PSSRU

A report on the developmental studies for the National Adult Social Care User Experience Survey

Juliette Malley, James Caiels, Diane Fox, Michelle McCarthy, Nick Smith, Julie Beadle-Brown, Ann Netten and Ann-Marie Towers

PSSRU Discussion Paper 2721
March 2010

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

www.PSSRU.ac.uk

Contents

Acknowledgements

This is an independent report commissioned and funded by the Policy Research Programme at the Department of Health. The views expressed are those of the researchers and not necessarily those of the Department of Health.

We are grateful to the members of the Social Services User Survey Group for their comments on an early draft of the report, to the councils who helped us recruit participants to the research and to the participants themselves. We are also grateful to the Care Quality Commission for their support in recruiting care homes and the care home managers and advocacy agencies who participated in this research. Finally we would like to thank Jane Dennett and Lesley Cox for their administrative support.

Executive summary

The Department of Health (DH) commissioned a team from the Personal Social Services Research Unit (PSSRU) and the Tizard Centre at the University of Kent to assist in developing a new National Adult Social Care User Experience Survey (NASCUES) for 2010/11. This work consists of several stages and this report focuses on the development work. The main aim of this work was to explore some of the challenges inherent in surveying certain client groups and put forward proposals to overcome these challenges, which could be tested in a pilot of the survey.

The team from PSSRU and Tizard conducted four exploratory studies covering the client groups and areas that were felt to present the most difficulties for the proposed method of self-completion postal survey. These studies were as follows:

A. To explore the variety of help received by service users in completing the questionnaire and consequences for the validity of the data.
B. To examine the feasibility of using the proposed approach and the suitability of the questionnaire for people living in care homes.
C. To develop a version of the questionnaire suitable for people with learning disabilities (PWLD) and explore the feasibility of the approach with this group.
D. To explore the feasibility of asking advocates to help service users to complete the questionnaire and the consequences for the validity of the data.

The main recommendations arising from these studies covered a number of aspects of the process of conducting the survey as well as the content of the introductory cover sheet and questionnaire. An important issue that emerged from the development work was the need to clarify the approach that local authorities (LAs) should take where members of sample lacked the capacity to consent to take part in the survey. Being mindful of duties under the Mental Capacity Act we therefore recommend that users who lack the capacity to consent to take part in the survey should be excluded from the sample and suggest that this is achieved by checking the sample with care managers.

A focus of the studies was on trying to identify ways in which people who needed help to answer the questionnaire could be engaged in the survey. One idea explored was whether it would be feasible to employ advocates. Our research suggests that this approach may not be feasible at present and we do not recommend that LAs encourage service users to seek help to complete the survey from advocacy agencies, except in circumstances where service users already have an *existing* relationship with an advocate.

In the past many people have had help to complete the questionnaire from relatives and a limited number from care staff. Our studies found that there is the possibility that the person helping may influence the responses of service user. However we felt that this should be balanced against the desire for the survey to be inclusive. We therefore recommend the following:

1. Service users should be encouraged to seek help from friends and family to answer the questionnaire, if they could not answer it without help.
2. Steps should be taken to minimise the potential for the person helping the service user to present their own views rather than those of the service user, or where this does occur, to minimise the effects on the validity of responses. Steps could include:
    a. Add instructions to the front cover for people helping.
    b. Add additional questions asking further questions about who helped and how the person helped to enable investigation of differences in responses in cases where users have had help to complete the questionnaire.
    c. Consider mentioning the survey for carers on the front cover.

In care homes there are additional barriers to participation because of the institutional nature of care. It is also the case that care staff are more likely to be on hand to help than relatives or friends of the resident. As in the community there is the need to balance the possibility of bias arising from having help from care staff against the desire to be inclusive and we recommend the following:

1. To improve response rates from residents care home staff should be engaged in the survey so they are on hand to help residents. In particular, a letter should also be sent to the care home manager to gain the care home's support for the survey.
2. Where service users are living in care homes, they can seek help from care home staff
3. Steps should be taken to minimise the potential for staff members to present a biased account of the service user's views. Steps could include:
    a. The care home manager's letter should outline what type of help is acceptable from staff
    b. Staff should encourage residents, in the first instance, to ask for help from regular visitors or a helpline, if it exists, rather than the member of staff.

c. Local authorities (LAs) may wish to consider making it clear to care homes the way in which the data are to be used. Staff and managers are more likely to present truthful accounts if they think the aim of the survey is not to judge the care home but to ensure residents are enjoying a good quality of life.

A further aim of the work was to ensure that the basic survey was understood by different client groups living in different circumstances and that where it was not steps were taken to improve its accessibility. In this regard we make the following recommendations:

1. The questionnaire should be adapted for care home residents to ensure all questions are applicable, by for example replacing “home” with “care home”.
2. The questionnaire should be adapted for people with learning disabilities. In particular, if the aim is to ensure accuracy of answers, questions should not have more than five response options, the language should be simpler and images should be used. We suggest considering commissioning an artist to harmonise the illustrations.

More detailed analysis of the suitability of questions revealed that certain questions were not suitable for everyone and we recommended that these should be dropped from the questionnaire. The questions to be dropped included:

1. Several questions on abilities in activities of daily living and instrumental activities of daily living which were not appropriate for care home residents
2. The questions on health were all found wanting. We recommend dropping the question on self-perceived health and some of the questions in the EQ-5D. Future surveys may wish to review the decision on health measures as and when more appropriate measures become available.
3. The question on health conditions was answered unreliably. Councils should instead report primary client group and aim to report secondary client group.

The next stage in this work is to test the questionnaire and the survey process proposed in this report in a pilot survey. Because of the new aspects introduced to the process associated with PWLD and care home residents, these client groups will be piloted separately. A key aim of the pilot is to explore whether the strategies suggested here to improve the quality of data collected are successful. In this regard we therefore suggest that the analysis of the pilot focuses on the following areas:

1. The effect of excluding people who lack the capacity to consent should be assessed. In particular the costs of excluding people should be examined in detail and the processes used should be captured to enable interpretation of differences between areas. The sample characteristics should be studied to ensure there is no bias.
2. The data should be analysed for differences in non-response rates between client groups and services.
3. Attempts should be made to understand the effects of strategies to improve response rates on the validity and quality of the data, in particular there should be analysis of the effect of having help on responses.

The survey should be reviewed in light of the findings from the pilot. It is therefore possible that recommendations made in this report may be changed before the survey is rolled out nationally.

In a feasibility report conducted prior to this work, we set out the key priorities for development for the first survey and a series of further activities that could be considered for future surveys (Malley and Netten, 2009). We discussed that the priorities for future development should be driven by the findings from the development studies and the pilot survey. Subject to findings from the pilot, the development work suggests that the following areas require most urgent attention:

1. To develop methods to include the experiences of people who lack the capacity to consent to take part.
2. To pilot stratified sampling.
3. To explore different ways of collecting the experiences of care home residents and PWLD, subject to consideration of the likely impact of such methods on the cost of the survey.

Introduction

National user experience surveys (UES) of publicly-funded social care clients have been conducted for some time now and 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. The Department of Health (DH) commissioned the Personal Social Services Research Unit (PSSRU) and the Tizard Centre at the University of Kent to assist in developing a new National Social Care UES (NASCUES) for 2010/11 that is consistent with the transformational agenda for social care set out in *Putting People First (PPF)* (Ministers, Local government, NHS, Social care, & Professional and Regulatory organisations, 2007), but draws on the methods, experiences and successes of the UESs to date.

During 2009, PSSRU conducted a feasibility study to identify potential question sets and a strategy for developing the survey to meet the ambitions of PPF. A discussion paper was published which sets out a data collection model for the survey based on the UES model and some of the challenges associated with surveying this population using this model (Malley and Netten, 2009). A key recommendation of this report was to conduct development work before piloting the self-completion survey to understand better some of the challenges inherent in surveying certain client groups. In particular, the authors identified four areas that required most urgent attention as the focus of the development work. These are:

A. To explore the variety of help received by service users in completing the questionnaire and consequences for the validity of the data.

B. To examine the feasibility of using the proposed approach and the suitability of the questionnaire for people living in care homes[1].

C. To develop a version of the questionnaire that is more suitable for people with learning disabilities (PWLD) and explore the feasibility of the approach with this group.

D. To explore the feasibility of asking advocates to help service users to complete the questionnaire and the consequences for the validity of the data.

This report summarises the central findings from the development work. We briefly consider the implications of our findings for the full survey and provide some recommendations that we hope will

---

[1] In this report we use the term care home to apply to both personal care and nursing care residential facilities.

help to improve the quality of the data collected. We report findings, implications and recommendations for each study separately, and draw together some of the cross-cutting issues related to the questionnaire items towards the end. We conclude by discussing next steps in terms of the focus of analysis of pilot data and priorities for future work that have emerged from the studies. The methods are discussed in more depth in a technical report (Caiels et al 2010).

Since the work reported here is exploratory in nature, based on interviews and focus groups with service users our findings should be treated as indicative of the types of issues that could arise when the survey is implemented. The pilot is the next stage of this work and will be a test bed for exploring whether the recommendations made in this report are successful in improving the quality of the data. The findings reported here have therefore been very important in shaping the pilot of the survey. However, it is possible that, dependent on the results of the pilot, some of the decisions made on the basis of this development work will be revised before the survey is rolled out nationally.

Study A: Understanding the impact of having help to complete the questionnaire on responses

The research team interviewed people who had reported having help to complete a previous UES in the presence of someone who would help them to complete the self-completion questionnaire. The aim was to understand the range of help given to service users to complete the questionnaire and to understand how the help given may affect the validity of answers.

The research team conducted a total of 12 interviews with users of a range of social care services. These were conducted together with people that would give the user help with completing a questionnaire. It was an iterative process with refinement of questions. People were recruited from four geographic locations to include London, the South East, Midlands and the North of England. Recruiting participants proved to be challenging in some areas so an additional focus group with service users was also conducted to test final versions of questions. Key findings are discussed below.

1. Range of help

The type of help that users had was extremely variable, but was largely dependent on the level of dependency of the user. Help ranged from reading the questionnaire aloud (and/or translating from English into another language) for the respondent and then recording their response, to answering on behalf of the respondent without consulting them (i.e. as a ‘proxy respondent’). In all the interviews conducted where a proxy respondent was required, this was due to severe cognitive impairment and the respondent’s lack of ability to understand questions.

2. Derivation of answers

When users are helped to answer questions, the way they arrive at answers to questions varies. Work carried out thus far suggests that there are a number of factors that contribute to the derivation of answers: the type of question being asked; the relationship between the service user and the helper; and the mental capacity and/or communicative ability of the service user.

a. Type of question being asked

Questions asking users how they ‘feel’ about the services they access or their own quality of life are particularly difficult for someone else to answer without input from the service user. In instances where the helper was a proxy we observed the proxy adopt very different strategies in answering questions, for example answering a question from a politically or morally motivated standpoint. The range of approaches to answering these questions used by proxies is likely to produce very random results. Questions that ask for reports of what happened tend to be easier for proxies to answer as they do not require the proxy to guess the feelings of the person for whom they are caring.

b. Relationship between the service user and the proxy

We found that the helper's views can differ from those of the service user and observed discussions between user and helper to decide what answer to give. Where help is given, patterns of dominance in the relationship between the service user and helper are important in determining whose views are reported. For example in some cases where the relationship between helper and user is quite evenly balanced, the user is asked the question and then their answer is recorded without question or input from the helper, but this situation was not common in the sample of people we interviewed. It is more common that the questions are discussed in terms of their meaning and responses are 'negotiated' between the user and the helper before an answer is given. Where the helper is particularly dominant and holds particularly strong views, the helper's view is enforced as part of the 'response negotiation'.

3. Mental capacity of the service user

Those with less mental capacity tend to have less input into the responses. Where the service user has a severe lack of mental capacity questions are answered entirely by the helper (i.e. as a proxy respondent) without any consultation with the user. There was also evidence that proxy respondents can under-estimate the abilities of the person they care for and presume they are unable to answer questions when they are able to express a view if asked. This may arise because they think the service user is not capable of answering the questions in the given format.

Recommendations

1. Service users should be encouraged to seek help from friends and family to answer the questionnaire, if they could not answer without help.

It is clear that without help to answer the questionnaire many service users who can provide views would not be able to complete the questionnaire. In previous UESs the proportion receiving help has been around 50 per cent of all respondents and this is likely to be higher in the NASCUES since this includes PWLD and people living in care homes, whose need for help is likely to be greater than users in client groups surveyed so far.

2. Steps should be taken to minimise the potential for the person helping the service user to present their own views rather than those of the service user, or, where this does occur, to minimise the effects on the validity of responses.

To maximise the chance that users views are presented when the user is receiving help, it may help to include instructions on the front cover to this effect. Providing helpers with an opportunity to comment on the services for the person they care for through a carer questionnaire may also help to ensure that carers do not present their own views in the questionnaire. When a carer's survey is established it may help to refer to this in the service user survey.

To minimise the effects of bias from helpers presenting their own views on the data collected, we recommend capturing more information in the survey about the person that helped the service user to answer the questionnaire and the type of help that was given. We have suggested and tested two questions (see questions 27 and 28 in Appendix 5) which can be used to explore whether the helper and type of help given affect responses. Data users can then decide how much weight to give responses where the person has received help when making decisions about services and providers based on the data[2].

3. People who lack the capacity to consent to take part in the survey should be excluded from the sample.

Helpers who responded on behalf of the service user (i.e. as proxy respondents), did not answer the questions on a consistent basis. Questions asking about feelings were particularly problematic, and these are common in the main social care outcome measure. Different strategies being employed by proxies in answering questions also created variation in responses. As a result the research team feel including proxies would introduce random error into the responses, inflating variance and so standard errors. The team, therefore, recommend that any service users who are unable to express opinions about their care and would therefore require a proxy respondent to take part should be excluded.

To ensure that samples are comparable across local authorities (LAs), it is important that each area follows the same procedure to exclude people who require a proxy. We recommend that LAs exclude people on the basis that the user lacks the capacity to consent to take part in the survey, as

---

[2] More detailed questions on the relationship between the service user and the person helping may also help to understand the effect of help on the validity of responses, but it is not clear whether such questions would be acceptable. We have not suggested any questions along these lines here, but future studies may wish to explore this issue in further detail should the results from pilot, or full, surveys suggest that this is important.

clear exclusion criteria can be constructed and if informed consent cannot be given there are legal and ethical concerns regarding participation. We discuss the criteria for assessing informed consent in Appendix 1 and outline guidance for LAs to aid their decision-making process.

Evidence from the 2009 and 2008 UESs of older people and equipment users, respectively, in Derbyshire suggests that around ten to 13 per cent of users lack the capacity to consent to take part. However, this proportion is likely to be higher for the NASCUES because of the inclusion of care homes and PWLD. A study conducted by PSSRU found that in the sample of care (nursing and residential) homes studied, 14 per cent[3] of residents had moderately severe impairment, 27 per cent had severe impairment and five per cent had very severe impairment, as assessed using the MDS cognitive performance scale (Darton et al., 2006). A review by Perkins (2007) found that people with Alzheimer's Disease can reliably self-report when they score above nine (Bucquet et al., 1990) or ten (Godlove et al., 1999; Logsdon et al., 1999) on the Mini Mental State Examination (MMSE), where scores between one and ten denote severe cognitive impairment. This implies that around 30 per cent of care home residents may be excluded.

Because users from certain groups (PWLD and care home residents) are more likely to be excluded it is important that a method is employed that does not produce a biased sample. The most robust approach would be for LAs to identify the people who lack capacity to consent and exclude them *prior to* sampling. However, this is extremely resource intensive and infeasible in large LAs. We therefore recommend excluding subsequent to sampling and using a method of replacement sampling to ensure there is not under-representation from key groups. To select the replacement sample the remaining population should be stratified into groups according to location of care and client group and additional people should be sampled from the group from which people are lost due to the exclusion criteria. For example if two older people in care homes are lost and one PWLD living in the community then two people should be sampled from the older people in care homes group and one person from the PWLD living in the community group. We recognise that this method may also be resource intensive and that the replacement method for sampling uses only two variables, meaning that matches are not perfect. On the former point, we suggest that the resources used are monitored to check whether this approach is overly burdensome; and on the latter point matching criteria are limited by what is recorded reliably on LA databases. In the longer run a stratified sampling method may be most appropriate, although this adds complexity.

---

[3] These percentages have been adjusted to take account of CQC data on number of placements in nursing and residential homes.

Study B: Understanding issues associated with conducting the survey in care homes

In this study the researchers interviewed care home managers and residents to understand what types of problems are likely to be encountered when running a postal survey in a care home and to test the appropriateness of the proposed questionnaire for care home residents. A selection of care homes who were interested in taking part in the survey were identified by the Care Quality Commission (CQC) and their inspectors. From this list four care homes were chosen to take part in the study. The aim was to reflect the diversity found amongst care homes, therefore homes of differing size and in different parts of the country were chosen. Moreover, our selection included not only care homes for older people, but also included those which catered for people with mental health problems and learning disabilities.

Interviews were carried out with care home managers and the questionnaire tested with a number of residents. Residents were chosen to be invited to take part with the help of the managers. They were also chosen so that they reflected the differences, particularly with regard to severity of needs, in the care home residents. This meant that some residents required help from either a member of staff or a relative to participate in the study. In total, four care home managers were interviewed and sixteen care home residents participated in the testing of the questionnaire, six of whom were aided by either a relative or a member of staff. Another three interviews with care home residents were attempted, but abandoned either just prior to the interview or in the first few minutes. The reasons for this included poor health and concerns that the interview might cause the resident distress.

The key findings from these interviews are:

1. Only a very small proportion of the care home population would be able to respond to the questionnaire without help.

Evidence from the interviews suggests that only a very small number of people in care homes would be able to fill in the questionnaire without any help. The researcher observed a range of help being provided from having help to physically to fill in the questionnaire/post it, through to needing help understanding the questions and coming to an answer. There are also care home residents for whom answering a postal questionnaire would be very difficult even with help. It should be noted that residents are not in fixed categories. Care home managers in different homes stressed that an individual resident's ability to answer the survey questions could change from day to day and even from one part of the day to another. As the level of help required varies across residents this raises questions over the availability, or lack thereof, of appropriate people to help. If help is not readily available then there is the potential for high rates of non response.

2. Problems with the survey format

It is important to note that every resident who took part in Study B was able express their opinion on some aspect of the questionnaire, albeit not in the format required of the survey. In particular, some residents found it difficult to respond to the questions by using the answer categories and to help staff (and family members) translated the respondent's 'free-form answers' into an answer category. Residents with more severe cognitive problems also found it difficult to respond to questions that included general terms such as 'social contact'. One of the more successful approaches used by staff and family members to help the person answer the question was to personalise the question for the resident. For example, when asking the question about social contact they might say it means things like the group you go to on Thursday and see your friends there. Personalising the questions so they are clear to the resident requires a degree of familiarity with the resident and their daily lives that can only be achieved through frequent contact. This limits the people that will be able to help certain residents to those who have frequent contact with the resident. Roughly half the people who were interviewed in this work would benefit from personalisation of questions.

3. Availability of people to help the residents complete the questionnaire

The research team explored who was best placed – relatives and friends, staff or professional advocates – to help residents complete the questionnaire. Some care homes were resistant to using relatives to help, and in at least one home the manager felt that families often had their own agenda and did not visit enough to really know what the daily life of the resident was like. There was a family member present in only two interviews to help out and in these cases it would not have been possible to carry out the interview without them. In both cases, the family member had frequent contact with the resident and seemed very aware of their daily lives. Their help was both in translating questions and, where necessary, answering the question on behalf of the resident, as well as acting a proxy for a significant number of questions where the resident was unable to answer, which raises questions about the validity of answers (as discussed in relation to Study A).

Staff members have a clear incentive to manipulate responses, especially as some of the questions in the survey were about the help the resident received, the state of the home and so forth. The possibility of bias resulting from using staff to help residents fill in questionnaires was recognised by a lot of care home managers, but they balanced this against the fact that they felt staff, in contrast to relatives, tended to have a good knowledge of residents' daily lives coupled with a rapport that had been built up with the residents, both of which would aid the process of helping the resident to answer the questions contained within the survey. Indeed in interviews conducted with staff present, staff tended to personalise the questions which did seem to aid the residents' ability to answer them. They also helped translate residents' answers to fit the response options available.

Whilst care home managers were very positive about what advocacy services could do in theory, and some had even used them in the past for a variety of reasons, they did note some practical problems. For example, some did not know how to go about finding an advocate and, even when they did, one care home manager stated that there was only one advocate in his area who was so busy that it was difficult to get an appointment at short notice. It was also noted that using advocates could be costly. Unless the advocate has an established relationship with the resident they are also unlikely to be able to provide the type of help, such as personalising questions, that is needed by a number of residents.

4. Gaining informed consent

All of the managers interviewed were aware of the notion of informed consent and outlined how this and the guidelines set out the Mental Capacity Act were translated into practice. However, despite this knowledge, the experience of carrying out interviews in care homes suggested that care home managers' approach to gaining informed consent from participants in the research was rather 'ad-hoc'. For example, on several occasions, the interviewer was not confident that the service user understood the purpose of the study before the interviewer arrived.

5. Methods for dealing with incoming mail for residents

Care homes operate various methods for distributing incoming mail ranging from mail going almost directly to residents to staff opening it with the resident or it being passed on to the family. There were not only differences between the homes in the study with regard to how incoming mail was dealt with, but differences within individual care homes depending, according to one care home manager, on the resident's 'level of skill and ability'. Since many residents require help to answer the questionnaire the way care homes deal with post is likely to impact on non-response.

6. Appropriateness of the questions for care home residents

The majority of the questions were appropriate for care home residents. However, some questions did cause problems, such as those referring to practical help and 'home'. Some care home residents found the term 'home' misleading, as they thought it referred to the home they had lived in before entering a care home. This misunderstanding was most common among older people (the majority of care home residents) as most had spent their lives living in what could be referred to as their own home and had only in later years moved into a care home.

Recommendations

1. To improve response rates care home staff should be engaged in the survey and on hand to help residents. In particular, a letter should also be sent to the care home manager to gain support for the survey.

To ensure good response rates, it is important that steps are taken to involve care home managers and staff in the survey from the outset so they are on hand to help residents as needed. A letter to care home managers may help to ensure the involvement of the home and staff in helping service users to complete the questionnaire. To be effective, the letter should explain which residents have been sent the survey, why, the importance of the survey, how the data will be used and how to the care home staff can help the resident. The supporting letter to the care home manager should explain both what help the resident could access and where the manager can find more information. The letter should also emphasise the importance of gaining informed consent and should outline the criteria for assessing informed consent (see Appendix 2 for example letter).

Thought should be given to whom to address the manager's letter. A number of difficulties were encountered in contacting care home managers. Out of the five homes contacted, three had experienced a change in manager since their details had been recorded by CQC. All letters were addressed to the person on CQC records, but in at least two cases, the new manager had not received the mail addressed to the old manager, suggesting that new managers do not automatically receive and/or open mail addressed to the old manager. We recommend that unless LAs are completely confident in the accuracy of their records that all correspondence to the care home manager be addressed to 'the manager' rather than by name.

2. Residents should seek help from staff to complete the questionnaire if required

In care homes help could be provided by relatives or friends (including other more able residents), staff and professional advocates. For all groups there is the potential that rather than helping the resident to answer the question the helper will present their own views. This is more likely to happen when there are incentives to do so or where the helper has an agenda, hence the advice in previous UESs has been to avoid seeking help from staff. However, bias also occurs when the helper lacks familiarity with the daily routine of the resident. In such instances the helper cannot provide adequate help to the resident and instead answers for the resident often using random criteria to make an assessment (see problems with proxy respondents identified in Study A). The evidence collected suggests that members of staff are likely to know the residents better than relatives and friends where the resident does not have regular visitors and would be preferable in such instances. Further research on the frequency of visits by relatives in England and the relationship between frequency and the validity of their reports, as has been conducted in other countries (see e.g. Cohen-Mansfield, 2002; Fukahori et al., 2007) , would be of value in assessing the extent to which residents could be helped by relatives. However, it seems likely that if staff members are not allowed to help, a large proportion of care home residents would not be able to take part.

3. Steps should be taken to minimise the potential for staff to present a biased account of the service user's views.

Staff have clear incentives to present biased accounts of service user views, particularly where LAs are using the data to assess provider performance. To minimise the potential for bias, the care home manager's letter could outline what level of help is acceptable from staff, and suggest using an advocate if there is an existing relationship, or getting family members or friends to help if they visit regularly. If available it could also direct managers towards any helplines that have been set up. Staff and managers may be more likely to present truthful accounts if they think the aim of the survey is not to judge the care home but to ensure residents are enjoying a good quality of life. We recommend that the care home manager's letter states that the data will not be used to judge care home performance.

4. A questionnaire specifically for care home residents may improve response rates.

Study B used the LD questionnaire in some of the care home interviews to test whether the simplified wording aided understanding. (This questionnaire differed slightly from the one used in Study C as it did not have the pictures.) A direct comparison between this questionnaire and the main questionnaire is difficult due the huge variety in abilities and needs of those interviewed for

Study B. Therefore there is no strong evidence to support using the LD questionnaire in care homes. However, there are a number of good reasons for using a slightly modified questionnaire in care homes. Firstly, having a separate questionnaire would allow there to be specific instructions for those in care homes which could make reference to getting help from staff and informing the resident that the care home manager is aware they have received a survey, which seems important for ethical reasons. Secondly, it would also allow very minor changes to questions which would clarify the questions for residents. A version of the questionnaire for care homes is provided in Appendix 6, with changes highlighted in blue. Please note that the LD version should be used for PWLD living in care homes.

Study C: Making the NASCUES accessible for people with learning disabilities

Tizard members of the research team conducted four focus groups with 23 PWLD to explore ways of making the questionnaire more accessible. Prior to the focus groups the Tizard staff translated the main questionnaire into a more accessible form for PWLD and this version was tested in the focus groups. (More detail about the way the questionnaire was translated into a form more understandable to PWLD is given in Appendix 3.) PWLD were recruited from a variety of local day or supported employment services. Staff were present in some groups and this helped people with severe communication and speech problems to participate.

After the focus groups, the questionnaire was amended. The amended version was piloted with 10 people with learning disabilities (also recruited from local day services) to test whether the questions were indeed understandable. The significant issues arising from the formulation of the LD version of the survey, which is shown in Appendix 7, are summarised below.

1. Informed consent

With those participating in both the focus groups and the pilot interviews, it was quite difficult to establish how far people were giving fully informed consent to the whole research process. Certainly everybody gave consent to helping researchers amend the survey, but it is doubtful that the majority fully understood how this relatively small task fitted into the bigger picture. When considering informed consent in broader terms for this project, it is advisable to take a pragmatic view about individuals' understanding; i.e. accept consent to the task they are being asked to do, rather than seek a more sophisticated understanding of the whole research process (see Appendix 1).

2. Level of help needed

Most PWLD cannot read, either at all or at the level required to confidently complete the original survey. Therefore the language was simplified and illustrations added to ease understanding. Despite these amendments, many people will need the survey read out to them. Others may be able to read the words on the page, but still need help in understanding the meaning and formulating their responses, as was common in Study B. Clearly the level of help required will vary from person to person, which raises questions of response bias and availability of help. If help is not readily available, this is likely to produce high rates of non response.

3. Use of illustrations

Illustrations were taken from freely available picture banks for people with learning disabilities (e.g. the CHANGE and Valuing People picture banks). This meant there was not one consistent style throughout. Nevertheless, in both the focus groups and pilot interviews, people liked having the illustrations and felt that it aided understanding. Some people wanted more illustrations and felt everything should be depicted in pictures as well as words (despite the difficulties inherent in this). Some people felt that photographs would be better than line drawings and most people agreed that colour illustrations would be better. Practical considerations such as the cost of producing and copying such images obviously need to be taken into account.

Generally, the use of smiling/unhappy faces and ticks/crosses of varying sizes seemed to help people in selecting their responses to questions.

4. Nature of the survey format

It is well established that many people with learning disabilities find concepts of time and frequency difficult to grasp, so questions were worded in such a way as to avoid these wherever possible. Generalisations are also difficult for many, so people often wanted to be able to answer in more detailed or direct ways than the very structured format of the question allowed. Questions which require people to sum up a variety of different aspects of their situation were problematic for most and people often wanted to answer “it depends”.

It was clear that having too many response options was a problem for most PWLD. Seven was certainly too many and even five was confusing for some.

In the focus groups and interviews, a frequent observation was that people seemed to feel constrained by the survey format with pre-defined answers. They wanted to be able to give their own answers in their own words. A format that allowed this may be more appropriate for PWLD.

Recommendations

1. **To ensure PWLD are able to accurately answer questions, the questionnaire should have the following attributes:**
    a. **It should use simple language**

    b. **It should include illustrations**

For the main survey the DH/IC may wish to consider whether the look of the illustrations should be harmonised and whether the images should be in colour. Practical considerations such as the cost of producing and copying such images obviously need to be taken into account.

c. **Questions with response scales (as opposed to response categories) should not have more than five options.**

At present only one of the questions in the questionnaire (question one) asking about satisfaction has a scale of more than five points. If the aim is to ensure PWLD answer the question accurately then this question will not be comparable with the main questionnaire. This question is not currently proposed as a performance indicator and was included to aid comparability with previous UESs, which did not cover PWLD. Lack of comparability for this question may be the price to be paid to enable PWLD to answer as accurately as they can. If the decision is rather to place comparability above accuracy, we do not recommend placing this question first as it may cause confusion and lead to high non-response if PWLD assume that the rest of the questionnaire is as difficult as the first question. It is anyway likely that a seven-point question for PWLD will have high rates of non-response and could possibly produce invalid data if PWLD do not fully understand the options but choose an answer anyway.

2. **PWLD will need to be encouraged to seek help to answer the questionnaire. Steps should be taken to prevent the person helping the service user to present their own views above those of the service user, or where this does occur, to minimise the effects on the validity of responses.**

The front cover of the questionnaire includes wording to encourage PWLD to seek help to answer the questionnaire (see Appendix 7).

Study D: Exploring the feasibility of using advocates to help people complete the NASCUES

Study D explored the extent to which advocates could be employed to help service users complete the NASCUES questionnaire and the impact that advocate involvement could have on survey responses. A literature search was conducted to identify whether any previous studies had used advocates in this way to see what lessons could be learnt. Telephone interviews were carried out with key informants, including five advocacy agency managers and seven LA user survey managers.

1. Experience of using advocates to help people complete surveys

A number of studies exploring the effects of proxy respondents were found, but none involved advocates as proxies. Only one study that enlisted advocates to help service users respond to a survey was identified[4]. Despite finding only one reported study, two of the advocacy agencies reported previous experience of helping organisations such as LAs and regulators to access service users' views. Advocates underwent expensive specialist training to enable them to effectively communicate with clients who had cognitive or communication difficulties.

2. Availability of advocacy

The key barrier identified by the interviewees was the variability in advocacy provision across different client groups and across different geographical areas. The lack of consistent access to advocacy would create bias in response rates if the utilisation of advocates was central to the methodology of the NASCUES.

The majority of the advocacy agency managers were enthusiastic about being involved in the NASCUES particularly in the light of its spirit of inclusion. All reported having the capacity to participate assuming there was sufficient funding (for travel and admin costs, etc), training and time to complete the work. However, none felt able to use their paid advocates to help service users to complete the NASCUES. Paid advocates are few in number and in order to fulfil their obligations to their funders, advocacy agency managers generally felt that their time should be used to fulfil the main aims of the organisation. Instead, all the advocacy agency managers envisaged involving their volunteers.

---

[4] Equal Lives Evaluation – Part 1, Social Care Services, Essex County Council, 2002.

3. Risks and safety concerns

Service users with high needs may need home visits but LA managers were concerned about the risks associated with advocates visiting service users in their own homes. The advocacy organisations that visit clients in their own homes routinely conduct risk assessments or have a policy of sending two advocates for the initial visit, which would add to costs.

4. Familiarity with clients and their circumstances

When working with clients not previously known to them, advocates sometimes need several visits to get to know the client well enough to represent their views accurately, particularly if the client has communication or cognitive difficulties. Although advocates seem ideally placed to fulfil this role because of their experience, the variable capacity and coverage of advocacy services may be problematic. It also seems unlikely that new advocacy relationships could be established within the timescale of the survey.

There is a role for advocates to help clients *already known* to them to complete the survey. Three of the advocacy agencies reported ongoing work within residential settings.

Recommendations

1. **We do not recommend that LAs encourage service users to seek help to complete the survey from advocacy agencies, except in circumstances where service users already have an *existing* relationship with an advocate.**

At present there seem to be too many barriers to involving advocates in helping people who are *not already known* to them to answer the questionnaire.

Questionnaire items

The main questionnaire that was tested is shown in Appendix 4. As well as questions on social care-related quality of life (SCRQOL), which are of central interest, a number of other questions were included to help understand differences in SCRQOL between individuals and areas. For some of these questions alternatives were included in the testing phase. This was the case for questions aimed at measuring disability, particularly important to understanding differences in SCRQOL as disability is associated with need for social care. The alternative questions are questions 17, 18 and 19, which capture ability in activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (see Appendix 4).

Alternative questions to measure health were also included in the questionnaire. A broad definition of health is common nowadays and this clearly overlaps with aspects of SCRQOL. There are, however, aspects of health that are not captured by SCRQOL, such as pain, aspects of mental health and mobility. One aim of the measure of health was to capture these aspects of health that are 'missing' from SCRQOL. Another reason to include a health measure was to enable future comparisons across health and social care services. For this reason we felt a widely used measure of health would be most appropriate as it is most likely to be used by health services. The alternative health questions are question 15, which is a widely-used question asking about self-perceived health, and question 16, which is a widely-used five-part question asking about different aspects of health known as the EQ-5D.

1. Most questions were understood well and elicited the responses intended by the team across all studies.

The majority of the questions were understood by the people interviewed and elicited the types of responses intended by the team. Some minor changes were made to a few questions to remove ambiguity and enhance understanding.

2. The question on health conditions (question 26) was not understood by participants in studies A to C.

This question was not understood well for a variety of reasons. The conditions in the list range from very specific conditions such as "dementia" to very general conditions such as "long-term health condition", which tended to confuse participants. The interviewees questioned why some conditions were included and others excluded, as this implied that some conditions were not as important, which some people found offensive.

Very general terms were unclear and interviewees did not understand what should be included in some of the categories, questioning whether diabetes is a ‘long term health condition’ and what should be classed as a ‘mental health problem’. In a couple of instances residents in a care home for people with mental health problems did not tick the box for mental health problems and very few PWLD reported having learning disabilities despite this being the criteria for their inclusion in Study C.

Adding descriptions of the condition by including symptoms to clarify what is meant by the condition, as was done in the LD questionnaire added more problems than it resolved. Since symptoms can describe a number of conditions and often simply transitory states that do not constitute a health condition, people were often misled into thinking they had conditions they did not. For example a man in a care home for people with mental health problems ticked that he had dementia because he sometimes got confused and a PWLD reported having dementia as he forgot things – confusion and forgetting things being descriptors for the health condition dementia.

It is not clear that this question would provide any useful information. Categories would probably need to be more specific and the list more exhaustive, in common with the approach taken in most national surveys. Detailed information on health conditions does not seem to be a priority for this survey, so we have not amended the question in this way.

3. Some of the disability questions were not appropriate for all client groups.

Question 17a which asked about ability with steps was particularly difficult for people in care homes as care homes tended not to have any steps and residents rarely went outside. For the same reason 17b, which asked about mobility outside was also difficult for care homes.

Question 18b asked about managing the household shopping which was not something care home residents needed to do. Similarly care homes residents did not need to prepare hot meals (question 18c).

4. Both of the alternative health questions caused problems for respondents.

Problems were encountered with both health questions. Question 15 was interpreted in many different ways according to the criteria respondents used to assess 'general health'. Some people discounted their long-term conditions, for example reporting excellent health despite the fact they had quite a severe illness or disability, arguing that they did not include illness or disability within their 'general health'. Time dependency was an issue for service users as pain and/or discomfort could fluctuate making it difficult for people to make a judgement. A good summary of the problems with this question, which is supported by our data, is provided in a review of health questions for the Department of Health (Sturgis et al., 2001).

Most of the EQ-5D items were understood well. However, the item on mobility (question 16a) was problematic for people in wheelchairs (hence the inclusion of question 19 to try to understand how people in wheelchairs answer this question). We discussed changing this item with the Euroqol group (who developed and license the EQ-5D for use) but they will not allow any changes to the wording of items. This also meant that they would not allow us to develop a version of EQ-5D for PWLD. It is therefore not possible to develop a version that is suitable for people in wheelchairs or PWLD. This is likely to mean that these questions are not suitable for a large number of clients. A five-level version of the EQ-5D (the EQ-5D-5L) is currently being developed and the wording is likely to be changed to make it more appropriate for people with disabilities. The new EQ-5D-5L may be a more suitable measure and could be appropriate for future surveys.

Recommendations

We recommend considering the following changes to the questionnaire:

1. Question 26 on health conditions should be dropped. The interest of this survey is not in health conditions but in client group. Therefore we recommend trying to capture client group information from LA records. To capture the complexity of some users' circumstances LAs should aim to also report secondary as well as primary client type.
2. The ADL/IADL questions, 17a, 17b, 18b, 18c should be dropped in the care home questionnaire as they are inappropriate for people in care homes
3. We do not recommend using question 15 on self-perceived health to measure health because of the problems with inconsistency.
4. We do not recommend using the EQ-5D (question 16) in its full form as it cannot be suitably adapted for PWLD and people in wheelchairs.

5. To ensure that aspects of health that are missing from SCRQOL are captured, we recommend including only the pain (16d) and anxiety/depression (16e) questions from the EQ-5D in the final questionnaire. (Aspects such as mobility and self-care are captured through the questions on disability and the question on usual activities overlaps with SCRQOL.) Using only these two items from the EQ-5D has the disadvantage that there is not a widely-used measure of health in the survey. However, it does not seem sensible to use questions that we know are not ideal, particularly when they may offend respondents, as question 16a could do. Future versions of the survey may wish to revisit this decision as the field of health measurement moves forward and alternative health measures become available.

Piloting the survey and next steps

The survey is due to be piloted in volunteer authorities before being rolled out as a national survey for 2011. This process will be managed by the IC. In this report we have identified a number of aspects of the survey, associated with both the process and the characteristics of the population that could affect the quality of data collected. We have suggested a variety of strategies and methods that we hope will help to improve the quality of the data, such as re-sampling to prevent sample bias from excluding people who lack the capacity to consent to take-part and involving care home managers in the survey to improve response rates from care home residents, but it is not clear that these methods will be entirely successful. The pilot is the ideal place to test out these methods and draw some conclusions about the quality of the data collected. In this regard we have made several recommendations for the analysis of the pilot data.

1. **The effect of excluding people who lack the capacity to consent should be assessed. In particular the costs of excluding people should be examined in detail and the sample characteristics should be studied to ensure there is no bias.**

Identifying those who should be excluded is a time-consuming task, but is necessary to ensure compliance with the Mental Capacity Act 2005. To decide whether a service user lacks capacity to consent to take part, it is necessary to know the service user well. LAs will therefore need to recruit care managers (or someone who knows the client well) for this task, unless this information is routinely recorded *and* regularly updated on management systems in a way that reflects the changing circumstances of individuals. This process could add significant pressure to the workload of care managers or other frontline staff. It may also be infeasible in instances where the care manager has a large number of clients on their books as they are unlikely to know the clients well enough to comment. Staff members closer to the frontline would need to make the decision in these instances and it may prove very difficult for the LA to manage this process where these staff are not employees of the LA. This may lead to many people who lack the capacity to consent being included in the survey on the basis that capacity to consent has to be presumed since the LA lacks adequate knowledge about the service user. It seems important, particularly in the current fiscal climate, to collect detailed information about the costs of complying with the Act, in terms of staff time required to assess capacity to consent adequately for the sample. To enable interpretation of differences between LAs detailed information on processes employed should also be collected.

A concern with the sampling method chosen to exclude people who lack the capacity to consent is that the sample is biased. It is possible that re-sampling by stratifying the remaining population by certain characteristics, could lead to the sample being biased along the characteristics not included in the stratification grid for re-sampling. Bias could occur, if, for example, the characteristics that are not included are more commonly associated with capacity to consent to take part among the different groups in the stratification grid. Because the population, i.e. service users who have the capacity to consent to take part, is not known, it is difficult to test this out. However, a comparison of the characteristics of the sample with those of the population would be informative. A fully stratified sampling approach may provide more robust results as the selection mechanism is explicit and can be accounted for in the presentation of results.

2. The data should be analysed for differences in non-response rates between client groups and services.

The development studies identified several reasons to suspect non-response rates may be quite high amongst sub-sections of the sample, in particular amongst care home residents and people who need help to answer the questionnaire because of their impairments. We have suggested a number of strategies that we hope will be successful in improving response rates, in particular involving care home staff, making it clear on the questionnaire that people should seek help if they need it and providing information about what types of help may be available. We do not know however, whether these steps will be successful. For this reason we have suggested that the survey is piloted separately for care homes and PWLD to enable detailed data to be collected about these two groups, as well as being piloted in full. We strongly recommend that detailed data is collected on the process of administering the data collection method and that the data are analysed for differences in non-response rates between key client groups, care settings, and other relevant variables.

If it does appear that there are significant differences between key groups, and it is deemed that response rates are high enough from all groups to still be valuable, it may be important to explore the factors predicting response in more detail following the full survey. In this situation, a response propensity model may be useful for disentangling relationships between variables. Adjustment of results to account for non response should also considered, its benefits weighed against its disbenefits.

3. Attempts should be made to understand the effects of strategies to improve response rates on the validity and quality of the data.

The research identified circumstances under which having help to answer the questionnaire could result in the helper's views being presented rather than those of the service user, so affecting the validity of responses. Instances of this include where the person helping is dominant in the relationship with the service user, where staff members are helping and feel their work is being assessed by the survey, and where the service user is unable to communicate their views so the helper becomes a proxy respondent. It would be informative to analyse the data for differences in ratings of quality of life between those who report having help and those who do not. It would also be of value to explore whether ratings vary according to who helps and what type of help is given. As differences in responses between groups may be indicative of bias, if differences are found in the pilot it may be considered important to explore these in more detail in the national survey. Detailed analysis and possibly further qualitative work is required as great care needs to be taken in analysing differences. This is because the different groups are self-selecting and so may vary systematically by other characteristics which themselves may have an effect of quality of life ratings. In such instances regression models are questionable because they are based on extrapolations of the data. Propensity score matching may be a useful method with which to explore differences, although it has its own limitations.

In the feasibility study discussion paper we set out the key priorities for development for the first survey and a series of further activities that could be considered for future surveys. We suggested that the priorities for future surveys should be driven by the findings from the development studies and the pilot survey (Malley and Netten, 2009). These tasks included:

1. Develop a valid version of the instrument in foreign languages
2. Test the effect of alternative methods of data collection, such as telephone or face-to-face interviews, on responses
3. Test the validity of the instrument for people with learning disabilities and identify the appropriate method for capturing responses from people with learning disabilities.
4. Test the most appropriate method for capturing responses from people with severe physical impairments.
4. Test the validity of the instrument for people with cognitive impairment and identify the appropriate method for capturing responses from people with cognitive impairment.
5. Further test the validity of the instrument for care homes residents and identify the most appropriate method for capturing responses from care home residents.

6. Test whether an independent organisation can be used to collect the data[5] before it is returned to the NHS IC for analysis and reporting.
7. Develop the survey to include privately funded social care users and users of voluntary social care services.
8. Research how the NASCUES survey can be linked in better with the activities of CQC and the NHS patient surveys.
9. Research how the NASCUES survey can be linked in better with the day-to-day activities of CASSRs.
10. Pilot the use of stratified sampling with CASSRs.
11. Develop additional question modules that capture aspects important locally, such as aspects of process which are useful for service improvement activities.

At this point, foreign language versions, telephone and face-to-face interviews seem set to play a minor role in the collection of data for the survey, so these areas do not seem to be priority areas for development. Having said this, we did find that one authority, Derbyshire County Council, made good use of telephone interviewing. Derbyshire has a telephone helpline and uses trained call centre operatives to conduct interviews over the telephone. This has minimised the number of clients requiring costly home visits for face-to-face interviews. We suggest that this model could be implemented elsewhere as best practice and if established it would make sense to test the validity of the telephone version.

It also does not seem the right time to develop the survey to include self-funders and those using voluntary services. There is no obvious sampling frame for a survey including self-funders or users of voluntary services. There are many potential routes to include these groups, such as sampling from those assessed by LAs but not offered services, using GP records, and using data from private and voluntary organisations. However, all of these options have a number of issues. The first option seems flawed on the basis that those assessed and not receiving services are by definition not in contact with the LA so there are question marks over the quality of any data recorded about that person, not least whether the person actually went on to purchase services. The other two options require organisations to share data to ensure that people are not sent duplicate questionnaires and therefore require organisations to comply with the Data Protection Act. This presents practical

---

[5] 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.

difficulties that need to be resolved before methods can be developed. In addition the quality of data collected by GPs and other organisations is unknown and would need to be investigated more thoroughly before this approach could be considered. We therefore think that a more useful direction is to consider how to improve the coverage and quality of the data collected for publicly-funded clients. The following areas are those that we consider to be priorities given the findings from this development work.

1. A priority is to develop methods to include the experiences of people who lack the capacity to consent to take part.

An important group that are excluded from the current survey are those who lack the capacity to consent to take part, who are arguably the most vulnerable and therefore exactly the people for whom we should be collecting data on their experiences. Those who lack the capacity to consent to take part are most likely to be, but not exclusively, care home residents, people with cognitive impairment and PWLD. One strategy to improve participation from this group is a proxy version of the questionnaire. The DEMQOL instrument, which is devised to measure quality of life for people with dementia, has a proxy version and a similar approach to this could be taken with the NASCUES survey (Smith et al., 2007). Research would need to establish the validity of the instrument and identify appropriate proxies. Work would also need to be carried out to identify how councils could identify a priori the people needing a proxy questionnaire and to whom to send the proxy questionnaire.

2. Stratified sampling should be piloted

This method is necessary to ensure the current sample is not biased, for the reasons already discussed. Where the stratification is used to bolster the numbers of people from small groups, it will also enable authorities to make better use of the data collected.

Councils are encouraged to use the data to explore differences in the experiences of users; however, some care needs to be taken when interpreting differences (or lack thereof) in experiences between people who have received different versions of the questionnaire or people with very different histories and characteristics. We have developed the LD version of the questionnaire in such a way to ensure that the meaning of the questions is the same across the versions, but there is not a straightforward way to test the validity of the two versions empirically. It is possible that a group of people with similar characteristics will systematically interpret the questions differently to other groups, which has consequences for how we interpret differences between groups.

It is important to understand whether the differences (or lack thereof) between groups are real or due to differences in interpretation as this can impact on how the results are presented. For example if we find that PWLD report worse experiences than everyone else, councils with on average more PWLD will appear to perform worse than other councils. If this finding represents a reality, that services for PWLD are worse than for other people, it is legitimate to simply add together the results of PWLD with those of other service users to present an average for the council. However, if this finding is a result of systematic differences in the interpretation of questions by PWLD compared to others, summing across responses would unfairly penalise councils with more PWLD. It may be more appropriate in the latter situation to introduce weights so that PWLD represent the same fraction of the results for each council. A follow-up study using in-depth interviews with a selection of people may help to unpick some of these issues and inform decisions about the need to weight, or otherwise, the results. For this survey it seems important to be transparent about the difficulties in this area to ensure the results are not interpreted in ways that are not supported by the data.

3. Depending on the results of the pilot, it may be useful to explore different ways of collecting the experiences of care home residents and PWLD.

In these studies we identified that many care home residents and PWLD find the current survey format difficult. But we also established that the majority of these people could express at least some views about their experiences and their quality of life. There is the possibility that adequate help is not be available to many of these clients to help them answer the questionnaire and it is possible that there will be high rates of non-response or high rates of proxy responses. If this is the case, it would be important to develop alternative methods that allow people to express their views in ways that are comfortable for them and that do not require someone being there to help them. Semi-structured face-to-face interviews, where interviewers are trained and receive instruction on how to code ‘free’ responses to ensure standardisation could be useful in this context. A combination of approaches, including observation, have been used in other pieces of PSSRU/Tizard research in care homes and this combination approach could work well in this context (Netten et al., 2010). It is clear that the methods suggested here place a greater burden on both resources and time than a postal questionnaire, and in deciding whether to take forward any development work in this area the impact of the additional costs of the approach would need to be considered. However, it is important to recognise that if the aim is to be as inclusive as possible then these methods may be the only way of reliably collecting the experiences of such service users.

References

Bucquet, D., Condon, S., and Ritchie, K. (1990) The French version of the Nottingham health profile. A comparison of items weights with those of the source version. *Social Science & Medicine, 30*(7), 829-835.

Caiels, J., Fox, D., McCarthy, M., Smith, N., Malley, J., Beadle-Brown, J., Netten, A., and Towers, A.-M. (2010) Development Studies for the National Adult Social Care User Experience Survey. Technical Report, PSSRU Discussion Paper No. 2724, Personal Social Services Research Unit, University of Kent.

Cohen-Mansfield, J. (2002) Relatives' Assessment of Pain in Cognitively Impaired Nursing Home Residents. *Journal of Pain and Symptom Management, 24*(6), 562-571.

Darton, R., Forder, J., Bebbington, A., Netten, A., Towers, A.-M., and Williams, J. (2006) *Analysis to support the Development of FSS Formulae for Older People: Final Report.* PSSRU Discussion Paper No. 2265/2, Personal Social Services Research Unit, University of Kent.

Fukahori, H., Matsui, N., Mizuno, Y., Yamamoto-Mitani, N., Sugai, Y., and Sugishita, C. (2007) Factors related to family visits to nursing home residents in Japan. *Archives of Gerontology and Geriatrics, 45*(1), 73-86.

Godlove Mozley, C., Huxley, P., Sutcliffe, C., Bagley, H., Burns, A., Challis, D., and. Cordingley, L. (1999) 'Not knowing where I am doesn't mean I don't know what I like': cognitive impairment and quality of life responses in elderly people. *International Journal of Geriatric Psychiatry, 14*(9), 776-783.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., and Teri, L. (1999) Quality of Life in Alzheimer's Disease: Patient and Caregiver Reports. *Journal of Mental Health and Aging, 5*, 21-32.

Malley, J., and Netten, A. (2009) *Putting People First: Development of the Putting People First User Experience Survey.* PSSRU Discussion Paper No.2637. Personal Social Services Research Unit, University of Kent.

Ministers, Local government, NHS, Social care, & Professional and Regulatory organisations. (2007) *Putting people first: a shared vision and commitment to the transformation of adult social care*. The Stationery Office, London.

Netten, A., Beadle-Brown, J., Trukeschitz, B., Towers, A.-M., Welch, E., Forder, J., Smith, J. and Alden, E. (2010) *Measuring the Outcomes of Care Homes,* PSSRU Discussion Paper No. 2696/2. Personal Social Services Research Unit, University of Kent.

Perkins, E. A. (2007) Self- and Proxy Reports Across Three Populations: Older Adults, Persons With Alzheimer's Disease, and Persons With Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities,* 4(1), 1-10.

Smith, S. C., Lamping, D. L., Banerjee, S., Harwood, R. H., Foley, B., Smith, P., et al. (2007) Development of a new measure of health-related quality of life for people with dementia: DEMQOL. *Psychological Medicine, 37*(05), 737-746.

Sturgis, P., Thomas, R., Purdon, S., Bridgwood, A., and Dodd, T. (2001) *Comparative Review and Assessment of Key Health State Measures of the General Population*. Department of Health, London.

Appendix 1: Gaining informed consent

The exploratory work by PSSRU and Tizard found that proxy respondents, i.e. people who respond on behalf of the service user, did not answer the questions on a consistent basis and the team, therefore, recommend that any service users who would need a proxy respondent to take part should be excluded. It is also a requirement of the Mental Capacity Act that informed consent is gained from all those who participate and in the case where the questionnaire is completed by a proxy it is not clear whether informed consent has been given by the service user. It is important to consider in this case what counts as informed consent.

Informed consent in the context of a postal survey

What was clear from the exploratory work was that the overwhelming majority of service users were able to express opinions about their care and their quality of life. However, many found the questionnaire format difficult for a variety of reasons, including cognitive, physical and so on, and would require substantial help to respond to a postal questionnaire. It is those service users that found the questionnaire difficult because of impairments affecting their cognitive abilities, where informed consent is a particular issue.

Many service users who participated in the exploratory work did not fully appreciate the concept of a survey, yet they did understand the following prior to the interview:

- Knowing that someone was going to ask questions about your life
- That lots of people were being asked these questions
- Knowing that the reason they were asking these questions was to make things better for people who use services

These three points seem most critical for informed consent and the researchers judged that consent had been gained when these criteria were met. If informed consent were extended to include understanding of the concept of a survey then many people who have opinions about their care and quality of life would be excluded. It seems important and in the spirit of the NASCUES to be as inclusive as possible so we recommend that people who can participate with help should not be excluded because they cannot fully appreciate the concept of a survey.

Guidance for LAs

To ensure compliance with the Mental Capacity Act, it is important to exclude people who lack the capacity to consent to take part in the survey. In this context consent is understood as 'informed consent', meaning that the person knows what they are agreeing to do. We recommend that the following guidance is issued to LAs to help them exclude people who lack the capacity to consent to take part.

To ensure that the 'right' people are excluded the following criteria should be used to assess whether the person understands what they are agreeing to do:

1. Does the person understand that the questions ask about the quality of their life and their services
2. Does the person understand that lots of people will be asked these questions and they are not being singled out
3. Does the person understand that these questions are being asked to make things better for people who are cared for or supported by services.

Please note that it is not important for the person to understand the concept of a survey. You should not exclude everyone with dementia or learning disabilities as exploratory work by PSSRU and Tizard has confirmed that many people with these impairments are able to answer the questions and give the level of informed consent required to take part.

The following process should be followed to exclude people who lack capacity to consent.

1. Draw sample from sample frame
2. Ask care managers to identify anyone who lacks the capacity to consent to take part. Care managers should use the criteria above to establish whether a person is able to consent.
3. All persons identified as lacking capacity should be excluded from the sample frame.
4. If care managers are unsure, capacity to consent should be presumed and the person should be included in the sample frame.
5. Draw a replacement sample for those excluded.

You will probably find that people who lack the capacity to consent to take part are more common amongst people with dementia, people in care homes and people with learning disabilities. This is why it is important that you resample to replace people who have been excluded from the sample. If this process is not followed your sample will have proportionately too few people with dementia, learning disabilities and living in care homes compared to your population figures in your RAP returns.

Appendix 2: Letter to care homes to gain support for NASCUES

Dear Care Home Manager

We are contacting you because the following residents in your home have been sent the 2010/11 National Social Care User Experience Survey.

1. Mr N Smith
2. Mrs N Smith

These residents have been selected at random to take part in this survey because they receive care and support services that are paid for (at least in part) by [Name of Social Services Department]. The Putting People First 2010/11 survey is a national survey carried out by the Department of Health and all local authorities with Social Services Responsibilities are required to take part. The survey asks service users about their quality of life and their experiences of the services they receive. It will be used by [Name of Social Services Department], the Care Quality Commission (CQC) and the Department of Health to assess the experiences of people using care and support services. It will not be used to assess the performance of individual care homes as procedures are already in place to do this via the CQC inspection regime. Safeguarding issues raised by the questionnaire, however, will be investigated in accordance with [Name of Social Services Department] duty of care to all residents.

Many care home residents will need some help filling in the survey. We would be grateful if you could assist your residents by, in the first instance, directing them to ask for help from any friends or relatives that visit them regularly or, perhaps if the resident has an existing relationship with an advocate, you could help the resident to contact the advocate. [LA delete as appropriate: You could also put the service users in touch with our helpline [Councils should mention here any telephone help line/advocacy group they have contact with through which assistance in completing the survey can be arranged] which would be able to provide some support over the phone if you think the resident would benefit from such help]. If you think it is more appropriate, for example because the resident has no regular visitors, you or your staff could help the resident.

The person who helps the resident complete the survey needs to ensure the following before they help the resident to complete the survey:

a) That the resident understands that the questions ask about the quality of their life and their services

b) That the resident understands that lots of people will be asked these questions and they are not being singled out

c) That the resident understands that these questions are asked to understand their experience and the experience of people like them.

d) That the resident is happy to take part and that not taking part will have no effect on the services or support they receive.

Please note that it is important that the answers given reflect the views of the resident. Help may be given to the resident to fill out and return the questionnaire, understand the questions and help the resident pick the most appropriate answer. However, if the resident is unable to answer the question the person helping should not answer on their behalf. In these cases, the question should be left blank.

The questionnaire should be returned in the envelope provided by [DATE]. If the resident cannot find the questionnaire or envelope provided, please ring this number ………………… to request a new one.

If you have questions you would like to ask about the survey please ring ……………… on Monday to Friday between 10.00 am and 12.00 pm or between 2.00 pm and 4.00 pm. [Councils can vary these hours or expand this sentence e.g. to say leave a message and someone will get back to you]

Appendix 3: Translation of the questionnaire to an LD version

The need to increase the accessibility of the survey was pressing, as most people with learning disabilities have problems with literacy and understanding written information (Rodgers and Namaganda, 2005). Whilst they could rely on others to read the information to them and complete the survey by proxy, good practice dictates that every effort should be made to enable them to access the information themselves. Moreover, the Disability Discrimination Act (2005) gives disabled people statutory rights to equal access to goods and services, and although surveys may not strictly be considered a good or service it is in the spirit of this Act to ensure that people with disability are treated equally.

When attempting to make information accessible, the importance of involving people with learning disabilities themselves in this process is well established (Ward and Townsley, 2005).

The process

An attempt was made to 'translate' standard written English into plain language. One of the main principles of using plain language is to try, as far as possible, to write the way you speak. The hope is that your audience will understand your written words as easily as they would understand you if you were having a conversation (Roeher Institute, 1997). Thus, the aim is to:

- cut out unnecessary words
- use concrete, straightforward and familiar words
- keep sentences short.

Clear words and phrases should replace less familiar words, e.g. *do* instead of *accomplish*, *help* instead of *assist*, *hard* instead of *difficult*, etc.

Some examples, from are the survey are found below.

The original survey said: I *get food and drink adequate for my needs.*
The LD version says: *I get enough food and drink*

The original survey said: *Having help sometimes undermines the way I think and feel about myself*

The LD version says: *Having help sometimes makes me feel a bit bad about myself*.

Testing the questions out on the focus groups and interviewees

After the preliminary attempt at simplifying the survey it was shown to participants. The researcher then explored with them ideas for increasing the accessibility of the content. Participants were essentially taken through a guided process to consider how the information could be presented differently to maximise people's ability to answer the questions. Emphasis was placed on the fact the *meaning* of the questions must not be altered; participants were helped to understand that words may be changed but the sense must remain the same.

The amended survey questions were then piloted with ten people with learning disabilities to test whether the questions were indeed understandable. Two versions of the interview were piloted: five with seven-point scale and LD version of EQ-5D and five with five-point scale and original EQ-5D. (The five-point response scale was without doubt easier for people to answer than the seven-point scale.) Audio recordings were made of both the focus groups and the pilot survey completion sessions.

Feedback from participants suggested that the survey was broadly understood by most people. Inevitably, given the differing levels of intellectual ability and communication skills amongst the participants, some people understood a lot more than others. Generally, feedback was not at the level of changing one word for another (perhaps partly because that groundwork had already been done) but was more related to increasing accessibility of the survey by adding or changing pictures and sometimes about changing the type of question. The most obvious example of the latter was the question on age. The original survey asked people to tick one of seven boxes to indicate their age. The vast majority of people with learning disabilities were unable to do this and suggested we change the question to simply ask people to write how old they were in a box or tick if they did not know their age.

Sometimes people would make suggestions for changing the wording of questions which may have eased understanding (for some) but which were not acceptable for other reasons. For instance, regarding the question about mental health, we had changed *anxious or depressed* to *worried or sad*, but one person suggested we just say 'going mad' instead.

Other feedback

We received feedback on the questionnaire from two other organisations (one an advocacy organisation and a council), which was conflicting. One felt that the smiley faces were patronising and the addition of thumbs up/down and ticks/ crosses would be confusing. The other felt that having the range of symbols was very good, as it would help people with differing communication needs. The advocacy organisation reported that the questionnaire was far too long and that even a five-point scale was probably too much for many people with learning disabilities, suggesting that two- or three-point response options are usually preferable.

Appendix 4: The questionnaire that was tested

Your Social Care and Support Services

Introduction

We are contacting you because you receive care and support services that are paid for (at least in part) by [your local Social Services Department]. By care and support services we mean you may be living in a care home, receiving a Personal Budget, home care, equipment, meals-on-wheels, Direct Payments, or attending a day centre. We want to improve and develop our services so we want to get your views on the services you receive. In particular, we want to hear about your quality of life and how services have affected the quality of your life.

Why you were selected

You have been selected at random from [Social Services'] records of people who are receiving social care and support services.

What we would like you to do

We would like you to help us by taking about ten minutes to give us your views about the care and support services you receive. If you choose not to answer this questionnaire this will not affect the services you receive.

What to do if you need help to give your views

If you would like, you can ask a friend, relative or an advocate to help you complete the questionnaire. Please remember that it is your views and your experiences that are important to us, rather than the views of anyone that helps you. You can also get in touch with [the telephone assistance line] to ask for someone independent from social services and your care provider to help you to complete the questionnaire. [Councils should mention here any telephone help line/advocacy group they have contact with through which assistance in completing the survey can be arranged] Staff from [Social Services] or anyone you pay who have been involved in the provision of your care or support should not help you.

If you are unable to complete this questionnaire either on your own, or by verbally giving answers for someone else to record, such as a friend or relative, then please either discard it or if you are able, return it uncompleted in the envelope enclosed.

What to do if you have queries or would like to know how to obtain information on the results

If you, or your friend or relative, have questions you would like to ask about the survey please ring ……………… on Monday to Friday between 10.00 am and 12.00 pm or between 2.00 pm and 4.00 pm [Councils can vary these hours or expand this sentence e.g. to say leave a message and someone will get back to you]

What will be done with the results of the survey

The results of the survey will be used by the Care Quality Commission, the Department of Health and your [social services department] to see how happy people are with their care and support services, whether improvements or developments need to be made to local care services and for further research or analysis.

Confidentiality

Your answers will be treated as confidential: they will not be passed on to your social worker, care manager, care and support worker or anyone providing you with services. You will not be personally identified and your answers will not affect the services you receive.

The code found [enter position] on this form is used for administration purposes only to make sure that when you return this questionnaire we do not send you another one. However, if you say on the form that you are being hurt or harmed by anybody or your safety or health is at risk then we will use this code to identify you so that someone (but not your care and support worker) can contact you to talk about it. This is the only circumstance under which this code will be used to identify you.

Reminder Letters

If you do not return this questionnaire then you may be sent reminder letters. If you do not wish to receive reminders then please send back an uncompleted questionnaire in the envelope provided.

Sending back the completed questionnaire

Once you have completed the questionnaire please return it in the envelope provided by **[DATE]**. You don’t need to put a stamp on the envelope.

Thank you for helping us by completing this questionnaire.

Section 1: Overall satisfaction with your social care and support

1. Overall, how satisfied are you with the care and support services you receive?

By 'care and support services' we mean any care delivered by staff who are paid to help you. The staff could be from [Social Services], an agency, a care home or bought by you using money from [Social Services] through a Direct Payment.

Please tick (✓) one box

I am extremely satisfied ☐

I am very satisfied ☐

I am quite satisfied ☐

I am neither satisfied nor dissatisfied ☐

I am quite dissatisfied ☐

I am very dissatisfied ☐

I am extremely dissatisfied ☐

Section 2: Your quality of life
When answering the following questions please think about the quality of your life as a whole, including the help you get from others as well as **[Social Services]**.

2. **Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?**

Please tick (✓) one box

So good, it could not be better ☐
Very good ☐
Good ☐
Alright ☐
Bad ☐
Very bad ☐
So bad, it could not be worse ☐

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

By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want

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 ☐

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

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 don’t feel at all clean or presentable ☐

5. 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 enough adequate food and drink when I want ☐

I don’t always get enough adequate food and drink when I want, but I don’t think there is a risk to my health ☐

I don’t always get enough adequate food and drink when I want, and I think there is a risk to my health ☐

6. 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 not quite clean or comfortable enough ☐

My home is not at all clean or comfortable ☐

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

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

Please tick (✓) one box

I feel as safe as I want ☐

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

I feel less than adequately safe ☐

I don't feel at all safe ☐

8. **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 ☐

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

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

Please tick (✓) one box

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

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

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

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

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

Please tick (✓) one box

Having help makes me think and feel better about myself ☐

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

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

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

11. 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	☐

Section 3: The impact of social care and support services on your quality of life

12. In what ways do care and support services help you?

By 'care and support services' we mean any care delivered by staff who are paid to help you. The staff can be from [Social Services], an agency or bought by you using money from Social Services, using a Direct Payment.

Please tick (✓) all that apply

To have control over my daily life ☐
With personal care ☐
Meals ☐
Social contact with people I like ☐
Doing things I value and enjoy ☐
Feeling safe and secure ☐
Keeping my home clean and comfortable ☐
Other (please tell us what in the box below) ☐

Section 4: Knowledge and information

13. In the past year, have you found it easy or difficult to find information and advice about support, services or benefits? *Please include information from different sources, such as voluntary organisations, and private agencies as well as* **[Social Services]**.

Please tick (✓) one box

Very easy to find ☐

Fairly easy to find ☐

Fairly difficult to find ☐

Very difficult to find ☐

I've never tried to find information or advice ☐

14. If you felt unsafe or were worried about something that had happened to you, who would you talk to?

Please tick (✓) <u>as many</u> boxes as apply

A member of your family ☐

A friend, neighbour or someone you work with ☐

Your keyworker, Personal Assistant or care worker ☐

The manager of your care home or day centre ☐

Your care manager or social worker ☐

Someone else (please tell us who they are – their job, not their name) ☐

No-one I wouldn't say anything ☐

I don't know ☐

Section 5: Your health

15. How is your health in general?

Please tick (✓) one box

Very Good ☐

Good ☐

Fair ☐

Bad ☐

Very Bad ☐

16. By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

a. Mobility

Please tick (✓) one box

I have no problems in walking about ☐

I have some problems in walking about ☐

I am confined to bed ☐

b. Self-care

Please tick (✓) one box

I have no problems with self-care ☐

I have some problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

c. **Usual activities *(e.g. work, study, housework, family or leisure activities)***

Please tick (✓) one box

I have no problems with performing my usual activities ☐

I have some problems with performing my usual activities ☐

I am unable to perform my usual activities ☐

d. **Pain or discomfort**

Please tick (✓) one box

I have no pain or discomfort ☐

I have moderate pain or discomfort ☐

I have extreme pain or discomfort ☐

e. **Anxiety or depression**

Please tick (✓) one box

I am not anxious or depressed ☐

I am moderately anxious or depressed ☐

I am extremely anxious or depressed ☐

17. **Please place a tick (✓) in the box that best describes your abilities for each of the following statements labelled from a to i.**

	I can do this easily by myself	I have difficulty doing this myself	I can't do this by myself
a. Do you usually manage to get up and down stairs or steps by yourself?	☐	☐	☐
b. Do you usually manage to go out of doors and walk down the road by yourself?	☐	☐	☐
c. Do you usually manage to get around indoors (except steps) by yourself?	☐	☐	☐
d. Do you usually manage to get in and out of a bed (or chair) by yourself?	☐	☐	☐
e. Do you usually manage to use the WC/toilet by yourself?	☐	☐	☐
f. Do you usually manage to wash your face and hands by yourself?	☐	☐	☐
g. Do you usually manage to bath, shower or wash all over by yourself?	☐	☐	☐
h. Do you usually manage to get dressed and undressed by yourself?	☐	☐	☐
i. Do you usually manage to feed yourself?	☐	☐	☐

18. Please place a tick (✓) in the box that best describes your abilities for each of the following statements labelled from a to c.

	I can do this easily by myself	I have difficulty doing this myself	I can't do this by myself
a. Do you usually deal with finances and paperwork- for example, paying bills, writing letters – by yourself?	☐	☐	☐
b. Do you usually manage to do the household shopping for yourself?	☐	☐	☐
c. Do you usually manage to prepare hot meals for yourself?	☐	☐	☐

19. Do you use a wheelchair to get about?

Please tick (✓) one box

Yes, all of the time	☐
Yes, some of the time	☐
No	☐

Section 6: About your surroundings

20. How well do you think your home is designed to meet your needs?

Please tick (✓) one box

My home meets my needs very well ☐

My home meets most of my needs ☐

My home meets some of my needs ☐

My home is totally inappropriate for my needs ☐

21. Thinking about getting around outside of your home, which of the following statements best describes your present situation?

You can include getting around by yourself or with help from someone else

Please tick (✓) one box

I can get to all the places in my local area that I want ☐

At times I find it difficult to get to all the places in my local area that I want ☐

I am unable to get to all the places in my local area that I want ☐

Section 7: About yourself, the service user

The answers to the next group of questions will be used to get a picture of who took part in this survey. For example, we will use these questions to help us make sure that services are delivered equally to people with different backgrounds.

22. Are you male or female?

Please tick (✓) one box

Male ☐

Female ☐

23. Which age group do you belong to?

Please tick (✓) one box

18-24 ☐

25-30 ☐

31-39 ☐

40-49 ☐

50-64 ☐

65-74 ☐

75-84 ☐

85 or over ☐

24. To which of these groups do you consider you belong?

Please tick (✓) one box

White (British, Irish, Traveller of Irish Heritage, Gypsy/Roma, any other white background) ☐

Mixed (White and Black Caribbean, White and Black African, White and Asian, any other mixed background) ☐

Asian or Asian British (Indian, Pakistani, Bangladeshi, any other Asian background) ☐

Black or Black British (Caribbean, African or any other Black background) ☐

Chinese ☐

Any other ethnic group ☐

25. What is your religion?

Please tick (✓) one box

None ☐

Christian ☐

Buddhist ☐

Hindu ☐

Jewish ☐

Muslim ☐

Sikh ☐

Other (please tell us what in box below) ☐

26. Do you have any of these health conditions?

Please tick (✓) <u>as many</u> boxes as apply

Dementia / Alzheimer's ☐

A physical disability ☐

Sight or hearing loss ☐

A mental health problem ☐

A learning disability ☐

Terminal illness ☐

Alcohol or drug dependency ☐

Other (please tell us what in box below) ☐

27. Do you receive any practical help on a regular basis from your husband/wife, partner, friends, neighbours or family members?

Please tick (✓) as many boxes as apply

Yes, from someone living in my household ☐

Yes, from someone living in another household ☐

No ☐

28. Do you buy any additional care or support privately or pay more to 'top up' your care and support?

Please tick (✓) as many boxes as apply

Yes, I buy some more care and support with my own money ☐

Yes, my family pays for some more care and support for me ☐

No ☐

29. Did you write the answers to this questionnaire by yourself or did you have help from someone else?

Please tick (✓) one box

Yes, I wrote the answers myself ☐

No, I had help from a care worker ☐

No, I had help from someone living in my household ☐

No, I had help from someone living outside my household ☐

30. What type of help did you have?

Please tick (✓) <u>as many</u> boxes as apply

None, because I wrote the answers myself ☐

Someone else read the questions to me ☐

Someone else translated the questions for me ☐

Someone else wrote down the answers for me ☐

I talked through the questions with someone else ☐

Someone answered for me, without asking me the questions ☐

Thank you for helping us by filling in this questionnaire.

Please tick (✓) this box if you would like to receive a copy of the report of this survey ☐

Please post it back to us in the envelope provided.
You don't need to put a stamp on the envelope.

For your views to count please return this form by DATE

Appendix 5: Main questionnaire

Your Social Care and Support Services

Introduction

We are contacting you because you receive care and support services that are paid for (at least in part) by [your local Social Services Department]. By care and support services we mean you may be living in a care home, receiving a Personal Budget, home care, equipment, meals-on-wheels, Direct Payments, or attending a day centre. We want to improve and develop our services so we want to get your views on the services you receive. In particular, we want to hear about your quality of life and how services have affected the quality of your life.

Why you were selected

You have been selected at random from [Social Services'] records of people who are receiving social care and support services.

What we would like you to do

We would like you to help us by taking about twenty minutes to give us your views about the care and support services you receive. If you choose not to answer this questionnaire this will not affect the services you receive.

What to do if you need help to give your views

If you would like, you can ask a friend, relative or an advocate to help you complete the questionnaire. Please remember that it is your views and your experiences that are important to us, rather than the views of anyone that helps you. You can also get in touch with [the telephone assistance line] to ask for someone independent from social services and your care provider to help you to complete the questionnaire. [Councils should mention here any telephone help line/advocacy group they have contact with through which assistance in completing the survey can be arranged] Staff from [Social Services] or anyone that you pay to care for you should not help you to fill it in.

If you are unable to complete this questionnaire either on your own, or by verbally giving answers for someone else to record, such as a friend or relative, then please either discard it or if you are able, return it uncompleted in the envelope enclosed.

What to do if you have queries or would like to know how to obtain information on the results

If you, or your friend or relative, have questions you would like to ask about the survey please ring ……………… on Monday to Friday between 10.00 am and 12.00 pm or between 2.00 pm and 4.00 pm [Councils can vary these hours or expand this sentence e.g. to say leave a message and someone will get back to you]

What will be done with the results of the survey

The results of the survey will be used by the Care Quality Commission, the Department of Health and your [Social services department] to see how happy people are with their care and support services and assess their experiences of local care services. The results will also be used for further research or analysis.

Confidentiality

Your answers will be treated as confidential: they will not be passed on to your social worker, care manager, care and support worker or anyone providing you with services. You will not be personally identified and your answers will not affect the services you receive.

The code found [enter position] on this form is used for administration purposes only to make sure that when you return this questionnaire we do not send you another one. However, if you say on the form at question 7 that you are being hurt or harmed by anybody or your safety or health at risk then we will use this code to identify you so that someone from the survey team (but not your care and support worker) will contact you initially to talk about it. This is the only circumstance under which this code will be used to identify you.

Reminder Letters

If you do not return this questionnaire then you may be sent reminder letters. If you do not wish to receive reminders then please send back an uncompleted questionnaire in the envelope provided.

Sending back the completed questionnaire

Once you have completed the questionnaire please return it in the envelope provided by **[DATE]**. You don’t need to put a stamp on the envelope.

Thank you for helping us by completing this questionnaire.

Section 1: Overall satisfaction with your social care and support

1. Overall, how satisfied are you with the care and support services you receive?

By ‘care and support services’ we mean any care provided by staff who are paid to help you. The staff could be from [Social Services], an agency, a care home or bought by you using money from [Social Services] through a Direct Payment.

Please tick (✓) one box

I am extremely satisfied ☐

I am very satisfied ☐

I am quite satisfied ☐

I am neither satisfied nor dissatisfied ☐

I am quite dissatisfied ☐

I am very dissatisfied ☐

I am extremely dissatisfied ☐

Section 2: Your quality of life

When answering the following questions please think about the quality of your life as a whole, including the help you get from others as well as **[Social Services]**.

2. Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?

Please tick (✓) one box

So good, it could not be better ☐
Very good ☐
Good ☐
Alright ☐
Bad ☐
Very bad ☐
So bad, it could not be worse ☐

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

By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want

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 ☐

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

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 don’t feel at all clean or presentable ☐

5. Thinking about the food and drink you get, 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 adequate food and drink at OK times ☐

I don’t always get adequate or timely food and drink ☐

I don’t always get adequate or timely food and drink, and I think there is a risk to my health ☐

6. 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 not quite clean or comfortable enough ☐

My home is not at all clean or comfortable ☐

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

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

Please tick (✓) one box

I feel as safe as I want ☐

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

I feel less than adequately safe ☐

I don't feel at all safe ☐

8. 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 ☐

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

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

Please tick (✓) one box

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

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

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

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

10. Which of these statements best describes <u>how having help to do things</u> makes you think and feel about yourself?

Please tick (✓) one box

Having help makes me think and feel better about myself ☐

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

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

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

11. Thinking about the <u>way you are helped and treated</u>, 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	☐

Section 3: The impact of social care and support services on your quality of life

12. In what ways do care and support services help you?

By ‘care and support services’ we mean any care provided by staff who are paid to help you. The staff can be from [Social Services], an agency or bought by you using money you receive from [Social Services], using a Direct Payment.

Please tick (✓) as many boxes as apply

To have control over my daily life ☐

With personal care ☐

Meals ☐

Social contact with people I like ☐

Doing things I value and enjoy ☐

Feeling safe and secure ☐

Keeping my home clean and comfortable ☐

Other (please tell us what in the box below) ☐

Section 4: Knowledge and information

13. In the past year, have you found it easy or difficult to find information and advice about support, services or benefits? *Please include information from different sources, such as voluntary organisations, and private agencies as well as* [Social Services].

Please tick (✓) one box

Very easy to find ☐

Fairly easy to find ☐

Fairly difficult to find ☐

Very difficult to find ☐

I've never tried to find information or advice ☐

14. Thinking about the care and support you receive, if you felt unsafe or were worried about something that had happened to you, who would you talk to?

Please tick (✓) <u>as many</u> boxes as apply

A member of your family ☐

A friend or neighbour ☐

Your keyworker, Personal Assistant or care worker ☐

The manager of your care home or day centre ☐

Your care manager or social worker ☐

Someone else (please tell us who they are – their job, not their name) ☐

No-one I wouldn't say anything ☐

I don't know ☐

Section 5: Your health

15. How is your health in general?

Please tick (✓) one box

Very Good ☐

Good ☐

Fair ☐

Bad ☐

Very Bad ☐

16. By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

a. Pain or discomfort

Please tick (✓) one box

I have no pain or discomfort ☐

I have moderate pain or discomfort ☐

I have extreme pain or discomfort ☐

b. Anxiety or depression

Please tick (✓) one box

I am not anxious or depressed ☐

I am moderately anxious or depressed ☐

I am extremely anxious or depressed ☐

17. Please place a tick (✓) in the box that best describes your abilities for each of the following questions labelled from a to d.

	I can do this easily by myself	I have difficulty doing this myself	I can't do this by myself
a. Do you usually manage to get around indoors (except steps) by yourself?	☐	☐	☐
b. Do you usually manage to get in and out of a bed (or chair) by yourself?	☐	☐	☐
c. Do you usually manage to feed yourself?	☐	☐	☐
d. Do you usually deal with finances and paperwork- for example, paying bills, writing letters – by yourself?	☐	☐	☐

18. Please place a tick (✓) in the box that best describes your abilities for each of the following questions labelled from a to d.

	I can do this easily by myself	I have difficulty doing this myself	I can't do this by myself
a. Do you usually manage to use the WC/toilet by yourself?	☐	☐	☐
b. Do you usually manage to wash your face and hands by yourself?	☐	☐	☐
c. Do you usually manage to wash all over by yourself, using either a bath or shower?	☐	☐	☐
d. Do you usually manage to get dressed and undressed by yourself?	☐	☐	☐

Section 6: About your surroundings

19. How well do you think your home is designed to meet your needs?

Please tick (✓) <u>one</u> box

My home meets my needs very well ☐

My home meets most of my needs ☐

My home meets some of my needs ☐

My home is totally inappropriate for my needs ☐

20. Thinking about getting around outside of your home, which of the following statements best describes your present situation?

You can include getting around by yourself or with help from someone else

Please tick (✓) <u>one</u> box

I can get to all the places in my local area that I want ☐

At times I find it difficult to get to all the places in my local area that I want ☐

I am unable to get to all the places in my local area that I want ☐

Section 7: About yourself, the service user

The answers to the next group of questions will be used to get a picture of who took part in this survey. For example, we will use these questions to help us make sure that services are delivered equally to people with different backgrounds.

21. Do you receive any practical help on a regular basis from your husband/wife, partner, friends, neighbours or family members?

Please tick (✓) as many boxes as apply

Yes, from someone living in my household ☐

Yes, from someone living in another household ☐

No ☐

22. Do you buy any additional care or support privately or pay more to 'top up' your care and support?

Please tick (✓) as many boxes as apply

Yes, I buy some more care and support with my own money ☐

Yes, my family pays for some more care and support for me ☐

No ☐

23. Did you write the answers to this questionnaire by yourself or did you have help from someone else?

Please tick (✓) <u>one</u> box

Yes, I wrote the answers myself ☐

No, I had help from a care worker ☐

No, I had help from someone living in my household ☐

No, I had help from someone living outside my household ☐

24. What type of help did you have?

Please tick (✓) <u>as many</u> boxes as apply

None, because I wrote the answers myself ☐

Someone else read the questions to me ☐

Someone else translated the questions for me ☐

Someone else wrote down the answers for me ☐

I talked through the questions with someone else ☐

Someone answered for me, without asking me the questions ☐

Thank you for helping us by filling in this questionnaire.

Please post it back to us in the envelope provided.
You don't need to put a stamp on the envelope.

For your views to count please return this form by DATE

Appendix 6: Care homes questionnaire

Your Social Care and Support Services

Introduction

We are contacting you because you receive care and support services that are paid for (at least in part) by [your local Social Services Department]. We want to improve and develop our services so we want to get your views on the care you receive. In particular, we want to hear about your quality of life and how services have affected the quality of your life.

Why you were selected

You have been selected at random from [Social Services'] records of people who are receiving social care and support services.

What we would like you to do

We would like you to help us by taking about twenty minutes to give us your views about the care and support services you receive. If you choose not to answer this questionnaire this will not affect the services you receive.

What to do if you need help to give your views

If you would like, you can ask a friend, relative or an advocate to help you complete the questionnaire. You can also ask your care home manager about getting help. They have been sent a letter informing them that you have been sent this survey. Please remember that it is your views and your experiences that are important to us, rather than the views of anyone that helps you. If you prefer, you can also get in touch with [the telephone assistance line] to ask for someone independent from social services and your care provider to help you to complete the questionnaire. [Councils should mention here any telephone help line/advocacy group they have contact with through which assistance in completing the survey can be arranged]. Staff from [Social Services] or anyone that you pay to care for you should not help you to fill it in.

If you are unable to complete this questionnaire either on your own, or by verbally giving answers for someone else to record, such as a friend or relative, then please either discard it or if you are able, return it uncompleted in the envelope enclosed.

What to do if you have queries or would like to know how to obtain information on the results

If you, or your friend or relative, have questions you would like to ask about the survey please ring ……………… on Monday to Friday between 10.00 am and 12.00 pm or between 2.00 pm and 4.00 pm [Councils can vary these hours or expand this sentence e.g. to say leave a message and someone will get back to you]

What will be done with the results of the survey

The results of the survey will be used by the Care Quality Commission, the Department of Health and your [Social services department] to see how happy people are with their care and support services and assess their experiences of local care services. The results will also be used for further research or analysis.

Confidentiality

Your answers will be treated as confidential: they will not be passed on to your social worker, care manager, care and support worker or anyone providing you with services. You will not be personally identified and your answers will not affect the services you receive.

The code found [enter position] on this form is used for administration purposes only to make sure that when you return this questionnaire we do not send you another one. However, if you say on the form at question 7 that you are being hurt or harmed by anybody or your safety or health at risk then we will use this code to identify you so that someone from the survey team (but not your care and support worker) will contact you initially to talk about it. This is the only circumstance under which this code will be used to identify you.

Reminder Letters

If you do not return this questionnaire then you may be sent reminder letters. If you do not wish to receive reminders then please send back an uncompleted questionnaire in the envelope provided.

Sending back the completed questionnaire

Once you have completed the questionnaire please return it in the envelope provided by **[DATE]**. You don’t need to put a stamp on the envelope.

Thank you for helping us by completing this questionnaire.

Section 1: Overall satisfaction with your social care and support

1. Overall, how satisfied are you with the care and support services you receive?

By 'care and support services' we mean any care provided by staff who are paid to help you. The staff could be from your care home or [Social Services].

Please tick (✓) one box

I am extremely satisfied ☐

I am very satisfied ☐

I am quite satisfied ☐

I am neither satisfied nor dissatisfied ☐

I am quite dissatisfied ☐

I am very dissatisfied ☐

I am extremely dissatisfied ☐

Section 2: Your quality of life

When answering the following questions please think about the quality of your life as a whole, including the help you get from others as well as **[Social Services]**.

2. Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?

Please tick (✓) one box

So good, it could not be better ☐

Very good ☐

Good ☐

Alright ☐

Bad ☐

Very bad ☐

So bad, it could not be worse ☐

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

By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want

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 ☐

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

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 don't feel at all clean or presentable ☐

5. **Thinking about the food and drink you get, 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 adequate food and drink at OK times ☐

I don't always get adequate or timely food and drink ☐

I don't always get adequate or timely food and drink, and I think there is a risk to my health ☐

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

Please tick (✓) one box

My care home is as clean and comfortable as I want ☐

My care home is adequately clean and comfortable ☐

My care home is not quite clean or comfortable enough ☐

My care home is not at all clean or comfortable ☐

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

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

Please tick (✓) one box

I feel as safe as I want ☐

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

I feel less than adequately safe ☐

I don’t feel at all safe ☐

8. 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 ☐

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

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

Please tick (✓) one box

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

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

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

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

10. Which of these statements best describes <u>how having help to do things</u> makes you think and feel about yourself?

Please tick (✓) <u>one</u> box

Having help makes me think and feel better about myself ☐

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

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

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

11. 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 ☐

Section 3: The impact of social care and support services on your quality of life

12. In what ways do care and support services help you?

By ‘care and support services’ we mean any care provided by staff who are paid to help you. The staff can be from your care home or [Social Services].

Please tick (✓) as many boxes as apply

To have control over my daily life	☐
With personal care	☐
Meals	☐
Social contact with people I like	☐
Doing things I value and enjoy	☐
Feeling safe and secure	☐
Keeping my home clean and comfortable	☐
Other (please tell us what in the box below)	☐

Section 4: Knowledge and information

13. In the past year, have you found it easy or difficult to find information and advice about support, services or benefits? *Please include information from different sources, such as voluntary organisations, and private agencies as well as* **[Social Services]**.

Please tick (✓) one box

Very easy to find ☐

Fairly easy to find ☐

Fairly difficult to find ☐

Very difficult to find ☐

I've never tried to find information or advice ☐

14. Thinking about the care and support you receive, if you felt unsafe or were worried about something that had happened to you, who would you talk to?

Please tick (✓) <u>as many</u> boxes as apply

A member of your family ☐

A friend or neighbour ☐

Your keyworker, Personal Assistant or care worker ☐

The manager of your care home or day centre ☐

Your care manager or social worker ☐

Someone else (please tell us who they are – their job, not their name) ☐

No-one I wouldn't say anything ☐

I don't know ☐

Section 5: Your health

15. How is your health in general?

Please tick (✓) one box

Very Good ☐

Good ☐

Fair ☐

Bad ☐

Very Bad ☐

16. By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

a. Pain or discomfort

Please tick (✓) one box

I have no pain or discomfort ☐

I have moderate pain or discomfort ☐

I have extreme pain or discomfort ☐

b. Anxiety or depression

Please tick (✓) one box

I am not anxious or depressed ☐

I am moderately anxious or depressed ☐

I am extremely anxious or depressed ☐

17. Please place a tick (✓) in the box that best describes your abilities for each of the following questions labelled from a to d.

	I can do this easily by myself	I have difficulty doing this myself	I can't do this by myself
a. Do you usually manage to get around indoors (except steps) by yourself?	☐	☐	☐
b. Do you usually manage to get in and out of a bed (or chair) by yourself?	☐	☐	☐
c. Do you usually manage to feed yourself?	☐	☐	☐
d. Do you usually deal with finances and paperwork- for example, paying bills, writing letters – by yourself?	☐	☐	☐

18. Please place a tick (✓) in the box that best describes your abilities for each of the following questions labelled from a to d.

	I can do this easily by myself	I have difficulty doing this myself	I can't do this by myself
a. Do you usually manage to use the WC/toilet by yourself?	☐	☐	☐
b. Do you usually manage to wash your face and hands by yourself?	☐	☐	☐
c. Do you usually manage to wash all over by yourself, using either a bath or shower?	☐	☐	☐
d. Do you usually manage to get dressed and undressed by yourself?	☐	☐	☐

Section 6: About your surroundings

19. How well do you think your care home is designed to meet your needs?

Please tick (✓) <u>one</u> box

My care home meets my needs very well ☐

My care home meets most of my needs ☐

My care home meets some of my needs ☐

My care home is totally inappropriate for my needs ☐

20. Thinking about getting around outside of the care home, which of the following statements best describes your present situation?

You can include getting around by yourself or with help from someone else

Please tick (✓) <u>one</u> box

I can get to all the places in my local area that I want ☐

At times I find it difficult to get to all the places in my local area that I want ☐

I am unable to get to all the places in my local area that I want ☐

Section 7: About yourself, the service user

The answers to the next group of questions will be used to get a picture of who took part in this survey. For example, we will use these questions to help us make sure that services are delivered equally to people with different backgrounds.

21. Do you receive any practical help on a regular basis from your husband/wife, partner, friends, neighbours or family members?

Please tick (✓) one box

Yes, from someone living in my care home ☐

Yes, from someone living outside my care home ☐

No ☐

22. Do you buy any additional care or support privately or pay more to 'top up' your care and support?

Please tick (✓) as many boxes as apply

Yes, I buy some more care and support with my own money ☐

Yes, my family pays for some more care and support for me ☐

No ☐

23. Did you write the answers to this questionnaire by yourself or did you have help from someone else?

Please tick (✓) <u>one</u> box

Yes, I wrote the answers myself ☐

- -

No, I had help from a care worker ☐

No, I had help from someone living in my care home ☐

No, I had help from someone living outside my care home ☐

24. What type of help did you have?

Please tick (✓) <u>as many</u> boxes as apply

None, because I wrote the answers myself ☐

Someone else read the questions to me ☐

Someone else translated the questions for me ☐

Someone else wrote down the answers for me ☐

I talked through the questions with someone else ☐

Someone answered for me, without asking me the questions ☐

Thank you for helping us by filling in this questionnaire.

Please post it back to us in the envelope provided.
You don't need to put a stamp on the envelope.

For your views to count please return this form by DATE

Appendix 7: People with Learning Difficulties questionnaire

Your social care and support services

This letter is to ask you if you could help us.

The Questions
There is a form with this letter which has lots of questions on it. The questions are all about the help you get and whether that help makes your life better. There are no right or wrong answers. We are just interested in what you think. We are asking these questions to lots and lots of people.

Why are we asking these questions?
If you answer these questions, we can learn more about what people think about the help they get.

Your decision
You do not have to answer the questions if you don't want to. It is up to you. It will make no difference to the help you already get.

If you need help
If you need help with reading the questions and filling in the form, then you can ask a friend or someone in your family to help you. If you don't have friends or family who can help, you can phone ……………………and someone there may be able to help you. But please remember, we want to know what you think about things, not what your friends or family think.

Keeping your information private
The answers you give us will be kept private. The only time we would tell anyone what you have said is if you tell us that you are being hurt by someone or you are in danger.

If you want to find out more
If you want to find out more about why we are asking these questions, you can phone………………………

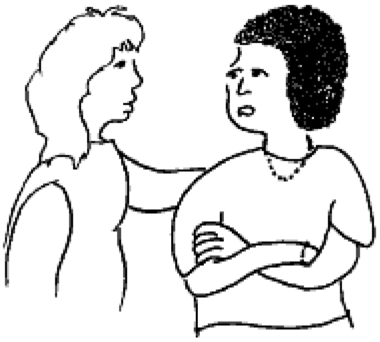
Sending the form back
When you have answered the questions, please put it in the envelope we have given you. This envelope does not need a stamp. Please post it back to us by……………..

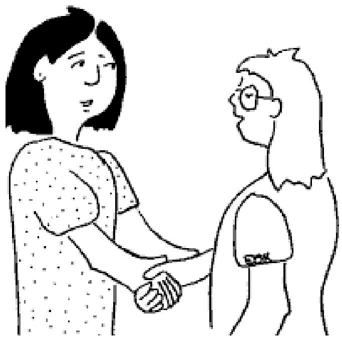
Thank you for your help.

These questions are all about your life.

SECTION 1

1. How happy are you with the way staff help you?





Please tick (✓) one box

I am **very** happy with the way staff help me, it's really good ☐ 😊 👍 ✓

I am quite happy with the way staff help me ☐ 😊 👍 ✓

The way staff help me is OK ☐ 😐 👎 x

I don't think the way staff help me is that good ☐ ☹ 👎 ✗

I think the way staff help me is really bad ☐ ☹ 👎 ✗

SECTION 2

2. Thinking about all the different things in your life, good and bad, how would you say you feel about your life in general:

Please tick (✓) one box

My life is really great ☐ 🙂 👍 ✓

My life is mostly good ☐ 🙂 👍 ✓

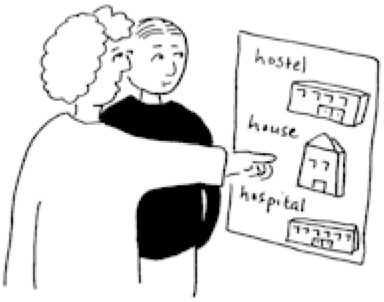
My life is OK, some good things, some bad things ☐ 😐 👎 x

My life is mostly bad ☐ 🙁 👎 ✗

My life is really terrible ☐ 🙁 👎 ✗

3. How much control you have in your life?

By 'control' we mean making choices about what happens.



Please tick (✓) one box

I make all the choices I want ☐ ☺ 👍 ✓

I make some choices, not all, but that's OK ☐ ☺ 👍 ✓

I make some choices but not enough ☐ 😐 👎 X

I don't get to make any choices ☐ ☹ 👎 ✗

4. **When it comes to keeping clean, and how you look (your clothes, your hair, etc.) how do you feel?**

Please tick (✓) one box

I feel clean and I like the way I look ☐ ☺ 👍 ✓

I quite like the way I feel and look, it's OK ☐ ☺ 👍 ✓

I feel a bit clean and tidy, but not enough ☐ 😐 👎 x

I don't feel at all clean or tidy ☐ ☹ 👎 ✗

5. What do you get to eat and drink?

Please tick (✓) one box

I get all the food and drink I like when I want it ☐ 😊 👍 ✓

I get enough food and drink ☐ 😊 👍 ✓

I don’t get all the food and drink I want, but I don’t think I will get ill because of it ☐ 😐 👎 x

I don’t get all the food and drink I need, and I think this might make me ill ☐ ☹ 👎 ✗

6. What do you think about your home?

Please tick (✓) one box

My home is as clean and nice as I want ☐ 😀 👍 ✓

My home is quite clean and nice, its OK ☐ 🙂 👍 ✓

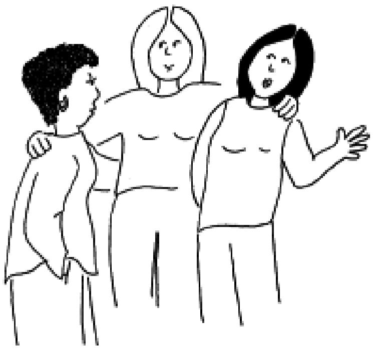
My home is not clean or nice enough ☐ 😐 👎 x

My home is not at all clean or nice ☐ ☹ 👎 ✗

7. How safe do you feel?

By feeling safe we mean feeling safe both at home and outside. This could be things like:

- *a. fear of abuse or being hurt,*
- *b. fear of having things stolen from you or*
- *c. fear of having an accident.*



Please tick (✓) one box

I feel very safe ☐ ☺ 👍 ✓

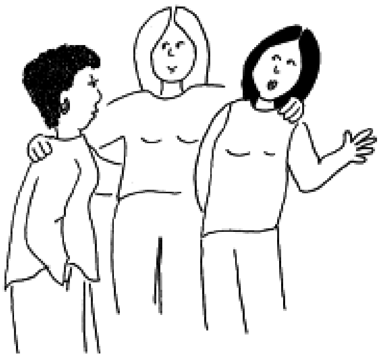
I feel quite safe, but not as safe as I would like ☐ ☺ 👍 ✓

I don't feel safe enough ☐ 😐 👎 X

I don't feel safe at all ☐ ☹ 👎 ✗

8. How do you feel about your social life?

By social life we mean the time you spend with friends and family.



Please tick (✓) one box

I see my friends and family as much I want ☐ 🙂 👍 ✓

I see my friends and family sometimes, it's OK ☐ 🙂 👍 ✓

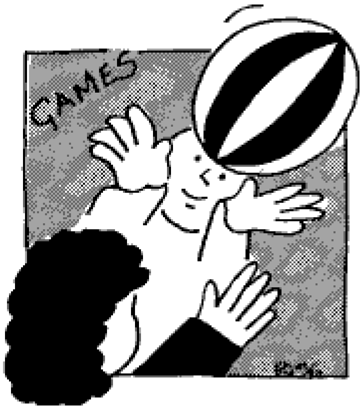
I do see friends and family, but not enough ☐ 😐 👎 x

I feel lonely because I don't see my friends and family very much or at all ☐ ☹ 👎 ✗

9. How do you spend your time?

When you are thinking about how you spend your time, please include:

d. anything you like doing
e. work, whether you get paid for it or not
f. looking after others.



Please tick (✓) one box

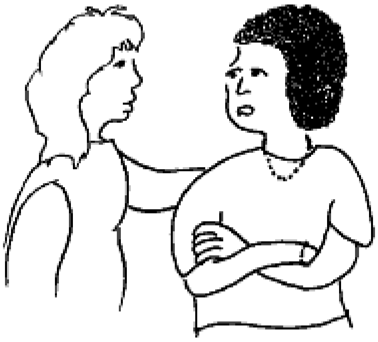
I spend my time as I want, doing the things I like ☐ 😀 👍 ✓

I can do quite lot of the things I like, it's OK ☐ 🙂 👍 ✓

I can do some of the things I like but not enough ☐ 😐 👎 x

I don't do any things I like ☐ ☹ 👎 ✗

10. How do you feel when you need help with things?



Please tick (✓) one box

Having help makes me feel better about myself ☐ ✓

Having help does not change the way I feel about myself ☐ ✓

Having help sometimes makes me feel a bit bad about myself ☐ X

Having help makes me feel really bad about myself ☐ ✗

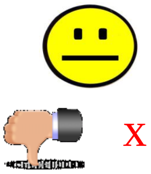
11. How you feel about the way other people treat you?

Please tick (✓) one box

The way I’m helped and treated makes me feel better about myself ☐

The way I’m helped and treated does not change the way I feel about myself ☐

The way I’m helped and treated sometimes makes me feel a bit bad about myself ☐

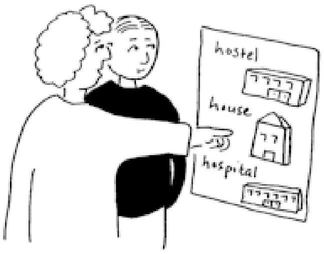


The way I’m helped and treated makes me feel very bad about myself ☐

SECTION 3

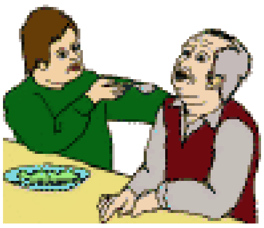
12.How do staff help you?

Please tick (✓) <u>as many</u> boxes as you need to

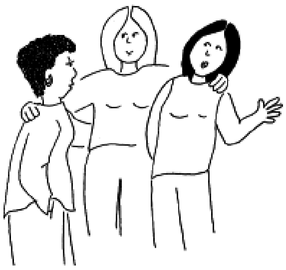


To make choices ☐

To keep clean and tidy ☐



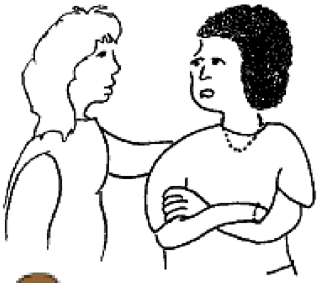
With eating and drinking ☐

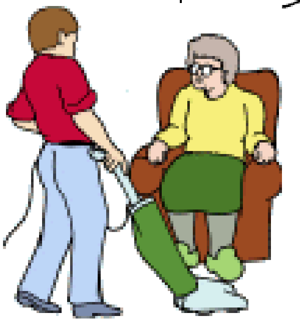


With seeing friends and family and keeping in touch ☐

Finding things to do ☐

Feeling safe ☐



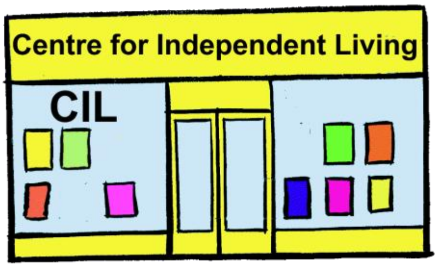


Keeping your home clean and nice ☐

Other things (please tell us what in the box below) ☐

SECTION 4

13.Do you find it difficult or easy to find out about things like the support you could get, and your money, things like that?



Please tick (✓) one box

It's <u>very</u> easy to find this out ☐

It's quite easy to find this out ☐

It's quite hard to find this out ☐

X

It's <u>very</u> hard to find this out ☐

I've never tried to find this out ☐

14. Thinking about the help you get, if you felt unsafe or were worried about something bad that happened to you, who would you tell?

Please tick (✓) as many boxes as you need to

Someone in your family ☐

A friend or neighbour ☐

Your key worker ☐

The manager of your home or day centre ☐

Your care manager or social worker ☐

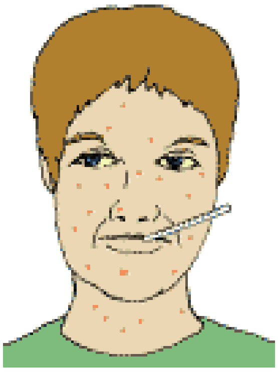
Someone else (please tell us this person's job, not their name) ☐

I wouldn't tell anyone ☐

I don't know ☐

SECTION 5

15.How is your health today?



Please tick (✓) one box

I am very healthy really ☐ ☺ 👍 ✓

I am quite healthy ☐ ☺ 👍 ✓

My health is OK ☐ 😐 👎 x

My health is not very good ☐ ☹ 👎 ✗

My health is really very bad ☐ ☹ 👎 ✗

16.a. Do you have any pains in your body?

Please tick (✓) one box

I don't have any pain ☐

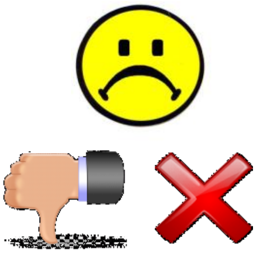
It's good

I have some pain but not a lot ☐

It's OK

I have a lot of bad pain ☐

It's Bad



16b. How do you feel in your mind or your feelings generally?

Please tick (✓) one box

I am not worried or sad at all ☐

It's good

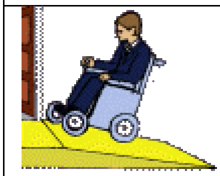
I am sometimes a bit worried or sad ☐

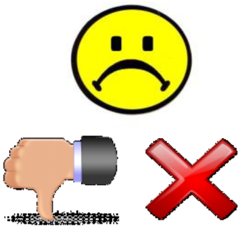
It's OK

I am a very worried or sad person ☐

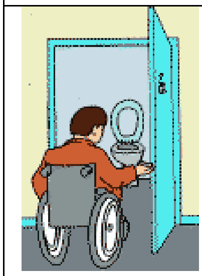
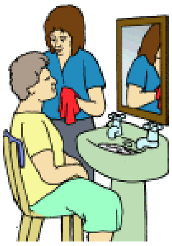
It's Bad

17. **What kinds of things can you do by yourself?**

	I can do this easily by myself	**I can do it by myself, but it is hard**	**No, I can't do it by myself (I need help)**
 a. Can you usually get around the house (except steps) by yourself?	☐	☐	☐
 b. Can you usually get in and out of bed (or a chair) by yourself?	☐	☐	☐
 c. Can you usually feed yourself ?	☐	☐	☐

	I can do this easily by myself 	I can do it by myself, but it is hard 	No, I can't do it by myself (I need help) 
 d. Can you usually pay bills, write letters, that kind of thing, by yourself?	☐	☐	☐

18. Can you do these things yourself?

	Yes, I do this myself	No, I need help with this	No, somebody else does this for me
 a. Can you usually use the toilet by yourself?	☐	☐	☐
 b. Can you usually wash your face and hands by yourself?	☐	☐	☐
 c. Do you usually manage to wash all over by yourself using a bath or shower?	☐	☐	☐

	Yes, I do this myself 🙂 👍 ✓	**No, I need help with this** 😐	**No, somebody else does this for me** ☹ 👎 ✗
 d. Can you usually get dressed and undressed by yourself?	☐	☐	☐

Getting about
SECTION 6

19.How well does your home suit you?

(By this we mean have you got enough space to move about and reach things, etc)

Please tick (✓) <u>one</u> box

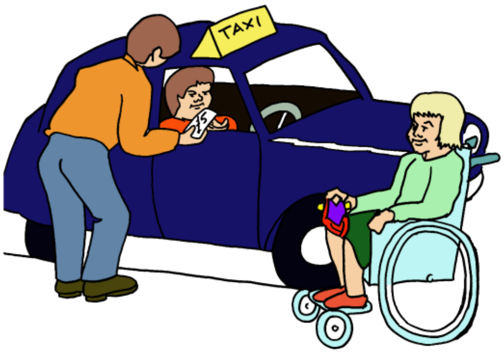
I can do everything I need to in my home ☐ 😊 👍 ✓

I can do most of what I need to in my home, it's OK ☐ 🙂 👍 ✓

I can do some of what I need to, but not enough ☐ 😐 👎 x

I can't do most of what I need to at all ☐ ☹ 👎 ✗

20. **Can you go out in your local area?**



Please tick (✓) one box

I can get to all the places that I want ☐

It's good

Sometimes it is difficult to get to all the places that I want ☐

It's OK

I can't get to all the places that I want ☐

It's Bad

SECTION 7

21. Do any of your family, friends or neighbours often help you to do things?

Please tick (✓) as <u>many boxes</u> as you need to

Yes, and it is someone who lives in the same house as me ☐

Yes, and it is someone who lives in a different house to me ☐

No, they don't help me ☐

22.Do you pay for any extra help or support from your own private money?

Please tick (✓) as many boxes as you need to

Yes, I pay for some extra help from my own money ☐

Yes, my family pays for some extra help for me ☐

No ☐

23.Did you write the answers to these questions by yourself?

Please tick (✓) <u>one</u> box

Yes, I wrote the answers myself	☐
Yes, I had help from a member of staff	☐
No, I had help from someone who lives with me	☐
No, I had help from someone who doesn’t live with me	☐

22.What type of help did you have?

Please tick (✓) <u>as many</u> boxes as you need to

None, because I wrote the answers myself ☐

Someone else read the questions out to me ☐

Someone else explained the questions to me ☐

Someone else wrote down the answers for me ☐

I talked about the questions with someone else ☐

Someone else answered for me, without asking me the questions ☐

This is the end of our questions.

Now please post this back to us in the envelope we sent you. You don’t need to put a stamp on it.

You need to post it back to us by …….