

The National Adult Social Care User Experience Survey: Results from Four Development Studies

PSSRU

RESEARCH
SUMMARY

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BACKGROUND

Councils with adult social services responsibilities have conducted user experience surveys (UES) of their clients for some time now, using either their own surveys or the national surveys collated by the Information Centre for Health and Social Care (IC). These surveys have made a valuable contribution towards putting the views of users at the heart of decision-making, but they need to change to fit today's policy environment. The aim is to focus the survey on people's outcomes from social care, such as their quality of life, health and so on. A further aim is to capture the experiences of all social care users.

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 Adult Social Care User Experience Survey (NASCUES) for 2010/11. This research summary presents the key findings and recommendations from a series of exploratory studies to improve understanding of some of the challenges to delivering such an ambitious survey.

The findings and recommendations from this work have informed the content of the questionnaire and have fed into guidance issued to the councils that have volunteered to pilot the survey. The aim is to roll the survey out nationally in 2011. The exact process for the survey may change slightly from what is recommended here, depending on the results of the pilot.

AIMS AND METHODS

The proposed self-completion postal survey method raises a number of challenges. We conducted four studies to research the areas felt to present the most difficulties. The aims of the four studies were as follows:

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

We used a variety of methods in these studies including cognitive interviews, semi-structured interviews with key informants (staff from the council who administer the survey, care home managers and staff from advocacy groups) and focus groups (see Caiels et al. (2010) for more details).

KEY FINDINGS AND RECOMMENDATIONS FOR THE PILOT

The help given and its effect on the quality of data

Previous UESs have found that over 50 per cent of those responding to the survey need help to answer the questionnaire. We found that the help given varied widely. Examples include holding a pen, translating questionnaires into a foreign language, navigating the questionnaire and responding on behalf of the service user without their input (i.e. a proxy respondent). The reliability and validity of the responses may be affected by the help given under certain conditions.

Questions asking about feelings are particularly difficult for helpers to answer as they can only respond on the basis of what they observe or are told. These are common in the main social care outcome measure. Where the service user is not able to communicate their feelings to the helper, the responses from the helper are unreliable. Proxies employed different strategies to arrive at an answer, resulting in random responses which cannot be reliably compared.

Validity is also affected where the helper is not neutral. We observed situations in which there was some discussion and negotiation of responses between service user and helper. Whose views were presented depended on the patterns of dominance in the relationship. Key informants from councils and care homes were also concerned that the helper might have their own agenda and might override or ignore the views of the service user. Most concerns were raised by councils over staff members helping.

Certain clients, particularly those with learning disabilities (LD) and care home residents, had difficulty with the survey format and needed quite active help to navigate the questionnaire. We observed problems with understanding the meaning of the questions, particularly where general terms were used or the question required the person to sum and then average across a number of aspects, and with formulating responses.

For these clients, helpers used strategies to 'personalise' the questions and drew on their detailed knowledge of the life of the user to help. For many clients, only staff will have the knowledge of their lives required to provide such help. We also observed helpers translating the free-form responses of the clients into answer categories. These forms of help rely on the judgement of the helper and could introduce substantial bias into the results. However, without such help these people would not be able to take part in the survey in its current format.

It is clear that without the variety of help given to service users, response rates to the survey would be very poor. Therefore, we recommend that users are encouraged to seek help from people who are most able to help them, which can include staff in care homes, and that structures are put in place to make help available:

- In care homes, the care home manager should be engaged in the survey to ensure staff are on hand to help residents. We recommend sending managers a letter with details about the purpose of the survey, which residents received it and how to help them.
- The availability of advocacy varies across England, and most organisations providing advocacy have limited capacity to respond to

a sudden increase in demand. In addition, research literature emphasises the importance of proxy responders' familiarity with the service user in gathering accurate reports of their well-being. Therefore, we do not recommend that councils encourage service users to seek help from advocacy agencies to complete the survey, except in circumstances where service users already have an existing relationship with an advocate.

We recognise that help can bias responses and we recommend steps are taken to minimise bias:

- Anyone who requires a proxy respondent should be excluded from the sample, on the basis that they lack capacity to consent to take part.
- Instructions on the survey should make it clear we want the user's views, and care home staff should be instructed on this point.
- Councils should make it clear that the data are not being used to assess the care home providers.
- Include questions about what help was given and by whom.

Suitability of questionnaire for specific client groups

We found that the questionnaire was suitable for care home residents, but required some adaptation. Some questions were not applicable to care home residents and we recommend these are dropped from the survey. Other questions needed some adaptation to remove ambiguity: for example replacing 'home' with 'care home'. The front cover also needed adaptation to include additional instructions about seeking help from staff, and also to let clients know that their care home managers know they received a questionnaire.

Most people with LD cannot read, either at all or at the level required to complete the survey confidently. Therefore the language was simplified and illustrations added, which did help with understanding. Despite these amendments, many people will need the survey read out to them or significant help to navigate the questionnaire. We recommend that this simplified version of the questionnaire is used for people with LD.

Some caveats...

Volunteer councils will pilot the survey to test the questionnaire and the processes we have outlined. The recommendations made include steps to improve response rates and the quality of the data. The pilot is an opportunity to test how easy these strategies are to implement and whether they are having the desired effect. We suggest that the analysis of the pilot focuses on the following areas:

- Assessing the effect of excluding people who lack the capacity to consent, paying particular attention to the costs of excluding people.
- Analysing for differences in non-response rates between client groups and services, paying particular attention to care homes and people with LD.
- Attempting to understand the effects of different types of help on the validity and quality of the data.

FUTURE DIRECTIONS

In a feasibility report, we set out the key priorities for development for the first survey and a series of further activities for consideration for future surveys (Malley and Netten, 2009). In this report we suggested that the priorities for future development should be driven by the findings from the development studies and the pilot survey. The analysis presented here points to the following as the areas requiring most urgent development:

- A significant missing group are those people who lack the capacity to consent to take part. It is a priority to develop methods to include the experiences of these people in the survey.
- We recommend that stratified sampling is piloted to ensure the sample is not biased by the exclusion of people who lack the capacity to consent to take part.
- The survey format is difficult for care home residents and people with LD. Depending on the response rates from the pilot and analysis examining the quality of data received from these two groups, it may be important to explore different ways of collecting the experiences of care home residents and people with LD. However, any decisions will need to be subject to consideration of the likely impact of such methods on the cost of the survey.

REFERENCES

- Malley, J. and Netten, A. (2009) Putting People First: Development of the Putting People First User Experience Survey, Discussion Paper 2637, Personal Social Services Research Unit, Canterbury.
- Caiels, J., Fox, D., McCarthy, M., Smith, N., Malley, J., Beadle-Brown, J., Netten, A., Towers, A.-M. (2010) Development Studies for the National Adult Social Care User Experience Survey. Technical Report, Discussion Paper 2724, Personal Social Services Research Unit, Canterbury.

Further information

The full report from this study can be downloaded from the PSSRU website at www.pssru.ac.uk.

The full reference for the report is:

Malley, J., Caiels, J., Fox, D., McCarthy, M., Smith, N., Beadle-Brown, J., Netten, A., Towers, A.-M. (2010) A Report on the Development Studies for the National Adult Social Care User Experience Survey, Discussion Paper 2721, Personal Social Services Research Unit, Canterbury.

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