

www.PSSRU.ac.uk

Downloaded publication in Acrobat format

The PSSRU retains the copyright in this publication.

All quotations must be acknowledged and permission for use of longer excerpts must be obtained in advance.

We welcome comments about PSSRU publications. We would particularly appreciate being told of any problems experienced with electronic versions as otherwise we may remain unaware of them.

Email: pssru_library@kent.ac.uk

Measuring Outcomes in Social Care: Second Interim Report

Quality Measurement Framework Project

Julien Forder, Ann Marie Towers, James Caiels, Julie Beadle-Brown and Ann Netten

PSSRU Discussion Paper 2542 May 2008

The **PERSONAL SOCIAL SERVICES RESEARCH UNIT** undertakes social and health care research, supported mainly by the Department of Health, and focusing particularly on policy research and analysis of equity and efficiency in community care, long-term care and related areas — including services for elderly people, people with mental health problems and children in care. Views expressed in PSSRU publications do not necessarily reflect those of funding organisations. The PSSRU was established at the University of Kent at Canterbury in 1974, and from 1996 it has operated from three branches:

University of Kent at Canterbury, Cornwallis Building, Canterbury, Kent, CT2 7NF London School of Economics, Houghton Street, London, WC2A 2AE University of Manchester, Dover Street Building, Oxford Road, Manchester, M13 9PL

The PSSRU Bulletin and publication lists are available free from the librarian at the PSSRU in Canterbury (01227 827773; email pssru_library@kent.ac.uk) and on the PSSRU website.

Email: PSSRU@kent.ac.uk Website: http://www.pssru.ac.uk

1. Introduction

The Quality Measurement Framework (QMF) programme began at the end of 2006 and is being funded for three years by the Treasury under Invest-to-Save and led by the Office of National Statistics (ONS). The QMF programme has two main aims. The first is to create methodologies for assessing the value-added of publicly funded services, and in this case, social care services. The second is to develop a toolkit usable by authorities to assess and monitor performance, and guide commissioning. The focus is on the measurement of the value of public services delivered by third sector organisations as it compares with value produced by public or private sector providers.

The motivation for this work – the need to measure the value of publicly-funded service outputs – stems from having to provide accountability for the spending of significant sums of public money in social care. Furthermore, information about the value of services is of crucial use to commissioners charged with securing the best value and equitable use of public resources.

The PSSRU's component of the QMF programme is to measure the value of:

- care services provided for frail older people and younger adults with learning disabilities in care homes:
- low-level services such as day centres and lunch clubs used by older people;
- information and advice services, with particular regard to the social care system

The work is sequenced into 4 phases. The first phase of the work is conceptual and developmental. It is primarily concerned with understanding the concept of 'value' (of social care services) and developing a methodology and empirical strategy that will lead to a way to assess value that is practical, replicable and robust. This first phase of the work is now largely completed.

The second phase is the start of the fieldwork and involves piloting and small scale testing of the instrumentation and methods developed in the first phase. The contribution of this work is in ensuring that the methods are workable prior to the main fieldwork phase. It is also to undertake a preliminary assessment of validity and robustness of the instruments, and make changes before the instruments are used in the main fieldwork.

The third phase of the work is the main fieldwork and analysis phase and involves two large surveys of service users and providers, one for the low-level services, and one for the care homes service areas. This phase is about collecting data to be able to assess the well-being and outcome implications of the use of social care services.

The final phase is the preference study. As outlined below, information on peoples' preferences is required to move from indicators of well-being to an overall measure of the value of different types of social care. The work will build on a pilot preference study (Burge, Gallo et al. 2006) and will use a range of 'preference elicitation' techniques (such as discrete choice and best-worst).

Structure

This report is structured as follows. This introduction closes with a discussion and examples of the use of value information. Section 2 outlines some of the theoretical developments since the publication of our first report in 2007. These developments have led to the design of our Adult Social Care Outcomes Toolkit (ASCOT) and this is described in Section 3. Section 4 goes over our latest empirical strategy. Section 5 reports on the empirical work to date regarding our study of care homes for older people and younger adults with learning disabilities. The section describes the fieldwork methods and reports on the results of the pre-pilot and pilot fieldwork. We are also

undertaking a study of low-level services and the empirical methods are reported in Section 6. This section includes discussion of the results of the work with service user and staff focus groups.

Value information and its uses

People use services because they value the consequences of their use. Assessing how well public resources are used therefore requires us to have some measure of *value*. Then public funds can be deployed where they generate the most value for each pound spent. Ideally, decision makers would have a measure of value on a single scale that fully captures and aggregates together all aspects of value that apply.

In social care, this measure would have at least three uses:

- to allow outcomes-based commissioning
- to support the regulation of providers of social care that ensured 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 outcomesrelated quality of care provided.

The 150 Councils in England have the chief responsibility of providing social care to disabled or frail adults and older people. Some £6.6bn was spent from the public purse on social care for older people alone in 2006/7. Councils commission services from in-house (public) sector providers, but now mostly from private and third-sector providers. Nearly 1m older people benefit from the care and support that is secured at any given time. Councils vary considerably in their practices, but much of the quantum of service that is commissioned is done on the basis of outputs – the number of care home places, the number of hours of home care, and so on – and is often heavily influenced by historical patterns of provision. With a robust measure of the value of services, commissioners could move away from these processes to deploy their limited resources to services that demonstrated the best cost-effectiveness (within the context of a regard for risk and equitable provision).

Commissioning

An example relates to the deployment of home care services. Figure 1 shows the impact of the use of home care services on an outcome-based value measure – the ADL adjusted life year as used in the Wanless Social Care Review (Wanless, Forder et al. 2006). We consider the properties of this measure below, but suppose at this stage that this measure is an accurate reflection of the value of using home care services. The relationships in the chart are based on an analysis of the 2005 Formula Spending Share (FFS) survey (Darton, Forder et al. 2006; Wanless, Forder et al. 2006). The data show that for each hour of additional home care received by the individual, their outcomes improve. Value is measured as a year of life adjusted by the person's quality of life or *well-being* over the year, the latter being measured on a 0 to 1 scale. With services improving a person's well-being (with assumed negligible effect on life expectancy), the gain in value from using services is proportional to the increase in well-being. The rate of increase is high for additional hours at low intensity but tails off at high intensity.¹

To demonstrate how this information could be used, we take an example population of 1000 older people with care needs. The cost of home care in this case is £11.50 per hour. So over the course of a year, the total cost in the population of an extra hour is: £11.50 x 52 weeks x 1000 users = £598,000 p.a. What are the cost-effectiveness implications of increasing the average level of provision beyond 10 hours per person?

¹ This diminishing return is due to the finite capacity of people to benefit from services. The graph shows the effect for the average person, but can be broken down by level of need (high need versus low need people).

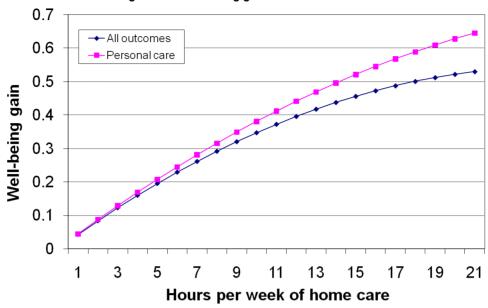


Figure 1. Well-being gain from home care

Reading from the chart, the total improvement in well-being is 31 units for the 10th to the 11th hour and 29 units from the 11th to 12th hour. We can look at the ratio of extra cost to extra benefit, the incremental cost-effectiveness ratio (ICER):

- 10th to 11th hour: 598,000/31=£19290
- 11th to 12th hour: 598,000/29=£20620

The 11th to 12th produces an improvement in well-being at a higher cost than the 10th to 11th hour. Is either increase worth funding? This decision will depend on our willingness to pay for well-being improvements. Conventionally this willingness is expressed as a monetary threshold e.g. we are willing to pay up to £20,000 per unit of well-being – our first report from the QMF programme, *Measuring Outcomes in Social Care: Conceptual Development and Empirical Design* (Forder, Netten et al. 2007) explored this issue in detail. This willingness to pay could reflect the opportunity costs of public funding of other services, and is an approach used by the National Institute for Health and Clinical Excellence (NICE) for health care interventions. At the £20,000 threshold, the 10th to 11th hour is a cost-effective increase but the increase to 12 hours is not.

Value information in this form can therefore be used by commissioners to determine appropriate levels of funding of care. In comparing different social care services e.g. home care versus day care, commissioners can prioritise according to the ICERs of each service type, and in so doing generate the greatest well-being improvement for the resources available.

Regulation

The Commission for Social Care Inspection (CSCI) is charged with ensuring that social care services achieve a minimum standard of quality. Providers are awarded quality ratings according to their performance in a number of domains. The corresponding indicators for the quality domains vary in type; some measure inputs (e.g. staffing), some processes (e.g. complaints procedures) and some relate more closely to outcomes or well-being indicators. The latter mainly rely on the judgment of inspectors. The use of generic well-being and value indicators could be used to inform these judgments.

National Accounts

To record the output of the public sector in the National Accounts a method is required for adding up the individual outputs of each service area. This requires that outputs can be measured in equivalent terms e.g. so we can add the value of the provision of one hour of home care for older people with one place in a care home. It requires having a judgment of the relative value of these

services. A standard approach is to weight outputs according to their costs and add up the total. There are, however, a number of problems with cost weights. Ultimately, cost is not the same as value, and yet it is the latter we wish to measure. Only in certain circumstances will costs be a good indicator of value, circumstances that may often not occur. If a generic direct measure of value were available, it could be used to weight outputs and provide a total measure of value.

2. Measuring value – theoretical considerations

In this sector we report our latest theoretical developments concerning the methodology used to assess value and on the resultant toolkit, the Adult Social Care Outcomes Toolkit (ASCOT).

Developing the methodology

The conceptual work has provided a methodology for developing a practical toolkit that can be used routinely to capture the value of social care services. There are two analysis tasks.

- First, what information, in principle, needs to be collected and in what form, to assess the value of social care services together, this can be called the value toolkit.
- Second, what empirical analyses are required to establish that the value information methodology developed in principle (i.e. the toolkit) can actually produce valid, reliable value information in a low-burden and practical way.

We can elaborate on each task.

What information is required and in what form – developing a value toolkit

Work from the first phase of the project has shown that for a toolkit to produce a measure of the value of social care, it must be able to:

- First, deploy a robust measure of a service user's well-being. This involves
 - o understanding the concepts of well-being, and
 - o developing, in principle, a practical measure of well-being (as it is defined)
- Second, have a means by which changes in peoples' well-being can be attributed to the use
 of services (and not any other factor in people's lives that may also have a bearing). This
 involves:
 - o understanding the concept of attribution, and
 - o finding a practical means by which a person's well-being without services can be subtracted from their current well-being (with services)

Testing the toolkit

Having developed a method in principle for collecting value information we need to be able to evaluate that this method works well in practice. There are three tests:

- First, that the well-being measure must actually produce a measurement consistent with the concept of value (it is *valid*), and do so repeatedly in different real-world applications (it is *reliable*). We also need to ensure that the toolkit meets the low-burden condition.
- Second, we need to establish whether our attribution method works in the sense of producing unbiased estimates of the impact of services, not the impact of other factors.
- Third, that where we draw on routinely available data sources e.g. CSCI's quality ratings of care home providers, this information is providing a measure of the relevant concept.

Satisfying these tests is an empirical task. Initially we will undertake a preliminary investigation with small pilot samples, using mainly qualitative techniques. The main testing will be undertaken on data from a large sample of social care providers and service users using quantitative, statistical techniques.

A value toolkit

In this section we summarise the conceptual work undertaken to develop the toolkit according to this methodology (i.e. the first task outlined above). The starting point is to get to grips with the concept of 'value'.

What is value?

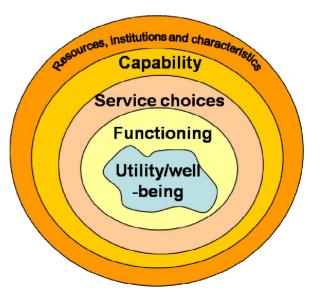
As a concept, the notion of 'value' appears to be relatively straightforward. However, closer inspection shows the concept to be more slippery than first imagined. In particular, developing robust, practical measures of the value of public services is very difficult. Where services (and other goods) are marketed in a (well-functioning) market, prices serve as a reflection of value. The more people value something, the more they are prepared to pay for it. The price is not the value, but it is a close correlate.

Where prices do not exist, or are likely to be distorted, value must be measured directly and this requires a more precise understanding of the concept. Our first report from the QMF programme, *Measuring Outcomes in Social Care: Conceptual Development and Empirical Design* (2007) explored this issue in detail. People do not value services *per se* but rather the consequences those services have for their well-being. In this sense well-being improvement is a fundamental motivation; in fact at an individual level well-being is really synonymous with value. The problem, however, is that we are not sure that well-being can be directly measured². People may be able to rate their well-being on some numerical scale, but there are at least potential problems. First, rating well-being is a cognitively demanding task and people could either make different interpretations of the same situation at different times or not be able to detect small changes sufficiently. Second, and closely related, people's responses are highly context specific, depending not only on mood at any given time, but also people expectations and adaptation to their current circumstances (Kahneman, Diener et al. 1999; Kahneman 2000).

In light of these potential problems, researchers have instead looked for more measurable indicators, having people rate a range of attributes that are known to closely correlate with well-being, but which are more 'objective', or at least more straightforward for people to assess – see Figure 2.

As the figure shows, there are a number of candidate indicators. To begin with, we could measure how well people function with respect to key activities of daily living (Sen 1985; Sen 1993). These 'functionings' include, for example, whether people are fed, clean, dressed and so on, and are basic functionings. More complex functionings include whether people are at risk, have high levels of social contact, experience leisure activities, etc. Generally speaking, the better people function in these ways, the higher we expect their wellbeing to be. The challenge is to establish the exact relationship between functioning and well-being where we do not have a measure of well-being. An approach is to make the

Figure 2. Measuring value



² Some psychologists believe that we might be able to use instruments to read well-being or happiness directly from our brains.

assumption that if people attain the highest level of functioning then they have a well-being score of 1. If they have such a low level of functioning that they would rather be dead, then well-being is given a score of 0. By making a further assumption about the shape of the distribution of well-being between 0 and 1, an underlying well-being score can be inferred, statistically, from information about how people rank different levels of attainment of the various functionings – this is called preference weighting (see Forder, Netten et al. 2007).

People's functioning at any given time ought to be closely related to well-being, particularly with regard to basic functioning. Although preferences might differ, it is hard to imagine that any person is not better off if they are fed, clothed and sheltered than not. But for complex functionings, the relationship with well-being may not be so clear cut. Some people might feel better off with some lower levels of functioning. For example, some people may prefer to have lower levels of social contact. Arguably, what is important is not actual functioning but the potential to function. This potential is often referred to as people's capabilities. To measure capability, people can be asked about their actual functioning and also any restrictions or constraints they face in achieving higher levels of functioning if they so wished.³

Developing well-being measures

In our previous report, we investigated what kinds of functionings in people's lives were most

important in affecting their well-being (and health), particularly with respect to their use of social care (see Box 1). There are a number of existing well-being scales that could potentially measure the effects of social care use, for example:

- General Health Questionnaire (GHQ) (see Goldberg and Hillier 1979)
- Quality Adjusted Life Year e.g. EuroQol (EQ5D) (see Brazier, Deverill et al. 1999)
- Quality of life capability measure (ICECAP) (see Grewal, Lewis et al. 2006; Flynn, Louviere et al. 2007)
- Older people's utility scale (OPUS) (see
- Netten, Ryan et al. 2002; Ryan, Netten et al. 2006)
- Control, Autonomy, Self-realisation, Pleasure (CASP 19) scale (see Hyde, Wiggins et al. 2003; Wiggins, Higgs et al. 2004)

In principle, some of these measures could be used to measure outcomes for people using low level services, but there are a number of theoretical reasons why they may not be particularly suitable. Part of the project is to consider these potential shortcomings in the development of a new bespoke measurement scale for social care, namely the Adult Social Care Outcomes Toolkit (ASCOT)

Box 1. Outcome domains

- Wellbeing:
 - Personal cleanliness and comfort
 - Social participation and involvement
 - Control over daily living
 - Food and nutrition
 - Safety
 - Clean and accessible accommodation
 - Occupation
 - Living in own home
 - Dianity
- Health (care related):
 - Anxiety, worry and depression
 - Pain

³ With regard to people with frailty or disability, functioning and, ultimately, well-being ought to be influenced by what services and support people use. People choices about the services they use should then tell us something about their well-being, so-called revealed preference. The problem, however, is that the way in which choices are offered, and how those choices are constrained, is of crucial importance. If choices are limited or distorted, then for any given level of funding, the services that people select need not be that configuration which maximises their well-being. For example, if people were only offered either a care home placement or intensive home care, but actually wanted day care, a personal assistant and some befriending support (which cost the same), then well-being is not maximised. In well-functioning markets (at least in theory), competition, good information and the action of price (change) can give people choices that will be consistent with best outcomes Forder, J., M. Knapp, et al. (1996). "Competition in the Mixed Economy of Care." Journal of Social Policy 25(2): 201-221.. But for publicly commissioned services, these conditions are very unlikely to hold. It is for these reasons that a direct measure of well-being is sought.

scale, which is outlined below (see also the section, Analysis of the Health Survey for England, on page 25).

Attribution

Measuring well-being on its own is not sufficient for us to be able to value the use of social care. We also need a way to attribute the change in well-being to the use of services. The basis of the attribution problem is being able measure the difference in people's well-being with the service and in its absence, holding everything else constant. The standard approach is to use a randomised controlled trial (RCT) design; that is to select a group of potential service users and to randomly allocate them to either a group that uses the new service or a group that receives the 'usual' arrangements. With sufficient sample size, the randomisation ensures that the two groups do not differ on average in any way except the service use. Often seen as a gold standard, RCTs do have a number of shortcomings: there are ethical problems in denying some people services that are likely to help them; trials often involve new services or interventions and results may not continue in routine use of these services; and perhaps most importantly, RCTs are very expensive to conduct. In particular, there is no prospect that RCTs can be conducted for routine measurement of the impact of social care services.

A second option is to use a non-randomised, naturalistic study where a target group of people are sampled that would include people using different levels of the service in question (including zero use). Without randomisation, differences in well-being between service users and non-service users may also be due to systematic differences in other characteristics and therefore these effects must be accounted for in the analysis. One approach is to use statistical modelling to attribute the degree of variation in well-being between sample individuals to (all) other relevant factors, and also to the use of services. Multiple regression techniques are appropriate. In theory if all other relevant factors are modelled correctly, any remaining difference in well-being between people using the service and those not using the service is due to the effects of the service. It is particularly important to account for all relevant *needs* factors that would imply reduced well-being in the absence of services. If these are not taken into account then the use of services – which will be highly correlated with high need – might show reduced wellbeing. People who are fitter and healthier than others are less likely to use the service and yet have higher well-being. A service use group will likely have greater need and so this baseline difference must be factored into the analysis.

This option has the advantages of being able to use any relevant survey that measures service use and need (and hence is lower cost than an RCT and requires far less time); looks at the impact of the service in routine use (not in a trial setting); and allows investigators to assess other relevant factors (e.g. the relationship between wellbeing, service use and, say, people's incomes). The disadvantage is that important factors might be omitted or mis-specified, which can introduce bias into the estimation of the size of the service effect on wellbeing. It also often requires surveying of people that are potential, but not actual service users, or where service use varies sufficiently for statistical inferences to be made.

A third alternative is to try to establish well-being in the absence of the service for the people using the service in question – the *expected well-being* approach. One method is to ask people directly to rate what they think their well-being levels would be in the absence of the service. The significant advantage of this approach is that it does not require a control group as such, because the service users also rate their expected outcome without services. Instead of using statistical techniques to infer a service user's well-being in the absence of services (based on their need), survey respondents are asked to make this judgement themselves. The disadvantage is that such a judgement might be hard for people to make since, in making it, they have to consider a

hypothetical situation. Their current circumstances might influence how they think about this hypothetical situation of being without the service.

3. Adult Social Care Outcomes Toolkit

The above theoretical considerations and the work outlined in our previous report underpin the development of our Adult Social Care Outcomes Toolkit (ASCOT). The ASCOT has two components: a well-being measurement scale and an expected outcomes (called *capacity for benefit*) attribution method. Together these components allow the outcomes of service use to be measured. The well-being scale is based on a levels-within-domains approach. The starting point is the full set of well-being domains as described in Box 1. Some domains are dropped for specific service areas where they are clearly not relevant (e.g. meals services providing personal care). Within each domain, service users are then rated (either by themselves in interview or self-completion questionnaire, or by the observation of a third-party researcher) on their functioning in that domain on one of either three or four levels. For example,

I get what I regard as the right meals for me at times suited to me	
I do not always get the right meals, but I don't think there is a risk to my health	
_	
I do not always get the right meals, and I think there is a risk to my health	

This task is repeated for all domains to build up a picture of current functioning. In addition, people are asked about their capability to achieve higher functioning in each domain if that current functioning shows some shortfall. Together this information is used to assess well-being within each domain. The results of a preference study will give a weighting for all levels across the domains (as mentioned above) and hence a basis for computing a single well-being score. The final specification of well-being scale will be settled in light of the cognitive testing in the fieldwork phase of the project. Two important issues need to be resolved:

- handling the distinction between capability and current functioning
- the extent to which functioning is measured in a more objective or more subjective sense (e.g. regarding social participation, either: "I regularly spend time with people I am fond of", or, "I have a good social life").

Regarding attribution, given our emphasis on finding low burden tools, the ASCOT uses the third option outlined above, the expected well-being approach. Specifically, ASCOT uses two variants of this approach. In both variants, the starting point is to conduct in-depth fieldwork with a large sample of people using the service in question. People are asked to rate their current well-being as described above and then asked to hypothetically rate, on the same scale, their expected well-being in the absence of services. The service outcome is the change in well-being:

$$\Delta = -$$

where $\;\;$ is current well-being and $\;\;$ is expected well-being in the absence of services. The term Δ is the outcome.

In a routine application, conducting the necessary in-depth fieldwork to establish current and expected well-being is far too burdensome. Instead, a number of shortcuts can be exploited. Firstly, expected outcomes in the absence of services will be highly correlated with people's needs i.e. their disability, impairment and their social situation. We have the function = (), with needs denoted z. Where needs information is collected in the large sample work, we can use regression

analysis to estimate the function z needs to be collected. The second shortcut comes in using the concept of *capacity for benefit*. This is the idea that if services worked perfectly they would improve service user's well-being to the maximum possible, a well-being score of 1. In practice, no service is perfect (or could indeed overcome other factors that reduce a person's well-being). To reflect this reality, we can apply an outcomes-related 'quality' factor, where $0 \le z \le 1$. In other words, (1) can be rewritten as follows:

$$\Delta = - = 1 - ()$$

As a shortcut we can see if this quality factor — can be inferred from the routine assessment of quality carried out by the regulator. For example, CSCI produce quality ratings for each provider, which is a number —. Then we can find — using information about well-being from the survey work and the quality rating provided from CSCI using a regression of: — = — (). This approach is the first variant and it used in the care homes study.

The advantage of this approach is in using information that is already being collected by the regulator. We can identify the full impact of the intervention rather than marginal changes and can identify whether changes in output are associated with changes in what the intervention or service in its current configuration can deliver or improvements/reductions in the quality of what has been delivered.

Previous work (Netten, Forder et al. 2006) demonstrated how the approach can be used to reflect the impact on outputs of care homes for older people of increased levels of dependency and changing levels of quality reported by the regulator (the Commission for Social Care Inspection (CSCI)). Necessarily this was based on a number of assumptions and available data. This project builds on that work to develop a validated approach to measuring the outputs of care homes drawing on routinely available information.

In some service areas – such as low level services – the regulator does not (currently) inspect these services, and so either quality, —, has to be measured in some other way or information on current outcomes is collected directly as part of the process to assess value. The latter approach is the second variant, and it involves a process to collect current outcomes. There may be a number of ways to collect this information, but with the onus on low burden, the plan is to use a self-completion tool (SCT). The SCT centrally involves a short questionnaire that is completed by users of each service. The SCT could be distributed by the provider to service users and returned directly to the commissioner. It is an approach that is more relevant to low-level services where the needs levels of service users is relatively low and therefore the chances of people being able to complete an SCT are relatively high. The SCT administers the current well-being scale,—; collects information on need,—, and also some rudimentary information on the provider. Outcomes are then inferred from the relationship:

$$\Delta = - ()$$

where the function is estimated from the first step large survey. The SCTs would be readministered on a regular basis to give a moving picture of outcome change over time.

4. Empirical strategy - aims

The aims of the fieldwork are:

to test our approach,

- to collect information about service outcomes (i.e. $\Delta = -$),
- to use well-being and needs information to estimate the parameters and to be used in the value toolkit (ASCOT)

Testing the toolkit

As we outlined above (see, Testing the toolkit, page 5), there are three tests of our approach. The first is to establish that the well-being scale in ASCOT is valid and reliable (in measuring), and we have several approaches that can be used. For the LLI study cognitive testing will be undertaken with a small sample of service users in the pilot fieldwork, assessing people's understanding of the questions about well-being. In the main fieldwork, we will look at the psychometric properties of the instruments. Item response theory (IRT) can cast light on whether all questions need to be asked or whether a subset will be sufficient (Thissen and Steinberg 1986; Edelen and Reeve 2007). Furthermore, by administering more than one instrument in the fieldwork we can compare them directly to assess their sensitivity and comprehensiveness. For example, in the low-level services project we will include EQ5D and GHQ12 as well as ASCOT.

The second test is whether people are able to assess their expected outcomes in the absence of services. Cognitive testing will be invaluable in this respect. But the best test will be to collect information from a non-service-user control group about their well-being (by definition in the absence of services). We will explore the feasibility of such an add-on study. An alternative is to use an existing survey such as the Health Survey for England (HSE). This does not include the ASCOT measure, but does have EQ5D and GHQ12. We can use the main fieldwork to establish the relationship between GHQ12 and ASCOT, and therefore to estimate what GHQ12 score corresponds to expected outcome in our fieldwork. Comparing this 'expected' GHQ12 score with the GHQ12 score of non-service users in the HSE sample, controlling for need and other factors, will give us an indication of any bias in the expected outcomes approach (see section, Analysis of the Health Survey for England, page 25, for further details).

The third test is look at the relationship between the quality ratings produced by the regulatory and the outcome scores estimated in the fieldwork using ASCOT. Clearly, between providers these two numbers have to correlate closely for this method to be valid. We are testing this in the care homes survey by staging the main fieldwork around inspections carried out by CSCI. We will therefore get timely inspection data alongside our own ASCOT measures for each home in our main fieldwork sample.

Particular methodological challenges are presented in the care homes study as the majority of residents of care homes are very vulnerable. Previous estimates of CfB have been based on interviews with mentally intact older people in their own homes. In this situation people are able to reflect on what their levels of need were likely to be in the absence of services (Netten et al 2006). This study is focusing on older people and people with learning disabilities in order to explore the degree to which the same approach can be used to measure CfB and quality for people with very different types and levels of impairment.

Observational methods and judgements form the foundation of the approach, which is described in detail below. Clearly it is particularly important that there is good inter-rater reliability if we are to be confident in the findings. Below we report on the findings of a pre-pilot and pilot exercise that was used to initially develop and then test the fieldwork instruments.

Collecting outcomes information

Subject to satisfactory testing above, the main fieldwork will give rich information on the outcomes of services in our surveys. Not only will this information provide an important snapshot of the current performance of services, it will also provide a baseline from which to compare changes over

time, and give us a platform to do further analysis to identify which providers produce good outcomes, and which do not. This information will be especially useful for commissioners, for example.

Calibration

The third task of the fieldwork is to provide the estimates for parameters needed for the routine use of ASCOT value toolkit, namely the relationship between needs/dependency and expected outcomes () and the relationship between CSCI quality rates and outcomes (). This also requires us to develop and validate a method for monitoring the dependency of residents in a way that can be used to reflect changing value of care home outputs over time.

Ethical Approval

Research governance application was submitted and all ethical issues were considered and scrutinised by Kent County Council. Both care home and low-level service studies were was granted unconditional approval by Kent County Council. Applications for ethical approval were also submitted to the School Research Committee (SRC) Ethical Panel at the University of Kent and approval was subsequently granted.

5. Care homes study

This section reports progress on the care homes study. For more detail, please refer to the standalone report (Towers, Beadle-Brown et al. 2008) and the appendix to that report.

Fieldwork methods

Pre-pilot study

Two local care homes with previous experience of working with the PSSRU or the Tizard Centre took part in a pre-pilot study to test the early drafts of the measures and give the fieldworkers practice using the measures and conducting observations in real care settings. One home provided care for adults with learning disabilities and the other provided personal care for older adults. Unlike the pilot and main study, we were not concerned with randomly selecting residents because the intention was not to look at the data in any detail, rather to use the opportunity to highlight problems with the measures and/or further training needs relating to the observational methodology in particular. Participating homes understood that this was the intention of the prepilot when they agreed to take part.

Approximately two weeks before the fieldwork was due to commence, resident user characteristic questionnaires were sent to managers for completion by staff. Managers (or a member of staff who knew the resident well) were asked to complete one questionnaire for each participating resident. Once again, the main priority here was to test the design and clarity of the questionnaire so that problems could be picked up and resolved before the piloting stage. Fieldworkers went through the questionnaires in some detail with managers on the first morning of fieldwork and the feedback we received led to changes and improvements for the piloting stage of the project (see the results section for further information).

Two fieldworkers conducted the observations in the pre-pilot homes. They observed simultaneously but coded independently from one another so that their ratings could be compared and any discrepancies discussed and learned from. The structured observational measure, designed to measure service users' engagement in meaningful activities was conducted during a fixed time period from 4pm until 6pm on day one of fieldwork. During this time, fieldworkers must not engage with staff/residents but instead must be unobtrusive observers. The measure employs a method of observation called momentary time sampling and involves coding behaviours (e.g. engaged in social activity, engaged in a non-social activity, not engaged in a meaningful activity) every minute with

the aid of a stopwatch. Observations are divided into 5 minute periods per focal resident and rotate between focal residents during the two hour period (e.g. observers record five minutes worth of data of person one, then five minutes on person two and so on). As this is a very detailed and structured methodology, further information and justification for why it should be conducted during the 4-6pm period can be found in the Appendix to the standalone report (Towers, Beadle-Brown et al. 2008).

Interviews with staff and residents were shared between the fieldworkers over the course of two days in the service. The aim was to conduct interviews about the five focal residents with members of staff who knew them well and also to conduct interviews directly with residents wherever possible. Methodologically, the aim in the pre-pilot was to identify difficulties and issues relating to clarity, consent and process so that they could be rectified before the pilot. Once again, this process highlighted several areas for improvement, which are reported in the results section below.

Pilot study

Recruitment of homes

For the pilot, care homes were recruited opportunistically from the two CSCI regions that had already agreed to take part in the main study (North West and West Midlands). Regional Change Managers made links between the research team and some of the local inspectors who were keen to be involved in the research and it was these inspectors who then recommended homes to take part in the research. It was important that the homes were about to be inspected because we wanted to pilot the process of trying to arrange fieldwork around inspection dates and we also wanted our data collection to take place close enough in time to key inspections that we could be confident in the comparability of the results.

To ensure our measures and processes were tested in different environments in each region, we asked inspectors to recommend a care home for older adults (personal care only), a care home for adults with learning disabilities and a nursing home in each pilot region. Inspectors approached the homes initially and if the home did not object, their details were handed to the research team and we contacted them directly to talk about the research and ask them to participate in the pilot. All of the homes recommended by CSCI agreed to take part in the pilot (see results section for more details about these homes). As it was an opportunistic sample and as quality ratings were still confidential at the time of piloting, we were unable to guarantee a range of quality in the piloting stage. However, inspectors were asked to include homes of all quality when recommending homes to take part in the pilot and the results section shows that at least one home (older adults) was judged to be failing the majority of the standards it was inspected against (see result section for further information).

Selection of residents and consent process

Unlike the pre-pilot, for the pilot stage it was important that we followed the resident selection and consent process planned for the main study. Pilot homes were asked to send us a copy of part one (self-assessment) of their most recently completed Annual Quality Assurance Assessment (AQAA). This form is sent out to homes approximately 10-12 weeks before a key inspection or annual service review and amongst other things, provides home level information about residents and staff, as well as more detailed, anonymous, information on a sample of up to 20 residents. This table provides information about residents' sex, age and ethnicity, as well as additional information such as whether the person has communication difficulties. Five focal service users were selected for the study using the information provided in the table. In small, learning disability services, where it is common to find there are five or less residents living in the home in total, all residents would be listed on the AQAA and all would be selected. In homes with six or more residents, we applied the following selection process to select five focal residents from the list:

- 1. Identify any resident listed in the table from a black or minority ethnic group.
- 2. The first resident from a minority ethnic group is selected; thereafter select every nth resident until 5 have been selected from the list.
- 3. If there are no residents from a minority ethnic group in the table, use a random number generator to decide which resident to start on and thereafter take every nth resident in the table until 5 focal residents have been selected.

As one of the aims of this study is to explore how well the needs of people from minority ethnic groups are met in care homes, it was particularly important that we include residents from ethnic groups other than White British in the pilot. This is why we purposively selected residents from BME groups using the information in the AQAA.

Following the same process as the pre-pilot, home managers were sent two types of consent form for each focal resident. One form was for gaining consent directly from the resident and was accompanied by an information leaflet to inform consent; the other was for gaining consent through consultation with representatives and was also accompanied by a leaflet to inform their decision. The project information for residents was presented differently for the different client groups, so as best to meet their different needs. For example, the information leaflet for adults with learning disabilities contained pictures to assist understanding. Please see the Appendix to the standalone report for copies of the final drafts of these leaflets. If consent was not given by the resident or their representatives, another resident was selected from the AQAA to replace them (following the procedure above). The aim was to gain consent for five focal residents, wherever the size of the home allowed.

Data collection

Three researchers conducted the fieldwork in the six pilot services, with two attending each home. This allowed us to calculate inter-rater reliability on the observational measures, the results of which are reported in the results section below. Fieldworkers met the home manager together on the morning of day one, at which point they answered any questions, discussed the plan for the next two days, collected the questionnaires and consent forms and were given a tour of the premises and introduced to the residents and staff. Fieldworkers conducted their observations at the same time as each other but made their ratings entirely independently of one another so that inter-rater reliability could be assessed. Interviews with staff and residents were shared between the fieldworkers, such that only one researcher sat in on an interview at any one time so as not to intimidate staff and/or residents. Further details are given for each aspect of data collection below.

User Characteristic Questionnaires

To reduce the burden on the homes, most of the data required for the study is collected by the fieldworkers during the two days of fieldwork in the service. However, as with the pre-pilot, approximately two weeks before the fieldwork dates, user characteristic questionnaires were sent to managers for completion by staff. Care home managers were asked to give the questionnaires (maximum of five per service; one for each focal service user) to a member of staff who knows the resident well so that they could be completed and ready for collection on day one of the fieldwork. User characteristic questionnaires collect more detailed information about the residents' health (physical and cognitive), mobility, care and nursing needs and take approximately 20 minutes to complete. The questionnaires identify the focal residents using a code so that this data can be matched to that collected through observation and interviews.

In addition to the user characteristic questionnaires for the five focal residents, homes were also sent brief, anonymous questionnaires about the other residents listed on the home's AQAA. These questionnaires are very short, taking less than ten minutes to complete and are designed to collect

basic information about the service user's age, ethnicity, health and care needs. The purpose of collecting this information is to give us a baseline level of needs against which to compare our focal residents. The aim is to confirm that the focal residents are representative (in terms of age, health and social care needs) of the home's residents in general. As even the largest homes have only to list up to 20 residents on the AQAA, at most homes would have to complete 15 (20 minus 5 focal residents) of these short questionnaires before the fieldwork dates and these should be shared between the care staff to reduce the burden on any one person. In small homes, where all the residents are taking part in the study, these forms were not used.

Finally, as the AQAA does not contain identifying information (no names or date of birth, only age in years) all short characteristic questionnaires were entirely anonymous and so consent was not required⁴. This meant that these questionnaires could be sent to the home as soon as consent was agreed for the focal residents and staff could complete them without further delay.

Observational Measures

There are seven sections of the observational toolkit. The two-hour structured observation of engagement in meaningful activities and relationships must be completed between the hours of 4pm and 6pm on day one of fieldwork (section 1), followed immediately by completion of two further scales, the active support measure and choice making scale (section 2) (see standalone report for details). Sections three (measuring the physical/environmental quality of the home), four (an existing scale measuring multidimensional aspects of care home quality), five (measuring pain and health) and six (examining the needs of focal residents from a black or minority ethnic group only) are all be completed as much as possible during day one and are then reviewed when the fieldworkers return home that evening. Any missing/further information needed for sections threesix can then be identified and collected on day two. Section seven (CfB) requires fieldworkers to consider all the evidence collected throughout the two days, including observations, questionnaires and interviews and so this section is completed away from the care home but within a day of completing the fieldwork so that all the evidence can be reviewed.

Interviews

The aim was to conduct structured interviews about the focal residents with members of staff who knew them well and also to also conduct structured interviews directly with residents wherever possible. Interviews with staff were designed to collect more detailed information about capacity for benefit domains and so focus on the resident's needs in the presence and absence of services. Interviews with service users were also designed to measure CfB by asking them adapted versions of these questions directly. The resident interviews also asked about experiences of life in the home, satisfaction with the help they received, control over aspects of their daily life and wellbeing. Although comparable information was collected in the interviews with older adults and adults with learning disabilities, the wording, phrasing and layout of the interviews varied to accommodate the higher needs of the adults with intellectual disabilities. Furthermore, although all interviews used A4 show cards with large print, only the learning disability show cards also used smiley face images to assist understanding.

Interviews were carried out during mutually convenient times over the course of the fieldwork and observations were generally fitted in around these⁵. All interviews were tape recorded (with permission) and service users were given the choice of being interviewed alone or with a friend, relative or member of staff there for support. If a third party was present during the interview, it was made clear that they were not to answer on behalf of the service user, rather they were there to assist communication and understanding and to offer emotional/physical support if the resident

⁴ This procedure has been approved by ethics and research governance

⁵ The exception being the 2-hour structured observation at the end of day one, which is fixed and cannot be moved to accommodate interview times.

required it. Consent was confirmed before the interviews began and respondents were informed that they could stop the interview at any time.

Inspection Reports and Inspector Questionnaires

After the fieldwork and key inspection for each pilot home had been completed, inspectors sent the research team a copy of their draft inspection report. The inspection report details how well the home meets the required minimum standards against which it was inspected. This information was then compared with our measures and is reported in the results section below.

Finally, inspectors were asked to complete a very short questionnaire detailing their own professional and academic background and informing us about what evidence they used to make their judgement about the home's quality rating. This is particularly important given that inspectors sometimes use information not publicly available when making their final assessments of the quality of the home. For example, they may be aware of complaints against the home or adult protection issues that have influenced their rating but that we cannot be made privy to. The inspector questionnaire aids our understanding of why our ratings may differ from those of the inspectors.

Pilot study results

Key objectives of the pre-pilot and pilot stages were to investigate whether our approach was likely to produce valid and reliable results and to test the practicality of the fieldwork process. Validity and reliability were investigated through analysis of the data gathered during the pilot. Practicality issues were identified and adapted after the pre-pilot and during the pilot process and then explored with inspectors in a feedback meeting.

Pre-Pilot stage

The pre-pilot was particularly helpful in giving us an early indication of problems with materials and processes that might need altering even before the pilot stage. In particular the pre-pilot highlighted areas of clarification in the project information for residents, problematic wording in the user characteristic questionnaires and raised training needs regarding interviewing skills (time keeping and keeping to structure) and observational skills (being unobtrusive, what to do if someone goes into their room, dealing with staff attitudes). To address these issues before the pilot study, another training day was held and fieldworkers were given guidance on structured interviewing and observations. The resident information leaflet was simplified to enhance clarity and wording and instructions were improved in the user characteristic questionnaire.

Pilot Study

Homes and Residents

Six care homes took part in the pilot study; three in the North West and three in the West Midlands. In each region one home was for older adults, one was for adults with learning disabilities and one was a nursing home. In the North West the nursing home was a large nursing home for older adults, many of whom had dementia. In the West Midlands the nursing home was a specialist home for adults with Down's Syndrome and end stage Dementia. The learning disability homes were small and registered for five or six places, whereas the older adults homes ranged from 30 (personal care) to 60 (nursing care) registered places.

Altogether, 28 residents took part in the study (15 older adults and 13 adults with learning disabilities). Of the 28 residents in the study, 13 were male and 15 were female. We managed to achieve five focal residents in five out of six of the pilot homes. Where five residents were not recruited, it was because the focal residents declined to participate and then could not be replaced because of low numbers of residents in the home. All residents were White; unfortunately we did not recruit any from Black or Minority Ethnic groups.

Analysis of data and implications for main stage

Inter-observer reliability for the formal observations was tested across the six homes (each home was visited by two researchers) and was found to be, in general, very good. A few of the behavioural categories were found to produce more disagreements and this has been highlighted and will be the emphasised in the training of the fieldworkers for the main stage. Agreement tested by the Kappa statistic on the three main sections of the observational toolkit is summarised in Table 1 below. Note that a Kappa value of 0.60 is generally considered acceptable.

Table 1. Summary of inter-observer/inter-rater reliability for the three main measures included in the observational toolkit averaged across items and observers

	Average Percentage agreement	Average Kappa value
Engagement in meaningful	92% (non-occurrence)	0.63
activity	55% (occurrence)	
Active support measure	86%	0.68
Capacity for benefit ratings	71% (With services)	0.57 (With services)
	87 % (In absence of services)	0.86 (In the absence of
		services)

Internal consistency for capacity for benefit ratings were also explored and again shown to be generally acceptable although it was higher for the ratings in the absence of services (Cronbach Alpha of over 0.95) than with services (Cronbach Alpha between 0.52 and 0.62). The implications for training on rating need with services have been noted and actioned.

Following the pilot study the measures were all reviewed and refined where possible. Interviews with residents in particular were shortened (they were taking nearly an hour in the pilot or were being terminated early because they were too long) and duplication was eliminated. Important changes to note include the removal of some of the other well-being indicators and the simplification of the CfB questions. CfB is now measured through resident interview by asking residents whether the home helps them with various aspects of their lives (relating to the CfB domains) and then by asking about their current needs in those domains. Of note is that needs in the absence of services is now only measured through staff interviews and observations. Staff interviews were very successful and were not altered following the pilot and in general, feedback from the observers was that the toolkit was sufficient to allow capacity for benefit to be rated at the end of the two day visit.

Data presented to inspectors at the feedback day is summarised in Tables 2 and 3 below. Table 2 presents a summary of the average engagement levels, assistance from staff, quality of staff support on the Active support measure and a measure of the homeliness of the environment. Table 3 illustrates the percentage of National Minimum standards met and exceeded by each home.

Variability in quality was higher in the learning disability services but in general there was little direct assistance from staff observed, apart from LD service 1 – interestingly this service was for people with very complex needs and the level of engagement was comparatively high for this service. This service was judged by the inspectors as having exceeded the most standards. LD service 2 also exceeded a substantial number of standards and had relatively high levels of engagement but this was without staff assistance – this is explained by the level of ability of the residents – the people in this service were generally more able than those in LD service 1. As might be expected engagement levels were lower in the older adults' (OA) services and in particular in the

larger service. Active support was less apparent in the OA services. The smaller LD services were generally more homely.

Table 2. Summary of the quality of home from some of research measures

Home	Size of	Social	Non-social	Assistance	Contact	Challenging	ASM	Home-
	home	activity	activity	from staff	from staff	Behaviour	percent score	likeness Score
Learning	g Disabilit	у						
1	6	2 (0–8)	22 (4–48)	10 (0-20)	5 (0-12)	0	30 (25-36)	17
2	5	9 (0-40)	41 (8-88)	0	6 (0-24)	1	47 (30-85)	14
3	6	7 (3–13)	25 (3-50)	1	5 (3-13)	5	18 (15-23)	12
Older pe	eople							
1	30	8	24	0	5	0	14 (2-19)	20
2	60	11	18	0	15	2	15 (2-40)	16
3	40	17	23	1	8	5	30 (20-59)	18

Table 3. Summary of CSCI ratings from most recent inspection

				<u> </u>	
Home	Size of home	% standards assessed and exceeded	% standards met	% standards not met/nearly met	SOFI used and important
Learning D	isability				
1	6	32	61	7	yes
2	5	23	77	0	no
3	6	0	89	11	no
Homes for	older adults	5			
1	30	0	23	77	no
2	60	17	83	0	yes
3	40	0	62	38	yes

Issues emerging from feedback day

At the feedback day with inspectors and change agents in each area, there were a number of important points raised which had implications for the main study. These are outlined below:

- The homes in the pilot study appeared to have found the pilot process very positive and there were no obvious problems highlighted.
- There was some discussion of whether staff ratio would be noted and its importance observed staff ratio would be collected during the observations.
- There was also some discussion about the fees charged and on the basis that inspection reports do not always include information about fees and these are not always accurate. It was agreed that we would include a question about fees on the user needs and characteristics questionnaire.
- It was noted that experts by experience would not be used in inspections happening between April and end of June but that we should pick up some in the latter half of the data collection.
- It was noted that individual feedback would not be given to services either on the day or afterwards. Services would be sent the general summary report from the project at the end of the process.

- In general inspectors would not know whether their service was to be visited until after the visit this was to try to ensure that inspectors inspect services "normally".
- It was agreed that pre-warning of homes which were problematic in some way (e.g. manager about to leave, home about to close etc) would be useful to have before sampling started.
- Initially it seemed acceptable to ask regions to help us with the lists of services for sampling but since the meeting it has become clear that this will have to be done more centrally and that sampling will have to be more random with a check on the dispersion of quality ratings in the sample at the end of June.

Main fieldwork stage method

Sampling

This information can be found in more detail in the standalone report's appendices on the PSSRU website (www.pssru.ac.uk).

There are four CSCI regions taking part in the study (North West, West Midlands, London and South East). The aim is to achieve a final sample of 200 care homes (100 older adults and 100 homes for people with intellectual disabilities) across the four regions. Our initial intention had been to purposively select homes by quality rating to ensure a good proportion of poor, adequate, good and excellent homes in the sample. However, as the quality ratings of the care homes were not made publicly available until the end of April (and even then only with the permission of the home), CSCI were unable to provide us with this level of information from which to make our selection.

Instead, CSCI provided a spreadsheet of all the adult care homes inspected/due for inspection between January and September 2008 in our four regions. However, care homes rated as excellent in their previous inspection, are not officially due an inspection this year. This means that if we were to only select homes based on inspection dates, there would be no excellent homes in our final sample. Consequently, it has proved necessary to treat the excellent homes differently to the poor/adequate and good homes.

Selection of poor, adequate and good homes

This spreadsheet was divided into four smaller sampling frames (older adults; inspected/due inspection; learning disability; inspected/due inspection). The data in each sampling frame was then sorted by date of inspection (to get a good spread of dates throughout the fieldwork period) and size of home (which is a random way of mixing up the regions and also ensure a good spread of small, medium and large homes in the sample).

To determine how many homes we needed to select from each sampling frame, we looked at the proportion of older adult and LD homes inspected/due inspection in the main spreadsheet. These proportions were then applied to our figures to calculate how many homes we should select from each. For example, if 35 per cent of older adult homes had already been inspected in the master spreadsheet, then we knew 35 per cent of the 200 homes for older adults we were going to select needed to have been inspected also.

Once we had calculated how many homes to select from each sampling frame, homes were selected by first using a random number generator to determine the starting point on each spreadsheet and by then taking every nth home until the correct number had been achieved.

In total 395 poor/adequate and good homes were selected from the CSCI spreadsheet. 199 of these were for younger adults with learning disabilities and 196 were for older adults (over 65 years). 81 homes (21 per cent) were registered as nursing, which is within our 20-25 per cent level of acceptability. No homes were identified as specialising in Black or Minority Ethnic groups (BME). The homes were divided proportionately between the four regions (see Table 4)

Table 4. Homes by region

Region	Number of homes	Proportion of homes (%)
London	83	21
South East	150	38
West Midlands	87	22
North West	75	19
Total	395	100

Spreadsheets of these homes have since been sent to the Regional Change Managers for additional information and checking. Some homes will be crossed off for reasons such as adult protection issues, home closing etc and some homes will be removed because their registration information is incorrect and they should not be in the sample.

As the spreadsheets are being returned to the PSSRU, we are sorting the homes by date of inspection and size and then allocating approximately half of the homes inspected/due inspection between January and the end of May to fieldworkers in each region. To date, letters have gone out to homes in three out of four regions and fieldworkers have begun contacting home managers to arrange fieldwork dates. As homes drop out/refuse to participate the sample of homes allocated to fieldworkers will be topped up from the database.

Excellent Homes

We are still in negotiations with the regions about how best to select the excellent homes for our sample. We want to achieve a final sample of at least 20 excellent homes so that we have enough homes (approximately 10 per cent of our expected final sample) to be able to conduct meaningful analyses at this level of quality but as mentioned already, this issue is complicated by the fact that excellent homes are not actually due an inspection this year. Having tried to find various ways around this issue, it seems likely that in the same vein as the poor/adequate/good homes, CSCI will have to send us a spreadsheet of the excellent homes so that we can do our selection, regardless of inspection date.

However, what we will ask is that they only send us the excellent homes that have already had or a due an Annual Service Review (ASR) between January and September 2008. Although an ASR is not a key inspection and will not provide comparable data to an inspection report, it will at least mean that the homes in the sample will have completed an up to date AQAA from which we can select residents. Using the AQAA from the previous key inspection would in this case be so out of date (up to a year) that many residents could have moved on or passed away.

Finally, every year the regions select some homes, not technically due an inspection, to inspect formally. Each region in our sample will therefore inspect some excellent homes (but as they are not picked randomly they could not make up our sample of excellent homes on their own). Once we have selected the excellent homes in our sample, we will ask the regions if they plan to inspect any and if so, we will liaise with the regions in the same way that we would poor/adequate and good homes. The excellent homes in our sample that are still not to be inspected will be allocated to fieldworkers and our data on these homes will have to be compared to previous key inspection reports, as this will be the best information we have available.

Process

Before fieldwork

Homes are sent letters inviting them to take part in the study approximately 8 weeks before (or within three months of) a key inspection. We are using information provided by CSCI to inform us of what those dates are. The exception to this rule is the excellent homes, which (as described above) are not being inspected in 2008. From first point of contact with the home to conducting the fieldwork, there are various key stages. These are most easily understood by looking at the Flowchart below. As reported in the pilot section of this report, residents are selected from the home's most recent AQAA, which means receipt of this is essential before consent forms and questionnaires can be sent out. It is for this reason that there is approximately 4 weeks between first point of contact with the home and fieldwork taking place.

Fieldwork

Fieldwork takes place over the course of two full days in the service. It is during this time that the majority of information is collected about the home. The only measures completed by the homes before the fieldwork dates are the questionnaires, which staff complete about residents.

As described in the pilot methodology, fieldworkers begin day one with a meeting with the home manager and it as this point that they collect the consent forms and completed questionnaires. During the meeting with the home manager fieldworkers find out further information about the home, the residents and discuss any changes that have been made since the last key inspection. Fieldworkers are then given a tour of the home and are introduced to staff and residents. It is important that they are able to navigate around the home and identify the focal residents for the remainder of the fieldwork.

Details of the order in which the observational measures and interviews are carried during the fieldwork out can be found in the Appendix to the standalone report, which is available on our website (www.pssru.ac.uk).

The 'buddy' system

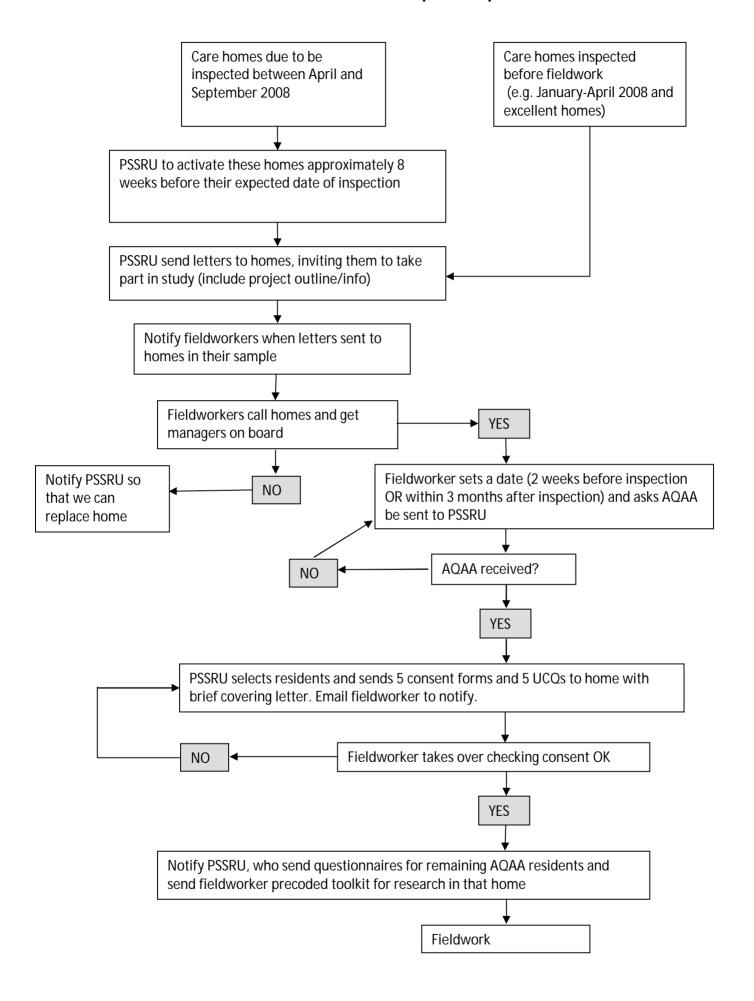
In order to calculate inter-rater reliability the fieldworkers have been paired with one another as part of a 'buddy' system. Each fieldworker will be accompanied by their buddy in the first care home they visit. This means that each fieldworker will do two homes paired with another person (one where they are the main point of contact for the home and one where they accompany another fieldworker) before they begin doing fieldwork on their own.

Where two fieldworkers visit a home together in this way, they have been instructed to code their observations independently and only compare answers after completing the toolkit and returning it to us for data entry. After this point, we have encouraged them to compare their ratings on the observational measures so that they can use the experience to learn from one another and highlight any further training needs. As all the early homes visited by two people will be completed before the refresher training day in June, this information will feed into the training they are given on the day. The buddying process will be repeated in July to calculate inter-rater reliability again mid-way through data collection.

Post-fieldwork

After the two days in the service, the fieldworker will complete the measures and send them recorded delivery to the research team for data entry. Once the key inspection for that home has been carried out, the research team contacts the inspector asking them to send us a copy of the draft inspection report (and quality rating) and to complete the inspector questionnaire described in the pilot section of this report.

QMF Care Homes Fieldwork: April to September 2008



Instrumentation

User Characteristic Questionnaires

User characteristic questionnaires collect detailed information about the focal residents' health (physical and cognitive), mobility, care and nursing needs. The questionnaire is completed by a member of staff who knows the resident well and takes approximately 20 minutes to complete. There are two versions of the questionnaire, one for older adults and one for adults with learning disabilities. This reflects variation in existing measures used to collect information about the needs and characteristics of the client groups and ensures our data will be comparable to data collected in previous studies.

Brief, anonymous, user characteristic questionnaires about the remaining AQAA residents are used to collect basic information about residents' age, ethnicity, health and care needs. Questionnaires are again completed by members of staff who know the residents well and usually take less than 10 minutes to complete. In small homes, where all the residents are focal residents, these questionnaires are not required. They are only used in larger homes to give a baseline level of needs against which to compare our focal residents. At most, homes would have to complete 15 short questionnaires and five longer ones about focal residents (because even the largest homes only list up to 20 residents on the AQAA).

Observational Measures

The observational measures have been put together in a toolkit, which contains seven sections:

- 1. A two-hour observation of engagement in meaningful activities and relationships.
- 2. The Active Support Measure (ASM) and Choice Making Scale (one to be completed for each service user immediately after section one is completed).
- 3. The Homelikeness Scale and physical quality scale (completed at service level during the course of the fieldwork to provide valuable information about the quality of the physical home environment).
- 4. An adaptation of the Nursing Home Care Quality Instrument (mostly at service level but with some questions adapted to collect information for each of the service users; this scale collects multidimensional information about care quality including interactions between staff and residents, type of care observed and even ratings of aspects of the physical environment not picked up in section three).
- 5. Health: Pain assessment measure based on Checklist of Non-verbal Pain Indicators (CNPI) (one to be completed for each person); observations about diet/nutrition and exercise/activity.
- 6. Cultural and ethnic needs (only completed for focal service users from BME groups).
- 7. Capacity for benefit ratings (fieldworkers are required to make judgements about what each focal resident's needs are currently and would be in the absence of services for eight domains of outcome).

As the whole toolkit (with correct numbers of copies of each instrument) is very large it has not been included in its final form. Instead, copies of the fieldworker guidance for each section can be found in the appendices of our standalone report (Towers, Beadle-Brown et al. 2008).

Interviews

Interviews with staff collect detailed information about capacity for benefit domains. Staff are asked three-part questions for each domain:

- 1. What are the resident's current needs (no needs, all needs met, low needs, high needs)?
- 2. Does the service help them with this domain?

3. What would the resident's needs be in the absence of services (no needs, low needs, high needs)?

Evidence from the pilot suggests these interviews take less than 15 minutes to complete.

Interviews with service users have been adapted and shortened since the pilot process, which showed them to be too long and some of the questions too difficult for people in care homes to understand. The interview is now seen as an opportunity to access the views of service users where possible and an opportunity to triangulate some information with provided through staff interviews, questionnaires or observations. Consequently, interviews should now take approximately 30 minutes to complete and focus on residents' experiences of living in the home, their views about staff and the help they receive and their current care needs.

Although much comparable information is still collected in the interviews with older adults and adults with learning disabilities, the wording, phrasing and layout of the interviews is different, reflecting the differing cognitive abilities of the two client groups. In particular, the learning disability interview has been adapted to allow more open-ended responses in places, which should give service users a greater opportunity to convey their experiences when they struggle to answer the more structured sections. All interviews are conducted using show cards but only the learning disability show cards also used smiley face images to assist understanding.

Fieldworker training

A recruitment and selection day was held in London in February, from which ten fieldworkers (all based in the South East, West Midlands or North West) were employed. These ten new fieldworkers and three existing PSSRU/Tizard members of staff were trained over the course of two days at the end of March.

The training was very intense, covering all aspects of the methodology and instrumentation from the importance of gaining consent through to interviewing skills and observational methodologies. Fieldworkers were divided into small groups and taken to services to practice the two-hour structured observations in a real care setting. Afterwards, trainers went through the codes so that fieldworkers could learn from their experiences and discuss any issues that had arisen. At the end of the two days fieldworkers went home with:

- 1. A fieldworker resource pack (training manual)
- 2. Further reading
- 3. Copies of the draft instrumentation
- 4. Stopwatches

Final drafts and additional materials were sent to their home addresses afterwards. A 'refresher' training day is being held early in June after all fieldworkers have been into one or two care homes (see process for details). By this stage we will know early inter-rater reliability scores and will be able to tailor the refresher day to the needs of fieldworkers and deal with any systematic problems that have arisen since fieldwork began.

Timetable

May 2008 Start of fieldwork

June 2008 Refresher day and review of progress
July 2008 Collect second wave of inter-rater reliability

September 2008 Last month of fieldwork

Ongoing Data entry Autumn 2008 Analysis

6. Low-level services study

Like the care homes study, the low-level services project has a pilot and a main fieldwork stage. In addition, we have undertaken secondary analysis of the Health Survey for England 2005 (HSE), which collects information on the use of low-level social care services. In what follows we describe: the HSE analysis, the methods used in the pilot fieldwork, the results of focus group analysis undertaken with the pilot sample, and then outline the main fieldwork methodology.

Analysis of the Health Survey for England

This analysis of the HSE was motivated in two ways. The first was to explore the performance of a number of commonly used well-being measures with regard to measuring the impact of day care services for older people, namely an adjusted version of the EQ5D QALY and the GHQ12 General Health Questionnaire (see above, Developing well-being measures, page 7). The second motivation was to investigate whether we could use non-randomised, naturalistic studies to meaningfully address the attribution problem, and, in particular, to test the capacity for benefit approach. If we can establish that multiple regression techniques can successfully control for differences between (non-randomised) service and non-service groups then the results it gives as to the impact of services on well-being can be used as a comparator or benchmark to test the expected outcomes method to be used with the capacity for benefit approach.

Annex 1 describes the results of the analysis. In summary, the analysis shows that EQ5D (adjusted) and GHQ12 are quite sensitive to the effects of low-level services, and producing consistent results (even over re-sampled data). Furthermore, regarding attribution, the analysis underlined the importance of accounting for relevant needs factors. When the models were run without needs factors, service use appeared to worsen well-being. But with needs factors, services showed significant positive effects to plausible orders of magnitude. The conclusion is that the HSE and other data on non-randomised control groups will be useful in testing the ASCOT toolkit.

Pilot fieldwork

The pilot study has two components:

- focus group analysis with small groups of service users from pilot sample provider organisations
- cognitive interviews with service users drawn from pilot sample providers

The focus group work is now complete and the results are reported below. The cognitive interviewing is in progress.

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 respondents' thought processes in answering a question; in particular peoples comprehension, recall, decisions and judgement, and response processes. The overall aim is to detect any problems people may have in answering questions. These techniques will be applied to a sub-sample of participants in developing questions for the SCT.

Focus groups

Focus groups are unstructured interviews with small groups of people who interact with each other and the group leader (Bowling 1997). They have the advantage of making use of group dynamics to stimulate discussion, gain insights and generate ideas in order to pursue a topic in greater depth. The group processes can help people to explore their views and generate questions in ways that would not occur in face-to-face interviews. In this sense, focus groups capitalise on communication between research participants in order to generate data.

In focus groups people are encouraged to talk to one another, asking questions, exchanging anecdotes and commenting on each other's experiences and point of view (Kitzinger 1995). This form of everyday communication may reveal what people know or experience. In this sense focus groups can reveal dimensions of understanding that often remain untapped by more conventional data collection techniques.

The purpose of conducting focus groups with users was to gather data on their perspectives on how services (generally) help them and to explore the key aspects of quality that are facilitated by services. More specifically these groups were about identifying the particular aspects of day care services that users value with regards to using services.

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 determine what services are (generally) providing for users as well as exploring the key aspects of quality that are facilitated by day care services that enable (or undermine) functioning states and quality of life.

All participants who took part in the focus groups each received a 'recruitment pack' which included an 'invitation to take part letter', a 'participant information sheet' which provides detailed information regarding exactly what is involved for participants who take part, and a 'consent form', which were also available at the time the focus groups took place. Participants received recruitment packs a week in advance of the focus groups taking place. This was to enable potential participants to make an informed decision about whether or not they wish to take part and to provide potential participants with an opportunity to ask any questions they may have about taking part.

In total five focus groups were held with service users and three groups were held with staff/providers of day care services. The focus groups were conducted in two separate day care settings.

Analysis of the focus groups was based on the narrative generated. This was analysed thematically using a process of generating codes and sub-categories. The analysis is supported by illustrative quotations from the focus groups. All quotations have been anonymised and are cited by code only.

Results - focus groups with users

During the focus groups conducted with users of day care services a number of broad themes emerged: users' perception of day care services; what users value about day care services; access to services unavailable elsewhere; and, rehabilitation after life events. These are explored with reference to a number of sub-themes.

Users' perception of day care services

Initially a number of participants described how they were somewhat apprehensive about attending a day care centre. Many participants described how they had some misconceptions about both what was available at centres and the people who used services: "people think that it's like an old people's home but it's not, I think people get the wrong idea" (FG3). Some participants were concerned that other people who may benefit from using services would not come because they did not fully understand what services could offer them. Indeed some users themselves said that they thought there was something of a stigma attached to using services, but had subsequently changed their view since beginning to use services.

"It's not what I expected it to be at all, I thought it would be full of old fuddy duddies but although we are old we are young at heart and I think that shows in what happens here" (FG3).

When asked about what participants' views were with regard to the purpose of day care centres, the majority of people felt that the purpose of services was as an extra support mechanism.

"It prevents you from being on your own, and if you've got any troubles you can come and talk to someone about it, I mean I've got two sons, and they're very good but you don't want to burden them too much with your troubles so it gives you someone else to turn to" (FG4).

A small number of users simply felt that there were simply no alternatives for them: "we're old people and there's no-where else to go" (FG2).

What users value about day care services

Participants gave a number of different reasons for attending/using day care services. According to participants the most important of these was social contact. However participants also highlighted personal care and being able to access services that they would not otherwise be able to access, as well as getting help with tasks that they would not otherwise be able to perform themselves, as reasons for attending/using day care services.

Social contact

The overwhelming reason that participants gave when asked about why they use or attend day care services was that it was for social contact. Participants described how they enjoyed attending services, and that despite some initial reservations from some participants, found that services provided a welcoming service where they could meet new people and develop new relationships. One participant stated:

"I like to come because I'm living on my own, and when you come here you can have a chat with people and it's a very friendly atmosphere here" (FG1).

Many participants who took part in focus groups explained how a large degree of their daily and weekly social lives (and contact with other people in general) was achieved by way of attending the day care centre. A number of participants explained that if they were unable to attend day care services, they would have very little social contact with other people:

"This is all I've got you see, because I've got osteoporosis, I can't really get out so if it wasn't for this I'd never go out, I'd never see anyone. The only reason I can get here is because the bus literally comes and picks me up and takes me door to door; otherwise I'd just be in doors. I wouldn't see anyone, I'd just be staring at the same four walls all the time, just watching the cars go by" (FG3).

Other participants also agreed that the transport service that was provided to take users to and from the centres was a major factor in 'enabling' people to come and use the facilities at the centre, and to take part in the activities that were available to them:

"Because they bring you right to the door, right inside, that's one of their rules, they will open the door for you and bring you safely home and do the same when they come and get you, you can hold their arm, I couldn't get here if it was just a normal bus where you have to get yourself there to the bus stop and back" (FG5).

Sense of purpose for the day

During the focus groups participants discussed that another aspect of attending day care services that people enjoyed, which was related to social contact, was the 'sense of purpose' that attending services gave them.

Participants explained that on those days they were due to attend a centre, it gave people a welcome structure to the day, one participant stated: "a reason to get up in the morning" (FG3). A number of participants described how this was the case for them and went on to describe how using day care services helped them both prior to attending, in creating a daily/weekly structure and also after attending. Participants described how attending a centre helped people to get through the rest of the day, and how they felt "uplifted" and "better able to cope" (FG2) even some hours after having attended. One participant made the following comment:

"When you're older, it's something to look forward to you see, we all really look forward to it, I come to life, even just getting ready, I wouldn't miss it. It makes us feel jolly and that helps us I think. If you're just at home you don't do that... it [loneliness] can get you down and you feel so much better afterwards, it lifts your mood see and then you can get on with the rest of things" (FG4).

Many participants held the view that this 'sense of purpose' that people gained helped them stave off the depression and anxiety that participants associated with being older and living on your own. Participants felt that without services, people would have seen an increased deterioration in terms of

both their physical and mental health. In this sense it was clear that participants felt that using day care services had something of a 'preventative' outcome for them, and this was due to the stimulation of both social contact and activities (such as bingo) that they were able to participate in.

"I wouldn't be here if it wasn't for them, it's kept us all going hasn't it, instead of giving up. I think it's good for us all health wise. It really does improve your health coming here, I'm sure it is because it's something to look forward to. Lots of people who've got something wrong with them and as they get older they get more things wrong with them and they're sitting at home dwelling on it and that is the worst thing you can do. But coming here, it makes you think that life is worth living" (FG1).

Personal care

According to participants in the focus groups, another benefit of attending day care services to users was related to personal care. Participants expressed the view that the purpose of day centres was two-fold for users. Firstly as a kind of 'social hub' for meeting people and socialising and secondly as a more practical care service. One participant expressed their view of the centre as follows:

"It's not only a welcoming and friendly place to come and see people and get out for a bit, but I can also get things done here that I can't at home. I have bath down here, I have my feet done. The reason I have a bath down here is because I can't get out of the bath at home and this one is made specially so you can walk in it" (FG5).

During the focus groups, when discussing the reasons why people used services, users initially often discussed the more 'social' aspects of services before going on to discuss more practical 'care related' reasons for attending. A number of participants explained how they attended services for 'the company' and while the practical care aspects of attending were important to users, in many cases this was something of an afterthought.

"Well, I like to come because of all the friendly people here, because it's nice to get out and see people, see some life...oh, but I also get my feet done here, and my hair cut, it's very good because it's much cheaper than anywhere else" (FG5).

Respite for carers

A small number of participants said that the reason they attended the day care centre was to give their spouse some respite from caring. Some of these participants had relatively high level needs and explained that attending the centre enabled their spouse to have both respite from their role as a carer and enable them to take part in other activities that they were not able to do whilst carrying out a carer role.

"I've got a wife, and if I was in the house all the time you can imagine what would happen! So I come here and it gives her the chance to do what she wants to do on the days that I'm here" (FG1).

In one case however, the participant had primarily begun attending the day care centre in order to give their spouse respite from their carer role, and over time realised that their spouse would benefit equally from attending the centre due to the social element of attending. In this case the centre was able to provide the correct care for the participant whilst providing both respite and also the other 'social' benefits that had been discussed by participants in the groups. This participant said the following:

"I was coming here on my own you see, but then when she started to see what was happening, and that actually she would quite like the things that I was doing we realised that she should just come as well" (FG4).

Access to services otherwise unavailable to people

Participants also discussed a number of other services that were made available to them by the centre that they would otherwise not be able to access. However many participants viewed some of these as 'basic needs' that they would not be able to fulfil if they were not able to access them via the centre. These activities included: a hairdressing service; laundry service; basic shopping services; handyman service; toe nail cutting service; and computer lessons. One participant described how important these services were to them:

"You can get your washing done and everything here, you can have your hair done and afterwards we can have our feet done...If it wasn't for this place I wouldn't be able to do any of these things, round here there's nothing, or if I want to get my hair done it costs much more than I get it done here" (FG2).

Another aspect of using day care services that was important to participants was the provision of a hot meal. A number of participants talked about their diet and in some cases stated that they were able to have their 'main meal' at the centre and would consequently have a smaller snack later in the evening. In cases where participants were living on their own, participants preferred this. Many said that they would not cook a meal for themselves which was of the same standard as what was available at the centre. A number of participants stated that they would not "eat as well" if they did not use the meal service provided by the centre (FG1).

"I come down here every day for my dinner. The thing is, if you're on your own at home you don't bother to do yourself a decent meal, you just have a tin of soup or something, I wouldn't do for myself what I can get here, not anymore" (FG1).

As well as these more practical aspects of care, participants also highlighted the role that centres play in advising and assisting people with filling in forms and helping people with domestic queries or problems. This extended to advising people on benefit entitlement as well as helping with people with domestic queries. One participant made the following comment:

"They checked the forms here to make sure that I was getting all the benefits that I was entitled to...if you've got a form that you don't understand or like me you've got bad eyesight, they'll fill it in for you and help explain everything to you" (FG3).

Rehabilitation after life events

Participants who had experienced what they regarded as a 'significant life event' expressed how the day centre that they were affiliated to had helped them to come to terms with changes to their life. One participant had the following experience:

"I was in a very bad car crash a few years ago, I was in hospital for six months and then I went into re-hab at [place name] for six weeks and, because my husband's died you see, after that they came to see me and then when I was able I started coming here and I tell you I just can't thank them enough" (FG5).

Another participant described a home service which they had received via the day care centre that they attended in order to help with the rehabilitation process. According to the participant this service had encouraged them to make a quick recovery:

"When you come out of hospital they come and see you for a certain length of time to see how you're getting on and also if you need any shopping, that sort of thing, they can help you" (FG4).

Participants also described how the day centre helped them come to terms with grief, particularly when losing a spouse. Many participants who had lost a spouse described how they struggled to come to terms with loss and became insular whilst also finding it difficult to cope both emotionally and physically. Participants who had experienced this type of loss explained how using day care services were invaluable in coming to terms with loss and helping them to continue to live their lives:

"I'd be lost without it, it's a life saver, it really is a life saver, since I lost my husband it's saved me, I don't know what I'd do without it" (FG2).

Results - focus groups with providers

Focus groups with providers were conducted with staff at the day care centres at all levels. This included paid staff, volunteer staff and managerial staff. A number of broad themes emerged: the purpose of day care services; provision of services; the benefits of day care; staff perceptions of why people use day care services. These are explored with reference to a number of sub-themes.

The purpose of day care services

Service provider staff who took part in the focus groups had a broadly a similar view to those of service users when discussing their perception of the overarching purpose of day care services. Many participants viewed the service as a means to help users maintain their independence living at home, but which could also provide them with a means of low-level support as and when they needed it.

"I think it's a good means of people maintaining their independence, especially in their own home, that's the main thing. They've got this outlet that provides all kinds of services and it provides a good support network that a lot of elderly people would need that they might not necessarily be getting anywhere else" (SFG2).

Staff also seemed to prioritise the purposes of the day care centre in a similar way to users. Staff explained how they thought the most important part of the day centres was to socially engage with users, as well as supporting people by offering personal care services.

"I think the whole purpose of us is really... the people are isolated and they come here and hopefully enjoy their day while they're here. And it's also the socialising and they meet new friends and all the different services they can use while they're here" (SFG1).

Day care services as a means of social engagement

Staff as well as users who took part in focus groups placed a great emphasis on the 'social' aspect of the provision of day care services. Participants felt that this was a major part of why people accessed services and of major benefit to people who used services. Staff also viewed this as part of their role – to engage with people and encourage them to engage with others.

"I think just having a listening ear, someone who they can turn to if necessary, I think that is one of the important aspects of this, and it is actually here every day and that's part of what we do, we sit and talk to people. We also try and facilitate people meeting everyone, we introduce them so people feel that they can chat and get on" (SFG2).

Day care as a preventative service?

Perhaps somewhat differently to users, staff viewed activities – such as social engagement and other activities that users were able to use at the centres – as performing a preventative role.

"I do think using something like this can delay or possible even prevent them [users] from having to go into a care home, in some cases anyway, obviously not all"

A number of participants in the focus groups discussed how they viewed services that kept people 'mentally active' as a positive and potentially preventative measure in terms of keeping people living safely in their own homes.

"Mind-wise I think it must keep them, because they interact with each-other, it must keep their mind a lot more active in a way, rather than sitting at home and there's no-one there other than the television or the radio, so I think in that way it's another good thing really" (SFG1).

A number of participants expressed the view that this social engagement had a preventative role to play in terms of helping users who may be lonely from deteriorating further into depression. One participant made the following comment:

"For example, depression, which can extremely debilitating, just knowing that they've got somebody to talk to, someone they can have a cup of tea with and just have a conversation, that probably staves it off for quite a while I would imagine" (SFG2).

Staff also placed quite a lot of emphasis on movement and exercise for those that attended day care services. Participants took the view that it was beneficial for users to remain active during the day rather than living a sedentary lifestyle.

"Even just moving around the day centre would help them I think because people do move around while they're here, if they were at home they might be just sat in an armchair or something" (SFG1).

According to participants, meal services provided by day care centres, were also viewed as something that would be valued by users as well as being part of the 'prevention package' which helped users maintain independence while living in their own home. Participants recognised that older people accessing day care services may not be fulfilling all their nutritional requirements due to no longer having a partner or spouse.

"I do see that as something that's quite important actually [provision of meals], I mean you get to the age where you think 'oh I can't be bothered to cook a meal for myself' so they use convenience foods, or, I know the odd one that doesn't eat properly at all. So at least they know when they're coming here, they can get a hot meal" (SFG1).

Participants also expressed a sense of 'realism' with regards to just how 'preventative' services could be. There was a sense that ageing is linked inevitably with both physical and mental deterioration. However, many participants explained that as long as users had gained in terms of their social engagement and benefited from using the low-level support services that were available to them, staff were happy that they had contributed to improving the quality of users' lives. Participants also felt encouraged by the possibility that they may have played a role in preventing either the onset of mental or physical illness, or the rate at which someone may deteriorate as a result of illness. One participant made the following comment:

"We have people here who do come for a long time, but we do see people deteriorate because of general ageing and with dementia and so on and sometimes they end up going into care. But hopefully what we do here, with the chair exercises and so on, it helps keep them able and independent I think" (SFG1).

Signposting

Participants in the focus groups explained that one reason why social contact with users was crucial in the day service was to enable them to signpost users on to different services. Participants stated that once a rapport had been established between service providers and users, that users were more likely to 'open up' to day centre staff. This was particularly important when dealing with issues that users may feel uncomfortable or self-conscious about, and therefore reluctant to get help with.

"if we think there's other services that we think can help then obviously we do refer on... and if they do have any worries, where people use it as a social centre really, they're more likely, in this sort of environment to just mention something that may be worrying them or whatever, and we can then take it up with the necessary agencies that would be able to help them" (SFG2).

Perception of services – what can services provide?

While discussing the services that were available to users via the day care centre, participants expressed the view that there were aspects of day care services that people might not be aware of. Participants expressed concern that there were others who might potentially benefit from using services who may not be aware that they were available to them.

"Before I started working here I didn't really know it existed, and then you hear the word 'day care' and you don't actually realise exactly what it encapsulates and I was quite amazed, I mean I used to have my Nan live with me and I'm sure that had she known that this was here she would have enjoyed coming along and meeting other people. I've only been here for four months but since then I've seen that there are a lot of different things that the centre gets involved with, that I wouldn't have been aware of before working here." (SFG2).

One participant in the focus groups talked about the range of services that were offered through the day care centres. They made the following comment.

"We offer a laundry service, there's a hairdressing service, a bathing service, computer lessons, we also do home help, a shopping service...it really does cover a lot" (SFG2).

The 'home from hospital' outreach service offered by one particular day care centre was also highlighted as one such service that people may not be aware of, but according to participants was a particularly valuable service to those who used it. Participants viewed this service very much as a crucial link for those who were recovering from a period in hospital, particularly for those who might be feeling anxious and did not have anyone close who could help to look after them.

"Like the home from hospital service which is a very easy and basic thing to do, to provide, but it is a very necessary and worthwhile service for people who use it. It's like a bit of a life line for them, it gets people into their homes and settled again after a stay in hospital making them feel relaxed and maybe less anxious" (SFG2).

A similar outreach service that was offered by the day care centres that took part in the focus groups again emphasised the 'social' aspect of services that were offered. This service was designed specifically for those people who did not feel that attending the day care centre was appropriate for them at that time, but were either living alone or were caring for someone else and thought that the older person would benefit from the company of someone else.

"For those who choose not to [attend the day care centre] we can offer the two's company service, which, if people don't want to come to the day centre two's company is a volunteer that goes to peoples' houses, perhaps just for one hour a week for a cup of tea and a chat. So

it's really just so people can see a face really, because apart from maybe carers going in or seeing the milkman sometimes they really don't see anyone" (SFG1).

Summary of focus groups

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 these 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 needs of its targeted recipients.

Users of day care services overwhelmingly reported that their reason for accessing services 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.

Users' views of why they accessed day care services and indeed what areas of peoples' lives services could have an effect on were largely mirrored by provider staff of services. 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 services 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.

Main fieldwork stage method

The main fieldwork method involves a survey of service users. Respondents will be 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 interview will collect information on user characteristics and need; it will administer the ASCOT; it will also use other well-being measures including GHQ12. Finally, the interview will seek information on other services used by respondents.

By having people complete an SCT and have an interview, we will be able to test the validity and reliability of the SCT using the interview data. We will also use the interview to explore the relationship between needs and well-being, and so calibrate the SCT. Finally, using both SCT and interview, we will have generated a sizeable baseline of detailed information on the well-being of people using day care services (see Section 4, page 10). The fieldwork data will also be benchmarked against that collected in population surveys such as the Health Survey for England (to look especially at attribution issues). We are also exploring the feasibility of administering the SCT on a sample of non-service users to provide a stratified (but not randomised) control group (see below).

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

Provider-based surveying

Our approach is to find individual service users via service providers. This provider-based sampling strategy will entail establishing a sample frame of provider organisations and then asking sampled

providers to hand out information packs to service users seeking consent for interview. Service users will then consent by returning to their contact details to us.

Our aim is to establish a full list of relevant organisations providing low-level social care services, by locality (local authority area or region). This sample frame will include the name and address of providers along with some characteristics of services provided, main clients and scale of operation. The sample frame will be used to select local provider units on a quasi-random basis, that is, a purposive plus randomly selected sample.

At present no externally available definitive list of providers exists. We are currently compiling a 'population' list from a number of sources:

- Requests of local authorities for lists of contracted providers
- A planned extract from the ONS Inter-departmental business register (IDBR)
- Social Services Yearbook of public providers
- Direct approaches to national provider organisations, including Age Concern, Salvation Army and so on
- National Council for Voluntary Organisations (NCVO)'s database of third sector organisations

Our aim is to construct a representative sample from the underlying population, however we also acknowledge the lack of any well defined sample frame. This is not a serious problem in that our aim is not to establish the size and scale of this sector, but to explore the effectiveness of tools to measure outcomes. It will be sufficient for us to have a reasonable spread of baseline characteristics in the sample.

Once provider organisations are selected, we will approach them for their agreement to participate in the project. If granted, we will ask providers to hand out an information pack to all their current service users. The information pack will include: a covering letter, a SCT and a returnable consent slip for the participant to agree to a follow-up interview. On consenting, the participant will either provide contact details (name, address, phone etc.) or an agreement to be contacted via the provider. We anticipate a relatively low agreement rate among service users and will over-sample providers accordingly. Any service user that does consent will be interviewed (unless they use appropriate opportunities to withdraw consent).

According to the IDBR there are 16,330 local provider units in the UK providing 'Social work activities without accommodation' (SIC2003 classification 85.32).

Sampling

We will approach around 1000 providers in England, selecting quasi-randomly from sample frames generated at the level of councils with social services responsibilities (CSSRs). We have gained research governance approval to approach CSSRs. Our aim is to secure agreement to participate from 100 providers. All clients aged over 65 will be given an information pack. We anticipate the following response: some complete refusals; some people to return just SCTs; and some people to agree to being interviewed as well. We aim to obtain consent from 2 or 3 service users from each of the 100 providers, to result in data from 250 interviews and more than 250 SCTs. Altogether, this would require response rates of around 5-10% of service users of given providers and 10% or so of providers from the population.

Interviews

Depending on response rates, we aim to conduct at least 250 interviews (with a ceiling of 500 if response rates are high). These will be face-to-face with structured, closed-ended questions, with some routing, which will be conducted using paper instruments or electronic systems. Interviews could occur in the person's own home or at a day care centre or perhaps elsewhere.

Computer Assisted Telephone Interviewing (CATI) survey

In addition to the provider-based surveying of service users, we are exploring the feasibility of a population-based sample of non-service users to provide a control group for testing attribution issues. One possibility is to use a sample of telephone numbers and addresses from a demographic database which contains the contact details of people who have taken part in BMRB's weekly omnibus survey. The survey collects demographic information, and each respondent is asked whether they would be willing to take part in future research. The telephone numbers and addresses of those aged 75+ who have agreed to this would make up our sample frame.

7. Summary and conclusion

People use services because they value the consequences of their use. Assessing how well public resources are used therefore requires us to have some measure of *value*. 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 that ensured 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 outcomesrelated quality of care provided.

In the absence of (well-behaved) market prices, value in public social care needs to be measured directly. Initial conceptual work has provided a methodology for developing a practical toolkit, which has two components.

The first is to determine what information needs to be collected (and in what form) to assess the value of social care services – together, this can be called a *value toolkit*. This step involves:

- specifying a well-being measure that is consistent with the concept of value (i.e. it is valid), and also is robust to repeated real-world applications (i.e. it is reliable). We also need to ensure that the toolkit meets the low-burden condition.
- establishing a method for attributing changes in the well-being measure to the impact of services, not the impact of other factors.
- ensuring that where we draw on routinely available data sources e.g. CSCI's quality ratings of care home providers, this information is providing a measure of the relevant concept.

To this end, we have developed the Adult Social Care Outcomes Toolkit (ASCOT). The ASCOT has two components: a well-being measurement scale and an expected outcomes (called *capacity for benefit*) attribution method. The well-being scale measures the extent of people's functioning and capability to function in a range of relevant outcome domains. Regarding attribution, people are asked to rate their current well-being and then asked to hypothetically rate, on the same scale, their *expected well-being* in the absence of services. In a routine application of ASCOT, a number of shortcuts are available:

- expected well-being in the absence of services will be highly correlated with people's needs
 i.e. their disability, impairment and their social situation, and so we can use measures of
 need in place of measuring (expected) well-being;
- how far a service improves people's well-being is correlated to the quality of the service and this can information can be drawn from the inspection process.

In the absence of inspection data, current well-being can, in principle, be measured using a self-completion tool (SCT) version of ASCOT.

The second part of the project is to undertake empirical analyses to establish that the value toolkit can actually produce valid, reliable value information in a low-burden and practical way. The aims of the fieldwork are:

- to test ASCOT,
- to collect information about current outcomes of service use (useful for establishing a baseline)
- to use well-being and needs information to estimate the relationships required for the shortcuts outlined above.

For the care home project the key test is of the relationship between CSCI's quality rating of care homes and ASCOT value estimates. This is achieved with fieldwork that collects ASCOT information and coincides with the routine inspection of homes. A main challenge in the fieldwork study is using observational techniques to assess the well-being of people with profound cognitive impairment.

For the low-level services project, the need is to test that an SCT approach can work. Here we use fieldwork to collect ASCOT value information and needs information (by interview) and simultaneously administer the SCT to survey participants.

Pre-pilot and pilot fieldwork for the care homes project shows that despite a very complex study design, meaningful results are forthcoming. The reliability of observational methods to inform ASCOT estimates appear to be sufficiently high. Inter-observer reliability for the formal observations was tested across six homes (each home was visited by two researchers), and in almost all cases the respective Kappa statistic exceeded the generally accepted 0.60 threshold. Internal consistency tests for the ASCOT ratings were also generally acceptable although they were higher for the ratings in the absence of services (Cronbach Alpha of over 0.95) than with services (Cronbach Alpha between 0.52 and 0.62). The implications for training on rating need with services have been noted and actioned.

Part of the pilot work for the low-level services project was to assess the validity of the ASCOT measure in this case. Focus group analysis assessed whether the right set of functionings or outcome domains were being used for gauging day care services. Users of day care services overwhelmingly reported that their reason for accessing services was for social contact. Personal care was also an area that users placed high value on in terms of the support that was offered by services. As well as these, respite for carers and support were also valued. Provider staff of services largely mirrored the views of users in this regard, although they 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. The social contact elements of ASCOT have been further developed in light of this work.

We also undertook an analysis of the Health Survey for England 2005 data to explore the performance of a number of commonly used well-being measures and to assess attribution in a non-randomised survey design. The analysis shows that Quality Adjusted Life Year (EQ5D, adjusted) and the general health questionnaire (GHQ12) are quite sensitive to the effects of low-level services, and producing consistent results (even over re-sampled data). Furthermore, with good specification of need, the conclusion is that the HSE and other data on non-randomised control groups will be useful in testing the ASCOT toolkit

The main fieldwork phase for both studies is now commencing and results are expected by the end of the year.

Annex 1. Measuring the cost-effectiveness of day care services

Introduction and methods

Day care services for older people fall into the category of 'low-level' community-based social care services. The low level services component of the QMF project is exploring how the outcomes of these services can be measured. This goal has two parts. The first is to develop practical measures of people's well-being that can potentially reflect the value of service use. The aim is to find measures that are sensitive and comprehensive in measuring changes in wellbeing resulting from service use, and also that are relatively low cost to administer. This is the *specification* problem. Sensitivity and comprehensiveness can be established by comparing instruments in terms of how much outcome change they measure for the same use of low-level services.

The second goal is to find ways to isolate the changes in peoples' well-being that stems from service use, that is, to find the actual difference in well-being produced by services. Well-being levels will vary between individuals and between points in time for many reasons, and service use is but one 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.

Comparing well-being measures in the Health Survey for England

Two potential well-being measures that can be used to assess the value of low-level services are the EuroQol (specifically the EQ5D) and General Health Questionnaire (specifically the GHQ 12) – see, *Developing well-being measures*, page 7. Both these measures are used in the 2005 Health Survey for England (HSE) which focused on older people and also asked detailed questions about the use of low-level social care services and also people's health and care needs, disability and impairment.

The HSE is a representative population survey and therefore picks up both people who use low-level services and those that do not. As regards the attribution problem, these data give us a non-randomised control group. Without randomisation, differences in well-being between service users and non-service users may also be due to systematic differences in other characteristics. We can account for these confounding effects using multiple regression. In theory, if all other relevant factors are modelled correctly, any remaining difference in well-being between people using the service and those not using the service is due to the effects of the service. It is particularly important to account for all relevant *needs* factors that would imply reduced well-being in the absence of services. People who are fitter and healthier than others are less likely to use the service and yet have higher well-being. A service use group will likely have greater need so this baseline difference must be factored into the analysis.

In this analysis of HSE we will look at day services for older people, that is, people over 65 who either use day centres or lunch clubs. Just under 5% in the sample of older people used these services, which is consistent with the rate of use in the older population of England overall.

The EQ5D EuroQol asks people to rate their well-being or *functioning state* with regard to 5 domains with 3 levels within each:

Q1 Mobility

- 1. I have no problems in walking about
- 2. I have some problems in walking about
- 3. I am confined to bed

O2 Self-Care

- 1. I have no problems with self-care
- 2. I have some problems washing or dressing myself
- 3. I am unable to wash or dress myself

O3 Usual activities

- 1. I have no problems with performing my usual activities (eg. work, study, housework, family or leisure activities)
- 2. I have some problems with performing my usual activities
- 3. I am unable to perform my usual activities

Q4 Pain/Discomfort

- 1. I have no pain or discomfort
- 2. I have moderate pain or discomfort
- 3. I have extreme pain or discomfort

Q5 Anxiety/Depression

- 1. I am not anxious or depressed
- 2. I am moderately anxious or depressed
- 3. I am extremely anxious or depressed

Each of the 3 levels within the domains are given a preference weighting, derived from general population survey work, and these are summed up to generate the overall score on a scale between 0 (dead) and 1 (perfect health).

The EQ5D was designed to measure the health-related consequences of medical interventions and not social care. It is not therefore especially well suited to assessing the consequences of day care services on older people. There are particular problems with the self-care and, to some extent, the mobility domains as they are phrased in the EQ5D self-completion set. Regarding self-care, people are asked whether they themselves can perform washing and dressing. Among other things, social care services are provided because people are unable to perform these tasks (see, Results - focus groups with users, page 27). Having these activities of daily living (ADL) problems is a need factor, not a social care outcome. To be a valid outcome measure, the question would have to ask whether people were washed and dressed (allowing the possibility that services helped frail people to do this), not (just) whether people could do it themselves. For this reason we use a version of EQ5D with this domain removed. The mobility domain potentially has a similar problem, but perhaps to a lesser extent, not being specifically worded as a need factor. Therefore, we use an adjusted version of EQ5D with the self-care domain removed, but with the usual preference weights applied to the other domains to create the overall score (EQ5Dr). In theory, not being able to capture the well-being implications of poor personal dignity (i.e. being clean and dressed) is a significant omission for the EQ5D measure. We would therefore expect social care services to show relatively poor well-being effects when using this EQ5Dr measure.

The General Health Questionnaire was developed to detect the presence of non-psychotic psychiatric morbidity in community settings and has been employed on the Health Survey every year except 1996. There are twelve questions:

- been able to concentrate on whatever you're doing?
- lost much sleep over worry?
- felt you were playing a useful part in things?
- felt capable of making decisions about things?
- felt constantly under strain?
- felt you couldn't overcome your difficulties?
- been able to enjoy your normal day-to-day activities?
- been able to face up to your problems?
- been feeling unhappy and depressed?
- been losing confidence in yourself?
- been thinking of yourself as a worthless person?
- been feeling reasonably happy, all things considered?

Responses to these questions can be taken as indication of a person state of psychiatric well-being. Interpretation of the answers in the HSE is based on a four point response scale scored using a bimodal method (symptom present: 'not at all' = 0, 'same as usual' = 0, 'more than usual' = 1 and 'much more than usual' = 1) to create a score between 0 and 12. For our purposes, the GHQ score was re-scaled to fall on the interval 0 to 1 (by dividing by 12).

The health survey also asks people, on a yes-no scale, "Are you basically satisfied with your life?" and "Do you feel happy most of the time?". Table 5 shows the correlation between the well-being measures in the HSE 2005, and also a need measure: a count of activities of daily living problems. There is a high degree of correlation between these measures, and particularly between EQ5D and GHO12r.

Table 5. Correlation matrix (older people)

	EQ5D	EQ5Dr	GHQ12 (inverse)	Happy? (Yes)	Satisfied? (Yes)	ADL count
EQ5D	1					
EQ5Dr	0.99	1				
GHQ12 (inverse)	0.53	0.509	1			
Happy? (Yes)	0.21	0.201	0.37	1		
Satisfied? (Yes)	0.27	0.255	0.40	0.42	1	
ADL count	-0.58	-0.559	-0.37	-0.13	-0.21	1

A simple comparison of well-being scores for people who are day services users or not shows that people who use services have *lower* outcomes not higher outcomes. However, this comparison does not take into account the different baseline characteristics of these people. If we make the comparison only looking at people with some form of disability, the difference in outcomes is significantly reduced. This is to control for just one need indicator; the full analysis must simultaneously account for a whole range of needs factors. Multiple regression is used to make such an adjustment.

Table 6. Correlation matrix (older people)

	rabio of contolation matrix (class people)					
	Day service	EQ5Dr	GHQ12 (inverse)	Happy? (Yes)	Satisfied? (Yes)	
All people over 65	No	0.80	0.92	0.95	0.93	_
	Yes	0.73	0.82	0.88	0.86	
	Diff	0.08	0.10	0.06	0.07	
Over 65 with disability	No	0.65	0.84	0.89	0.89	
	Yes	0.64	0.75	0.85	0.86	
	Diff	0.01	0.09	0.04	0.03	

The regression model should aim to account for all factors that will have a bearing on a person's well-being and are likely to differ systematically between people using services and those not using services. Table 7 below reports the results of the regression analysis and lists three sets of factors: first, the use of services, including other relevant services in addition to day services. Here we include local authority home help. The second set includes relevant needs factors, which are principally health conditions and impairments. The third set covers personal characteristics such as age, sex, household composition, tenure, ethnicity, and local circumstances.

The EQ5Dr measure appears to be strongly censored at a score of 1 i.e. full health – see Figure 3 (which shows a strong peak at 1). In other words, the score does not differentiate people's well-being above a score of 1, and yet it would appear quite possible that of people on a score of 1, some will have higher well-being than others. For this reason, we use a Tobit estimation technique, which

assesses a probability that a person's underlying or implicit well-being is greater than 1 (Dow and Norton 2003). Using this model generally gives larger (in magnitude) coefficients on the independent variables than using an ordinary least squares model.

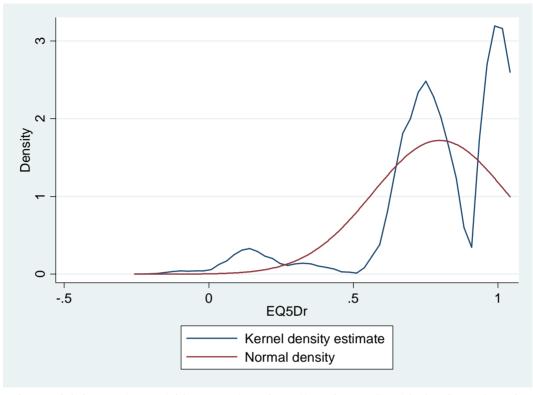


Figure 3. Distribution of EQ5Dr score

In the model the service variables were found to offer a better fit with the data when they were interacted with a needs factor, either the count of ADL problems, or the level of self-care problems. This forces the service variable to have a zero effect for people with zero reported disability. Where both the straight service use variable and the interacted form were used, the results suggested that service users with zero need had lower well-being. In view of the small numbers of people that this combination covers, only the interacted variable was used.

The data show that service users (of both day services and LA home help) have better well-being than non-service users, given the same set of needs. Table 7 reports the detailed results of both an ADL interaction and a self-care problems interaction. The greater the person's need, the higher is the positive impact of service use.

Table 7. EQ5Dr OLS model

	ADL inter	ADL interaction		
	Coeff	Prob	Coeff	Prob
Service use				
Day service x ADL count	0.046	0.001		
, ,			0.019	0.028
LA home help x ADL count	0.029	0.041	0.032	0.023
Needs factors	0.027	0.0	0.002	0.020
Some probs washing & dressing self	-0.190	< 0.0001	-0.196	<0.0001
Unable to wash & dress self	-0.309	< 0.0001	-0.329	<0.0001
Count of ADL difficulties	-0.100	< 0.0001	-0.097	<0.0001
Blood pressure (dias) (sqrd)	8.36E-08	0.961	5.99E-08	0.972
Diagnosed: COPD	-0.027	0.128	-0.028	0.113
Diagnosed: asthma	-0.027	0.068	-0.026	0.084
Diagnosed: arthritis	-0.171	< 0.0001	-0.171	<0.0001
Diagnosed: osteoporosis	-0.053	0.003	-0.053	0.003
Diagnosed: cancer	-0.001	0.937	-0.001	0.954
Diagnosed: Parkinson's	0.020	0.673	0.019	0.696
Diagnosed: psychiatric	-0.094	<0.0001	-0.092	<0.0001
Not limited by illness in the last 2 weeks	0.094	<0.0001	0.094	<0.0001
Urinary incontinence	-0.057	<0.0001	-0.057	<0.0001
Has not fallen in last year	0.043	<0.0001	0.043	<0.0001
Has no memory problems	0.050	<0.0001	0.043	<0.0001
Mobility problems due to confusion	-0.028	0.316	-0.027	0.34
Able to self-complete questionnaire	0.004	0.316	0.003	0.805
Personal and local characteristics	0.004	0.771	0.003	0.805
	0.01/	0.5/0	0.017	0.540
Lives alone	-0.016	0.568	-0.017	0.543
Single or divorced	-0.030	0.214	-0.028	0.241
Widowed	0.004	0.861	0.006	0.8
Household size: numbers of people	-0.028	0.036	-0.028	0.039
Owns home	0.008	0.529	0.007	0.6
Number of bedrooms	-0.010	0.584	-0.010	0.596
Number of bedrooms (sqrd)	0.004	0.201	0.004	0.208
Male	0.019	0.064	0.019	0.072
Age	-7.02E-05	0.996	1.17E-03	0.935
Age (sqrd)	2.82E-06	0.976	-5.26E-06	0.955
Difficult to get to local shops (score 1 to 4)	-0.020	0.001	-0.021	0.001
Difficult to use local leisure (1 to 4)	-0.019	0.001	-0.020	0.001
Mixed race	-0.193	0.03	-0.196	0.028
Asian	-0.067	0.082	-0.067	0.082
Black	-0.028	0.579	-0.031	0.549
Chinese (or other)	0.007	0.94	0.007	0.941
Further education (left at 17 or 18)	0.045	0.006	0.046	0.006
Higher education (left at 19 or older)	0.051	0.002	0.051	0.002
Constant	0.848	0.12	0.804	0.141
Model	Tobit		Tobit	
LR	1809.74		1804.05	
Prob	< 0.0001		< 0.0001	
R sqrd	0.5294		0.5277	
N	3142		3142	

Table 8. GHQ12 (inverse) model

Table o. G	HQ12 (inverse) m	
	Coeff	Prob
Service use		
Day service	-0.097	0.04
Day service x Self care (sqrd)	0.040	0.029
LA home help x ADL	0.044	0.032
Needs factors		
Some probs washing & dressing self	-0.180	< 0.0001
Unable to wash & dress self	-0.281	< 0.0001
Some probs walking about	-0.152	< 0.0001
Confined to bed	-0.415	0.044
Count of ADL difficulties	-0.045	< 0.0001
Blood pressure (dias) (sqrd)	0.000	0.283
Diagnosed: COPD	-0.057	0.031
Diagnosed: asthma	-0.005	0.819
Diagnosed: arthritis	-0.040	0.011
Diagnosed: osteoporosis	-0.066	0.016
Diagnosed: cancer	-0.045	0.062
Diagnosed: Parkinson's	-0.109	0.099
Diagnosed: psychiatric	-0.218	<0.0001
Urinary incontinence	-0.081	<0.0001
Has not fallen in last year	0.065	<0.0001
Has no memory problems	0.219	<0.0001
Mobility problems due to confusion	-0.068	0.086
Able to self-complete questionnaire	0.027	0.192
Personal and local characteristics	0.027	0.172
Lives alone	-0.032	0.474
Single or divorced	0.033	0.378
Widowed	0.027	0.444
Household size: numbers of people	-0.008	0.714
Owns home	-0.013	0.714
Number of bedrooms	0.023	0.317
Number of bedrooms (sqrd)	-0.002	0.723
Male	0.026	0.723
Age	-0.426	0.618
Age (sqrd)	0.000	0.494
Difficult to get to local shops (score 1 to 4)	-0.039	
Difficult to use local leisure (1 to 4)		<0.0001
Mixed race	-0.018	0.055
Asian	-0.193	0.134
Black	-0.142	0.015
	-0.019	0.804
Chinese (or other)	-0.059	0.669
Further education (left at 17 or 18)	-0.001	0.972
Higher education (left at 19 or older)	0.024	0.364
Constant	2.463	0.451
Model	Tobit	
LR	1093.73	
Prob	< 0.0001	
R sqrd	0.3284	
N	3089	
1 4	3007	

Table 8 gives the results for the GHQ12 measure, which is also censored at a score of 1 (see Figure 4). In this case, day service use was interacted with the self-care needs variable. In this model, day service use showed a weaker effect on the GHQ12 measure. Only for people with the greatest self-care problems is there a statistically significant positive impact of day services on well-being (as measured by GHQ). LA home help services have a significant impact on GHQ12 in a similar way to the above EQ5Dr model.

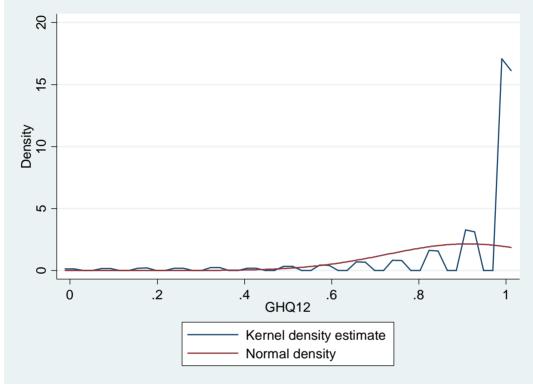


Figure 4. Distribution of GHQ12 score

Table 9 reports the main results of modelling the yes/no questions on happiness and satisfaction. The same model specification was used as above, but with probit estimation in view of the binary nature of the dependent variables. The satisfaction question was not significantly influenced by use of day care services, although there was some indication that these services improve reported happiness of people with disabilities or frailty.

Table 9. Happiness and satisfaction global ratings

	Coeff	Prob
Are you basically satisfied with your life? (Yes)	0.005	0.222
Do you feel happy most of the time? (Yes)	0.009	0.098

Discussion

This analysis of the HSE was motivated in two ways. First, to broadly investigate whether population surveys could give meaningful results when we are attempting to attribute changes in well-being that results from the use of services. Second, to explore the performance of a number of commonly used well-being measures with regard to measuring the impact of day care services for older people.

Regarding the former, the analysis underlines the importance of accounting for relevant needs factors. When the models were run without needs factors, the service variables showed highly significant *negative* relationships with well-being (as we would expect), and this is only corrected where appropriate need factors are included. We cannot make direct comparisons between this kind

of analysis and the results of an RCT, but the results do suggest that we can get quite far in using multiple regression techniques to control for baseline differences between service and non-service groups.

Turning to the second objective, the results suggested (a) that these well-being measures are sensitive enough to pick up the effects of low-level services and (b) that both produced results of similar magnitudes. To look at consistency between the measures, we produced bootstrapped estimates for the marginal effect of service use on the EQ5Dr and GHQ12r measures and compared them (using the models with a self-care problems interaction). The aim is to see how closely the estimated marginal effects of services on these two measures compare when the data are resampled. Re-sampling allows us to generate a distribution of marginal effects for each measure and we compare the correlation between them.

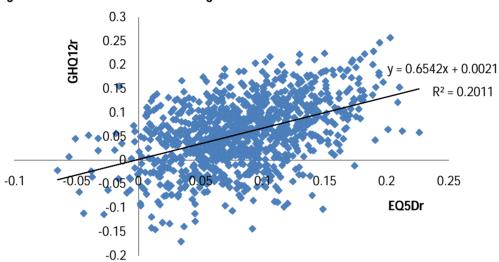


Figure 5. Correlation between marginal effects of service use on EQ5Dr and GHQ12r measures

In this case, the correlation was high, at R = 0.448 (p < 0.001), and this suggests that the two measures are capturing similar well-being effects as they stem from use of day care services, given needs and other factors – see Figure 5. Differences between the measures do remain, nonetheless, each with a slightly different focus. For our purposes, it is difficult to conclude that one measure is 'better' than the other. The un-adjusted EQ5D does have the problem of measuring well-being in terms of the *ability of the individual* to self-care – that is, to achieve personal dignity (through being dressed and washed) -- rather than the achievement of personal dignity *per se.* Alternatively, the GHQ12 appears to focus on measuring emotional state, which can be seen as the consequence of good physical as well as psychological functioning, but may not fully capture the consequences of the former. The relatively high correlation between the scores suggest that the overlap between physical and psychological functioning are quite high, but a measure that embodies both will appear most suited to gauging the well-being consequences of service use in social care. The ASCOT measure is designed in this way, although in the fieldwork phase of the project either EQ5D or GHQ12, or both, measures will be used as well as the ASCOT measure.

References

Bowling, A. (1997). <u>Researching methods in health: investigating health and health services</u>. Buckingham, Open University Press.

Brazier, J., M. Deverill, et al. (1999). "A review of the use of health status measures in economic evaluation." Health Technology Assessment **3**(9): 1-164.

- Burge, P., F. Gallo, et al. (2006). <u>Valuing PSS outputs and quality changes</u>. Canterbury, PSSRU University of Kent. Discussion Paper 2356/3
- Darton, R., J. Forder, et al. (2006). <u>Analysis to Support the Development of FSS Formulae for Older People: Final report.</u> Canterbury, PSSRU University of Kent and London School of Economics
- Dow, W. H. and E. C. Norton (2003). "Choosing Between and Interpreting the Heckit and Two-Part Models for Corner Solutions." <u>Health Services and Outcomes Research Methodology</u> **4**(1): 5-18.
- Edelen, M. and B. Reeve (2007). "Applying item response theory (IRT) modeling to questionnaire development, evaluation, and refinement." Quality of Life Research 16(1): 5-16.
- Flynn, T. N., J. J. Louviere, et al. (2007). "Best-worst scaling: What it can do for health care research and how to do it." Journal of Health Economics **26**(1): 171-189.
- Forder, J., M. Knapp, et al. (1996). "Competition in the Mixed Economy of Care." <u>Journal of Social</u> <u>Policy</u> **25**(2): 201-221.
- Forder, J., A. Netten, et al. (2007). <u>Measuring Outcomes in Social Care: Conceptual Development and</u> Empirical Design, PSSRU, University of Kent. PSSRU Discussion Paper 2422
- Goldberg, D. and V. Hillier (1979). "A scaled version of the General Health Questionnaire." Psychological Medicine **9**: 139–145.
- Grewal, I., J. Lewis, et al. (2006). "Developing attributes for a generic quality of life measure for older people: Preferences or capabilities?" <u>Social Science and Medicine</u> **62**(8): 1891-1901.
- Hyde, M., R. D. Wiggins, et al. (2003). "A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model (CASP-19)." <u>Aging and Mental</u> Health **7**(3): 186-194.
- Kahneman, D. (2000). Experienced Utility and Objective Happiness: A Moment-Based Approach.

 <u>Choices, values and frames.</u> D. Kahneman and A. Tversky. Cambridge University Press, New York.
- Kahneman, D., E. Diener, et al. (1999). <u>Well-Being: The Foundations of Hedonic Psychology</u>. New York, Russel Sage Foundation.
- Kitzinger, J. (1995). "Introducing focus groups." British Medical Journal 311: 299-302.
- Netten, A., J. Forder, et al. (2006). <u>Measuring Personal Social Services Outputs for National Accounts:</u>
 <u>Services for Older People</u>. Canterbury, PSSRU University of Kent. PSSRU Discussion Paper 2267/3
- Netten, A., M. Ryan, et al. (2002). <u>The development of a measure of social care outcome for older</u> people. Canterbury, PSSRU University of Kent. Discussion Paper 1690/2
- Ryan, M., A. Netten, et al. (2006). "Using discrete choice experiments to estimate a preference-based measure of outcome-An application to social care for older people." <u>Journal of Health Economics</u> **25**(5): 927-944.
- Sen, A. (1985). Commodities and capabilities. Amsterdam, North-Holland.
- Sen, A. (1993). Capability and well-being. <u>The Quality of Life</u>. M. Nussbaum and A. Sen. Oxford, Clarenden Press.
- Thissen, T. and L. Steinberg (1986). "A taxonomy of item response models." <u>Psychometrika</u> **51**(4): 567–577.
- Towers, A.-M., J. Beadle-Brown, et al. (2008). <u>OMF Care Homes Pilot Report</u>. Canterbury, PSSRU. Discussion Paper 2534
- Wanless, D., J. Forder, et al. (2006). <u>Securing Good Care for Older People: Taking a long term view</u>. London, King's Fund
- Wiggins, R. D., P. F. D. Higgs, et al. (2004). "Quality of life in the third age: key predictors of the CASP-19 measure." Ageing and Society **24**(5): 693-708.
- Willis, G. (2005). Cognitive Interviewing: A Tool for Improving Questionnaire Design. London, Sage.