Appendix E Expert testimony papers

Section A: NCCSC to complete	
Name:	Dr Ossie Stuart
Job title:	Independent Equality and Diversity Consultant and PA employer
Guidance title:	Improving adults' experience of social care services
Committee:	Guideline Committee Meeting 7, 16/02/2017
Subject of expert testimony:	Service user experiences of Personal Assistants
Evidence gaps or uncertainties:	We have searched for evidence in relation to service user experience in using Personal Assistants. We have found very little evidence which meets the criteria for any of our review questions. We would therefore like you to speak on the basis of your expertise, having worked with the National Skills Academy for Social Care on the micro employers' project and from your own experience of using personal assistants.

The Department of Health in England has asked NICE to develop a guideline on the experience of people who use adult social care services. This guideline will provide recommendations on the aspects of social care services that are important to the people who use them. It will also provide recommendations on how to improve adults' experiences of social care services.

The Guideline Committee raised concerns that there was not enough good quality research evidence on the experiences of people who used personal assistants, and this was felt to be a gap in the evidence to not adequately represent the experiences of people who use personal assistants.

Where the research evidence is lacking, or inconclusive, Guideline Committee members can invite expert witnesses to the group to provide expert evidence, and recommendations can be drawn from this expert witness evidence and Guideline Committee consensus.

For this Guideline Committee meeting, the Committee would like to ask you the following questions, with reference specifically to personal assistants:

1. Which aspects of the experience of using adult social care services are positive or valued by people who use services?
2. For people who use adult social care services, what are the barriers related to improving their experience of care?
3. For people who use adult social care services, what would help improve their experience of care?

We are particularly interested in how use of personal assistants has an impact on people's experience in the following areas:

1. Wellbeing and quality of life (related to health, mental health and social wellbeing).
2. Engagement with services and care, including understanding relevant care and management issues where appropriate.
3. Choice and control.
4. Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).
5. Perceived and objectively measured independence.
6. Ability to carry out activities of daily living with or without support.
7. Continuity of care.
8. Participation in social and community activities, including training and education, paid and unpaid employment.
9. Resource use.
10. Security and personal safety

Section B: Expert to complete

Summary testimony:	[Please use the space below to summarise your testimony in 250–1000 words – continue over page if necessary]

It is important to remember that the use of personal assistance was an initiative that disabled people themselves developed in the early 1980s and 90s, before any government involvement. Indeed, I, myself, recruited my first personal assistant in 1983 to allow me to study for a PhD at the School of Oriental and African Studies in London. One of my PA I recruited in 1987 still works for me to this day. Disabled people, like myself, chose to employ our own support because social care at that time was unable to meet our needs and allow us to the live full and varied lives that non-disabled people enjoyed. I would not have been able to complete my PhD or work as an academic had I not employed my own PAs.

"Which aspects of the experience of using social services are positive or value by people who use services?"

My concern about the NICE Committee questions is that they seem to be 'care' focused rather than focussed upon choice and control. This makes it hard for me, as a result, to talk about anything positive or of value to people who use services. However, I will try.

Social care always seems to assume that the starting point of the PA role is the same as the carer role; they are there to keep somebody safe and to enhance their well-being. This, in my opinion, has never been the role of a PA. They are not like-for-like replacements for care workers. In my opinion, they are very different to care workers. So, it is very hard to feel positive about social care if this remains a core assumption.

The areas NICE is interested in do make reference to choice and control and participation in paid employment. Yet, these seem to be a relatively low priority in my experience of using social care and is an indication of how the original idea as put forward by disabled people has been reimagined by the State to meet its social care needs in general. This has always been a concern to me and others disabled people who first began to employ their own personal assistants. We saw the PA role very differently as one being much more about choice and control and employability. These are the two areas that Social care, in our experience, has been very poor at facilitating.

Social care, in my opinion, has never fully understood what choice and control is or been able to facilitate it affectively. Also, it has invariably always excluded disabled people who are employed from its provision.

The only positive aspects of experience using social care I can think of is meeting social worker who understands the circumstances in which I live. This means that they will actually leave me alone to get on with running my life as long as my direct payment is accounted for. The two-yearly meeting, I have with ‘my’ Social worker will only be a conversation about my well-being and any questions I might have about the system as it is designed at that moment. As you can imagine, this is always a short conversation.

Now I do understand that the majority of disabled people who use social care services may not share my same circumstances, but perhaps that is the point. One of the biggest issues preventing positive outcomes from social services in relation to personal assistants is the lack of individuality built into the system.

“For people who use adult social services, what are the barriers related to improving their experience of care”

Barrier one, a lack of trust

Personal budgets would be more positive if they were actually designed around the individual to meet individual need, rather than policed as if the individual would steal the money given half a chance.

Barrier two, a lack of flexibility and individuality

Issues like safeguarding, personal satisfaction, well-being, daily activities, a desire for employment, etc., are very different concepts to different people. For example, safeguarding and engagement with social care services are both extremely low priorities for me. For others, and their families, they might be high priorities. Also, this could change in my lifetime, but I sense there is no flexibility in social care to cope with this variety in ‘need’. You are either in need or ignored. There is no third option to support somebody who has the capacity and the income to support themselves but does require additional support to do so.

Barrier Three, a lack of citizenship

This is tricky, because of the dependency nature of social care, there appears to be a lack of recognition that individuals who use social care are the experts of their circumstances and should be treated as such. What I mean by this is that their expertise or their knowledge of their lives remains the least exploited area of social care. There is always a fear that if you were to ask somebody how they would want to solve their social care need they would ask for things that were unaffordable. Therefore, as always, decisions about how to solve a need will be made by the social care system and not the individual. The power remains with the social care system.

Barrier four: employability or PAs

Because of the history of PAs and the fact that it was disabled people with the most capacity who initiated this scheme, there has been an assumption that everyone employing PAs should be responsible for their employment rights etc., and the development of the PA employment market. This would not be responsibility of local councils or social care services.

These two key PA recruitment resources have not been developed. Employing PAs as an individual employer is an extremely difficult thing to do. Yet, there is little support to help individuals do this, and it has been made more difficult by the way Inland Revenue rules apply to individual employers as if they are small businesses.

There is no London wide or UK wide PA employment market. Consequently, many individual employers find it very difficult to find and recruit PAs.

One could argue that this is down to choice and control and that if social care services were to intervene in this area it would limit independence. I would argue that the opposite would be true. Alongside direct payments and personal budgets there should have been work done to develop the PA market and make the recruitment of PA's as easy and fair to PAs as possible. This has never happened.

Barrier five: a lack of blue sky thinking

Individualised care is, or was, an opportunity to re-think social care differently. To achieve a truly personalised service all the old assumptions about social care needed to be challenged. Assumptions, such as disabled people cannot ultimately be trusted to design and run their own care system, that they needed professional help, that they need to be protected from abuse, that they lacked capacity, that there is a need for a social care industry, that it could be done on the cheap needed to challenged and tested afresh.

These, and other assumptions have prevented the development of a social care system that could meet the needs of people in the 21st-century. People want individualised care, people want to be the ones who design their own care, people want good advice and help to do this, and people want the right resources put in place to make sure that they can do so in a way that suits their personal situation.

"For people who use adult social care services, what would help improve their experience of care?"

The first improvement would be more money…

The second improvement would be greater flexibility and autonomy in how personal budgets are spent by individuals.

The third improvement would be the creation proper PA employment market and support with recruitment of PAs.

The fourth improvement would be recognition that personal budgets and direct payments have to be designed around individual and not around what social care services think is possible or appropriate. This might mean a rethink of the purpose of personal budgets and how they work. For example, people, like myself, do benefit greatly from direct payments, whereas someone with high support needs or limited capacity might seek a different solution that was not budget related at all. The latter solution would not be a return to social care as we knew it the 20th century. Rather, it should be a more nuanced understanding of individual and how to meet their identified need in the way that suits them best.

The fifth improvement is a recognition within the profession of social care that the individuals they work with are equal citizens of this society. This is a plea for a relook at the power relationship between social care and those who are "cared for". The balance has not shifted towards the individual far enough to make any of the improvements I suggest above possible.

References (if applicable):

N/A

Section A: NCCSC to complete	
Name:	Juliette Malley
Job title:	Assistant Professorial Research Fellow
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Guidance title:	Improving adults' experience of social care services
Committee:	Guideline Committee Meeting 10, 24/05/2017
Subject of expert testimony:	What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?
Evidence gaps or uncertainties:	
There is a lack of information about the best methods to elicit service users' experiences of the care and services received and issues such as maximising response rate, consistency, reliability, and validity of survey results. In particular, there is little information about how best surveys should be adapted to meet the different needs of different service user groups and the subsequent cost implications of adapting surveys.	
Section B: Expert to complete	
Summary testimony:	[Please use the space below to summarise your testimony in 250–1000 words – continue over page if necessary]

Introduction

The focus of this review is on the effectiveness and cost-effectiveness of survey methods to gather service users' views on their experience of services. Alternative methods can be used (e.g. focus groups, systematic analysis of compliments and complaints), but these are not considered here.

One way of thinking about the effectiveness of a survey is in terms of (1) the unit response or participation rate (i.e. the percentage of individuals that participate out of those invited to participate) and (2) the item response or question completion rate (i.e. the extent to which questions in the questionnaire are answered or left blank). A well-designed survey will try to maximise both the participation and question completion rates. This is because surveys with low participation and question completion rates have high levels of missing data. Where there are high levels of missing data, the survey findings have questionable validity since we cannot know what those who did not answer the questions were thinking.

To evaluate the effectiveness of survey methods, experimental studies (ideally randomised controlled trials, RCTs) are needed that compare participation and completion rates. Since the survey features and the target population affect participation and completion rates, RCTs must be conducted with the same target population in order for the findings to be useful. There are, however, no RCTs examining the effectiveness of different survey methods for gathering data on the experiences of social care users. The research in this area considers more the appropriateness of different survey methods and how these can be adapted to be more accessible for groups of social care users. The limitations of the evidence base need to be carefully considered when making recommendations based on this testimony.

The testimony is organised as follows: first, we consider why a single approach to surveying social care users is unlikely to be effective. Second, how surveys can be designed to ensure they do not systematically exclude groups of social care users. This discussion draws on studies around the appropriateness of survey methods and adaptations to surveys. Third, we give examples of how a survey could be adapted for a social care population by making reference to the methods used by the ASCOT team to adapt the ASCOT measure for different groups of social care users (the ASCOT is a measure of social care-related quality of life that can be used to generate a social care QALY). It is important to note that ASCOT is not strictly an experience measure since it focuses on quality of life rather than the experience of care delivery; however, the methods are highly relevant to this discussion. Finally, we consider how surveys could be used to monitor and improve practice drawing on a study using the ASCOT instrument to provide feedback to care home staff.

(1) Why is a single approach to surveying social care users unlikely to be effective?

Survey participation rates have been falling for many years now. Consequently there is a large literature that explores the factors associated with non-participation in surveys and how to increase participation, although it is mostly limited to general population surveys. This literature suggests that survey participation can be increased by minimising the costs of participation, maximising the benefits of participation, and increasing levels of trust. In sum, the best results are therefore achieved by ‘tailoring’ the survey design to the characteristics of the population of interest. This means choosing methods, materials and content that are accessible and attractive to the intended participants.

Many social care users face high participation and survey completion costs due to communication barriers (due to cognitive, memory or language difficulties) and/or physical barriers (due to sensory or physical disability). There is fairly good evidence that participation rates are lower among groups of users with communication problems and sensory impairments. Although there is less evidence of the impact of physical disability on participation, there is evidence that people with physical disabilities require help to complete the questionnaire, which suggests that where help is not forthcoming participation rates will suffer. Since prevalence rates of these problems are high among social care users, they are likely to be a significant impediment to survey participation in this population.

When discussing how to maximise participation and completion, this testimony focuses on the following groups of social care users:

1. cognitively impaired
2. user groups with low levels of literacy in English (i.e. people with intellectual impairments and people for whom English is not their first language)
3. sensorily impaired
4. physically disabled.

This testimony does not discuss approaches to increase participation among social care users who may also be a member of communities that are known to disengage with research, e.g. the traveller or LBGT community. Interested readers are directed to the two systematic reviews mentioned in the next section.

(2) How can surveys be designed to ensure they do not systematically exclude groups of social care users?

There are two systematic reviews that are of relevance to this question. The first by Beadle-Brown et al. (2012) looked very broadly at the question of how to engage people with long-term conditions in health and social care research. The review therefore touches on survey research but also looked at other study designs. It provides general advice about how to improve survey participation rates among hard-to-reach groups. They define "hard-to-reach" as an individual whose characteristics or circumstances make it difficult for them to participate. As such, it can include a wide range of populations.

The second is by Sheldon et al. (2007) and looked at how to increase survey response rates amongst black and minority ethnic and seldom heard groups, as part of the development work for the NHS acute patient survey programme. This review addresses how to improve postal survey participation rates and therefore is highly relevant for this discussion.

(2.1) General advice to improve survey participation rates among hard-to-reach groups

A systematic review by Beadle-Brown et al (2012) focused on the barriers and facilitators to engaging "hard to reach" people who have long-term conditions and use health and social care services. Their systematic review was very comprehensive and included a total of 83 studies. The types of study designs included were mainly mixed methods, with under half of the studies being qualitative. Only 8 studies were comparative.

Beadle-Brown et al (2012, p.7) found that most of the research focused on individuals with intellectual disabilities, older adults, those with mental health conditions, and those from minority ethnic groups. Based on their findings, they came up with several recommendations:

1. "Researchers should involve user reference groups or individual user consultants in designing the survey, including recruitment strategies, the methods of data collection and on adaptations needed to involve as many people as possible."

2. "When working with people from seldom heard groups, more time and resources should be allowed in order to recruit people to studies using more than one recruitment strategy where needed. More time, flexibility and adapted materials and procedures are also required in order to maximise involvement, responsiveness and reliability of responses during data collection. However this has implications for funders and commissioners of research or service evaluation with these groups of people."

3. "Information materials should be clear and accessible to the target population."

(2.1.1) Where research is needed

Beadle-Brown et al (2012, p.7) recommend more research in the following areas:

- More generally, research on “The comparative cost implications and effectiveness of recruitment and data collection methods which promote more inclusive research”

- They found, “Few papers were available for those with physical and sensory disabilities”.

(2.2) When are self-completion surveys appropriate?

Self-completion surveys can be appropriate for people with communication problems and physical disabilities. Whether someone is excluded from a self-completion survey depends on the survey design and content, as well as the type and severity of the disability. In many instances the survey can be adapted to make it possible for someone with communication problems to participate and complete the questionnaire unaided.

There are, however, serious limitations regarding the evidence base for assessing the effectiveness and cost-effectiveness of these strategies. As Sheldon et al. (2007) note, “(t)here is limited evidence about the impact of strategies in general and virtually no published evidence about the impact of some strategies for increasing response rates amongst seldom heard groups. For example, we found no studies measuring the impact of increasing font size to accommodate people with a visual impairment or of increasing the readability of a questionnaire (including visual prompts, signposting and making translations available).” This is not to say that that increasing font size is not effective. It is just that there are no studies that have measured whether it is effective (or not).

(2.2.1) Alternative modes of delivery and adapting the presentation of the questions

How the self-completion survey is sent out will also affect the participation rate. For example, questionnaires sent by e-mail or text message and completed online may be cheaper and easier to analyse than postal questionnaires, but they are likely to systematically exclude older people who are less likely to have email addresses and feel comfortable completing an online survey. On the other hand online surveys may be more accessible for people with physical or mobility impairments who may find it difficult to mail back postal questionnaires.

Physical impairments

It may also be easier to adapt the format of online surveys to the needs of the respondent, although this has not been explored. Postal surveys can be adapted to be more accessible to people with barriers to communication and physical disabilities, but it may be difficult to identify the people who need adapted versions. An alternative option would be to provide detailed accessible instructions about the availability of alternative formats for people to request. Ultimately however, there is no UK research that explores the (1) effectiveness of the different modes for delivering surveys to people with communication problems and physical disabilities, or (2) how best to target adapted versions of self-completion surveys.

Visual impairments

Guidance from organisations like the Royal National Institute for Blind People (RNIB) suggests a range of ways of making postal surveys accessible for individuals with visual impairments. For example, providing surveys in larger font size or in braille, and making audio-based versions available, which may be delivered by phone or computer. There is no research, however, exploring the (1) effectiveness of these different options for delivering surveys to people with visual impairments, or (2) how best to target such versions to the people who need them.

Questions to aid the Guideline Committee in drafting recommendations (during group sessions): Would you advise delivering surveys using a single mode or multiple modes? What advice would you give regarding how to target particular modes or adapted versions? What evidence would you use to support your advice?

(2.2.2) Adapting the content of the questionnaire

For people with intellectual disabilities it is often recommended to use an Easy Read version of the self-completion questionnaire. Easy Read versions have simplified language, in terms of both sentence structure and conceptual content. Text is also supported by pictures and symbols to aid comprehension. Developing Easy Read versions that are faithful to the original can be a resource intensive exercise (see section 3.1). A consideration when adapting questionnaires in this way is that it may overly simplify the content, affecting the meaning of questions and leading to problems with comparability to the original. Ideally therefore such versions should be targeted only towards those who need them. There is no research, however, to guide the targeting of Easy Read versions (see section 3.1).

Questions to aid the Guideline Committee in drafting recommendations (during group sessions): What characteristics of users would you use to define who to target with the Easy Read version?

(2.2.3) Translation and cultural adaptation

Research shows that the translation of survey questions is not always straightforward. Literal translations may not convey the intended meaning of the original questions or they may be culturally or linguistically inappropriate. Both issues are a concern for research. Literal translation affects the comparability of the English and translated versions; while culturally or linguistically inappropriate translations affect the completion rate for survey questions. A key part of the translation process is the cultural adaptation of the questions.

Research has shown that translations are better when the following sequence of steps is adhered to: preparation and concept elaboration (elaborating in detail the meaning of key phrases), forward translations, forward translation reconciliation, back translations, back translation review, developer review, professional review and pilot testing with users, pilot testing review. This process can be costly but it is important because a simple ‘forward’ translation from English into another language may produce a poor and inappropriate translation. We recommend a practical guide as published in a peer-reviewed journal:

Wild D, Grove A, Martin M, et al. Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: report of the ISPOR task force for translating adaptation. Value in Health 2005; 2: 94-104. http://www.ispor.org/workpaper/research_practices/PROTranslation_Adaptation.pdf

It is important to note that cultural adaptation may be required for English-speakers with different cultural backgrounds. For example, American or Australian English-speakers and English-speakers from ethnic minorities living in England may need questions phrased differently if cultural differences mean that question may not be understood correctly. This process is not as costly as translation, but it would involve at least the following stages: pilot testing with users, pilot testing review.

(2.3) When are self-completion surveys not appropriate?

For many people with communication problems self-completion surveys – even the adapted versions described above – will not be appropriate. In such instances alternative methods will be needed to capture users' experience of social care services.

A systematic review by Beadle-Brown et al (2016, pp.38-39) makes some recommendations for collecting data on the experience of service users who have severe cognitive and intellectual impairments, including:

1. “Triangulation of data collection methods… This could involve combining, for example, a self-report measure with a perspective taken from someone who knows the person well with observation of what happens to the person or information taken from records.”
2. “Use different ways of obtaining the same information across different groups of people. For example, surveys often have to be simplified and combined with pictures or other media to allow those with communication or cognitive impairments to understand them.”

Beadle-Brown et al (2016, p.33) note, however, the limitations of the evidence they found to support their recommendations. They state: “recommendations for facilitating the involvement of seldom-heard groups appear…often focused more towards generic good research practice than the identification of effective and innovative methods, techniques and processes for particular groups of people.”

(3) Facilitating the participation and completion of surveys: an example using ASCOT

There is a standardised measure of social-care related quality of life that is widely used in the UK. This is the Adult Social Care Outcomes Toolkit (ASCOT). It asks people to rate their life in the areas of (1) food and drink (2) personal cleanliness and comfort (3) accommodation cleanliness and comfort (4) safety (5) social participation and involvement (6) occupation (7) control over life and (8) dignity. ASCOT is currently used in the national Adult Social Care Survey (ASCS).

NHS Digital recognises that not everyone can complete ASCOT (and the other ASCS questions) in the self-completion postal questionnaire format, so local authorities have some discretion to deviate from the guidance to increase participation and completion rates among hard-to-reach groups. NHS Digital also makes available translations, an Easy Read version, and an interview script. It is also assumed that the care user will ask for help from relatives or friends to complete the survey. The Easy Read and translated versions of ASCOT used in the ASCS are not official versions of ASCOT and do not use the methods described below.

The ASCOT tool is available in:

- Self-completion format (SCT4)
- Structured interview format (INT4)

Adaptations of the ASCOT include:

- For people with intellectual impairments, the SCT4 Easy Read, which can be self-completed. This is a beta version that is currently undergoing further testing and validation. On completion of this work the measure will be made available.

- For people with severe communication problems, a Proxy response. This is a beta version that is currently undergoing further testing and validation. On completion of this work the measure will be made available.

- For people living in care homes (nursing or residential), more than one method is used to provide a rating of an individual's social-care related quality of life. Information is collected from interviews with family/staff and resident (CH3 INT) and observation (CH3-Obs).

(3.1) For people with intellectual impairments, the SCT4 Easy Read

The Easy Read version of ASCOT was developed with input from people with intellectual impairments in a series of steps to build up the content and presentation of the questions (Turnpenny et al 2016). Most participants in the development study were able to use and engage with the Easy Read version. The researchers did note, however, that people who were receiving more support had more difficulties with the questions and needed more help to complete the questionnaire (Turnpenny et al 2016). Further pilot testing of the tool is required to establish its feasibility, validity and reliability in a larger population of people with intellectual impairments.

A goal of the development of the Easy Read version was to create a version that, as far as possible, individuals with intellectual impairments could complete without help. This is important because research suggests that having help to complete questionnaires can bias responses, although the extent and direction of bias depends on the relationship of the 'helper' to the service user. Ideally the tool would be targeted at those people with intellectual impairments who could complete it without help; alternative methods may be more suitable for those who need support to use the tool. The researchers suggest that ideally the Easy Read version of ASCOT should be paired with a pre-screening tool to identify those who can complete the survey on their own. They note that this is an area that needs further research, for example, to identify at which threshold individuals are able to complete the self-completion survey.

(3.2) Proxy completion instrument

The ASCOT-Proxy instrument was developed with input from unpaid and paid carers. Researchers first explored the challenges involved in assessing quality of life by proxy and the ways in which they could be mitigated. The researchers then developed the ASCOT-Proxy instrument (Rand et al, 2017). The ASCOT-Proxy instrument appeared to have acceptable face and content validity for proxy-report of social care-related quality of life and is acceptable to care workers and family carers invited to rate quality of life by proxy. Further pilot testing of the tool is required to establish its feasibility, validity and reliability. Additionally work is needed to identify when this tool should be administered.

(3.3) People living in care homes

The ASCOT is also available as a "care homes toolkit" (CH3), developed to capture the quality of life of people living in care homes. ASCOT CH3 scores have good inter-rater reliability as measured to collect individual's experiences of their care (based on measures of inter-rater reliability) (Towers et al 2016, p.5).

(4) Using ASCOT to improve practice

Towers et al (2016) evaluated whether the CH3 can be used to provide feedback to staff using specific examples from observation and interviews collected for the CH3 survey. In this study, all members of staff were included: administrative, catering, domestic and estate (Towers et al 2016, p.4). Feedback was shared on an aggregate level. Positive feedback was provided first, followed by areas that needed improvement.

Staff responded to feedback well. In one care home, staff requested that feedback be shared with management. In a case where the service provider was part of a large organisation, the staff wanted feedback to be sent to even higher levels of management. This was particularly important because staff felt that a big barrier to improving practice was insufficient staffing levels. This meant that whilst they did very well in areas of personal cleanliness and comfort, accommodation cleanliness and comfort, safety and dignity, they felt they did not have enough time to address the areas needing improvement, including choice over food, control over daily life, social participation and occupation (Towers et al 2016, p.10). In another care home, there were similar issues relating to staffing levels, but staff decided to change their approach, away from task-oriented activities, and reorganised their time to focus on social-care related activities on “the little things” like “painting nails, lipstick” (Towers et al 2016, p.10).

It is not clear, however, whether the feedback intervention actually led to improvement in people’s quality of life, as the results at 12 weeks found no difference in before and after quality of life scores. It is thought that a much longer time horizon is needed before changes in practices are reflected in individual’s perceptions of their social-care related quality of life (Towers et al 2016, p.12). Furthermore, the researchers recommend potentially more than one measurement, rather than a single ‘snapshot’ of individuals’ quality of life, especially considering that individuals have ‘good’ and ‘bad’ days, which would bias the results (Towers et al 2016, p.12).

Although the research in the care homes used aggregate data to provide feedback to staff, the researchers recommend that the ASCOT tool be used in the care planning process, to provide user-specific improvements (Towers et al 2016, p.12). This would embed the process of collecting feedback from the ASCOT into everyday practice.

(5) Conclusions

In conclusion, the question of how to best gather, monitor and evaluate the experiences of people using adult social care services is an under-researched area, especially in relation to how to ensure participation of people with communication problems and physical disabilities. While there is a paucity of research on the effectiveness of different approaches, adapted versions of instruments have been used successfully with people with communication problems and physical disabilities. Mixed methods and proxy approaches have also been used successfully to gather experiences where people have severe communication problems. For example, the ASCOT team have developed a number of tools to suit different groups of social care users. More research, however, is needed to assess the comparability of responses obtained from different versions of instruments and to determine which to tool to use, when and with whom.

References (if applicable):

1. Beadle-Brown J, Ryan S, Windle K, Holder J, Turnpenny A, Smith N, Richardson L, Whelton R (2012). Engagement of people with long-term conditions in health and social care research: a review of barriers and facilitators to capturing the views of seldom-heard populations.

2. Sheldon H, Graham C, Pothecary N, Rasul Farhat (2007) Increasing response rates amongst black and minority ethnic and seldom heard groups: A review of literature relevant to the national acute patients’ survey. Picker Institute, Oxford

3. Turnpenny A, Caiels J, Crowther T, Richardson L, Whelton R, Beadle-Brown J, Rand S. (2016). Developing an Easy Read version of the Adult Social Care Outcomes Toolkit (ASCOT). Journal of Applied Research in Intellectual Disabilities

4. Towers A, Smith N, Palmer S, Welch E, & Netten A (2016) The acceptability and feasibility of using the Adult Social Care Outcomes Toolkit (ASCOT) to inform practice in care homes. BMC Health Services Research, 16:523.

5. Rand S, Caiels J, Collins G & Forder J (2017) Developing a proxy-report version of the Adult Social Care Outcome Toolkit (ASCOT). Health and Quality of Life Outcomes 15:108