

Measuring the outcomes of low-level services: Final report

‘Measuring Outcomes for Public Service Users’ Project

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1. Introduction

1.1 Background

Decisions about how limited resources are used in social care must reflect some underlying set of aims and objectives that act to prioritise which people with needs receive support, the form of this support, and its intensity. The Government and the sector have clearly signalled that a key aim should be the improvement of the *outcomes* of people using services (Commission for Social Care Inspection, 2006; Department of Health, 2006; Office of the Deputy Prime Minister, 2006; Wanless, 2006). Broadly speaking, outcomes are the valued consequences of social care support for service users and other people. The outcome of service use in this case is the improvement in *wellbeing* or *quality of life* that people experience. Therefore, measuring wellbeing outcomes, rather than units of service *output* (e.g. the numbers of care home placements), gives us a much better indication of *value*. Estimates of the value of services and support can then be set against their costs to inform *cost-effectiveness*, access and equity issues when prioritising resource use. In particular, an outcomes measure would have at least three uses in social care:

- to allow outcome-based commissioning
- to support the regulation of providers of social care, ensuring a minimum standard of care according to the outcomes the care generates for service users
- to allow the National Accounting of social care spending and output to be adjusted for the outcomes-related quality of care provided

The challenge is finding a way that enables us to robustly and consistently measure outcomes, where we anticipate that social care can impact not only on **people's personal care**, dignity and safety, but also on their emotional wellbeing and quality of life more generally. The focus for this project is on how outcome tools can be developed and applied to low level services. Other PSSRU projects in the '**Measuring Outcomes for Public Service Users**'¹ (MOPSU) project are considering applications to care homes and to information and advice services. The MOPSU project was funded for three years by the Treasury under Invest to

¹ Formerly Quality Measurement Framework (QMF) project

Save Budget and is led by the Office for National Statistics (ONS). The MOPSU project consists of three work-strand working towards the overall aims of:

- more efficient and effective commissioning and procurement of services, placing the issues of quality and value for money at the heart of the decision-making process
- **encouraging the use of 'outcomes' measures to assess the impact of services** on their users, across the spectrum of providers
- examining the extent to which the third sector is involved in public service delivery and helping to alleviate barriers to entry to third sector organisations

The focus on low level services is highly relevant because these services impact on the more intangible quality of life domains, but very little research has been undertaken in this area. More intensive services, such as care home services, have a stronger *prima facie* impact on personal care domains even if to date there has been little research work actually quantifying the impact. Care home services impact on the more fundamental domains of quality of life, such as being clean, fed and transferred out of bed or out of a chair. Low level services do not attend so closely to these basic needs, but offer potential outcomes by improvements in people's social life, activities, sense of independence and so on. **There is also an argument that low level services can have a 'preventative effect'**, that is, rather than just helping people to overcome impairment and need, they help delay the onset of greater need by encouraging people to stay independent and giving people the confidence to undertake activities of daily living by themselves (see annex 1). However, while low level services are important the present prioritisation of resources by councils (e.g. applying eligibility criteria on the basis of need) implies relatively low resourcing of these services.

1.2 Day care centres

As outlined in our initial and interim reports (Forder et al., 2007, 2008), we focus our attention on day care centres for older people, for the low level services project. Day care centres were chosen because they are a good example of low level services that still receive mainstream public funding. Also, the third sector plays a significant role in the provision of day care centres. Another reason is that some commentators regard this as an under-rated service (Wanless, 2006). Day care involves a variety of activities and caters for a range of people with differing

levels of needs and dependency. It is also valued by carers (by offering carer respite). In 2007/8 councils spent £360m on day care for older people in England.

1.3 Aims and objectives

The principal aim of the research was to develop and validate an approach to measuring the impact of low-level services on service users, specifically day care centres. Specific aims of the overall project were to:

- identify key domains of outcome valued by service users and also indicators of the *quality* of these services
- develop practical measures to determine the level of outcomes services deliver
- test these measures, including developing a set of evaluation criteria with which to rate the performance of the toolkit
- develop a general approach for commissioners and funders to determine and monitor the value of the output of low-level services (day care) services
- develop some practical criteria to help guide commissioners to cost-effectively secure valued outcomes (see section 6.1)
- enhance understanding of the role of low-level services and the outcome domains (and levels within these domains) that the services address

Broadly, addressing these aims involves two steps. The first step is to develop practical outcome measures of people's quality of life that can potentially reflect the value of service use. The aim is to find measures that are sufficiently sensitive and comprehensive in measuring changes in quality of life resulting from service use, and that are also relatively low cost to administer. This is the *specification* problem.

The second step is to find ways to isolate the changes in peoples' quality of life that stem from service use, that is, to find the actual difference in quality of life produced by services. Levels of quality of life will vary between individuals and also at different points in time with service use being only one contributing factor. Therefore, we need to establish how much of the variation is due to using services rather than other factors. This is the *attribution* problem.

Together these steps are used to produce an outcomes toolkit, the Adult Social Care Outcomes Toolkit (ASCOT), containing outcome measures and a method for

applying them to produce outcomes information for commissioning (and other) purposes. The third of the above aims, testing, is particularly important and most of the work reported here is focused around ensuring that the outcomes toolkit is fit for purpose. The main fieldwork of this project was primarily aimed at testing, but also produced outcomes information on day care which can be used to illustrate how such information can be used for commissioning decisions.

1.4 Study design

The work reported here was built on previous research (Netten et al., 2006) that fed into the Atkinson review of the measurement of government outputs and productivity for the purposes of National Accounts (Atkinson, 2005). It also draws on other research e.g. the analysis of home care services for development of the Relative Needs Formula (Darton R et al., 2006) and the user experience survey for younger adults project (Malley and Cox, 2007). The Atkinson work developed an approach which uses research findings and routinely collected information to identify the value of services in terms of their potential to achieve (called *capacity for benefit*) and the degree to which this is achieved (quality).

The capacity for benefit approach aims to attribute well-being changes at the service or intervention level rather than the individual level. The capacity for benefit measure represents the potential of the service or intervention to deliver outcomes according to the domains of social-care-related quality of life that the service affects, the degree to which users are reliant on that service (i.e. compared to their functionings state without the service) and the quality of the service.

This project comprises four different research phases:

- initial instrument design and sample frame development – the development phase
- exploratory work with day care providers – piloting phase
- fieldwork for evaluation and testing of toolkit – main fieldwork phase
- analysis and reporting phase

Using a range of theories that have been developed from health economics through to psychology, this project aimed to identify what outcomes are important to people and how they can be specified. The main result of the

development phase was to refine a tool for measuring outcomes, ASCOT, which is described below.

The main fieldwork phase involved a survey of low level service users. Participants were asked to return a self-completion questionnaire (SCT) to the research team, and in that process, consent (or not) to being interviewed face-to-face. The SCT collected information on user characteristics and need, and administered the ASCOT to collect outcomes information. The interview repeated the collection of this information as well as including a more comprehensive set of outcomes questions, demographics and dependency measures.

Having people complete a SCT and take part in an interview enabled us to test the validity and reliability of the SCT using the interview data. We were also able to use the interview to explore the relationship between needs and wellbeing, and apply the findings to the SCT data. Furthermore, using both the SCT and interview, we were able to generate a sizeable baseline of detailed information on the wellbeing of people using day care centres.

In this report, quantitative data are used first to describe service usage (sex, age, ethnicity, current levels of dependency) and the impact that services have on users (outcome measures using the ASCOT). These data are then interrogated using statistical techniques to assess whether findings are significant and can be **relied upon, and to assess the reliability, validity and general 'fitness for purpose'** of the toolkit. Qualitative data were used in two ways.

- To describe the mechanisms, concepts, processes and other factors that contribute to the benefits for users of using day care centres (see Forder et al., 2008)
- To test the toolkit in terms of assessing its relevance for users as well as developing the structure and wording of the SCT

We commissioned the British Market Research Board (BMRB) to undertake the sampling and interviews in the main stage of the project.

2. Conceptual development

2.1 Why, and which, outcomes should be measured

Earlier conceptual work completed as part of this project and described in our interim report (Forder et al., 2007) provided a method or approach that could be used to address the project aims. It underpins the design of the ASCOT. As explained in section 1.1, and as suggested by development work, the goal or outcome of service use is the improvement in *wellbeing* or *quality of life* that people experience, so for particular services we aim to measure the improvement in quality of life, the *outcomes*, they confer to service users.

In our previous work we argued that outcomes reflect our fundamental motives i.e. quality of life, wellbeing, happiness, utility and so on. These are hard to define specifically enough to allow a measurement framework to be developed. Instead, we break down these fundamental motivations into important components or *domains*. The development work identified the activities and opportunities regarding quality of life that are most relevant in the case of social care. These are the domains that constitute our measure of social care-related quality of life² and are listed in Box 2.1.

Box 2.1 ASCOT domains for low-level services

Personal cleanliness; Safety; Meals and nutrition; Activities/occupation; Control over daily life; Social participation; Home cleanliness and comfort; Anxiety; Dignity and respect

2.2 Measuring current quality of life

Having identified relevant domains we then need people to be able to rate their experiences within each one. The main choice here is whether we ask people directly to give their own *subjective* evaluation of their experience for each domain, or whether we infer this from a more *objective* measure. With the former

² For brevity we often use the term 'quality of life' when more precisely what we are measuring is social-care-related quality of life.

we ask people to rate on a scale ranging from 'good' to 'bad', where they are drawing on their own frame of reference about what these levels mean. These subjective measures relate directly to a person's *capabilities* i.e. the extent to which their economic, physical and physiological environment allows people to choose their experiences. As the concept of 'bad' relates to an individual's own assessment, it follows that that person would not choose to be in such a situation unless they had no choice.

A more objective scale tries to use a more universal frame of reference to rate an experience. For example, instead of asking people how good their social life is, we ask how often they have contact with people they are fond of. In this case, we are rating between 'high' and 'low' (rather than good and bad). But this means that a person could rate such an indicator as low but also subjectively see this as a good situation e.g. a person that prefers their own company is happiest with low social contact.

We can more explicitly link the rating of subjective scales to capability by asking people whether the relevant experience is at the level they 'want' rather than if it is 'good'. Instead of 'bad' experiences, we can ask if their experience was below the level they want. This latter approach emphasises capability constraints, although it remains very closely aligned with the more general 'good' versus 'bad' approach.

There is a risk that people may never feel that their experiences are as good as they want because they could always want more. For example, if a person's ideal situation **far exceeds what might be regarded as 'normal' (e.g. a social life to rival a Hollywood star)** then it is likely that they would never achieve a level that they would regard as **'as good as they want'**. We assume however that people evaluate achieving their desired level within a perception that their capability set is 'normal' for a person in that position. It is only when people feel their capability is more limiting than it ought to be that they rate down their experiences. In other words a 'good' level of capability allows people to achieve the experiences they want.

This is the approach used for the ASCOT and tested with the data from the fieldwork, as described below. The rating of the current level of social-care related quality of life is done by people either in an interview or using a SCT. The

full set of questions used in ASCOT is given in Annex 2, but take the general form of the examples in Box 2.2.

Box 2.2 Example current rating questions

Thinking about your home, which of the following statements best describes your present situation?

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

Which of the following statements best describes your social situation?

By social situation we mean keeping in touch with people and spending time with people that you want to be with.

- My social situation and relationships are as good as I want
- Sometimes I feel my social situation and relationships are not as good as I want
- I feel socially isolated and often feel lonely

Suppose we think of a 'good' capability set (which we can call Q_j^* for person j).

The experiences people choose in this context are at the levels they want. The rating of the relevant domain is therefore the desired level b_{zj}^* (where there are z domains, which in the ASCOT case $z = 9$ - see Box above).

The ASCOT (day care) measure uses 3 levels for each subjective domain. People rate domains at either:

- the desired level ($b_{zj} = b_{zj}^*$) or
- an 'adequate' level i.e. below the desired level, but above a self-rated cut-off point below which experiences are rated as very poor ($b_{zj}^* > b_{zj} > \underline{b}_{zj}$) or
- the very poor level ($b_{zj} \leq \underline{b}_{zj}$)

2.3 Combining quality of life domains

We need to be able to 'add-up' people's social-care related quality of life rating across all the domains in order to come up with an overall social-care related

quality of life rating. This requires importance weights for each level within each domain. In other words we need to know how a person might compare the value of a poor rating on one domain with a good rating on another – in particular, how much better is the good rating compared with the poor one? As detailed in our previous interim report (Forder et al., 2007), we use a technique called *preference weighting*. This technique involves having a large sample of people make a series of discrete choices between sets of domains at different levels. One version – *Best-Worse scaling* – has people pick the best and worse domain rating from a list of selected possibilities. This experiment is repeated for sample participants until a sufficiently large number of choices have been made. The frequency of choice of each domain level combination compared to the others gives a relative importance. With a large sample this process gives population weights for each level of each domain (which we denote α_z). These are applied to the experience rating of services users to give a utility score for that person:

$$b_j = \alpha_1 b_{1j} + \dots + \alpha_z b_{zj} + \dots + \alpha_9 b_{9j}.$$

2.4 Isolating the impact of service use

The final step of the ASCOT approach is to apply this value measurement method to specifically determine the impact of service use on social-care related quality of life. The general nature of the quality of life domains makes it clear that many factors in people's lives can affect them, in addition to services. Isolating the impact of services requires us to establish the counter-factual, that is, what would the person's quality of life be in the *absence* of the service. This is called the *attribution* problem. For example, it is entirely possible that some people's quality of life would improve even if they did not have the service – e.g. through informal care or improvements in their condition. We would not want to attribute this effect to the service.

A simple 'before-and-after' method could easily give misleading results. Ideally, we would randomly select a control group of people that did not have the service and compare their level of quality of life with those in the service group. This type of study is, however, expensive and may present ethical difficulties as access to services which could improve wellbeing is being denied.

Another option in social care is to ask people directly what they expect their quality of life would be in the absence of services. This option is less robust, but

far more practical, and therefore more useful in routine applications. These questions could be posed in interviews, with people asked to rate their *expected quality of life* if the service (here day care) had not been used (and nothing, such as informal care, stepped in to replace it).

A further version, the lowest burden option, is to have people only rate their current social-care related level of quality of life and also supply information on their needs and other service use. This approach requires us to have established the relationship between need factors, other service use and expected quality of life in bespoke, one-off studies. Previous studies have suggested a close relationship exists which means that need factors – e.g. peoples’ ability to carry out activities of daily living (ADLs) without help – are good predictors or markers of expected quality of life. Since these are relatively simple (and well established) questions to ask, self-completion questionnaire approaches are likely to be sufficient; this is the approach we have used here. The aim of the interview data is to provide estimates of the relationship between needs indicators and expected social-care related quality of life. We will assess whether this is a viable methodology.

3. Methodology

Our data collections have been designed to correspond to the conceptual approach set out above.

- First, the focus groups and pilot interviews with service users aimed to **capture users' views on what** domains we should measure
- Second, cognitive testing with service users was used to test the understanding of potential participants about the questions and their meaning
- Third, the SCT was designed to collect information on (a) current quality of life and (b) markers of expected quality of life (i.e. in the absence of services), which mainly include ADL need measures
- Finally, the face-to-face interviews with users sought to collect a comprehensive bank of existing and alternative outcome-related measures (e.g. the EQ5D health-related quality of life measure) for validation/comparison purposes with ASCOT. These measures were also used to ascertain the best markers of quality of life in the absence of services (expected quality of life)

3.1 Pilot phase

The pilot work, reported fully in the initial and interim reports (Forder et al., 2007, 2008), was carried out in two day care centres, identified in collaboration with Age Concern England (ACE) and targeted because of their location (Kent) **and because they were recommended as 'research friendly' by ACE. Due to an** internal audit that was being conducted at the time of the pilot work, four other sites identified were unable to take part; this was not a problem as we had initially agreed to conduct the pilot work with two centres.

The aim of the pilot phase was to assess the validity of the ASCOT and a summary of the findings are presented below. More detailed findings from this phase of the work can be found in the second interim report (Forder et al., 2008). A number of methods were used in this phase of the work, these were:

- consultation with service users (using focus groups)
- consultation with stakeholders (interviews and focus groups with managers and care workers)

- cognitive testing with service users

Overall the outputs from this phase were a piloted questionnaire in two formats, interview and self-completion.

3.1.1 Focus groups with service users

The purpose of conducting focus groups with service users was to gather data on their perspectives on how services (generally) help them and to examine whether the way (or process) in which this help is delivered is important to users. These groups were also used to identify the outcome domains that were most effected by day care centres from the perspective of users. In other words, which outcome domains were improved the most, or were perceived by users as the most important to improve, by using day care centres. Analysis of the focus groups was based on the narrative generated. This was analysed thematically using a process of generating codes and sub-categories. Focus group analysis also assessed whether the right set of functionings or outcome domains were being used for gauging the value of day care centres.

In general, participants who took part in the focus groups had a high regard for the services they were accessing. This may of course be regarded as unsurprising due to service usage reflecting the needs of users. Nonetheless the findings from **the focus groups highlight the different aspects or domains of people's lives** where low-level service provision, specifically day care, can have an effect on the wellbeing of its targeted recipients.

Users of day care centres overwhelmingly reported that their reason for accessing these was for social contact. Users placed high value on having contact with others of a similar age and with shared experiences and expressed that these experiences gave them support in other areas of their lives such as having a **'sense of purpose' and 'something to look forward to'**.

Personal care was also an area that users placed high value on in terms of the support that was offered by services. Services such as bathing, chiropody and hairdressing were examples of services that users felt they would be unable to access (either due to cost or unavailability) without the support of day care centres. Further to this, respite for carers and support (either at home or at

centres) after major life events were reasons given by users for accessing services, as well as help with filling in forms and other administrative tasks.

3.1.2 Focus groups with service providers

The purpose of conducting focus groups with service providers was to explore **providers' views** of the services that they are involved in delivering and the **perceived differences that services make to users' lives**. Another aim of these groups was to explore the concept of outcome domains with providers in relation to day care centres. Here it was important to ensure that these were appropriate to **'capture' the effects of services on people's** quality of life. Focus groups with provider staff were also used to feed into the design of the main service user questionnaire.

Users' views of why they used day care centres and indeed **what areas of peoples' lives** services could have an effect on were largely mirrored by those of providers. Providers saw the purpose of services as a means of social engagement as well as providing personal care. Providers also identified day care centres as a kind **'intelligence hub' where users could be signposted to further services if they** presented with any issues that day care centres were not able to manage. **Providers also expressed a sense that services could have a 'preventative' effect** on some users, specifically in terms of the onset of depression and anxiety for people living at home on their own.

As a result of these findings and in light of the importance attributed to the social contact element by both users and providers, this element of ASCOT was further **developed to reflect users' and providers' views**.

3.1.3 Cognitive interviewing

Cognitive interviewing is a method used to critically evaluate the transfer of information (e.g. from questionnaire to person). More specifically, cognitive interviewing techniques are used to examine the manner in which targeted audiences understand, mentally process, and respond to materials that are presented to them (Willis, 2005). Cognitive interviews focus on participants' thought processes in answering a question; in particular people's comprehension, recall, decisions and judgement, and response processes. The overall aim of this part of the pilot work was to test **people's understanding of the questions in**

terms of whether the answers they elicit are consistent with our theoretical concepts regarding functioning states. The process was also designed to detect any problems people may have in answering questions.

In total 10 cognitive interviews with service users were conducted in developing questions for the SCT. This was an iterative process with refinement of questions during the fieldwork period. As a result of the cognitive interview phase a number of changes were made to the wording and structure of both the SCT and the face-to-face interview. These included testing the **feasibility of two 'occupation' domains broken down into 'leisure activities'** (interests, hobbies, pastimes, entertainment) **and 'purposeful activities'** (work, caring for others, voluntary activity, spiritual activities). This split domain was not successful as participants found it difficult to divide and compartmentalise their day-to-day activities into **such defined categories. As a result the combined 'activities' domain was** developed in order to reflect these findings.

As well as testing and re-organising the domain structure, many words and phrases included in the provisional toolkit were re-designed and then re-tested until participants were happy with their meaning. The interpretation and understanding of questions and possible responses is crucial in developing a valid tool with which to measure the outcomes of day care centres. An example of the raw data generated by the cognitive interviewing process can be found in Annex 3.

3.1.4 Analysis of alternative wellbeing measures

As part of the pilot phase we also undertook an analysis of the Health Survey for England (HSE) 2005 data to explore the performance of a number of commonly used wellbeing measures and to assess attribution in a non-randomised survey design. Detailed findings from this work can be found in the second interim report (Forder et al., 2008). In summary the analysis showed that the Quality Adjusted Life Year (EQ5D, adjusted) and the general health questionnaire (GHQ12) are quite sensitive to the effects of low-level services, and produce consistent results (even over re-sampled data). The conclusion here is that with good specification of need, the HSE and other data on non-randomised control groups can be useful in testing the ASCOT toolkit. This will be discussed and further developed later in the report.

3.2 Main fieldwork phase

3.2.1 Sampling frame

At the time of the study there was no existing national register of providers of day care. Therefore one of the methodological challenges involved in undertaking this project was to develop and build a list of providers of day care centres from which to sample from.

The sample frame was constructed by a postal survey of all 150 Councils with Social Services Responsibility in England (CSSRs). Each CSSR was asked to provide details of all the organisations that they contract to provide day care (see Annex 4). Of these 31 replied and provided information on a total of 497 providers which made up the sample frame. Descriptive information about the individual services provided was also included by 102 services. Examples of the types of service available to users included: nail cutting; hairdressing; lunch; activities (such as dancing, cards, bingo); bathing and cooking lessons.

3.2.2 Recruitment of providers and users

From the sample frame of 497 service providers 100 were randomly selected to take part in the study. Each provider was initially contacted by telephone to ask if they would be able to take part in the study. The interview schedule used to recruit providers to take part in the study can be found in Annex 5. Taking part for providers involved receiving up to 50 recruitment packs (depending on the size of the day care centre and the number of users using the service per week). Providers were then asked to distribute the recruitment packs to users that met the inclusion criteria for taking part in the study. These criteria comprised being aged 65 years and over and having sufficient cognitive functioning to understand the informed consent process and be able to participate in a face-to-face interview with a researcher. Recruitment packs were made up of the SCT (see Annex 2), a letter inviting people to take part in the study (Annex 6), and a participant information sheet explaining in detail what was involved for users taking part (Annex 7).

At the beginning of the project it was anticipated that 100 providers would yield a return of 1000 SCTs completed by users and 250 face-to-face interviews with service users. These would be generated from 5000 recruitment packs handed

out by all service providers taking part, a response rate of 20% and 25% respectively. However, a number of service providers were not able to hand out 50 recruitment packs due to their size and the number of service users that they provide services for. The mean number of recruitment packs that were handed out by each provider was 37, therefore it was necessary to recruit an additional 37 service providers to take part in the study to ensure that 5000 recruitment packs were sent out to providers to recruit a sufficient number of service users to the study. This was exceeded and the final number of recruitment packs that were handed out to users via service providers was 5029.

The 137 providers were situated across eight Government Office Regions (GORs), see Table 3.1, and across 29 local authorities³.

Table 3.1 Government Office Regions (GORs) that took part in the study

Government Office Region (GOR)	Number of providers
North East	10
North West	31
Yorkshire and The Humber	29
East Midlands	7
West Midlands	24
East of England	0
London	2
South East	15
South West	19
Total	137

The packs distributed to providers yielded a total of 961 valid responses and returned SCTs from participants, a response rate of 19%. A valid response was deemed to be someone who had correctly completed 10 or more questions of the SCT, however, only those participants that had correctly completed 18 questions of the SCT were asked to take part in a face-to-face interview. This was to ensure that valid comparisons could be made between participants' SCT responses and responses in the face-to-face interview.

³ Two of the 31 local authorities who initially responded dropped out after the sampling

3.2.3 Face-to-face interviews

The final question of the SCT asked users whether or not they would be prepared to take part in a face-to-face interview with a researcher. Participants that answered yes were asked to provide contact details so that a researcher could contact them within a two week period to arrange and conduct the face-to-face interview. Of the 961 participants who completed and returned a valid SCT, 262 participants stated that they would be prepared to take part in a face-to-face interview, a response rate of 27%. During the process of conducting these interviews however, 38 participants opted out of the face-to-face interview (an attrition rate of 15%), meaning that 224 participants agreed to (and took part in) a face-to-face interview, leaving a final response rate of 23%. The reasons that people dropped out of participating in an interview are listed in Box 3.1 below.

Box 3.1 Reasons for attrition

Moved – no forwarding address
No contact
Refusals
Physically/cognitively unable
Ill at home
Away or in hospital
Inadequate English
Participant deceased
Other unproductive

The face-to-face interview comprised 72 questions (see Annex 8). The interview was designed to allow a more comprehensive assessment of outcomes for users **including 'in the absence of service' questions in order to create a baseline measure for comparing participants' outcomes. More detailed demographic and socio-economic data, dependency measures and service usage data were also collected here. As well as being valuable in terms of validating the SCT, these data were collected in order to examine any relationships that may exist between socio-economic status and outcomes.**

A number of established and standardised health and wellbeing measures were also included in the face-to-face interview. These included:

- the EQ5D measure (Dolan et al., 1995)
- a single (global) quality of life measure using a seven-point scale (Bowling, 1997)
- activities of daily living (ADLs) (e.g. getting dressed, in/out of a chair, washing, preparing meals, walking)
- different types of activities known as *instrumental* activities of daily living (IADLs) (e.g. dealing with finances/paperwork with or without help).
- a single (global) health measure using a five point scale (Bowling, 1997)

Measures of satisfaction and quality of care were also incorporated in the face-to-face interview, these were based on indicators used in previous national surveys of service user experiences (Jones et al., 2007).

Six participants that volunteered to take part in a face-to-face interview did not speak English. For these participants a translator was employed to enable them to take part.

Table 3.2 shows the number of face-to-face interviews that were conducted in each Government Office Region (GOR) from a number of different providers. It also shows how many SCTs were completed and returned from each GOR.

Table 3.2 Number of interviewees in each local authority

Government Office Region (GOR)	Number of Interviewees	SCTs completed
North East	6	16
North West	9	109
Yorkshire and The Humber	57	277
East Midlands	15	60
West Midlands	66	200
East of England	0	0
London	5	11
South East	36	168
South West	30	120
Total	224	961

Table 3.3 provides a summary of the response rates from each phase of the study.

Table 3.3 Response rates

Item	Number	Response rate (%)
Recruitment Packs Distributed	5029	-
Valid SCTs returned	961	19
Face-to-face interview volunteers	262	27
Face-to-face interviews completed	224	23

3.2.4 Ethical considerations

Care was taken in designing this study to ensure that all participants, from service users to frontline care workers, managers and commissioners were given full information about the study. They were also made fully aware of their right to refuse or withdraw from the study at any time, and were made fully aware of the confidentiality with which all data would be treated. Consent to participate in the study was obtained from all service users (either directly or by proxy) for all fieldwork that was carried out.

All participants were assured that data from them would be treated in absolute confidence and at no point would individual users be identified. Only those who were specifically assigned to work on this project had access to the data collected. Electronic data were stored on a password protected database at the PSSRU while hardcopies were stored in a locked filing cabinet at the PSSRU.

Risks to participants

The areas addressed in the interviews and questionnaires were not considered to be of an exceptionally personal nature. However, the interviews and questionnaires did contain questions regarding participants' **views of themselves and their current 'life situation'**. Therefore, it was possible that some participants may have found reflecting on any problems that they had, or had recently, distressing.

Prior to interviews being conducted, participants were reminded that they were not required to answer any questions that they felt uncomfortable with, and that they were free to terminate the interview, without giving a reason, and without affecting any of the services that they currently receive.

Instructions for those that completed a SCT stated that they need not answer questions if they did not wish to, and that they were under no obligation to take part in the study. Further to this, participants were free to withdraw from the study at any point, without giving a reason, and without affecting any of the services that they used or received.

During the fieldwork period, no interviews were terminated part way through and no complaints or distressing incidents were reported.

Language issues

The aim of the study was to be as inclusive as possible. To this end, on six occasions it emerged that individuals were not able to take part due to language issues, here we engaged with community interpreters in order to capture the views of participants from black or minority ethnic groups. Participants were also free to have assistance in filling out the SCT, data were not collected on the numbers of people requiring assistance.

Participants unable to give informed consent

Prior to embarking on the fieldwork element of this study, it was considered likely that people accessing low-level services would have (relatively) low level needs and, therefore, would be able to understand the informed consent process. Any potential participants that were unable to give informed consent were excluded from the study. Participants unable to take part due to not being able to give informed consent were identified by providers.

4. Results and analysis

In this section we draw on the results of the main fieldwork phase – the SCT and face-to-face interview data. We report analysis:

- to determine the outcomes of people using day care from the interview data
- to estimate the relationship between current quality of life and need
- to model the relationship between (expected) quality of life in the absence of services and need indicators
- to test the validity and reliability of the tool

In making these assessments it is important to understand the characteristics of the sample populations.

4.1 User characteristics

Demographic information was collected in both the SCT and face-to-face interview. The SCT was designed to be low-burden both for those administering it and those completing it. Therefore, it collected minimal information about participants. During the face-to-face interview stage we were able to collect more information about those who took part. This was more important at this stage to enable us to make comparisons for those who completed the SCT *and* took part in a face-to-face interview. For the purposes of describing the study population the SCT and face-to-face interview data will be treated separately, but participants that took part in a face-to-face interview also completed a (matched) SCT. Rounding is used in all tables and as a result percentage figures might not always equal 100.

4.1.1 SCT participants

Age and sex

Table 4.1 shows the age of the SCT participants. Of the 898 participants who stated their age, the majority (40%) were aged 75 to 84. Of these 67% were female and 32% were male. The second most frequent age group in the study population were those aged 85 and over (33%). Of these 71% were female and 28% were male. Twenty-two participants were aged under 65, despite this group

being excluded from the study criteria during the data collection period. These participants were included in the main sample, however, and they amount to only 2% of the study population. These participants were aged between 53 and 64 years and were split evenly in terms of sex. Sixty-three participants did not state their age. The mean age of people that took part was 81.

Table 4.1 Age of SCT participants

Age group	Number	Per cent
Under 65	22	2
65 to 74	175	18
75 to 84	383	40
85+	318	33
Not stated	63	7
Total	961	100

Overall in the study population 31% were male and 68% were female. As the age of participants' increases the ratio between males and females that took part in the study also increases. In part this reflects what we would expect to see in the national population figures for people of this age range (Office of National Statistics, 2008).

Table 4.2 Sex of SCT participants

Sex	Number	Per cent
Male	294	31
Female	649	68
Not Stated	18	2
Total	961	100

Household composition

Among the study population 63% stated that they live on their own (n=601) while 35% live with someone else (n=340). Of those who lived on their own 41% were aged 75 to 84 (n=247) and 38% were aged 85 years or over (n=228). Of those living with someone else 39% were aged 75 to 84 (n=131); 25% were aged 65 to 74 (n=84); and 24% (n=81) were aged 85 years or over. Twenty participants (2%) did not state what their living arrangement was.

Of those who stated that they lived on their own 76% were female (n=454) while 24% were male (n=141).

Table 4.3 Household composition of SCT participants

Household composition	Number	Per cent
Live on my own	601	63
Live with someone else	340	35
Not Stated	20	2
Total	961	100

4.1.2 Face-to-face interview participants

We were able to establish a more detailed picture of participants who completed a SCT and then also took part in a subsequent face-to-face interview.

Ethnicity

The majority of people that took part in the face-to-face interview stated that they were white- British (80%, n=179). The second largest group in ethnicity was 'white- other white background' (7%, n=15). Four participants stated that they were white- Irish (2%). In total the number of participants from black or minority ethnic groups was 25 (11%). One participant declined to answer.

Table 4.4 Ethnicity of face-to-face participants

Ethnicity	Number	Per cent
White- British	179	80
White- Other white background	15	7
White- Irish	4	2
Black or minority ethnic group	25	11
Not Stated	1	0
Total	224	100

Income

Table 4.5 below shows that 92 participants who took part in the face-to-face interview had a total annual income (after tax) of between £0 – £9,999 (55%). The next largest income bracket was for those earning between £10k - £19,999

(39%, n=65). Six people had an income of between £20k - £39,999 (4%) with four people having an income of £40k or more (2%).

Due to the sensitive nature of asking people about their income, it is perhaps unsurprising that 25% of participants stated that they either did not know or declined to answer this question (n=57).

Table 4.5 Face-to-face participants' total income after tax

Income	Number	Per cent
0 - 9,999k	92	55
10k - 19,999	65	39
20k - 39,999	6	4
40k or more	4	2
Total	167	100

Housing status

Almost half of the participants (49%) that took part in the face-to-face interviews were owner occupiers or had a mortgage (n=110). Forty per cent of participants were living in accommodation provided by either the local authority or the housing association.

Table 4.6 Housing status of face-to-face participants

Housing Status	Number	Per cent
Owner occupier / mortgage	110	49
Private rented	11	5
Provided by local authority / housing association	89	40
Live here rent free (including rent free in relatives' homes)	12	5
Other	1	0
Declined to answer	1	0
Total	224	100

Voluntary work

Thirteen per cent of those who took part in the face-to-face interviews said that they took part in unpaid voluntary activity of some kind. Of those that did 16 (57%) volunteered for 1-4 hours per week while 5 (18%) did between 5-8 hours per week and 3 people did 13 hours or more per week.

Table 4.7 Face-to-face participants involved in voluntary work

Voluntary work	Number	Per cent
Involved in voluntary work	28	13
Not involved in voluntary work	196	88
Total	224	100

Benefits

In the face-to-face interview we asked people about the benefits they were receiving. Overall 122 people were receiving two or more benefits (54%). Overall 114 people were receiving attendance allowance (51%), 20 stated that they did not know (9%); 105 people were receiving pension credit (or minimum income guarantee) (47%), 17 stated that they did not know (8%); 78 people were receiving housing benefit (35%), 13 stated that they did not know (6%); 50

people were receiving disability living allowance (DLA) for mobility (22%), 22 stated that they did not know (10%); 39 people were receiving DLA for care (17%), 26 stated that they did not know (12%); 28 people were receiving income support (13%), 19 stated that they did not know (9%); 7 people were receiving severe disablement allowance (3%), 24 stated that they did not know (11%); 7 people were receiving incapacity benefit (3%), 20 stated that they did not know (9%). No-one stated that they were on working / child tax credit, 5 people (2%) said they did not know.

Table 4.8 Face-to-face participants and benefits

Benefit	Number	Per cent
Attendance allowance	114	51
Pension credit (minimum income guarantee)	105	47
Housing benefit	78	35
Disability living allowance (DLA) for mobility	50	22
Disability living allowance (DLA) for care	39	17
Income support	28	13
Severe disablement allowance	7	3
Incapacity benefit	7	3

Health in general

Participants were also asked to self-report about their general health by asking a 'global' health question in the face-to-face interviews (Bowling, 1997). It was not anticipated that participants would report particularly poor levels of health here due to day care centres being a low-level service and therefore not directed at those with high levels of dependency. Table 4.9 illustrates this and shows that **76% of people reported their health as being between 'very good' to 'fair'** while only 3% people reported **their health as 'very bad'**.

Table 4.9 Participants' self-reported health in general

Health	Number	Per Cent
Very good	17	7.6
Good	60	26.8
Fair	94	42.0
Bad	46	20.5
Very bad	7	3.1
Total	224	100

4.2 Need

Overall, the participants that took part in the study had difficulties with 1.67 out of 5 ADLs on average.

Most participants (60%, n=572) reported that they were able to get dressed or undressed 'on your own'; 26% stated that they were able to get dressed 'on your own with difficulty' (n=252) and 12% stated that they could not get dressed 'at all on your own' (n=117). Two per cent either did not know or declined to answer (n=20).

Table 4.10 Whether able to get dressed / undressed ADL

Ability to dress	Number	Per cent
On your own	572	60
On your own with difficulty	252	26
Not at all on your own	117	12
Don't Know	7	1
Not Stated	13	1
Total	961	100

For getting in and out of bed or a chair most participants (65%) stated that they were able to get in and out of bed or a chair 'on your own' (n=622); 26% stated that they were able to get in and out of bed or a chair 'on your own with difficulty' (n=249) and 6% stated that they could not get in and out of bed or a chair 'at all on your own' (n=60). Four per cent either did not know or declined to answer (n=30).

Table 4.11 Whether able to get in and out of bed or a chair ADL

Ability to get out of a bed or chair	Number	Per cent
On your own	622	65
On your own with difficulty	249	26
Not at all on your own	60	6
Don't Know	5	1
Not Stated	25	3
Total	961	100

A large majority of participants who completed a SCT (75%) stated that they were able to 'wash your face and hands on your own' (n=721); 16% stated that they were able to wash their face and hands 'on your own with difficulty' (n=158) and 5% stated that they could not wash their face and hands 'at all on your own' (n=44). Four per cent either did not know or declined to answer (n=38).

Table 4.12 Whether able to wash face and hands ADL

Ability to wash face and hands	Number	Per cent
On your own	721	75
On your own with difficulty	158	16
Not at all on your own	44	5
Don't Know	4	0
Not Stated	34	4
Total	961	100

Participants were asked whether or not they could prepare hot meals 'on your own'; 'on your own with difficulty'; or 'not at all on your own'. The needs of participants were higher here than with the ADLs described above. Forty-four per cent stated that they could prepare hot meals 'on your own' (n=426) while 19% stated that they were able to prepare hot meals 'on your own with difficulty' (n=184). For this ADL 33% stated that they were not able to prepare hot meals 'at all on your own' (n=314) (the highest level of need). More participants reported this level of need here than the ADLs reported above. Four per cent either did not know or declined to answer (n=37).

Table 4.13 Whether able to prepare hot meals ADL

Ability to prepare hot meals	Number	Per cent
On your own	426	44
On your own with difficulty	184	19
Not at all on your own	314	33
Don't Know	5	1
Not Stated	32	3
Total	961	100

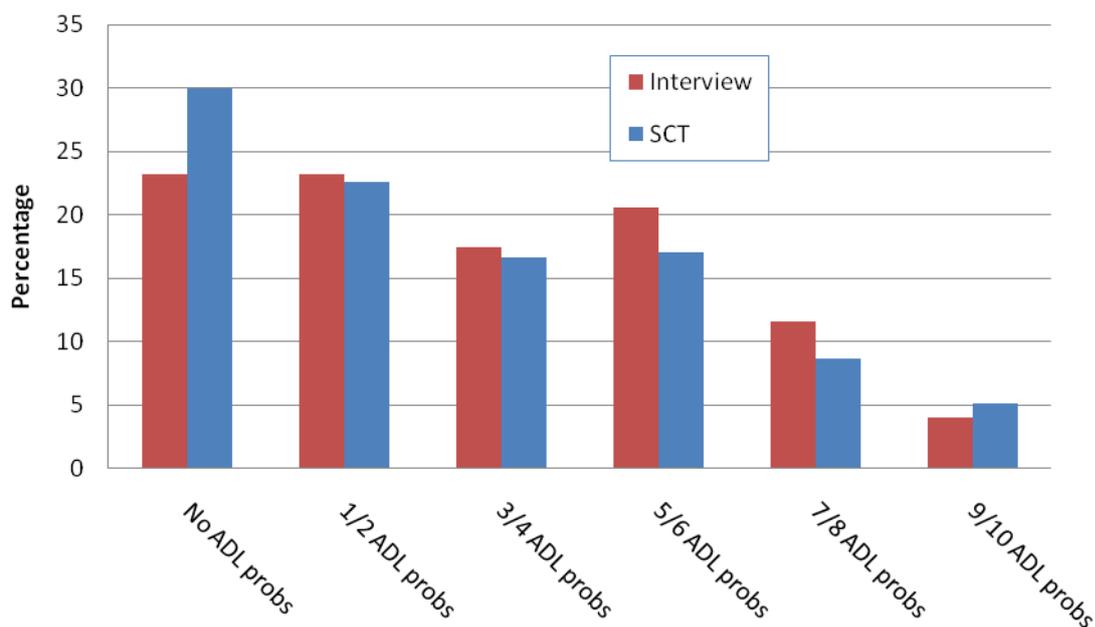
Walking at least 10 minutes was another ADL where participants reported slightly higher needs. Here 38% of participants stated that they could walk at least minutes 'on your own' (n=367) while 26% stated that they were able to walk at least 10 minutes 'on your own with difficulty' (n=253). For this ADL 32% stated that they would not be able to walk at least 10 minutes 'at all on your own' (n=308) (the highest level of need). Three per cent either did not know or declined to answer (n=33).

Table 4.14 Whether able to walk at least 10 minutes

Ability to walk for 10 minutes	Number	Per cent
On your own	367	38
On your own with difficulty	253	26
Not at all on your own	308	32
Don't Know	4	0
Not Stated	29	3
Total	961	100

The total number of ADL problems that people have from these 5 categories is a good indicator of need. Scoring 'with difficulty' at 1 and 'not at all' at 2, we summed over the 5 types of ADL problem. Figure 4.1 reports the percentages of people with different numbers of ADL problems. It shows that the SCT sample (n = 896) and the interview (n = 224) sub-sample were similar in terms of need which is good for comparative analysis of the study cohorts. The SCT sample has a marginally higher percentage of people with none and also with the highest number of ADL problems. Nonetheless as shown in figure 4.1 the interview sub-sample is a good reflection of the SCT sample. There was no statistically significant difference between the SCT and interview sub-sample.

Figure 4.1 Activities of daily living need



In both the SCT and interview samples, 35% of people also reported an inability to deal with finances and paperwork.

4.3 Satisfaction and global outcome measures

In the face-to-face interview participants were asked about their level of satisfaction with services, which can be seen as an indicator of service quality. In addition participants reported their current quality of life on a global scale and their health-related quality of life on the EuroQoL EQ5D scale (Brazier et al., 1999).

4.3.1 Satisfaction

In the interview, people were questioned about how satisfied they were with the support they got from day care centres. The results can be seen in Table 4.15. As is often the case with these questions, people reported very high levels of satisfaction overall. Those people reporting anything less than satisfied (i.e. 18 cases) can be taken as indicative of having a poor regard for the service.

Table 4.15 Reported satisfaction with day care centres

Satisfaction with support	Number	Per cent
very satisfied	129	61
quite satisfied	66	31
neither satisfied nor dissatisfied	11	5
quite or very dissatisfied	7	3

4.3.2 Global quality of life

People were asked 'how would you rate the quality of your life as a whole'. Table 4.16 gives the responses of people in the interview sample (1 person was unable to answer).

Table 4.16 Global quality of life

Quality of life	Number	Per cent
so good, it could not be better	5	2
very good	29	13
good	72	32
alright	84	38
bad	24	11
very bad	9	4

4.3.3 Health-related quality of life

The EQ5D measure is a well-established 5 domain composite outcome measure (Drummond et al., 2005). This indicator is focused on measuring the extent of personal impairment i.e. the extent to which the respondent is *unable* to do things for themselves and the extent of their personal pain and depression levels. ASCOT is set up to measure how well people function in spite of their impairment, where care support and services can help people. For example, EQ5D asks people if they have problems in carrying out activities like self-care, walking, 'usual activities' like work, family activities and so on. ASCOT asks not if people have problems with doing these things themselves but whether they are achieved or not (to a desired level), allowing for people to be helped in these activities. ASCOT also covers domains relating to social and emotional wellbeing to a

greater extent than EQ5D where previous preference analysis has shown these dimensions to be important to people.

EQ5D measures current outcomes. The outcome domains are:

- mobility
- self-care
- usual activities (such as work, study, housework, family or leisure activities)
- pain or discomfort
- anxiety or depression

Each domain has three levels ranging from no problems to extreme problems. We use standard weights for each level in each domain to aggregate for a composite score. The EQ5D score is anchored so that being dead has a score of 0 and being in full health has a score of 1. Negative values are possible, where some states are regarded as worse than death. Table 4.17 shows that the mean EQ5D score was 0.41 in the sample. Some 87% of people in the sample reported scores below 0.75.

Table 4.17 EQ5D Outcome scores

Mean	Std. Dev.	Median	Min	Max
0.41	0.35	0.52	-0.43	1.00

There is high correlation between EQ5D score and number of ADL problems that people report (as expected given the need-problem focus of EQ5D) – see Table 4.18

Table 4.18 EQ5D Outcome scores – by number of ADL problems

Number of ADL problems	Mean EQ5D
None	0.66
1	0.54
2	0.37
3	0.26
4	0.07
5	0.03

Despite the differences in emphasis, we would also expect ASCOT outcomes to be closely related to EQ5D outcomes. These correlations help us to judge the reliability of the ASCOT and we cover these issues below.

4.4 ASCOT Indicators

The ASCOT indicator was developed to capture a range of social-care related quality of life domains. In ASCOT there are three types of 'indicator' number:

- current quality of life
- expected quality of life
- outcome (current – expected quality of life)

4.4.1 Current quality of life

Current quality of life is where people are asked to rate their social-care-related quality of life at present in each of the 9 domains. The current quality of life score is calculated by attaching importance weights (in number form) to the chosen level for each domain and adding these numbers up. The results of an earlier preference study (Burge et al., 2006) provided importance weights for 7 of the 9 domains (with dignity and anxiety un-matched). These weights were estimated using the Best-Worst approach (see table 4.5 Burge et al., 2006). The Outcomes of Social Care for Adults (OSCA) project currently in progress is estimating preference weights and we used (unpublished) results from the preliminary study to infer weights for the remaining two domains. All of these preference weights will be updated using the results of the MOPSU preference study (Burge et al., 2010) when these are available.⁴

Table 4.19 gives the weights that we applied to each of the domains. For example, if a person reported that their personal cleanliness was at a desired level then this would be scored at 3.3. In this way all 9 domains are weighted and added up for a total score. The maximum possible score is 25.3 and the minimum possible is -2.5. The measure was rescaled by dividing the total by 25.3 (i.e. the best score is 1 and the worst is -0.1).

Table 4.19 Preference weights for domains and levels

⁴ This study is the final component of this work and was in progress at the time of writing.

Domain	Desired level	Adequate level	Poor level
Home cleanliness and comfort	2.8	1.3	0.2
Safety	2.5	0.6	-0.2
Meals and nutrition	2.4	0.9	-0.3
Personal cleanliness	3.3	-0.1	-0.8
Activities/occupation	2.7	1.0	0.0
Control over daily life	3.7	1.5	-0.9
Social participation	3.0	1.3	-0.5
Anxiety	3.0	1.0	0.0
Dignity and respect	1.9	0.5	0.0

This suggests that people are most concerned about being in control of their daily life and personal cleanliness and least concerned about dignity and meals and nutrition.

The results in table 4.20 show that current quality of life was 0.74 on average.

4.4.2 Expected quality of life

Expected quality of life is determined by asking people to hypothetically rate their outcome levels in each of the 9 domains if they were not able to access their day care centre. Again each domain is weighted using the weights in Table 4.19 and re-scaled.

Expected social-care-related quality of life was 0.56 on average.

4.4.3 Outcome

The third outcome number is the *outcome* or quality of life gain which is the difference between current and expected quality of life. It is possible that this number might be negative if expected quality of life without the service was better than current quality of life with the service i.e. if the service is thought to worsen a person's wellbeing.

The interview data includes both current and expected quality of life. We also asked people directly if they felt that the service helped with each of the nine outcome domains. If people reported that the service did help, their outcome

score is the difference between their current quality of life score and their expected quality of life score (see example in Box 4.1). If people reported that the service did not help, then the outcome is either 0 or if the difference is negative, then that number is used i.e. people felt that the service actually worsened their wellbeing.

Box 4.1 Calculating outcome

Person A rates themselves as being at the desired level for social participation: 'My social situation and relationships are as good as I want'. The outcome score = 3

They are then asked whether or not services help them achieve this level, person A says yes.

Person A is then asked to hypothetically rate where they think they would be on the same scale if they did not receive or access the services that were being delivered (in this case day care). This is their expected quality of life in the absence of services.

Person A chooses the adequate level for social participation: 'Sometimes my social situation and relationships would not be as good as I want'. The outcome score = 1.3

Person A's expected quality of life in the absence of services for social participation is worse than what they are currently achieving (by using the service). In other words they think that their level of quality of life (for social participation) would be worse if they were not accessing the service.

Person A's outcome is current level of quality of life (3) minus person A's expected level of quality of life in the absence of service (1.3) which equals 1.7.

Person A's outcome is calculated: $3 - 1.3 = 1.7$

Table 4.20 gives the level of current and expected quality of life and outcome. The mean improvement due to service use was 0.18. The distribution of the outcome measure is given in Figure 4.2. Just under 20% of people in the interview reported no outcome.

Table 4.20 ASCOT scores on social-care-related quality of life

ASCOT measure	Mean	Std Deviation	Min	Max
Current quality of life	0.74	0.20	0.08	1.00
Expected quality of life	0.56	0.29	-0.10	1.00
Outcome	0.18	0.21	-0.14	0.87

Figure 4.2 Distribution of outcome scores

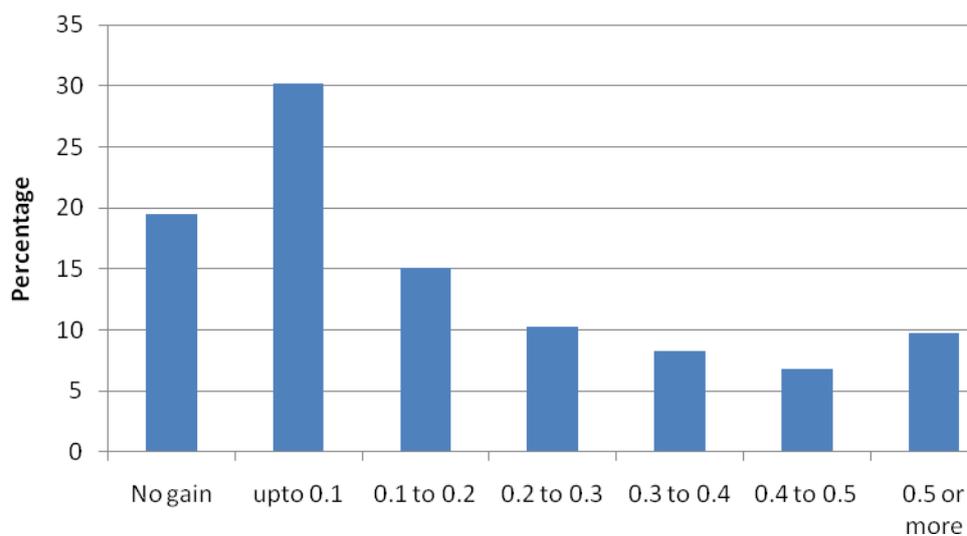
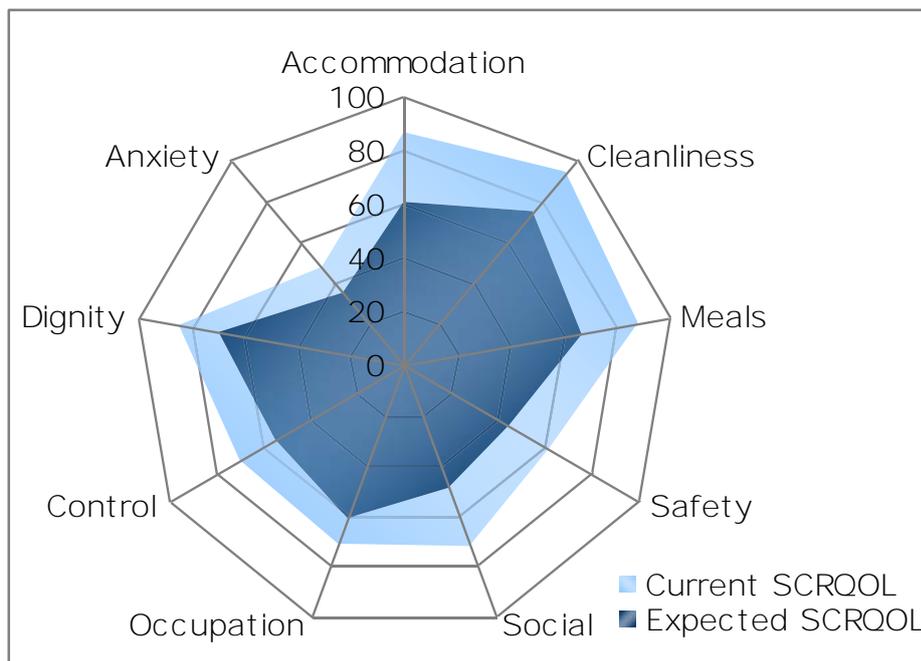


Figure 4.3 shows unweighted current and expected SCRQOL in each domain, for the face-to-face interview sample⁵, with 100 representing the best possible SCRQOL rating in each domain. The darker shaded area reflects the expected SCRQOL while the pale area shows the level of SCRQOL gain in each domain. This gives an indication of outcome; however, it does not take account of the relative importance of the domains and levels.

⁵ As noted, in view of the potential difficulty of the concept of expected SCRQOL and the aim to minimise burden, expected SCRQOL was only collected from the interview sample. Section 3.3.3 sets out a method to predict expected SCRQOL from other data in the self-completion questionnaire.

Figure 4.3

Unweighted current and expected SCRQOL for the face-to-face interview sample



The figure shows that service users felt that day care centres help in many domains, particularly, social contact, but also meals and even accommodation. 40 per cent of respondents said that day care directly helped in relation to their home cleanliness and comfort. This may be due to reducing the tasks associated with food preparation and personal cleanliness that would otherwise take place at home. By way of contrast 61 per cent of people felt that day care helped with social contact outcomes.

4.4.4 Adjusting outcome for other service use

We use expected quality of life in order to attribute outcome to the use of services. We ask people to think about and isolate the effects of (in this case) the day care centre on quality of life. This is, nonetheless, a challenging task for people and this work is concerned with assessing the degree to which people can do this successfully.

In theory outcome should be solely due to the use of the day care centre, although it is possible that people cannot easily isolate the effects of other services and support, including, in particular, informal care help and other

community-based social care like home care services. If this is the case, expected quality of life will be too low and too much outcome improvement will be attributed to the use of day care. We can test this proposition by looking at how reported outcome varies in the sample between people that do and do not have these other forms of support. We can also look at how outcomes vary according to the different levels of ADL need people report in the sample.

Multiple regression can account for these differences simultaneously. The dependent variable is the outcome as described above. We estimate an OLS regression model and also, because the outcome variable is somewhat skewed to the right (see Figure 4.2) a model with a square root transformation of the outcome variable (using a Generalised Linear Model estimator). The results can be seen in Table 4.21.

Table 4.21 Multiple regression: ASCOT outcome

Variable	GLM model		OLS model	
	Coefficient	Probability	Coefficient	Probability
Needs				
ADL count	0.018	0.004	0.018	0.001
Lives alone	0.038	0.384	0.029	0.364
Poor vision	0.072	0.079	0.042	0.124
Registered blind	0.076	0.174	0.037	0.462
Services and support				
Visits day centre 2 or 3 times a wk (cf. 1/wk)	0.069	0.071	0.045	0.097
Visits day centre 3+ /wk (cf. 1/wk)	0.159	0.009	0.164	0.005
Home care	0.098	0.005	0.073	0.006
Informal care (no of carers + 1) (log)	0.087	0.001	0.065	0.002
Income				
Claims Pension Credit	0.076	0.054	0.058	0.043
Constant				
RESET	0.054	0.468	-0.089	0.029
			0.95	0.416

N = 202, R² = 0.246 (GLM), 0.238 (OLS), F-test = 8.47, p<0.001 (OLS)

As expected, people with higher levels of need are more likely to report higher outcome as these people have a greater capacity to benefit from help). Also, the amount of outcome is positively related to the number of visits a person makes to the centre. However, in both models (GLM and OLS) we find that people who receive home care services (as well as day care) report high outcomes on average, other things being equal. Furthermore, people with informal care also average higher outcomes. These two variables might be indicating higher levels of need, but given we already include a set of relevant need indicators, it seems more likely that some people are reporting outcome that is due to other forms of social care services or support.

Fortunately, this analysis gives us an easy way to deal with this problem. We just calculate the level of outcome on the assumption that people only use day care, and have zero levels of home care and informal care. This calculation is made by subtracting the (marginal) effect of home care and informal care from the person's outcome score if they reported using these other forms of support (where the marginal effects are determined from the coefficients in the regression models). We can then re-calculate the mean outcome.

Table 4.22 shows the marginal effects. For example, people using home care on average report outcomes that are 0.07 higher than those without home care (bearing in mind that the mean outcome reported in the sample is 0.18). Some 47.9% of people in the sample use home care.

Table 4.22 ASCOT outcome – regression results for other care and support

Variable	Marginal effect		Sample average value	
	Mean	Std. Dev.	Mean	Std. Dev.
Informal care (no of carers + 1) (log)	0.062	0.045	0.903	0.553
Home care	0.070	0.051	0.479	0.501

For people with home or informal care we increase their expected quality of life by these marginal effect amounts. The adjusted results, in contrast to those results in Table 4.20, are given in Table 4.23. As we can see, average outcome for the use of day care centres are about half of the unadjusted total, at 0.09. Adjusted expected quality of life was also higher because some people receive informal care and a range of services other than day care. As outlined above, the adjustment is based on the results of a stochastic regression (with error). The

adjustment strictly holds at the mean of the sample. Reflecting the stochastic nature of the adjustment, bootstrapping was used to estimate 95% confidence intervals for this (mean) outcome estimate and these range from 0.06 to 0.13. Similarly, bootstrapping was used to estimate the 95% confidence interval of the mean value of adjusted expected quality of life.

The distributional characteristics of the adjusted scores would reflect that of the unadjusted scores but with a shift factor (and error). The standard deviation of adjusted expected quality of life is 0.22 and for adjusted outcome it is 0.13. Bootstrapping of the standard deviation of these two numbers, gives confidence interval ranges of 0.21 to 0.24 and 0.11 to 0.15 respectively.

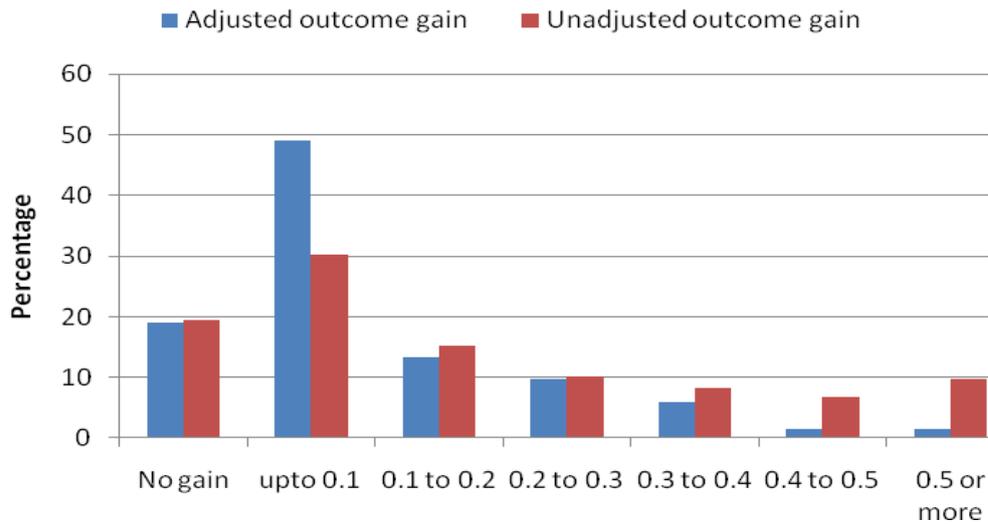
Table 4.23 ASCOT scores (adjusted)

ASCOT measure	Mean	Std deviation/std error*
Current quality of life	0.74	0.20
Adjusted expected quality of life	0.65	0.02*
Adjusted outcome	0.09	0.18*

* standard error

The GLM model results shown in Figure 4.4 can also give us an estimate of the distribution of adjusted outcomes. This distribution compares with the unadjusted distribution in Figure 4.2 (and shown again here), but the rightward tail is more compressed.

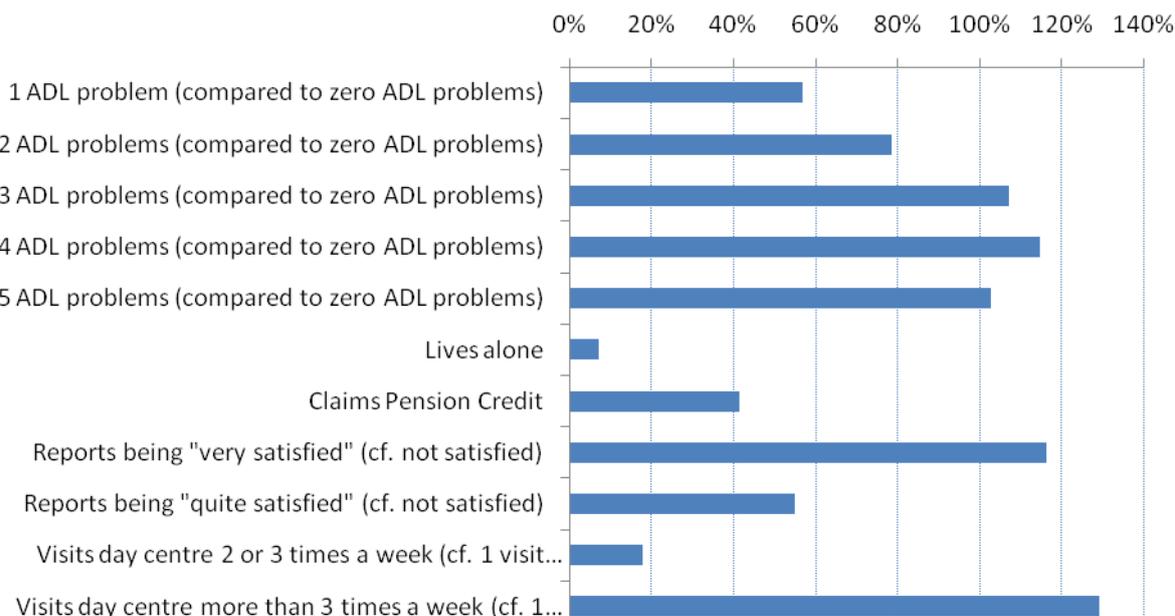
Figure 4.4 Distribution of adjusted outcome scores



Regression analysis can also be used to see how these adjusted outcomes vary according to the characteristics of the people in the sample. Figure 4.5 describes the size of adjusted outcome from service use for different groups in the population. It shows the relative size of the improvement in outcome score as a percentage of the mean effect (of 0.09). Other things equal, people with one ADL problem report outcome from services that is 0.05 higher than people with zero reported ADL need – this amount is 57% of the sample mean effect of 0.09. By contrast, people with 4 or more ADL problems have an average improvement of 0.10 – some 115% of the mean – higher than people with zero reported ADL need. In other words, people with high levels of need benefit the most from accessing day care centres, although there is some suggestion that people with very high needs (5 ADLs) do not benefit quite as much (although the numbers are low). People that live alone compared to people that live with others, and people that claim Pension Credit compared to those that do not, also benefit more from services.

People that visit the day care centre more often show greater improvement (other things being equal, including their level of need). Finally, people that report being most satisfied also have the highest outcome. There is, in other words, a correlation between reporting high satisfaction and showing the greatest outcome improvement.

Figure 4.5 Outcomes – variations by sub-group



4.5 Expected quality of life and needs

One of the aims of the study was to be able to infer the ASCOT expected social-care related quality of life indicator from easy to collect, standard measures. Results from the SCT data that were collected from users of day care centres show a number of **statistically significant associations between people's levels of dependency** (measured by the ADLs) and the ASCOT domains.

Table 4.24 shows the results of a series of multiple regression analyses for each domain in the ASCOT expected quality of life measure (weighted) against the set of 5 ADLs and age, sex and whether the person lives alone. The table shows the level of statistical significance of the correlation between the need and the listed domain. It shows that each ASCOT domain has a statistically significant association with at least one of the ADL measures collected.

Table 4.24 Significance of ADL measures

	Able to get dressed	In/out of chair	Wash face/hands	Prepare hot meals	Walk 10 mins	Over 85	Male	Alone
Home cleanliness and comfort	*	-	-	*	**	-	-	**
Safety	-	**	-	**	**	-	-	-
Meals and nutrition	*	-	-	**	-	-	-	**
Personal cleanliness	**	-	-	**	-	-	-	**
Activities/occupation	-	-	-	**	*	-	-	-
Control over daily life	-	-	**	**	-	-	-	-
Social participation	-	**	-	-	-	**	-	-
Anxiety	-	-	-	-	*	-	-	-
Dignity and respect	-	-	*	**	-	-	-	-

** significant at 5%; * significant 10%; - Not significant

The results required from the exercise are the overall outcomes associated with the service on which the SCT is administered. The SCT directly collects information on current quality of life domains and this data can be converted into the overall (composite) current quality of life score by applying the weights reported in Table 4.19. The SCT does not collect information about expected social-care-related quality of life. Instead we use the close correspondence between need measures (which are collected) and expected social-care-related quality of life collected in the interview sample to develop a simple formula that can be applied to the SCT data to calculate an overall expected social-care-related quality of life score. Outcome is then simply the difference between the two overall scores.

In theory, as outlined above, expected quality of life ratings are current quality of life with the effects of day care centres removed. For a given level of need, people receiving other support, like informal care, or services such as home care, should have a higher level of expected quality of life than people not getting this form of help. However, the above results cast some doubt on this position. It appears more likely that expected quality of life are reflecting basic levels of need with only limited consideration of other forms of support. The problem is that the people would be expected to include the impact of other services (e.g. home care) and informal care on *current* quality of life. But they also should be including this effect on *expected* quality of life so that these effects cancel out in the outcome calculation as it applies to day care. If people are not sufficiently accounting for other service impacts on expected quality of life we will need to make an adjustment on outcome, reflecting that expected quality of life rating is too low (and so the outcome too high). This is the adjustment we made above, adding the (positive) adjustment factor to expected quality of life which is the same as subtracting it from outcome (since outcome is current quality of life *less* expected quality of life).

We develop the needs to expected social-care-related quality of life (in the absence of services) formula using regression analysis with the interview data, where un-adjusted expected quality of life (in the absence of services) are used as the dependent variable – see Table 4.25. We also re-estimated with home care and informal care variables, but as anticipated, these were not significant.

Table 4.25 Expected quality of life estimation

Variable	Coefficient	Probability
Needs		
ADL count	-0.046	<0.001
Cannot manage finances	-0.098	0.019
Over 85	-0.010	0.791
Male	-0.044	0.250
Lives alone	-0.079	0.048
Care managed case	-0.092	0.019
Poor vision *	-0.082	0.026
Registered blind	-0.050	0.490
Constant		
RESET	0.893	<0.001
Het. Test	1.200	0.313
	0.910	0.341

N = 205, R² = 0.346, F-test = 14.51, p<0.001

At present the SCT does not ask about whether people have poor vision, although it subsequently proved to be significant using the interview data. This question will be added in the new version of the SCT. For our purposes here we have removed this variable and adjusted the constant. The basic formula applied to the SCT is therefore:

SCT expected quality of life (basic)

$$\begin{aligned}
 &= \text{ADL count} \times -0.046 \\
 &- 0.098 \text{ if person cannot manage finances} \\
 &- 0.010 \text{ if person over 85} \\
 &- 0.044 \text{ if male} \\
 &- 0.079 \text{ if lives alone} \\
 &- 0.092 \text{ if a care managed case} \\
 &+ 0.838
 \end{aligned}$$

If this formula is applied to measure the expected quality of life of people using day care who were also getting informal care and home care, then we also need to add the following:

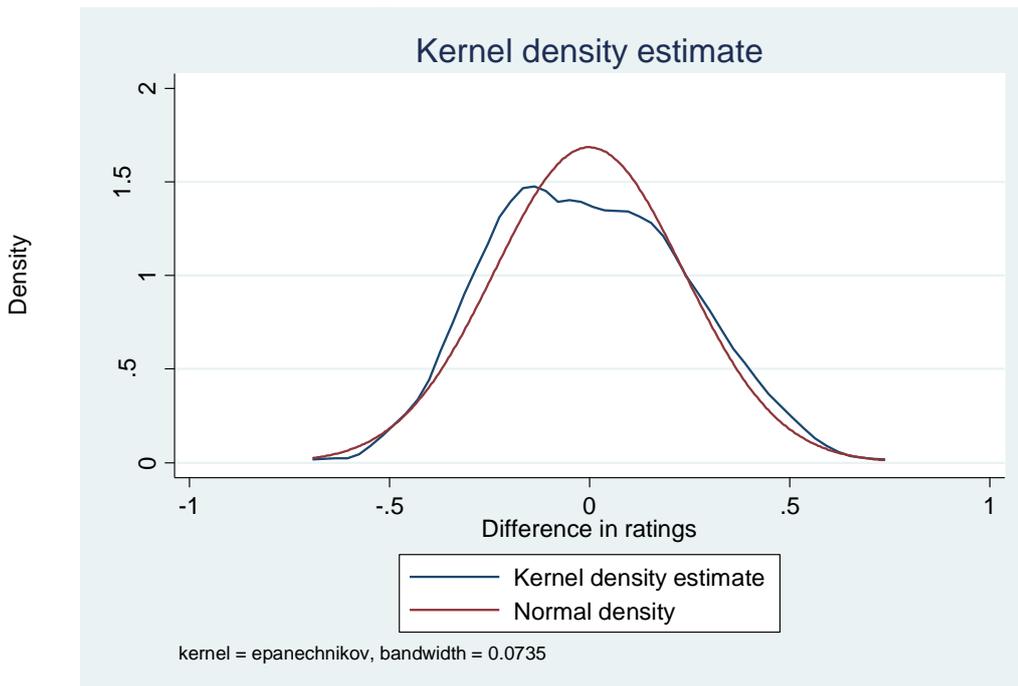
SCT expected quality of life

$$\begin{aligned}
&= \text{SCT expected quality of life (basic)} \\
&+ \log(\text{informal care helpers} + 1) \times 0.062 \\
&+ 0.070 \text{ if person uses home care}
\end{aligned}$$

All people who were interviewed had initially completed a SCT and so we are able to compare predicted SCT expected quality of life with actual expected quality of life as measured in the face-to-face interview. Applying the basic formula to the SCT data for interviewees produces a mean expected quality of life score of 0.56 which is exactly the same as the actual score in the interview data. The individual predicted scores did differ from the actual scores in some cases, but the deviation was close to normally distributed – see Figure 4.6. The key issue is whether or not the predicting formula is biased. Noise is inevitable in regression analyses on **which such formulae are based. In this case 'explained' variation (R squared) was 35%**, but what is important is that the error/noise is independently distributed from the other factors and this condition was supported by the RESET test ($p = 0.313$) in this case. In other words, there may be factors that relate to expected quality of life which are not included in the formula, but these omissions do not bias the coefficients of the included factors. In this case, we would expect the application of the formula to produce a similar distribution in the SCT data, and this was what we found.

We explore validity and reliability issues in the next section.

Figure 4.6 Difference between SCT predicted and actual expected quality of life in the interview sample



We apply this formula to the full SCT sample, resulting in an average outcome of 0.08 see Table 4.26. These numbers accord well with the results in the interview, where the average outcome was 0.09 (see Table 4.23). We should note, however, that for people whose characteristics are significantly removed from the sample average, predictions of expected quality of life are subject to more noise.

Table 4.26 SCT outcomes

ASCOT measures	Mean	Std. Dev.	Min	Max	N
Current quality of life	0.74	0.24	-0.10	1.00	881
Expected quality of life	0.57	0.17	0.11	0.84	868
Expected quality of life - adjusted	0.65	0.15	0.20	0.98	868
Outcome	0.08	0.22	-0.70	0.72	804

4.6 User experience of services and current quality of life

People that took part in a face-to-face interview were asked their views on how satisfied they were with the help, care and support that they received from the day care centres that they accessed. It is worth noting here that people in receipt of services are often glad of any help they receive (regardless of quality) and that

this can be reflected in a reluctance to report services as poor quality, particularly if there is a fear that these may be taken away (Francis and Netten, 2004).

Face-to-face interviewee participants were asked about their feelings towards the way they were treated by the care workers that helped support and assist them at the day care centre. This was specifically related to whether or not people thought that day care centre staff were understanding and treated them (the users) with dignity and respect. Table 4.27 shows that 96% of people that gave a valid response (n=210) reported that they were either 'always' or 'usually' 'happy with the way that the care workers treat you'.

Table 4.27 Users' feelings about treatment by care workers at day care centre

Rating of treatment by care workers	Number	Per cent
Are always happy with the way that the care workers treat you	175	80
You are usually happy with the way that the care workers treat you	35	16
You are sometimes happy with the way that the care workers treat you	7	3
You are never happy with the way that the care workers treat you	1	0
Total	218	100

Participants that reported it were overwhelmingly positive about how often the people that offer support or assistance do the things the participant wants done. Sixty-two per cent of participants stated that they (day care centre staff) 'always do the things you want done'. Eighteen participants answered negatively (10%)

Table 4.28 How often people who offer support or assistance do the things the participant wants done

Rating of support	Number	Per cent
Always do the things you want done	122	62
Nearly always do the things you want done	58	29
Sometimes do the things you want done	17	9
Never do the things you want done	1	1
Total	198	100

Participants were asked to report how often the people who offer support or assistance are professional and do a good job. Again participants that answered were very positive with the majority stating that they are 'always' professional and do a good job.

Table 4.29 How often the people who offer support or assistance are professional and do a good job

Rating of support	Number	Per cent
Always	165	77
Usually	42	20
Sometimes	5	2
Never	2	1
Total	214	100

This was reflected in participants' response to being asked to rate the relationship they had with day care centre staff. Almost all participants stated that this was either 'excellent' or 'good' (see Table 4.30).

Table 4.30 Relationship with people who provide support or assistance

Rating of relationship with people who provide support	Number	Per cent
Excellent	136	63
Good	69	32
Okay	10	5
Bad	1	0
Total	216	100

As part of the face-to-face interview process people were asked how often they used day care centres (see Table 4.31). Most participants (79%, n=166) used day care centres either once or twice per week. When people were asked whether or not they visit the day care centre as much as they want (see Table 4.32) 26% (n=56) stated 'no, I would like to visit the day care centre more than I do'. Three people stated 'no, I visit the day care centre more than I want', which qualitative findings suggest may be related to carer respite.

Table 4.31 How often people visit the day care centre

Frequency of visits	Number	Per cent
Once a week	86	41
Twice a week	80	38
Three times a week	29	14
More than three times a week	15	7
Total	210	100

Table 4.32 Do people visit the day care centre as much as they want

Rating of frequency of visits	Number	Per cent
Yes, I visit as much as I want	155	72
No, I would like to visit the day care centre more than I do	56	26
No, I visit the day care centre more than I want	3	1
Total	214	100

Multiple regression analysis indicates that some of these quality indicators do correlate with ASCOT current social-care-related quality of life scores. We looked at four indicators – whether staff were responsive to people's wishes; whether people were happy with how they were treated by staff; whether staff were considered to be professional; and, people's views about the quality of their relationship with staff. The latter two indicators did not show any correlation with the current quality of life score. Table 4.33 shows, however, that the former two indicators are statistically significant and the size of the effect was consistent with our expectations. People who were only sometimes or never happy with their treatment by staff had significantly lower current quality of life, other things being equal.

Table 4.33 Regression analysis: impact of user satisfaction indicators on current levels of quality of life

Variable	Coefficient	Probability
Needs		
ADL count	-0.022	<0.001
Cannot manage finances	-0.045	0.127
Over 85	0.040	0.117
Male	-0.042	0.146
Lives alone	-0.046	0.109
Quality		
Staff support people the way they want		
Always	0	
Nearly always	-0.052	0.067
Sometimes or never	-0.101	0.032
Happy about treatment by staff		
Always happy	0	
Usually happy	-0.080	0.038
Sometimes or never	-0.256	<0.001
Constant		
RESET	0.190	0.902

N = 191, R² = 0.297, F-test = 14.09, p<0.001

These results suggest that quality measures can be useful indicators of social-care-related current quality of life, although they only partially account for the variation people report in quality of life scores. In other words, good quality as indicated by these measures tends to suggest that people would also have good quality of life, but that is not always the case and we would need to be cautious about drawing conclusions from quality measures alone.

5. Testing ASCOT

There are three ways in which we test the ASCOT. First, we consider the *validity* of the measure i.e. the extent to which ASCOT measures the service related wellbeing improvements it aims to measure. Second, we look at the re-test reliability of ASCOT (current) social-care-related quality of life by comparing the quality of life reported in the SCT and the quality of life reported by the same (sub-sample) of people also completing an interview. Third, we look at the reliability of the SCT approach measure in predicting ASCOT outcome. This is done by measuring this estimate against the actual outcomes reported by people in the interview sample.

5.1 Validity

We aim to assess construct validity by looking at the degree to which the instrument measures wellbeing improvements we theorise to occur as a result of service use (Carmines and Zeller, 1979). We also consider convergent validity by looking at the correlation between independent measures that ought to be theoretically related, which in this case are satisfaction, need, frequency of use and EQ5D.

A validly constructed measure should capture improvements, or indeed deterioration, that stem from service use. We have seen above that outcomes do result from day care use overall and that these vary in an expected way with the frequency of use and level of need of service users (Figure 4.5). However, we still might legitimately question whether the full range and intensity of service effects are being captured. We can never be entirely certain about this point, but we can assess construct validity in a relative way, by determining whether ASCOT is more sensitive to service change than other measures. In particular, we can compare ASCOT's performance against EQ5D, where the latter is in mainstream use for health service research.

Table 5.1 gives (raw) correlations between the main outcome and need measures. The ASCOT current quality of life score is correlated with ADL need (-.42), as is the EQ5D measure (-0.59). We would expect this result because need measures (such as ADL **count**) are indicative of people's capability to achieve quality of life on their own. Services will help people to overcome need,

but are unlikely to be perfect, so that people with highest need will still have the lowest current quality of life, other things being equal. This result shows a degree of internal consistency of the outcome measures we are using. In addition, we also find that the ASCOT *expected* indicator (i.e. the rating in the absence of services and support) shows a greater (raw) correlation (-0.60) than for current quality of life, but to a similar degree of correlation as EQ5D with ADL need. This is not surprising given the construction of both expected quality of life and EQ5D as being essentially personal need measures. That ASCOT current quality of life is less correlated might also indicate it is more sensitive to measuring service effects. Simple correlations are indicative but there are many potential confounding factors. We can assess this issue more closely by looking at the impact of services on both outcome measures, accounting for relevant factors.

Table 5.1 Correlation matrix

	ASCOT current	ADL count	EQ5D	ASCOT expected
ASCOT current	1			
ADL count	-0.42	1		
EQ5D	0.48	-0.59	1	
ASCOT expected	0.65	-0.60	0.56	1
EQ5D_mobility	-0.12	0.39	-0.39	-0.29
EQ5D_usual activity	-0.40	0.73	-0.64	-0.60
EQ5D_self care	-0.30	0.73	-0.61	-0.47
EQ5D_pain	-0.30	0.12	-0.75	-0.24
EQ5D_anxiety	-0.48	0.24	-0.55	-0.40

We have a sample of day care users and EQ5D is a measure of current quality of life. We do not therefore have a counterfactual for day care (i.e. people with EQ5D scores who do not use day care). However, we do have a mix of *home care* service use in the sample. Just under 48% of the sample reported using home care services. After controlling for baseline differences – such as need, socio-economic characteristics and so on – we can compare EQ5D scores for the home care recipient and non-recipient group. The difference in EQ5D between groups is an estimate of the improvement in outcome associated with the use of home care. We can repeat this comparison – using the same baseline control – using

ASCOT (current quality of life). ASCOT has better validity if it shows (proportionately) greater improvements than EQ5D.

Regression analysis was used to control for baseline differences between the home care recipient and non-recipient groups (by estimating the degree to which outcome scores vary with baseline factors such as ADL count, informal care use, other service use and income and isolating these effects). The remaining effect of home care is therefore estimated as if these other factors were equal between groups. Table 5.2 gives the results. The analysis shows that whilst ASCOT was significantly different (at the 5% level) between groups ($p = 0.02$), EQ5D was not ($p = 0.487$). In other words, there is a significant outcome difference, but the EQ5D measure is not sensitive to these differences in the home care case.

Table 51.2 OLS regression: ASCOT current and EQ5D indicators

Variables	ASCOT		EQ5D	
	Coefficient	Probability	Coefficient	Probability
Needs				
ADL count (ln)	-0.087	<0.001	-0.201	<0.001
LLSI	-0.046	0.121	-0.145	0.001
No informal care	-0.057	0.065	-0.046	0.378
Poor vision	-0.047	0.059	-0.064	0.132
Registered blind	-0.042	0.298	-0.128	0.153
Good cognitive skills	0.073	0.002	0.075	0.072
DLA	-0.061	0.020	-0.113	0.026
Services				
Home care	0.054	0.020	0.028	0.487
OT/Physio	0.027	0.383	-0.012	0.817
Quite satisfied w/ Day Care	-0.054	0.044	0.060	0.150
Not satisfied	-0.141	0.014	-0.077	0.276
Income				
Claims Pension Credit	-0.027	0.275	0.013	0.755
Constant				
RESET	0.873	<0.001	0.760	<0.001
RESET	1.95	0.123	1.50	0.217

N=208, $R^2 = 0.350$ (ASCOT), 0.410 (EQ5D), F-test = 11.19, $p < 0.001$ (ASCOT), 17.79, $p < 0.001$ (EQ5D)

Although we do not have a sample of people that are not day care users, we do have information about the satisfaction people express with services and also the intensity at which people used these services – see Table 5.3. The above multivariate results show that ASCOT is correlated with satisfaction reports whereas the EQ5D score is not. Compared to people who are very satisfied (Table 5.2) people who are quite satisfied have lower ASCOT current quality of life ($p = 0.044$). People who are not satisfied report even lower current quality of life ($p = 0.014$). These results are not repeated with the EQ5D measure.

Table 5.3 Day care: intensity of use

Frequency of visit	Number	Per cent
Once a week	86	41
Twice a week	80	38
3 times a week	29	14
More than 3 times a week	15	7
Total	210	100

Theoretically we would expect that people using services more frequently will show greater outcomes, although it is especially important to control for level of need. In particular, a person's level of need will not only affect their capacity to benefit from services (of a given intensity) but also the likelihood and frequency of service use. As we are directly concerned with day care centres, we included the expected quality of life in the absence of (day care centre) services indicator as a need factor.

Simple bivariate analysis indicates that people attending 3 or more times per week have an expected quality of life score that is just under 30% less than those attending only once a week. Their ADL count is also about 30% higher. Multivariate analysis – which accounts for a number of need and other indicators simultaneously – showed that people who attend day care 3 or more times per week have significantly better outcomes on the ASCOT scale than people only going once per week ($p = 0.032$) – see Table 5.4. The EQ5D measure showed a weakly significant result for the same comparison ($p = 0.074$). People going twice a week compared to those going once per week did not show significant improvement for either measure.

Table 5.4 OLS regression: ASCOT current and EQ5D indicators

Variable	ASCOT		EQ5D	
	Coefficient	Probability	Coefficient	Probability
Needs				
ADL count (ln)	-0.031	0.067	-0.167	<0.001
LLSI	-0.021	0.463	-0.116	0.01
No informal care	-0.074	0.007	-0.024	0.651
Poor vision	-0.013	0.544	-0.039	0.367
Registered blind	-0.005	0.897	-0.086	0.367
Good cognitive skills	0.056	0.013	0.066	0.112
DLA	-0.047	0.079	-0.114	0.029
Exp. quality of life absent services	0.405	<0.001	0.208	0.032
Male	-0.030	0.247	-0.005	0.911
Services				
Home care	0.062	0.003	0.024	0.575
OT/Physio	0.007	0.786	-0.033	0.543
DC twice/wk	0.011	0.658	0.070	0.114
DC 3+/wk	0.064	0.032	0.108	0.074
Income				
Claims Pension Credit	-0.002	0.942	0.034	0.449
Constant				
RESET	0.528	<0.001	0.517	<0.001
RESET	0.719	0.509	0.650	<0.001

N=199, R² = 0.509 (ASCOT), 0.420 (EQ5D), F-test = 16.140, p<0.001 (ASCOT), 15.640, p<0.001 (EQ5D)

We have tested construct validity of the ASCOT by benchmarking against the EQ5D measure. These are not definitive analyses but they do show that whilst these two measures are correlated, ASCOT performs better in detecting the impact of service use than EQ5D. The ASCOT results also show better internal consistency with reports about satisfaction with service use than EQ5D results.

5.1.1 Correlation between ASCOT and other outcome indicators

We also find high degrees of correlation between ASCOT and other indicators, such as satisfaction and self-reported quality of life (see Table 5.5). These results suggest a good degree of convergent validity.

Table 5.5 ASCOT domains and self-reported quality of life

Domain	Quality of life
Home cleanliness and comfort	**
Safety	***
Meals and nutrition	*
Personal cleanliness	-
Activities/occupation	***
Control over daily life	***
Social participation	***
Anxiety	***
Dignity and respect	*

*** p<0.001; ** p<0.005; * p<0.05; - Not significant

5.1.2 Adaptation effects

As outlined in our previous reports, we would expect, theoretically, that subjectively reported outcomes will vary with people's preferences and that these preferences might change in response to the situations in which people find themselves. In particular, people in poor situations – economically, socially or in terms of their disability – might revise their expectations after a time so as to come to think of this poor situation as not so bad after all. This behaviour is called *adaptation* by psychologists (Kahneman et al., 1999) and a number of empirical studies have supported this theory. These ideas relate to our work because if we find similar behaviours in our data, this gives us further confidence about the validity of the ASCOT.

In our study we have people's responses about their degree of social contact in **both subjective terms (is this the level of contact you would want...)** and **objective terms (how often do you have contact with people you are fond of...)**. Generally, we expect these measures to be correlated. However, we find that older people in our sample are more likely to rate poor objective quality of life more highly in

subjective terms than younger people. Both younger and older people rate good objective quality of life to about the same extent using the subjective measure. This result might just mean that of the group of oldest people in our sample we happen to have a higher number of 'loners' i.e. prefer their own company and be subjectively happy with low levels of objective contact. More likely is that older people are more likely to adapt to more limited opportunities in life. In any case, this pattern of behaviour as measured by ASCOT suggests that it is behaving in the way it was intended (although it also raises issues about how we deal with adaptation from a policy perspective).

5.2 Re-test reliability

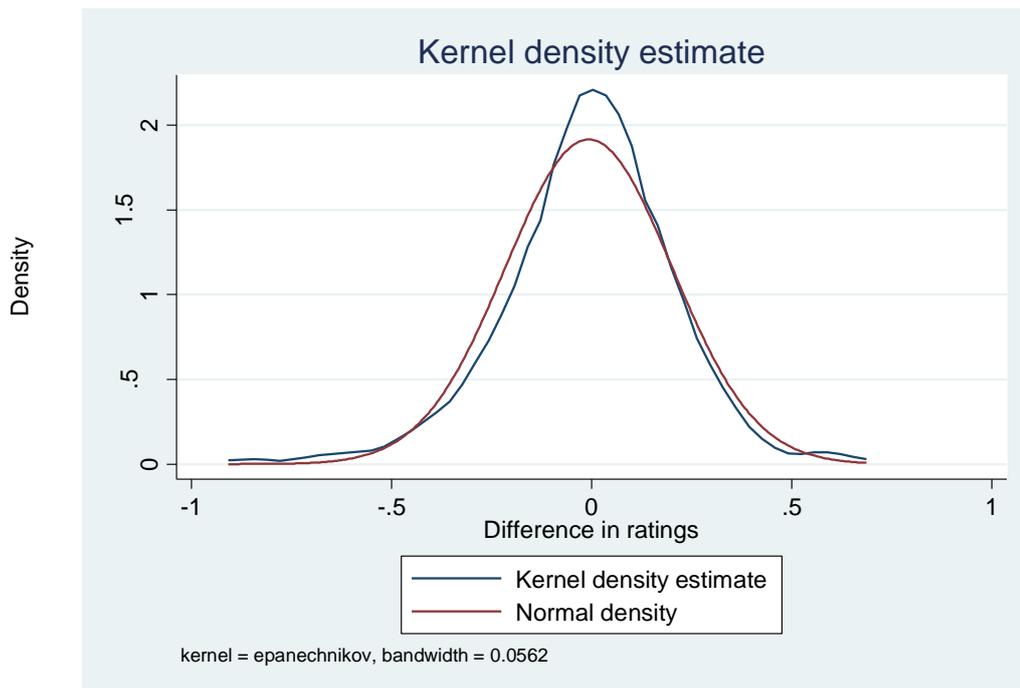
All people in the interview sample were drawn from the sample of people completing a SCT. In both samples, people were asked the same ASCOT current quality of life questions and this gives us an opportunity to assess the re-test reliability of ASCOT. Although the time varied, people were interviewed between 1 and 6 weeks after completing SCTs. In this period we would expect only a few people to have experienced a significant change in their circumstances. The current quality of life scores should then be very similar between the instruments if the reliability of the measure is high. Table 5.6 shows this to be the case.

Table 5.6 Current quality of life scores between instruments

Sample	N	Mean	Std. Dev.	Median	5th %tile	95th %tile
SCT	213	0.74	0.23	0.78	0.28	1.00
F2F	213	0.74	0.20	0.78	0.37	1.00

The means are almost identical, although the sample distribution of the current quality of life score at the two time points is slightly different. At the individual level (rather than the sample average), we do see differences, but the distribution of these differences is not skewed – see Figure 5.1.

Figure 5.1 Differences in current quality of life scores



Volatility of individual responses at different time periods is expected – these outcome questions relate to people's current experiences, preferences and moods and they could quite possibly change on a day-to-day basis. What is important is that mean outcome ratings within sub-groups do not change e.g. the mean value for high need people does not change between re-tests, or for low need people, or older or younger, etc. Regression analysis shows that the difference in reported current quality of life score between SCT and interview is not significantly different from the sample mean of zero for any need sub-group – see Table 5.7.

Table 5.7 Differences in reported current quality of life score between SCT and interview

Variable	Coefficient	Probability
1 ADL problem (compared to zero ADL problems)	0.017	0.708
2 ADL problems (compared to zero ADL problems)	-0.002	0.963
3 ADL problems (compared to zero ADL problems)	0.041	0.365
4 ADL problems (compared to zero ADL problems)	0.045	0.414
5 ADL problems (compared to zero ADL problems)	-0.048	0.587
Male	0.000	0.999
Over 85	-0.037	0.281
Constant	-0.014	0.668
RESET	1.01	0.389

N = 213, R² = -0.019, F-test = 0.450, p=0.871

We can also look at the re-test reliability as regards the individual domains in ASCOT. Table 5.8 shows that reported levels within domains remained largely similar at both points of measurement (SCT or face-to-face interview). Minor differences can be observed between some outcome domains. For example **participants' mean** current quality of life for meals eaten improves by 0.10 at the face-to-face **interview stage while participants' mean** current quality of life for control over daily life decreases by 0.09 at this stage. For the most part, however, current quality of life as measured by ASCOT was similar at both SCT and face-to-face interview points. Therefore the re-test reliability of ASCOT is good.

Table 5.8 Current quality of life scores between instruments by outcome domain

Outcome domain	SCT/F2F	N	Mean	Std. Dev.	Variance
Cleanliness and comfort of home	SCT	223	1.23	0.50	0.25
	F2F	221	1.20	0.48	0.23
Feelings of safety	SCT	222	1.55	0.64	0.41
	F2F	224	1.54	0.68	0.47
Meals eaten	SCT	220	1.27	0.52	0.27
	F2F	222	1.17	0.42	0.18
Personal cleanliness and dress	SCT	224	1.10	0.35	0.12
	F2F	222	1.09	0.32	0.10
Accomplishment of activities	SCT	222	1.86	0.77	0.60
	F2F	222	1.89	0.71	0.50
Control over daily life	SCT	222	1.37	0.57	0.33
	F2F	224	1.46	0.63	0.40
Social situation	SCT	224	1.53	0.68	0.47
	F2F	223	1.51	0.67	0.45
Extent of worry and concern	SCT	222	1.75	0.61	0.37
	F2F	223	1.73	0.66	0.43
Feelings of dignity and respect	SCT	221	1.22	0.42	0.18
	F2F	223	1.16	0.36	0.13

5.3 Reliability of SCT method

In an attempt to minimise the burden imposed on people in completing a SCT, we do not directly ask expected quality of life questions. As described above, we instead calculate expected quality of life using a needs formula. The results in Figure 4.5 suggest, at the sample mean at least, that the prediction of expected quality of life is a reliable estimate of actual expected quality of life responses. We would, nonetheless, want to ensure a reasonably large sample size, and to ensure that this equation was applied to groups of people that were mainly in line with the characteristics of people in the SCT. In this sense, the expected quality of life formula works well in its prediction of expected quality of life (as these are not asked about in the SCT); however, the populations need to have similar characteristics to make these predictions.

Self-completion as a method of collecting outcomes related information has a number of advantages (May, 2001).

- It is low cost
- The anonymity afforded to self-completion can be beneficial, particularly if people feel self-conscious or embarrassed about responses they wish to give
- People can take their time to fill in a questionnaire at their own convenience and give considered responses
- Interviewer bias is not an issue as people read the same questions in the same format

There are of course a number of disadvantages related to collecting outcomes information in this way. The greatest disadvantages are almost certainly response rates and sources of bias, these will be discussed below. Other drawbacks include the need to keep questions short and simple, the absence of probing as a way of unpacking why a person may respond in a certain way, and a certain lack of control over who completes (or helps to complete) a questionnaire. For example, a service user may be influenced in their response if they know that the person that provides care for them will see their responses.

Notwithstanding the relative merits of self-completion in general, in order to gauge general opinion participants were asked how easy they found completing the SCT in the face-to-face interview. Table 5.9 shows that 61% stated that the **SCT was either 'very easy' or 'quite easy' to complete while 16% stated that they found it either 'quite difficult' or 'very difficult'.**

Table 5.9 Ease of completing SCT questionnaire

Ease of completing SCT	Number	Per cent
It was very easy	65	29
It was quite easy	72	32
It was neither difficult nor easy	32	14
It was quite difficult	15	7
It was very difficult	21	9
Don't Know	19	9
Total	224	100

5.4 Response rates and sources of bias

The sampling was administered through providers and therefore there are risks that the service users sampled are not representative. At best, providers are unlikely to selected the sample using random sample methods, the accepted best method. At worst, providers might cherry pick or influence people's responses. However, this study is not a national evaluation of day care centres and is not attempting to provide national estimates of social-care related quality of life and outcomes. Our primary aim was to test the measurement tool, and for that purpose departures from a fully representative sample methodology are not critical.

From a practical point of view, no national sample frame (registers, databases etc.) of individuals using day care centres exists and so direct individual level sampling would not have been possible. Without national data on day care centre users we cannot compare our sample characteristics with the national picture and it is not possible to make an assessment of response bias. This highlights the difficulties of carrying out research on day care services, and the lack of any robust data about the users of these services. In that context our study, although based on an imperfect sample, provides one of the best sources of information available.

Furthermore, despite possible biases, the data show a significant variation in the needs and reported outcomes of people in the studies, and respectable levels of internal validity and reliability. We are therefore satisfied that our survey methodology is fit for purpose.

These issues of sampling and response also have implications for the administration of the toolkit by providers and commissioners: see Section 6.5 for further discussion.

6. Practical applications of ASCOT and outcomes data

As set out in the introduction, there are a number of applications of ASCOT and the outcomes data it generates.

- It can be used to inform cost-effectiveness by examining which types of services improve outcomes within each domain
- It can aid outcomes-based commissioning by allowing commissioners to measure outcomes
- It can be used by the regulators and commissioners to monitor service performance in addition to current quality ratings
- The data can be used to adjust adult social care in the National Accounts
- It could also be utilised by service users to allow them to determine what it is they want to gain from service use and which services are, therefore, best suited to their requirements

The following section sets out these potential uses in more detail.

6.1 Cost-effectiveness

One method of calculating the cost-effectiveness of day care centres is to take the ratio of costs to benefits measured as outcome improvements. It is standard to report this information as the annual cost of day care required to produce an outcome improvement of 1 on the ASCOT scale. We use an average per session cost of £23.40 for day care as taken from Department of Health Unit Cost returns (PSSEX1) (The NHS Information Centre, 2009). Yearly day care costs then come to an average of £2410 in the sample, where average attendance was around 2 sessions per week. Table 6.1 gives breakdowns according to frequency of visit.

Table 6.1 Costs and outcomes

Frequency of visits	Adjusted outcome	Cost per annum (£)
Once a week	0.07	1220
Twice a week	0.08	2430
Three times a week	0.14	3650
More than three	0.19	6690

Table 6.2 gives the cost-effectiveness results, with the upper and lower 95% confidence interval. The latter reflects the statistical uncertainty or error associated with the point estimation of £24770.⁶

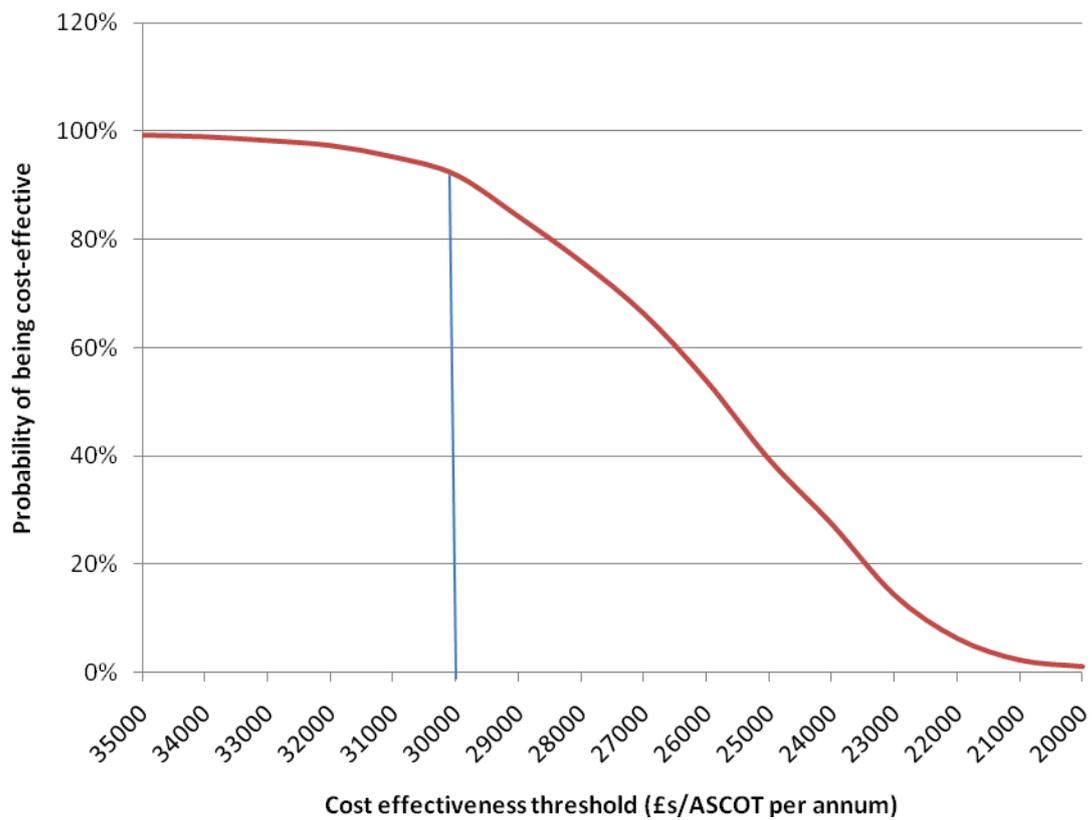
Table 6.2 Cost-effectiveness of day care

Cost-effectiveness measure	£/annum
Mean	24770
Lower 95% CI	19030
Upper 95% CI	30520

Whether this cost-effectiveness ratio is acceptable will depend on how much policy makers and society are prepared to pay per extra ASCOT outcome. For health services the National Institute for Health and Clinical Excellence (NICE) operate with a guideline figure of around £30,000 i.e. the global willingness to **pay for an increase in one person's health**-related outcomes for a year from being in full health compared to dead (QALY) is £30,000 per year. The point estimate for day care is below this threshold, although this is subject to uncertainty. We can instead think about this problem in terms of the probability that day care is cost-effective at a range of thresholds, given the inherent error. Figure 6.1 presents a curve that shows the probability that day care is cost-effective at different thresholds. There is a 92% probability that day care is cost-effective at a £30,000 per ASCOT threshold.

⁶ These confidence intervals (and standard errors) of the estimate are determined by bootstrapping the cost-effectiveness ratio calculated in the sample.

Figure 6.1 Cost-effectiveness acceptability curve



Cost-effectiveness can also be used to compare services. Generally speaking if the increase in quality of life from service use (per pound of expenditure) is greater for service *i* than for the best alternative comparator service, then more funding should be devoted to service *i* and less to the comparator. This involves a comparison of the ratio outcome over costs for one service against the other with resources allocation being shifting to the service with the lower cost per ASCOT wellbeing improvement.

As outlined in the interim report (Forder et al., 2007), if social services authorities adopt a cost-effectiveness rule of this nature, then this is likely to change the balance of services that are funded. An outcomes-based cost-effectiveness rule, for example, will have different implications than a needs-based rule, and in particular is likely to lead to a greater improvement in total wellbeing if adopted. The above results show that outcome improvements for day care do increase with the level of need of the service user. However, there is a diminishing effect size with greater need, meaning that a needs based rule which only prioritised high needs potential recipients would generally not produce the greatest wellbeing improvement in the population for a given budget.

6.2 Outcomes-based commissioning

The gains from outcome measurement come from being able to provide services to the range of potential users in a configuration that best achieves desired objectives at an appropriate level of spend. A relevant 'desired objective' in this case would be the improvement in wellbeing conferred by services.

In principle, an outcomes-based rule can be derived that can guide an efficient configuration of services. This requires an estimate of the impact of services on wellbeing (i.e. ASCOT) and a set of value judgments about the desired distribution of wellbeing improvement in the population. As regards the latter, we would, for example, need to make judgments about whether a given increase in the ASCOT wellbeing score was of the same societal value whoever benefited from it.

6.3 Regulation and service monitoring

The ASCOT approach can be used by commissioners, providers, regulators and others wishing to evaluate services. They would select a sample population of service users for their specific purposes and then ask these people to complete a SCT. Steps would need to be taken to ensure that the sample was broadly representative in the normal way. The tool could be applied in a case and control fashion where the experiences of some people using a service is compared to that of other people using the existing service. Alternatively, the tool could be used in a before/after type mode, where a comprehensive change is made.

Another application is monitoring. In this case, service users are asked to complete a SCT as they begin with a service and then asked to complete another SCT at various stages down the line. The aim would be to see whether people were benefiting from services and by how much. Potentially it could also be used as a regulatory tool, or form part of the regulatory process. In this case, for example, the tool could be included as part of the user experience survey (UES) by the Care Quality Commission (CQC).

Even where regulators saw their role as just safeguarding, outcome measurement is important. Safeguarding is about protecting people from harm, neglect and abuse, but how broadly is harm, and especially neglect, defined. Clearly

safeguarding approaches would consider physical hurt, but harm and neglect is also evident if people are left with needs unmet – that is poor ASCOT outcomes – where services would have been able to help these people. Here the focus would be on a reasonable level of current quality of life, rather than looking only at the outcomes produced by the service.

6.4 National Accounting

As outlined in our first interim report (Forder et al., 2007), outcomes information can be used for National Accounting purposes. The main challenge to measuring the total value of publicly funded social care output is in finding a way to add up all service production in the year in a way that reflects the value contribution of each service type. To date different output types (e.g. care home placements and home care hours) have been cost-weighted i.e. changes in outputs are weighted by their share of expenditure in order to obtain a measure of overall output change. But unit cost is a poor indicator of value. Instead, we propose that ASCOT outcome scores are used to weight service output. In other words, each unit of day care output (each person-attendance) would be given (currently) a value weight of 0.09 (see Table 4.23). Other services would also be weighted according to their ASCOT outcome impact to give the total value of social care output in terms of the total wellbeing improvement generated by social care in that year.

Over time this yearly total would change because either the level of output of services changes or because the outcome improvement they confer changes. The latter may occur for many reasons, such as improvements in care technology, but a particularly relevant reason would be a change in the level of need of people using services. Figure 4.4 shows that the level of need of people using day care has a direct impact on the size of the outcome. It also gives a basis for adjusting the outcome weight without a new outcomes study.

Whatever the reason for the change, the total outcome can be compared with the total public spend on social care through time to calculate an overall productivity change indicator.

6.5 Gaming and non-response issues

The methodology involved in the administration of the toolkit is potentially open to gaming. This is where data collected by organisations (which is used to assess, monitor and set targets for providers) is collected in a 'selective' way. This results in individuals that are taking part in the study or evaluation being 'cherry picked' by staff or providers to show an exaggerated 'improvement' in service delivery.

This could conceivably be resolved by asking all users to complete forms.

However, this would be costly. A more practical resolution would be to follow up a sample of users to check that they had taken part and filled in the toolkit, or have the data collected by a third party.

Non-response is another issue that needs to be considered when thinking about the administration of the toolkit and the interpretation of the data collected. Non-response in both its forms – unit (non-response to the whole questionnaire) and item (non-response to particular questions) – can cause bias in the estimates where missing data are missing systematically according to characteristics of the service users. This is not easy to deal with, although some methods are available. Unit non-response can be adjusted for by weighting the estimates to take account of sections of the population that are missing from the sample that responded. However, this is only necessary should the missing population have characteristics that explain variation in the estimates of interest. For example, if gender explained satisfaction and men were less likely to respond than women we might want to weight for non-response by gender. This method of adjustment has its limitations because it implicitly assumes that non-responders are similar to responders, and they may not be.

There may be several reasons for both unit and item non-response. In some cases it is likely that non-response is a result of difficulties answering the questions. However, in the case of some questions people may just not want to respond, perhaps seeing the question as intrusive.

The response rates were good for the face-to-face interview phase of the study which used an incentive system to encourage people to take part. While the use of incentives may present other issues (such as only certain types of people choosing to take part), careful random sampling could mitigate against such issues. Response was less good for the self-completion phase. This was expected

- the methodological literature shows that self-completion methods generally have lower response rates than face-to-face or telephone interviews. It does, however, indicate the challenge of obtaining acceptable response rates when administering by self-completion and the needs to adopt some of the standard methods for increasing SCT response, such as reminders and other active chasing for responses.

7. Conclusion

Measurement of the quantity and intensity of publicly funded service provision is routine. But on its own this information cannot tell us about the *value* of those services. People benefit from the *consequences* of service use, not from services *per se*. Assessing how well public resources are used therefore requires us to measure the impact of services, the outcomes for service users. In social care, such a measure would have at least three uses:

- to allow outcomes-based commissioning
- to support the regulation of providers of social care to ensure a minimum standard of care according to the outcomes the care generates for service users
- to allow the National Accounting of social care spending to be adjusted for the outcomes-related quality of care provided

The central contention of this work is that the impact of social care services is measured in terms of how they improve the quality of life or wellbeing of service users. The definition of a good service then depends on the degree to which it improves wellbeing.

In theory, in (well-behaved) markets, prices can tell us about the relative impact or value of services because those prices will reflect the choices people make. Highly valued services will be in demand and so secure a higher price. Markets do exist in social care but public authorities play a large part in funding and buying services, not service users, and the likelihood is that prices will be distorted. Personal budgets will move purchasing power closer to service users although in any case the envelope of funding will still be set by public authorities. In the absence, therefore, of textbook markets, we need to measure this impact directly. The methodology we adopt has three elements:

- first, we need to clarify and define the concept of wellbeing for our purposes
- second, we need to develop practical measures of wellbeing
- third, we need to be able to attribute changes in wellbeing, so measured, to the use of services

The Adult Social Care Outcomes Toolkit (ASCOT) for day care breaks-down the concept of wellbeing into 9 quality of life domains with an emphasis on measuring people's capability to achieve good experiences in each domain. Wellbeing is measured in this way by asking people to rate their experiences using either interview or self-completion questionnaires. An overall score is calculated by adding up the ratings in the 9 domains with each level weighted for relative importance. The effect of service use is measured by asking people to rate the quality of life they experience both currently with services (current quality of life) and also hypothetically in the absence of services (expected quality of life).

The aim of the work described in this report is to assess whether the ASCOT methodology is valid and reliable as well as being practical and minimally burdensome, compared to alternative approaches that could be taken.

The study fieldwork consisted of a self-completion survey of 961 people using day care and a follow-up interview with 224 of these people. Day care centres were chosen to test our tool because, of services that receive mainstream public funding, they cater for people with relatively low needs. They are services that are not narrowly focused on personal care tasks, such as home care, or people with high levels of need as in care homes. A key aim was to test how well ASCOT could measure the more intangible aspects of service use, such as having a good social life, being meaningfully occupied and feeling in control, outcomes likely to be affected by day care centres.

A significant challenge with choosing day care centres is that no national register or database of service providers, let alone service users, exists. This precludes us from a direct national sampling approach. Population sampling, even in the over 75 age group, was likely to produce only 10-15% of people using day care and finding a 1000 service user sample in this way was too expensive. Instead, we contacted local authorities who supplied lists of day care providers. We then asked providers to distribute ASCOT packs to service users who would then complete and return the self-completion tool (SCT) and at the same time consent or otherwise to a follow-up interview. This was the only feasible approach within the resource constraints of the study. But it does mean we are reliant on providers in handing out SCTs. As expected, this part of the process yielded the lowest response rates.

7.1 Evaluating the measure

Overall, the ASCOT outcome measures performed well against validity and reliability tests. Construct validity was assessed by looking at the degree to which the ASCOT current quality of life indicator is able to measure wellbeing improvements we theorise should occur as a result of service use. We found that ASCOT did detect wellbeing improvements as resulting from the use of home care, day care and informal care, as expected. Moreover, it consistently measured greater degrees of improvement than the EuroQol (EQ5D), a routinely-used health-related outcome measure. The ASCOT also showed convergent validity in that it was correlated with independent measures that ought to be theoretically related, which in this case were satisfaction ratings, ADL need levels, and service quality indicators.

As regards reliability, we were able to compare current quality of life ratings in the SCT and then in the follow-up interview. Individual outcome scores did change through time as we would expect (in that the measure is of *current* quality of life). However, the overall sample mean outcome score was almost identical: i.e. sample mean differences in scores were zero. Furthermore, regression analysis showed that the difference in reported current quality of life score between SCT and interview was not significantly different from the sample mean of zero for any need sub-group. In other words, mean scores were not significantly different between test and re-test for sub-groups of the overall sample.

The SCT design was chosen in part because it is a (relatively) low burden approach. With only just over 20 sets of yes/no type questions, it can be completed quickly. We tested whether this minimum dataset is enough to calculate wellbeing changes. The follow-up interview was able to go into much greater depth and was used to produce wellbeing estimates to benchmark the data from the SCT. Current quality of life is directly measured in the SCT but expected quality of life is not. These are instead calculated from need and service use information that is collected in the SCT using a formula that was derived using the interview data. We found that the SCT formula predicting expected quality of life scores that were very close to expected quality of life scores measured directly in the interview.

7.2 Attribution

Although the ASCOT worked well, the assessment of attribution method of asking people to hypothetically rate quality of life in the absence of services (their expected quality of life) did raise some issues. We asked people to think about quality of life if their day care centre was removed and no other form of support stepped in to help them. Our results, however, suggest that some people found it hard to isolate the effects of day care centres from other forms of support, such as informal care they might be receiving or other service inputs such as home care. The difference between current and expected quality of life was larger than for people without other inputs, even after accounting for differences in baseline characteristics (such as need levels). This means that some of the wellbeing improvements resulting from these other forms of support might be inappropriately attributed to the use of day care centres. Although this result was not intended, by collecting information on other forms of support we have a way to adjust or correct expected quality of life to remove any spurious other-service effect. This correction reduced the mean size of outcome attributed to use of day care. We also used this correction in the formula that calculates (adjusted) expected quality of life for the SCT.

The expected quality of life approach is easy and low cost to implement. More robust results based on actual outcomes could perhaps be obtained from case-control studies which compared people's ASCOT *current* quality of life between a randomised intervention group of service users that have the new service and a control group of people with the existing service option. Studies of this type are routine in the health field (and to a growing extent in social care), but are far more costly to undertake and can raise ethical issues.

The variant of ASCOT we used in this study has 3 levels – good, intermediate and bad – for each domain. The interview data suggested that these may not be enough. In a number of cases people reported that day care centres did help them in particular outcome domains, but then did not rate expected quality of life any lower than current quality of life. This could occur if people did not think the service alone warranted an increase in outcome from bad to intermediate or intermediate to good. Overall, with 9 domains and 3 levels in each, there are nearly 20,000 possible combinations, although by design these domains are intended to be independent. As such, if a service only affects a small number of domains then insensitivity could be a problem. The version of ASCOT evaluated in

the Outcomes of Social Care for Adults (OSCA) project now has 4 levels, rather than 3 (Netten et al., 2009).

ASCOT in this study asks people to rate subjective outcomes. These ought to be dependent on people's preferences and aspirations. The study found that some people adapt to poor circumstances by downgrading their expectations, which leads them to subjectively rate experiences more highly than they might have done before. Finding this behaviour offers further validation of the measure. But it does raise questions about how we interpret and apply the results. Should we, for example, try to take into account the possibility of adaptation by participants? This question is addressed in a broader debate (Menzel et al., 2002).

The study found that day care centres do improve outcomes at a cost equivalent to just under £25,000 per 0.1 unit improvement, on the 0-1 scale, in ASCOT per service user on average. Mirroring guidance used by NICE if it were applied to this case, we would conclude that day care for older people is cost-effective.

7.3 Application

The ASCOT was shown to be valid and reliable in this study, but for it to produce valuable information for decision makers requires the tool to be appropriately used in practice. The aim would be to ask a *representative* sample of service users to complete SCTs and process the results. But like all surveys, there is the potential for selective sampling and influence on people's responses. It is important that users of this toolkit ensure that these potential biases are minimised. Ideally, independent, third-party organisations would be used administer these surveys, or at least to spot check results.

7.4 Wider applications

The study here concerns day care centres, but the approach should be applicable to other social care services such as home care, residential care and so on. The current quality of life measure was designed to be relevant to generic social care experiences and so could be used, as is, for case-control type studies. For the expected quality of life approach, we would need to recalibrate the SCT formula to the service in question, rather than day care, and this would require a bespoke

interview study. Once calibrated, however, the tool could be used routinely for other services.

Some people argue that low level services can have a preventative effect in that they slow the rate at which people's needs increase. The ASCOT approach can address these questions in studies that follow people through time, and where both current and expected quality of life are measured. If services have prevention effects then in comparison to a control group, expected quality of life would not decline as quickly in the intervention group. In turn, current quality of life at follow-up stages would also be higher in the intervention group compared to the control group, other things being equal.

7.5 An outcomes based approach

This study has shown that the ASCOT offers an approach which decision makers can use to measure robustly the impact of services at relatively low cost. Ultimately this should allow resources to be focused on services and support that best improves people's wellbeing within the overall financial constraints of the public system. ASCOT provides decision-makers with the tools, but the true potential of an outcomes-based approach will also depend on the extent to which resourcing and service decisions are actually made with outcome considerations at the heart of the decision making process.

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