

Feasibility Study for Survey of Incomes and Assets of Adults with Social Care Needs

Workstream 3 phase 2: Options report

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Margaret Blake, Claire Lambert, Freddie Gregory, Laura Tuhou



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This research was commissioned under the previous administration (11th May 2010 to 5th July 2024) and therefore does not reflect the policies of the current government. The views expressed are the authors' and do not necessarily reflect those of the government.

1 Executive Summary

This summary presents the key findings of workstream 3 phase 2. Workstream 3 consisted of secondary data analysis (phase 1) and an options appraisal (phase 2). For the secondary analysis CPEC investigated the response rates to questions about the financial circumstances of respondents in two major national longitudinal surveys, the English Longitudinal Study of Aging (ELSA) and the UK Household Longitudinal Survey (UKHLS). The objective was to identify how well these questions in ELSA and UKHLS capture the corresponding financial information they are designed to capture.

In the options appraisals, Ipsos looked at the different data collection options available. Three groups of options were considered, and their benefits and drawbacks identified. Each option was appraised on a range of topics including: coverage of the target population, information that the option would provide and whether this would meet DHSC needs, impact on people with care needs and their carers and families, required involvement of organisations, technical and practical considerations, data analysis and use. Findings from Workstreams 1 and 2 and from CPEC's secondary data analysis fed into the options' appraisal. This options' appraisal was conducted in spring 2022, before the 2022 Autumn Statement announcement that the implementation of the charging reforms would be delayed.

The two phases were followed by an Expert Reference Group (ERG) meeting, to discuss the views and considerations related to the approaches being considered as part of this study.

1.1 Exploring the methodology of previous surveys and secondary analysis

A range of key methodological challenges were raised based on past experience of surveys and current knowledge of the sector, as summarised below:

- challenges related to privacy and financial resources
- low levels of awareness of financial arrangements to pay for care found in older people aged over 65
- difficulty obtaining data from people in care homes and there is also a challenge in assessing assets and income as people move through the care system
- for ethical reasons care providers know little about people's finances on admission
- trust in the organisation collecting the data is key, organisations such as Age UK or TLAP (Think Local Act Personal) may generate this type of trust and confidence
- being transparent about why the data is being collected is important
- unlikely to obtain the same detail and accuracy as local authority financial assessments since researchers and interviewers lack the financial knowledge, and people with care needs have no reason to provide this level of detail
- the frequency of data collection will increase the burden placed on survey participants

- linkage of data is problematic, participants will need to be assured about privacy, information and data governance and clear limits established on what data is used (and not used) for

1.2 Options appraisal: Short-term data collection

For data collection to be delivered in the short term the only suitable approach is the analysis of existing general population survey data. Although the coverage and sample sizes are limited, by combining waves or surveys, and modelling future care needs this would provide information for DHSC at pace.

1.3 Options appraisal: Long-term data collection

For data available over the long term, the options could include a survey conducted centrally using local authority provided sample. However, this will have a high cost and burden on local authorities. It would also need to collect some data already held by local authorities about local authority-funded people (unless combined with local authority admin data). Consideration would be needed around including care users in research, especially those lacking capacity.

Another approach includes using individual level administrative data held by local authorities, supported by local authority reference to central government sources (e.g., checking DWP records as part of assessments). However, this would again increase burden on local authorities. There would be information governance challenges and data linkage across government departments would take time to secure permissions. The data would also not cover self-funders.

A final option is to boost samples of existing general population surveys. The limitations of this approach include longer lead in time, increased costs and a lack of data for people in care homes and of working age.

2 Introduction

2.1 Background and aims of project

This report presents findings from workstream 3 phase 2 of a project about the feasibility of collecting data about income and assets from people with care needs. This workstream involved holding an expert reference group, exploring the methodology of previous surveys of people using care services, carrying out limited secondary analysis of existing surveys and conducting an options appraisal.

The work has been undertaken by Ipsos and the Care Policy and Evaluation Centre (CPEC) at LSE on behalf of the Department of Health and Social Care (DHSC).

The project was commissioned by DHSC as there is currently a lack of robust data about the income and assets of the population using care services, as well as other information such as demographics and spending on care. The collection of this data can be complex and sensitive with important ethical implications. The overall project therefore looks to explore the different options for data collection and their benefits and drawbacks. This will help DHSC to have a better understanding of the different options available to them and what these options may look like.

From the different options explored throughout this project, DHSC would like to understand how feasible it is to answer the following questions from any data:

- how people with care and support needs' assets are impacted as they move through the care system
- how funding arrangements play out in the real world, and the issues faced by those in different funding scenarios
- what the demographic characteristics of people with care and support needs are

Improved data on the income, assets and wealth of people using care services will help DHSC to better understand the impacts of government policy and inform work to shape the charging reform DHSC is interested in data which could be collected or analysed in advance of the implementation of the charging reforms, as well as future collection when the reforms are implemented. Existing survey data, administrative data and new surveys are all potential options to be considered.

2.2 The five workstreams

Workstream 3 is one of 5 workstreams forming part of this research. The 5 workstreams were conducted mostly iteratively between December 2021 and October 2023:

Workstream 1: CPEC at LSE carried out a rapid evidence review of past studies on income and assets of people with care needs. They looked at existing large scale national population datasets, as well as previous bespoke surveys of people receiving care and support and their carers which collected data on income and savings. This provided DHSC with an overview of previous and current data collection.

Workstream 2: Ipsos explored the views of stakeholders with an interest in or understanding of the adult social care (ASC) sector. Participants were asked about the different ways that data on the income, assets and wealth of people with care and support needs are currently recorded or collected and their

thoughts on further potential data collection activities (such as a survey). A first Expert Reference Group (ERG) meeting was then held to discuss findings from WS1 and WS2 and inform the next phase.

Workstream 3: It consisted of secondary data analysis (phase 1) and an options appraisal (phase 2). For the secondary analysis CPEC investigated the response rates to questions about the financial circumstances of respondents in two major national longitudinal surveys, ELSA and UKHLS. The objective was to identify how well these questions in ELSA and UKHLS capture the financial information they are designed to capture. In the options appraisals, Ipsos looked at the different data collection options available. Three groups of options were considered, and their benefits and drawbacks identified. Each option was appraised on a range of topics including: coverage of the target population, information that the option would provide and whether this would meet DHSC needs, impact on people with care needs, impact on carers and families, required involvement of organisations, technical and practical considerations and, data analysis and use. Findings from Workstreams 1 and 2 and from CPEC's secondary data analysis fed into the options' appraisal. This options' appraisal was conducted prior to the 2022 Autumn Statement announcement that the implementation of charging reform would be delayed.

Workstream 4 phase 1: It explored the views of people with care needs, unpaid carers, and people with Power of Attorney for the financial affairs of a family member with care needs, focusing on:

- their willingness to take part in a survey asking about their income and assets, or those of the family member they support;
- what level of detail they would be willing to provide when answering questions on care needs, assets and income for themselves, or for the family member they support;
- how easy or difficult it would be to provide the required information about care needs, current care plan, income and wealth;
- the role of family members in helping to provide the required information;
- possible concerns about how the data may be used; and
- how concerns could be reduced and alleviated and how people should be approached

Findings from these interviews informed the design of questions aiming to collect information on care needs, income and assets, which are included in this report. Once finalised these questions were cognitively tested during the second phase of WS4.

Workstream 4 phase 2: In this phase, Ipsos cognitively tested the survey questions drafted on the basis of the findings from WS4 phase 1. The cognitive interviews sought to understand:

- the extent to which unpaid carers and people with care needs understood the draft questions in the way they were intended;
- how easy or difficult it would be for carers and people with care needs to complete a survey using these questions; and

- the acceptability of the draft questions

A second ERG meeting was convened at the end of WS4 to discuss WS4 findings, the overall project findings and their implications.

Workstream 5: CPEC conducted further secondary analysis of ELSA data to explore how high level potential proxy measures of financial circumstances were related to more detailed financial evidence of the type needed for modelling the impact of charging reform.

Following the announcement of the delay to charging reform at the 2022 Autumn Statement and of the publication of a Social Care White Paper, which had taken place since the tender for the work was issued, DHSC clarified some of the parameters for the options appraisal for workstream 3. These were:

- there is greatest interest in a new survey to meet information needs in DHSC
- the focus should be on people entering care, including homecare and care homes, self-funders and local authority funded, working age and older adults
- different modes for any surveys should be considered
- proxy information can be considered:
 - proxy participants on behalf of people with care needs
 - simplified measures that people can provide information on rather than the ideal information required
- a longitudinal approach is not necessary. A cross section of those entering care would be adequate
- there is interest in data which could be provided in the short term as well as in longer term data collections

2.3 This report

Chapter 3 provides key findings from workstreams 1 and 2, describes some key points of discussion from the expert reference group meeting which was the first activity of workstream 3, outlines some key methodological lessons from previous surveys of people with care and support needs and some key findings from the secondary analysis of existing survey data. This chapter also outlines the approach to the options appraisal.

Chapter 4 summarises the conclusions of the options appraisal.

2.4 Acknowledgements

Ipsos would like to thank those who participated in the Expert Reference Group which helped shape and guide this feasibility study.

3 Approach and other evidence

3.1 Previous workstreams

Here we outline some of the key findings from previous workstreams which have informed the activities and options in workstream 3.

3.1.1 Literature and data review (workstream 1)

The review explored the methodology and data from four general population surveys, the English Longitudinal Survey of Aging (ELSA), the Family Resources Survey (FRS), the Health Survey England (HSE) and UK Household Longitudinal Survey (UKHLS). A summary of the findings is outlined below in Table 1.

Table 1: Methodology and data review findings

| | ELSA | FRS | HSE | UKHLS |
|-------------------------|---|------------------------------|--|--|
| Type | Longitudinal | Cross-sectional | Cross-sectional | Longitudinal |
| Sample size | 8,445 individuals (2016-17) | 19,000 households (2018-19) | 10,250 individuals (2018-19) | 49,685 individuals (2017-19) |
| Sample frame | Follow up from Health Survey England (HSE) - private households but follows into care homes | Private households | Private households except for care home sample in 2000 | Private households with some proxy information on people in care homes |
| Social Care information | 50+ social care module | All adults but limited | 65+ social care module | 65+ social care module |
| Income | Detailed | Detailed | Detailed | Detailed |
| Assets | Detailed | Only financial, not property | Only financial, not property | Detailed |
| Paying for care | Detailed | Not included | Detailed | Detailed |
| Additional features | End of life module (but not since 2012 when social care module was introduced) | Focus on financial resources | | Large immigrant and ethnic boost sample |

In addition, a review of recent research involving surveys about the incomes and assets of people receiving social care identified very few examples. Most research of this type took place many years ago. Since there is limited recent evidence and the methodology of older surveys can provide some useful insights (though bearing in mind the changed context), in this report (section 3.3) we have provided some detail for some older but still relevant research on the finances of this population.

3.1.2 Stakeholder interviews (workstream 2)

The key findings from the interviews with a range of stakeholders with experience of adult social care provision, administration and research are outlined below. None of the options explored with participants would enable DHSC to collect all the information it requires, and it is likely that a combination of options will be needed. Full findings are provided in a separate report.

New survey of people receiving care

- the advantage of a new survey is that it would potentially enable collection of data **regardless of funding status, reduce data sharing considerations and focus on the data needed by DHSC**
- however, conducting a survey collecting **sensitive personal data** such as the income, assets and care needs of people in receipt of paid care would also have a number of challenges which would affect the response rate, representativeness and quality of the data
- a survey would also raise some important **ethical considerations** regarding the collection of data about people who lack capacity to consent for taking part, the sensitivity of financial arrangements within families, and the role of family members in answering the survey
- **involvement of local authorities or care providers** in running the surveys could improve response and access to the survey but capacity and workload issues would be challenging for local authorities and care providers. A centrally administered survey would be less burdensome but would require data sharing with important information governance considerations

Existing general population surveys

- well-established surveys such as UKHLS, ELSA FRS provide **high quality financial data as well as information on care needs and receipt**
- however, they **do not cover all the populations of interest** (e.g. ELSA is only 50+) and have small samples of the population of interest (e.g. people with care needs, especially in residential care). Boost samples offer an option for overcoming these challenges, though large numbers in residential care, or of people of working age would be challenging to achieve

Administrative data

- **care providers** collect detailed information about the care needs of the people they support but hold minimal or no financial information on them. This includes local authority funded, self-funded and continuing health care
- **local authorities** hold robust and consistent financial data about people with care and support needs who qualify for funded care services but hold little or no information on self-funders and those receiving continuing health care
- **a number of issues need to be resolved regarding information governance** before data held by local authorities can be shared including local authorities' privacy notices, consent forms, identify the people the data relate to, clarity of the exact data required by DHSC, the level of granularity needed, and whether the data can be fully anonymised

- **central government** holds information which may be relevant such as HMRC tax records, DWP benefit records and land registry property records. However, linking this with information about receipt of care and overcoming the information governance requirements would be challenging

3.2 Expert reference group

Following the literature and data review (workstream 1) and the stakeholder interviews (workstream 2) an online meeting of the expert reference group was held. The group was attended by representatives from the Local Government Association (LGA) and Association of Directors of Adult Social Services (ADASS), care provider umbrella organisations, academics specialising in collecting or analysing data about finances, an expert in social care related ethics, central government (DHSC and NHS Digital) as well as the client team at DHSC and the research teams from Ipsos and CPEC. The research team presented the aims of the research, an overview of the approach and the findings from the review of data and literature (workstream 1) and the interviews with stakeholders (workstream 2).

This was followed by a discussion about views and considerations related to the approaches being considered. Here we present some key findings from this discussion as a context for the options appraisal which follows. A general overarching theme across the discussion was the need for clarity on the questions of:

- what information is needed,
- for what purpose, and
- when it is needed

Specifically there is a question of whether DHSC are happy to wait until people start to be assessed for 'metering' toward the cap or need data sooner. Those involved (local authorities, care providers, people with care and support needs) need to feel there is something in it for them and any data collection activities need to be properly resourced. The approach taken needs to be informed by these considerations.

3.2.1 New survey of people with care needs

Personal Social Science Research Unit (PSSR) carried out a number of surveys with people receiving care services (whether local authority or self-funded) to fill in gaps in the information that nationally representative general population surveys provide. The documentation of the methodological challenges around collecting information and participant knowledge of information would still be relevant, though these studies were carried out between 25 and 15 years ago (see section 3.3 for some key points from the documentation of those surveys). The methodological challenges raised based on past experience of the surveys and current knowledge of the sector included:

- for those in care homes, care home managers played a key role in making contact with people living in their homes and their family and there were challenges related to privacy. At present care homes are very busy and there are process issues which would need to be dealt with to take this approach
- collecting data related to COVID for government requirements has been very challenging for care providers – it is resource intensive and not effectively resourced. Even when a head office

engages with the research it relies on people at the setting level providing the information and they may not have capacity

- older people in receipt of care have very little knowledge of the financial arrangements being made on their behalf – an increase in dementia over 20 years means this is likely to have got worse compared with the surveys previously carried out
- it is difficult to obtain data from people in care homes and by the time they are in a care home they will already have used some of their assets, so this will not provide information about assets before entering care. There is a challenge in assessing assets and income as people move through the care system. A longitudinal approach would be needed but previous surveys showed this to be challenging – it is challenging for care providers to do this and reach the right person
- care providers know little about people's finances on admission. It was pointed out that it is not ethical to hold data for which there is no purpose
- the obligation to provide full and accurate data is less than during a statutory local authority financial assessment. People need to trust the organisation collecting the data and be clear why it is being collected. Organisations such as Age UK or TLAP (Think Local Act Personal) may generate this type of trust and confidence
- collecting the data with the same level of detail and accuracy as local authority financial assessments is unlikely to be possible because researchers lack the necessary understanding and interviewers are not trained financial assessors
- the frequency of data collected affects the burden of any survey on participants

It was suggested that including extra care and other forms of supported housing is important, given the White Paper emphasis on housing with care.

3.2.2 Use of existing survey data

It was pointed out that older people who need social care are a subset of the wider population and everyone is a potential social care user of the future. It should be possible to use data about the wider general population of older people and the proportion who go on to develop care needs to predict the income and assets of those with care needs. The existing datasets have value and may contain more information than would be available from a new survey and also have the advantage that they provide information on the assets held before entering care.

Among care providers, there is an interest in the customer of the future and cohorts of future care users in terms of their financial situation, what they are prepared to spend, their preferences for different types of care and related policy drivers (e.g. move away from accommodation-based settings).

Analysts at DHSC and academics have already done modelling about people who are future care users from general population data¹. The models are only as good as the data that goes into it so a better understanding of the relationship between income, wealth and care needs is needed.

¹ <https://assets.publishing.service.gov.uk/media/61d5d4bfd3bf7f1f6f74330f/adult-social-care-charging-reform-impact-assessment.pdf>

At the moment local authorities are reliant on existing general population surveys for information about self-funders as there is currently no way for local authorities to survey this group directly.

A question was raised about whether a search on literature in economic rather than health and social care journals might generate more examples of research about the income and assets of people with care and support needs.

3.2.3 Use of administrative data

Charging reform implementation is likely to mean that local authorities will have to collect information about spending on eligible care needs from self-funders wanting to meter towards the cap on care costs and a question was raised of whether these changes could be linked with this work. There was a recognition that information might be needed sooner to try and predict the future costs. The systems for metering and dealing with the larger volume are not in place and only those who are eligible for social care based on a needs assessment would have their data held by the local authority.

Local authority financial assessments provide a source of good quality data, though even local authorities find they don't always get to the absolute bottom of people's income and savings. They have to go back 2 or 3 times to get the information they need and those involved in collecting it are experts. It was noted that it would be even harder in a survey.

It would be best if a model financial system was used for collecting this information, rather than each local authority negotiating with the tech provider of their software. If this could also be automated rather than local authorities having to fill in special forms or stitch things together this would be better.

Triangulating data from central government (e.g. HMRC, DWP, Land registry) would involve putting the right frameworks in place and would involve approval – see section 2.2.4. But one also needs to map out these sources of information and what would be available to identify whether what would be gained is worth the effort.

3.2.4 Other approaches

ONS has done some research on self-funders which is relevant.²

3.2.5 General points relating to information governance

Any new data collections or changes to data (whether survey or administrative) need to involve consideration of information governance processes. Any changes need to be considered by the Data Alliance Partnership Board which is a cross governmental body including NHSD, DHSC, NHSX (as was), and NHSEI.³ This board oversees all health and care related collections that place a burden on data providers.

The more aggregated the data provided the better to minimise information governance issues. There are also specific issues related to those who lack capacity.

²

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/carehomesandestimatingtheselffundingpopulationengland/2019to2020>

³ <https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/data-alliance-partnership-board>

Linkage of data is problematic and with 150 local authorities this is even more challenging as it would effectively be a multisite study. Any data collection needs to be dealt with in the busy operation of services so the clear benefit would need to be set out so people can see the purpose for policy making. There are even more care providers and they would need support on how to manage a survey: assurance, information governance; with clear limits on what it is and what it is used for.

3.3 Previous surveys of people with care needs

The literature review provided top level information about some surveys previous carried out. Here we set out some key methodological features of challenges from a selection of relevant past surveys which provide insights into issues to be considered in designing any new surveys. It is worth noting that none of these have been repeated within the last decade and were carried out prior to the Mental Capacity Act 2005 and the introduction of GDPR in 2018. They also took place prior to austerity, cuts to local authority social care research teams and the growing pressures on social care providers. The challenges faced in running similar surveys now would be considerably greater.

3.3.1 Self-funded admissions to care homes 1999-2000

This was carried out for DWP, led by Ann Netten with the feasibility and main survey run by NatCen.⁴

The feasibility study included some analyses which suggested that gender, marital status, housing tenure, council tax band and age left full-time education would be valuable as a broad proxy for information on income and assets. They would not allow income and assets to be predicted with accuracy but would give a broad indication of the likely range.

500 care homes were approached for the mainstage and information was obtained about residents in 292 homes which reported an admission of one or more self-funded residents during the survey period. In this study ‘resident’ information was provided by the care home since the feasibility study findings recommended no data should be collected directly from the residents and so no residents took part in the research. It instead involved speaking to relatives or friends and care home managers. The main stage involved an opt out approach to contacting family and friends, but some care homes were reluctant to provide details without specific permission which resulted in fewer carer interviews than envisaged. 921 residents were in scope, 651 had a family or friend who could be potentially contacted, and details were obtained for 609 cases. Of these 331 relatives or friends provided a response. Family and friends were the most reliable source of information about finances, as often no one at the care home knew about finances.

Looking across the information provided by care homes and relatives or friends information on home ownership was available for 848 of the residents and average weekly income was available for 309 residents. Despite the fact that all would be expected to be eligible for a disability related benefit, only 67 percent were reported to be claiming attendance allowance.

The methodology for this study concluded that: “Necessarily the design has meant that the number of people for whom we have detailed and complete data is limited. While every attempt has been made to make the information as nationally representative as possible, the results must be treated with caution.”

⁴ Feasibility study, main report and summary are here: [self funded admissions](#)
[Self-Funded Admissions to Care Homes \(nationalarchives.gov.uk\) – main report \(online\)](#)

3.3.2 Survey of admissions to residential care (SARC) (1995-99)

This was carried out for the Department of Health: “to improve the Standard Spending Assessment (SSA) formulae for allocating funds to local authorities for the support of elderly people.” It was led by Robin Darton with fieldwork done by Research Services Limited (RSL), with one of the researchers involved now at Ipsos. This was longitudinal and involved baseline, 6 month, 18 months, 30 month and 42 month follow up.⁵ In the initial study data for 2,573 cases were obtained from case records and financial assessment data, of whom 1,720 were eligible for analysis, of whom 267 had no information their income, assets or costs of care.⁶ At the six month follow-up, information was obtained for 1,920 of the 2,544 individuals included in the admissions survey – others had moved, died or had no information.

Feedback from those involved (academic and agency) suggests that managing the data collection was quite demanding, the data processing involved a lot of work matching the data collected at each round to the file of existing data and creating a usable file for analysis, before starting again on the next follow-up.

This study relied on comparison with data from the General Household Survey and advocated the use of data about the population not in residential care to predict future demand for care based on characteristics which are associated with an increased probability of admission to residential care.

3.3.3 Survey to support the development of the relative needs formula for older people (2004-06)

This survey in 2004-6 for the Department of Health, led by Robin Darton and run by NOP was a repeat of the survey of admissions to residential care carried out between 1995 and 1999. In the end small sample sizes meant that reweighted data from 1995 and small area estimates were used, at least for the initial analysis because the fieldwork took longer than expected. The section in the report⁷ on methodological issues and recommendations for future studies comments that “individual-level data provide the most theoretically sound basis for the Relative Needs Formula. The results of the individual-level data collection were very disappointing, and it is important to draw lessons from this for the purposes of future work.” “While all fieldwork can run into problems at some stage, there appear to be a number of more fundamental problems that would be important to consider in the commissioning and conduct of future research, both to feed into the older persons RNF and more generally.”

Of 25 selected local authorities, 14 agreed to take part, and an additional 2 were later recruited. The study experienced unexpectedly high and last minute dropouts from local authorities. The research design had assumed the expected numbers would be recruited over 3 months but some local authorities could not start until at least 2 months after the intended time and in five local authorities recruitment took 21 weeks, rather than 12 weeks.

The collection of financial information for individuals was based on the financial assessment by the local authority but it was not possible to collect this for all individuals. In 11 of the 16 local authorities, information on the number of eligible cases admitted to care homes was provided and in the remaining 5 it had to be estimated.

It was not possible to carry out a pilot (because of a lack of flexibility in the timescales) and this meant the consent arrangements were not tested. Some local authorities required written consent and “The implementation of consent procedures within the data collection process proved difficult, and staff in one

⁵ 42 month follow up report is [here](#). Six month follow up is [here](#)

⁶ Baseline survey: <https://www.pssru.ac.uk/pub/dp1217~3.pdf>

⁷ https://www.pssru.ac.uk/pub/dp2265_3.pdf

authority claimed that the older people being assessed were too old and frail to give their consent, despite their providing other information.”

There was also a survey of home care recipients (13 of 16 local authorities took part in this element) which used an opt out approach. A response rate of 50% was assumed but there was a higher level of opt outs in some local authorities than expected and not all local authorities were able to provide a supplementary sample to make up for this. Where a local authority insisted that only an opt in could be done it was removed from the sample as it would have resulted in a biased sample.

Local authorities were asked to provide individual information from financial assessments, subject to the older person’s consent and 6 of 13 local authorities in the home care sample agreed to this.

Overall, from 2,613 care home admissions, 1,335 sample cases were issued to the fieldwork agency, 1,069 had consent for data to be used in the study and of these 826 responded. Information from the financial assessment was available for 694 of these cases. Response rates varied, being about 10% in four local authorities and 90% in one local authority. 771 cases were issued in the home care sample which was 55% of the selected sample and of these 384 responded. The overall response rate to the selected home care sample was just under 28%. 81 cases were proxy responses, but it was felt that it was not sufficiently clear in some local authorities that proxies were allowed if the service user could not participate and proxy rates could have been higher.

The report notes: “In addition, it was clear that local authorities had much less capacity to deal with this type of work than in the past. During the recruitment of local authorities, one authority requested financial support for its participation, but this was not possible, and the authority did not participate in the study. When resources are limited, participating in a research study tends to fall to the bottom of the priorities of those directly responsible for collecting the data, whatever the enthusiasm for the study at the top of an organisation.”

Resource pressures affected local authorities' ability to identify and report admissions. In addition, there is delay built into the process since the needs assessment takes place initially, later followed by a financial assessment.

The appendix of this research report includes the following recommendations for those considering similar projects in the future:

We would recommend that, prior to commissioning any work to feed into subsequent formulae or for other specific purposes, a scoping exercise should be undertaken to identify the likely resource requirements, including the demands on local authorities and their staff.

We would recommend that the data collections to be used for the purposes of developing Relative Needs Formulae are separated from the wider RNF review timetable, or at least are planned to be complete at least six months prior to the time when the data are needed for the relevant analyses. The Invitation to Tender recognised that the data collected would have wider policy-related uses, and initial reports focusing on these would be of value in their own right.

We would recommend that a very low response rate is assumed for similar future surveys, and that communications with potential interviewees ensure that it is clear that a proxy can be interviewed rather than the service user.

We would recommend that local authorities:

- are provided with guidance from the Department of Health on good practice, in terms of informed consent and data sharing;
- ideally, routinely ask service users if they are happy to have their data, suitably anonymised, used for research purposes, preferably at the time of their needs assessment; and
- are required to have governance policies that are made publicly available, so that researchers can identify if there are likely to be any problems prior to approaching them to participate in research studies

We would recommend that, as part of the general review of routine data collection, the Department considers whether data needed for small area analyses for RNF purposes could be collected on a routine basis.

3.3.4 Research in extra care settings (2005-2006)

Robin Darton has carried out research in extra care settings with colleagues. These are smaller scale studies with less detailed methodological outputs.

3.4 Findings from secondary analysis of ELSA and UKHLS data

Based on the literature review (workstream 1) it was decided to focus further exploration of existing datasets on ELSA and UKHLS since they provide the best combination of data on finances and care needs and receipt, have large enough samples of the most relevant groups and do at least follow people into care homes, even if the samples are small. The secondary analysis carried out as part of workstream 3 focused on item non-response and which groups are most likely to have missing data. The relevance of this is to understand the robustness of existing data and identify where issues of missing data are most likely to be found in any new surveys which might be set up.

The detailed findings of this analysis are provided in a separate report prepared by CPEC. The key conclusions of relevance to the options appraisal are:

- both surveys collected financial data through a large number of detailed questions
- overall the level of missing data on financial questions in these general population surveys is relatively low (and even lower if less detailed information such as responses provided at unfolding brackets questions is included). This means overall these surveys provide a very complete source of information on finances
- the missing levels of ELSA are lower than on UKHLS (perhaps because ELSA does not include online methods and analysis of UKHLS showed that online and telephone modes were associated with higher levels of item non-response in financial data compared with face-to-face surveys)
- there is some variation with missing data being lowest on questions about housing and highest on savings/ current accounts and income from work – this gives some clue to the types of questions which could be included in simpler proxy financial questions
- even where information is not missing, outlier values (particularly of £0 or other very low values) could be considered a type of missing value

- missingness increases with age, suggesting that among a population receiving care services who are likely to be older and more disabled, levels of missingness would be higher than in these general population surveys
- missingness was higher for proxy respondents on ELSA than among those responding for themselves
- if education level is taken as a proxy for wealth, there is no indication of higher levels of missing financial data among those who may have higher income or assets – if anything the reverse is true
- despite the potential of these surveys to provide detailed information on the financial circumstances of people for whom information on care needs and receipts is known, the number of cases is relatively small. Considering payments for care, UKHLS Wave 11 had only 230 self-funders aged 65+ and it was not possible to identify this group from ELSA

The implications are that:

- these existing surveys are a good source of complete data and efforts should be taken to maximise the use of these existing data
- boosting the samples on these surveys to increase the number with care needs – which is most feasible in the older populations - would enable better use to be made of questions which are already being asked about finances and social care need and use
- focussing any new surveys among the population receiving care on questions about housing, mortgage payments, benefits (with lower levels of missingness) rather than detailed questions on interest from savings etc may generate useful responses about financial status. It would be very challenging to collect financial data of the level of detail provided by ELSA and UKHLS in a new survey of people receiving care. Instead simpler questions focussed on key differentiators of income and wealth status should be collected
- in a survey of people receiving care (who may be older and/or more disabled) which does not include a face-to-face interview and where information will be collected from proxies, levels of missing data on finances would likely be higher than in these well-established surveys

3.5 Approach taken to options appraisal

The options considered were worked up and set out in detail for DHSC. A template containing the issues to be considered for all options was prepared and worked through for each of the options. This covered an overview of the approach; coverage of the key groups of interest; quality and detail of data; involvement and burden for people with care and support needs and carers and adult social care sector organisations; technical, ethical and information governance considerations; strengths and limitations; and further work needed to take the option forward.

The full options appraisal provided a great deal of detail which is summarised in Chapter 4

3.6 Options being considered

There are three overall options with several sub-options.

3.6.1 New survey of people with care needs

- A. Survey administered by local authorities
- B. Survey administered by care providers: home care
- C. Survey administered by care providers: care home
- D. Survey administered by care providers: housing provider
- E. Survey administered by third party with sample from care providers
- F. Survey administered by third party with sample from local authorities

3.6.2 Use of existing survey data

- G. Existing ELSA data
- H. Boost sample on ELSA
- I. Existing UKHLS data
- J. Boost sample on UKHLS (with sub-option to extend social care module to all adults, not just 65+)
- K. Using ELSA or UKHLS to test some simple proxy measures for use on other surveys
- L. Combining data from existing surveys in a minimum dataset

3.6.3 Use of administrative data (local or central)

- M. Use of financial and care assessment data held by local authorities (now and post charging reform implementation and assuming other changes are possible)
- N. Use of financial and care assessment data held by care providers
- O. Linking centrally held data (e.g. HMRC, land registry, DWP) with surveys or local authority financial and care assessment data

4 Overall evaluation of options and next steps

4.1 Summary of strengths and weaknesses of the three overall options

Our options appraisal shows that all approaches have strengths and weaknesses. Some of the options have large limitations or weaknesses or offer no advantages over other options which can meet the same data needs. This means they can be discarded at this stage without being taken forward for further consideration. In table 2 below S stands for strength and W for weakness.

Table 2: Strengths and weaknesses of options presented at the appraisal

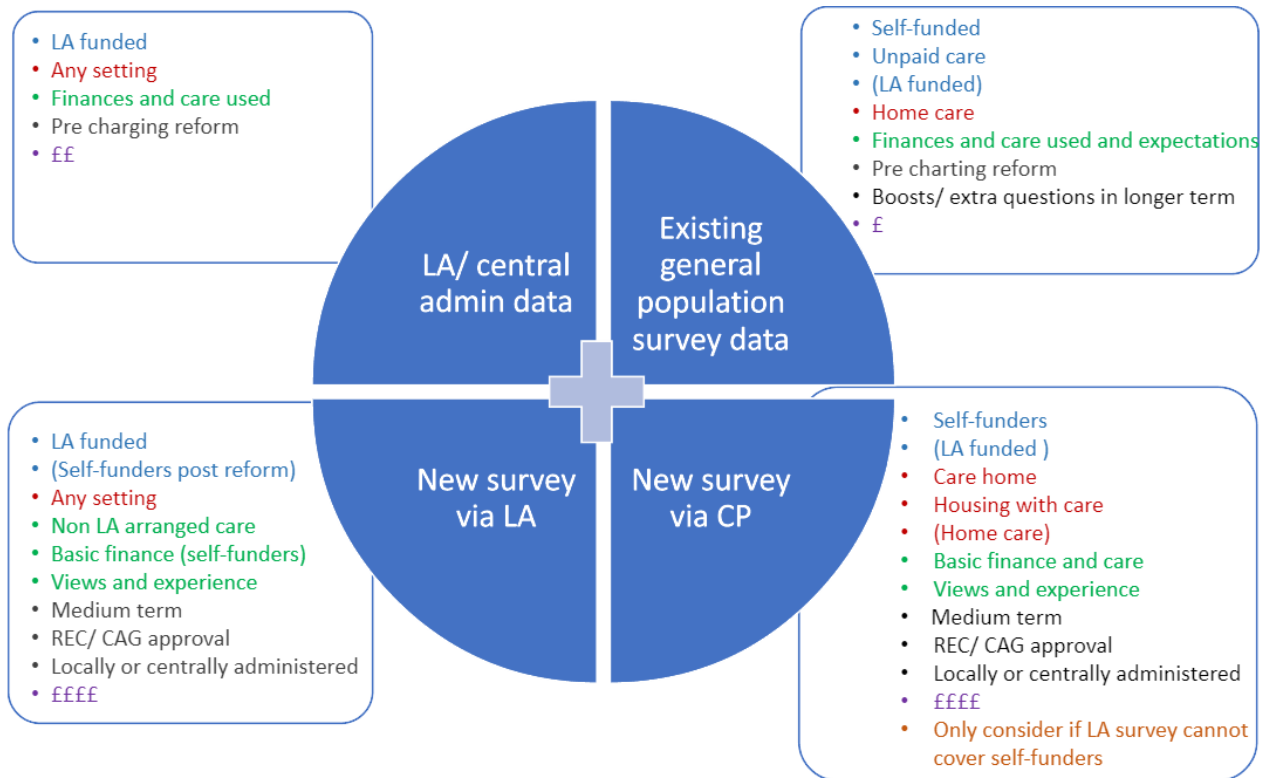
| 1. New survey of people with care needs | |
|---|---|
| A. Survey administered by local authorities | <p>S (Strength): In future could include self-funders</p> <p>S: Could supplement data local authorities hold to meet DHSC needs</p> <p>W (Weakness): Longer lead in time for data</p> <p>W: High cost and burden on local authorities</p> <p>W: Would collect some data already held by LAs about LA-funded people (unless combined with local authorities admin data)</p> <p>W: Challenges to include care users in research, especially those lacking capacity so would rely on carer participation</p> |
| <p>B. Survey administered by care providers: home care</p> <p>C. Survey administered by care providers: care home</p> <p>D. Survey administered by care providers: housing provider</p> | <p>S: Might include population not available via local authorities (housing provider)</p> <p>W: Data not available currently</p> <p>W: High cost and burden on CPs, participation has no benefit to CPs</p> <p>W: Local authorities would likely be a better approach after charging reform implementation</p> <p>W: Challenges to include care users in research, especially those lacking capacity so would rely on carer participation</p> |
| E. Survey administered by third party with sample from care providers | <p>S: Seeking approval from CAG (Confidentiality Advisory Group) might reduce some IG challenges</p> <p>W/S: Burden on CPs but less than CP administered (options B, C or D)</p> <p>W: Information governance challenges, lack of trust</p> |

| | |
|--|---|
| | <p>W: Longer lead in time for data</p> <p>W: Local authorities would likely be a better approach after charging reform implementation</p> <p>W: Challenges to include care users in research, especially those lacking capacity</p> <p>W: High cost</p> |
| F. Survey administered by third party with sample from local authorities | <p>S: May be easier to implement than option E due to DHSC existing relationship with local authorities.</p> <p>S: Seeking approval from CAG might reduce some IG challenges</p> <p>S: After charging reform implementation, could include self-funders</p> <p>S: Could supplement data local authorities hold to meet DHSC needs</p> <p>W/S: Burden on local authorities but less than responsibility for administering (option A)</p> <p>W: Longer lead in time for data</p> <p>W: Information governance challenges, lack of trust</p> <p>W: Challenges to include care users in research, especially those lacking capacity</p> <p>W: High cost</p> |
| 2. Use of existing survey data | |
| G. Existing ELSA data | <p>S: Available now</p> <p>S: Low cost</p> <p>S: High quality financial and care data</p> <p>S: Includes all funding types (but self-funders can be hard to identify as a distinct group)</p> <p>W: Small sample of care users, esp care homes</p> <p>W: Only 50+ age group</p> |
| H. Boost sample on ELSA | <p>S: High quality financial and care data</p> <p>S: Increase sample size of people with care needs</p> <p>W: Longer lead in time</p> <p>W: Will cost more than existing data</p> <p>W: Care homes and working age will still be lacking</p> |
| I. Existing UKHLS data | <p>S: Available now</p> <p>S: Low cost</p> <p>S: High quality financial and care data</p> <p>S: Includes all funding types</p> |

| | |
|--|---|
| | <p>W: Small sample of care users, esp care homes</p> <p>W: Only 65+ for detailed social care info</p> |
| J. Boost sample on UKHLS (with sub-option to extend social care module to all adults, not just 65+) | <p>S: High quality financial and care data</p> <p>S: Increase sample size of people with care needs</p> <p>W: Longer lead in time</p> <p>W: Will cost more than existing data</p> <p>W: Care homes and working age will still be lacking</p> |
| K. Using ELSA or UKHLS to test some simple proxy measures for use on other surveys | <p>S: Robust way to test simpler questions if they were to be included on a survey</p> <p>W: Could not be tested until after any new survey would need to start</p> <p>W: Add to length and complexity of long survey</p> |
| L. Combining data from existing surveys in a minimum dataset | <p>S: Available now</p> <p>S: Low cost</p> <p>W: compromises would be needed as questions are not consistent (further assessment of this needed)</p> |
| 3. Use of administrative data (local or central) | |
| M. Use of financial and care assessment data held by local authorities (now and post charging reform implementation and assuming other changes are possible) | <p>S: Local authorities hold the most accurate and detailed financial data of any source</p> <p>S: Already collected as part of operations (for local authority funded or potentially funded)</p> <p>S: Lower cost than a survey</p> <p>S: Minimises burden on those who have already provided this information</p> <p>W: Burden on local authorities</p> <p>W: Information governance challenges</p> <p>W: Does not cover self-funders and even after charging reform financial data on assets and income are unlikely to be available for this group.</p> |
| N. Use of financial and care assessment data held by care providers | <p>W: CPs do not hold such data</p> <p>W: Information governance would be challenging even if such data were held</p> |
| O. Linking centrally held data (e.g. HMRC, land registry, DWP) with surveys or local authority financial and care assessment data | <p>S: Could be incorporated as part of local authority financial checks and built into local authority admin data (Option M)</p> <p>W: IG aspects of data linkage is challenging</p> <p>W: Not clear how individuals with care needs would be identified if not done via local authorities</p> <p>W: obtaining permissions and implementing takes time</p> |

The diagram below (Figure 1) shows a summary of the four overall viable options, their coverage, potential content and key features.

Figure 1: Options for future data collection



4.2 Overall recommendations

4.2.1 For data collection to be delivered in the short term

After exploring the three broad options, the only option which is certain to generate findings at pace is analysis of existing general population survey data (Option 2: G, I and L). Although these data have limitations in terms of coverage and sample size, by combining waves or surveys and modelling future care needs these data are the best option for providing DHSC with information at pace. This could be supplemented by other work carried out by ONS to explore information about self-funders using CQC regulated providers and census information with future plans to gain insight into the individual characteristics of those who self-fund their care.⁸ This approach which relies on information provided by care providers, supplemented by information about the local population may be able to address some of the data needs of DHSC.

Administrative data is currently available in local authorities for local authority funded care users, however setting up the systems to share the data and dealing with information governance requirements would take time. It might be possible to access these data in the future and this could act as a pilot for future collection from local authorities once self-funders are being metered towards the cap in large numbers across local authorities (Option 3: M).

When considering any of the new survey options the time required for designing, piloting, securing partner buy in, meeting information governance and ethical requirements, conducting fieldwork and preparing data would mean that data would not be available in the short term. These represent a medium term option. Prior experience of research with this population shows that such research cannot be rushed (see section 3.3).

4.2.2 For longer term data collection

For data available in the long term all of the options are possible, though not all are likely to be effective and we would recommend this combination of approaches:

Option F: Survey conducted centrally using local authority provided sample

The focus of this survey would be on data not held by the local authority including:

- basic financial data on income and assets (only for those who have not had a local authority financial assessment, mainly self-funders),
- wider care and support which local authorities may not have on record (unregulated provision, unpaid support, top ups outside the scope of local authority needs eligibility),
- attitudes, plans, experience relating to paying for care,
- demographics not held by local authorities,

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/carehomesandestimatingtheselffundingpopulatioonengland/2019to2020>

- permission for linkage with local authority held data on care assessment and provision and financial assessment (the feasibility of this will need to be explored first and local authorities would need to be able to provide information in a consistent format)

We recommend that basic finance and care package information should only be collected in the survey when better information is not available from local authority admin data.

Individual contact details would be provided to a third party organisation to enable contact to be made with people with care and support needs who have been assessed by the local authority (needs assessment for local authority and self-funders). The approach would need to enable proxy respondents (family or friends) to respond on behalf of the person with care needs with their consent or through a consultee process if the person lacks capacity. The Confidentiality Advisory Group (CAG) and REC would need to advise on what is permissible. Ideally this would be done with CAG approval which means the data could be provided without opt in consent, though people interacting with the local authority would need to be told their data could be used in this way.

This survey could be conducted on point of entry into the care system or as a snapshot at the same point in time. Given the content, we recommend a snapshot survey as it is less burdensome and cheaper. Ideally this would include both initial information and information at reviews. Support from care providers would be needed for the survey to be effective and achieve the response rates needed, particularly in care homes, however we do not recommend that the sample is obtained from care providers, if it can be obtained from LAs for self-funders. Ideally a face-to-face approach would be used (to maximise response and minimise missing data at question item level), but since this is unlikely to be affordable a mixed mode approach with paper and online is most likely.

The survey could initially be carried out just with those eligible for local authority funded support (or who have had an assessment for this) before being extended to self-funders for data collection after charging reform implementation.

Option M (and O): Individual level administrative data held by local authorities, supported by local authority reference to central government sources (e.g. checking DWP records as part of assessments)

This would provide financial data for those eligible for or potentially eligible for local authority funded support, information about care received for all and spending on care for part funders and self-funders who have had a needs assessment with the local authority and are being metered towards the cap (after charging reform implementation).

This would be combined with survey responses where permission was given for linkage, or could be analysed separately where this permission is not given. Ideally analysis of admin data would be done with CAG approval which means the data could be provided without opt in consent, though people interacting with the local authority would need to be told their data could be used in this way through appropriate privacy policies at the point of collection.

Suppliers of the financial assessment tool would be asked to create a standard report which is consistent across providers to make extraction of the relevant data less burdensome for local authorities.

Given the challenges faced in linking central government data we recommend that, where possible, this central source is accessed via systems used by local authorities to check financial assessment evidence. At the moment local authorities can use DWP systems but this could potentially be extended.

Options G, H, I, J, L: General population surveys

Longer term there is potential for boost samples to increase the sample of people receiving care, extending the social care module to a wider age group and adapting the questions to overcome some of the limitations identified.

Table 3: Outlining how information can be collated across options

Options marked with an asterisk (*) are those which we judge would not be feasible because of limitations but are the only potential approach.

| Groups covered | Initial Income and Assets | Spending down of income and assets | Demographics | Use of care | Views and experience of paying for care |
|---------------------------|---|---|---|---|---|
| Self-funders | General population surveys | General population surveys (longitudinal and modelling) | General population surveys | General population surveys | General population surveys (ELSA) |
| Self-funders | Central survey using LA sample | LA admin (review) or modelling | LA admin data Central survey using LA sample | LA admin data Central survey using LA sample | Central survey using LA sample |
| Local authority funded | General population surveys LA admin (initial assessment) | General population surveys (longitudinal and modelling) LA admin (review) or modelling | General population surveys LA admin data | General population surveys LA admin data | General population surveys (ELSA) ELSA has expectations but sample small |
| Local authority funded | LA admin (initial assessment) | LA admin (review) or modelling | LA admin data Central survey using LA sample | LA admin data Central survey using LA sample | Central survey using LA sample |
| Unpaid care received only | General population surveys | General population surveys (longitudinal and modelling) | General population surveys | General population surveys | General population surveys (ELSA) |
| Unpaid care received only | General population surveys | General population surveys (longitudinal and modelling) | General population surveys | General population surveys | General population surveys (ELSA) |

| Groups covered | Initial Income and Assets | Spending down of income and assets | Demographics | Use of care | Views and experience of paying for care |
|-----------------------|--|---|---|---|---|
| Older people | General population surveys | General population surveys (longitudinal and modelling) | General population surveys | General population surveys | General population surveys (ELSA) |
| Older people | LA admin (initial assessment if LA funded) Central survey using LA sample General population surveys | LA admin (review) or modelling Central survey using LA sample General population surveys (longitudinal and modelling) | LA admin data Central survey using LA sample General population surveys | LA admin data Central survey using LA sample General population surveys | Central survey using LA sample General population surveys (ELSA) |
| Working age people | *General population surveys (ELSA 50+ only and other small sample) | *General population surveys (longitudinal and modelling) (ELSA 50+ and other small sample) | *General population surveys (ELSA 50+ and other small sample) | *General population surveys (ELSA 50+ and other small sample) | *General population surveys (ELSA 50+ only) |
| Working age people | LA admin (initial assessment if LA funded) Central survey using LA sample | LA admin (review) or modelling Central survey using LA sample | LA admin data Central survey using LA sample | LA admin data Central survey using LA sample | Central survey using LA sample |

| Groups covered | Initial Income and Assets | Spending down of income and assets | Demographics | Use of care | Views and experience of paying for care |
|-----------------------|--|---|---|---|---|
| Residential care | *Modelling of general population surveys | *Modelling of general population surveys | *Modelling of general population surveys | *Modelling of general population surveys | *Modelling of general population surveys |
| Residential care | LA admin (initial assessment if LA funded) Central survey using LA sample | LA admin (review) or modelling | LA admin data Central survey using LA sample | LA admin data Central survey using LA sample | Central survey using LA sample |
| Home care | General population surveys | General population surveys (longitudinal and modelling) | General population surveys | General population surveys | General population surveys (ELSA) |
| Home care | LA admin (initial assessment if LA funded) Central survey using LA sample General population surveys | LA admin (review) or modelling General population surveys (longitudinal and modelling) | LA admin data Central survey using LA sample General population surveys | LA admin data Central survey using LA sample General population surveys | Central survey using LA sample General population surveys (ELSA) |
| Housing with Care | General population surveys | General population surveys (longitudinal and modelling) | General population surveys | General population surveys | General population surveys (ELSA) |

| | | | | | |
|--------------------------|--|--|--|--|--|
| <p>Housing with Care</p> | <p>LA admin (initial assessment) (if in contact with LA and LA funded)</p> <p>Central survey using LA sample (if in contact with LA)</p> <p>General population surveys</p> | <p>LA admin (review) or modelling (if in contact with LA)</p> <p>General population surveys (longitudinal and modelling)</p> | <p>LA admin data (if in contact with LA)</p> <p>Central survey using LA sample (if in contact with LA)</p> <p>General population surveys</p> | <p>LA admin data (if in contact with LA)</p> <p>Central survey using LA sample (if in contact with LA)</p> <p>General population surveys</p> | <p>Central survey using LA sample (if in contact with LA)</p> <p>General population surveys (ELSA)</p> |
|--------------------------|--|--|--|--|--|

4.3 Next steps

Next steps for workstream 4 are shown below.

1. Discussions about the specific options being considered with a range of key stakeholders (internal and external).
2. Workshop with DHSC to discuss the options and trade-offs and next steps for taking forward the viable options.
3. Development of survey content for local authority sample survey focussing on questions which generate data which cannot be provided by local authorities. This could be followed by some small scale cognitive testing to understand how they work and the acceptability of these questions and motivations for taking part. If this was carried out HRA REC approval would be needed:
 - basic proxy measures of financial assets and income
 - other forms of care and support which are not provided via local authorities or are not eligible for local authority support (needs based)
 - attitudes, experience and plans for paying for care
 - demographics not available from local authority admin data

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For more information

3 Thomas More Square
London
E1W 1YW

t: +44 (0)20 3059 5000

www.ipsos.com/en-uk
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