

# ○ Adult Social Care Survey Feasibility Study

FINAL REPORT

PICKER INSTITUTE EUROPE & THE KING'S FUND

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# 1 Executive Summary

## 1.1 Scope of Project

The Adult Social Care Survey Feasibility Study was a joint undertaking by the Picker Institute Europe and the King's Fund to examine the feasibility of developing and implementing a new survey of adult social care for the Care Quality Commission (CQC). It spanned eleven weeks and included three distinct phases: desk research, consultation, and analysis/ reporting.

This is the final report of the project and reviews the developments and findings from each stage of the study with contributions from both the Picker Institute and the King's Fund. It culminates in a discussion of possible scenarios and recommendations for rolling out a national survey and the advantages and disadvantages of each one. Ultimately it demonstrates original investigation into the feasibility of running an adult social care survey and outlines evidence-based recommendations for a national survey.

## 1.2 Social Care Provider Landscape

The first step in determining the feasibility of a survey of adult social care involved drawing a detailed picture of the social care provider landscape throughout England. This information was used to inform and guide the consultation and development of possible scenarios. The section includes the following:

- Information about the social care provider market, including recent developments in service constellations and changing patterns of service provision and uptake;
- Current and foreseeable-future forces in the environment – including demographic changes and business trends within the provider market – that are likely to influence the social care landscape over the next three to five years;
- Relevant health and social care policy drivers and developments, and;
- The implications of all these, taken together, for the design and implementation of a national adult social care service user survey.

## 1.3 Previous Surveys

A major part of understanding the feasibility of such a survey involved finding and evaluating previous surveys of adult social care. Information from these surveys shed light on important aspects of surveying social care; it helps identify which methods have been successful and which ones incurred the most problems. Furthermore, previous surveys provide relevant examples of questionnaire topics and wording for consideration should a national survey be administered.

The surveys evaluated in this study include the following:

- Health and Social Care Information Centre (HSCIC)<sup>1</sup> Surveys

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<sup>1</sup> Previously named the NHS Information Centre

- CQC and CSCI surveys
- Two Ipsos Mori Surveys (Your Care Rating and Perceptions of Care)
- Local surveys
- Unstructured feedback such as care rating websites

Each individual survey is specified in the ‘Previous Surveys’ section of this report and thorough details of their sampling and methods are listed in Appendix A.

## 1.4 Consultation

The feasibility study included a comprehensive consultation phase to gather feedback from a broad range of stakeholders. The Picker Institute and the King’s Fund led consultations with CQC and external stakeholders respectively.

Consultation with CQC included conversations with representatives from a range of directorates. This helped us gain a more thorough understanding of CQC’s requirements for a survey. Additionally a focus group facilitated by the Picker Institute with a group of ‘Experts by Experience’ provided insight about survey requirements from the perspective of people personally familiar with using social care services. This group allowed for a better understanding of what type of survey and questionnaire items would best meet the needs of service users.

A separate part of the consultation conducted by the Picker Institute was an online survey sent to all providers and councils. This was intended to collect their views on surveying social care service users. Specifically it asked questions about obstacles they have found in using different survey methods and whether or not they would find a national survey useful, as well as whether or not they could identify certain service user information like their capacity to complete a questionnaire.

The King’s Fund conducted the consultation with external stakeholders such as Shared Lives Plus, Barchester Healthcare, Patient Opinion, Age UK and many others (a complete list of organisations and representatives who participated is available in Appendix B). This component of the consultation obtained information from a diverse body of stakeholders to augment our understanding of survey requirements from those involved in social care provision and advocacy.

The consultation’s main findings are explicated in the Consultation Section of this report. Broadly the consultation revealed that stakeholders would value a survey that captures the views of the most vulnerable service users and provided feedback at the location or provider level.

## 1.5 Scenarios

The findings of the consultation, as well as information from the provider landscape and previous surveys’ research, were integrated to create possible scenarios for the roll out of a national survey. While many scenarios were discussed during the consultation phase, only five are listed in this report, as the others were rejected either for their inability to meet CQC’s requirements or for their prohibitively high costs.

The report proposes the following five potential scenarios:

- A postal survey of domiciliary care users.

- A mixed-methods survey of domiciliary care users.
- A postal survey of care homes.
- A mixed-methods survey of care homes.
- A postal survey of domiciliary care users based on a subset of larger providers.

This section of the report begins with a discussion of common challenges that cross-cut all scenarios and an explanation of the standard methods required for each of these options. These include low number of service users per location and/or provider (which has implications for protecting the confidentiality of respondents and producing statistically robust results) and the challenge of using proxy responses.

Each scenario is then discussed in terms of the specific methodology, challenges to capturing information for the population (either domiciliary care users or care home residents) and details of its advantages and disadvantages and estimated costs.

## 1.6 Recommendations

The recommendations are derived from the review of existing surveys and analysis of the possible scenarios. The recommendations section first acknowledges the complexity of the social care landscape and the challenges involved in designing a feasible and affordable study.

The primary short term recommendation calls for the development of a postal survey of domiciliary care users that can be implemented with larger home care providers. For this to be possible, it is recommended that CQC need to conduct a data collection exercise to obtain accurate data on the number and size of the home care providers. Utilising CQC's existing home care survey, used in the themed inspection programme, is the recommended alternative if changes can be made to the questionnaire and sampling methodology. Secondary recommendations include enhancing the coverage and sharing of information from other surveys, for example the Ipsos MORI 'Your Care Rating' survey, and providing social care service providers with a recommended methodology to help ensure good standards in survey design and implementation.

In the longer term, it is recommended that CQC seek to use the Health and Social Care Information Centre Adult Social Care Survey to systematically capture the experiences of adults who use social care services. Although the survey as currently designed provides robust, reliable data at council level, this does not align with CQC's requirements. The sampling approach and questionnaire currently used would need some modification to extend the survey to cover CQC's needs: this would require negotiation and agreement with the Information Centre and may or may not prove to be feasible. This should be explored in detail in the longer term, but consequently use of the survey as it stands is not a viable option for CQC in the short to medium term.

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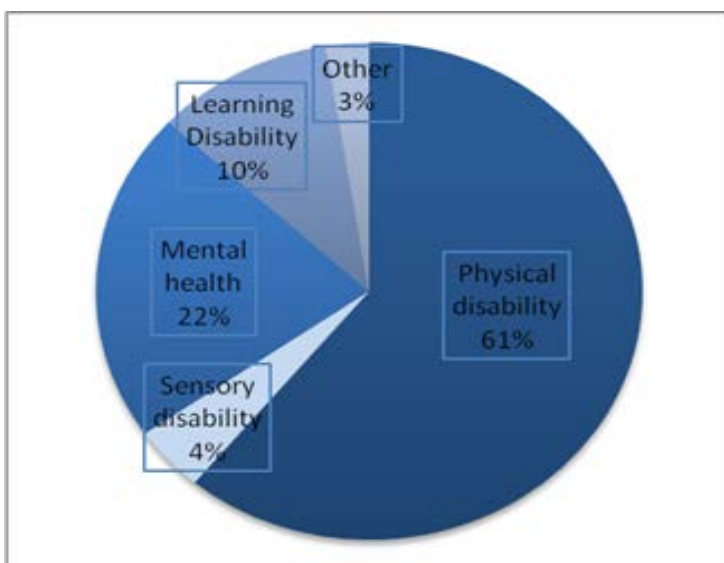
## 2 Social care provider landscape

As the Care Quality Commission's (CQC) 2011/12 State of Care report observes, the adult social care sector has been changing, with the development of new types of support and provision that enable people to live at home for longer.<sup>2</sup> The number and diversity of social care providers and the fluidity of the landscape all distinguish social care from the NHS, and are key factors in this study.

### 2.1 People who use social care services - the public system

Before considering the provider landscape per se, it is worth looking at key characteristics of people with social care needs and recent trends in the use of publicly funded services as this will have implications for survey approach and design.

#### (1) Primary needs of people using adult social care (as % of total)

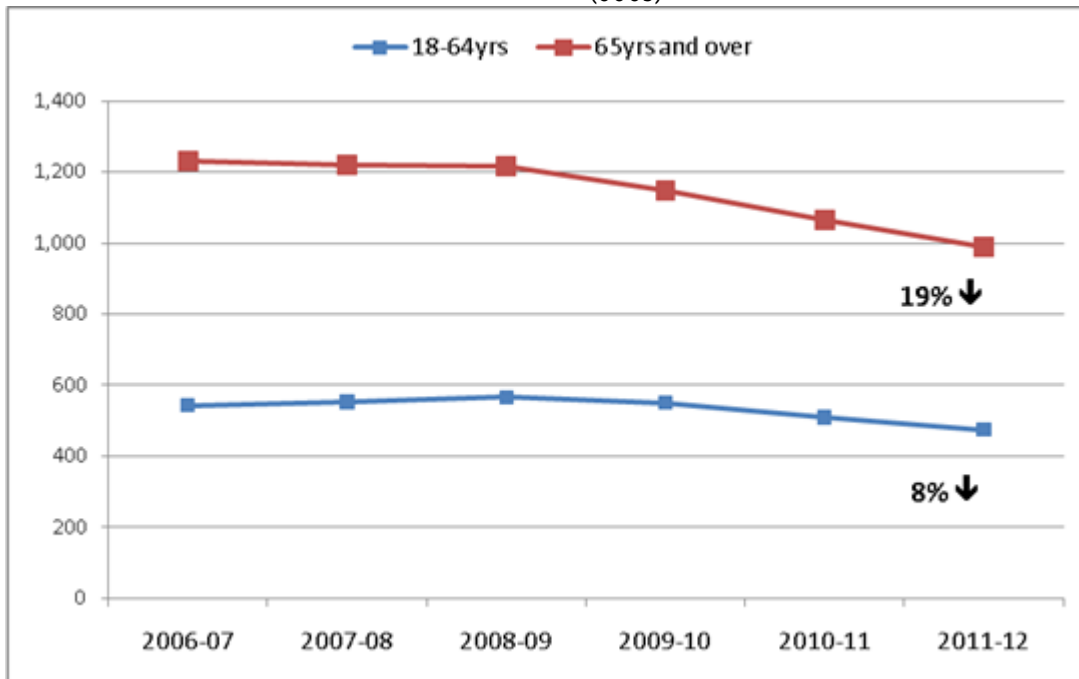


Source: NHS Information Centre 2012

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<sup>2</sup> Care Quality Commission (2012). *The state of health care and adult social care in England. An overview of key themes in care 2011/12*. London: The Stationery Office, 2011.

(2) How the numbers of people using adult social care have fallen in recent years  
(000s)



Source: NHS Information Centre 2012

- Of the 1.5 m people using publicly funded social care, just over two thirds are older people (aged 65 years and over); although media coverage of social care is often concerned with older people, the substantial numbers of working-age people needing care and support should not be overlooked.
- For most people using publicly funded social care services, physical disability remains the most common primary need, although for over a fifth it is mental health (see figure 1, above). People with learning disabilities represent 10% of the total. People with sensory (ie visual and/or hearing) impairments account for just 4% but there will be particular issues in ensuring the engagement of this group.
- There has been a downward trend in the number of people using services, with the highest fall amongst older people - 19% since 2007, over double that for 18-64 year olds (see figure 2, above). For all groups, the reduction has become steeper since 2008 and in 2011/12 alone fell by 7%. There are a number of possible explanations for this fall including: data cleaning by local authorities; the tightening of eligibility criteria; fewer older people being entitled to public funding; more services being provided on a universal basis. Irrespective of the explanation, it is certain that the social care needs of many people will be displaced into informal care, the NHS or self-funding arrangements with private and voluntary providers, as we shall see.

What kind of services do people use?

- The overwhelming majority use community-based services rather than residential or nursing home care (see figure 3, below). This reflects an established, though not dramatic, shift away from residential care (although the use of publicly funded

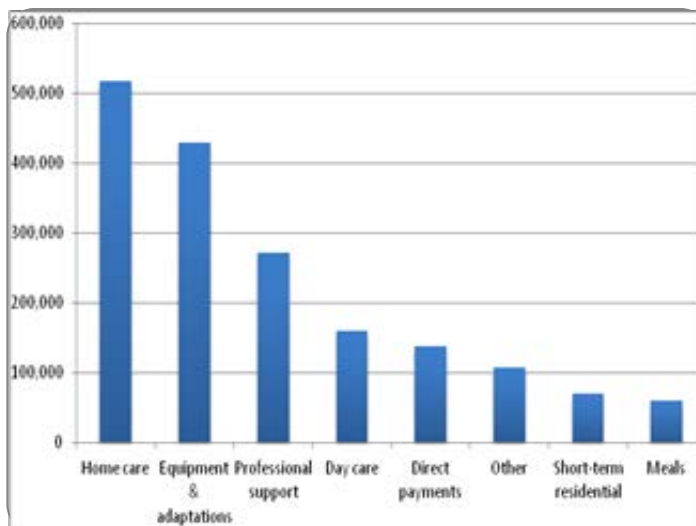
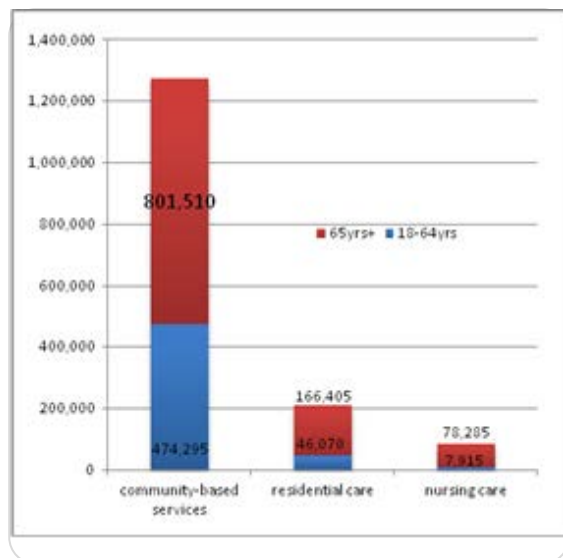


residential care rose for the first time in 2011/12 and there is evidence of a wider market trend towards greater use of residential care by older people).

- Younger people (aged 18-64 year olds) are more likely to be using community based services than older people - 90% and 77% respectively.

**(3) What kind of services do people use?**

**(4) What kind of community-based services do people use ?**



Source: NHS Information Centre 2012

Identifying the particular community-based services people use is complicated by the fact that many use more than one service. Home care and equipment & adaptations are two of the most frequently used services.

The number of service users receiving self directed support has increased substantially (up 40% from 2010/11). Of these, 139,000 received a direct payment (up 11% from 2010/11) but much of the increase has taken the form of local authority managed personal budgets. The number of carers receiving self directed support was 78,000 (up 12% from 2010/11) Of those receiving community based services not in the form of direct payments in 2011/12, 517,000 received home care, 429,000 received equipment, 272,000 received professional support, 159,000 received day care, 70,000 received short term residential care (excluding respite care), 60,000 received meals and 107,000 received other services.

## 2.2 People who use social care services - the private market

Another distinctive feature of social care is that a significant proportion is arranged and funded by individuals themselves, or by their families, without recourse to local authority assessment or funding. People who fund their own social care are currently excluded from the NHS Information Centre annual national user survey; the feasibility study will need to establish whether and how self-funders might be included in a provider-based survey and how methodological and logistical issues might be overcome - in particular,

how service user populations will be identified and how sampling frames and strategies might be developed.

There is a dearth of accurate data about how many private individuals and families fund their own care, what services they use, and how much they pay. Nevertheless there is good evidence to suggest that in many parts of the country this private economy of care is outstripping the publicly funded system.

Within the current means testing arrangements, self-funders will be drawn from older people who have accumulated sufficient assets to place them above financial assessment thresholds or those whose needs are not high enough to meet local authority eligibility criteria.

Laing & Buisson estimate that 43% of older and physically disabled residents of independent care homes fund the entire cost of their care. It is significantly higher for nursing home residents (49%) than residential care home residents (39%). These figures are broadly consistent with other estimates by the NAO, NHS Information Centre. If third party top ups are included, then the total number who contribute their own money reaches 57%.

There is even less reliable data about people who fund their own care at home. Estimates suggest around 70,000 older people pay for care in their own home. This increases to 270,000 if it is widened to include help with activities such as housework and shopping<sup>3</sup>. Laing & Buisson calculate that £1.1b is spent privately on non-residential services.

The extent of the private market varies widely across the country. The highest proportion of self-funding care home residents is in the South East (55%) and the lowest in the North East (22%). This could have significant implications for how a national survey sample is constructed if this growing group of social care users is to be reflected appropriately.

## 2.3 The provider market

CQC is well positioned to understand the current size and shape of social care services that are required to be registered with the regulator. In summary, CQC data indicates that:

- There were 12,500 social care providers registered with CQC to provide regulated services, operating services in just over 25,000 locations in England (CQC registration data March 2012)
- There were 17,510 care homes with 462,226 beds registered in England (CQC Active Care Home Locations Data, March 2013)
- There were 6,830 agencies providing domiciliary care, an increase of 16% since 2011. There are more in the South East, London and the North West but there is considerable variation in the size of agencies, the number of staff they employ and the numbers of people using their services (CQC data at 31 March 2012)

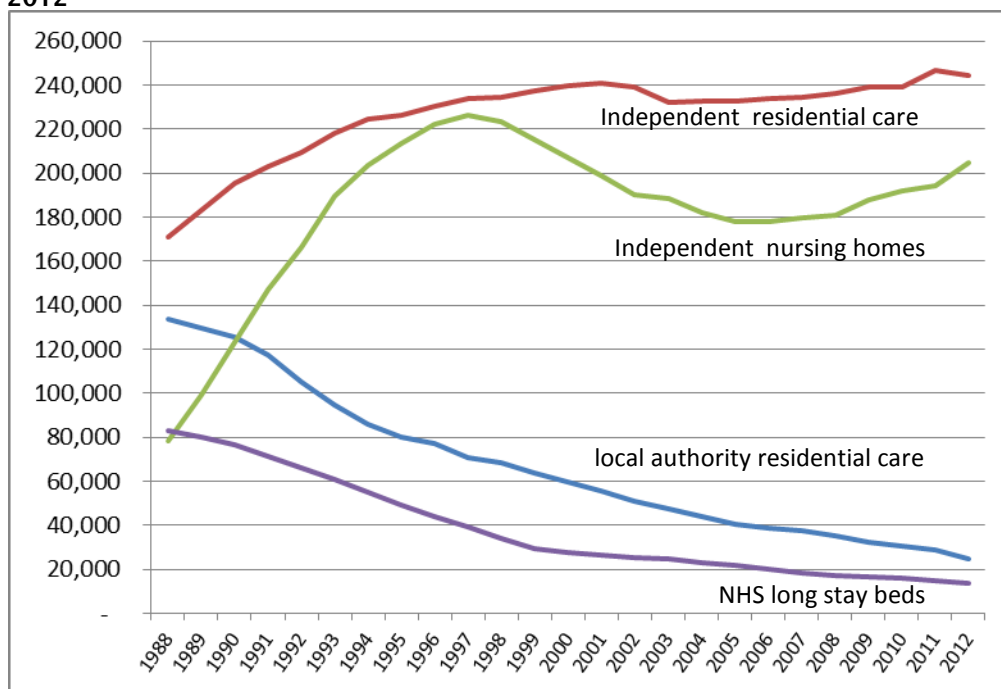
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<sup>3</sup> (IPC, 2012) "An Analysis of Self-Funders in the Social Care Market" available from <http://ipc.brookes.ac.uk/publications/index.php?absid=646>.

Data from the Laing & Buisson 2012 market survey shows that:

- 92% of all residential & nursing care provision is delivered by independent providers; 87% of local authority funded home care is delivered through independent providers (Laing & Buisson 2012).
- There has been some consolidation in residential and nursing home care where the ten largest providers account for 25% of the market, but even so 42% of care homes are run by single proprietors with no more than three establishments. This fragmentation is even more apparent in domiciliary care, where 60% of domiciliary care providers are single agency businesses. For this reason it can be described as a cottage industry.
- This is a small but growing volume of other community based social care, including supported living services (1,555 locations), extra care housing (569 locations) and Shared Lives schemes (160 locations).
- Social care is highly differentiated in terms of business models, ranging from big corporate companies, to small agencies and independent family-run business, social enterprise, micro enterprises, mutuals, and registered social landlords. There is no evidence about any associations between users' views and business models or organisational size and type.

**(5) Trends in residential, nursing and long-stay NHS care for older and disabled people 1987-2012**



Source: Laing & Buisson Care of Elderly People UK Market Survey 2012/13

The last 25 years has seen a long term shift away from public sector provision towards services from voluntary and private ('independent') providers as figure 5 (above) shows. The most striking change has been the reduction of NHS long-stay places and the decline in local authority direct provision.

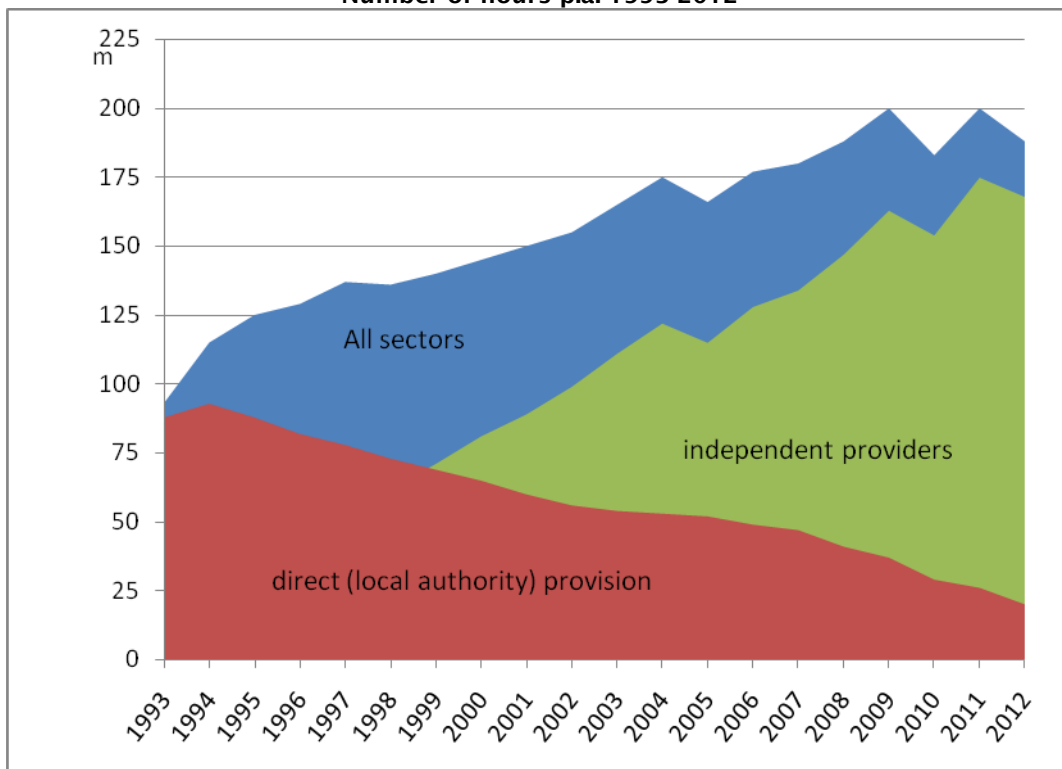
Although there was a major expansion of independent residential care and nursing homes during the 1980s fuelled by the availability of social security payments, the

community care reforms in the 1990s and the renewed priority to supporting people in their own homes saw a slow reduction in capacity. But since 2007 demand and capacity have begun to grow.

Within the independent sector there has been a significant shift from nursing home to residential care provision, reflecting local authority commissioning practice which has sought to achieve less expensive placements where possible. However most of recent expansion in residential care capacity has been in nursing homes.

In home care, there has been strong long term growth in the number of hours provided but this fell in 2010 and 2012 (Figure 6). This in part reflects the switch of some service users to personal budgets and whose use of home care is no longer recorded as such. But the reduction in local authority spending on adult social care over the last 2 years will also have taken its toll. As noted earlier, the number of people receiving publicly funded home care has declined steadily, with local authorities concentrating their resources on those with the highest need.

**(6) Local authority funded home care  
Number of hours p.a. 1993-2012**



Source: DH/NHS Information Centre

## 2.4 What will drive change in the social care provider market?

Over the next 3-5 years the principal factors that will affect the shape and direction of services arise from demographic trends, changes in the pattern of illness and disability and the fiscal and business environment that will affect commissioner and provider behaviour, and the impact of policy changes, especially the Health and Social Care Act and the Care and Support Bill.

**Demographic trends** are well established with an ageing population seeing substantial increases in the oldest old; but longevity also sees more younger people with disabilities and chronic illness living longer. This indicates that irrespective of economic circumstances the underlying need and demand for social care will remain buoyant.

Changes in the age structure of the population will also expose shifts in the **pattern of disease and disability**. One of the biggest budget pressures experienced by local authorities in recent years has arisen from rising numbers of working age adults with learning disabilities. A particular concern is the rapid increase in the 'oldest old' - frail older people with comorbidities and those with dementia. The current dividing lines between 'health' needs and 'social care' needs will become increasingly fragile; whereas the current system of health and care is configured around single, acute episodes of illness punctuated by admission to and discharge from hospitals, changing needs will call for longer term care and support that is closely coordinated across professional and service boundaries and is delivered closer to, or at, home. It is unlikely that rapid progress will be made in the short term, but it is reasonable to assume that over the next 3-5 years there will be some kind of integrated care programme in place in most places.

The Chancellor's autumn statement in 2012 confirmed that the **fiscal environment** will be dominated by continuing uncertainty about prospects for the national and international economy. The next spending review is likely to confirm that the NHS will receive at best flat real terms funding and still need to achieve productivity gains of at least £20b. The Government's deficit reduction programme will not protect local government spending, with further reduction in central grant of 2% in 2014/15. This will make it harder for local authorities to protect social care budgets. Delivering public services in an age of austerity will raise profound challenges and from the gap between public expectations and resources will generate difficult choices for individuals, organisations as well as the government. This suggests that the cost of care will play a bigger part in influencing people's perceptions of the services they receive.

For commissioners this will mean further pressure to reduce costs and most local authorities are trying to avoid reductions in service by achieving greater efficiencies and redesigning services. Providers will face fee increases of less than inflation and renegotiation of contracts (ADASS Budget Survey, 2012). On the other hand, public commissioners will be interested in provider innovation, and providers themselves will benefit from the growth in numbers and market share of self funders. The rate of owner occupation will continue to expand amongst the older population who are most likely to need social care. For these reasons Laing and Buisson believe that demand and capacity for residential and nursing care will increase over the next 10 years despite public spending constraints.

Turning to **policy developments**, the Health and Social Care Act 2012 ushers in a completely different organisational landscape from 1<sup>st</sup> April 2013. It will take some time for new roles and responsibilities to settle down, especially at a time of severe financial challenge. In short term there may be disruption to commissioner and provider relationships.

The Care and Support Bill and implementation of the recommendations of the Dilnot Commission will have profound implications for how the social care market operates and in particular the division between the publicly funded system and private arrangements (self-funding). Specific impacts will arise from:

- New population-level duties on local authorities to provide information and advice, prevention services and shape the market for care and support services;
- The introduction of new arrangements for market oversight with strengthened regulation of the business and financial viability of providers (in part in response to the failure of Southern Cross);
- The introduction of a limited liability model of funding in which individual liabilities for care costs are subject to a maximum lifetime 'cap' beyond which the State will assume responsibility for further costs of care; and the introduction of a similar cap in relation to the costs of accommodation.

It is difficult at this stage to predict how these measures will affect the development of the social care market and how it operates. But it is clear that the introduction of Dilnot's capped cost model will begin to dissolve the traditional divide between public and privately funded care. Local authorities will have legal requirements - and a financial interest - in identifying and monitoring the spending of people who use their own resources to fund their care. One positive consequence should be to generate better information about social care needs and service usage across the whole population – not just those with current entitlements to publicly funded care.

It is reasonable to conclude that the drive towards personalisation and personal budgets will continue unabated, and there will be stronger interest in promoting the integration of health and social care at scale and pace. But much of recent growth in personal budgets has been in the form of local authority managed budgets and it is unclear whether these give as much choice and control as direct payments. Finally it may be worthwhile to signal the growing media and public interest in the quality of care offered to people in the wake of the Winterbourne review and the Francis Report. Although the British Social Attitudes Survey and the national adult social care user survey have elicited generally high satisfaction ratings, media publicity and the decline in trust in public institutions is likely to reinforce the need for the survey and ensure heightened interest in the results and outcomes.

## 2.5 The implications for the design and implementation of a new national adult social care service user survey

What does this mean for a survey? The sheer number of agencies, the diversity of individual needs, and variations in the nature of services and their geography should not be underestimated. The provider landscape is completely different to the NHS, and there

are multiple and substantive implications for survey coverage and costs. The key implications for the survey are summarised as follows:

1. Despite reduction in the use of residential and nursing care and the growth in new forms of provision, most social care – irrespective of whether it is publicly or privately funded – is provided in the traditional settings of residential care, nursing homes, and in peoples’ own homes. This is unlikely to change in the next 3-5 years so it will be these services from which the bulk of the sample should be drawn;
2. Nevertheless it will be important to capture the experience of those who are using newer types of services. There may be significant nuances within these categories, for example between recipients of direct payments as opposed to local authority managed budgets. Current survey evidence suggests that people are more likely to be satisfied with residential care.
3. Development of better coordinated and integrated care across health and social care – and possibly housing also – could make it harder to ensure clarity about what particular element of the service individuals are being asked about and whose responsibility (organisational and financial) this rests with. This needs consideration possibly in the context of work to develop user/patient measures of integrated care.
4. The proportion of social care users who fund their own care is substantial and growing. Should the survey seek to elicit any differences in the views of self-funders about their care as opposed to publicly funded users? How important is this to the primary purpose of the survey?
5. A similar question could be posed about the different business and organisational models through which services are provided. A simple categorisation of whether it is a public, private or voluntary organisation may not reflect the increasing diversification of delivery vehicles.
6. There are characteristics of some users of social care that will require particular thought in terms of how the survey is designed and implemented and the degree of assistance that individuals might require. A significant number of respondents will have cognitive, physical, or sensory impairments. Some will not meet Mental Capacity Act tests for consent. Alternative methods for seeking views at scale will be costly.

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## 3 Review of existing surveys

### 3.1 Introduction

Previous user experience surveys in social care across England offer unique insight into established approaches and potential challenges associated with designing a new survey of adult social care. They provide the most directly relevant examples of content and methodology from which to guide development of a new survey tool. Surveys for this review have been identified based on their ability to inform development of a new national survey. Whilst locally administered surveys would have provided useful material, only one is included due to lack of available information regarding most local surveys' content and methodology. The main surveys that contributed to this evaluation include:

- Health and Social Care Information Centre (HSCIC)<sup>4</sup> Personal Social Services (PSS) Adult Social Care Survey 2011-12.
- HSCIC PSS Home Care Users in England aged 65 and over Surveys, 2002-03, 2005-06 and 2008-09.
- HSCIC PSS Survey of Physically Disabled and Sensory Impaired Users in England Aged 18-64, 2003-04.
- HSCIC PSS Survey of Adults Receiving Community Equipment and Minor Adaptations in England, 2007-08 and 2009-10.
- HSCIC PSS Survey of Adult Carers in England 2009-10.
- Care Quality Commission (CQC) 'Not just a number': home care inspection programme 2013.
- Commission for Social Care Inspection (CSCI) Shared Lives Survey.
- CSCI People who live in care homes - 18-65.
- CSCI People who live in care homes - older adults.
- CSCI People who use domiciliary care services.
- Ipsos MORI Your Care Rating Survey 2012 .
- Ipsos MORI Perceptions of Social Care.
- Bradford LINK: Adult Mental Health Day Services Survey.

In addition to this list, feedback from councils and information from online care evaluation websites is also considered in this report.

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<sup>4</sup> Previously named the NHS Information Centre



## 3.2 Questionnaire Content

The topics addressed by each questionnaire vary with respect to the overall aim of the survey. However, the items across all surveys can broadly be divided into three categories: questions about service transactions, questions about service user relationships, and questions on social care-related quality of life. These categories encompass all the questions shown to be the most important to patients and provide a label to the different types of such questions<sup>5</sup>.

The first category, questions about service transactions are the most uniform across surveys and range from availability of information to cleanliness of facilities. The aim of these questions is to ascertain users' experience of the delivery of care, and make up the majority of most questionnaires. The topics covered in this category include:

- Overall satisfaction with services.
- Cleanliness/ freshness.
- Food and drink.
- Safety.
- Frequency of staff visits and time spent with care workers.
- Activities provided.
- Arrival and move-in procedure.
- Receiving support (in health maintenance, decision making etc).
- Receiving information about the service (financial or house protocols) .
- Access to information.
- Signposting to other services.
- Knowledge of how to make a complaint.
- Knowledge of who to speak to about general support.
- Services available for people with specific disabilities.

The second category includes questions that probe relational aspects of user experience. Such questions are necessary to assess the users' experiences of care and their relationships with staff, relatives, friends and acquaintances. The topics include:

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<sup>5</sup> Robert, G., Cornwell., J., et al. (2011). *'What matters to patients'?* *Developing the evidence base for measuring and improving patient experience.*

[http://www.institute.nhs.uk/images/Patient\\_Experience/Final%20Project%20Report%20pdf%20doc%20january%2012.pdf](http://www.institute.nhs.uk/images/Patient_Experience/Final%20Project%20Report%20pdf%20doc%20january%2012.pdf)

- Contact with others.
- Closeness with staff.
- Staffs' listening ability.
- Staffs' helpfulness.
- Comfort level speaking to staff about topics of a personal nature.
- Feelings of being treated with dignity and respect.
- The visitor procedure at care facilities (both for children and adult visitors).
- Ability to contact with people of your choice.
- The happiness of other patrons of the same service.

The final category focuses on users' emotions and perceptions of personal health status and social care-related quality of life. These questions are designed to grant insight into the personal and mental well-being of social care users so far as it is impacted by the care they receive (ie 'outcome' questions). This category includes the following:

- Ability in activities of daily living.
- General and social care-related quality of life measures.
- Control over daily life / ability to make decisions.
- Feelings about self worth.
- Self-perceived health status.
- Perceptions of safety and security (safeguarding vulnerable adults).

A user's quality of life can be affected by a number of factors other than social care services. It is worth noting that the NHS Information Centre's Adult Social Care Survey included questions to capture such factors, such as whether the respondent received any informal support, so that the quality of life scores could then be adjusted. The NHS Information Centre (IC)<sup>6</sup> also requested that councils submit additional data on the intensity of service receipt (measured by the gross annual budget for each person) and the needs of the service user (captured in the questionnaire items about activities of daily living) to ensure any variations in the quality of life outcome indicator could be attributed to the service. However, this process relies on the assumption that people receive the level of services that they require and that there is no unmet need or waste in the system.

Many of the questionnaires include basic healthcare questions that ask respondents to note any long term illnesses or compromises to health, senses or mobility. One questionnaire item worth noting that appeared on each of these surveys was whether or not the respondent filled in the form themselves or had some form of help (eg from a

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<sup>6</sup> The NHS Information Centre is now known as the Health and Social Care Information Centre (HSCIC) to reflect their broader social care responsibilities

friend, relative, or carer acting as a proxy respondent). This question is important to social care user experience surveys due to the high proportion of participants that require help with completion, and the potential bias associated with a member of the social care staff assisting them with the evaluation. This question is useful in the analysis stage to help councils understand variations in responses to other questionnaire items with respect to those who received help. The advantages and disadvantages associated with proxy respondents are addressed in section 3.5.4 of this report. Finally, all previous surveys asked a selection of demographic questions at the end of the form.

### 3.3 Local flexibility in questions asked

Across the NHS Information Centre Personal Social Services Surveys that focused on a single client group or service type, councils were provided with a sample questionnaire (with guidance on the wording and ordering of compulsory questions), but were able to include additional questions and local branding. For instance, the Home Care Users aged 65 and over Survey showed that almost half of councils (48%) included additional questions in the 2008-09 survey. An extended version of this survey was also available to councils on a voluntary basis. The extended survey was developed by PSSRU with the aim of adding value by enhancing comparability between councils on additional questions.

The 2002-03 Home Care Users Survey revealed that, for those councils who used an extended survey, it was not practical to carry out telephone or face to face interviews.

It is perhaps worth highlighting, however, that some questionnaire design errors were made by councils who had added or removed questions. For instance, in the 2002-03 Home Care Users Survey the four compulsory questions were asked in the wrong order or the format of response options were changed by some councils. Similarly, in the Adult Carers Survey, five councils removed one or more of the 39 core questions.

### 3.4 Questionnaire Formatting

Before explicating the methodologies used in these surveys, it is necessary to describe the various ways in which items appear on surveys and the procedures participants must follow to answer them correctly.

First it should be noted that most surveys had multiple formatting designs to account for service users with learning disabilities and or physical impairments that limit their ability to complete a standard text survey. For instance, the PSSRU survey offered a standard print, Braille, large print and an easy-read version for People with Learning Disabilities (PWLD). They also offered a face to face interview option for those who were unable to complete any kind of paper format. The PWLD version was the only one to differ in question wording and visuals, as its aim was to aid question comprehension. Different questionnaire versions are also made for specific settings such as care homes. While the pros and cons of these formats will be discussed in the methods section, administrators of these surveys highlight the importance of such alternative formats, as they vastly expand scope for service user participation. They also cited questions that were 'outcomes based' and not process based or yes/no yield the most relevant information.

In terms of standard print survey, questions are posed in a variety of ways:

- Rating questions (eg 'How would you rate your care out of 10?').

- Questions prefaced with ‘Thinking about’ to indicate which part of care the question is referencing.
- Yes / no format (eg ‘Do you know who to speak to if you are not happy? Yes/ no).
- Multiple response questions (eg ‘(e.g. ‘What type of help did you have?’).
- Likert Scale (eg an ordinal five point list from ‘strongly agree’ to ‘strongly disagree’.
- Free text comments.

During the development of the ‘Your Care Rating’ survey, Ipsos Mori conducted cognitive interviews with residents to test the questionnaire design and content. The testing showed the importance of keeping the questionnaire as simple and short as possible. One of the key findings from the testing was that some residents had difficulty in answering ‘concept’ statements, such as ‘I feel valued’, so these statements were shortened and simplified or even removed if the concept was considered too complicated to convey in a short statement. In terms of the overall layout of the questionnaire, reducing the number of questions shown on each page and including spaces for respondents to write their own comments was regarded as beneficial.

## 3.5 Discussion on methodology

This section will use examples from previous surveys to expose the major challenges associated with gathering feedback from social care users and establish the methodologies that would be most useful to a new survey instrument. For a more detailed description of each previous survey, the appendix includes exact sampling methods and survey administration procedures for all surveys considered in this report.

### 3.5.1 Sampling

The surveys provide examples of different sampling procedures, each with their own implications to the overall survey and considerations for applicability to a new national survey. This section presents and evaluates the sampling techniques of previous social care surveys but in no way provides an exhaustive list of all possible techniques.

The NHS IC employs a sample procedure whereby all people in receipt of a service across all Councils with Adult Social Service Responsibilities (CASSRs) are eligible to take part and exclusions are made for those unable to consent (see Appendix A). This enables a high degree of coverage across service users, and combined with many councils’ comprehensive electronic databases of patient records, it allows councils to easily draw a stratified sample (with systematic sampling within strata) of eligible service users. Such electronic databases are not a feature of all CASSRs and it can therefore not be assumed that all councils will be able to provide extensive demographic information for sampling purposes. The NHS IC emphasised the importance of stratification to bolster numbers from small groups. Stratification can be done on the basis of age, gender, learning difficulties, or by the length of time people have been receiving care. Such stratification in social care is particularly important due to the range of service users; a simple random sample may not capture enough feedback from each user group. However, sampling at the provider-level is unlikely to yield population sizes large enough for a stratification method of sampling to be feasible. As discussed in section 5.2, due to the large number

of provider organisations that provide care to a small number of people, most providers would need to include all their service users in a survey (i.e. take a census rather than draw a sample).

In contrast to this national survey, CQC's recent themed inspection on the quality of home care was based on a random sample of home care agencies (250 were included which represents 4% of all service locations). CQC tested a range of methods for gathering the views of people receiving home care services (See section 7.1.6, Appendix A for details). Whilst using different approaches to gaining feedback demonstrated the potential for more people to give their views, particularly from those people who were less able to complete a questionnaire due to cognitive impairment, it is not clear how any 'mode effects'<sup>7</sup> were minimised. Furthermore, the degree to which the results are representative of the experiences of all users is questionable, given that the response rate to the postal survey was low (21% overall) and only a relatively small proportion of telephone interviews and home visits were conducted. Building on the 2011 domiciliary care pilot and the 2012 themed inspection, in April 2013 the CQC launched a methodology for inspecting domiciliary care. This specifies that inspectors can use a combination of methods for gathering the views of people using the service (telephone interviews, questionnaires, and face to face visits). Inspectors are advised to choose the most appropriate method(s) by considering the size of the service the people they provide care for. The guidance states that inspectors should sample 20% of the people using the service (or all users if it's a 'micro' service). However, it is not clear whether the sample size should be 20% of the total people using the service or whether the inspector should obtain responses (via questionnaires and/or interviews and/or face to face visits) from 20% of the people using the service (ie an 'achieved' sample). If it's the former, then the percentage of users whose views are actually captured by the inspector may be considerably less if there is a poor response/uptake. The guidance also states that if using questionnaires to gather user's views, the size of the sample should relate to the size of the agency (ie 20% of the people using the service). However, the guidance states that a maximum of 60 people should be included in the sample list sent to the support agency who administers the survey, so this will not reflect the size of the largest providers (For instance, an agency that provides care to over 500 people would need to sample over 100 people for this to reflect 20% of the people using the service). As the service providers are asked to draw the sample themselves by selecting every third or fourth person from a name-sorted list, there is a risk that providers may omit the names of those users for whom they feel may give a less favourable view of the service and/or not sort the list correctly before taking a sample. It is not clear if there is a verification process in place or if the support agency run checks on the samples submitted.

The sampling approach used in previous CSCI surveys follows a slightly different trajectory. For these setting specific surveys such as those focused on care homes (ie 'People who live in Care homes (18-65)' and 'People who live in Care homes (older adults)'), an inspector contacted the care homes they wanted to include in the survey. Based on information from the Annual Quality Assurance Assessment (AQAA), and guidance provided on who should be included in the sample from each care home, the inspector drew a sample of either 25% of current service users or ten current service

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<sup>7</sup> Surveys using different modes of data collection may produce different results even from identical questions, which are known as mode effects. Mode effects are a methodological artifact, limiting the ability to compare results from different modes.

users (whichever is more)<sup>8</sup> from each home. If the information was not available on the AQAA, the inspector drew the sample based on a discussion with the care home manager. The provider then informed the inspector of anyone in the sample with a mental capacity difficulty or communication need that would bar them from being able to complete the survey independently or require them to receive a survey in an alternative format. The inspector would then send sample details to the Regional Inspection Team (RIT) to enable them to print the appropriate documents needed and compile and send a survey pack to the care home. Whilst the care home received the survey packs, from the RIT, each survey pack was addressed personally to the sampled resident, or their representative. This differs from the approach adopted for the Ipsos MORI 'Your Care Rating' survey, for example: in this survey, care home managers were involved in determining eligibility of residents on receipt of the packs and did not substitute those unable to consent with proxy representatives.

The CSCI surveys regarding agency services (such as 'People who use Domiciliary Care Services') applied a similar sampling approach as their care home surveys. The samples were drawn by inspectors based on lists provided by the care agency and information in the AQAA, with a particular focus on similar key demographic or minority groups criteria as per the care homes surveys. The sample size for each agency was 10% of service users or a maximum of 50 people (whichever is the larger). Data was also collected from relatives of service users and agency staff.

The main limitation around these CSCI surveys concerned the low sample sizes, the method of sampling and the frequency with which the surveys were conducted. It is not clear from the guidance documents how inspectors were to sample, ie simple random or stratified sample, which may have introduced elements of sampling bias. General information was provided in the guidance documentation on the types of people that should be included in the sample, though no quotas were set for how many people from each demographic or minority group should have been included. The small sample size selected from each care home or agency would not allow enough responses to be gathered to provide statistically reliable data at care home/ agency level, though it could have potentially been aggregated to provider level. However, the CSCI surveys did gather data from service users' relatives, friends, advocates and agency staff, providing a 360 degree view of the service. As inspectors were responsible for deciding when to run a survey, and which care homes or agencies should be included in the survey population, not all care homes or agencies were surveyed at exactly the same point in time. This limits the comparability options available for the surveys- cross-sectional data would arguably only be directly comparable between providers included in the same round of the survey, limiting the potential to produce overall national findings.

### **3.5.2 Administration Procedure**

The review of previous surveys also shed light on the established methods of administering social care surveys and their accompanying costs and benefits. The most resource intensive of the surveys were the Ipsos Mori Public Perceptions of Care survey and the Bradford LINK survey, as they exclusively used face to face interview techniques. Face-to-face methods are valued for their ability to generate high quality data and strong response rates, especially from service users with disabilities, but they also incur

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<sup>8</sup> There is no specified procedure in the CQC guidance for how they deal with smaller care homes that have less than 10 service users.

significantly higher costs due to the labour resources involved. Consequently other modes of data collection are potentially more desirable for very large samples where a face-to-face survey approach would be cost prohibitive. The NHS IC and CSCI surveys included a face-to-face option for those deemed unable to complete a paper survey; however this was not their primary mode of administration. Only 1% of those who responded to the NHS IC Adult Social Care Survey (and where the method of collection is known), received either a face-to-face or telephone interview<sup>9</sup>. In recognising the challenge in surveying people who receive care in their own home, CQC used a mixed-method approach in their home care inspection programme (Not Just a Number) to gather data on people's experiences. In addition to a paper-based survey, an alternative web-based form was developed and telephone interviews and home visits were carried out.

On the other end of the cost spectrum lie online surveys which require very little labour or resources beyond their initial setup. Despite their nominal 'per unit' cost, online surveys suffer from poor coverage of some sections of the population: for example, 69% of people aged 75 or over and 33% of people with a disability (as defined under the Disability Discrimination Act) have *never* used the internet<sup>10</sup>. The methodology for CQC's 2012 home care inspection programme included the option for people to provide feedback about their experiences using a web-based questionnaire (See Appendix A for further information). The majority of responses were received from a friend/relative of the service user (79%, n=103). Whilst the inclusion of proxy data in an adult social care survey is likely to be necessary given the high proportion of people with a physical and/or cognitive impairment, there may be a greater concern with web-based surveys that the relative/friend is more likely to complete the survey in their own home without the presence of the user, which may result in responses being less likely to reflect the views and experiences of the person receiving the service<sup>11</sup>. Hypothetically, then, there is a risk that proxy data obtained through a web-based survey may not be comparable to proxy data obtained through a paper-based survey; its inclusion as an optional mode of completion for a national survey of adult social care services would therefore require careful consideration. The number of responses received from a web-based survey is also likely to be too low to justify the costs of providing the option to complete the survey online; a recent pilot conducted on the national patient experience 2012 Accident and Emergency Survey found that only 5% of respondents completed the survey online, and that there were differences in the demographic characteristics of those who completed the survey online compared to those who completed the paper questionnaire.

The standard postal survey supplemented by alternative formats and face-to-face interviews when necessary, as used by CQC and NHS IC, seems to strike the best balance between being economical and eliciting the highest response rate for a large-scale, locally representative adult care social survey. However, there are likely to be related challenges associated with mail in care homes (See section 3.5.3 below). This in itself could increase costs indirectly if it requires more labour, but the cost would be unlikely to outweigh the

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<sup>9</sup> The Health and Social Care Information Centre (2012). Personal Social Services Adult Social Care Survey, England 2010-11 (Final Release). Retrieved from <https://catalogue.ic.nhs.uk/publications/social-care/surveys/per-soc-ser-adu-soc-car-sur-eng-2011-12-fin/per-soc-ser-adu-soc-car-sur-eng-2011-12-fin-report.pdf> (p138).

<sup>10</sup> Office for National Statistics. (2013) Internet Access Quarterly Update, Q4 2012. Retrieved from <http://www.ons.gov.uk/ons/rel/rdit2/internet-access-quarterly-update/2012-q4/stb-ia-2012-q4.html>

<sup>11</sup> Users who are resident in care homes, and older people receiving care in their own homes, are less likely to have access to the internet which would necessitate the relative/friend completing the questionnaire in another location. In contrast, a relative/friend could help the user complete a paper-based questionnaire in the location of their residence.

benefit. There are other disadvantages in carrying out mixed-mode survey designs which would need to be taken into consideration.<sup>12,13</sup>

Finally, it is important to note the wide array of websites available to the general public that dispense information about social care services. Whilst they are primarily designed to help users and potential users compare service options (predominately care homes), they also include service user testimony and evaluations of care. There are approximately 40 of these websites in operation in England, most notably 'Compare Care Homes' ([www.comparecarehomes.com](http://www.comparecarehomes.com)) and 'Find Me Good Care' ([www.findmegoodcare.co.uk](http://www.findmegoodcare.co.uk)) and a new site being developed by the Social Care Institute for Excellence (SCIE). In April 2013, the Department of Health launched new online profiles on the NHS Choices website ([www.nhs.uk](http://www.nhs.uk)) for every registered care and support provider (previously the 'provider quality profiles') which will include comments by users of the services, their families and carers, which have been submitted to NHS Choices or other feedback websites which meet strict moderation criteria.<sup>14</sup> The advantage of this site is that it will include social care services provided to people in their homes, in addition to care homes. Care Opinion ([www.careopinion.org.uk](http://www.careopinion.org.uk)) is another relatively new site that gives service users, their families and carers the opportunity to publish their personal experiences of the adult social care system. Care Opinion is wholly owned by the fore runner, Patient Opinion ([www.patientopinion.org.uk](http://www.patientopinion.org.uk)) which covers health services, and is not-for-profit with all surplus reinvested in the company. Care Opinion is integrated with Patient Opinion so stories about health, social care or both can easily be shared on either site.

'Compare Care Homes' includes a rating of the care homes (bronze, silver and gold) which is solely based on the aggregated reviews submitted by members of the public to the website.<sup>15</sup> Users wishing to submit a review on the 'Find Me Good Care' website have to register first. For both sites, when a review is submitted, it is not automatically published as reviews are moderated to ensure compliance with the site's posting and submission policy rules; any violations of these rules will result in the submission being rejected. On the 'Compare Care Homes' site, people submitting a review are also required to accept two declarations, the second being that they have "read, understand, and agree to be bound by, the Terms and Conditions, and the Site Posting and Submission Policy." Both sites share the reviews with the relevant provider to seek their response before the review is posted. Whilst such steps may help to ensure the reviews are genuine and fairly protect the reputations of care home providers, it is difficult to make robust comparisons between care homes based on the user ratings when it is not known how representative these views are of all residents at the home. It is also worth noting that users can only submit a review on the 'Find Me Good Care' if the provider has paid for an enhanced listing.

Across both these websites, it is notable that very few care homes have been reviewed or rated. Unless more reviews are submitted by members of the public, the value of such sites for evaluating user experience is profoundly limited. Given that they have only just been launched, it is unclear at this time how comprehensive the user feedback information on the NHS Choices and Care Opinion websites will be. Whilst the NHS

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<sup>12</sup> De Leeuw, E. D. (2005). To mix or not to mix data collection modes in surveys, *Journal of Official Statistics*, 21(5), 233–255.

<sup>13</sup> Graham, C. (2007). *Mixed mode surveys: a review for the NHS acute patient survey programme*, Picker Institute Europe, <http://www.nhssurveys.org/survey/526>

<sup>14</sup> It is not clear which websites are being referred to

<sup>15</sup> It is not stated on the websites how many reviews have to be submitted before a rating is calculated



Choices website will draw on comments posted on other websites, members of the public may be confused with regard to which site they should submit their review.

### 3.5.3 Mail in care home facilities

The method for collecting and distributing mail varies from one care home to another and cannot be guaranteed to be timely or confidential, as some individuals will need staff to open and read incoming post for them. This applies primarily to incoming post, meaning that responses to surveys should remain confidential. However, although responses should remain confidential, there are likely to be a number of residents that would be unable to post back their questionnaire without the help of a member of staff (ie those without a relative/carer who visits regularly). Users may therefore be reluctant to provide honest feedback for fear that staff may view their completed questionnaire and/or staff may have an incentive not to return the questionnaires for users for whom they believe may be less positive about their experiences.

The direct involvement of care home staff in the Your Care Rating Survey was identified by Ipsos MORI as a potential challenge, as an element of control in the survey process is lost. However, the survey included a validation stage to monitor the survey fieldwork which included contacting care homes to verify the receipt and distribution of survey packs and to identify process and compliance with the prescribed approach.

Complications can arise even when the residents do receive their post directly and they receive postal surveys in a format that they cannot read or understand. In the NHS IC Adult Social Care Survey, councils have the option to offer service users a face to face or telephone interview in the reminder letter to maximise response. The guidance states these methods should only be used for people who request it or who the council know, because of their condition, would not be able to complete a postal questionnaire.<sup>16</sup>

### 3.5.4 Proxy respondents & assistance in completion

Results from previous surveys indicate that over 50% of survey respondents need help answering a questionnaire<sup>17</sup>. Needing 'help' varies from requiring assistance holding a pen to needing a proxy respondent to complete the entire questionnaire. Helpers are essential to achieving high response rates; however, the standard approaches to helping are accompanied by their own potentially detrimental complications. Relatives or advocates of users in care homes may not visit enough or have an in-depth knowledge of day to day service experience, and staff members pose a threat to response accuracy as they may have incentives to encourage certain responses: similarly, the presence of staff may make the respondent feel uncomfortable about criticising their care. In light of these complications, PSSRU proposes that the best option is to keep care home managers aware of the purpose of the survey so they can ensure residents receive help from the most appropriate person. This could be a family member or advocate who is very familiar with the resident or a staff member who is trained in how to deliver unbiased assistance. In the NHS IC survey, care home managers were sent a letter informing them of the purpose of the survey and explaining how the results would be used (i.e. not used to assess the performance of the care home). Ipsos MORI also provided detailed

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<sup>16</sup> *The Health and Social Care Information Centre (2011) Personal Social Services Adult Social Care Survey Guidance Document – 2011-12 (p11).*

<sup>17</sup> *PSSRU (2010). The National Adult Social Care User Experience Survey: Results from Four Development Studies*

information to care home managers participating in the 'Your Care Rating' survey on helping residents find some assistance to complete the questionnaire (care home staff were instructed not to help residents with completing the survey).

Relying so heavily on proxy respondents and helpers involves unavoidable complications. However, they are critical to many social care users' ability to express their views and necessary for broadening the scope of service user experience feedback.

### **3.5.5 Mental Capacity Exclusions**

One further complication in social care sampling exists around excluding people from the sample for capacity reasons. Under the Mental Capacity Act 2005 people who are unable to give their consent to take part should not be included as respondents in a survey. Both the Adult Social Care and Your Care Rating surveys have introduced steps to filter out ineligible people based on their capacity to consent. This is often decided by a care manager who knows the respondent well and is based on whether a person is able to express their opinion. If a person is not able to express their opinion they are considered not eligible to participate in the survey. A compromise in this case would be to get a carer to respond and act as a proxy respondent for the user in question; however, this could introduce bias and would not be consistent with responses from other groups. As the responsibility for assessing the capacity of service users to provide informed consent rests with care managers', the criteria for exclusion criteria must be uniform.

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## 4 Stakeholder Consultation: main findings

### 4.1 Introduction

The second phase of the feasibility study was to consult with key stakeholders to develop a thorough understanding of the regulator's and providers' requirements for an adult social care survey. The consultation was carried out in a number of stages, using different approaches, in order to collect feedback from a wide variety of stakeholders:

1. Individual telephone interviews were conducted with nine CQC compliance inspectors to gain a better understanding of how inspections are conducted, and how survey data could contribute to pre-inspection information or post-inspection reporting.
2. A face to face meeting was held with six CQC stakeholders from the following directorates: Regulatory Development, Intelligence and Governance and Legal Services. Individual telephone interviews were also carried out with three people that could not attend the meeting from the Intelligence and Strategic Marketing and Comms directorates. Talking to these stakeholders was important for gaining a more comprehensive understanding of CQC's requirements for a national survey and the main challenges they foresee in administering one.
3. A focus group with CQC Experts by Experience<sup>18</sup> to collect the input of those personally acquainted with social care services and understand how they thought a national survey would benefit other service users as well as inspections.
4. An online survey of councils and registered service providers to gather their views on the practicality and value of different approaches to collecting service user experience data. The overall findings from this survey are presented in Appendix C.
5. A roundtable discussion for providers and their representatives to learn from their experiences of gaining the views of people using their services, identify issues that should be considered and the implications of introducing a new survey for providers. Six stakeholders attended the discussion: one large home care provider (Mears Group), a membership based body for the home care providers in the UK (The United Kingdom Homecare Association Ltd), a residential home care provider (Barchester Healthcare), a provider of services for people with learning disabilities (Dimensions) and representatives from the Registered Nursing Home Association and the National Housing Federation.
6. A roundtable discussion for organisations representing people who use services to understand the issues involved in surveying service users, including the Royal National Institute of Blind People, Age UK, Scope and Patient Opinion.

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<sup>18</sup> The Experts by Experience consulted in this study were people who have a personal experience of social care services whether that be from using the services themselves or caring for a relative or close friend who uses services. The CQC's Experts by Experience assist in inspections of services and contribute to the reporting. The experts by experience are recruited, trained, supported and paid by a number of different voluntary sector organisations.

7. Written feedback was also sought from organisations who could not attend the roundtable discussions. Responses were received from the National Care Forum, Shared Lives Plus and Carers UK.

## 4.2 Focus of the survey

### 4.2.1 Priority groups for inclusion

Most of the CQC stakeholders agreed that the most vulnerable service users groups and/or those 'lacking a voice' were the most important to include in a survey of adult social care. These primarily include domiciliary care users, people with cognitive and/or intellectual impairment (including people with a diagnosis of dementia) and people with learning difficulties/disabilities. Service users with cognitive impairment and/or a learning difficulty not only represent a large proportion of social care service users, but they face profound challenges in exerting their voice about care through standard mechanisms. Domiciliary care users were felt to be the most vulnerable service user group, particularly by the Experts by Experience, for three reasons: CQC does not routinely visit people in their own homes as part of a domiciliary care inspection (meaning poor care could go unnoticed), people who use domiciliary services are often unsure of who to complain to about their care because there is no obvious hierarchy of authority, and domiciliary care users are the most isolated, often with limited access to information about their care package or how to amend their care package.

The challenges involved in surveying service users with a cognitive impairment and/or a learning disability were recognised by stakeholders. It was acknowledged that different approaches to a traditional paper-based survey would need to be used in order to get meaningful data directly from these groups of service users, such as 'Talking Mats' for people with learning difficulties. However, it was recognised that such approaches would significantly increase the costs of the survey and may not be practical to administer at a national level. The stakeholders agreed that an alternative way of ensuring that these user groups are included in the survey would be to accept proxy data (the use of proxy data is discussed further in the next section). The Experts by Experience even went as far to suggest that if a survey is not feasible, there need to be new procedures for vulnerable service users to express their views.

The CQC stakeholders and providers discussed the importance of ensuring the survey captured the views of those service users that fund their own social care. It was noted that there has been very little research on privately-funded social care and that in some areas of the county, such as Surrey, up to 80% of people using social services are funding their own care. In order to capture self-funders, the sample for the survey would need to be drawn by the service providers. One of the stakeholders commented that Local Authorities could continue to run the existing NHS Information Centre Adult Social Care Survey, as this does not include self-funders, whilst the new CQC survey could be aligned with this work by including self-funders. There are some concerns with this option however, first that the Information Centre survey does not produce data at the level the CQC requires and using providers to draw samples can be controversial in terms of potential sampling bias (as discussed in the next section). Additionally consultation with service providers revealed concern over the implementation of different social care surveys, not only due to the increased burden on providers, but also due to the risk of service users being over-surveyed which could contribute to low response rates. It was

noted that in many residential care homes there is not a big turnover of service users so there is a greater risk of a person experiencing ‘survey fatigue’.

## 4.2.2 Location-level sampling

The need for the survey samples to be drawn by service providers was further strengthened by CQC stakeholders who maintain that for the survey to be useful for inspections, the sampling and reporting would need to be at location-level, rather than just provider-level. It was argued that there is considerable variation within a provider and surveying at the provider-level only would not provide the full picture as some of the large providers, such as Four Seasons, work across different locations. However, the difference in the size of providers was recognised to have implications for the design of the survey if sampling and reporting at location-level. It was queried whether all locations should be surveyed or whether specific locations or a specific type of service could be sampled. The challenge of potentially providing comparative data whilst protecting the anonymity of respondents in small providers was raised by all stakeholders. Whilst locality-level data could be aggregated where necessary to allow people’s experiences of care at the organisational level to be considered, users of small providers are still likely to be reluctant to provide honest feedback about their experiences.

A potential problem in providers being responsible for drawing the sample of service users is that provider organisations may purposely create a biased sample. During the consultation, stakeholders highlighted the risk that some providers may deliberately exclude service users for whom they believe may give less favourable reports on their care. Consideration would therefore need to be given when designing the survey on how best to verify the accuracy of the samples drawn by providers. A second option would be to use a methodology like that used in the DCA themed inspection work, ‘Not Just a Number.’ This work relied on inspectors to draw a sample during their visit rather than attempting to design a survey to reduce provider bias. It might be simpler to put a more rigorous sampling mechanism into the inspection methodology to provide a ‘cross check.’

## 4.3 Administration of a national adult social care survey

### 4.3.1 Pragmatism

The general message from stakeholders was that the survey needs to be developed and administered in a pragmatic way; it needs to accept the caveats to perfection involved in surveying a diverse range of services and user groups, including a large proportion of people who are unable to respond independently to traditional surveys.<sup>19</sup> The providers discussed the danger that in attempting to make the survey very robust it could make it too ‘academically pure’ which would result in the survey being unworkable. It was recognised that trade-offs would need to be made and a pragmatic approach taken in order for the survey to be feasible.

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<sup>19</sup> Of those providers that responded to the online survey, 30% reported that over 45% of their service users would not be able to reliably evaluate their care through any survey format without assistance from somebody.

### 4.3.2 Proxy responses

In recognising that a pragmatic approach would be needed in the implementation of the survey, stakeholders agreed that in order to try and capture the experiences of service users who lack capacity to respond to surveys a method of collecting proxy responses would be required. Stakeholders were clear that the 'type' of proxy used was important in affecting the quality of responses received. It was noted that relatives/carers of the user are often the best type of proxy as they are familiar enough with the user to comment accurately on their experiences. Stakeholders agreed that using social care staff as proxies is likely to provide biased responses and would not be considered an acceptable approach. Some stakeholders commented that the proxy should be someone that is wholly independent from the service providing the care. Whilst the use of independent advocacies was regarded positively by stakeholders, it was recognised that only a small proportion of service users actually have access to an advocate. A few stakeholders were concerned about the use of proxy data in the survey; one CQC stakeholder felt that proxies should only be used if all other avenues to collecting experience data directly from the user had been explored whilst a stakeholder from a national organisation representing service users commented that the use of family/friends as proxies would only be of benefit if the aim of the survey is to monitor compliance and ensure the safety of users; it was felt proxy data would not necessarily provide a measure of how the user feels about the service and how improvements can be made.

The most appropriate method for capturing proxy data in a national survey would need to be considered. The survey could be designed for the proxy to complete and sent directly to them. This approach would necessitate that providers hold comprehensive and up-to-date contact details of potential proxies. Of those providers that responded to the online survey, 59% said they can easily identify unpaid carers from their records and a further 15% felt they could identify such individuals, although not easily. However, a significant minority of providers reported either not being able to identify carers (15%) or not knowing if carers could be identified (8%). The proportion of providers that would not be able to identify unpaid carers could be considerably higher than this online consultation survey suggests as those providers with less comprehensive records may have also been less likely to respond to the survey. An alternative approach would be for the survey to be sent to the service user with instructions on how the survey can be completed by a relative or friend if help was needed. During the roundtable discussion, providers noted that if proxy data was used in the national survey, this would need to be clearly acknowledged when presenting the results and any marked differences between user and proxy responses could be minimised by weighting the data during the analysis.

The consultation also highlighted the value of using observational approaches for measuring the quality of care, particularly when it is not feasible to collect information directly from the user because of a cognitive impairment (such as dementia) or a learning disability. The CQC compliance inspectors use a 'short observational framework for inspections' (SOFI), and although such an approach does not provide data directly from the user's perspective, by using SOFI an observer can attempt to tune into the person's experience and inspectors regarded it as an important and powerful tool. The roundtable discussion with providers also noted that observational approaches can be beneficial to gain an understanding of the nature and quality of care being delivered to service users that lack capacity to respond independently to surveys.

### **4.3.3 Rolling survey programme**

All stakeholders recognised the challenge in designing a survey that is applicable to all services and users. The difficulty not only lies in designing a tool (such as a questionnaire) that would be appropriate for different services and settings, but also in being able to use the survey data to compare services (as discussed in the following section). It was noted that even just surveying domiciliary care service users would necessitate two care models to be taken into consideration; one for people in their own homes and one for people living in supported living settings which can resemble care home settings. Given the diverse range of services and user groups, a few stakeholders suggested that a rolling survey programme could be implemented with a focus on different services or groups at one time. It was noted, however, that depending on which survey model is adopted, a rolling programme could be difficult and burdensome for some providers that supply a range of services and careful consideration would need to be given to the timing of the surveys.

### **4.3.4 Survey frequency and timing**

The timing of surveys emerged as an important issue from the consultation. CQC inspectors agreed that for the survey data to be useful in their inspection process, the survey would need to be conducted more frequently than once a year in order that the time lag between a survey being conducted and an inspection taking place is minimised. On the other hand, however, providers suggested that they should be able to use the survey data to make improvements to their service users' experiences before an inspection is conducted. Furthermore, some providers responding to the online survey expressed concern about the frequency of surveys due to the burden this places on the provider organisation.

### **4.3.5 Challenge in eliciting honest feedback**

A very strong message to emerge from the consultation was the challenge in engaging service users to respond to a survey about their experiences. All stakeholders discussed the difficulty not only in achieving a good response rate to an adult social care survey, but in obtaining honest reports from users about their experiences of the care received. There is a potential barrier in service users reporting less positive aspects of their care as many users do not want to "rock the boat" and potentially upset the staff providing their care. Stakeholders commented that many service users may not provide honest reports on their experiences due to the fear of reprisal from their provider. It was noted that this may be less of an issue for people using domiciliary care services as the survey could be completed and returned without the knowledge of the person/organisation providing the care. However, if results go back to providers, for smaller providers there is a reasonable chance they would know who gave a certain response.

The use of proxy respondents in the survey may help to address this issue to some extent as users' relatives/carers are more likely to feel able to report less positive aspects of care being provided. The method used for collecting user experience data will also be important in helping to address this concern; the value in carrying out a postal survey so that users can return their responses anonymously to an independent organisation was noted. The challenge for frailer people in posting back their completed questionnaire would need to be considered, however, when designing the survey; the use of volunteers from national and/or local organisations to provide help with returning the

questionnaires on behalf of the user is one possible solution. Other stakeholders felt that conducting face to face interviews was the best approach in their experience for engaging service users and for providing a more accurate reflection on the user's experience. It was recognised that the interviewer would need to be someone that the service user trusted and be independent from the organisation providing the service. One of the national organisations representing people who use services, described working in partnership with voluntary organisations to conduct interviews with users. This suggests that undertaking a mixed-method approach might be required in order to meet the needs of all stakeholders and enable the survey to be accessible to as many users as possible.

### **4.3.6 Engaging service providers**

It was recognised by CQC stakeholders, and the providers themselves, that the engagement of service provider organisations is central to the successful implementation of a national social care survey. Both CQC and other stakeholders were clear that providers would be reticent to support a national survey if it did not have explicit benefits for their organisation. Providers' responses to the online survey corroborated this finding as they expressed some apprehension around rolling out a resource-heavy survey if they could not guarantee it would be useful.

The same message materialised from both the consultation with CQC stakeholders and with the provider organisations; the data from the survey would need to give providers information that would enable them to improve the experiences of their users (this point is discussed further in the next section). For this to be possible, it was recommended that providers are involved in the design and development of the survey so that there is greater ownership over the data collected. The provider organisations also felt that if a new national survey was implemented, then this should replace other existing surveys in order to streamline effort and reduce the burden on providers. One of the stakeholders further suggested that to encourage the engagement of service providers in the survey, those organisations taking part should get a discount on CQC's registration fees.

## **4.4 Purpose & usefulness of survey results**

### **4.4.1 Survey needs to drive quality improvement**

Stakeholders were clear that in order for a new survey to be worthwhile – and to get the support from providers – the survey would need to be designed so that it produces actionable data. The provider organisations, in particular, voiced concern that the survey would only be used by CQC as a narrow regulatory tool for compliance; for the survey to be a success it would need to provide data that can be used by providers to improve their user's experiences prior to an inspection. It was argued that what the providers decide to do with their survey results would provide an indication of what the organisation thinks about quality assurance. It was suggested that CQC could examine this although this is not standard practice for the national patient survey program. It was also recognised by CQC stakeholders that consideration would need to be given on how CQC could inspect against quality improvement measures if the survey is to genuinely drive improvements in the services being provided.

One of the CQC stakeholders interviewed believed that one of the biggest challenges for a new adult social care survey would be on how to obtain timely data from the survey; it



was argued that provider organisations are not likely to take the results of a survey seriously if the data was more than a few months old.

#### 4.4.2 CQC's data requirements

- Operational-level: the data would be used to inspect against the CQC's essential standards and to provide a **framework for predicting risk** (risk modelling). One stakeholder described the need for the survey to provide a 'smoke alarm' to alert them to possible 'fires'. As previously mentioned, recent data was regarded as being most useful to alert inspectors to any problems, accurately contribute to Quality Risk Profile information and help guide inspections. However, CQC stakeholders commented that the survey data should be used to evaluate providers beyond the 'compliant' or 'non-compliant' inspections; it was highlighted that some providers may be 'compliant' but not score well in people's experiences of care and vice versa so survey data would be important for obtaining the full picture.
- Strategic-level: Data from the survey would be used by CQC for setting priorities and to trigger themed work into specific areas. The stakeholders also discussed the importance in being able to explore correlations between people's reported experiences and compliance data, Skills for Care data (on staffing levels and staff training), notifications of service incidents (such as safeguarding issues) and other information on the quality of care. The importance in being able to cut the data by key groups of users to identify any inequalities was also noted.
- Results of the survey could also feed into the CQC's annual State of Care report and/or if more frequent surveys were conducted then the findings could be drawn upon in the quarterly Market Reports.

#### 4.4.3 Comparative analysis (benchmarking)

Of the providers that responded to the online survey, three quarters (76%) thought it would be practical to compare results across providers offering similar services. The stakeholders commented that the social care sector does not have very much in the way of comparative information. However, providers and councils as well as some CQC members were keen to point out the uniqueness of many services and the complications that could arise with trying to compare dissimilar services. As previously mentioned, it will not be possible to compare the performance of all providers, particularly if reporting at the location-level, due to small sample sizes. Provider organisations also drew attention to the fact that there are commissioning and funding issues that will affect a person's experience of care which are outside the control of the provider organisation; these issues would need to be taken into account for a comparative analysis to be fair. Some of the stakeholders also mentioned the importance of understanding the culture of an organisation when measuring people's experiences of care.

It was recognised by some CQC stakeholders that there are other uses for the survey, other than producing location-level results, particularly as this may not be possible for domiciliary care users. It was felt it could be useful to produce results at the corporate provider or national levels; if themes are evident at these levels, they can be addressed and improved across all levels of care. As part of a wider piece of work that the CQC is embarking on for the adult social care sector, the Commission plan to work with providers to agree a set of metrics that measure the quality of care experienced by users.

Many of the larger corporate providers use their own metrics but it was felt that it would be beneficial to get a common set of metrics that can be used by all providers. One of the stakeholders felt that the survey could play an important role in measuring performance against these metrics.

In recognition that the survey would need to get the support of provider organisations, the stakeholders agreed that providers would need to see the value and cost-effectiveness of the survey by being able to use the results for marketing purposes. It was felt that being able to feed the survey data into sites such as 'Care Opinion' would be an incentive for providers. (During the roundtable discussion, one of the providers queried whether the survey could be tied into the Nuffield's Trust 'health and social care ratings review'<sup>20</sup> as this is regarded positively by providers and could be a fundamental selling point.)

#### 4.4.4 Future-proofing

The consultation highlighted the importance of designing the survey so that it is flexible to measure new models of service provision. Some CQC stakeholders also discussed the potential value of the survey in evaluating the performance of different types of providers, in terms of their ownership status (e.g. public, private, voluntary, not-for-profit etc.). In light of the Southern Cross Healthcare failure, one of the stakeholders also suggested that a survey could help to identify providers that are not financially fit to fulfil their role by including questions that may indicate financial instability.

Policy and demographic shifts were also cited as being an influence on adult social care which could change the relevance of certain types of surveys in the future. The upcoming changes to the cap each person will have to pay for social care could affect the proportions of people using publicly funded social care rather than self-funding, and with an aging population more people will be needing social care longer which could change how providers need to operate and how they should be evaluated in terms of offering long term affordable care.

Some of the CQC stakeholders discussed the importance of recognising the greater integration of health and social care when designing the survey (i.e. consider the patient journey through health and social care services). However some of the providers felt that whilst it is undeniably a better model of care, in reality service providers are still a long way from providing it and service users will not necessarily know what integrated care looks like. It is nevertheless important to consider for future-proofing the survey.

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<sup>20</sup> <http://www.nuffieldtrust.org.uk/ratings-review>

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## 5 Scenarios

### 5.1 Introduction to scenario modelling

This report brings together input from all phases of the stakeholder consultation to create five potential scenarios for the design of a national survey of adult social care. The aim of these models is to produce an options list from which to compare possibilities and determine whether there is a feasible way to roll out a national survey of adult social care.

Each scenario details the service user group to be surveyed, the method for administering the survey, and any implications around the reporting and publication of the results. It also includes the advantages and disadvantages of each option.

Some survey options have been discounted prior to this scenario modelling, as stakeholders have deemed them impractical for use in surveying social care service users. These include surveying all social care users, as that has been rejected as overreaching and impractical, or using purely online or telephone surveys which have proven to be inaccessible to this service user group. While these are not delineated in this report, some more feasible options are discussed with clearly stated caveats about their challenges and complications.

### 5.2 Cross-cutting methodological challenges

Three methodological challenges cross-cut many, or all, of the scenarios, which are discussed before each of the scenarios are outlined.

#### 5.2.1 Small sample sizes

First is the challenge of small population sizes and the related difficulties in producing statistically robust comparisons between units of analysis, whether these are locations or providers. Drawing a sample sufficiently large to yield statistically robust comparisons presents a challenge to almost all the scenarios set out below. Even where numbers allow, caution may need to be exercised in making comparisons, since some services are unique in particular respects and there may be commissioning or funding issues outside of the control of the provider that affect users' experiences.

From formulae supplied by Cochran (1977)<sup>21</sup> it can be estimated that to make statistically robust comparisons between providers or locations, and assuming a 40% response rate and confidence intervals of +/- 5 percentage points, a sample size of approximately 1000 per unit is required. Based on CQC Active Care Home Locations Data (March 2013), none of the 17510 care home locations, and only 0.4% of the 8449 care home providers has 1000 or more beds. Under certain conditions (using the "finite population correction," working on the basis of sampling a whole population and that a margin of error of +/- 5

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<sup>21</sup> Cochran, W. G. (1977). *Sampling techniques* (3rd ed.). New York: John Wiley & Sons.

percentage points is acceptable) a population of approximately 580 may be sufficient to make robust comparisons between units of analysis (locations or providers). None of the care home locations, and less than 1% of care home providers, has this many beds. A margin of error of +/- 10 percentage points is deemed acceptable, a minimum population of 150 is required (for further information, including the calculation used for this minimum population size, please see Appendix E). 2.1% of the care home locations and 4.5% of care home providers have 150 or more beds. Again, these assumptions are based on a 40% response rate: lower response rates would require larger sample sizes<sup>22</sup>.

**Table 7: The number and percentage of care home locations and care home providers with >150 beds, >580 beds and >1000 beds**

	Care home locations (n=17510)	Care home providers (n=8449)
>150 beds	371 (2.1%)	384 (4.5%)
>580 beds	0	74 (0.9%)
>1000 beds	0	35 (0.4%)

Source: CQC Active Care Home Locations Data (March 2013)

Detailed data on service user numbers for home care (domiciliary care) locations or providers were not available. The best available figures are those quoted in CQC's report on the home inspection programme, "Not Just a Number", although these are based on a sample of 250 home care agencies (locations) that were included rather than all 6,830 registered domiciliary care locations.

**Table 8: The size of home care agency based on number of people using home care services at the time of inspection**

Type of home care agency	Number of services	Number of people using services
<b>Micro</b> (1 to 5 people receiving services)	8 (3%)	27
<b>Small</b> (6 to 100 people receiving services)	101 (40%)	4,661
<b>Medium</b> (101 to 200 people receiving services)	48 (19%)	7,072
<b>Large</b> (201 or more people receiving services)	42 (17%)	14,659
Unknown	51 (20%)	Unknown

Source: CQC Not just a number: Home care inspection programme, National Overview (February 2013).

If it is assumed that the services included in the themed inspection are representative of all domiciliary care services, this suggests that only 17% of domiciliary care locations (n=1161) provide services to more than 200 people (i.e. are classed as 'large' agencies). A further 19% provide services to over 100 people. However, it should be noted that the size of agency was unknown for 20% of the agencies that were inspected in the programme, so this estimate should be viewed with caution. Furthermore, these figures are based on domiciliary care 'services' (ie agency locations) rather than 'providers' so the proportion of domiciliary care provider organisations that provide care to more than 200 people may actually be greater.

From the data that is available, it is apparent that the number of people receiving social care services (i.e. in care homes or in their own homes) render it impossible to make

<sup>22</sup> In the 2011-12 PSS Adult Social Care Survey, the response rates by councils ranged from 22% to 91% and the response rate to the CQC's home care inspection programme survey was only 21%.

robust statistical comparisons between most locations or providers. Making such comparisons between domiciliary care providers may be feasible in a larger proportion of cases than care home providers, although the results could not be generalised to all organisations providing domiciliary care (see scenario 5 for details on such an approach). This arguably detracts from the potential usefulness of survey results to both CQC and providers in terms of benchmarking and comparisons.

Although the majority of provider organisations would be unable to achieve a sufficient sample size to enable CQC to benchmark and readily identify services where people's experiences are poor, it may be practical to combine small providers and present them as a certain care type within a given area: this would allow users from smaller organisations to have their results presented in the survey. Survey data aggregated across services with low sample sizes can still contribute to national level results which can be used by CQC to identify future inspection themes and areas for quality improvement across all levels of care. Those provider organisations providing services to fewer than 150 people could participate on a voluntary basis given that, based on a response rate of 40%, they would expect to elicit too few responses to produce comparative/benchmarking data. Such providers could make use of the data (particularly qualitative comments) locally for quality improvement, assuming numbers are large enough to preserve confidentiality. However, if providers are to pay for such a survey they will need to be convinced of its usefulness. Without a guarantee of statistically robust results or comparisons, the cost may be more difficult to justify. They may see the value and cost-effectiveness of the survey by being able to use the results for marketing purposes or to feed into sites such as 'Care Opinion'.

Low sample sizes do not necessarily limit the results' ability to drive quality improvement. As long as results are treated with appropriate caution, provider-level data presented in relation to national results, or to results from similar providers could indicate strengths and weaknesses of individual services. This would require users, particularly CQC, to think of and treat the provider and location level data rather differently than in, say, healthcare patient surveys: it would provide the granularity required by the services to action improvements in particular aspects of service delivery. As the data will typically be indicative, it could be used by CQC to undertake a themed inspection if any of the findings raise concerns leading to improvement guidelines being introduced.

## 5.2.2 Protecting the confidentiality of respondents

The second concern is that of protecting the confidentiality of respondents. The national patient surveys programme maintains that there need to be 30 respondents to avoid confidentiality issues. If we assume a response rate of 40% for a new adult social care survey, then a minimum sample size of 75 users per provider/location would be required to achieve this. This limits the ability of results to be disaggregated to the **location level**, as according to CQC data, 96% of care homes (i.e. locations) have fewer than 75 beds and presumably fewer than 75 residents. Even if sampling and reporting at the **provider level** only a relatively small proportion of providers would have a sufficient number of respondents to allow data to be reported without concerns for confidentiality. Only 12% of care home providers have 75 or more beds (although this does not necessarily translate into 75 service users) which would allow data to be gathered and reported

without concerns for confidentiality<sup>23</sup>. There is no universally agreed standard as to the minimum base number for reporting survey estimates, though, and other surveys use lower figures of 10 or 20 responses.

The basic guideline we can offer to providers participating in a national survey or running local surveys is as follows. Providers with over 75 service users can administer a survey without fear of breaching confidentiality of respondents (providing a 40% response rate is achieved and other aspects of survey design ensure service user confidentiality). Those with between 50 and 75 can administer a survey, but should be wary of reporting results if they have fewer than 20 responses. Those with between 25 and 50 users may be able to administer an anonymous survey, but they should seek expert advice where possible to evaluate their individual situation. Finally, providers with fewer than 25 service users are advised not to use anonymous surveys as a form of feedback unless they are confident of achieving a high response rate and more than ten completed questionnaires. The Office for National Statistics has published guidance on disclosure issues around published tables of health statistics, including 'high risk' data<sup>24</sup>. This guidance outlines methods to help control the risk of disclosure and which approach is appropriate for different data uses.

Even with the numbers of service users quotes above, to help assure the confidentiality of respondents to a survey, sample lists could be sent securely to an independent organisation to administer the survey on the provider's behalf; this would also reduce the burden on providers. There would need to be safeguards in place with regard to reporting the results and feeding back data to providers. Furthermore, service users would need to be actively reassured that their responses would remain confidential and not affect their care. Response bias has been demonstrated particularly in older service users who may fear that complaints may lead to services being withdrawn or may undermine their relationship with their carer<sup>25</sup> (Bauld et al, 2000).

### 5.2.3 Accessibility of a postal survey

The third common issue is around the accessibility of traditional paper-based postal surveys. During the consultation, a majority of providers stated that postal surveys are the most cost-effective method that they use. However, a purely paper-based survey could exclude some service users with communication difficulties and/or physical or cognitive impairments. This opens the door to the second aspect of this issue - the use of proxy respondents. Due to the needs of many social care users, a high proportion of respondents in each scenario may need assistance completing a paper questionnaire, which could bias the results depending on who is helping the respondent. The questionnaire would need to record who completed it, and evidence of the introduction of bias would have to be sought.

Some service users may not have a relative/friend who can assist them in completing a questionnaire. They may be reachable only through the use of less standardised

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<sup>23</sup> There is not any available data to indicate the proportion of domiciliary care providers (or locations) that would have less than 75 service users

<sup>24</sup> See: <http://www.ons.gov.uk/ons/guide-method/best-practice/disclosure-control-of-health-statistics/index.html> [Accessed July 2013]

<sup>25</sup> Bauld L, Chesterman J, Judge K. (2000) *Measuring satisfaction with social care amongst older service users: issues from the literature. Health & Social Care in the Community.* 8(5):316.

approaches to gathering service-user feedback which allow the views of people who are unable to respond to standardised questionnaires to be obtained when they would otherwise be under-represented or excluded. Such approaches do not lend themselves to robust comparisons or benchmarking, and they may also present challenges to preserving confidentiality for the service user. However, the insights they potentially offer into the service-user experience within the context of their expectations and circumstances can provide rich information on which to base changes in practice. “Supported conversation” is one example of the use of techniques to enable a person with communication impairments to understand and make sense of things that are said or written and to express themselves in some way<sup>26</sup>. An alternative approach would be to use observational methods for developing an understanding of the quality of care being provided to those service users that lack capacity to respond independently to traditional surveys, such as people with severe dementia. This approach is discussed further in section 6.1.

#### 5.2.4 Other considerations

Approval for the secure transmission of confidential personal information between organisations would need to be obtained from the Social Care Research Ethics Committee and Confidentiality Advisory Group. Providers participating in the survey should indicate their ownership status (public, private, voluntary, not-for-profit) as this would be useful to CQC for analysis purposes. Information that could be collected and included in a sample file by providers: user’s name and address, year of birth, ethnic group (if recorded), length of time in receipt of service (if recorded), state funded or self-funded, and the ‘type’ of survey mailed to user (i.e. standard or an alternative format, such as easy-read).

To overcome concerns about biased sampling (providers excluding users who they think will respond unfavourably), measures may be required to verify the accuracy of the samples drawn by providers.

In terms of long term methodology it is worth considering that each of these scenarios could be combined into a rolling survey programme with surveys of domiciliary care and care homes alternating each year. This may be a way of reconciling high costs with the degree of coverage in each scenario, although it is recognised that biennial data will not be useful for CQC’s regulatory purposes.

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<sup>26</sup> *Connect (2007) Including People with Communication Disability in Stroke Research and Consultation [Internet]. London: Connect. Available from: [https://www.ukconnect.org/publications\\_27\\_124.aspx](https://www.ukconnect.org/publications_27_124.aspx)*

## 5.3 Scenario 1: Postal Survey of Domiciliary Care Users

**Group:** Domiciliary care (home care)<sup>27</sup> users aged 18 and over receiving ‘personal care’. All 4,515 home care providers (i.e. 6,830 locations) would be included (i.e. privately owned, council owned and voluntary owned).

**Sampling:** Each provider would compile a list of all users receiving personal care services (both publicly funded and self-funded users). Large providers could take a systematic sample of up to 500 service users, possibly stratified by location, age of respondent and whether their care is publicly or self-funded, using a stratification method that allows that some providers may work with particular age groups. This would reduce administration costs and ensure that at a national level the data can be cut by key groups of users to identify any inequalities.

**Method:** Postal survey with two reminders sent to non-respondents (second reminder to include another copy of the questionnaire).

Alternative formats would need to be provided: large print and easy-read versions. Ideally, providers would identify from their records which of their users would require a large print or easy read versions of the questionnaire. However, if this was not possible, an alternative format could be provided to users on request following the first mailing. Users would be encouraged to get help from a relative, informal carer, or friend if they are unable to independently complete a paper-based survey.

In recognition of the challenge for frailer people and/or those with physical disabilities in posting back a questionnaire, volunteers from third sector (voluntary) support groups (e.g. Age UK, Crossroads Care) and local Healthwatch groups could provide help to users in posting back their completed questionnaire to the independent organisation administering the survey using the freepost envelope provided. It would need to be specified that this help is solely for posting back the questionnaire and not to assist the user in completing the survey.

### Advantages

- Domiciliary care users were cited by stakeholders as one of the more vulnerable social care user groups, and were therefore regarded as a priority for inclusion in a national survey.
- Conducting a postal survey will enable good coverage (potentially all agencies providing home care) at relatively low costs.
- The numbers of service users served per domiciliary care provider are higher than per care home provider, making statistical comparisons and benchmarking of results more feasible with domiciliary care than in care home settings.

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<sup>27</sup> The Care Quality Commission (2012). The state of care and adult social care in England, <http://www.cqc.org.uk/public/reports-surveys-and-reviews/reports/state-care-report-2011/12>



### Disadvantages / Challenges

- This would not account for people that lack capacity to respond to a postal survey (and who do not have access to someone that can help them complete the questionnaire) by offering alternative modes, such as a face-to-face interview.
- Domiciliary care services work in partnership with other health and social care professionals, such as District Nurses and Occupational Therapists, so the design of the questionnaire would need careful consideration to limit the likelihood that feedback reflected users' experience of services other than domiciliary social care.
- Although the numbers of users per domiciliary care provider is higher than care home settings, based on the limited data we have about provider and location service user numbers, in most cases the robustness of these would most likely be sub-optimal for any meaningful comparisons.

### Estimated costs:

The costs would be prohibitively high if all 4,515 providers were to be included.

Activity	Lower Estimate	Upper Estimate
Survey set-up and project management, including analysis and reporting	£2,257,500 (£500 x 4515 providers)	£3,386,250 (£750 x 4515 providers)
Survey fieldwork (mailing and postage costs, managing survey freephone helpline) based on estimate of sample of 200 per provider	£2,257,500 (£2.50 x 200 x 4515)	£3,160,500 (£3.50 x 200 x 4515)
<b>Total excluding VAT</b>	<b>£4,515,000</b>	<b>£6,546,750</b>

Costs per provider would vary due to the differing sample sizes.

Sample sizes will depend on the size of the provider. It is important to note that project management costs are high because sample sizes would need to be determined with each provider and there is no way of determining a sample centrally from a national database; this requires more work with individual providers to identify a sample.

CQC could cover costs incurred by voluntary orgs in providing support to users by posting back their completed questionnaires. This compensation would be minimal, and would mostly likely not exceed £90,300 (based on £2 per occasion and ten occasions per provider).

## 5.4 Scenario 2: Mixed Methods Survey of Domiciliary care users

**Group:** Domiciliary care users aged 18 and over receiving 'personal care'.

All 4,515 home care providers (i.e. 6,830 locations) would be included (i.e. privately owned, council owned and voluntary owned).

**Method:**

This method would supplement the postal survey (which includes large print and easy-read versions of the questionnaire) with face-to-face interviews. During the consultation providers expressed a view that postal surveys can be limiting in terms of the depth of information they gather and the type of people they can access. A standard postal survey methodology as described in scenario 1, would be accompanied by face-to-face interviews to suit the needs of certain service users.

The face to face interviews would be conducted using a Computer Assisted Personal Interview (CAPI), meaning the interviewer would have a computer and fill in the questions as the respondent speaks to them. Interviewers would be trained researchers with expertise in data protection and confidentiality, and would be provided through the survey contractor.

Interviews would be arranged for those who could not easily complete a questionnaire either because of a physical or cognitive disability or, in some cases, because they were unable to identify an appropriate helper or proxy respondent. (This method does not, however, eliminate the need for proxy respondents, or discourage service users from asking for help completing the questionnaire.) The provider would be asked to identify service users who are likely to require a face-to-face interview on the basis of their records of the user's disability and whether or not they have a formal carer. The care provider would be asked to indicate this requirement when providing the sample data. They would contact the survey contractor to request an interview and liaise with the service user and survey contractor to confirm a time. The service user would then have a choice of where to meet and an option to bring someone with them.

**Advantages:**

- The mixed method format makes the survey more accessible to a greater proportion of the service user population.
- This scenario has the potential to yield more responses than a standard postal survey, and could therefore produce more statistically valuable data. The scope of the results will be representative of a broader, more diverse population.
- Face to face interviews were preferred by providers for allowing them to gather in depth, personalized information from vulnerable service users.

**Disadvantages:**

- A mixed methods approach is more costly in terms of resources and time required. It would require organising, training and compensating for interviewers.
- It may be difficult to identify service users
- It could be time consuming to determine which methods to use in what order, and for which participants.
- Surveys using different modes of data collection may produce different results even from identical questions. Careful consideration will need to be given to the design of the survey to minimise 'mode effects'.<sup>28</sup>

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<sup>28</sup>See Graham, C. (2007) Mixed mode surveys: a review for the NHS patient survey programme. Picker Institute Europe and De Leeuw, E.D. (2005) To mix or not to mix data collection modes in surveys, Journal of Official Statistics, 21(5), 233-255.

## Estimated costs:

Again, the costs would be prohibitively high if all 4,515 providers were to be included.

Activity	Lower Estimate	Upper Estimate
Survey set-up and project management	£2,257,500 (£500 x 4515)	£3,386,250 (£750 x 4515)
Postal survey fieldwork (mailing and postage costs, managing survey freephone helpline) based on sample of 200 per provider	£2,257,500 (£2.50 x 200 x 4515)	£3,160,500 (£3.50 x 200 x 4515)
CAPI set-up and interviewing (based on 10-12 interviews per provider or ~45-55,000 nationally)	£8,127,000 (£1,800x4515)	£8,127,000 (£1,800x4515)
<b>Total excluding VAT</b>	<b>£12,642,000</b>	<b>£14,673,750</b>

## 5.5 Scenario 3: Postal Survey of All Care Homes

**Group:** All care home providers registered in England (8449 providers, 17,510 care homes<sup>29</sup>)

**Sampling:** Each care home provider would provide their list of current service users (both publicly funded and self-funded users). Most providers would need to take a census of their residents due to small numbers. Large providers could take a systematic sample of 500 service users, stratified by age, to reduce administration costs.

**Method:** Postal survey with up to two reminders sent to non-respondents (second reminder to include another copy of the questionnaire)

The methodology in this scenario would follow that of Scenario 1; however, the mailings would be sent directly to care homes rather than individual home addresses. They would then be distributed to the service user in accordance with the home's mail delivery system and the specific needs of the service user. Ideally guidance to care home managers would stipulate that the post not be opened by staff unless necessary due to a service user's physical or cognitive inability to open their post.

As in scenario 1, alternative questionnaire formats would need to be provided. Again, ideally, care homes would identify from their records and/or knowledge from care workers which of their users would require a large print or easy read version of the questionnaire. However, if this was not possible, an alternative format could be provided to users on request following the first mailing. Users would be encouraged to get help from a relative/ friend if they are unable to independently complete a paper-based survey.

<sup>29</sup> This number is based on the CQC dataset on social care (Active ASC locations for providers in CRM' Accessed January 2013)

## Advantages

- A survey of all care homes will be broad in scope and include many different types of service users
- Care home managers would be more likely to identify those who would need proxy respondents or alternative survey formats (this could also save money in terms of mailing).
- This scenario eliminates the burden of searching for addresses of domiciliary care users. Furthermore, there is less risk of sending a questionnaire to a deceased service user.
- As mentioned in Scenario 1, conducting a postal survey will enable good coverage at relatively low costs.

## Disadvantages / Challenges

- Most care home providers (**88%**) would be excluded on the basis that they have less than 75 beds and therefore are likely to have too few respondents to preserve confidentiality (ie less than 30 respondents if we assume a 40% response rate)<sup>30</sup>. If sampling and reporting at care home level (i.e. location), this proportion would be even greater (**96%**). This clearly limits the ability to make statistically robust comparisons between providers.
- As mentioned in Scenario 1, this method does not account for people who lack capacity to respond to a postal survey (and who do not have access to someone that can help them complete the questionnaire) by offering alternative modes, such as a face to face interview
- The major drawback with the sample is that it does not include domiciliary care users or any of the more vulnerable user groups mentioned in the consultation.
- Care homes are varied in the services they provide and it could be difficult to design a questionnaire appropriate for all care homes
- In terms of results, it was noted many times throughout the consultation that the services care homes provide are often unique and not suitable for comparison with other homes.
- There is a challenge in the reliance on care home managers to distribute questionnaires

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<sup>30</sup> If 20 respondents per provider was regarded to be sufficient to maintain confidentiality (i.e. sample size of 50 beds if a 40% response rate is assumed), a high proportion of care home providers (n=6567, 78%) would still be excluded.

### Estimated costs:

These costs are based on the inclusion of just those care home providers with more than 75 beds (n=998).

Activity	Lower Estimate	Upper Estimate
Survey set-up and project management	£499,000 (£500 x 998)	£748,500 (£750 x 998)
Survey fieldwork (mailing and postage costs, managing survey freephone helpline (based on estimate of sample of 75 per provider)	£187,125 (£2.50 x 75 x 998)	£261,975 (£3.50 x 75 x 998)
<b>Total excluding VAT</b>	<b>£686,125</b>	<b>£1,010,475</b>

## 5.6 Scenario 4: Mixed Methods Survey of All Care Homes

**Group:** All care home providers registered in England (8449 providers, 17,510 care homes<sup>31</sup>)

**Method:** Postal survey with alternative formats for people who cannot complete traditional paper-based surveys and optional face to face interviews. This scenario would follow a mixed-method similar to that outlined in scenario 2. As in Scenario 3, mailings would be sent directly to care homes and distributed to the service users.. The procedure from scenario 3 would be applied in this scenario for service users who require an alternative format. In addition to this, the methodology would also include an option for a face to face interview. The methodology for the interviews would follow the same approach as in scenario 2 except that interviews could be held centrally in care homes and therefore eliminate costs involved in interviewer transportation and date arrangement.

### Advantages:

- As in scenario 2, a mixed methods approach is optimal for obtaining feedback from the most service users. The mixed method does allow for more comprehensive response data and may be more useful to providers, as it would be representative of a higher proportion of their clientele.
- This method scenario might present less sampling challenges, as sampling would reply upon a register of care providers and residents that does not exist in domiciliary care.
- Care home managers would be more likely to identify those who would need proxy respondents or alternative survey formats

<sup>31</sup> This number is based on the CQC dataset on social care (Active ASC locations for providers in CRM' Accessed January 2013)

- This scenario eliminates the burden of searching for addresses of domiciliary care users.

**Disadvantages:**

- This method, as in scenario 2, does attempt to increase responses by being accessible to more people, yet it cannot mitigate the fact that some homes will simply not have enough residents.
- Additionally, it could be quite time consuming to determine which methods to use in what order and for what participants. Unlike in domiciliary care, this decision would have to be made in collaboration with carer /who have a better understanding of each service users’ needs.

**Estimated costs:**

The costs are based on the inclusion of just those care home providers with more than 75 beds (n=998).

Activity	Lower Estimate	Upper Estimate
Survey set-up and project management	£499,000 (£500 x 998)	£748,500 (£750 x 998)
Survey fieldwork (mailing and postage costs, managing survey freephone helpline, administering face to face interviews, compensating interviewers)	£187,125 (£2.50 x 75 x 998)	£261,975 (£3.50 x 75 x 998)
CAPI set-up and interviewing	£1,497,000 (£1,500 x 998)	£1,497,000 (£1,500 x 998)
<b>Total excluding VAT</b>	<b>£2,183,125</b>	<b>£2,507,475</b>

## 5.7 Scenario 5: Postal Survey of the larger domiciliary care providers

**Group:** Domiciliary care (home care) users aged 18 and over receiving ‘personal care’. Include only a subset of the larger home care providers (including privately owned, council owned and voluntary owned).

**Please note:** in order to identify all the large domiciliary care providers, CQC would need to undertake a preliminary data collection exercise to ascertain the size of each of the registered domiciliary care agencies in terms of the number of service users they provide care to (and the number of different service locations).

For this survey to provide data that is valuable both for regulation **and** for obtaining a nationally representative picture, a systematic sampling method would be used to select the agencies to be included in the survey, stratified by their 'quality' (over time this could be based ratings). A systematic sample of disproportionate sizes would then be taken; ie over-sampling the agencies at different ends of the ratings scale. This approach would be useful for regulation purposes as CQC may wish to verify the rating of the best agencies and/or to check whether other agencies have improved. However, in order for the data to also be used for reporting nationally, design weights would be used to correct for the different probabilities of agency selection, thereby making the sample more representative of a national sample<sup>32</sup>.

**Sampling:** Each agency/provider would need to take a census of their users receiving personal care services (both publicly funded and self-funded users). To manage administration costs the 'large providers' (ie those providing services to more than 200 people) could take a systematic sample of up to 500 people, stratified by age of respondent and whether their care is publicly or self-funded, using a stratification method that allows that some providers may work with particular age groups. This would reduce administration costs for the largest providers and ensure that at a national level the data can be cut by key groups of users to identify any inequalities. Although sampling at the provider level, the location at which the services are being provided could be recorded in the sample file to allow comparisons to be made between locations (if the number of respondents was sufficient).

**Method:** Postal survey with up to two reminders sent to non-respondents (second reminder to include another copy of the questionnaire). Large print and easy-read versions would need to be provided. As detailed in scenario 1, providers would identify from their records which of their users would require a large print or easy read versions of the questionnaire (if this was not possible, an alternative format could be provided to users on request following the first mailing). Users would be encouraged to get help from a relative/friend if they are unable to independently complete the questionnaire.

As specified in scenario 1, volunteers from third sector support groups and local Healthwatch groups could provide help to users in posting back their completed questionnaire to the organisation administering the survey.

## Advantages

As per those cited in scenario 1, plus:

- The inclusion of just the large home care providers should ensure a sufficient number of respondents per provider to give robust results for analysis and reporting. Furthermore, including just the larger providers will address the concerns over protecting the confidentiality of respondents.
- Surveying just a subset of providers will substantially reduce the costs of the survey (the cost of including all providers at one time is likely to be prohibitively high).

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<sup>32</sup> The information from each unit (ie agency) is weighted inversely proportional to its probability of selection

## Disadvantages / Challenges

As per those cited in scenario 1, plus:

- Sampling only a subset of providers means that full coverage is not achieved and any generalisations of survey results would only be applicable to the large providers, rather than all providers. There may be issues or areas of concern that are specific to the smaller or micro providers that would not be identified from this survey.

## Estimated costs

To illustrate the likely costs of carrying out a survey with a subset of larger home care providers, the following costs are based on the inclusion of 350 providers with an estimated averaged sample size of 300 service users per provider (n=105,000 nationally). This represents roughly 50% of all large providers based on the figures quoted in CQC's 'Not Just a Number' report<sup>33</sup>. Please note: these figures are subject to verifying actual service users numbers per provider/ location.

Activity	Lower Estimate	Upper Estimate
Survey set-up and project management, including analysis and reporting	£87,500 (£250 x 350 providers)	£175,000 (£500 x 350 providers)
Survey fieldwork (mailing and postage costs, managing survey freephone helpline) based on estimate of sample of 300 per provider	£262,500 (£2.50 x 300 x 350)	£367,500 (£3.50 x 300 x 350)
<b>Total excluding VAT</b>	<b>£350,000</b>	<b>£542,500</b>

Note that the unit costs – the ratio of the total cost to the number in the sample – are considerably lower for this scenario than for others. This reflects both the high costs associated with project management for smaller providers and assumed lower per-provider costs for dealing with the relatively more homogeneous set of larger providers only.

## Estimated timings

We anticipate it would take approximately 9-10 months to develop a new domiciliary care survey, which would include consultation with stakeholders, a sampling review, obtaining ethical approval and section 251 support, focus groups with service users, questionnaire drafting and cognitive testing with service users. If a pilot survey was deemed necessary then this survey development period would be increased to 12-13 months. The implementation of the survey is estimated to take a further 5 months which would include the analysis and reporting.

<sup>33</sup> This figure is based on the CQC's "Not Just a Number" report which indicates that 17% of all 250 services included in the themed inspection were classed as 'large'. Thus, 17% of the 4515 providers is 768 large providers (assuming the proportion of large providers covered in the home care inspection programme is representative of all providers).



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## 6 Discussion and recommendations

### 6.1 Feasibility of options for a new survey

The previous section outlined potential scenarios for the design and implementation of a new adult social care survey for CQC. There are a number of advantages and drawbacks to each of the options and certain decisions and trade-offs have to be considered.

The most notable challenge, which may ultimately prove insurmountable for some locations and/or providers, is small sample sizes<sup>34</sup>. As previously discussed, most providers have too few service users to obtain survey results that would allow robust and meaningful comparisons to be made. A related concern is around confidentiality and minimising the risk of accidental identification of respondents. We recommend that for providers with fewer than 30 respondents, their results should only contribute to national level findings and be used for local quality improvement initiatives (with reassurances around the presentation of results to ensure the identity of respondents is protected). The option of including just the larger domiciliary care providers in a survey (ie scenario 5), helps to address the issue of small numbers as these providers should have enough service users to draw sufficiently sized samples to allow robust comparisons to be made.<sup>35</sup> However, the drawback of surveying only a subset of home care providers means that the results can only be generalised to the population of larger providers, rather than all providers. It is a possibility that there are issues with the quality of care provided that are specific to the smaller or micro providers that would not be identified from this survey alone.

The second major issue is around the cost and value for money of the different options. The desk research and consultation revealed the importance of ensuring that the most vulnerable service user groups and/or those 'lacking a voice' are included in a new survey of adult social care (ie domiciliary care users, people with cognitive and/or intellectual impairment and people with learning difficulties). Whilst some of the scenarios focus on surveying people receiving domiciliary care services, scenarios two and four propose a mixed-mode approach including CAPI interviews in order to improve the proportion of responses received from those users who could not easily complete a paper-based questionnaire (either because of a physical or cognitive disability or because an appropriate proxy respondent is not available). Whilst using a mixed-mode approach may have the potential to obtain a greater proportion of responses from the more vulnerable service users (and hence ensure the data is more representative of all social care users), it very considerably increases the administration costs of the survey. Furthermore, the use of a mixed-mode approach would require work to test and potentially correct for mode effects which would increase the length of time required to develop the survey.

Those scenarios using a postal survey methodology appear to be the most feasible options, not only because the use of a standardised single survey mode will provide data

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<sup>34</sup> However, as discussed in section 6.3, data is required on the size of home care providers (in terms of the number of service user in receipt of care from each provider) for a better understanding of this.

<sup>35</sup> If a margin of error of +/- 10 percentage points is deemed acceptable, a minimum population size of 150 is required.

for CQC's intended uses (ie provide high quality standardised data that allows legitimate and meaningful comparisons between providers, service user groups and over time), but also because a large number of service users can be surveyed at a more acceptable cost<sup>36</sup>. However, a significant limitation of a postal-based survey is that it is not as accessible for people that have a physical and/or cognitive impairment. This is particularly an issue when surveying adult social care users due to the relatively high proportion of people who lack the capacity to respond independently to paper-based surveys. Whilst alternative formats of the questionnaire can be provided (such as large print and easy read versions) and people may be able to get help from a relative/friend to complete the questionnaire on their behalf, this approach is still likely to result in such groups being underrepresented in the survey findings. CQC should therefore continue to carry out additional work, such as using an observational method, to get a better understanding of the experiences of the more vulnerable service users.

An observational approach is already used by some CQC inspectors when carrying out inspections of care homes. As previously discussed in section 4.3.2, inspectors use the Short Observational Framework for Inspections (SOFI) which is regarded to be a valuable tool for use in situations where people are not able to verbalise their experience, such as people with dementia. This observational framework could be used more extensively to provide information that could supplement the findings from a large scale postal survey. Whilst the findings from the observations may not necessarily contribute to comparative analysis (benchmarking), the information collected may provide a better understanding of the quality of care being delivered and could be used to potentially identify any particular areas of concern that would require further investigation. The framework was developed by CQC with Bradford University for use in care homes, and has also recently been tested by Bradford University for home care settings (SOFI2). In the recent CQC themed home care inspection programme, inspectors who were trained and had practiced using the tool were given the option of using it in situations where people were unable to respond verbally, after its use had been explained to relatives. However, we understand that inspectors did not use the framework during this programme as they felt it was unsuitable for home care settings. Reasons cited for not using it included: it being too intrusive, the difficulty in overcoming the 'Hawthorne effect' (ie. care workers improve or modify their behaviour in response to being observed) and because much of domiciliary care service delivery is personal care, this type of care cannot be observed. Therefore, unless some further development work and testing is carried out on the feasibility of the framework for use in community settings, then this observational approach can only have limited coverage.

If SOFI /SOFI2 can be used in both care home and community settings, it could provide valuable insight into how care is being delivered to service users who lack capacity to directly provide feedback about their experiences in a postal survey. This information could be used locally by providers for quality improvement and aggregated to generate key themes at a national level for CQC. However, consideration would need to be given to the numbers of observations that would be required per provider for the data to be seen as sufficiently robust and how the observational work could be implemented. Currently only CQC inspectors have been trained to use the framework, but training could be given to Experts by Experience (and/or researchers from an independent research organisation) in using the tool to ensure a sufficient number of observations could be

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<sup>36</sup> As previously noted, online surveys – whilst considerably cheaper to implement – are ruled out on the basis of significant gaps in coverage of key populations.

carried out for each provider without overburdening the inspectors. If the observational method was being used to supplement the findings from a national postal survey, providers could indicate in their sample files those users who lack capacity to independently respond to a postal survey so that an inspector (or other trained individual) can conduct an observation with a sample of these users. The number of observations carried out per provider should ideally be proportional to the number of service users who lack capacity to respond independently to a survey. To balance the burden of conducting observations with obtaining adequate coverage, we recommend that at least 20% of those users who would not be able to respond independently to a survey should have their care delivery observed. For example, if a provider organisation provides care to 90 service users, and of those service users, 40 people are felt to lack capacity to respond independently to a survey, the inspector (or Expert by Experience or researcher) should conduct an observational approach, using SOFI, with 8 service users. A minimum number of 3 observations per provider could be set to ensure that this approach is used by even the smaller providers. Given that an observational approach to measuring the quality of care provided to users is fairly resource heavy in terms of both time and financial costs, a maximum number of observations per provider could be set at 10, unless the inspector felt more was to be gained from carrying out additional observations.

As noted above, there is a possibility, particularly in a home care setting, that the care worker alters their behaviour and the level or quality of the care being provided in the presence of the person carrying out the observation (the Hawthorne effect). To help overcome this, the service user could be encouraged to ask a relative/friend/informal carer who is familiar with the care provided to the user to be present when the observation is scheduled. The person carrying out the observation could then talk to the user's relative/friend after the care worker has left to get an understanding of how closely the observed visit reflects the quality of care usually provided and to allow the relative/friend the opportunity to provide any additional feedback. However, there is the possibility that the presence of a relative/friend may have an even greater impact on the care worker's behaviour, ie it intensifies rather than minimises the Hawthorne effect.

## 6.2 Feasibility of using existing surveys

Given that there are substantial challenges and costs around designing a new national survey, it is important to consider the feasibility of using data from an existing social care survey (or extending an existing survey) and whether this would be a more viable option for CQC than designing and implementing a new survey. The cost, burden and timeliness in relation to development and data collection are reduced if using an existing survey. Existing surveys generally have had considerable developmental work so are a good foundation to build on. Unlike the development of a new survey the costs incurred for amending the content of an existing questionnaire(s), by the addition of a few questions, would be minimal. However, the disadvantages of using existing surveys revolve around the lack of flexibility to dictate survey design considerations such as population coverage, ie how inclusive the sampling approach and sample size is, and how quickly data would be reported. Furthermore, questionnaire space should be considered to be 'at a premium' in any existing surveys, especially those already used to populate other

indicators, so it may not always be possible to have new questions added to existing collections.<sup>37</sup>

Based on the review of previous surveys, the feasibility of using one (or more) of the following four existing surveys is examined:

### **HSCIC PSS Adult Social Care Survey**

Of the existing social care surveys, the PSS Adult Social Care Survey has the greatest coverage as it is a national survey<sup>38</sup> and includes service users receiving community based care at home and also those in residential and nursing care homes. A random probability sampling approach enables robust and statistically valid data to be collected and allows analysis at a sub-group level to be statistically reliable (if sufficient numbers of responses are achieved). The survey primarily uses a standardised approach of paper self-completion questionnaires. Respondents have the option of requesting a telephone or face-to-face interview instead of a postal survey: however, in 2010/11 99% of response came from paper questionnaires, minimising any bias attributable to mode of response<sup>39</sup>.

In its current form, there are three main drawbacks to this survey for supporting CQC's regulatory activities and functions. Firstly, the survey does not necessarily include service users who are wholly funding their own care; in some areas of the country a high proportion of people are self-funders and so it will not provide a full picture or allow the experiences of people funding their own care to be compared with those whose care is state-funded. Secondly, as the sampling is undertaken at local authority level there is unlikely to be a sufficient number of respondents to allow the comparison of individual provider organisations (particularly at location level), and the collection of additional sample information on provider would be required by local authorities for this breakdown to be possible<sup>40</sup>. However, if the numbers of users sampled was increased then this comparative analysis is likely to be possible for the larger providers. Thirdly, the questionnaire is focused on user's reported quality of life, health and wellbeing and overall satisfaction with services, rather than experiences of the services received. This may limit its usefulness not only for comparing and benchmarking providers (to identify services where people's experience are poor) but also for readily identifying any themes at a national level that could be used by CQC for setting priorities and to trigger themed work into specific areas. However, if each of these issues could be addressed, ideally with changes or additions being made to the sample frame and questionnaire, then this survey would provide CQC with data that will directly and systematically collect the views and experiences of adults in receipt of social care services.

### **Ipsos MORI 'Your Care Rating' Survey**

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<sup>37</sup> A systematic review of randomised controlled trials of any method to influence response to postal questionnaires showed that response was more likely when short questionnaires were used. See Edwards, P.J. et al (2009) *Methods to increase response to postal and electronic questionnaires (Review)*, The Cochrane Collaboration.

<sup>38</sup> The survey is mandatory for Councils with Adult Social Service Responsibilities (CASSRs). However, councils with less than 150 eligible users are not included

<sup>39</sup> The Health and Social Care Information Centre (2012). Personal Social Services Adult Social Care Survey, England 2010-11 (Final Release). Retrieved from <https://catalogue.ic.nhs.uk/publications/social-care/surveys/per-soc-ser-adu-soc-car-sur-eng-2011-12-fin/per-soc-ser-adu-soc-car-sur-eng-2011-12-fin-report.pdf> (p146). Note that there appears to have been a degree of clustering in non-postal response: the report notes that one council, Bury, conducted more than half of their surveys by telephone interviews.

<sup>40</sup> It is not known if councils are currently able to identify from their records which provider organisation is providing the care to the service users

This is a standardised survey designed to be conducted in care homes that primarily serve older people (aged 65 or over). Participation in the survey by providers is currently voluntary meaning that it is unlikely to cover the full population of interest; for the 2012 survey, only 13 providers took part covering a total of 791 care homes. However, this survey offers the potential to provide data that is useful to CQC if it was extended to cover a much greater proportion of care home providers (the intention for the survey is to increase the participation of care home providers and consideration is also being given to widening the scope of the survey to areas such as housing with care, younger adults' services and domiciliary care). In recognising the challenges in designing a large scale survey that uses a standardised approach, Ipsos MORI undertook a staged process of development in order that robust and statistically reliable data would be provided.

The survey uses a postal, self-completion methodology with survey packs being sent to participating care homes for distribution to each resident. Care home staff are directly involved in the administration of the survey, not only in helping residents find some assistance from a relative/friend to complete the questionnaire if needed, but also in determining the eligibility of each resident by assessing their capacity to provide consent. This introduces a risk of sampling bias as care home managers are able to influence who should or should not receive a survey<sup>41</sup>. Furthermore whilst care home staff were instructed not to help residents complete the questionnaire, it is difficult to ascertain whether or not this took place; staff may be keen to help residents complete a questionnaire if they did not have any relatives or friends visiting them. However, the survey included a validation stage to monitor the survey fieldwork which included contacting care homes to verify the receipt and distribution of survey packs and to identify process and compliance with the prescribed approach.

For this survey to meet CQC's requirements for an adult social care survey, the following issues would need to be addressed:

- It is likely the survey would need to be mandated to ensure greater coverage. Small providers (ie those with fewer than 50 registered beds) could participate on a voluntary basis given that the number of respondents are likely to be too small for their results to be published online.
- The sample sizes are likely to be too small to allow robust comparisons between most providers. However, the survey data could be used to alert CQC inspectors to any problems and help guide inspections. The data could also be used at a national level for setting priorities and to trigger work into specific areas.
- The robustness of the validation process would need to be examined to ensure the survey is conducted in a manner that will allow survey results to be fairly compared across providers. It may be necessary for additional steps to be added, such as care home managers providing an anonymous sample list of all residents in the care home (on the date the questionnaires are distributed), indicating which service users were excluded on the basis of consent requirements under the Mental Capacity Act and which residents required help from someone to complete the questionnaire. If demographic information was included in this sample file for each resident, in addition to information such as whether they are state or self-funded, this would allow some analysis to determine how representative the respondents are to the care home

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<sup>41</sup> However, the alternative approach of questionnaires being mailed directly to residents does not necessarily overcome the risk of introducing sampling bias to the survey as care home staff may open and read incoming post for some residents and decide that they do not have the capacity to complete the survey.

population. On site spot checks could also be conducted by researchers (or trained volunteers) or CQC inspectors/Experts by Experience to verify the information on the sample frame supplied by the care home (ie on the numbers resident and the proportion excluded for capacity reasons) to help minimise the risk of bias or gaming.

- Alternative formats of the questionnaire may be considered necessary to improve the accessibility of the survey, such as large-print and easy-read versions. For those residents that require help to complete the questionnaire but for whom an appropriate relative/friend is not available, support could be provided by trained volunteers from local support groups and/or CQC's Experts by Experience.
- It is not clear what steps (if any) will be put in place to ensure that results are only presented if the respondent sample is a sufficient size to allow comparisons between care homes, and to ensure the confidentiality of respondents.
- Additional questions may need to be added to the questionnaire in order for the results to meet CQC's data requirements.
- Until the scope of this survey is widened to include other social care services, such as domiciliary care, CQC would also need to consider conducting additional survey(s) to cover those services not included by this survey. This will create additional complexity to gathering user feedback in terms of the timings and implementation of different surveys – both for CQC and providers.

### **CQC Home care inspection programme survey**

CQC carried out a themed inspection programme in 2012 that focused on the experiences of people using home care services. Since this programme, CQC has published guidance, methods and tools to support inspections of domiciliary care services. It is worth considering whether the methodology used in the inspections might offer CQC a more cost-effective option to gathering data on people's experiences of domiciliary care than designing a new survey. Details on the sample frames and methodologies, and the main advantages and drawbacks of the programme/inspections, are outlined in sections 7.1.6 and 7.1.7 (Appendix A).

In order for the survey to meet CQC's requirements for a social care survey that provides nationally representative data, the following changes to the methodology are considered necessary:

- In the 2012 themed inspection, the contact details of people receiving home care could not be obtained from the service provider and were sought from local authorities. However, this approach excluded those people who are wholly funding their own care. To ensure that the views of people buying their own care are included in the survey, contact details would need to be obtained from providers (and securely sent to CQC or an independent organisation(s) employed to administer the survey on behalf of providers). Therefore, it may not be possible for the results of the survey to be used as part of an inspection. However, if the survey was carried out biennially (or more frequently if funds allowed), the results of the survey could still be used by inspectors to identify key issues to examine in 'unannounced' inspections at the office site and for questioning staff. It should be noted, that the revised guidance (published by CQC April 2013) states that inspections require a short notice '48 hours' announcement to ensure the manager is in the office and to enable the manager to provide the inspector with a sample of people to be sent a questionnaire

(if this is the method being used in the inspection); this approach should therefore include people who are wholly funding their own care, in addition to those whose care is being paid by the local authority.

- Four different approaches were used in the themed inspection for gathering data on people's experiences of home care and it's not clear if consideration was given to the design of the survey to minimise 'mode effects' (In the revised 'inspecting domiciliary care' guidance, inspectors can still use a combination of methods: telephone interviews, questionnaires, and visiting people in their homes) . For the purposes of providing high quality data that allows legitimate and meaningful comparisons between providers, just the paper-based survey could be conducted: this may reduce the overall accessibility of the survey, but would ensure that data collected could be usefully compared without mode differences confounding results. However, to increase the response rate to the survey, at least one reminder should ideally be sent to non-respondents and alternative formats could be made available (such as large print and easy-read versions). For those people who require help to complete a questionnaire (perhaps due to a physical and/or cognitive impairment), and who do not have a relative/friend that can assist them, if there were sufficient funds, support could be provided by trained volunteers or Experts by Experience (It is likely that in many cases questionnaires could be completed over the phone). Support could also be given to users in posting back their completed questionnaires.
- The questionnaire is focused on users' experiences of the care received and includes space for respondents to write any additional comments. However, for the survey to provide data that will meet CQC's requirements, additional questions are likely to be required that will first need to be cognitively tested with users.
- The sample size used in the 2012 inspection programme (~2,500) will generate nationally representative data. However, for comparisons to be made between providers, the sample size would need to be increased.
- Using this existing survey will only provide CQC with information on people's experiences of domiciliary care. Whilst the consultation with stakeholders indicated that this group of users was of particular interest, in the longer term additional surveys would need to be conducted to gather the views of people using a wider range of social care services.

### Costs and timing

The **estimated** costs for contracting out the development and implementation of the existing home care survey are detailed below. The costs are based on an overall sample size of 2,500<sup>42</sup> (approximately 250 home care agencies) with just one copy of the questionnaire being sent to each user (the user's relative/friend can help the user complete the questionnaire if needed). The costs include one reminder letter being sent to people in order to try and improve the response rate to the survey. However, if CQC wished to undertake additional steps to gather feedback from service users, such as telephone interviews and home visits (or observations using SOFI) then the costs of these additional approaches to gathering feedback would need to be incorporated.

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<sup>42</sup> This is based on the sample size of the 2012 themed inspection which was 2,397. However, it is important to note the limitation of this sample size; only nationally representative data could be generated as the number of respondents per provider are likely to be too small for robust comparisons to be made between providers.

Revise questionnaire (including small stakeholder consultation and cognitive testing with ~15 service users)	£6,500
Sampling design / provide guidance for providers	£3,175
Field costs (printing, mailing and data entry)	£8,750
Analysis and reporting	£10,150
<b>Overall estimate</b>	<b>£28,575</b>

The length of time to revise and test the questionnaire and to set-up the survey (ie confirming sampling strategy and drafting guidance for providers) is estimated to be two to three months. The fieldwork period would need to be at least 6 weeks to allow time for a reminder to be sent and sufficient time for people to respond. The data collation/cleaning and analysis/reporting is estimated to take a further 4-5 weeks. Therefore, to revise, run and report on the postal survey should take in the region of 6 months. If CQC wished to use a mixed mode approach by including telephone interviews and/or home visits (or observations) then time would need to be allocated to ensure the design of these approaches minimise any potential mode effects, in addition to the time required to actually conduct these.

### **Department of Health - General Practice Patient Survey (GPPS)**

Aside from existing social care surveys, it is perhaps also worth considering the potential for the General Practice Patient Survey (GPPS) to provide CQC with the information it requires for systematically capturing the views and experiences of adults who use social care services. The survey is currently conducted by Ipsos MORI and administered twice a year. The GPPS covers an exceptionally large sample of people (nearly three million people annually) and is methodologically robust, producing reliable and accurate data that can be aggregated meaningfully, such as to Clinical Commissioning Groups (CCG). The survey focuses on people's experiences of general practice, management of long term conditions, and dentistry to some extent. The GPPS also asks questions about chronic conditions and includes a number of demographic and health status variables (including the EQ5D), meaning that key cohorts – including older people and people with long-term conditions – can be identified and investigated. Although the questionnaire is NHS branded and focussed on GP services, it appears conceptually possible for the survey to be used as a vehicle to cover people's wider experiences of social care. There are a number of measures in place to help people with completing the questionnaire, including the provision of different formats of the questionnaire (large print and Braille) and allowing the questionnaire to be completed online (the questionnaire is also available from the GPPS website in British Sign Language).

There are significant limitations, however, of this survey for CQC as a tool for measuring people's experiences of social care. Firstly, the data from the survey will only provide CQC with national or regional data. Although the data can be aggregated to smaller units of analysis, such as CCGs, it would not be possible to identify social care providers. Unless a number of questions could be added to the survey, it is also unlikely that even



the 'type' of provider (such as care home, domiciliary care or supported living services) could be identified. Therefore, the ability for CQC to use this survey, even at the strategic level for setting priorities for further investigation, would be severely limited.

[Furthermore, it is possible that the views of people resident in care homes may be underrepresented in the sample as their registered address may be their home address, rather than their care home address, and/or people in care homes may be in the process of registering at an alternative GP practice that is favoured by the care home]. Secondly, the questionnaire is already eight pages, so it is unlikely that many questions on people's experiences of social care services could be added (particularly when the questions will only be applicable to a subset of the population). Therefore there is scope only to include a small set of questions at most, and this would come at the cost of removal of some existing items. Given the complexity of the social care landscape, a number of questions are likely to be needed, however, in order to provide even a basic understanding of people's experiences of social care received.

### **Local surveys used by providers**

Most providers carry out their own local surveys to collect data on the views and experiences of the people using their services. However, the consultation highlighted that there is no consistency in survey design and implementation between providers and hence the quality of the survey data is variable. Given the challenges involved in designing and implementing a new national survey of adult social care services, an alternative solution could be to encourage providers to carry out their own local surveys according to a prescribed methodology that is approved by CQC. This would reduce the burden on providers having to carry out their own surveys in addition to national surveys.

Providers carrying out their local surveys in accordance with the recommended methodology could potentially submit their survey data to CQC for use in Quality and Risk Profiles and to allow CQC to potentially identify specific themes that require further investigation at the national-level. However, unless there is an incentive for providers to submit their survey data to CQC (such as reduced registration fees), it's unlikely that many providers will do this; those providers that do submit their survey response data are most likely to have positive results. Any data received from providers is therefore unlikely to meet CQC's requirement of providing high quality data that allows robust comparisons to be made between services.

Although it is unlikely that all providers would agree to share their local survey results with CQC without some incentives, there may still be value in CQC providing guidance to providers on the basic principles of good survey design and implementation with the aim of improving the quality of local user experience surveys. This would not only benefit the providers, in terms of getting more useful data for quality improvement measures, but would generate better data to inform and support the work of CQC's social care inspection teams. Example guidance is presented in Appendix D.

## **6.3 Recommendations**

Following evaluation of the social care landscape and previous surveys of adult social care, as well as considerable discussion amongst stakeholders, our recommendations focus on two key considerations:

- Meeting the requirements of CQC and providers in terms of providing actionable, statistically robust results at a reasonable cost.
- Promoting development of an affordable survey that will obtain a high degree of service user coverage especially across vulnerable service user groups.

These priorities are conflicting, but in our perspective not entirely irreconcilable. The tension between them comes from the problem discussed throughout this report that the small population sizes in most locations and providers, especially across care homes, compromise the ability to produce statistically robust results. To achieve national coverage would require surveying residents in small care homes or service users from small domiciliary care agencies. Assuming confidentiality of respondents can be preserved, this information would not be able to yield comparisons at the location level and in many cases not even at the provider level.

The costs listed for the potential survey scenarios are high compared to the cost of many surveys within the national patient survey programme: however, this is mostly because the implementation of an entirely new survey for such a large range of providers is very resource heavy. The following recommendations for both the short and long term aim to meet the above two objectives while abiding to a reasonable budget.

### 6.3.1 Short to medium term

- We recommend that a new **postal survey of domiciliary care users is developed and conducted with a subset of the large providers** (ie scenario 5). Domiciliary care users were regarded by stakeholders as a priority for inclusion in a national survey as they are considered one of the more vulnerable social care user groups. The inclusion of just the large home care providers should ensure a sufficient number of respondents per provider organisation to provide results for robust analysis and reporting. Furthermore, the use of a single survey mode is preferable in terms of producing consistent findings.
- We strongly recommend that before this survey is developed, however, CQC should undertake a **data collection exercise** to ascertain the size of each of the registered domiciliary care providers in terms of the number of service users they provide care to (and the number of different service locations). Accurate figures on the number of service users per provider/location is necessary, not only for ensuring an appropriate sampling methodology is used, but for allowing a more robust calculation on the likely costs.
- Developing a new domiciliary care survey is considered preferable to using the existing home care inspection programme due to the limitations of coverage and methodology (outlined in sections 7.1.6 and 7.1.7). However, if CQC could build on this programme and make the recommended changes to the questionnaire and sampling methodology, then this could offer the potential to collect information on user experience more quickly and at a lower cost.
- We recommend that for capturing the views and experiences of people in care homes, CQC should consider using data from the Ipsos MORI **Your Care Rating Survey** if

coverage of this survey is increased. As previously discussed, consideration would need to be given to the minimum number of respondents required per provider in order for the data to be published.

- Finally, in the short term, we suggest that providers are encouraged to carry out their own surveys using a recommended methodology to help ensure good standards in survey design and implementation.

### 6.3.2 Longer term

- In the longer term, we recommend that CQC explore the possibilities to use the Health and Social Care Information Centre Adult Social Care Survey to systematically capture the experiences of adults who use social care services. Conducting one national survey of adult social care services will reduce the burden on providers and minimise the risk of service users being over surveyed.

The sample frame and questionnaire tool used in this survey would require modification in order to fully meet CQC's needs which is why this is not a feasible option in the short to medium term. However, if such amendments – which would amount to an expansion of the existing survey – can be made, this survey has the potential to provide CQC with high quality data that will readily identify services where people's experience are poor and inform and support the work of the inspection teams. The survey data should allow for meaningful comparisons to be made between providers (where sample sizes are large enough) and contribute to CQC's assessment of providers in terms of non-compliance with regulatory standards of quality and safety.

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## 7 Appendix A: Previous Survey Methodologies

This section will review the methodologies of previous surveys on a case by case basis, discussing both the sampling and administration process for each of the relevant surveys.

### 7.1.1 The NHS Information Centre<sup>43</sup> PSS Adult Social Care survey (2011-12)

**Sampling:** Eligibility to partake in this survey was based on being in receipt of a service provided by the council. For example, those users who would qualify for inclusion on the RAP P forms and were in receipt of services. Exclusion criteria were applied where a service user was deemed unable to consent to the terms and conditions of the survey in accordance with the Mental Health Act 2005.<sup>44</sup> Where service users who lack the capacity to consent were removed, re-sampling was performed to replace these individuals. Otherwise all people in receipt of a service provided or commissioned by social services were assumed to have capacity to consent. Individuals funding their care themselves may not have been adequately captured in this sample method.

Since 2010/11, the Adult Social Care Survey has followed a robust probability sampling approach. A systematic random sampling method was used in 2010/11<sup>45</sup> with the most recent surveys (2011/12 and 2012/13) further refining this approach by implementing stratification to further ensure representation of key subgroups within the service user population: for example, people with learning difficulties (LD). Following this approach, separate systematic samples are drawn for four 'strata' or groups of service users:

**Table 1: Stratification for Adult Social Care Survey (ASCS) 2012/13<sup>46</sup>**

Stratum	Description
Stratum 1	LD – all ages
Stratum 2	Non LD, 18-64
Stratum 3	Non LD, 65+, In Residential and Nursing Care
Stratum 4	Non LD, 65+, Receiving Community Based Services

The population coverage is substantial, encompassing not only service users receiving community based care at home, but also those in residential and nursing care. However,

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<sup>43</sup> Now known as the Health and Social Care Information Centre

<sup>44</sup> Other exclusions included: service users that had died, service users that were hospitalised, service users known to be in dispute with the council where sending a questionnaire would be deemed unduly insensitive. Councils could also remove users – albeit with provisos- if they had already been recently surveyed

<sup>45</sup> Note that the systematic sampling method used is slightly unusual as it does not feature any list sorting. Systematic sampling involves selecting every kth record - eg every fifth service user – from a list of all eligible service users. Typically this list will be pre-sorted by some critical dimension – often age – to ensure representativeness across that dimension. The sampling methodology for 2010/11 does not, however, specify a sorting order for the sampling frame: this creates a very small risk of what are known as 'periodicity effects' if the sample frame was sorted in a way that involved repeating patterns. Such effects are very rare in practice, but we would recommend that consideration be given to introducing an explicit sorting requirement into the sampling in future to mitigate against this risk.

<sup>46</sup> Reproduced from: *The Health and Social Care Information Centre (2012). Personal Social Services Adult Social Care Survey Guidance Document – 2012/13. Retrieved from <http://www.ic.nhs.uk/article/2215/User-Experience-Survey-Adult-Social-Care-Guidance-2012-13>. (15.7).*

it is important to note that this survey does not necessarily cover recipients of social care services who wholly fund their own care. Implementing a random probability sampling approach enables robust and statistically valid data to be collected and allows analysis at a sub-group level to be statistically reliable (if sufficient numbers of responses are achieved)

Administration: This survey was administered as a postal survey delivered through CASSRs. Users receive a paper questionnaire, however respondents could request a face to face or telephone interview. Respondents have the option of requesting a telephone or face-to-face interview instead of a postal survey, but in 2010/11 99% of response came from paper questionnaires, minimising any bias attributable to mode of response<sup>47</sup>. There were six versions of the questionnaire to be used in different settings; service users living in a residential or nursing care home (and an alternative easy-read version for people with learning difficulties), those living in the community (and an alternative easy-read version for people with learning difficulties) and also large print versions for people living in the community and those living in care homes. The participating councils were asked to anticipate and identify which version of the questionnaire was required for each user. They encourage the use of mixed modes to allow all groups to participate, meaning they do not repeatedly send out the same questionnaire but alternative formats to help ensure everyone receives one they can complete. Finally the NHS IC does not recommend the internet as a survey mode due to the low accessibility and usage among the target population. This view was supported in an ONS review of the survey methodology.<sup>48</sup> Importantly, the ASCS is now mandated for eligible local authorities and is included on the Department of Communities and Local Government's Single Data List of mandated collections<sup>49</sup>. This ensures comprehensive coverage. Data from the survey contributes to a number of indicators within the Adult Social Care Outcomes Framework (namely 1A, 1B, 3A, 3D, 4A and 4B) and is used by the Department of Health for national benchmarking and performance management.

### Advantages

- The survey coverage: all CASSRs were included<sup>50</sup> and all service users receiving one or more social care service(s) were included rather than a specific service or user group. Alternative versions of the questionnaire and modes of administration increased the accessibility to the survey. The ONS review of the survey's methodology stated that the mixed mode design should improve the response rates over the postal mode only and enhance the quality of data by reducing non-response bias.
- Sample frame: comprehensive electronic list of service users with good sample information<sup>51</sup> (eg age, gender, ethnicity, primary and secondary client group, cost of care package etc.). The sampling frame allows councils to easily identify and take a systematic random sample of eligible service users, stratify the sample and establish which format of questionnaire service users require.

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<sup>47</sup> The Health and Social Care Information Centre (2012). Personal Social Services Adult Social Care Survey, England 2010-11 (Final Release). Retrieved from <https://catalogue.ic.nhs.uk/publications/social-care/surveys/per-soc-ser-adu-soc-car-sur-eng-2011-12-fin/per-soc-ser-adu-soc-car-sur-eng-2011-12-fin-report.pdf> (p146). Note that there appears to have been a degree of clustering in non-postal response: the report notes that one council, Bury, conducted more than half of their surveys by telephone interviews.

<sup>48</sup> Williams, S. and Betts, P. (2010), Review of Methodology for the National Adult Social Care User Experience Survey, Office for National Statistics.

<sup>49</sup> Retrieved from <https://www.gov.uk/government/policies/making-local-councils-more-transparent-and-accountable-to-local-people/supporting-pages/single-data-list>

<sup>50</sup> A council was exempt from the survey if they had fewer than 150 eligible service users

<sup>51</sup> However, the guidance suggests that not all councils have a centralised electronic database of service users

- The data collected can also be used by councils to identify where improvement is needed at the local level. Analysis can also be undertaken to focus on particular demographic sub-groups, such as age groups, or to focus on the type of support or care service users receives – ie home care, meals, short term residential care, and so on.

#### Disadvantages

- The sample frame does not include service users who wholly fund their own care
- The use of interviewers may induce bias due to socially desirable responding or acquiescence.
- Using a mixed-mode approach: as noted in the ONS review, if councils vary in the extent to which they are able to conduct interviews, and thus differ in the levels and types of non-response bias and measurement error obtained, this might affect comparability of results between them. The ONS review states that while the model questionnaires are virtually identical for self-completion and interviewer administration, they are not strictly unimode because they were not developed in tandem to be appropriate to both modes; the self-completion questionnaire has simply been used for interview administration with minimal adaptation. The ONS suggests consideration should be given to assess whether it is desirable or feasible to redevelop the questions to be suitable for different modes.
- Only one reminder was sent and the follow-up interview was optional for councils (best available data suggest that only 1% of all respondents had an interview).
- Alternatives to completing the paper questionnaire were not offered by all councils, creating variation in the methodology for the survey.

### **7.1.2 Home Care Users aged 65 and over 2002-03 and 2008-09**

Sampling: The eligible population was defined as those users receiving care in their own homes funded wholly or in part by social services, who were aged 65 or over when the questionnaires were distributed. For the 2008-09 Survey, service users in receipt of Direct Payments (DP) and/or Personal Budgets (PB) were excluded unless it was known that some or all of their DP/PB was spent on Home Care Services provided or contracted by the Local Authority. Other exclusions were those users who had moved or died. Councils selected a random sample of service users based on the size of their eligible population. If the council had fewer than 150 eligible service users, they not to complete the survey, but contact the Information Centre and notify them that they have too few service users to participate. The reason for this exemption is that a council with under 150 service users would not receive enough responses to produce statistically robust data.

Administration: For both surveys the method of collection varied across councils/service users; in 2008-09 approximately 97% of respondents received the questionnaire in the post, less than 1% via face to face interviews, and 2% via telephone interviews. In the 2002-03 survey many councils supplied comments alongside their data; one observation was that it was not practical to carry out telephone or face to face interviews for those councils that used an extended survey. Another concern raised was that the response rate was low for some councils (range

was 20% - 94%) due to the large number of users surveyed and the limited resources available to send reminders.

### **7.1.3 Survey of Physically Disabled and Sensory Impaired Users in England Aged 18-64: 2003-04**

Sampling: Councils were asked to draw a sample of users aged 18-64 who had a physical disability or sensory impairment but who did not have a learning disability. Users had to be in receipt of community based services as defined in the Referrals Assessment and Packages of Care (RAP) return. Users in temporary residential care or those only in receipt of equipment were excluded from the sample. Nine councils were exempt from the survey as they had fewer than 150 eligible users.

Administration: Councils had the option of administering the survey by post, through face to face interviews, or via telephone interviews between January and March 2004. Most councils posted questionnaires to the majority of their service users, although one council administered the survey through face to face interviews to all sampled users. No councils carried out telephone interviews for the majority of their service users.

### **7.1.4 Survey of Adults Receiving Community Equipment and Minor Adaptations in England, 2007-08 and 2009-10**

Sampling: Users were eligible if they received equipment or a minor adaptation to their home during a four month period (i.e. September to December 2009 in the 2009-10 survey), funded wholly or in part by social services, living in their own home, and aged 18 or over when the form was distributed. Service users who had equipment on their care plan but received a direct payment instead were excluded from the survey as it could not be determined whether the equipment or minor adaptation was actually purchased. Care was taken to remove users from the sample that had moved away or died.

Administration: Most councils distributed the surveys in February 2010. As with the other service specific NHS Information Centre surveys, the method of data collection varied across service users; in the 2009-10 survey the Information Centre reported that approximately 94% received the questionnaire in the post, 1% through telephone interviews and 1% carrying out face to face interviews

### **7.1.5 NHS Information Centre PSS Survey of Adult Carers in England 2009-10**

Note: This was a voluntary survey; 59% of councils took part.

Sampling: Those eligible for the survey were unpaid carers (aged 18 and over) or carers by association<sup>52</sup> who had been assessed or reviewed, either separately or jointly with the cared for person, by social services during the past 12 months when the sample was chosen (the survey fieldwork was carried out in November 2009). In

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<sup>52</sup> Carers by association in this survey are defined as carers who have been named on the files of service users who have been assessed or reviewed in the 12 months prior to the sample being chosen (HSC IC, 2009)

addition, councils were asked to include carers who were named on the file of carers who had been assessed or reviewed in the last 12 months when the sample was chosen. These carers were referred to as “carers known by association”. However, not all councils held enough detailed information to identify carers known by association, so not all councils were able to include this further group of carers.

Administration: The NHS IC provided councils with survey guidance, questionnaires, letters to send to carers, translations of the questionnaires into foreign languages, large print versions, and telephone and face-to-face. Councils carried out the survey in line with the guidance by selecting carers from their records, sending a questionnaire to them and then coding up the returned questionnaires which were then sent to the NHS IC.

### **7.1.6 Care Quality Commission ‘Not just a number’ – Home care inspection programme 2012**

As part of this inspection programme carried out April-November 2012, CQC gathered information on the experiences of people using home care services using a mix of approaches; paper-based survey, webforms, telephone interviews and home visits.

Sample: A random sample of 250 home care agencies (208 privately owned, 22 council owned and 20 owned by voluntary organisations) across CQC’s four regions. The sample was selected so that the proportion of each type of provider category, within the sample, matched the region’s overall proportion of home care providers. However, some locations had to be removed from this initial selection if they were owned by a provider that had already been included in the sample, if they exclusively provided certain services (e.g. drug and alcohol services) or if they had been inspected in the last six months. This process resulted in changes to the proportions of different size providers although this was not considered to have significantly compromised the randomness of the sample locations.

#### Administration:

1. Questionnaire Survey Sample - Questionnaires were sent to 4,794 people (2,397 were for people who used the services and 2,397 were for the user to pass on to their carers or relatives for their views). The users’ contact details were obtained from local authorities as CQC needed to maintain the principle of unannounced inspections without alerting the provider. A total of 1003 completed questionnaires were received, representing a response rate of 21%.

2. Webforms: A web-based form was developed as an alternative to the paper questionnaire, for both people using the services and for care workers, which was publicised through LINKs. Responses were received from 130 people (27 from people who used a service and 103 from a carer or relative<sup>53</sup>). It was recognised by CQC that it was difficult to promote the availability of the web questionnaires as they did not want to alert the provider to the forthcoming inspection.

3. Telephone interviews: Experts by Experience were used to carry out the majority of the 2,742 interviews conducted as it was felt users would feel more comfortable giving honest feedback to people who have had a similar experience. Letters were sent to the people prior to the Expert by Experience calling them to inform them about the

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<sup>53</sup> It is not clear how many questionnaires were



programme and their right to opt out. Whilst the Experts by Experience were provided with an introductory script and a set of questions, they were encouraged to hold a conversation rather than an interview. The Experts by experience received telephone training from their support agency. It is not clear from the report on the methodology what criteria was used to select the service users that were contacted and the numbers of users that opted out (and if replacements were made). Interviews were carried out after the inspection site visit.

4. Home visits: inspectors carried out home visits with a total of 738 people who were receiving care from the home care agency (average of 4 home visits per inspection). These were arranged during the site inspection at the office and most took place when a care worker was available to introduce the inspector to the service user. Where possible the home visits were carried out with people who were less able to complete a questionnaire or speak to the inspector/Expert by Experience on the phone.

#### Advantages:

- Using different approaches to gathering feedback improves the accessibility to the survey, as interviews and home visits could be carried out with people with communication difficulties or dementia.
- The inspections could remain 'unannounced' as contact details for users were obtained from local authorities without the provider's knowledge.
- The use of Experts by Experience in carrying out most of the telephone interviews is beneficial for gathering honest feedback from users; service users are likely to feel more comfortable reporting negative experiences to someone who had similar experiences and is understanding of their situation.

#### Disadvantages:

- Four different approaches were used for gathering data on people's experiences of home care. Surveys using different modes of data collection may produce different results even from identical questions and it's not clear if consideration was given to the design of the survey to minimise 'mode effects'.
- The response rate to the survey was low (21%) which raises concerns about the reliability of the findings because responders may differ from non-responders.
- The paper-based survey was only sent to people whose care was funded by the local authority. Although other methods were used to elicit the views of people who fund their own care, it is not clear what proportion of people providing feedback about their experiences were from this group of users. It's likely that the views from people who fund their own care were underrepresented in the results as only a small percentage of the people using a service were contacted for a telephone interview or received a home visit (of these it's not clear what proportion were actually conducted with people who fund their own care).
- Although not documented, it is presumed that questionnaires were sent out to all state-funded users of each of the services included in the inspection programme (i.e. census was taken for each service). However, there do not appear to be any steps in place to ensure a minimum number of responses were achieved before using the data for assessing the provider and for protecting the confidentiality of respondents.

- The web-based form was publicised through LINKs. It is not clear from the report on the methodology how this approach ensured that the respondents were providing feedback about one of the home care agencies included in the inspection programme. It is possible that people who completed a webform may have been receiving care from a service not included in the programme and/or some home care agencies may have been over or under represented in the online response data if the level of publicity varied between LINKs.
- The home visits were conducted in the presence of the user's care worker which may have resulted in biased responses as some people will have been reluctant to provide any negative feedback. It is also not clear how the users were selected and providers may not have been forthcoming with the contact details of people for whom they suspected may give less favourable reports on their experiences. Furthermore, the number of home visits conducted did not appear to reflect the size of the provider, as an average of four home visits per inspection were carried out irrespective of how many service users the provider organisation provide care to.

### 7.1.7 Care Quality Commission – Inspecting domiciliary care (home care) services 2013

Building on learning from the 2011 domiciliary care pilot and the 2012 themed inspection of domiciliary care agencies, CQC has recently released guidance, methods and tools to support inspectors in making judgements about the quality of care provided.

Sampling: Inspectors may use a combination of different methods to gather views when inspecting a domiciliary care provider; they are advised to think about the size of the agency, the people they provide care for and what information is needed to help them decide the most appropriate method(s) to use. The guidance states that inspectors should aim to capture the views of 20% of the people who use the service and to cover a range of people. However, in the briefing pack for inspectors, it states that the sample size for capturing views of people who use domiciliary care services should be 20% (or most or all users if it is a 'micro' agency providing care to 1-5 people). It is therefore unclear whether inspectors should include 20% of the people using the service in the initial sample<sup>54</sup> or whether they should achieve a response (ie obtain the views) from 20% of the people using the service. If inspectors choose to carry out a postal survey, they are instructed to ask the agency to create a list of people using their service and then sort it by their name before taking every 3<sup>rd</sup> or 4<sup>th</sup> record (up to a maximum of 60 contacts).

#### Advantages

- Using different approaches to gathering feedback improves the accessibility to the survey, as interviews and home visits could be carried out with people with communication difficulties or dementia.
- The inspections now require a 'short notice' (48 hours) announcement; this allows the agency to provide the inspector with the contact details of people using the service who can then be sent a questionnaire to gather their views. This approach has the

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<sup>54</sup> ie. the sample of people that will be sent a questionnaire or the list of people from which the inspector and/or Expert by Experience will contact to try and conduct an interview

advantage of including both local authority funded and people funding their own care in the sample.

- The use of Experts by Experience in carrying out some of the telephone interviews is beneficial for gathering honest feedback from users; service users are likely to feel more comfortable reporting negative experiences to someone who had similar experiences and is understanding of their situation.

### Disadvantages

- Three different methods can be used by inspectors to gather the views of people using the service (telephone interviews, postal survey and face to face home visits). Using different modes of data collection may produce different results even from identical questions and it's not clear if consideration was given to the design of the survey to minimise 'mode effects'. Furthermore, inspectors can adapt the methods/tools, such as the questions used when interviewing people; it may be difficult to compare the quality of care between agencies.
- There is no specified method given to inspectors on how to select the 20% of people receiving care from the providers' list to carry out a telephone interview.
- There do not appear to be any steps in place to ensure a minimum number of responses are achieved before using the data for assessing the provider and for protecting the confidentiality of respondents.
- Providers may not be forthcoming with the contact details of people for whom they suspect may give less favourable reports on their experiences. Furthermore, mistakes may be made by the provider when compiling the sample for the postal survey.
- Inspectors are instructed to sample 20% of the people using the service. However, if a postal survey is being conducted, a maximum of 60 contacts is required which will not reflect 20% of the people using the service for the larger providers.

## **7.1.8 CSCI Surveys: setting specific surveys**

Sampling: The CSCI used a standard procedure for all social care surveys. It involved first contacting the care home to discuss and select survey samples. An inspector used information in the Annual Quality Assurance Assessment (AQAA) to draw up a draft survey of people currently using the service. The resulting sample was 25% of the people who use the service or ten people, whichever was greater. Once this was established, inspectors collected the associated sample information like name and contact details. The inspector contacted the provider to ascertain if anyone in the sample had either a mental capacity difficulty or communication need that would bar them from being able to complete the survey or require them to receive a survey in an alternative form. The inspector also established which service users in the sample had an advocate or active contact with a social or health care professional (such as a care manager, district nurse or GP). Finally, at this stage the inspector also asked for any needed lasting power of attorney (LPA) or legal representative details for people whose liberty to complete the survey was deprived under the Mental Capacity Act guidance. Then the inspector sent sample details to the Regional Inspection Team

(RIT) to enable them to print the appropriate documents needed and compile and send a survey pack to the care home.

CQC's regulatory approach allowed them to pool information from these surveys as well as other evaluations and inspections of service providers to produce thorough information on service user experience.

Administration: The RIT sent a survey pack with the following: a standard letter to the provider, named envelopes for each of the residents' survey's sample. Each named envelope included a resident survey form, a relative's survey form, and two stamped addressed envelopes. At the same time the RIT also sent out a survey pack to staff at each facility. The RIT then recorded the number of survey forms sent and tracked them as they were posted back.

One option that CQC inspectors could use to help get feedback from care home residents was the 'Link Resident Methodology'. Link residents distributed and collected surveys to/from other people in their care homes (this does not include helping residents to complete them). The aim of this method was to increase response rates to the survey and to gain more honest responses. CQC noted that Link Resident methodology pilots demonstrated that service users give more 'truthful' responses when they know they are giving the completed survey to one of their fellow residents than a manager or inspector of the home.<sup>55</sup>

#### Advantages

- Inclusivity: these surveys not only covered service users, but also staff and relatives.
- Coverage: Their methods ensured at least ten service users commented from each provider
- Accessibility: four alternative types of survey are offered including: Easy Read, Braille, tape and community languages.

#### Disadvantages

- Delivery of survey: the guidance indicated that some surveys are handed out by advocates or inspectors. This could be problematic depending on the influence of the advocate or inspector and their perceived relation to the service provider.

### 7.1.9 Your Care Rating 2012 Survey (Ipsos MORI)

The survey is run by Ipsos Mori on behalf of Your Care Rating Limited, an organisation established in 2011 primarily geared towards providing an independent and standardised mechanism for care home residents to provide their feedback and views on the standards and quality of care that they receive. The focus of the survey was to gather user reported experience data from residents in care homes that primarily serve those aged 65 or older<sup>56</sup>.

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<sup>55</sup> CQC Guidance for inspectors, Link resident methodology

<sup>56</sup> Younger people were covered by default if they happened to be resident at one of the participating care homes but they were not actively sampled.

Sample: The survey was open to all care homes in the UK and 791 took part. This included homes from 13 providers. Each participating care home received a copy of the questionnaire for every registered bed in order to allow all residents to take part. Care home managers were asked to assess the ability of residents to consent to the survey and then distribute the survey to those they believed could consent.

Administration: The surveys were delivered to the participating care homes in survey packs containing instructions and an explanation of the survey purposes for care home managers, staff and respondents. Surveys were in paper, self-completion format, but service users were encouraged to receive help from relatives or friends. The paper survey packs also included freepost envelopes so results could be sent confidentially to Ipsos Mori.

### Advantages

- Ipsos Mori conducted an in depth developmental process with the aim of designing a national level survey that will provide robust and statistically reliable data on for both care homes and providers: The questionnaire itself was cognitively tested with a specific focus on testing the wording, length and type of questions, layout of the questionnaire overall and the response options including the use of graphic aids with care home residents. Ipsos Mori focused on making their survey short and simple in order to hold participants' interests for the duration of the survey and gather thorough information from each person. A small scale pilot was also run with a sample of care homes to refine the survey methodology, which included qualitative interviews with care home staff on the survey implementation process.
- Ipsos Mori monitored the survey fieldwork with follow up phone calls and interviews with staff at 10% of the participating care homes to ensure that surveys were being administered as intended

### Disadvantages

- Whilst the survey has been designed as a national survey, able to provide data at both the national and provider level, participation in the survey by providers is currently voluntary meaning that it is unlikely to cover the full population of interest. For the 2012 survey, only 13 providers took part covering a total of 791 care homes in England, Scotland, Wales and Northern Ireland. Whilst the voluntary nature of this survey does not detract from its potential to provide improvement data at the local level, in its current form it would not be a viable mechanism for providing national comparisons or overall headline figures.
- At each care home, the care home manager is responsible for administering the survey pack to each resident, however they are not permitted to assist the resident in completing the survey. Proxies are allowed but they must be a friend, relative or another person close to the resident. Even though care home managers, and staff, are unable to assist with completing the actual questionnaire, they are responsible for determining the eligibility of each resident by assessing their capacity to provide consent. This introduces an element of sampling bias as care home managers are able to influence who should or should not complete a survey which is not ideal.

### 7.1.10 Public Perceptions of the NHS and Social Care Survey (Ipsos MORI)

Sampling: Six local authorities were recruited from across England with multiple levels of deprivation. Ipsos Mori drew a total sample of 50 people from the lists of personal budget holders. Seeing as this survey primarily focused on perceptions of care rather than experience of care it is unlikely that their sampling or administration procedures are relevant to the development of our survey tool.

Administration: Interviews were carried out in people's homes with computer assisted interviewing (CAPI). Forty-eight comprehensive face-to-face interviews were completed with personal budget holders and/or their carers across six local authority areas in England (eight in each local authority), as well as six telephone depth interviews with the member of staff leading on the implementation of personal budget in each of these local authorities. Due to cost and resources, this procedure is not amenable to a locally representative national survey

### 7.1.11 Bradford LINK: Adult Mental Health Day Services Survey

The following survey provides an example of one of the many ways councils conduct local surveys to gather feedback from their specific locality.

Sampling: The Bradford LINK: Adult Mental Health Day Services Survey collected feedback not only from current service users, but also from past and potential service users. Reports of their exact sampling procedures are limited, but they do explain that only one centre the group of twenty current ADCS users, and Bradford Council identified twenty more service users who previously used ADCS centres for the former service user group. Additionally twenty more service users who had not used adult mental health services previously were identified through support groups not funded by Bradford Council.

Administration: The survey was administered using a semi-structures interview format. While the guidance specifies that all interviews took place in a quiet place, however, a report on the results of the study notes that one of the major challenges of the interview technique was that it was hard to find such a place and more interviews were conducted in noisy 'wellbeing cafes.' The second major challenge obstacle with conducting face to face interviews was cost. The scope of participation could not be as broad as hoped because of the cost of face to face interviews.

### 7.1.12 User experience websites

In addition to surveys, we are aware of a number of 40 other collections designed to obtain feedback from social care users via non-survey methods. Most notably, we understand that Patient Opinion – an online feedback website for health services – has developed a social care version of their website, called 'Care Opinion'. This will provide qualitative feedback in the form of comments and stories from users, and information will be entirely user-generated: feedback will rely on people seeking out the site and offering their views. A similar online system exists at <http://www.comparecarehomes.com/>, with ratings for the typical areas like staff, cleanliness and quality of life. but this website appears to only include only a small

level of user feedback<sup>57</sup>. Another similar example is <http://www.findmegoodcare.co.uk>, a new site being developed by the Social Care Institute for Excellence (SCIE). This site will allow users to compare providers and offer feedback on them, but will be funded by charging providers a listing fee: this means that its coverage is likely to be less than universal. Findmegoodcare.co.uk focuses more on helping people plan their care and confront common obstacles in finding good care and, as yet, does not provide any evaluation of individual providers.

These websites do not have a specified sample frame and people offer feedback in a non-standardised format. It is still valuable, however, to recognize that it address the same content as surveys and provides service user testimonials that may assist in understanding user experience.

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<sup>57</sup> For example, a search within a ten mile radius of the Picker Institute's Oxford office found more than sixty care homes, with a total of one rating from a user, posted in February 2012.

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## 8 Appendix B: Stakeholders who participated

### 8.1 CQC stakeholders

Samantha Booth  
Richard Clarke  
Karen Culshaw  
Chris Day  
Paul Durham  
David Farrell  
Glynis Gaffney  
Richard Green  
Sue Moffatt  
Simon Richardson  
Alan Rosenbach  
Emma Steel  
Helen Stevenson  
Susan Towers  
Marina Warwicker  
Tamatha Webster  
Karen Westhead  
Natalie Young

#### Experts by Experience

7 Experts by Experience who will remain anonymous

### 8.2 External Stakeholders

Alex Fox*	Shared Lives Plus
Colin Angel	United Kingdom Homecare Association Ltd
Sarah Barrett	Mears Group
John Clarke	Dimensions
Anne-Marie Hamilton	Department of Health
Chris Manthorp	Barchester Healthcare
Sheila Scott	National Care Association
Amy Swan	National Housing Federation
Frank Ursell	Registered Nursing Home Association
Jasmine Ali	Patient Opinion
Karen Deacon	Royal National Institute of Blind People
Ruthe Isden	Age UK
Marjie Woodward	Scope
Des Kelly*	National Care Forum
Emily Holzhausen*	Carers UK

\*written comments



## 8.2.1 Providers and Councils

### Providers & Councils

499 providers and 37 councils took part in the consultation by completing the online survey. These organisations will remain anonymous in accordance with the terms of the survey. The results of the survey are outlined in Appendix C.

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## 9 Appendix C: Summary findings from the online survey of councils and social care providers

### 9.1 Introduction

An online survey of all councils and registered individual providers was conducted to gather their views on the practicality and value of different approaches of data collection from social care service users.

Each council and service provider received an email containing a link to the online survey which was designed using Snap, a survey software programme. The survey fieldwork was kept open for almost three weeks.

#### 9.1.1 Response rates

All councils (n=154) were invited to take part in the survey and responses were received from 37, representing a 24% response rate. 15,714 providers were invited to participate in the survey, and responses were received from 449, representing a 3% response rate. Given the low response rates to the survey, it should be noted that the responses received are not representative of all councils and providers.

Of those providers that responded to the survey, most provided more than one type of service. The most common services provided by the respondents to the survey were residential or care home services (n=192), domiciliary care services (n=186), and nursing care home services (n=45). A small number of the providers that responded to the survey said they provided supported living services, Shared Lives service and day care services.

### 9.2 Key findings

#### 9.2.1 Providers and Councils existing approaches to gathering service user experience data

- Most providers carry out a mix of postal surveys and face to face or telephone interviews with service users; only 7 providers said that they have not collected any service user experience data. All councils said that they have some way of collecting experience data from service users; most carry out a mix of postal surveys and face to face or telephone interviews with service users.
- For those providers that have carried out more than one type of survey, most considered face to face interviews to be the most successful approach. Some of the

reasons listed why this approach was considered the most successful include: providing more detailed data, a range of communication methods can be used to help the user understand the questions (i.e. can be tailored to meet service user needs), it can provide information immediately, and gives clients the opportunity to discuss a wide range of issues. However, it was noted that this approach is very time consuming. In contrast, for those councils that have carried out more than one type of survey, most considered postal surveys to be the most successful approach. Some of the reasons listed why this approach was considered the most successful include: cost effectiveness, its ability to yield quantitative data and to reach a large sample size.

- Those providers which reported that postal surveys is the most successful approach, stated the following reasons why: greater coverage and more cost effective, allows users to provide more honest responses as they can respond anonymously, provides greater time for users to consider their responses and provide feedback. A few councils considered face to face interviews were the most successful approach to gathering feedback because respondents could understand the questions better and it could provide more detailed information about care.
- A number of providers and some councils also stated that a mix of methods is required to make the survey accessible to all users and to gather the most comprehensive feedback.
- The majority of providers appear to survey all of their clients although some refer to taking a random sample of service users.
- Most providers (73%) and councils (58%) did not experience any difficulties in carrying out their user experience surveys. Those providers and councils that did experience some difficulties, stated the following challenges:
  - Low return rate of paper surveys
  - Service users' capacity/ ability to respond on their own
  - Credibility of responses; difficulty in getting honest responses
  - Suitability of survey for all service users
  - Gathering feedback has been burdensome in terms of time, cost and labour.

## 9.2.2 Sampling service users

Providers were asked in what format information is held for users of the social services they provide:

- 67% have a mix of electronic and paper records
- 26% have paper records only
- 5% have electronic records
- 0.5% have no records

Councils were asked in what format information is held for users of different social care services including:

- Domiciliary care services
- Residential or care home services

- Nursing care home services
- Day care services
- Extra care or other housing-based services

For each of these services the information formats were as follows (13% did not respond):

- 62% Electronic records
- 2% Paper records
- 22% Mix of electronic and paper records

### 9.2.3 Users that require an alternative format

The majority of providers (69%) can easily identify users that would require an alternative format to a paper-based questionnaire due to physical or cognitive impairments, whilst 18% said they could identify such users but not easily (only 8% reported they could not identify these users). In contrast, only 13% of councils said they could easily identify users that would require an alternative format; most councils (54%) said they can identify such users but not very easily (13% reported they could not).

Although the majority of providers (46%) reported that between 0-15% of their users would require an alternative format, 22% of providers reported that over 45% of their users would require an alternative format to a standard paper-based questionnaire.

### 9.2.4 Users that would require help to provide feedback

Most providers (30%) reported that over 45% of their service users would not be able to reliably evaluate their care through any survey format without assistance from somebody. The councils that responded to this question were less certain; 38% of councils reported that they did not know the proportion of residential care service users who could reliably evaluate their care without assistance, and 43% reported that they did not know this information for community social service users.

Identifying unpaid carers from service user records: 59% of providers can easily identify carers, 13% can but not very easily, 15% cannot identify carers and 8% of providers did not know. Councils were not asked specifically about being able to identify unpaid carers, as such details exist in individual service user records which would not likely be available to all councils.

### 9.2.5 Capacity to consent

Most providers (73%) can easily identify users that lack the capacity to consent to take part in a survey (15% could identify such users, but not very easily and 6% of providers cannot identify such users from their records). As for the councils, the majority (43%)

said they could identify such service users but not very easily (only 8% could identify such users easily and 30% could not identify them at all from their records.)

### 9.2.6 Reporting survey results

76% of providers thought it would be practical to compare results across different social care providers offering similar services. The reasons given by those providers who did not think this would be practical included:

- There is too much variability in what social care providers offer and what the needs of their service users are for the comparisons to be useful.
- There is too much regional variability in terms of standards and culture for providers for comparisons to be useful
- Some providers are reluctant to endorse comparisons, as they worry about how their results would look in relation to others
- Comparisons could create unnecessary and/or unfair competition amongst providers

67% of councils thought it would be practical to compare results across different social care councils offering similar services. The reasons given by those councils who did not think this would be practical included:

- There is too much variability in what social care providers offer and what the needs of their service users are for the comparisons to be useful.
- The size of many of the service providers are too small to provide robust, comparable data

72% of councils thought it would be practical to compare results across different local authorities. The reasons given by those councils who did not think this would be practical included:

- There is too much regional variability in terms of standards and culture for providers for comparisons to be useful
- The concern that response rates will be too low especially amongst those with lower levels of education.

## 9.3 General points

73% of providers felt a new provider-level survey of adult social care would be useful to them (32% said it would 'definitely' be useful and 42% said it would be useful 'to some extent'). Of those providers that did not think a new survey would be useful (14%), some of the reasons stated included:

- There are already a number of different surveys; users are being over-surveyed
- Burden of conducting surveys – time and cost resources
- Concerns over quality of survey responses (bias or skewed data)

- Provider already gathers service user experience data

59% of councils agreed that such a survey would be useful to them (45% said it would 'definitely' be useful and 14% said it would be useful 'to some extent'). Those councils that did not think a new survey would be useful (8%), offered the following reasons:

- The burden of conducting surveys – time and cost resources
- Concerns over quality of survey responses (bias or skewed data)

At the end of the questionnaire there was space for respondents to add any additional comments. For providers, these largely covered the following themes:

- Uncertainty on what providers would gain from the survey (fears that a national survey would be irrelevant and not as important as other things like funding, staffing).
- Overlap with existing surveys (as mentioned above)

"...too many different bodies are doing the same thing (ie CQC/CSSIW, Local Authorities, Local Health Boards). Can't you all use the same surveys?"

"There are a number of surveys carried out in the Local Authority where I am a provider, these include, contract monitoring from Social Services, quality assurance inspections from PCT, compliance inspections from CQC, Links visits soon to be Health Watch. All of these visits include user experience"

- Usefulness of survey is dependent on the questions being asked and whether it will help people make informed choices, raise standards and improve services
- Survey approach: standardised survey vs needing the survey to be service specific

"The survey would have to be tailored to each type of service. It should be administered by an independent body at no cost [to] the service provider"

"A lot of community care providers provide a lot of different services and therefore the survey would need to be detailed enough to show the care and services to make it comparable."

"I think it would but it would need to be service specific ie. Rehab and reablement are different from residential and domiciliary services"

"For a survey to work the would need to be a uniform set of questions"

"If there was a standard questionnaire that would help greatly, but local authorities would have to recognize it and use it so that we are not having to use 2 or 3 different ones."

- Some providers commented on responder capacity and proxy data

"With survey, communication is the key - it has to be undertaken with someone the service user trusts."

"We would need to include the views of others, service users family, advocates etc, other professional visiting and supporting service users."

“I think the opinions of the people that use services should be paramount in assessing that services quality. The process of consulting should not only consist of an individual service, but in larger organisations the management infra-structure from which it arises i.e. the organisations culture. This may have to include the views of staff as well.”

For providers, the final free comments covered the following general themes:

- Uncertainty on what councils would gain from the survey (fears that the data produced would not be helpful).

“The usefulness of any survey would depend on the questions to be asked and would be useful for benchmarking”

“Although the data might be useful, we have concerns about sample sizes, and feel that running 2 surveys would negatively impact on return rates.”

- Survey approach: standardised survey vs needing the survey to be service specific
- Concerns that surveys in general are not the best approach to gathering feedback

“Surveys are really limited by methodology and the user group characteristics, whilst some of these issues can be overcome there is a real problem finding out what experience vulnerable adults and those with a high level of need for care and support actually have by surveys”

- Some councils commented on the burden it would create for them and the need for a cost benefit analysis

“The impact of yet another survey on a limited pool of service users and the usefulness of the data generated.”

“Potential to overload the same service users with surveys.”

“The sheer number of surveys the SU are expected to complete is becoming excessive more targeted joined up approach would be better.”

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# 10 Appendix D. A guide to measuring service user experiences: basic principles for providers of adult social care services

## 10.1 Purpose of this guide

This guide has been written for providers of adult social care services conducting surveys of their service users. It provides an overview of the basic principles to be considered when measuring people's experiences of social care services. This is not an exhaustive guide as it focuses solely on surveys and not other approaches to gaining service user feedback. The information is structured into the following four main sections: sampling, methodological considerations, questionnaire design and reporting results.

## 10.2 Sampling

### 10.2.1 Deciding on a sample size

The level of certainty or confidence in the findings of a survey is affected by the response rate and, ultimately, the number of respondents. The more respondents to a survey, the more statistically certain you can be about the survey findings (see 'Additional notes' for information on the level of confidence you would achieve for various numbers of respondents).

When deciding how many people should be surveyed, it is first important to consider the purpose of the survey and how the results will be used. For instance, if you plan to compare the survey findings between different groups of respondents (such as different service locations or different groups of service users), you will need to consider the number of respondents needed in each group in order to make such comparisons feasible.

It is essential that any survey is conducted in a way that service user confidentiality is respected and given a high priority. To protect the identity of people responding to the survey, we recommend the minimum number of respondents should be 30 when reporting survey estimates. When deciding on your sample size it is therefore important to consider the likely response rate to the survey. The response rate to the Health and Social Care Information Centre (HSCIC) Adult Social Care Survey was 40% in 2011-12, so if a 40% response rate is assumed, this would necessitate a minimum sample size of 75 service users.<sup>58</sup> With regard to protecting the confidentiality of respondents, the basic guideline we can offer to providers is as follows Providers with over 75 service users can administer a survey without fear of breaching confidentiality of respondents (assuming a 40% response rate is achieved). Those with between 50 and 75 can administer a survey, but should be wary of reporting results if they have fewer than 20 responses. Those with

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<sup>58</sup>If you are a small provider and are unable to achieve 30 responses, then care should be taken when reporting results to ensure the identity of the respondents is protected



between 25 and 50 users may be able to administer an anonymous survey, but they should seek expert advice where possible to evaluate their individual situation. Finally, providers with fewer than 25 service users are advised not to use anonymous surveys as a form of feedback unless they are confident of achieving a high response rate and more than ten completed questionnaires.

## 10.2.2 Sampling frame / drawing a sample

Central to the implementation and use of any survey is the construction of a sampling frame as it determines the population to which results can be generalised. A sampling frame should ideally include all service users eligible to be sampled so this may necessitate combining paper and electronically held records and/or improving the quality of the information, such as checking the service user database(s) is up-to-date and does not contain duplicates. Coverage error from missing service user records introduces bias to the results. If carrying out a postal survey, records should be checked for any deceased service users to avoid sending a questionnaire to a bereaved family.

If you are constrained by low numbers of service users for whom you provide care, best practice would be to take a census rather than a sample of service users to achieve a higher number of total responses.

If you provide services to a large number of service users, it is likely to be cost prohibitive to include all users in your survey so you will need to take a sample of people. Best practice is to draw a probability sample, or a sample where chance methods such as random numbers, are applied to all elements of the sampling frame and each person in each element of the sampling frame has a known, nonzero, chance of being selected (Groves et al., 2004)<sup>59</sup>. The sample frame can still be stratified by age or condition (for instance dementia or learning disabilities) depending on the aim of the survey or to ensure a voice from the most vulnerable groups.

It is recommended that under the Mental Capacity Act 2005, people who are unable to give their consent to take part in a survey should not be included. The HSCIC Adult Social Care Survey include steps to filter out ineligible people based on their capacity to consent.

When compiling your list of service users to be surveyed, it is useful to include additional information on the service users (where recorded), such as gender, age, ethnic group, and whether they are state or self-funded. This information can be used to determine how representative your respondents are to the population surveyed, and also allow the survey findings to be compared between different groups of respondents.

## 10.3 Methodological considerations

### 10.3.1 Types of surveys

There are a number of different ways or modes of conducting surveys, depending on where and with whom you want to carry them out. Each mode of administering a survey

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<sup>59</sup> Groves, Robert M. 2009. *Survey Methodology*. 2nd ed. Chichester: Wiley.

has its strengths and drawbacks – there is no one 'best' method to use. The table below outlines some of the main advantages and disadvantages of the more common approaches for carrying out surveys.

Survey Type	Advantages	Disadvantages
Postal Survey	<ul style="list-style-type: none"> <li>• Can collect high volumes of data at an acceptable cost</li> <li>• No interviewer – respondents may be more willing to share information</li> </ul>	<ul style="list-style-type: none"> <li>• Response rates are typically lower</li> <li>• Not accessible for all users such as those with physical and/or cognitive impairment</li> <li>• Takes a relatively long time to produce results</li> </ul>
Telephone Survey	<ul style="list-style-type: none"> <li>• Issues can be explored in greater depth as they arise in conversation</li> <li>• Rapid data collection</li> </ul>	<ul style="list-style-type: none"> <li>• Limited open-end questions or time constraints due to more limited survey length</li> <li>• Call screening is common</li> </ul>
Online Survey	<ul style="list-style-type: none"> <li>• Low costs</li> <li>• Automation and real-time access</li> <li>• No interviewer – respondents may be more willing to share information</li> </ul>	<ul style="list-style-type: none"> <li>• Requires internet access and computer knowledge (many adult social care users will not have regular access to the internet<sup>60</sup>)</li> </ul>
Face to face interview	<ul style="list-style-type: none"> <li>• Typically good response rates</li> <li>• Normally better at obtaining representative samples</li> <li>• Attitude can be observed</li> </ul>	<ul style="list-style-type: none"> <li>• Expensive</li> <li>• Time-consuming</li> <li>• Interviewer may influence how people respond (response bias)</li> </ul>

### 10.3.2 Mixed-mode approach

Given the diverse range of services and user groups – and the high proportion of people that will have cognitive and/or physical impairments – a survey using different modes of administration may be considered beneficial in order to try and improve the accessibility of the survey (such as a paper questionnaire supplemented with additional face to face or phone interviews). It is important to recognise, however, that surveys using different modes of data collection may produce different results even from identical questions. Careful consideration will need to be given to the design of the survey to minimise 'mode effects'.<sup>61</sup>

<sup>60</sup> 69% of people aged 75 or over and 33% of people with a disability (as defined under the Disability Discrimination Act) have never used the internet (Source: Office for National Statistics. (2013) Internet Access Quarterly Update, Q4 2012. Retrieved from <http://www.ons.gov.uk/ons/rel/rdit2/internet-access-quarterly-update/2012-q4/stb-ia-2012-q4.html>)

<sup>61</sup> See De Leeu, E.D. (2005) To mix or not to mix data collection modes in surveys, Journal of Official Statistics, 21(5), 233-255.

### 10.3.3 Practicalities in administering a survey

The following recommendations may help improve response rates to postal surveys:

- **Send out reminders** to non-respondents to help boost the number of returned completed questionnaires received. In the NHS patient survey programme, up to two reminders are sent to non-respondents. However, multiple mailings could be distressing for certain user groups (such as a service user who lacks capacity to consent or take part in the survey), so sending just one reminder might be considered more appropriate, although this will result in lower response rates from some groups.
- Include a **FREEPOST or stamped addressed envelope** so respondents can return their completed questionnaires at no cost to themselves. Given the challenge for frailer people in posting back their questionnaires, it may be advantageous to work in partnership with volunteers from local support groups and organisations, so that volunteers can provide help with returning the questionnaires on behalf of the service user.
- Provide a **survey helpline** (ideally a freephone line) to give people who have received a questionnaire easy access to advice from staff about the survey, or to opt out. Staff should be available to help callers complete the questionnaire over the phone (with or without the help from an interpreter).
- Employing an **independent organisation** to administer the survey on your behalf may encourage more users to respond, and also provide more honest feedback as respondents can return their questionnaire anonymously without fear of reprisal from their provider. Using the expertise of a survey organisation may also add credibility to the survey findings in the eyes of staff, service users and the general public. Steps should be taken to ensure the secure transmission of confidential personal information between organisations to comply with the Data Protection Act

### 10.3.4 Proxy respondents

A high proportion of users of social care services are likely to need help with completing a questionnaire due to physical and/or cognitive impairments; 68% of respondents to the 2011-12 Adult Social Care Survey required help with completing the questionnaire. The 'type' of proxy used is important in affecting the quality of responses received. Relatives or informal carers of the user are often the best type of proxy as they are familiar enough with the user to comment accurately on their experiences. Using social care staff as proxies is likely to provide biased responses as staff may have an incentive to give certain responses and/or users are less likely to report more negative aspects of their care.

If you hold comprehensive and up-to-date contact details for potential proxies (i.e. informal carers), then the survey could be designed for the proxy to complete and sent directly to them. Alternatively, the survey could be sent to the service user with instructions on how the survey can be completed by a relative or friend if help was needed.

## 10.4 Questionnaire design

### 10.4.1 Type of questions

For a survey to produce accurate and useful results, the questions must be rooted in what service users say is important to them. Focus groups and complaint lines can be a good source of potential topics for survey questions.

#### **Measure service user 'experience' rather than 'satisfaction'**

Survey questions generally fall into two categories: those that ask people to report about their experience and those that ask them to rate their experiences. For example,

"Did \_\_ happen?" and "How much of \_\_ did you get?" are *report* questions.

"How would you rate \_\_?" and "Please rate \_\_ as poor, fair, good, very good, or excellent," are *rating* questions.

Traditional 'satisfaction' or 'rating' style questions are used to elicit opinions about the impact of care for the user or summary judgements about care. These can be difficult to interpret as factors other than the care provided can influence the response. Reporting questions are more factual assessments of specific processes of care and can provide more useful information for improvement because they highlight precisely where the problems are, and what needs to be done to improve particular elements of care.

#### **Basic principles in question development**

It is important that questions (in any format) are worded in an easily comprehensible way by using simple and straightforward language. In line with Dillman's recommendations for survey question development, it is important to consider the following in designing a survey of adult social care: make sure the question applies to the respondent, use simple and familiar words, use specific terms, and provide exhaustive response options (Dillman et al., 2007).<sup>62</sup> The topics should be specific enough to be relevant, but not so specific that the questions become tedious to answer. Avoid leading or biased questions and topics that are politically sensitive or might embarrass service users.

In the development of the 'Your Care Rating' survey, testing showed the importance of keeping the questionnaire as simple and short as possible. One of the key findings was that some residents had difficulty in answering concept statements, such as 'I feel valued', so these statements were shortened and simplified or even removed if the concept was considered too complicated to convey in a short statement.<sup>63</sup>

#### **Multiple care settings**

If surveying service users in different care settings, it is important to remember that the terminology used in the questionnaire should reflect the care setting. A person receiving care in their home would require differently worded questions to someone in a care home to avoid confusion.

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<sup>62</sup> Dillman, D.A., Smyth, J.D., Christian LM. 2009 *Internet, mail, and mixed-mode surveys : the tailored design method*. 3rd ed.. Hodoken, NJ: Wiley

<sup>63</sup> Ipsos MORI (2012) Your Care Rating Survey

## Questions for subsequent analysis

You may wish to consider including questions that will provide useful information for subsequent data analyses. The inclusion of a question that asks who completed the questionnaire is important in social care user experience surveys due to the high proportion of participants that require help with completion. This question is useful to help providers understand variations in responses to other questionnaire items with respect to those who received help. If your survey includes questions to measure users' quality of life, you may want to consider including questions which capture the factors, other than social care services, which can affect a person's quality of life. For instance, the Adult Social Care Survey included questions on whether the person received any informal support and the needs of the user (activities of daily living) so that the quality of life scores could be adjusted to ensure any variations in the quality of life outcome indicator could be attributed to the service. However, this type of analysis will only be possible if there are a sufficient number of people in the sample.

### 10.4.2 Alternative formats

In surveying adult social care users, there is likely to be a relatively high proportion of people who lack the capacity to respond independently to traditional surveys, such as people with sensory impairments or people with learning difficulties. It may be necessary to provide alternative formats of the questionnaire to improve the accessibility of the survey, such as large print and easy-read versions.

### 10.4.3 Pre-test survey questions

All questions should be pre-tested in face-to-face cognitive interviews with a small but carefully chosen sample of respondents — that is, a sample chosen to represent all types of service users who will be surveyed.<sup>64</sup> Pre-testing is essential in order to:

- **Identify questions that are unclear, liable to misinterpretation, or difficult to answer:** All items in a survey must lend themselves to uniform interpretation if the information they generate is to be reliable and valid. If respondents misunderstand or cannot answer questions, the data collection is fruitless. Pre-testing each question allows you to avoid wasting valuable resources collecting information that cannot be interpreted.
- **Discover parts of the questionnaire that place an unacceptable burden on the respondent:** By mixing types of questions (but not topics), you can avoid wearing respondents out. Asking too many questions about times and dates or other specific knowledge can cause a respondent to become frustrated and terminate an interview or toss aside a questionnaire before completing it.
- **Discover parts of the questionnaire that do not work, or that work with one population but not with another**

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<sup>64</sup>For more information about pre-testing survey questions, you may find the following publication useful: Willis, G. (2005), *Cognitive Interviewing: A Tool for Improving Questionnaire Design*, Thousand Oaks, CA: Sage.

## 10.5 Reporting results

### 10.5.1 Data analysis

The usefulness of your survey data will depend on how well you plan the survey process and on how effectively you analyse the data. Standard data analysis usually involves examination of the frequency of responses to each question and some crosstabulation of responses against demographic and other information. The following suggestions may help you make the data analysis more useful and focused.

**Use the data to help pinpoint problems:** Identifying specific weaknesses provides constructive targets to work towards. The most straightforward method of prioritising is to rank issues in order of the size of the problem and to focus first on those that are the greatest.

**Group similar questions together to provide summary analysis:** To make the data more compelling for others, and to speed up the analysis, we suggest:

- Linking questions that cover similar topics or processes
- Combining several questions into a single composite measure (by averaging responses, for example)

**Perform analysis by sub-groups:** You may want to compare the answer to a survey question between two different groups to see if the differences are significantly different (e.g. the answers for different aged users or between different service locations). However, this considerably reduces the number of responses in each group. This will impact upon the level of confidence you have in the results and, therefore, your ability to accurately detect differences between these groups (refer to Table 1 in Appendix)

**Make use of the open-ended comments:** Users' freetext written comments can provide valuable feedback on their experiences. Such data illustrate responses to closed questions, and allow respondents to identify new issues not captured elsewhere in the questionnaire. It can be effective to group comments made about similar topics to identify themes in users' experiences. Any information that could allow respondents to be identified, such as user and staff names should be removed.

**Compare results over time:** Investigating trends in survey results over time is a powerful analytical tool for prioritizing areas for improvement. Analysis of trends allows you to focus on addressing aspects of performance that are deteriorating, and promoting those that are showing progress. You should confirm that any apparent changes between years are statistically significant. The nature of a trend in the data (does the trend go up, or down, or is there no trend) and the extent of any trends or changes are good starting points for making comparisons over time. It should also be possible to measure the impact of any initiatives that have been introduced.

**Standardising data:** The composition of both the samples and the respondents can vary significantly between surveys, even if the sampling criteria remain unchanged. Certain groups can respond more positively than others; if your results improve significantly from one survey to the next the improvement may be due to a change in those responding. One solution to this issue is to "standardise" your data, ie to control for these variations

in population so that you can be more confident that any change reported is due to changes in service quality, not just those who are responding.

## **10.5.2 Prioritising your findings**

To make sure that the survey data is used, the results must be presented clearly and logically. To help you with this task, you may like to consider the following suggestions:

### **Rank results by their magnitude**

The most straightforward method of prioritising is to rank issues in order of the size of the problem and to focus first on those that will make a difference to a larger proportion of people.

### **Examine performance along themes**

If people using social care services report more problems with certain aspects of their care, it may be appropriate to pay extra attention to these areas. Dividing your results into themes for analysis (eg: dignity and respect, information) can also help identify provider strengths and weaknesses.

### **Compare results over time**

Investigating trends in survey results over time is a powerful analytical tool for prioritising areas for improvement. Analysis of trends allows you to focus on addressing aspects of performance that are deteriorating, and promoting those that are showing progress. You should confirm that any apparent changes between years are statistically significant. The nature of a trend in the data (does the trend go up, or down, or is there no trend) and the extent of any trends or changes (are they steady, sharp rises or falls, or erratic) are good starting points for making comparisons over time. It should also be possible to measure the impact of any initiatives that have been introduced.

However, the composition of both the samples and the respondents can vary significantly between surveys, even if the sampling criteria remain unchanged. Certain groups of people are likely to respond more positively than others, such as older people when compared to young people; if your results improve significantly from one survey to the next but the proportion of older patients has increased, the improvement may be due to a change in those responding. One solution to this issue is to “standardise” your data, ie to control for these variations in population so that you can be more confident that any change reported is due to changes in service quality, not just those who are responding.

### **Ease of action**

It may be wise to focus initially on the issues that are easiest to improve. By demonstrating successful interventions, this prioritisation method can rally support for more difficult improvement efforts later on.

### **Areas of excellence**

A provider will want to maintain excellence in areas where it is already perceived to be doing well. This approach can provide a clear and positive focus for clinical and administrative staff.

## Summarise your data

Translating the large quantity of data you collect into accessible information is vital for informing staff. Too much data will be overwhelming and make it difficult to identify key issues. Summarising your data will also help management make important decisions in response to the survey.

## Don't overlook insignificant results

If there are areas that have shown little or no change from previous years, this suggests that additional work is needed for improvements to occur. This is often true of areas where making changes poses a significant challenge, and where attention to quality improvement is particularly important.

### 10.5.3 Publishing survey findings

Service users' responses must not be presented to anyone in a way that allows individuals to be identified. It would be unlawful to provide staff who may have had contact with respondents any information that would allow these respondents to be identified. The following recommendations are made:

- 1) The raw data set should not be provided to any member of staff who does not need to view it, i.e. those who are not directly working on the project
- 2) If data are to be presented to other staff, only the aggregated totals for each question should be provided. If analysis by subgroup is carried out, (such as comparisons between ethnic groups of people) the results for any group consisting of fewer than **30 respondents** should be suppressed (replaced by a dash).

## Develop an action plan

Having used your survey results to identify areas for improvement, we recommend you work with staff and users of the service to prioritise the work needed, and then identify the actions required. Initially it is a good idea to focus on one or two key areas for improvement and not to attempt to tackle all of the issues at once. Set your goals and objectives and then divide tasks into manageable steps and achievable targets. Choose areas that show clear potential for improvement. If plans are too ambitious they may fail so it is important to be realistic and choose approaches that are likely to succeed. Small successes will help keep the momentum going and encourage continuous improvement. Focusing on issues that present solutions will help to gain the ownership and involvement of staff and service users and avoid duplication of effort.

Work out realistic timescales for reaching your goals as well as details of how and when progress will be measured. Identify the individuals who will be responsible for taking this work forward. This will form the basis of an action plan which can be updated on a regular basis.



### **Additional Notes**

The tables below shows the level of confidence<sup>65</sup> you would achieve for various numbers of respondents at a 95% confidence level (Table 1) and 90% confidence level (Table 2).

**Table 1: Confidence intervals (at a 95% confidence level)**

<b>Number of respondents</b>	<b>Widest Confidence Interval (+/-)</b>
50	13.9%
100	9.8%
200	6.9%
300	5.7%
400	4.9%
500	4.4%
600	4.0%
700	3.7%
800	3.5%
900	3.3%
1000	3.1%
1100	3.0%

**Note:** The above confidence intervals relate to the number of respondents. So when thinking about your sample size you will need to take into account the expected response rate.

**Table 2: Confidence intervals (at a 90% confidence level)**

<b>Number of respondents</b>	<b>Widest Confidence Interval (+/-)</b>
50	11.6%
100	8.2%
200	5.8%
300	4.7%
400	4.1%
500	3.7%
600	3.4%
700	3.1%
800	2.9%
900	2.7%
1000	2.6%
1100	2.5%

**Note:** The above confidence intervals relate to the number of respondents. So when thinking about your sample size you will need to take into account the expected response rate.

<sup>65</sup> A **confidence interval** is an upper and lower limit within which you have a stated level of confidence that the provider mean (average) lies somewhere in that range. The width of the confidence interval gives some indication of how cautious we should be; a very wide interval may indicate that more data should be collected before any conclusions are made. This column (the widest confidence interval) shows the **maximum** margin of error for binomial estimates of proportions

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## 11 Appendix E: The minimum population size calculation

Sample size for a simple random sample (without replacement):

$$n_0 = \frac{z^2 * p(1 - p)}{e^2}$$

For a  $\pm 5\%$  margin of error and a 95% confidence interval, this is:

$$n_0 = \frac{1.96^2 * 0.5^2}{0.05^2}$$
$$n_0 = 384.16$$

With an estimated 40% response rate, in order to get a sample of 385 we need to send the questionnaire out to

$$N \geq \frac{385}{0.4}$$
$$N \geq 962.5$$

This gives us our estimate that a sample size of approximately 1000 per unit is required. However, by relaxing the margin of error to  $\pm 10\%$  and noting that when the sample size is a large proportion of the total population a finite population adjustment is justified, we can do the following:

Sample size for a simple random sample (without replacement) is as above:

$$n_0 = \frac{z^2 * p(1 - p)}{e^2}$$

Finite population adjustment is:

$$n = \frac{Nn_0}{n_0 + N - 1}$$

If we assume that a census will be required for small organisations, then

$$r = Nx \quad \text{where } r = \text{number of respondents}$$
$$N = \text{population/census size}$$
$$x = \text{response rate (estimated at 40\%)}$$

Based on this, we can calculate the minimum viable population size as:

$$Nx \geq \frac{Nn_0}{n_0 + N - 1}$$

Which simplifies to:

$$x(n_0 + N - 1) \geq n_0$$
$$n_0x + Nx - x \geq n_0$$

$$Nx \geq n_0 - n_0x + x$$

$$Nx \geq n_0(1 - x) + x$$

$$N \geq \frac{n_0(1 - x) + x}{x}$$

$$N \geq n_0 \frac{1 - x}{x} + 1$$

$p(1 - p)$  reaches its maximal value at  $p = 0.5$ , and we wish to calculate the sample size based on a 95% confidence level and  $\pm \leq 10\%$  margin of error<sup>66</sup>, therefore:

$$n_0 = \frac{1.96^2 * 0.5^2}{0.1^2} = 96.04$$

$$N \geq 96.04 * \frac{0.6}{0.4} + 1 = 145.06$$

This figure is rounded to  $N = 150$  in the report to give a minimum population size.

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<sup>66</sup> Please note there is no estimate of non-response bias (just a random chance error margin of 10%); non-response bias is likely to reduce accuracy further.

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