

THE DEVELOPMENT OF THE ADULT SOCIAL CARE SURVEY (ASCS)

The development of the Adult Social Care Survey (ASCS) was based on **A vision for adult social care** (Department of Health, 2010) in which the sector strives to improve outcomes for users and put users and their carers at the heart of local decision-making. There was a clear brief to develop a survey that measured the outcomes from as wide a variety of social care service users as possible, marking a break with the past focus on measuring specific user groups' experiences of care quality.

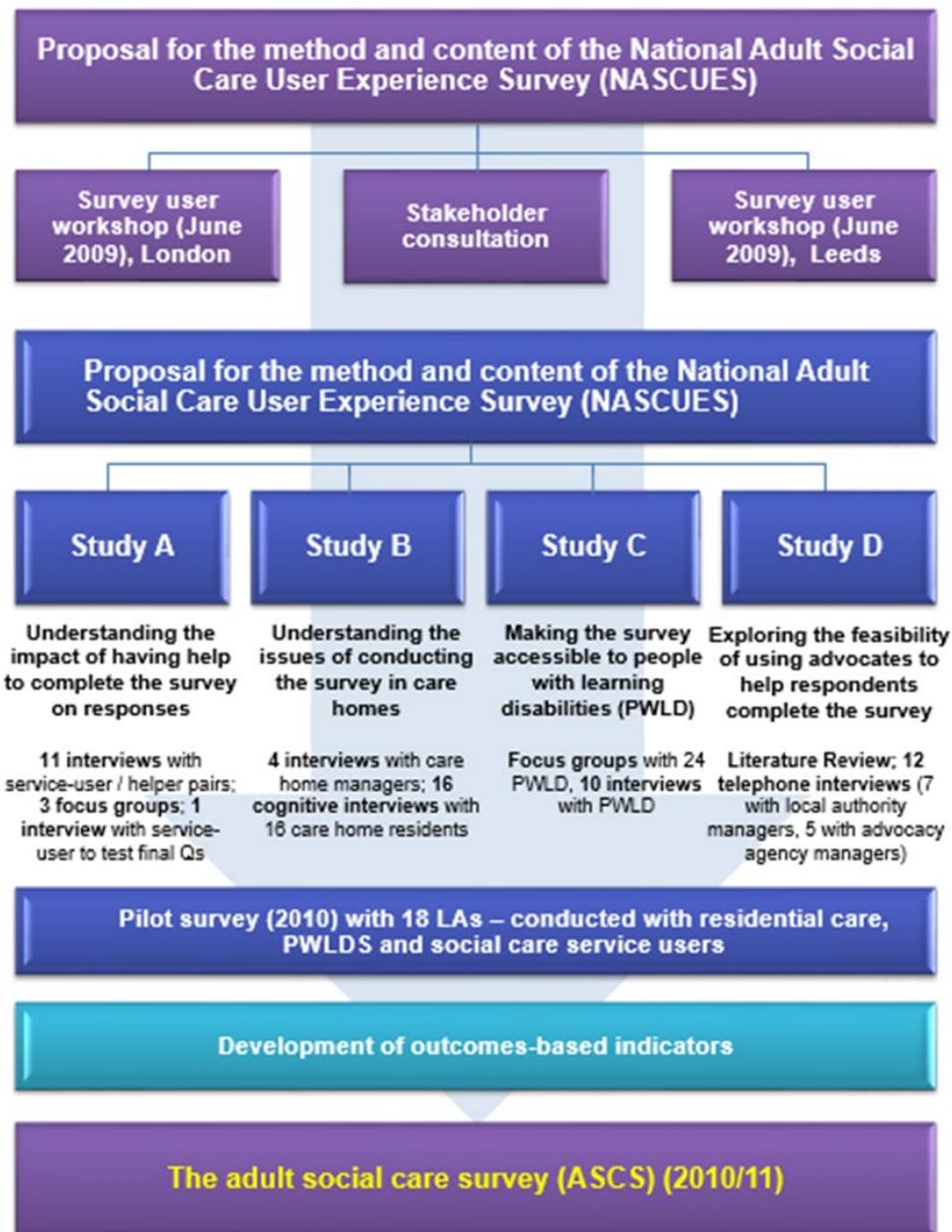
Researchers at the Personal Social Services Research Unit (PSSRU) at the University of Kent developed the survey in several stages following recommended practice in questionnaire design. The stages are shown in Figure 1 overleaf and further details are given in a series of discussion papers (see further reading). The aim of this summary is to present the findings from this work in terms of their consequences for the design features and interpretation of the ASCS. Specifically this summary examines consequences for (1) the content of the questionnaire, (2) instructions for users and their carers, (3) instructions for data collection, and (4) the quality of the data.

1. THE CONTENT OF THE QUESTIONNAIRE

PSSRU researchers consulted with stakeholders on proposals for the content of the survey. The consultation considered options for questions to measure the core social (and health) care outcomes of interest, as defined by central government, and 'additional questions' to enable interpretation of the core questions. In general the approach advised by researchers at PSSRU (and accepted by stakeholders) was to use, wherever possible, tested and well-validated existing measures rather than develop new measures. For these reasons

stakeholders agreed that the most appropriate outcome measures would be based on questions from the Adult Social Care Outcomes toolkit (ASCOT – see www.pssru.ac.uk/ascot).

Figure 1: the development of the Adult Social Care Survey (ASCS)



Where self-reported outcome measures are used the research evidence is clear about the need to also measure factors that affect a person’s potential to achieve good outcomes.

Self-reported outcome measures capture only the outcome state of the person and not the contribution that social care organisations make towards individual outcomes – without additional information about an individual’s social care need, for example, interpretation of outcome scores is very difficult. The researchers advised that research should be commissioned to develop an ‘adjusted’ outcome measure that captures social care effectiveness (Malley and Netten, 2010). This research was conducted by PSSRU researchers as part of the Identifying the Impact of Adult Social Care (IIASC) study (Forder, et al., 2015).

2. INSTRUCTIONS FOR USERS AND THEIR CARERS

Due to historical, financial and practical reasons a postal survey was chosen. Since there are high levels of severe disability among social care users it was expected that a large proportion of people would need help to complete the survey (possibly over 50% based on past experience (Malley et al., 2010)). For some people living alone and with no living relatives the only source of help may be care staff. Through literature reviews, interviews and focus groups with care staff, service users and the people who would or could help them complete the survey, PSSRU researchers investigated the types of help needed, the impact of help on responses and the feasibility of using advocates to help people to complete the survey (Malley et al., 2010).

Help seemed to influence service users’ responses, but the researchers felt the possible bias resulting from this was much smaller than the bias that would result if everyone requiring help was excluded from the survey. The researchers recommended that service users should be encouraged to ask for help from someone to answer the questionnaire, if they need it, but to minimise bias from the person helping, instructions for the helper should also be provided, and information about the relationship of the helper to the user and how they helped should be captured in the survey. For care homes, the researchers recommended that care home managers should be assured via a letter prior to data collection that the data will not be used to assess the care home or its staff. Service users should only be

excluded if they were unable to participate even with help, for example due to severe cognitive or intellectual impairment.

The researchers identified a number of barriers to using advocates to help people complete the survey. This coupled with limited research and evidence supporting the use of advocates to provide help to complete surveys, led the researchers to recommend not encouraging respondents to use advocacy agencies, unless there was an existing relationship with an advocate.

3. INSTRUCTIONS FOR DATA COLLECTION

The consultation acknowledged that surveying adult social care users using a self-completion questionnaire would be challenging, particularly in the case of care home residents and people with learning disabilities (PWLD) due to the more pronounced effect of gatekeepers (e.g. care home managers, family members) and disability on their ability to participate compared to other social care client groups. Researchers at PSSRU investigated what effect these issues would have on participation of these groups through interviews and focus groups with care staff, care home managers, and service users, with a view to providing guidance around implementation (Malley et al., 2010).

In care homes, staff involvement and support is important for good response rates. The researchers recommended sending a letter to care home managers explaining the purpose and value of the survey, how the data will be used and how the staff can help the resident complete the survey. In the context of the care home, the researchers felt that having staff, as opposed to family or friends, help to complete the questionnaire was preferable as staff were likely to be more familiar with the residents' daily routine, so have greater insight into their quality of life. It was also recommended to develop a care home specific questionnaire, including instructions for people helping residents to complete the survey.

An accessible version of the questionnaire was tested and piloted for PWLD. This version used more simple language and illustrations, reduced response scales to a maximum of five options, and encouraged people to seek help to complete the questionnaire. The researchers outlined a number of recommendations to improve accessibility (Malley et al., 2010).

4. THE QUALITY OF THE DATA PRODUCED

In addition to the recommendations around administering the survey and instructions that were both designed to minimise bias and ensure good response rates, the researchers also tested the wording of the questions to ensure the quality of the ASCS data (Malley et al., 2010). The survey was also piloted in volunteer authorities before being rolled out as a national survey in 2011.

To ensure the questions were suitable and could be understood by all adult social care users, PSSRU researchers used cognitive testing techniques to explore understanding of key terms and questions. The majority of the questions elicited the intended responses, but some changes were necessary. For example, the researchers adapted some questions for care home residents and PWLD.

A pilot using all three versions of the questionnaire was carried out in 18 local authorities (LA), following guidance issued by the Health and Social Care Information Centre (HSCIC)¹. Response rates were good across the three versions (approximately 40%, HSCIC 2011), and sending reminders to nonrespondents seemed to be effective for increasing response rates (51% in LAs that sent reminders and 31% in those that did not). Response rates to the ASCOT questions were very high (over 95%). The good response rates alongside the

¹ Now NHS Digital

demonstrated validity of ASCOT enabled the researchers to recommend the ASCOT multi-item measure of social-care-related quality of life as an outcome indicator (ASCOF 1A). (Malley & Netten 2010)

CONCLUSION

The current ASCS guidance and questionnaires are based on detailed developmental work, which followed recommended practice in survey design. While there is always room for improvement, the ASCS uses what are currently the best available measures and methods for data collection for adult social care users. The content and ASCS method is kept under review by the Social Services User Survey Group (SSUSG) to ensure that superior methods and measures are incorporated into the ASCS, where feasible, as they become available. As a result of the work of this group, for example, guidance around the removal of people lacking the capacity to consent has been improved and instructions for users have also been clarified.

DISCLAIMER

The MAX toolkit and website are based on independent research commissioned and funded by the NIHR Policy Research Programme (Maximising the value of survey data in adult social care (MAX) project and the MAX toolkit implementation and impact project). The views expressed on the website and in publications are those of the author(s) and not necessarily those of the NHS, the NIHR, the Department of Health and Social Care or its arm's length bodies or other government departments.

FURTHER READING AND REFERENCES

Adult Social Care Outcomes Toolkit (ASCOT) website: www.pssru.ac.uk/ascot

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