

## Putting People First

### Development of the Putting People First User Experience Survey

Juliette Malley and Ann Netten

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#### PERSONAL SOCIAL SERVICES RESEARCH UNIT

##### University of Kent

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

##### London School of Economics

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

##### University of Manchester

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

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# 1 Introduction

The new agenda for adult social care set out in *Putting People First* places the emphasis squarely upon delivering improved outcomes for people through personalised services. Evidencing progress towards this transformation agenda is a major task, and requires a new approach to management data which moves away from the services themselves and towards the effect they have on those who use services.

If personalisation demands putting the user at the heart of care planning and provision, then user experience information should be a crucial lever for directing services and informing policy development. Whilst the old social care survey programme displayed some significant successes for certain groups, too often the national surveys have been limited in scope, or not best aligned to priorities on the ground, and have not played their full part in supporting the wider agenda. This situation needs to change – to reflect the changing policy world, to evidence how outcomes can be achieved cost-effectively, and to accord the right importance to the experience of those who use services.

This paper sets out proposals for a new national survey to begin to tackle those issues. The approach to the survey is a step-change from past arrangements, and some of the proposals will need to be dealt with over time. There are many areas in which we need your advice and expertise to help develop the strategy, and there are some specific questions we are asking in this paper where we would like your views. Please do think about the issues raised here and comment through the Information Centre by 3 July 2009.

Robert Lake  
Director for Social Care Information, NHS IC

Richard Campbell  
Deputy Director, Dignity and Quality, Department of Health

## 2 Your views on the Putting People First survey

### 2.1 Reasons for seeking your views

Since 2001 all councils with adult social services responsibilities (CASSRs) have been required to conduct annual user experience surveys (UES) (Department of Health 1998). These surveys have covered a number of client groups and service forms including newly assessed clients (2001 and 2002), older people receiving home care (2003, 2006 and 2009), clients with physical or sensory impairments aged 18-64 receiving services to support them to live in their own homes (2004), users of equipment and minor adaptations (2008 and 2010), and carers (2010).

Despite the valuable contribution that these surveys have made towards putting the views of users at the heart of decision-making there is a feeling that they need to change to fit today's policy environment. In particular, the current focus of performance management on outcomes is not reflected in the questions. Previous surveys have tended to focus on users' experiences and perceptions of the way care is delivered, for example whether their carers arrived on time and so on, which, whilst important, do not inform us whether the services provided are improving the well-being and quality of life of those who receive social care. In addition, the surveys have tended to focus on only one client group or service so are not representative of social care services as a whole.

With these issues in mind, the Department of Health (DH) commissioned the Personal Social Services Research Unit (PSSRU) at the University of Kent to assist in developing a new social care UES for 2010/11 that is consistent with the transformational agenda for social care set out in *Putting People First (PPF)* (Ministers, Local government et al., 2007). The key elements of the PPF agenda in relation to the UES are discussed in Appendix 1.

**The aim of this paper is to seek your views on the development and content of the new PPF survey.**

### 2.2 Why we are seeking your views

It is essential that everyone with an interest in or use for adult social care information has the opportunity to comment on our proposals before we begin developing the new PPF survey.

We need your views on these proposals and how these may impact on policy, research or other work.

### 2.3 How to take part

We really want to hear your views. Please read sections 2 to 5 carefully since these sections set out our proposals for developing the first PPF survey, later surveys and the content of the questionnaire. Opportunities are provided in section 6, which summarises the questions, for you to record your comments. We have also included

a longer discussion of some of the issues in an appendix, which you can use to refer to if you require more detail.

Responses can be sent to:

By e-mail to: XXX

By post to: XXXX

Please send any queries to XXXXXX

The closing date is 3<sup>rd</sup> July 2009.

A summary of the responses received will be published on the Information Centre website as soon as possible following the closing date for submitting your views. The responses will be used to finalise decisions about the direction and content of the first PPF survey and later PPF surveys.

We look forward to hearing from you.

## 3 Background to the PPF survey

### 3.1 How the survey will be used

Survey data should be a key strand of management information, and one flexible enough to be used locally and nationally in different ways. In considering the need for a new national user survey, we need to think about fulfilling these needs:

- *Local uses*

This is a key purpose for the survey: it must be able to inform local decision-making and support improvement as part of the pool of information available to service managers. A standard national survey providing data on outcomes for users could be an important benchmarking tool for Councils. It should not stand alone, however, but should supplement existing or planned local surveys, to allow Councils to test experience further in particular areas or groups, in line with their own assessment of need.

The NHS Information Centre has an important role to play in supporting Councils to make the best use of experience information locally. Through the Social Services User Survey Group, work is currently planned to assist Councils in developing and analysing their own surveys: an approved question bank to build bespoke surveys, and analytical tools to consider the results.

- *National uses*

A national survey needs to be sufficiently robust to be able to be used at that national level. Different organisations will have differing uses – for benchmarking, performance monitoring and assessment, policy development and accountability purposes.

In 2010/11, the new survey will be used to populate two indicators in the National Indicator Set: NI127 (self-reported experience of social care users) and NI128 (user-reported dignity and respect in their treatment). Deciding how the indicators will be calculated for this purpose will be one of several important tasks to fulfil as work develops.

From 2011/12, a new performance cycle will begin, and the contents of the National Indicator Set will be open for discussion and renewal. Separate work being co-produced between the Department of Health and ADASS is looking to develop a new suite of indicators for the next iteration of the NIS, and this survey sits firmly within the context of that work. Pending development of the new survey and feedback from piloting, it is likely that this survey will occupy a place in future performance arrangements, providing a composite measure of user experience to be used alongside other outcome indicators.

### 3.2 What will the survey look like?

To support the PPF agenda and the uses identified above, the DH has stipulated a series of objectives for the PPF survey (Metcalf, 2008):

- 1. It should focus on developing questions to fit the outcome themes of PPF,** i.e. quality of life, choice and control, inclusion and contribution, health and well-being, and dignity and safety.
- 2. It should be as inclusive as possible:** the same set of questions should be applicable and accessible to all service users and their carers. This includes users living in residential care settings who may have severe dementia, users with self-directed support packages, carers and people who fund their own care.
- 3. The questions should be able to be turned into measures or performance indicators that can easily be used for benchmarking, monitoring trends nationally and locally and supporting service improvement locally.** In particular, the questions will be used to populate NIs 127 and 128 in the first year (2010/11).
- 4. It should provide information that promotes the overall direction of policy,** i.e. it should enable authorities and government more generally to monitor efficiency and equity, promote improvements in universal services and early intervention and prevention, and improve the personalisation of services.
- 5. In the longer-term, it should consider new methods for collecting the information beyond the traditional postal route, to reflect the needs of groups which are harder to reach,** although we recognise that in the first year at least the survey may need to be primarily a self-completion postal questionnaire.
- 6. It should aim to provide information and performance indicators that are compatible with the NHS patient survey programme.**

This set of objectives is ambitious since it requires a survey that is applicable across the spectrum of people who use social care services, from those who receive low level help, perhaps to manage their home and garden, to those who require 24-hour support, seven days-a-week; and one that provides data to meet a number of different requirements. It is important to recognise from the outset that it will not be possible to achieve all of these objectives straightaway. One aim of this paper, therefore, is to propose a staged strategy for developing a survey that meets these objectives.

### 3.3 Structure of the paper

This paper is organised into two sections. In the first section of this paper we set out the research problems that need to be tackled to develop the PPF survey and identify the priorities for the first PPF survey. We describe the development activities to be conducted under the first stage and set out the activities for subsequent stages of development. In the second section we discuss the content of the questionnaire.



## 4 Strategy for developing the PPF survey

It is not straightforward to develop a survey that meets all the objectives set out above. There are a considerable number of practical and research problems, which we discuss in detail in Appendix 2.

The problems raise a number of research questions and impose constraints on the development of the survey. For example, we know that it will not be possible for some segments of the population to self-administer postal questionnaires without some form of help. This raises a number of questions: What is the best method to engage with these segments of the population? Is one method appropriate for all hard-to-reach groups? Do alternative methods produce results comparable with those from a self-completion postal questionnaire? These three questions can only be answered through empirical research and given the variety of different hard-to-reach groups it is unlikely that each question can be answered in its entirety in one study.

It is also clear that there is an order to the development suggested by these questions. We cannot know whether alternative methods produce comparable results until we have decided a set of questions, decided which methods will be used to collect the data, and collected some data. The short time horizon to develop the PPF survey means that it will not possible to address all the research questions raised in Appendix 2 within the time frame. In table 1 we set out each of the research questions, summarise the problems and prioritise the solutions.

**Table 1: Research problems, their solutions and priorities for developing the first PPF survey**

<b>Research question</b>	<b>Key problems</b>	<b>Prioritisation of solutions</b>
<i>Developing the questionnaire</i>		
What questions should be asked?	The questions should focus on individual outcomes, in line with the aims of PPF.	The priority should be to develop a core set of individual outcome questions.
	The goals of the various social care services are all slightly different and it is important that the questions are sensitive to the goals of each service. Services for carers, children (under 18) and residential care are most different in terms of the service goals (see Appendix 2, point 2 for fuller discussion).	The questions would need to be tested carefully to ensure they are adequate for each of these groups of users. There will not be time to adequately test for all these groups so they will need to be prioritised.
	Ideally we would want to be able to compare user outcomes across health and social care. However, the current health surveys focus on aspects of process and not individual outcomes, meaning that the questions are not directly comparable (see Appendix 2, point 3 for fuller discussion).	Given the divergent directions of the PPF survey and the NHS survey, it cannot be a priority to develop questions that are comparable across health and social care.
	A number of factors impact on individual outcomes, including social care services. Studies have tended to show that services have a very small effect on individual outcomes compared to characteristics of the individuals. It is important to be able to attribute good and poor outcomes to the effect of services to ensure that what appears to be good performance, but is actually operation in benign conditions, is not unfairly rewarded and what appears to be poor performance, but is actually operation in difficult conditions, is not unfairly punished (see Appendix 2, point 5 for fuller discussion).	Information about individuals, such as their level of disability, and the number of hours of care they receive, is critical for interpreting outcomes. These questions will need to be included in the core set of questions and should be a development priority.

Research question	Key problems	Prioritisation of solutions
<i>Sampling</i>		
What data source can be used as a sample frame to capture all users of social care?	Past UESs have used the CASSR database of all those who receive publicly-funded services as part of a care plan as a sampling frame. Several groups are excluded from this source, including those who pay for care or equipment privately or have it paid for by a third party, those carers who are not known to social services, and those people who use day centres on a drop-in basis and not as part of a care plan. It may be possible to capture some of these groups by using provider records as a sampling frame, but this would require some form of data-sharing to ensure there are no duplicates and it is not clear whether provider records are of high enough quality to form the basis of sampling frame. Some groups, such as those who purchase care from the grey market will still be excluded (see Appendix 2, point 4 for fuller discussion).	The only feasible option for a sampling frame in the short-term is CASSR records. This means self-funders cannot be included in the first PPF survey.
What approach to sampling is most appropriate?	In previous UESs samples have been collected by simple random sampling within each CASSR and the size of the sample has been determined by the Best Value requirement that the 95% confidence interval should be between $\pm 4\%$ . Since the PPF sample frame is likely to be dominated by older people, the same method applied to the PPF survey would lead to a sample composed mostly of older people. This may make comparisons between sub-groups difficult, as some client groups or age groups may have very few respondents. Stratification of the sample frame prior to random sampling is often used to ensure a certain number of responses are achieved from smaller groups.	Stratified sampling may be a good way to ensure the data can be used for many purposes. However, to ensure the estimates obtained from the sample are accurate CASSRs need calculate and include sample weights in their datasets. This process can be complicated to implement and would need to be piloted carefully.

Research question	Key problems	Prioritisation of solutions
<i>Collecting the data</i>		
How should the data be collected?	<p>Self-completion postal surveys generally have lower response rates than other modes, such as interview. However, they cost much less to conduct than other modes and will be the main mode of collecting data for the PPF survey. A significant problem for the PPF survey is that certain segments of the service user population will require help to complete the questionnaire. Groups who are likely to experience problems are those who are visually impaired, those with severe physical impairments who are no longer able to write, and those with severe cognitive impairments, learning disabilities or whose first language is not English who are not able to understand the questions. Because social care, particularly publicly-funded social care, tends to be concentrated on those with the highest levels of need, the proportion of those who will need some form of help to answer is likely to be high (see Appendix 2, point 1 for fuller discussion).</p>	<p>Alternative ways of collecting the data will need to be considered as the nature of the population means that many social care users will not be able to self-complete the questionnaire.</p>
What is the best way of collecting data from the hard-to-reach groups?	<p>There are various options for collecting data from hard-to-reach groups that can be considered. These vary by group, as follows:</p> <ul style="list-style-type: none"> <li>• Visually impaired: interview (by telephone or face-to-face), Braille version, audio version or allow someone else to complete the questionnaire in their place (proxy respondent)</li> <li>• Severely physically impaired: interview (by telephone or face-to-face), or proxy respondent</li> <li>• Severely cognitively impaired: proxy respondent</li> <li>• Learning disabled: Easy Read version, or proxy respondent</li> <li>• First language not English: foreign language versions, or proxy respondent</li> </ul>	<p>To decide which method works best for each group requires empirical work to test the methods against each other. There is not adequate time to conduct this work for each group for the first PPF survey.</p>

Research question	Key problems	Prioritisation of solutions
	<p>In addition, certain care locations may have an effect on how well methods will work. For example, trying to use proxy respondents in care homes will be complicated by the fact that the only readily available proxies are the care home staff and the other residents. Observational methods may be more appropriate in institutional locations. It is not immediately clear which of these methods will be the best way of collecting data and the best method may vary according to the group (see Appendix 2, point 1 for fuller discussion).</p>	
<p>Do alternative methods for collecting data produce equivalent data?</p>	<p>There is evidence that different methods, such as interview or self-completion, may not produce equivalent data, because the different conditions under which the questionnaire is administered can affect the way people respond. If these methods are used without assessing the effect they have on the way people respond it will make it very difficult to interpret the findings (see Appendix 2, point 1 for fuller discussion).</p>	<p>Detailed studies are required to compare the responses of users under these different conditions. There is not adequate time to conduct this work for the first PPF survey.</p>
	<p>Proxy respondents have a different perspective (and experiences) compared to the service user and they may answer the question differently to the way the user would have answered it. In addition, the relationship between the user and the proxy respondent may significantly affect the response or influence the way the user would respond compared to if he/she was alone (see Appendix 2, point 1 for fuller discussion).</p>	<p>A detailed study is required to compare the responses of proxy respondents to users. There is not adequate time to conduct this work for the first PPF survey.</p>
	<p>Alternative versions of the questionnaire e.g. Easy Read and foreign language versions are more likely to be invalid because in the process of translation the sense of the question can be lost. This means that the questions in the translated version are not conceptually equivalent to the questions in the standard version (see Appendix 2, point 1 for fuller discussion).</p>	<p>Detailed studies are required to develop valid alternative forms of the questionnaire. There is not adequate time to conduct this work for the first PPF survey.</p>

Research question	Key problems	Prioritisation of solutions
<i>Using the data</i>		
Are the questions valid?	Valid questions capture the concepts they are intended to capture. Validity can be partially assessed using a method of interviewing known as cognitive testing. Different groups of people may have different understandings of key terms within the questions so it is important that the questions are tested with people from a variety of different backgrounds (see Appendix 2, point 6 for fuller discussion).	It will be important to ensure that the questions are tested on people receiving different types of services and from different backgrounds within the first stage.
What should be considered when developing PIs?	If the questions are to be used to measure performance it is important that the measure captures the performance of the organisation e.g. CASSR or provider and not the conditions in which they operate. In designing the PI, we need to consider how we can adjust the PI to ensure that it captures the effect of services on outcomes and not factors beyond the control of the service (see Appendix 2, point 5 for fuller discussion).	The Capacity for Benefit (CfB) approach is one possible way of identifying the contribution of services to outcomes. In order to use the CfB approach additional data needs to be collected to assess CfB for each type of service. The contextual value-added (CVA) method is used by the DCSF to adjust pupil outcomes (key stage results) for factors beyond the control of schools and could be adapted to this context. Detailed studies need to be conducted to isolate which factors should be controlled for either within a CVA-like approach (see Appendix 2, point 5 for fuller discussion).
	Differences between groups of individuals may be caused by a variety of factors, including real differences in services. However, differences in interpretation of key terms in questions between groups may also explain group differences. For example a difference between the learning disabled and physically disabled population may actually be explained by differences in the proportion of proxy respondents in each group, or perhaps age-related differences in the way people respond to the questions (see Appendix 2, point 6 for fuller discussion).	
	Non-response is a significant problem in surveys since it can bias results. Steps can be taken to minimise non-response, and these should be part of the standard survey approach. They should not vary by CASSR because differences in data collection methods can	

<b>Research question</b>	<b>Key problems</b>	<b>Prioritisation of solutions</b>
	introduce further non-response bias into the results. There are methods for adjusting for non-response and remedying the degree of bias.	adjusting for non-response should be employed to ensure that PIs are not biased. This analysis should be a priority.
Is the PI reliable?	Reliability means that if the measure gives consistent answers, i.e. if measurements were repeated on the same subjects under the same conditions the subject's measurements would be the same. Reliability applies both at the level of the individual whose outcomes we are assessing and also at the level of the CASSR (or provider) whose performance we are assessing. In the latter case, if the measure is a reliable indicator of CASSR (or provider) performance we would expect there to be a high level of agreement (or inter-rater reliability) across the people sampled.	It is important to examine the reliability of the PIs for assessing individuals and institutions, such as the CASSR and providers. This should form part of the first stage of development.
Is the PI valid?	Establishing the validity of the questions goes some way to establishing the validity of the PI. Since the PI is designed to capture organisational performance its validity can be affected by a number of other factors. One issue is the effect of factors beyond the control of the organisation; another is the potential for gaming. Incentives to game the PI operate where PIs are used to control the behaviour of organisations. Opportunities are presented at the sampling stage, e.g. over-sampling those client groups that respond more favourably, and at the data entry stage, by inputting more favourable opinions. Gaming is very difficult to identify but can seriously undermine the usefulness of the PPF survey and the faith of the public in the data.	It is important to take steps to prevent potential gaming by CASSRs. One approach, which has a precedent in the NHS patient survey, is to use an independent organisation to conduct the survey. This would also ensure comparability of the data collection process across CASSRs.
Is the data useful for all stakeholders?	It is important that the PI can be used to monitor performance of key organisations and monitor trends in performance. A PI adjusted for factors beyond the control of the organisation is key to monitoring performance.	Because of the sensitivity of the performance data, work to adjust the PI for factors beyond the control of organisations should be scheduled into the first stage of development.

Research question	Key problems	Prioritisation of solutions
	<p>The questions should help to promote the overall direction of policy. Since local and national objectives may not always be aligned it is possible that the questions will not address some local objectives.</p> <p>The questions should also help with service improvement. Information on individual outcomes can be used by managers to examine allocative efficiency, so think about the optimum deployment of resources. However, it will not necessarily help managers to think about how they might improve the efficiency of a particular service since information on individual outcomes identifies poor end results, or inefficiency, and not what is going wrong with the process.</p>	<p>It may be possible to develop a question bank that has modules addressing local objectives and questions on aspects of process that are useful for identifying reasons for poor outcomes. However, it will take time to develop such questions if there are not already suitable questions available. This cannot be a priority since they are not critical to interpreting outcomes, although they may be useful for service improvement.</p>
<i>Burden</i>		
<p>How can the survey burden be reduced for social care users?</p>	<p>Researchers have argued that the proliferation of surveys has led to survey fatigue and decreasing response rates. Many of the stakeholders may already have survey programmes in place. For example, CSCI (now CQC) have conducted surveys of residents of care home and users of domiciliary care providers as part of their regulatory role and performance assessment. Local councils have the own performance management programmes and many of these include surveys. Providers are also encouraged by the regulator to conduct their own surveys and many of the unregulated provider organisations (e.g. for day centres) also have their own customer surveys (see Appendix 2, point 7 for a fuller discussion).</p>	<p>It is important to consider how the PPF survey and the survey programmes of the social care regulator, local authorities and provider organisations can be streamlined to minimise burden on service users.</p>



<b>Research question</b>	<b>Key problems</b>	<b>Prioritisation of solutions</b>
<p>How can the burden of surveys be reduced for CASSRs?</p>	<p>Many councils collect data from service users about their services. Some LAs have implemented systems to collect information about users' experiences at review, others maintain survey programmes that collect information at a single point in the year, and others collect information at several points in the year. One way to reduce burden would be to use these existing systems to gather information from users. A problem with this would be ensuring CASSRs collect the same questions for benchmarking and PIs. Another problem would be ensuring the data are comparable since collecting data at review may introduce bias into the results; individuals may have incentives to present their situation in a more or less positive light depending on how they thought this would influence their review and services. Another way to reduce the burden upon CASSRs is to use an independent organisation to collect the data. This would also improve the comparability of results but would introduce other problems around data protection (see Appendix, point 7 for a fuller discussion).</p>	<p>Two options that could be considered for future surveys are collection of data at review and collection of data by a third party. Since these solutions both have their own problems, these approaches would need to be piloted to ensure they were feasible, and in the case of collection at review, provide valid and reliable data.</p>

#### 4.1.1 Questions: Data collection

A key question is whether alternative methods to self-completion postal questionnaires should be used to collect data? There is a clear trade-off between the quality of the data on the one hand and response rates and coverage on the other.

Multiple methods are known to be of value in improving response rates (although if not used with caution this method can bias results), but different methods can also affect the quality of the data, as the method of collection can have an effect on the way people respond. The use of proxy respondents, not validated translated questionnaires and interviews are known to affect the responses people give. Using different versions of the questionnaire or methods may introduce a response bias into the answers. However, a large proportion of the social care population are likely to be unable to participate in the survey if only self-completed postal questionnaires are used. This may lead to high rates of non-response and potentially (if those who do not respond have different opinions to those who do) non-response bias. Since it is not possible to develop validated alternative forms of the questionnaire or test the effect of different methods in time for the first PPF survey, it is necessary to balance response bias or quality against coverage and non-response bias when considering whether alternative methods to self-completion should be used.

There are three options that could be taken:

1. *Allow only self-completion for postal questionnaires*, which would ensure high quality responses but would probably have very low response rates.
2. *Allow proxy respondents in addition to self-completion [DN: and develop a version for people with learning disabilities]*. This would affect quality (although the extent could be tentatively assessed subsequent to sending out the survey). It would ensure relatively good coverage as proxy respondents would be available for most people in most circumstances. For those living in residential homes and for people living on their own without any recourse to friends, neighbours or family for practical help we would need to consider how to interpret any proxy responses, but this could be tentatively assessed with cognitive interviews with proxies.
3. *Allow CASSRs to use any method and allow ad-hoc versions of instrument to be used*, which would do the most to ensure coverage, but would affect the quality of the data the most, and in an unknown way, since different and not validated versions of the instrument would be used. It would also be very difficult to assess the effect of methods on quality because of the number of methods.

***For this first PPF survey, we take the view that option 2, allowing proxy respondents [and developing a version for people with learning disabilities] in addition to self-completion, ensures the right balance between data quality and coverage. Do you agree that this is the right approach to take?***

#### 4.1.2 Questions: Sampling frame

For practical reasons we have taken the view that self-funders should be excluded from the first PPF survey and that CASSRs will use their records as a sampling frame. Therefore for the first PPF survey we propose that the sample population will be people receiving publicly-funded social care as part of their care plan.

However, those receiving publicly-funded care are not a homogeneous group. As we have already discussed, in order to capture their opinions we will need to use a variety of methods and detailed work needs to be undertaken to explore the validity of questions with each group. We therefore need to ask whether all publicly-funded social care users should be included in the sample frame.

For the following groups of social care users there are questions over what should be included in questions, how the data should be collected and the effect of different methods on the validity of the questions. It is therefore these groups that we may want to consider omitting. The groups are:

1. Children under 18
2. Carers of social care users
3. Visually impaired people
4. Severely physically impaired people
5. Severely cognitively impaired people
6. Learning disabled
7. First language not English
8. People in residential care homes

We have taken the view that due to the distinctiveness of children's services, all children under 18 will be excluded from the first PPF survey. We also have taken the view that because a carers' survey is currently being developed, carers will also be excluded from the first PPF survey.

We propose to include all users who fall into groups 3 to 7 in the first PPF survey on the basis that if they cannot answer the questionnaire without help then proxy respondents should be available to enable them to answer.

Those people living in residential care homes pose the biggest problem for using proxy respondents; how we identify suitable proxy respondents needs careful consideration. We propose drawing on CQC's experience of conducting surveys in residential homes since they have designed a process that ensures someone close to the resident is present to help the resident answer the questionnaire. However, it is not clear how successful this method will be for the PPF survey and it will require good communication between CASSR and care home provider to ensure it works as intended.

***We have taken the view that care homes residents should be included in the first PPF survey. We ask for your comments on this proposal.***

### 4.1.3 Questions: Approach to sampling

It is possible to use a variety of methods to collect a sample, including collection at review, simple random sampling, continuous sampling and so on. We have taken the view that for the first survey it is best to stick with the simplest approach to sampling and the method that has been tried and tested in the past and shown to work. Ideally we would want to stratify as this will maximise the usefulness of the data at the local level, but the method is more complicated and we feel would require detailed piloting in trial sites before being used for a national data collection.

***We therefore propose that for the first PPF survey each CASSR should select a sample by simple random sampling at one point in time from their case records.***

## 4.2 Proposed development activities for the first PPF survey

### Step 1: Developing a core set of questions

The first step in the development of the PPF survey is to identify the outcome questions and the key questions required to interpret them for performance measurement purposes since together they will form the core set of questions for the PPF survey.

### Step 2: Testing the core set of questions for validity

Following the identification of themes and questions, we plan to test the validity of the questions using cognitive interviews. The questions will only be tested on those groups that will be included in the sample frame for the first PPF survey.

The focus of the testing will depend on the choice of questions. If questions are chosen that have been used in other surveys then we can focus testing on those groups that have specific requirements or different perspectives e.g. people from ethnic minorities and proxy respondents. Because of the likely number of proxy respondents, our preference would be to focus on testing the questions with proxy respondents.

Depending on your views as to the inclusion or otherwise of people in residential care, we will decide whether or not to test the questionnaire on people in residential care. This testing will include testing with proxy respondents.

### Step 3: Pilot the PPF survey

A pilot survey should be conducted to ensure that the questionnaire is appropriate for the population and to check that sampling and data collection processes are sound. Depending on your views as to whether users in residential care homes are included in the first PPF survey, piloting the mechanism for conducting the survey with care home residents should be an important focus.

Depending on your views as to how the data is collected, another issue that should be addressed in the pilot study is whether response rates are affected by the way data is collected. Analysis of response rates by client group and other key personal

characteristics of users would help indicate the effect of methods for data collection (or indeed the relevance of the survey) on social care users. The results of this analysis should inform the main PPF survey and help to prioritise future developmental work.

#### **Step 4: Conduct the first PPF survey**

We believe that it is important to examine non-response and where action is indicated to take the necessary steps to 'correct' for non-response. This work can build on the PSSRU 2007 UES of adults aged 18 to 64.

#### **Step 5: Develop PIs**

The following sets of analysis are important stages in the development of PIs

- Ascertain the validity of the PI.
- Testing of the reliability of the PI as a measure of individual outcomes, provider-level performance and CASSR-level performance. This work can build on the PSSRU 2009 older people's home care extension study.
- Exploration of the individual-level, provider-level and CASSR-level factors that influence individual outcomes to identify factors beyond the control of the CASSR. This work can build on the PSSRU 2009 older people's home care extension study.
- Develop a method for capturing the 'value-added' by CASSRs and adjusting PIs for factors beyond the control of the CASSR. This work can build upon the PSSRU 2009 older people's home care extension study and the Capacity for Benefit (CfB) approach (see Appendix 2, point 5) being developed as part of the Quality Measurement Framework project led by ONS. Although this work will be associated with the first PPF survey this PI for this first survey is unlikely to be able to be adjusted because the development work will not be completed in time for publishing the first PIs. However, the adjustments could be applied retrospectively to ensure continuity in the dataset.

#### **Step 6: Optional additional analysis to support development of PIs and the PPF survey**

We have described some options for developing a method to capture the 'value-added' by CASSRs and adjusting PIs for factors beyond the control of CASSRs (see Appendix 2, under point 5 for detailed discussion). Before it is possible to use the CfB method, additional work needs to be conducted with a sub-sample of those who took part in the survey to establish how to measure and monitor CfB for the diverse PPF survey population.

If you agree that we should include proxy respondents, it would be sensible to explore the effect of proxy respondents on individual outcomes. It is possible to use the matching method of Rosenbaum and Rubin (Rosenbaum and Rubin, 1983), which balances the sample to adjust for differences in the underlying characteristics of proxy respondents and self-completion respondents, to explore this (see Appendix 2, under point 1 for discussion). However, given the likely significant differences in the proxy respondents and self-completion populations this method may not yield conclusive results and further research is likely to be necessary. The aim of this

analysis would be to indicate whether there might be any significant differences between the responses of proxies and those who are able to self-complete to inform the construction and interpretation of PIs from the first PPF survey.

#### 4.2.1 Questions: Development activities for the first PPF survey

Because of the very large proportion of respondents that have required help in the past to complete the questionnaire, we have expressed a preference for the cognitive testing of questions to be conducted with proxy respondents.

<b><i>Do you have any views as to the focus of the cognitive testing?</i></b>
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#### 4.3 Development activities for later PPF surveys

We have identified a number of research questions, mostly associated with the need to use different methods in order to capture responses from certain segments of the service user population, which cannot be answered within the time frame of the first PPF study. We have listed these questions as tasks below:

1. Develop a valid version of the instrument in foreign languages
2. Further test the validity of the instrument for proxy respondents
3. Test the effect of alternative methods of data collection on responses
4. Test the validity of the instrument for people with learning disabilities and identify the appropriate method for capturing responses from people with learning disabilities.
5. Test the most appropriate method for capturing responses from people with severe physical impairments.
6. Test the validity of the instrument for people with cognitive impairment and identify the appropriate method for capturing responses from people with cognitive impairment.
7. Further test the validity of the instrument for people in residential care homes and identify the most appropriate method for capturing responses from people in residential care homes.
8. Test whether an independent organisation can be used to collect the data. Note that councils would still have a role to play under this option as they would need to provide details of those eligible for the survey so the independent organisation can construct the sample before returning the data to the NHS IC.
9. Research how the PPF survey can be linked in better with the activities of CQC and the NHS patient surveys.
10. Research how the PPF survey can be linked in better with the day-to-day activities of CASSRs.
11. Pilot the use of stratified sampling with CASSRs.
12. Develop additional question modules that capture aspects important locally, such as aspects of process which are useful for service improvement activities.

#### **4.3.1 Questions: Future development activities**

We believe that this work is necessary to ensure the results of the PPF survey have validity across the range of service users included in the survey. The prioritisation of this work we believe should be driven by the relative budgetary importance of the groups and by any differences in response rates or responses between the groups. For example, if there was very poor response rates for the learning disabled population and for those that did respond the value of the PI appeared to be significantly different to other client groups, this would be an argument for studying the validity of the tool and the most appropriate method for capturing responses with people with learning disabilities.

***Do you have any views as to importance of these further activities?***

## 5 Questionnaire content

We proposed that the core questions should be of two types:

- Questions on individual outcomes, which capture the themes of PPF
- Questions that enable interpretation of individual outcomes, which need to draw on the available evidence.

### 5.1 Outcome questions

The themes of PPF are discussed in detail in Appendix 1, but are summarised here as:

- Quality of life
- Choice and control
- Inclusion and contribution
- Health and well-being
- Dignity and safety.

To identify questions to capture these themes we have identified three options that could be taken. These are:

1. Develop a new set of questions specific to outcome domains of PPF
2. Use existing scales or questions to capture each outcome domain of PPF (examples shown in Appendix 3)
3. Use the adult social care outcomes toolkit (ASCOT) (questions shown in Appendix 4)

There are various pros and cons associated with these options and these are summarised in table 2.



**Table 2: Pros and cons of options for questions**

Option	Points for...	Points against...
<p>1. Develop a new set of questions specific to outcome domains of PPF</p>	<ul style="list-style-type: none"> <li>• Clear relationship between PPF survey and policy objectives.</li> </ul>	<ul style="list-style-type: none"> <li>• There is conceptual overlap between the PPF domains. Indeed the quality of life domain could be said to encompass all of the other domains. In a recent review of the literature (Schalock, 2004), identifies the following domains as part of quality of life: interpersonal relations; social inclusion; personal development; physical wellbeing; self-determination; material wellbeing; emotional wellbeing; and rights. The overlap could be frustrating for respondents.</li> <li>• Although general themes tend to be consistent over time, the headline policy objectives change frequently. When policy changes, the questions may not be seen as relevant, requiring development of new questions at great expense.</li> <li>• New questions require a lot of development, which may mean not all the issues with questions will be resolved by the time of the pilot.</li> <li>• A study will need to be conducted to examine the validity and psychometric properties of a single scale (composite measure).</li> </ul>

Option	Points for...	Points against...
<p>2. Use existing scales or questions to capture each outcome domain of PPF (examples shown in Appendix 3)</p>	<ul style="list-style-type: none"> <li>• Clear relationship between PPF survey and policy objectives.</li> <li>• Questions have already been tested on the general population and have been used in a number of settings, so less testing would be required. We can focus development activities on populations that have specific needs e.g. people in residential care, people from ethnic minorities, people with learning disabilities etc.</li> <li>• Candidate scales for aspects such as quality of life and health have preference weights so they can be used in economic evaluation, broadening the use of the survey data.</li> <li>• Candidate scales have already been validated and have good psychometric properties.</li> </ul>	<ul style="list-style-type: none"> <li>• Because of the conceptual overlap between PPF domains there is likely to be significant overlap between the types of questions asked in the scales, which could be frustrating for respondents.</li> <li>• The measures were not developed to assess social care outcomes, so the sensitivity of the questions for the social care population is unknown.</li> </ul>
<p>3. Use adult social care outcomes toolkit (ASCOT) (questions shown in Appendix 4)</p>	<ul style="list-style-type: none"> <li>• ASCOT covers the PPF domains albeit with different emphasis.</li> <li>• The measure has been developed to be sensitive to the impact of social care on people's lives.</li> <li>• Questions have already been tested on social care clients so less development is required. We can focus development activities on specific populations on which the measure has not yet been tested thoroughly e.g. people in</li> </ul>	<ul style="list-style-type: none"> <li>• It is not obvious how ASCOT can provide evidence for achievement of PPF outcomes. However, in Appendix 5 we demonstrate how the ASCOT measure maps to the PPF domains.</li> <li>• ASCOT does not capture all of the domains. In particular it does not capture health outcomes. The ASCOT questions could be supplemented with health measures.</li> </ul>

Option	Points for...	Points against...
	<p>residential care, people from ethnic minorities, people with learning disabilities etc.</p> <ul style="list-style-type: none"> <li>• The measure has been used in a variety of studies which include older people, people with mental health problems, adults with physical and sensory impairments and people with learning disabilities and seems to work with these populations.</li> <li>• ASCOT has been used in self-completion format.</li> <li>• ASCOT is currently being validated and its psychometric properties are being investigated. Preliminary work, however, indicates that the scale is valid and has good psychometric properties.</li> <li>• ASCOT has preference weights so it can be used in economic evaluation, broadening the use of the survey data.</li> </ul>	

### 5.1.1 Questions: Core outcome questions

We propose option 3, using the ASCOT measure, because it has been developed specifically for the social care population and has been tested already on social care users. This would mean that the development work could focus on one of the groups that has specific needs or a different perspective that may influence their responses e.g. proxy respondents.

***Do you agree that the ASCOT measure should be used as the basis for the core questions?***

Where the measure is weakest is in its coverage of health outcomes. One option is to supplement the measure with a limited number of other questions or measures that capture aspects of health. Widely used health questions and scales are discussed in Appendix 3.

Of the options discussed in Appendix 3, we propose using either the self-perceived health question or EQ-5D (see Appendix 3 for details of the EQ-5D). Both options do not add much length to the questionnaire and are both widely used in self-completion format. The EQ-5D has particular value since it is used in economic assessments of health technology and drugs and is widely used in a variety of national surveys. It may also prove valuable to include it for any future collaboration with health.

However, there is some overlap with domains in the ASCOT measure, e.g. self-care and usual activities, and how this is presented in the questionnaire will need to be carefully considered if it is not to feel too repetitious. The overlapping questions could be excluded, although the EQ-5D could then not be used for economic evaluation and the results would not be comparable with data from other surveys diminishing its usefulness.

***Do you think that a health measure should be included alongside the ASCOT measure?***

***Of the options considered we have a preference for the EQ-5D because of the potential for long-term benefits in terms of linking with health. We ask for your comments on this proposal.***

### 5.2 Questions for interpreting outcomes

If we want to be able to understand how our actions are impacting on individual's outcomes it is important to try to measure as many of the influences on outcomes as possible. Research demonstrates that outcomes are influenced by a variety of factors, from the type and amount of service delivered to the specific characteristics of the individual and the environment within which they receive their care. Various studies have demonstrated that the contribution of needs-related factors to outcomes is greater than that of services (Davies and Knapp, 1981; Davies, 1985;

Fernández and Knapp, 2004). A useful framework, which builds on findings from empirical research as well as theory, for identifying the factors that influence outcomes is the Production of Welfare framework (Davies and Knapp, 1981). This framework is discussed in more detail in Appendix 6.

### 5.2.1 Questions: additional questions for interpreting outcomes

The most important variables for interpreting outcomes are those capturing need-related user characteristics, and describing the package of care i.e. the resource inputs and outputs. The structural, environmental and managerial factors are much harder to measure and although useful for thinking about improvement are not essential to understanding outcomes.

We propose to collect the following information about service users alongside the ASCOT measure:

#### *Information collected from the questionnaire<sup>1</sup>*

- level of disability e.g. activities of daily living, and instrumental activities of daily living
- receipt of informal care
- accessibility of the home
- accessibility of the local area

#### *Information collected from CASSR databases*

- general demographic information e.g. age, gender etc
- services received as part of the care package
- weekly cost of total care package (£s)

***Do you agree that these questions should be collected alongside the ASCOT measure?***

We have proposed that some of the data can be collected from CASSR database to minimise the length of the questionnaire for users. Previous experience has also shown that it is very difficult to obtain data from users about their receipt of services (Malley, Sandhu et al., 2006; Malley, Netten et al., 2007). However, we realise that this places a burden on CASSRs. In previous UESs demographic information, service receipt and information on the amount of care received has been collected, although we know that some CASSRs find this particular part of the collection difficult.

***Do you have any opinions about how the additional questions should be collected, i.e. through CASSR databases or as additional questions on the questionnaire?***

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<sup>1</sup> The Department of Health and the Nuffield Foundation have funded PSSRU colleagues at LSE, University of Kent, Natcen and UEA to develop a module of questions about social care services for use in surveys. This module will capture receipt of care and support services; payment for social care; receipt of informal care; and provision of informal care. Although the focus of this work is on older people we would expect to be able to draw upon this work to identify the form of questions around receipt of care and support services and informal care.

## 6 Have your say

We really want to hear your views. The questions are repeated below with space for you to enter any comments you may have. There is a space after all the questions for any more general comments you may have.

### 6.1 Questionnaire for seeking your views

#### 6.1.1 Data collection

We propose that the first PPF survey should be primarily a self-completion postal questionnaire. To ensure as many people as possible are able to respond, we propose allowing proxy respondents to answer on behalf of the service user. We propose that this is the only method used to capture responses from those who are unable to self-administer the questionnaire.

**1. We ask you to comment on the proposal to only use proxy respondents to encourage responses from those who are unable to self-administer the questionnaire.**

#### 6.1.2 Sampling frame

For practical reasons we have taken the view that self-funders should be excluded from the first PPF survey and that CASSRs will use their records as a sampling frame. We have taken the view that due to the distinctiveness of children's services, all children under 18 will be excluded from the first PPF survey. Because a carers' survey is currently being developed, carers will also be excluded from the first PPF survey.

We plan therefore to include everyone on the records of the CASSR receiving a publicly-funded social care service. This includes the following client groups:

1. Visually impaired people
2. Physically impaired people
3. Cognitively impaired people
4. Learning disabled
5. First language not English
6. People in residential care homes

The most difficult group to access using the proxy respondent method is likely to be those in care homes since there are practical difficulties associated with identifying suitable proxy respondents.

**2. *We have taken the view that care homes residents should be included in the first PPF survey. We ask for your comments on this proposal.***

### **6.1.3 Method for sampling**

We have taken the view that for the first survey it is best to stick with the simplest approach to sampling and the method that has been tried and tested in the past and shown to work, that is simple random sampling within CASSRs. Although this may limit comparisons between sub-groups within CASSRs and lead to overlap with existing programmes in CASSRs we feel that any more complicated method needs to be piloted thoroughly before being used for a national data collection.

**3. *We propose that for the first PPF survey each CASSR should select a sample by simple random sampling at one point in time from their case records. We ask for your comments on this proposal.***

### **6.1.4 Development activities for the first PPF survey**

Cognitive testing of questions prior to a pilot of the survey helps to make sure the questions make sense to people and produce valid responses. Assuming that the PPF survey will draw upon already developed questions, because of the very large proportion of respondents that have required help in the past to complete the questionnaire, we suggest that the cognitive testing of questions is conducted with proxy respondents.

**4. *Do you have any views as to the focus of the cognitive testing?***

### **6.1.5 Future development activities**

We suggest that the following are development activities for future PPF surveys:

1. Develop a valid version of the instrument in foreign languages
2. Further test the validity of the instrument for proxy respondents
3. Test the effect of alternative methods of data collection on responses
4. Test the validity of the instrument for people with learning disabilities and identify the appropriate method for capturing responses from people with learning disabilities.
5. Test the most appropriate method for capturing responses from people with severe physical impairments.
6. Test the validity of the instrument for people with cognitive impairment and identify the appropriate method for capturing responses from people with cognitive impairment.
7. Further test the validity of the instrument for people in residential care homes and identify the most appropriate method for capturing responses from people in residential care homes.
8. Test whether an independent organisation can be used to collect the data. Note that councils would still have a role to play under this option as they would need to provide details of those eligible for the survey so the independent organisation can construct the sample before returning the data to the NHS IC.
9. Research how the PPF survey can be linked in better with the activities of CQC and the NHS patient surveys.
10. Research how the PPF survey can be linked in better with the day-to-day activities of CASSRs.
11. Pilot the use of stratified sampling with CASSRs.
12. Develop additional question modules that capture aspects important locally, such as aspects of process which are useful for service improvement activities.

We believe that the prioritisation of this work should be driven by the relative budgetary importance of the groups and by any differences in response rates or responses between the groups.

**5. Do you have any views as to importance of the further activities that are suggested?**

### 6.1.6 Questionnaire content: Core questions on outcomes

We identified three options that could be taken for developing outcome questions. These are:

1. Develop a new set of questions specific to outcome domains of PPF
2. Use existing scales or questions to capture each outcome domain of PPF (examples shown in Appendix 3)



3. Use the adult social care outcomes toolkit (ASCOT) (see Appendix 4 for overview of the measure)

We propose that the option 3, the ASCOT measure is used to collect information on outcomes.

**6. We ask you to comment on the proposal to use the ASCOT questions as the basis for the core questions.**

We propose that additional questions on health could be collected alongside the ASCOT measure and have suggested either a question on self-perceived health or the EQ-5D.

**7. Do you think additional questions on aspects of health should be included alongside ASCOT?**

Of the options considered we have a preference for the EQ-5D because of the potential for long-term benefits in terms of linking with health.

**8. Do you have any comments on the proposal to include the EQ-5D alongside ASCOT?**

**9. Do you have any more general comments on the core questions?**

### 6.1.7 Questionnaire content: additional questions for interpreting outcomes

We propose that the following information should be collected alongside the ASCOT measure:

*Information collected from the questionnaire*

- level of disability e.g. activities of daily living, and instrumental activities of daily living
- receipt of informal care
- accessibility of the home
- accessibility of the local area

*Information collected from CASSR databases*

- general demographic information e.g. age, gender etc
- services received as part of the care package
- weekly cost of total care package (£s)

**10. Do you agree that the questions specified above should be collected alongside the ASCOT measure?**

**11. Do you have any opinions about how these data should be collected, i.e. through CASSR databases or as additional questions on the questionnaire?**

**12. Do you have any other comments to make about the additional questions?**

### 6.1.8 General comments

**13. Do you have any more general comments?**

## 6.2 How to respond

You can respond in one of two ways:

By email to: XXXXXXXXXXXX

By post to: XXXXXXXXXXXX

Please send any queries you may have to: XXXXXXXXXXXX

The deadline for responses is 3<sup>rd</sup> July 2009

A summary of the responses received will be published on the Information Centre website as soon as possible following the deadline for submitting your views. The responses will be used to finalise decisions about the direction and content of the first PPF survey and later PPF surveys.

## Appendix 1: PPF and the role of the user experience survey

PPF is an ambitious programme of reform for adult social care. It sets out the outcomes users want from services and services are in turn encouraged to deliver; it also sets a direction for policy.

### Outcome themes from PPF

The outcome themes identified in PPF draw upon those espoused in previous documents, in particular *Our Health, Our Care, Our Say* (Department of Health, 2006). The themes identified in *Our Health, Our Care, Our Say* were developed through dialogue with service users and the public. They therefore reflect the types of outcomes that people want from social care services. The outcomes have been summarised as follows (Medcalf, 2008):

1. *Quality of life*, encompassing ideas of access to leisure, social activities and life-long learning and to universal, public and commercial services. Security at home, access to transport and confidence in safety outside the home.
2. *Choice and control*: through maximum independence and access to information. Being able to choose and control services. Managing risk in personal life.
3. *Inclusion and contribution*: includes making a positive contribution through active participation in the community through employment or voluntary opportunities. Maintaining involvement in local activities and being involved in policy development and decision making. It also includes the concept of economic well-being, meaning access to income and resources sufficient for a good diet, accommodation and participation in family and community life. Ability to meet costs arising from specific individual needs.
4. *Health and well-being* includes enjoying good physical and mental health (including protection from abuse and exploitation). Access to appropriate treatment and support in managing long-term conditions independently. Opportunities for physical activity.
5. *Dignity and safety*, includes personal dignity meaning keeping clean and comfortable. Enjoying a clean and orderly environment. Availability of appropriate personal care. It also includes freedom from discrimination and harassment defined as equality of access to services. Not being subject to abuse.

These outcome themes are broader than those considered in the King's Fund Social Care Review to be the core business of social care. Core business in this report was understood as the provision of personal care and ensuring safety (Wanless, 2006). The greater breadth of outcomes expressed in PPF is a reflection of aspirations to improve universal services, such as leisure, housing and health, for people with social care needs, improve early intervention and prevention, and build social capital.

## Key areas for the direction of policy

- Personalisation: This continues to be a central policy theme and to direct the transformational agenda. It requires councils and their partners to consider the provision of services from the perspective of the individual and to promote services tailored to individual needs that deliver the outcomes users (and their carers) want.
- Improving early intervention and prevention: This means providing services to people who have in the recent past perhaps not been eligible for services because their needs have not been seen to be critical enough to warrant intervention. The types of help envisaged are support to recover from the effects of illness, or manage a long-term condition, help to safely maintain the home or a garden, training to return to work after a break, or support to start exercising.
- Improving universal services for people with social care needs: The aim is to ensure that social care users are able to access universal services such as transport, leisure services and health care as easily as non-social care users.
- Efficiency and providing value for money continue to be important policy themes. There are efficiency targets for social care within the new single set of national indicators (Communities and Local Government, 2007). A key issue here is ensuring that savings are real efficiency savings that is that they provide better outcomes at a lower cost (or at the same cost).
- Equality is also an important theme and applies not just across client groups and age groups, but also across the spectrum of social care users. An important issue is whether there is equality in outcomes and provision between those who are self-funded, partly LA-funded, and wholly LA-funded.

The role of the survey programme has historically been closely linked to performance assessment and improvement (Department of Health, 1998; Department of Health, 2006). However, within this framework it can fulfil a number of functions. First the survey can give users and carers a voice. Second, it can be used alongside other information to support service delivery and improvement from the user's perspective. Third, the data can be used like other performance information to account for progress against national and local priorities (Medcalf, 2008). This third role provides one of the key motivations for the new survey since it is required to populate two of the new indicators from the national indicator set, NI127 (self-reported experience of social care users) and NI128 (user-reported measure of dignity and respect in treatment). The focus of the transformational agenda on achieving personalised services and importantly the outcomes that users want implies a greater reliance on experiential data to measure performance. Thus it seems likely that future performance indicators will draw on and rely to a greater extent on survey data.

## Appendix 2: The research problems for survey development

- 1. There are barriers to responding to postal questionnaires for certain groups of users so alternative questionnaires and modes of participation are required to ensure people are not excluded. These alternative forms and modes require assessment to ensure they produce equivalent responses. It is also not clear which strategy is most appropriate for which group.**

Previous user experience surveys have all used postal questionnaires as the main mode for collecting data. This is because it is much cheaper than either telephone or face-to-face interviews and captures a more representative group of people than web-based questionnaires. Dillman (Dillman, 1978) estimates that face-to-face interviews cost about five times more than telephone interviews and about 20 times more than a postal survey. For these reasons there is a preference for the PPF survey to be a postal questionnaire.

There are, however, some limitations of this mode of surveying. In particular, postal questionnaires may exclude the types of people who are likely to be over-represented in the social care service user population. People who cannot read or understand the questions either because they are visually impaired, suffer from intellectual problems or dementia will not be able to answer the questionnaire without help. In addition, those who are severely physically disabled and are unable to write may not be able to respond to the questionnaires without help. Postal questionnaires also exclude those who are not literate in English. There are several solutions to this problem including providing alternative versions of the questionnaire, allowing for multiple modes of data collection and allowing someone close to the service user to answer in their place, a proxy respondent. Indeed research has demonstrated that using multiple modes can improve response rates and coverage in general population surveys (de Leeuw, 2005).

Previous UESs have used multiple modes to collect data. Councils have provided those who request them with alternative versions in foreign languages, Easy Read, Braille and audiotape. There is also evidence of councils using face-to-face interviews or telephone interviews to collect data from hard to reach individuals. Whilst this approach to data collection ensures that as many people as possible are reached it does suffer from some problems. In particular it assumes that each version of the questionnaire or mode for collecting data produces equivalent data, an assumption that has not been tested in the previous UESs.

Alternative versions of the questionnaire may not replicate the conceptual (rather than literal) meaning of the original English language questions. In previous UESs, foreign language and Easy Read questionnaires have tended to be developed in an ad hoc manner. This could introduce systematic error into the survey and bias results. It presents a particular problem for interpreting any differences found between ethnic groups or those with and without learning disabilities since differences could be due to differences in the meaning of translated versions of questionnaires or differences in services. Methods of forward and back-translation

along with cognitive testing of the translated version of the questionnaire are recommended to ensure the instrument is conceptually equivalent to the English language version (World Health Organisation, 2009).

There is evidence from the research literature that alternative modes of data collection can have an effect on responses (Schwarz, Strack et al. 1991; Dillman and Christian, 2005). These result from the different circumstances under which the data is collected, although can be minimised with careful preparation of scripts and interviewers (Dillman and Christian, 2005). Previous analysis of the UES has found differences in responses by mode of administration, with those who respond by self-completion tending to be more satisfied (Netten, Francis et al., 2004). However, because authorities tend to use alternative modes where self-completion fails, those answering using different modes are a self-selecting group and may differ from those who self-complete in significant ways. To understand whether there are real differences by mode of administration we would need to control for these differences ideally using a randomised-control trial (RCT) or we could attempt to mimic this using existing data using the matching method of Rosenbaum and Rubin (Rosenbaum and Rubin, 1983).

Proxy respondents for people with disabilities are also known to have an effect on responses, with evidence suggesting that proxies report disability differently to the disabled person (Todorov and Kirchner, 2000). A very large proportion of responses, roughly 60 per cent to the older people's UES, have been completed by proxies and studies have found significant differences in perceptions of quality and satisfaction (Netten, Francis et al., 2004). As we discussed for survey mode, however, because those people who have proxies completing the questionnaire for them are a self-selecting group, it is difficult to assess whether these differences are a result of differences in how proxies respond to questions compared to those who complete the questionnaire without help or a result of differences in the characteristics of the two groups. To understand differences between proxies and non-proxies, the matching methods above could be used, although this may not provide conclusive evidence. Alternative approaches would be to employ a randomised-controlled trial method or to have each questionnaire completed by the respondent and the proxy, so responses can be compared.

It is clear that these problems will be more prevalent for certain user groups and service types. In particular, given the high prevalence of dementia in care homes and levels of severe physical disability there is unlikely to be many respondents who are able to complete the questionnaire without some form of help. A variety of options could be used for care home residents, including observation, face-to-face interviews for those without dementia but who are unable to fill in the questionnaire, or proxies. It is not clear which of these methods is most appropriate and many variants exist, for example using care staff as proxies, relatives as proxies or other non-cognitively impaired residents as proxies (Kane, 2003). The 'best' method will clearly need to make trade-offs between accuracy, cost and the practicalities of research, but this should be answered empirically.

Users with learning disabilities are also more likely to be unable to answer the postal questionnaire. Again there are several options that could be used to allow these users to participate, including an Easy Read version and a proxy. Which method is best will depend on how straightforward it is to develop an Easy Read version that provides equivalent responses and the extent of bias in responses from proxies. Again this is an empirical question.

Users with severe physical disabilities will also be unlikely to be able to complete the questionnaire unaided. Proxy respondents or interviews would seem to be appropriate alternatives. Again there is a trade-off between cost and accuracy which should be investigated empirically. There are also hidden costs to using interviews since it is important to use experienced interviewers to avoid seriously biasing the results.

**2. Services have different aims so have an impact on different areas of outcome. The types of questions that are most relevant to measure outcomes may vary by service. It will be important to consider the aims of services when choosing questions on outcomes.**

A significant problem that needs addressing when developing a questionnaire for such a diverse population is finding questions that make sense to everyone in that population and are sensitive to differences in the quality of care provided. Previous UESs have tended to ask questions that focus on aspects of the process of care. Clearly, processes are highly dependent on the form of care delivered. For example, the domiciliary care service involves a carer coming to the home of the service user and carrying out various activities of daily living on their behalf or with them. By contrast users of day centres have to travel to the centre where they may participate in various activities, socialise and so on. Questions that interrogate aspects of process such as promptness of arrival of care workers will only be relevant to those services where a care worker comes to the home of the service user. Indeed evidence from the recent PSSRU study of adults aged 18 to 64 shows that such types of questions are of limited use for those not receiving domiciliary care or direct payments (author's own analysis).

The focus of PPF and *Our Health, Our Care, Our Say* is however on outcomes of social care rather than processes. The domains of outcome – quality of life, choice and control, inclusion and contribution, health and well-being, and dignity and safety – are broad enough to be equally relevant to all social care services. However, it is clear that certain types of services will have more of an impact, and are designed to have more of an impact, on the different domains. For example day centres are designed to provide activities, learning opportunities and social interaction, whereas domiciliary care is designed to support people to undertake activities of daily living such as washing, dressing and so on. Carer support services are usually designed to give carers a break from their caring role and might be expected to have effects across all domains. It is therefore expected that different services will make different contributions to the domains of outcome<sup>2</sup>.

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<sup>2</sup> This leads to some complexities in interpreting outcomes which are discussed under point 5.



This has important consequences for how we may go about trying to operationalise these domains into questions. If questions are to be useful to help assess the performance of social care interventions they need to capture what social care interventions are actually achieving. If interventions aim to achieve very different types of outcomes then the kind of broad brush questions that may work for all types of interventions may end up being insensitive to changes in outcomes specific to that service.

For example, the aim of many social care interventions is not to restore people to perfect health, but rather to compensate for their disability. It is important to bear in mind that the core business of social care (certainly as it is currently provided and given the current user population) is to provide help with activities of daily living and enable people who, for example, are not able to dress or wash themselves to look presentable and feel clean. Questions that assessed outcomes linked to such activities would provide a much more sensitive assessment of the impact of social care than a series of questions that focussed on assessing the physical health of social care users, since most social care interventions have a limited effect on physical health.

However, questions on outcomes linked to support with activities of daily living would be of limited usefulness in assessing the impact of social care interventions designed to support carers in their caring activities, so called carer-break type interventions. These are not there to compensate carers for their lack of ability but to prevent exhaustion and possible ill health. Although a carer suffering from exhaustion may well think that she doesn't look as presentable or feel as clean as she may wish to a better indication of the impact of carer-break interventions might be an assessment of whether the carer feels he is neglecting himself or the carer's physical and mental health.

The critical problem is to identify questions that are relevant to all social care users and carers no matter what service they are receiving; yet are also specific enough to the objectives of the service that they are sensitive to any positive (or negative) effects the service may produce. This issue is discussed in some detail under point 5.

**3. The patient experience surveys conducted in the NHS currently focus on users' experiences of processes and the questions are not compatible with the current UES questions. Since both surveys currently do not ask users about PPF outcomes there may be an opportunity to develop questions that are relevant to both surveys.**

The Picker Institute have developed a number of surveys to capture the experiences of users of the NHS. The focus of the surveys is on specific aspects of care and treatment which patients themselves identify as being important to them. Because of this focus on the quality of processes associated with care delivery, there are therefore different surveys for inpatient services, outpatient services, emergency and local health services. The range of surveys can be viewed at <http://www.nhssurveys.org/>.

The style of survey is in many ways similar to the style of the social care UESs; the questionnaires both focus on the quality of aspects of the process of care delivery that users identify as important to them; and there are different surveys for different types of services. An important difference is in the response categories for questions. The Picker surveys use what they term a 'problem score' (Jenkinson, Coulter et al., 2002), whereas the UESs use a sliding scale. Thus the Picker survey may ask users "Were you involved as much as you wanted to be in decisions about your care and treatment?" and the options for response are "yes, definitely", "yes, to some extent", and "no". In the UES a similar question is asked "Do you feel that your opinions and preferences are taken into account when decisions are taken about what services are provided to you?" and the options for response are "always", "usually", "sometimes", and "never". Bringing together data from the questionnaires as they stand, even for similar questions, would therefore be difficult because of the differences in the way response options are presented.

The Picker Institute has also developed a multi-item measure from the questions, which is similar to the type of composite, multi-item measure developed by PSSRU (Jones, Netten et al., 2007; Malley and Netten, 2008). The Picker inpatient measure is called the PPE-15 and is formed from 15 questions which focus on the quality of aspects in the process of care delivery (Jenkinson, Coulter et al., 2002). Although there is similarity in the method used to develop these multi-item measures, the content of the measures is very different and it would not be wise to compare the scores from these measures directly.

With the current form of the NHS surveys, it is difficult to see how the results could be meaningfully compared across health and social care without some changes to either of the surveys to make the response options to items compatible. Given the focus of the NHS surveys on care delivery processes it seems that there would also be limited opportunity for comparison, as the way, for example, inpatient care is delivered is very different to the way, for example, home care is delivered. There may be more similarities with care homes. However, many of the Picker questions focus specifically on the behaviour of certain staff groups, doctors, nurses and so on and many of these groups would not be found regularly delivering care in care homes. Given both surveys currently do not include outcome questions there is the possibility to develop items that could be used in NHS and social care surveys and are relevant to both. Outcome measures, such as the EQ-5D of SF-36 that are currently used widely by health services to assess health outcomes may be good measures to include in the PPF survey.

**4. It is very difficult to find a comprehensive record base to use as a sampling frame for the PPF survey. Until a comprehensive record base is found some types of social care users cannot be included.**

It is very difficult to find a data source that identifies all users of social care services and their carers. Councils only collect information about social care users who are receiving care paid for, at least in part, by the council. Moreover councils only record those services received as agreed in a care plan. This means that certain types of users and the use of certain types of services are under-recorded.

The key service that is likely to be under-recorded is the use of day centres since these are often used as drop-in centres and are not specifically part of an individual's care plan. Many are funded through grants from the local council rather than contracts for placements and are often in the voluntary sector. It might be possible to use the records of these providers to supplement those from the council, but to ensure there are no duplicates it is important that the council and provider have high quality records of their users. It is unlikely that the day centres, particularly where they operate on a drop-in basis, will have high quality records on their service users. It also seems likely that there would need to be some form of data-sharing between the provider and council to ensure the survey runs smoothly (e.g. who would send out and collate the questionnaires?) and such agreements would need to be set up ahead of time.

The other service users who would be missing from council records are those who purchase their care or equipment and adaptations using private monies. Such people are estimated to form a substantial proportion of those receiving care (about 25%) – a figure which is projected to increase if the current criteria operated by councils continue to be used (Malley, Comas-Herrera et al., 2006; Forder, 2007). It may be possible to use provider records to supplement council records to identify some of these users, particularly those purchasing care from care homes for which we would expect records to be very good. However, community-based care providers are unlikely to be a good source of information since very little care is purchased directly from providers; users tend to purchase from the 'grey market' (Forder 2007). Again there would also need to be some form of data-sharing between the provider and council to ensure the survey runs smoothly and to avoid duplication of entries.

To identify those who purchase care from the 'grey market' seems a very difficult task at this stage. Although some of these people may have been turned down as ineligible on financial grounds for care paid for by the council and may be recorded at some point by the council, many will bypass the council altogether. Because the numbers receiving care are a very small percentage of the resident population a general population survey would be infeasible. It is possible that General Practitioners (GPs) may record this information but it is not clear whether they do this as a matter of course and as a result whether their records are of high quality.

Evidence from a recent survey of carers indicates that CASSR records for carers are lower quality than those for service users. Coverage of carers is also poorer since many carers are not in contact with social services. Council records are likely to over-represent carers of older people and carers of people who live in the same household as the person they care for as these groups are more likely to be known to social services. Provider records are also of low quality and cannot be used as a sampling frame.

At this stage the only feasible sampling frame is council records. Supplementation of these records with provider records may be possible in the future but there needs to be significant improvements in data quality and agreements for data-sharing need to

be implemented before this is feasible. People who pay for community-based care privately and many carers are likely to be excluded from council and provider records. However, there is no feasible option at this stage that would enable us to include them. In the future it may be possible to exploit the data records of GPs, but they would need to be encouraged to collect this information and data-sharing agreements would need to be implemented to carry out the survey.

**5. Studies have shown that services can usually only hope to have a very small impact on user outcomes. Characteristics of individuals are much more important. Therefore questions designed to interrogate outcomes require detailed analysis before they can be interpreted as PIs and information on individual characteristics needs to be collected alongside outcomes information.**

Although it is generally accepted that outcomes are what matter when it comes to assessing the quality and performance of services, the task of measuring outcomes is more complex than simply assessing whether, for example, a person thinks they are well-fed or feel safe and secure. This is because individual characteristics of the service user, for example their degree of impairment, ability to access care from friends, family and neighbours and so on, have a much greater impact on outcomes than do services (Davies and Knapp, 1981; Davies, Fernández et al., 2000; Fernández and Knapp, 2004). Because of this, simply comparing outcome states across CASSRs in order to gauge performance is likely to be unfair because CASSRs have very different populations and apply different eligibility criteria. When interpreting outcomes it is therefore crucially important to take into account such individual differences so the effect of services – service performance – is accurately attributed.

Ideally when measuring outcomes we want to monitor changes in the ‘value added’ by social service interventions. This is challenging for a number of reasons including:

- The variety of other factors that will influence outcome states, not least receipt of informal care
- Difficulty and expense of reliable measures of before and after allowing for these other factors
- ‘Before and after’ reflecting only marginal change in long term care, underestimating the full value of services provided, including the impact of changes in underlying conditions.

An indirect approach to monitoring outcome is being developed as part of a Treasury funded project led by ONS: the Quality Measurement Framework. This project is looking across a variety of areas where the Third Sector plays a major role in providing publicly funded services. In the field of social care we are developing an indirect approach to measuring and monitoring social care interventions.

In this approach the Capacity for Benefit (CfB) of an intervention is identified through the domains of outcome it addresses and the degree to which people using the services are reliant on that service. This is identified through interviews or observational techniques. While this is resource intensive, CfB is highly associated with measures such as abilities in activities in daily living (ADLs), level of service

receipt and use of informal care. Once this relationship is established CfB of any given intervention can be monitored through changes using these more easily measured items. These measures put along current outcome states (which can be represented as the 'quality' – the degree to which the outcomes are achieved) to provide us with a measure of the outcome of the interventions.

Current work is investigating the potential of this approach for monitoring the value of low-level interventions, such as day care, and care homes, using regulatory data. While further work would be required to identify the best markers to reflect CfB for the variety of interventions and user groups covered by the PPF UES, this approach potentially could allow for a better understanding of the changes in the value and, once put together with cost information, the productivity of social care interventions. From a health service perspective this would be a validated way of allowing for 'case-mix' on reported outcomes.

**6. All words have some degree of indeterminacy, which means questions used in surveys may be interpreted differently by respondents. If a particular interpretation is more commonly attributed to a word by a group of people then this could bias comparisons between groups of users. Careful development and analysis of questions needs to be conducted to minimise problems arising from such problems.**

A problem with using survey questions to derive PIs is that questions and their responses tend to be open to interpretation because the words that are used to compose them have a degree of indeterminacy. For example key words in the question, such as 'satisfaction' have multiple meanings and response scales are full of vague quantifiers such as 'very', 'quite' and 'rarely' which can mean different things to different people and are highly sensitive to context. For example, imagine the situation in which someone whose care worker is regularly five minutes late is asked to assess whether her care worker arrives on time, using the options "always", "usually", "sometimes", "never". A person who likes their care worker and perceives the care worker's lateness is the fault of the provider may rate them more kindly than a person who dislikes their care worker. It is likely that this problem will persist for questions designed to capture outcomes. Cognitive testing of questions can be used to minimise the indeterminacy, by reducing the number of vague words. However, questions need to be interpreted carefully as a residual amount of indeterminacy will remain.

The problem of indeterminacy only really arises when comparing groups. If a particular interpretation is more commonly attributed to a word by a group of people then there are likely to be differences between groups that are due to differences in interpretation and not due to real differences in the reality of care or outcomes. A common finding in satisfaction research is that older people tend to report higher satisfaction than younger people e.g.(Donovan, Brown et al., 2001; Calnan, Almond et al., 2003). Differences between ages in interpretation matter not just for comparisons between age-groups where distortion is obvious but to comparisons between councils or providers where the composition or 'case-mix' of clients may vary. It would seem unfair to reward a council that appears to perform

well as a result of having a high number of older people compared to a council that appears to perform poorly because of a high number of younger people and we would want to adjust for the age-mix before conducting comparisons. However, before adjusting it is important to be clear whether the differences between age-groups are due to 'error' or are 'true' differences and this requires careful investigation.

**7. There are many different stakeholders who have different need and uses for the survey data. It seems unlikely that one set of outcomes questions will meet all these needs and be as effective for each usage. Specific modules and question banks could be developed. Some thought should be given to streamlining different surveys that cut across the PPF survey.**

Arguably the most important objective is that the survey (and any PIs derived from it) should help to promote the overall direction of policy. Whilst this may seem relatively straightforward, because of the variety of stakeholders, the survey data could be put to many different uses all of which may promote the overall direction of policy. For example, the DH may be interested in using the data to monitor the performance of councils and demonstrate the impact of their policies to the public. Councils may be interested in using the data to monitor the performance of providers or to identify areas that they may wish to target to improve the outcomes of their population. For providers of services, the data is useful only in so far as it can direct their service improvement activities. In addition because of the different circumstances that providers and councils find themselves in priorities may not be aligned throughout the system.

It is unlikely that the core set of questions for the PPF survey will be able to address all the local objectives. However, since differences in local and national policy objectives are accommodated in the new performance regime based around local area agreements (LAAs) it is important that the PPF survey also accommodates local differences. In previous UESs, councils have been allowed to include their own questions to help them assess their local objectives. Clearly this could be continued for the PPF survey. However, if the locally developed questions are to be used as local PIs for LAAs, councils need to be aware that the problems discussed here are likely to apply to these questions as well and they would be advised to bear these in mind when interpreting their results. One solution may be to develop a question bank containing questions that meet local objectives with details about how these questions can be used as, or with, other PIs.

It also seems likely that questions on outcomes will be more useful for monitoring performance than thinking about how to implement steps to improve it. For a service provider to simply know how good they are at promoting outcomes compared to the next provider is useful in the sense that it lets them know how good their services are but it is not terribly useful for helping them to think about how they might improve their services. Providers need to know what their clients want from services and how the process of care delivery can be improved to achieve the goals their clients set for them. It is exactly this reasoning that is behind the choice of the Picker Institute to focus on processes in the NHS patient surveys (Swain,

2003). It would seem particularly important to continue to collect this information in any collaboration with providers but councils may also find this information useful particularly if it is linked to information about for example waiting times for equipment or promptness of care workers. One possibility would be to develop modules that focus on the process of care delivery for each type of service which could be included in a mix-and-match fashion in questionnaires.

Many LAs have developed their own survey programmes along a number of different lines. As well as developing their own questions, some LAs have also chosen to develop a system for collection that is intimately linked with their own systems for performance management. These programmes have been developed to meet the needs of the locality and should be held up examples of best practice.

However, because they use very different methods for data collection, the data collected will not be comparable across LAs. For example, some LAs collect information about users' experiences at review while others maintain survey programmes that collect information at a single point in the year, and others collect information at several points in the year. We have emphasised the importance of having a single set of questions for comparability, but it is also the case that a single system for data collection is needed for comparability. There are clearly a variety of incentives and disincentives associated with the collection of data at review because of the established relationship between social worker and service user. For example, users may think they should report that their circumstances are worse than they really are in order to ensure they receive adequate services, or they may feel unable to tell the social worker how they really feel in case they are seen as ungrateful. With so many complicated mechanisms underpinning responses it is clear that detailed work would need to be undertaken to establish the validity of responses obtained from a questionnaire administered at review and ensure the responses are equivalent to those obtained from a standard survey.

In the past social care surveys have been conducted by a variety of organisations, including CSCI, LAs, the DH/IC UES and surveys for specific research questions. Researchers have argued that the proliferation of surveys has led to survey fatigue and poor response rates. To ensure response rates remain relatively high and for the sake of service users, it is important to consider whether the various surveys in this area could be developed such that only one collection of data is required to fulfil each organisation's needs.

**8. There may be a lack of research and analytical skills required for interpreting the data within councils and providers. This may thwart their attempts to implement initiatives to improve services.**

A recurring theme in this discussion has been the need for detailed statistical analysis to interpret questions that examine outcomes of care. Particularly at the level of service providers but also within a number of councils these skills may be lacking. To ensure that the full and best use of the PPF survey is made we will need to find ways of helping providers and councils to make good use of the data.

## Appendix 3: Example questions to capture PPF domains

This appendix provides a brief overview of the types of questions that could be used to capture the domains of outcome found in PPF. The list is by no means exhaustive and is not intended to be so. It presents the scales that the authors judge to be the most widely used and most relevant for capturing the PPF domains.

### 6.3 Quality of life

There is a large (and expanding) number of quality of life scales, although few focus on people of all ages, or can be self-administered and many are quite long.

The *WHOQOL* is a 100 item questionnaire, although a shorter 26-item questionnaire the *WHOQOL-BREF* is available and can be self-administered. The *WHOQOL* consists of 24 domains covering physical health (energy and fatigue; pain and discomfort; sleep and rest); psychological (bodily image and appearance; negative feelings; positive feelings; self-esteem; thinking, learning, memory and concentration); level of independence (mobility; activities of daily living; dependence on medicinal substances and medical aids; work capacity); social relations (personal relationships; social support; sexual activity); environment (financial resources; freedom, physical safety and security; health and social care: accessibility and quality; home environment; opportunities for acquiring new information and skills; participation in and opportunities for recreation/leisure; physical environment (pollution/ noise/ traffic/ climate); transport); spirituality/ religion/ personal beliefs (*WHOQOL* group 1998; *WHOQOL* group 1998).

The *ICECAP* is a new measure of quality of life measure for older people with 5 items, capturing 5 domains of quality of life. The domains covered are love and friendship, thinking about the future, doing things that make you feel valued, enjoyment and pleasure, and independence. The measure has preference weights so can be used in economic evaluations and can be self-administered (Grewal, Lewis et al. 2006; Coast, Flynn et al. 2008).

The *CASP-19* is another relatively new quality of life measure that focuses on older people. It has 19 items that cover 4 domains of quality of life. These are: control, autonomy, self-realisation and pleasure. The measure can be self-administered (Higgs, Hyde et al. 2003; Hyde, Wiggins et al. 2003).

### 6.4 Choice and control

There are numerous scales that capture perceived control, in terms of perceived autonomy, self-efficacy and perceived control, but these scales tend to be related to specific situations, such a gaining control over financial situations, control over arthritis and so on. A detailed search of the broad literature in this area may unearth measures that would be applicable to the social care population, but there was not time to do this. Several of the quality of life scales and Ryff's well-being scale do, however, have questions that capture control and autonomy.



## 6.5 Inclusion and contribution

There is currently no scale that captures comprehensively the main components inclusion and contribution, but there are a variety of scales capturing aspects of social networks and support (Bowling, 2005).

A module of questions capturing aspects of *social capital* was developed for the 2000 General Household Survey (Coulthard, Walker et al., 2001). The questions cover length of residence in the area, enjoyment of the area, ratings of local services and facilities, safety, perception of power to influence neighbourhood decisions and civic engagement, crime and experience of crime, ratings of anti-social behaviour, litter, dog mess, noise, teenagers hanging around, drug problems, feelings about their immediate neighbourhood of residence, including neighbourliness, trust in neighbours, and social contacts.

RAND has developed a *social support* scale, which consists of 19 items and can be self-administered. It captures subjective impressions of social support in the context of health and covers tangible support, involving the provision of material aid or behavioural assistance; affectionate support, involving expressions of love and affection; positive social interaction, involving the availability of other persons to do pleasurable things with; and emotional/ informational support, involving the expression of positive affect, empathetic understanding, and the offering of advice, guidance or feedback (Sherbourne and Stewart, 1991).

De Jong Gierveld and colleagues have developed a scale for *loneliness*, which consists of 11 items and captures both emotional and social loneliness. The instrument can be self-completed and seems to be widely used across the world (de Jong-Gierveld and Kamphuls, 1985).

Another widely-used *loneliness* scale is the UCLA scale, which consists of 20 items and can be self-administered (Russell, 1996). A shorter 3-item loneliness scale was developed recently based on the UCLA scale (Hughes, Waite et al., 2004).

## 6.6 Health and well-being

There are a number of questions and scales that measure health and well-being, or health-related quality of life (HRQOL).

A popular single-item question is *self-perceived health*, which asks the respondent to rate their health as 'Very good, Good, Fair, Bad, Very Bad'. This measure has been used in a number of surveys, including the General Household Survey, Health Survey for England and the European Social Survey. It has also been asked in previous PSSRU UES extension studies.

The *SF-36* is a general health measure that can be self-administered. It has 36 items and takes 5-10 minutes to complete, although shorter 12 and 8 item versions of the instrument have been developed. It is the most commonly used instrument to capture health worldwide (Bowling, 2005). The measure captures eight domains of HRQOL including physical functioning, social functioning, role limitations due to

physical problems, role limitations due to emotional problems, mental health, energy/vitality, pain, and a general health perception (Ware, Snow et al., 1997; Jenkinson, Stewart-Brown et al., 1999). The measure has preference weights so can be used in economic evaluations (Brazier, Roberts et al., 2002).

The *EQ-5D* (or *Euroqol*, as it was previously known) is a five item measure that covers five domains of HRQOL and can be self-administered. These domains cover mobility, self-care, usual activities, pain/discomfort, and anxiety/depression (EuroQol group, 1990; Brooks, 1996). The measure has preference weights so can be used in economic evaluations (Dolan, Gudex et al., 1996; Dolan, 1997). This measure is used widely in the UK, in particular by NICE for health technology assessments.

Ryff's scale of psychological well-being has six domains: autonomy, positive relations with others, purpose in life, self-acceptance, environmental mastery and personal growth. The original scale consisted of 20 items per domain, but a newer version has been reduced to three items per domain (Ryff, 1989; Clarke, Marshall et al., 2001).

## 6.7 Dignity and safety

The dignity and safety captures a complex set of ideas. There are likely to be a number of measures and scales that capture different aspects of dignity and safety. A series of studies funded by Help the Aged have examined the meaning of dignity and how it could be measured, but they focus on older people (Levenson, 2007; Magee, Parsons et al., 2008). The report by the Picker Institute proposes a set of around 60 indicators, covering nine domains, although not all indicators have questions. The domains include: autonomy, communication, eating and nutrition, end-of-life, pain, personal hygiene, practical assistance/personal care, privacy, and social inclusion (Magee, Parsons et al. 2008).

## Appendix 4: The ASCOT measure

These questions are currently undergoing cognitive testing so some of these questions may change slightly.

### 1. Could you tell me which of the following statements best describes how much control you have over your daily life?

**Please tick (✓) one box**

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

I have adequate control over my daily life

I have some control over my daily life but not enough

I have no control over my daily life

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

**Please tick (✓) one box**

I feel clean and am able to present myself the way I like

I feel adequately clean and presentable

I feel less than adequately clean or presentable

I have poor personal hygiene, so I don't feel at all clean or presentable

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

**Please tick (✓) one box**

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

I get food and drink adequate for my needs

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

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

**4. Could you tell me which of the following statements best describes how clean and comfortable your home is?**

**Please tick (✓) one box**

My home is as clean and comfortable as I want

My home is adequately clean and comfortable

My home is less than adequately clean or comfortable

My home is not at all clean or comfortable

**5. Could you tell me which of the following statements best describes how safe you feel?**

**Please tick (✓) one box**

Generally I feel as safe as I want

Generally I feel adequately safe

I feel less than adequately safe

I don't feel at all safe

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

**Please tick (✓) one box**

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

I have adequate social contact with people

I have some social contact with people, but not enough

I have little social contact with people and feel socially isolated

**7. Could you tell me which of the following statements best describes how you spend your time?**

**Please tick (✓) one box**

I'm able to spend my time as I want, doing things I value or enjoy

Usually I'm able to do enough of the things I value or enjoy with my time

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

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

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

**Please tick (✓) one box**

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

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

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

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

## Appendix 5: Mapping of ASCOT domains to PPF domains

Table 3 shows how the ASCOT domains can be mapped onto the PPF domains in order to provide evidence for targets associated with PPF outcomes. The mapping is based on a diagram produced by Mike Charnley-Fischer of Care Services Efficiency Delivery Programme in the DH.

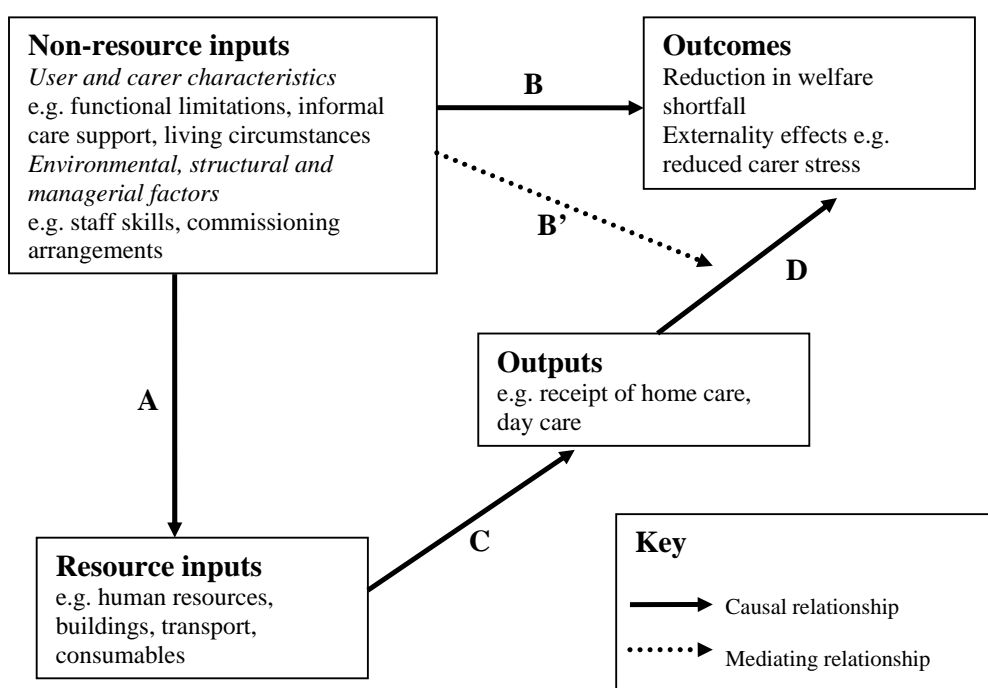
**Table 3: Mapping of ASCOT domains to PPF domains**

<b>PPF domain</b>	<b>ASCOT domain</b>
Quality of life	<i>Whole ASCOT measure</i>
Choice and control	Control over daily life
Inclusion and contribution	Social participation and involvement Occupation
Health and well-being	Food and nutrition <i>Other aspects of health not captured</i>
Dignity and safety	Personal care Clean and comfortable accommodation Dignity Safety <i>Analysis for equity of outcomes / access</i>

## Appendix 6: The Production of Welfare framework

The Production of Welfare (POW) framework is a valuable tool for any researcher thinking about examining outcomes in social care. In essence POW is a model that shows how, in the simplest terms, social services produce outcomes for individuals. Its language draws heavily on economic theories of production. However, the model is also informed by empirical evidence (Davies and Knapp, 1981; Davies, 1985; Fernández and Knapp, 2004). The model is shown schematically in diagram 1.

**Diagram 1: The Production of Welfare Framework**



The model consists of four components, which are largely related to each other in a causal chain. Thus, the resources (inputs) employed influence the outputs for individuals, which go on to influence the outcomes for individuals. Non-resource inputs fit slightly outside of this familiar (input-output-outcome) causal chain. Non-resource inputs are those factors that influence the input-output-outcome chain. Non-resource inputs capture the needs-related characteristics of individuals that influence what types of resources need to be employed or the extent to which the individual is able to derive benefit from the intervention. For example, research has demonstrated that those with the greatest need in terms of the highest level of disability derive less benefit than someone with a lower level of need from the same amount of service. The environment within which care is delivered may also influence the extent to which users can derive benefit from services, as will policy

and other structural and managerial factors (Lynn, Heinrich et al., 2001). The various factors are shown in table 4.



**Table 4: Factors influencing individual outcomes**

<b>POW theme</b>	<b>Factors influencing individual outcomes</b>
Resource inputs	Cost of service package/ personal budget
	Other costs inc. capital expenditure and overheads
Non-resource inputs	Need-related client characteristics, such as level of disability, receipt of informal care, living circumstances, accessibility of the local area
	Environmental characteristics such as political structures, degree of competition, the wider economy, the extent of system-wide coordination, and legal practices, accessibility of the home
	Structural factors such as organization type, level of integration, degree of centralization, administrative rules, budget, contractual/commissioning arrangements, local site management, and institutional culture or values.
	Managerial roles and actions, such as the interpretation of policy directives, leadership practices, staff management, professionalism, and accountability mechanisms.
Outputs	Services received as part of care package e.g. residential care, home care, direct payments and so on

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