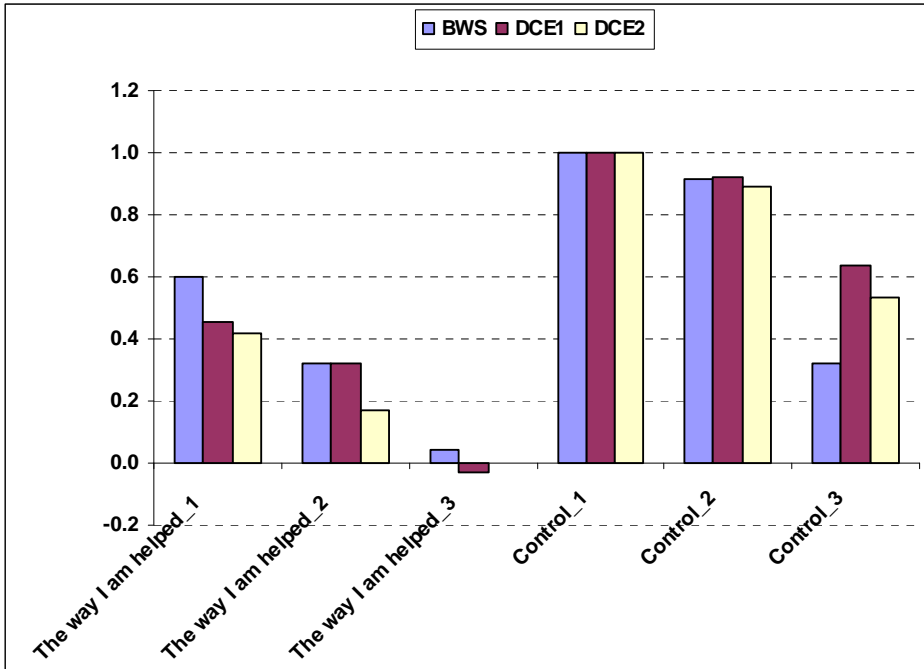
The results from the two discrete choice experiments (i.e., DCE1 and DCE2) and the Best-Worst Scaling approaches can be compared if we look at the marginal values of moving between levels in each domain. The models have different scales so the coefficients cannot be directly compared, but we can look at the relative size of the differences by using one of the domains as a common denominator and scaling all others relative to this. In this case we have chosen the highest level of the control domain, which was strongly estimated in all the models; as a result this takes a value of 1.0 for all three models and all of the other coefficients are presented relative to this in figures 1a - c. These figures then show the extent to which the models produce similar results once the differences in the model parameter scales have been taken in to consideration.

In figures 1a - c the different levels in each domain are labelled so that the suffix 1 reflects highest level need with 3 reflecting the least need or most desirable situation². Figure 1a presents the comparison of domains that were common in DCE1 and DCE2, Figure 1b shows the comparison of domains between BWS and DCE1 and finally, Figure 1c shows the domains that appeared in DCE2 against those estimated in BWS.

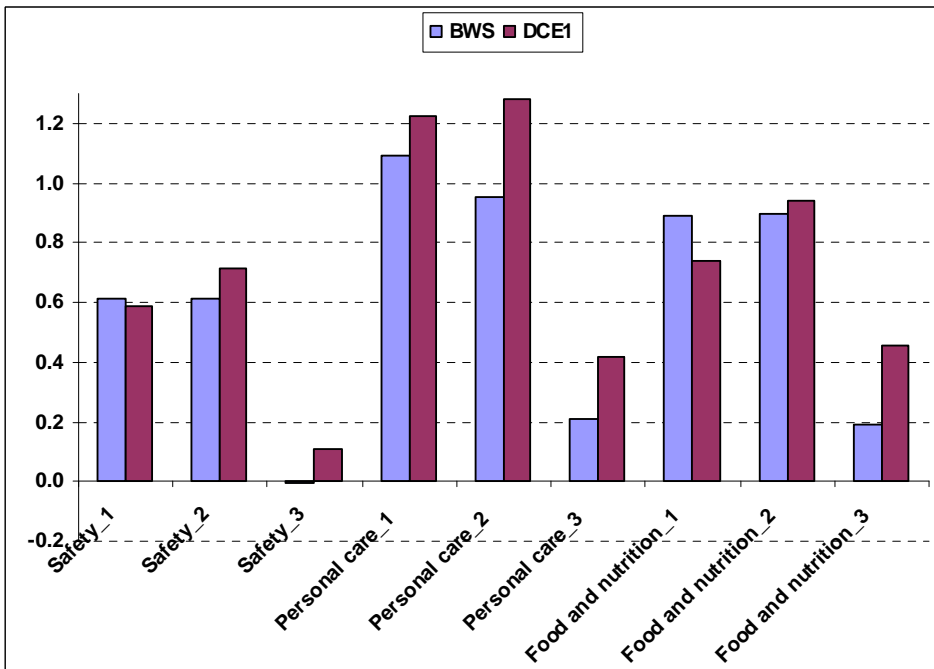
² The value of lowest level need for each domain is not shown in the figures as the other levels are estimated relative to these, i.e. the values presented for levels 1-3 of each domain are relative to the value placed on the lowest level of need within the same domain.

Figure 1: Comparison of normalised domain weights

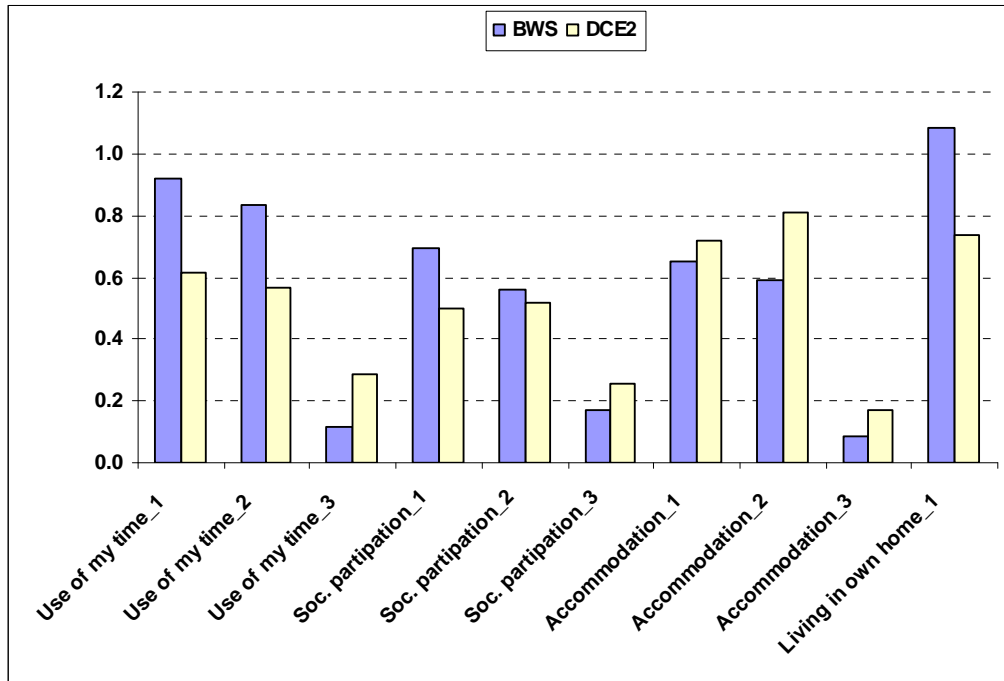
(a) BWS and domains common in DCE1 and DCE2



(b) BWS against domains in DCE1



(c) BWS and domains in DCE2



It is worth noting that the values placed on dignity and control between the two separate DCE tasks (for which these were the common domains) were broadly comparable. We can also compare the DCE results with those from the BWS and again see a degree of consistency between the two. It would appear that where there are differences, these are typically the BWS providing a higher value than the DCE, and this appears to be most significant with respect to “occupation”, “social participation” “food and nutrition” (particularly level 3) and “living in own home”. However, it is reassuring that the two different approaches do reveal a broadly similar pattern in preferences.

Next steps

Developing the SCRQOL measure

The instrument to be taken forward to the next stage of testing is shown in Appendix A. This incorporates the lessons from the analysis of previous datasets, consultation and cognitive testing of the instrument to date. The aim of the next stage of the work is to test the psychometric properties, including the validity of our measure.

In developing the theoretical basis of validation of the SCRQOL measure we are drawing on the production of welfare (POW) framework (Davies and Knapp, 1981; Fernández, 2005). This attempts to explicate the complicated relationships between service use, informal care, individual characteristics and outcomes. This is needed because many factors influence an individual’s current SCRQOL. These include the action of social care services, the action of any informal support network, the level of impairment the person has, and any preferences the individual has which they have acted out. The joint action

of these factors makes it difficult to construct a single hypothesis about the relationship between, what may be thought of as, explanatory variables and SCRQOL. For example disability level is likely to be related in some way with SCRQOL. However, the relationship is likely to depend on a host of other factors. In the absence of services or informal support, disability level would be expected to be correlated negatively with quality of life; but in the presence of services or informal support the correlation is likely to be severely attenuated and could even be reversed in situations where services are better at improving SCRQOL for those with the most severe impairments.

Many of the domains are difficult to validate for the same reasons that the SCRQOL measure as a whole is difficult to validate. The questions do not aim to capture underlying ability but whether the person is fulfilled within that domain irrespective of the means by which that end is achieved. We would therefore not expect there to be particularly strong relationships between the responses and measures of disability, although it may be the case that the hypothetical-SCRQOL attributes have a stronger correlation with disability (taking account of informal care).

There are, however, some relationships that we would expect to observe. First, we would expect accommodation cleanliness and comfort to be correlated with the design of home, since a poorly designed home is likely to be uncomfortable for the person and will make it more difficult for optimal care to be provided. We would also expect safety to be related to people's perceptions of their neighbourhood, sense of social support and also to design of home since all of these aspects will affect a person's sense of security within and outside of their home.

We would also expect a relatively strong relationship between the occupation and social well-being attributes and questions about perceptions of social support, social contact, social participation, employment and voluntary work and a person's living situation. We would also expect these domains to be related to perceptions about ease of getting around their area and the design of a person's home, since these aspects could act as barriers to achievement within these attributes. One key relationship that we would expect to observe is between loneliness and the social well-being attribute (Victor, et al., 2000).

As far as possible in reflecting all these factors we are drawing on existing well validated measures. Box 3 shows the measures that we are including in the survey of service users.

Ideally at this stage we would test the SCRQOL measure in a survey of all service user groups. In practice recruiting such a sample is far from straightforward, especially for a methodological study such as this. Service users are surveyed annually by local councils in the User Experience Survey (UES), but to date these surveys have focused on particular services or groups. As part of these surveys councils often ask if respondents would be prepared to participate in further research. We took advantage of this in our project design and plan to recruit service users from the UES conducted in 2009 for the validation study and 2010 for the preference study.

Box 3: Measures to be included in service user interview

Individual characteristics

- Age
- Gender
- Ethnicity
- Disability level (based on GHS questions)
- Other general socio-economic characteristics (includes income, SEG, tenure)

Nature of services/ support

- Amount of service received (based on GHS questions)
- Receipt of services (based on GHS questions with a question on equipment from equipment UES)
- Informal care/practical help (based on GHS questions)
- Quality of care (Jones, Netten et al., 2007)

Health-related quality of life

- Self-perceived health
- EQ-5D (ref)

Psychological well-being

- GHQ-12 (Goldberg, 1992)

General quality of life

- Quality of life single item

Control/ autonomy

- CASP-12 control and autonomy sub-scale (Wiggins, Netuveli et al., 2008)

Nature of locality and environment

- Design of home (based on younger adults UES(Malley, Sandhu et al., 2006))
- Getting around local area (adapted from equipment UES)
- Whether they like/happy in area (based on ONS social capital module)

Social support and social contact

- Living situation (marital status and household composition)
- Frequency have contact with others (friends, family, neighbours) (based on ONS social capital module)
- 3-item UCLA loneliness scale (Hughes, Waite et al., 2004)

Social participation

- Employment status
- Volunteering (based on ONS social capital module)
- Group activities (based on ONS social capital module)

In 2009 the UES is being conducted with older home care service users. This will allow us to test the reliability and validity of the measure in depth with this group, including the hypothetical 'expected needs' scale. The aim is to achieve a sample of 300 people. We will be including people who had help to complete the UES and exploring the impact

of including other people (usually relatives and friends) to support and help people in responding to the questions as such support is frequently needed by people who use services.

In 2010 the UES is being conducted with people who have received equipment in the preceding period. This includes people from all service user groups. We will be including the 'current state' instrument when interviewing service users about their preferences. This will facilitate further analysis of the performance of the questions and scale.

One of the issues that has been raised over the course of the project is that, while the objective is to make the measure applicable across all service user groups, the measure has not been tested with people with learning disabilities (who are unable to be involved in the type of cognitive testing undertaken to date) and there is only an English language version. We feel it is important to have a soundly based measure in terms of concepts and terminology before such developments. However, planned work as part of the development of the successor to the current UES, which is intended to include all user groups and care settings each year from 2011, is providing the opportunity to take things forward in to some extent in these areas. The proposal is to include the self completion version of ASCOT in the survey and as part of the development work to develop a version that is accessible for people with learning disabilities. The development work will also be focusing on the effect of help people receive to complete the questionnaire and use of proxies, including when English is not spoken or understood.

Preference elicitation

In taking forward the preference elicitation side of the work it has been decided to exclude the 'living at home' domain, because of the issues identified in the cognitive testing with service users. While this also identified some potential problems in establishing preferences, overall people were able to undertake the tasks and we feel it is important to investigate, and ideally reflect, the service user perspective in weighting our measure. We can investigate the incidence of strategies such as only taking into account certain domains and analyse the impact of these on our results.

The BWS approach has the advantage that respondents are presented with all domains at the same time, allowing either analysis of interactions or a high degree of disaggregation in estimation of preferences. Moreover, BWS provides more information than a traditional DCE for a given set of choices as coefficients are estimated on a common scale. Finally, as our findings from the preference elicitation survey of the general population suggest BW scaling appears to perform at least as well as the DCE approach and have decided to use this as our primary approach to preference elicitation

One of the challenges in using DCEs and BWS is that estimated utility weights would not correspond directly into QALY-equivalent weights for social care outcomes. In health, the solution to this issue is to employ a form of anchoring so that utility weights are linked into a zero-to-one scale with zero representing "death" and one to "perfect health". In this study, anchoring would be desirable to be undertaken as it allows integration of information about quality of life and the length of time over which that quality of life is maintained and wider comparisons across health and social care interventions. However,

this brings with it some methodological challenges, both in how to get respondents to consider a "death" situation in the context of choices regarding the outcomes of social care, and how respondents interpret the impact of social care (and resulting life state) in this context. Our proposed approach to this issue is to use a time-trade off (TTO) study as a complementary stage that will link preference weights to 'death' and therefore, allow QALY equivalents to be estimated. This can be achieved by asking respondents to value as few as six states using TTO, including the extreme states. The use of a number of states across the utility range would be desirable as previous work (Burge 2006) has suggested that there are potential non-linearities in respondents' preferences across the range. We are proposing a sample of 100 respondents for the TTO experiment, with the instrument being initially developed with 20 respondents through piloting and cognitive testing.

A preference study being conducted as part of the Quality Measurement Framework project will allow us to test the proposed approach with a general population sample during 2009. The results of this will feed into the design of the main stage of this project which is to be conducted in 2010.

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Appendix A: The instrument

To help us to measure the impact of services and support we are talking to the people who actually use them. We think people themselves are best able to judge what things would be like if services or support were not there. The next set of questions may seem strange to you but we are trying to get your views on the impact of services.

When we talk about services and support from Social Services in the next set of questions we mean for you to think about <<...>>

Interviewer note: Insert an automated statement that comes from the set of questions about services.

1. Which of the following statements best describes how much control you have over your daily life?

If needs a prompt then please say: By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want

I have as much control over my daily life as I want

I have adequate control over my daily life

I have some control over my daily life but not enough

I have no control over my daily life

2. Do the support and services that you get from Social Services help you to maintain control over your daily life?

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above)

Yes

No

Don't know

If 2=yes, then

3. **Imagine that you didn't have the support and services from Social Services that you do now and no other help stepped in. In that situation, which of the following would best describe the amount of control you'd have over your daily life?**

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above). It is important that people do not base their answers on the assumption that any help steps in, please emphasise this to interviewees.

(Reassure if necessary: please be assured that this is purely imaginary and does not affect the services you receive in any way.)

- I would have as much control over my daily life as I want
- I would have adequate control over my daily life
- I would have some control over my daily life but not enough
- I would have no control over my daily life

4. **Thinking about your personal care, by which we mean being clean and presentable in appearance, which of the following statements best describes your situation?**

- I feel clean and am able to present myself the way I like
- I feel adequately clean and presentable
- I feel less than adequately clean or presentable
- I don't feel at all clean or presentable

5. **Do the support and services that you get from Social Services help you to stay clean and presentable?**

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above)

- Yes
- No
- Don't know

If 5=yes, then

6. **Imagine that you didn't have the support and services from Social Services that you do now and no other help stepped in. Which of the following would then best describe your situation with regard to your personal care?**

*NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above)
It is important that people do not base their answers on the assumption that any help steps in, please emphasise this to interviewees.
(Reassure if necessary: please be assured that this is purely imaginary and does not affect the services you receive in any way.)*

I would feel clean and would be able to present myself the way I like

I would feel adequately clean and presentable

I would feel less than adequately clean or presentable

I wouldn't feel at all clean or presentable

7. **Thinking about the food and drink you have, which of the following statements best describes your situation?**

I get all the food and drink I like when I want

I get food and drink adequate for my needs

I don't get all the food and drink I need, but I don't think there is a risk to my health

I don't get all the food and drink I need, and I think there is a risk to my health

8. **Do the support and services that you get from Social Services help you to get the food and drink you want or need?**

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above)

Yes

No

Don't know

If 8= yes then

9. Imagine that you didn't have the support and services from Social Services that you do now and no other help stepped in. Which of the following would then best describe your situation with regard to food and drink?

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above) It is important that people do not base their answers on the assumption that any help steps in, please emphasise this to interviewees.

(Reassure if necessary: please be assured that this is purely imaginary and does not affect the services you receive in any way.)

- I would get all the food and drink I like when I want
- I would get food and drink adequate for my needs
- I wouldn't get all the food and drink I need, but I don't think there would be a risk to my health
- I wouldn't get all the food and drink I need, and I think there would be a risk to my health

10. Which of the following statements best describes how clean and comfortable your home is?

- My home is as clean and comfortable as I want
- My home is adequately clean and comfortable
- My home is less than adequately clean or comfortable
- My home is not at all clean or comfortable

11. Do the support and services that you get from Social Services help you to keep your home clean and comfortable?

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above)

- Yes
- No
- Don't know

If 11= yes then

12. Imagine that you didn't have the support and services from Social Services that you do now and no other help stepped in. In that situation, which of the following would best describe how clean and comfortable your home is?

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above) It is important that people do not base their answers on the assumption that any help steps in, please emphasise this to interviewees. (Reassure if necessary: please be assured that this is purely imaginary and does not affect the services you receive in any way.)

My home would be as clean and comfortable as I want

My home would be adequately clean and comfortable

My home would be less than adequately clean or comfortable

My home would not be at all clean or comfortable

13. Which of the following statements best describes how safe you feel?

By feeling safe we mean feeling safe both inside and outside the home. This includes fear of abuse, falling or other physical harm and fear of being attacked or robbed

I feel as safe as I want

Generally I feel adequately safe, but not as safe as I would like

I feel less than adequately safe

I don't feel at all safe

14. Do the support and services that you get from Social Services help you to feel safe?

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above)

Yes

No

Don't know

If 14 = yes then

15. Imagine that you didn't have the support and services from Social Services that you do now and no other help stepped in. In that situation, which of the following would best describe how safe you feel?

*NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above)
It is important that people do not base their answers on the assumption that any help steps in, please emphasise this to interviewees.
(Reassure if necessary: please be assured that this is purely imaginary and does not affect the services you receive in any way.)*

I would feel as safe as I want

Generally I would feel adequately safe, but not as safe as I would like

I would feel less than adequately safe

I wouldn't feel at all safe

16. Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?

I have as much social contact as I want with people I like

I have adequate social contact with people

I have some social contact with people, but not enough

I have little social contact with people and feel socially isolated

17. Do the support and services that you get from Social Services help you to have contact with people you like?

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above)

Yes

No

Don't know

If 17 = yes then

18. Imagine that you didn't have the support and services from Social Services that you do now and no other help stepped in. In that situation, which of the following would best describe how much contact you have with people you like?

*NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above)
It is important that people do not base their answers on the assumption that any help steps in, please emphasise this to interviewees.
(Reassure if necessary: please be assured that this is purely imaginary and does not affect the services you receive in any way.)*

- I would have as much social contact as I want with people I like
- I would have adequate social contact with people
- I would have some social contact with people, but not enough
- I would have little social contact with people and would feel socially isolated

19. Which of the following statements best describes how you spend your time?

If respondent needs prompting please say: When you are thinking about how you spend your time, please include anything you value or enjoy including formal employment, voluntary or unpaid work, caring for others and leisure activities.

- I'm able to spend my time as I want, doing things I value or enjoy
- I'm able do enough of the things I value or enjoy with my time
- I do some of the things I value or enjoy with my time but not enough
- I don't do anything I value or enjoy with my time

20. Do the support and services that you get from Social Services help you to spend your time doing things you value and enjoy?

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above)

- Yes
- No
- Don't know

If 20 = yes then

21. Imagine that you didn't have the support and services from Social Services that you do now and no other help stepped in. In that situation, which of the following would best describe how you spend your time? Please assume that any other help you currently have would remain the same.

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<...>> (filled in as above) It is important that people do not base their answers on the assumption that any help steps in, please emphasise this to interviewees.

(Reassure if necessary: please be assured that this is purely imaginary and does not affect the services you receive in any way.)

I would be able to spend my time as I want, doing things I value or enjoy

I wouldn't be able to do enough of the things I value or enjoy with my time

I would do some of the things I value or enjoy with my time but not enough

I wouldn't do anything I value or enjoy with my time

22. Which of these statements best describes how having help to do things makes you think about feel about yourself?

Having help makes me think and feel better about myself

Having help does not affect the way I think or feel about myself

Having help sometimes undermines the way I think and feel about myself

Having help completely undermines the way I think and feel about myself

23. Thinking about the way you are helped and treated, and how that makes you think and feel about yourself, which of these statements best describes your situation?

The way I'm helped and treated makes me think and feel better about myself

The way I'm helped and treated does not affect the way I think or feel about myself

The way I'm helped and treated sometimes undermines the way I think and feel about myself

The way I'm helped and treated completely undermines the way I think and feel about myself

Appendix 2: Acronyms

ASCOT	Adult Social Care Outcome Toolkit
BWS	Best-Worst Scaling
DCE	Discrete Choice Experiment
IBSEN	Individual Budget Evaluation
OSCA	Outcomes of Social Care for Adults
POW	Production of Welfare
QMF	Quality Measurement Framework
SCRQOL	Social Care Related Quality of Life
SG	Standard Gamble
TTO	Time Trade-Off
UES	User Experience Survey
YA UES	Younger Adults User Experience Survey