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

Workstream 4 (phase 1) report: Findings from in-depth interviews with people with care needs and unpaid carers

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Margaret Blake, Claire Lambert, Freddie Gregory, Laura Tuhou, Laura Dale

Contents

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 outlines the key findings from 20 in-depth interviews with people with care needs, unpaid carers and people with Power of Attorney for a family member, exploring their views on taking part in a survey asking about the care needs, assets and income of people with care needs. These interviews constitute Phase 1 of Workstream 4 of a larger project commissioned by the Department for Health and Social Care (DHSC) exploring the feasibility of collecting data on the care needs and finances of people with care needs to inform government policy.

1.1 Care needs

Participants showed greater willingness to provide information about their care needs (or those of the family member they cared for) than about their income and assets.

Collecting information about care and support needs as part of a survey was considered acceptable. The interviews uncovered concerns which would need to be addressed before a survey about care and support needs and financial information is implemented, namely the possible intrusiveness of questions on care needs; how the data collected would be used and who would have access to them; and the effort (and, in some cases, distress) of having to repeat their story multiple times.

There were few, if any, concerns from participants about their ability to provide information about their current care and support needs.

1.2 Financial information

When first asked how they would feel about providing information about their income and assets participants were apprehensive, with particular concerns around being scammed or defrauded. Participants were also concerned about the security of the information they would be asked to provide.

After discussing the type of financial information that would be collected in the survey in more detail, participants were more open to providing some types of information than others. Information that participants were more willing to provide included whether they owned their home, its value; and the type of benefits they may receive. However, information about income, pensions, and particularly savings and other assets was seen as more sensitive, and participants were noticeably less comfortable about the idea of sharing detailed information on these in a survey.

Concerns were also raised about how DHSC would use the information collected, considering both the implications of the research for policy as well as how their individual information might be used to make decisions about them.

There are some measures that could be put in place to alleviate these concerns, including:

- a trusted source requesting information;
- a website or helpline to verify the authenticity of the survey; and
- a greater focus on experiences of, and views of, paying for care

Leaving aside their reluctance to provide information on their income, pension and savings, participants felt they would have the ability to gather and submit the financial information required – although it may be difficult to find some of the information.

1.3 Survey purpose

Although participants were willing to respond to high-level questions about care and support needs, and to some questions about finances, it was important that the purpose of the data collection was made clear and appeared worthwhile. Indeed, participants' willingness to take part in the survey was affected by the information provided about the purpose of the survey. It was considered acceptable for the government to ask for information on care needs, assets and income if it was used to 'inform government policy', but participants were not clear on the benefits of providing detailed information on these matters, especially when it was clarified that they or the person they cared for would not receive more or better care as a result of taking part. A feeling that taking part would make a difference and benefit others in the future was a motivating factor for some, but not all participants, and this would need to be clearly explained with a strong positive message and vision. Concerns that the findings from the survey could be used to reduce the eligibility criteria for free and partly-funded care (through policy or making assessments about them individually) would also need to be addressed.

1.4 Survey mode and methodology

There was a clear preference for the survey to be administered via a paper self-completion approach, for reasons related to accessibility, and having time to read the information provided about the survey to decide about participation and think about responses. Supplementing the paper mode with an online mode would be beneficial, especially for younger and more tech-savvy participants. However, participants were split as to whether a telephone interview would be an appropriate way to administer the survey, with some concerns about the practicality of this mode for answering questions that may require time to find the required information.

Participants with care needs thought that asking a close family member to complete the survey on behalf of someone unable to provide the information themselves was acceptable, providing that the person responding to the survey (who would act as a consultee) knew the person with care needs very well. Similarly, carers and people with Power of Attorney could see the rational for inviting people with these responsibilities to complete the survey on behalf of people with care needs who were unable to do it for themselves. This was considered acceptable, as long as consultees took into account the wishes and feelings of the person with care needs when deciding about their participation and answering questions.

1.5 Implications for cognitive interviews

When designing questions for the cognitive testing phase, the following points should be considered:

- collect the minimum amount of information that DHSC require
- do not ask questions about intimate care needs as these are considered intrusive and unnecessary for the stated purpose. Questions about care needs history should be asked in a way that does not require people to look for information or health records to be able to answer them
- ensure all questions have a 'prefer not to say' code
- use financial ranges, for example when asking about property values and benefits
- consider using existing sources of information and proxy measures to minimise the amount of financial data requested. For example, collect postcodes rather than home value, and append average property value in the area for those who own their home

- rather than asking people about the value of their pension, consider asking whether they are in receipt of state pension and/or a private pension
- Carefully consider the ordering of the questions, starting with topics which participants are most comfortable answering and then ask about more sensitive areas to minimise the number of participants dropping out from the survey early on
- To encourage participation in the survey, explanations should be provided about:
    - what information will be requested so people know what to expect
    - all questions being optional, to encourage at least partial completion and submission
    - the process to anonymise/depersonalise the data collected, and what data will be shared with DHSC
    - the purpose of the survey, and why people should take part, including why DHSC does not have access to the information people may have already provided to other organisations

1.6 Implications for the survey

The findings clearly show the risks associated with the survey, in relation to the potential for the survey to cause distress to the target audience, have a very low response rate, and receive incomplete questionnaires. The risk of distress will need to be carefully considered with mitigating actions in place ahead of the pilot and REC approval, which could include a survey helpline and a webpage with contact details within DHSC and the survey contractor which people can call or email to enquire about the survey.

To reduce the risks of a low response rate and partial responses, a well-designed cover letter about the survey will be required that addresses the concerns expressed during the interviews. It is important that this is tested in full, jointly with the survey webpage, to ensure key messages are understood as intended and that all concerns raised by participants are properly addressed.

While proxy responses from a family member were considered acceptable to collect data about people who lack mental capacity, the ethical implications of this approach will also need to be considered, ahead of the REC approval process for the survey.

2 Introduction

This report presents findings from workstream 4 (WS4) phase 1 of a project exploring the feasibility of collecting data about the income and assets of people with care and support needs. Following this, at phase 2, 20 cognitive interviews with people with care needs, unpaid carers and people with Power of Attorney for a family member were conducted. These interviews aimed to test questions asking about the care needs, assets and income of people with care needs, explore the acceptability of these questions, and participants' willingness and ability to answer them. The results of Phase 2 of workstream 4 have been presented in a separate report.

This section starts with an outline of the aims and objectives of the project as a whole, describes the progress made so far, and then focuses on the objectives and methodology of WS4 which involved in-depth interviews with people with care needs and carers.

2.1 Background and objectives of the Paying for Care Survey project

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 these data can be complex and sensitive with important ethical implications. The overall project therefore looks to explore the different options for potential data collection and their benefits and drawbacks. This will help DHSC to have a better understanding of the different future options available to them and what these options may look like.

Continuing to develop the existing evidence base on the funding issues, income, and assets (e.g. property and/or savings) of people with care and support needs is essential to understand the needs of care users and how well they are supported by the systems and policies in place. However, there are challenges involved in collecting robust data on individuals' funding status, incomes and assets, particularly from a population that includes vulnerable people. DHSC has therefore commissioned Ipsos and the Care Policy and Evaluation Centre (CPEC) at LSE to conduct a study to explore the feasibility and acceptability of conducting a survey to collect data on the characteristics of people with care needs, including financial data.

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 work to shape charging reform in the ASC sector. 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 work streams

The project was divided into five work streams which were mostly conducted iteratively between December 2021 and October 2023. Earlier workstreams, which have been reported separately, involved conducting interviews with care providers, local authorities and other key informants to assess the feasibility of collecting data on the income and assets of people with care and support needs:

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 incomes 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, the English Longitudinal Study of Ageing (ELSA) and UK Household Longitudinal Study (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 workstream's report. Once finalised these questions were tested using cognitive interviews 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 the workstreams 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.

2.3 REC approval

On 7 November 2022 Ipsos submitted an application for approval of this study with the Health Research Authority's (HRA) Research Ethics Committee (REC). As part of this process, the REC reviewed draft research materials for this phase of the study (in-depth interviews) and the following phase (cognitive testing). The materials reviewed were participant information sheets; consent forms; topic guides; support information; the project privacy notice; quotas and screening questions for recruitment. In addition, DHSC provided a letter of support as the research commissioner. The REC provided confirmation of its favourable ethical opinion for the research on 25 January 2023.

2.4 Methodology

A total of 20 in-depth interviews were conducted for this first phase of WS4. Each interview lasted up to one hour and took place via Microsoft Teams or by telephone in February and March 2023. Interviews were carried out with people with care needs, unpaid carers, and people who have Power of Attorney for the financial affairs of a family member with care needs. Most interviews with people with care needs were conducted by telephone rather than MS Teams. The unpaid carers and people who have Power of Attorney who were interviewed in relation to their own role as an unpaid carer or someone with Power of Attorney were not related to the participants with care needs. Four people with care needs took part with the support of a family member or friend who was present during the interview, and in one case the interview had to take place with the carer instead of the person with care needs who was too unwell to take part on the day.

The tables below outlines the number of interviews completed across the two groups, and demographic information about the participants.

Table 2.1: In-depth interviews

Interview type	Number of interviews
People with care needs	9
Unpaid carers and people who have Power of Attorney for the financial affairs of a family member with care needs	11
Total	20

Table 2.2: Demographic information: people with care needs (x9)

Age	Social grade	Sex	Paid support
4x aged 18 to 64 3x aged 65 to 79 2x aged 80+	3x AB 3x C1C2 3x DE	5x females 4x males	3x people who receive local authority funded care

Table 2.3: Demographic information: unpaid carers/people with Power of Attorney (x11)

Age	Social grade	Sex	Power of Attorney
6 people aged 36 to 64 5 people aged 65+	3x AB 5x C1C2 3x DE	5x females 6x males	3x people exercising power of attorney for the financial affairs of a family member who lacks mental capacity 3x people who have (but are not yet exercising) power of attorney for the financial affairs of a family member who lacks mental capacity

2.5 Notes about the interpretation of findings

In-depth interviews offer a well-rounded and nuanced view of complex issues and considerations. Unlike quantitative surveys, this approach is not designed to provide statistically reliable data which is representative of the target population, but rather it is designed to be illustrative and exploratory, with findings presented thematically rather than quantified throughout this report.

Verbatim comments from the interviews have been included in this report. These should not be interpreted as defining the views of all participants but have been selected to provide insight into a particular issue or topic expressed at a particular point in time.

2.6 Acknowledgements

Ipsos would like to thank those who participated in the research and shared their views with us.

3 Care need

This section discusses participants' views about the acceptability of collecting information about care and support needs in a survey, and their willingness and ability to provide such information. It also looks at the concerns participants raised, and at mitigating actions which could be taken to address these concerns.

Key findings

Both groups (people with care and support needs, and unpaid carers/people with Power of Attorney) tended to be willing to share at least some information about care needs if the purpose was made clear. Sharing information about care needs felt safe, and participants were used to be asked for this sort of information.

Although questions about care needs in general were considered acceptable, questions about detailed aspects of care and support needs that were considered private were not. For example, questions about intimate care or personal hygiene were considered particularly intrusive and unnecessary for the purpose of the survey.

Other concerns about a survey asking about people's care and support needs included who would have access to identifiable data, the safe storage of the data collected, and why the information which had already been provided elsewhere needed to be collected in a survey.

3.1 Acceptability of collecting information on care and support needs

Participants considered that collecting information about care and support needs as part of a survey was acceptable.

Participants commented that they were asked to share information about their care needs (or those of the person they care for) in many circumstances – for example, when accessing support from their local authority social care services; to access benefits; or to attend an event accompanied by a carer. This generated a perception that asking someone about their care needs was acceptable when there was a clearly explained purpose.

3.2 Willingness to provide the required information

Participants were willing to respond to high level questions about care and support needs, if the purpose of the data collection was made clear and appeared worthwhile, and providing concerns were addressed.

Collecting information on care and support needs *to inform government policy* was a message some participants responded well to, explaining that if their participation in a survey could make a difference and benefit others in the future, this would be a motivating factor to take part. A (related) motivating factor was that the data collected would help government develop appropriate policies on social care:

> **"I would hope that information that was provided by a multitude of people from across the country in regard to this care aspect. I would hope that they would inform the government, and [the government] would take policies forward in relation to that; to realise that there is a general issue of care.''**
>
> **Person with care needs**

However, other participants wanted to know more precisely what change could be expected as a result of this survey to help them decide whether or not to answer questions on care needs. Others found the purpose of 'informing government policy' unclear, and assumed that providing information about their care needs or those of the person they cared for would benefit them personally, for instance by bringing improvements to the care and support they or their family member were already receiving (or not).

> **"If I could give any information that will help with the care of my mum, then I'd be all ears, do you know what I mean? If it makes life easier as a carer, it's got to be done, because like I say, it's blooming hard work."**
>
> **Unpaid carer**

> **"As long it's confidential, and it's providing information to help in getting information to provide the services we need, I'd think that's okay."**
>
> **Unpaid carer**

Once the rational for the data collection was clarified, there was a decrease in these participants' enthusiasm for the survey and in their willingness to take part. It was considered acceptable for the government to ask for information on care needs, if it was used to 'inform government policy', but participants were not clear on the benefits of providing detailed information on these matters, especially when it was clarified that they or the person they cared for would not receive more or better care as a result of taking part.

Turning to people's ability to provide the information required, participants identified no major barriers to their ability to provide information about their care and support needs (or those of the person they care for). However, participants observed that the process of collating the necessary information would likely require time and effort. There was a practical concern about the level of detail, and how many months or years of data might be requested if the survey asked about care history; there is likely to be a limit to how much detail people can remember about past care and support needs.

3.3 Concerns and worries about providing information about care needs

While on the whole there was willingness to provide information about one's care and support needs as part of a survey conducted on behalf of DHSC, a number of concerns were raised regarding: the possible intrusiveness of the questions, how the data would be used, having to repeat their story multiple times.

The level of details that people would be asked to provide was a concern for people with substantial care needs or those caring for them: they did not want to be asked about aspects of their conditions or support needs which they thought were private. This was particularly the case in relation to questions about intimate care or personal hygiene. Participants were generally not willing to provide information about these types of care needs. These questions were considered intrusive and unnecessary for the purpose stated: if someone needed help preparing, cutting food or eating it could be assumed they would also need help with personal hygiene. There was also a risk of becoming upset when answering such questions: recounting and reflecting on care needs can be emotionally difficult for people who struggle to accept the extent of their needs in the first place, or who do not feel comfortable having to ask someone else for help repeatedly. This has clear implications regarding the level of details and the number of questions on care needs that could be included in the survey, and the response options to provide.

Next, concerns were raised about how the data would be used – beyond the stated purpose of informing government policy – such as whether survey responses would be compared with other information participants had already provided elsewhere about their care needs (e.g. to the local authority), generating worries about accuracy and consistency, whether the government would have access to identifiable personal data, who would have access to the data collected more generally, and reassurance that the data collected would be stored safely. This was mentioned alongside a low level of trust in the government's ability to hold personal data securely in general, which appeared more prevalent in the younger age groups.

> **"[Before providing information about my dad's care needs, I would want to know] how private it was and who it was going to be disseminated to."**
>
> **Unpaid carer**

Queries were also raised as to why the government needed to collect this information in a survey, when other organisations already held the information, with people expressing their frustration at having to repeat their story multiple times.

> **"I've probably had to repeat [the process of explaining my care needs] probably 50 times with different doctors and hospitals over the years. I know that the data is not commonly held across all these different care areas. So, I'm used to that, [but it causes] a general little frustration of, 'Oh, why have I got to do this again?' but I want the best outcome, so you do it. I'd like it [if information were shared across organisations, to minimise repetition] as long as it's held securely and it's held by the right people."**
>
> **Person with care needs**

4 Financial information

This section describes participants' views on providing information on their income and assets in a survey conducted to inform government policy in ASC. This includes people with care needs who would complete the survey themselves and people who would complete the survey on behalf of a family member they care for or for whom they have Power of Attorney. It also explores participants' views on acceptability and their willingness to provide detailed information about specific assets (e.g., their home) and income or pension, as well as their main concerns and what measures would help alleviate these concerns.

Key findings

There was apprehension at the idea of providing information about income and asset as part of a survey aiming to inform government policy. These was driven by a view that these topics are private, by widespread concerns about fraud and scams and by concern over the security and usage of the data that would be provided.

After discussing the type of financial information that would be collected in the survey in more detail, participants were more open to providing some types of information compared to others: home ownership and receipt of benefits were the information people were most willing to provide. There was more reluctance to provide detailed information on income and pensions. Most concern was expressed about sharing information on the value of savings and other assets.

Willingness to take part in the survey and to provide detailed financial information was closely related to people's understanding of the purpose of the survey, how they would benefit personally and what changes could be expected as a result of the survey. Those with lower levels of savings and assets were more willing to provide information.

No major concerns were raised regarding people's ability to provide the information requested, but participants would need to look at files or papers, and/or seek help from close family members to find the required information.

4.1 Initial views on providing financial information

When first asked how they would feel about providing information about their income and assets participants were apprehensive.

Initially, participants were asked how they would feel about being invited to complete a survey in which they were asked in detail about their assets and income or the assets and income of the person they care for. Considerable reluctance and discomfort were expressed about this idea. Participants suggested this was a sensitive topic and it was important to keep this type of information private and treat it with cautious.

> **“This is a sensitive area…I would need to know more about it”.**
>
> **Person with care needs**

For people who cared for someone and held power of attorney, this feeling of caution and discomfort was particularly strong.

> **“I would be very uncomfortable. It feels intrusive, because it is personal details – I wouldn't feel comfortable. Maybe it’s a generational thing? I don't like giving details about my personal situation, anyway, let alone my mum’s.”**
>
> **Unpaid carer**

Participants were concerned about how the person they cared for would feel about their financial information being shared in a survey. They suggested they would need to check they were happy for this information to be shared, and in cases where the person they cared for did not have the mental capacity, they would want to check with other family members to ensure it was appropriate.

Where participants were more open to providing financial information in a survey, they tended to be younger people with care needs who had not yet acquired many financial assets.

4.2 Concerns and worries about providing financial information

Participants were concerned about being scammed or defrauded.

Participants in the in-depth interviews were asked what their main concerns would be about providing financial information in a survey. Worries about knowing whether the survey was from a genuine source, or whether it was a scam were expressed. Older participants and those who cared for someone were particularly worried about this, with a few having experience of being contacted by telephone by someone they did not know which they believed was a scam. Older participants were also worried they would find it difficult to judge the legitimacy of the survey without the assistance of family or friends.

> **“If you're working on the government's behalf, I think it's all got to be done officially and in the right manner because even today, I received a phone call on my mobile and it was a voice, not a real person but it was just saying that it was from the HMRC and I hadn't paid so much and it was clearly a scam.”**
>
> **Unpaid carer**

This would suggest that any future survey should not be carried out via telephone or face-to-face, as this may be seen as suspicious by participants. A helpline which participants can contact to help them complete the survey would be helpful and would capture responses from people who may be digitally excluded (the mode and administration of the survey is covered in more detail in section 5).

Although it was not explicitly mentioned, the findings suggest that any future survey should also consider the risk of retrospective distress, as someone may complete the survey and then worry about whether they have done the right thing, particularly if they ask for advice from family or friends after taking part. This will be an important consideration when seeking REC approval for the survey.

Participants were also concerned about the security of the information they would be asked to provide. They were concerned that it could be accessed by hackers or leaked in some way, and that their information could be accessed by criminals who would then target them.

> **"Anything on computers can be accessed by someone, I would need to know it's really secure and limited."**
>
> **Person with care needs**

This would indicate that any communications about the survey should emphasise that the information will be held securely, and the data would be anonymised so that no individual response could be identified.

4.3 Willingness and acceptability of providing the financial information required

After discussing the type of financial information that would be collected in the survey in more detail, participants were more open to providing some types of information compared to others.

After exploring participants' top of mind views and concerns on providing financial information in a survey, more detail on the types of information the survey would collect were provided. This included:

- the value of their income or pension
- any benefits they received including the type and value
- whether they own their own home and how much it is worth
- the total value of their savings if they have any
- the value of other assets they may have such as property or shares

Information which participants appeared most willing to provide were whether they owned their home, and its value – this is because property value was seen as information that could easily be obtained by looking at general property values and was to some extent already publicly available.

> **"I think I would be okay to say the value of my home, you can look that up it's already out there if people want to find it."**
>
> **Person with care needs**

Similarly, participants felt comfortable providing information about the type of benefits they may receive. The rationale was that the government already held information about their benefits anyway, and some thought they had previously submitted this information as part of support assessments. However, this was seen as slightly repetitive and placing a burden on the participant to provide information the government may already have access to. This view was underpinned by the belief that local and central government would have access to, and share information about individuals.

Although participants were more comfortable providing information about the value of their home, whether they owned it and the benefits they receive, there was reluctance at the idea of providing exact figures: this was seen as too intrusive. Providing a numeric range was considered more appropriate and less intrusive. There was a lot of uncertainty regarding people's ability to provide the exact value of their property, primarily because many participants did not know how much their home was worth.

> **"No, I don't think an exact value is good, because I would not know exactly but I could look on Right Move or what the house over the road went for…it would be good to select a range, as there are differences in people's properties."**
>
> **Unpaid carer**

This suggests that questions about property value or benefits should have answer codes with financial ranges that people can choose from.

Since people do not generally know the value of their property but would usually need to look it up, an alternative approach would be to ask for proxy information such as postcode so that it could be matched with the average property value in the area (using Office for National Statistics data).

Information on income, pensions, savings and other assets was seen as more sensitive and participants were less comfortable providing this information in a survey. Participants suggested they would be more comfortable answering proxy questions that could be used to provide an estimate. For example, this would include whether they are in receipt of a state pension and whether they have a private pension. A few participants said they would be comfortable providing a range for the level of savings or investments they have, but this was uncommon. As mentioned previously, participants were more cautious around this type of information as they considered it private, and were worried about scams and the security of the information. They also had concerns about how the information would be used by DHSC (this is covered in further detail later in this section).

As there will be questions that people do not want to answer, it will be important that all questions on personal finances include a 'prefer not to say' answer code to reduce the risk dropping out and not returning the survey at all despite being willing to provide some of the information required. To mitigate against questions receiving a high proportion of prefer not to say answers, the questions in the survey should be ordered in such a way to encourage responses early on to questions perceived as less intrusive, followed by more sensitive questions. This should be considered when ordering questions for cognitive testing. For example, questions about house values and benefits could be asked before questions on savings and other assets.

4.4 Purpose of the survey

Participants' willingness to take part in the survey was affected by the information provided about the purpose of the survey. It was considered acceptable for the government to ask for financial information if it was used to inform government policy, but participants were not clear on the benefits of providing financial information.

Participants in the in-depth interviews were asked whether they felt it was acceptable for DHSC to collect information on assets and income if the findings were used to inform the development of government policy. Generally, participants saw this as a worthwhile aim and could see how this information would be useful. However, they questioned whether the government already had access to some of this information (as mentioned earlier) and whether the survey would be relevant to them. It was not clear to participants what the benefit of completing the survey would be to them personally or what they would get out of it. At first, some participants actually misunderstood the purpose of the survey and thought that it would lead to better care for themselves or for other family members (see section 3).

A small number of participants had completed financial assessments in order to access social care services. In contrast to providing information for a survey, when information was provided for an assessment, they clearly knew what they could expect to happen as a result of providing detailed financial information. Those who had had a financial assessment from their local authority were happy for the information they had already provided to be used for research purposes.

Concerns were also raised regarding how DHSC would use the information collected. At an individual level, in a context of austerity, some participants were concerned that their survey responses could be used against them in some way in the future, e.g. to reduce social care services and support for them and the people they cared for, or that it could be checked against information they had provided elsewhere (e.g. to the local authority), with any discrepancies having to be accounted for.

> **“The thing is, what will they do with the information. How do I know we won’t lose support because we’ve given them information.”**
>
> **Unpaid carer**

At a national level, there were concerns about the wider policy decisions and implications, for example that the findings from the survey could be used to increase taxes, reduce eligibility for free care and support services or make policy decisions that are detrimental to people with care needs. This concern was directly related to a wider concern about the (un)fairness of the care system.

> **“Why should my dad have to pay for care and support that other would receive for free just because he has worked hard and saved for his old age, when other people haven’t. I wouldn’t want this information used against me.”**
>
> **Unpaid carer**

This suggests that the introduction to the questions should clearly state how participants will benefit from providing this information, making it clear that it will not result in decisions about care plans or funding at an individual level and that local authorities would not have access to the survey findings for individuals. The information should also make it clear how the data will and won’t be used by DHSC, how it will help DHSC in their work and what impacts this could eventually have on those with care and support needs and their carers. This introduction should be tested during the cognitive interviews to ensure that people understand it, that it allays concerns and encourages people to take part.

4.5 Measures to mitigate concerns and encourage participation in a survey

There were some measures that could be put in place to alleviate participant concerns.

When asked what measures could be put in place to mitigate their concerns and worries about providing financial information in a survey conducted on behalf of DHSC, participants suggested:

- a trusted source requesting information: Participants felt it would be important for the survey to conducted by an organisation they had heard of before and which they would know how to get in touch with. This could be a well-known charity or research organisation

- a website or helpline to verify the authenticity of the survey: Participants would like to be able to check online or via telephone if the survey was genuine. They would like this information to be clear on any research materials they are sent such as an invitation letter or information sheet

- a greater focus on experiences of, and views of, paying for care: As outlined in this section, participants were generally apprehensive about providing income and asset information in a survey. They suggested that instead of asking for detailed information, the survey could focus more on experiences of paying for care and views of paying for care in the future, for example, how affordable it would be to pay for based on different care scenarios

Leaving aside their reluctance to provide information on their income, pension and savings, participants felt they would have the ability to gather and submit the financial information required although it may be difficult to find some of the information.

Older participants with care needs said they may need to check with their family for more detailed information such as the value of their pensions, and similarly, those who cared for someone and held power of attorney felt they would need to check with other family members. It will therefore be important for participants to be able to complete part of the survey and then return to it at a later date once they have gathered the required information. It also means that a self-completion rather than interviewer administered approach would be more suitable. This is discussed in more detail in section 5.

5 Survey mode and methodology

During the interviews, participants were asked how they would most like to be approached to take part in a survey about their care needs, assets, and income, and who should be invited to complete the survey in the situation where a person with care needs is unable to take part. This section outlines and assesses options for the administration of the survey.

Key findings

There was strong support for a self-completion approach for the survey, as it would give people time to decide if they want to take part, ensure the survey is genuine, consider the questions, find the relevant information and decide about their responses. It would also allow people to discuss these points with a family member.

A dual approach with paper and online both offered appears to be most appropriate, allowing engagement from those who are digitally excluded and providing ease and convenience to those who prefer online.

Regardless of the mode, there should be a telephone helpline for those invited to complete the survey to answer any queries respondents might have and provide reassurance.

Asking a third-party to complete the survey on behalf of people lacking capacity was considered acceptable, but only in certain circumstances.

5.1 Survey mode(s)

Participants were asked for their preference regarding the survey mode, with paper, online and telephone options being considered. They were also asked who they would feel comfortable being contacted by for this survey.

5.1.1 Paper questionnaire

There was a strong preference for paper self-completion among people with care and support needs, for reasons related to accessibility, having time to think about their participation and their responses to the questions.

The general feeling was that a paper survey would be preferable for those who are digitally excluded or do not feel comfortable with digital technology. Indeed, a number of participants mentioned that they do not use the internet and would therefore be unable to complete the survey online.

Participants also mentioned that a self-completion approach would enable survey participants to fully consider the information provided before deciding to take part, and where appropriate to discuss their participation with someone else and/or seek reassurance that the survey was genuine, without feeling pressured to make a prompt decision regarding their participation. Having a paper copy of the questionnaire and being able to see the actual questions was thought to be particularly useful to that effect.

> **"I think it would give you a chance to, rather than over the phone, it would give you chance to read it and think about it a bit longer before you answer the questions."**
>
> **Unpaid carer**

In addition, as the survey would aim to collect data on assets, savings and income, it was felt that some questions might require people to look for the required information in their papers or files, or to seek input from someone else to answer some of the questions. A self-completion questionnaire would give people the time to find the required information (leading to more accurate responses), as well as the time and flexibility to decide whether or not they want to answer individual questions. Having the questions on paper would help people know which information they need to look up, even if they later submit their survey responses online.

5.1.2 Option to complete online

An online mode was considered useful, for reasons related to ease and convenience. The online mode appealed primarily to younger participants, unpaid carers and people who had Power of Attorney, and/or those who were more confident using digital technology.

> **"I think it's just because everything's more digital these days and everything's online and I find it easier. I'd say I'm quite competent online, so yes, I just find it easier and quicker."**
>
> **Unpaid carer**

An online only approach was ruled out, for reasons related to digital literacy.

> **"I'd think you can't just do it one way; it'd have to be done in the old-fashioned way, say a hard copy for people who aren't necessarily computer literate, but personally, it would be easier for me to do complete a survey online."**
>
> **Person with care needs**

Given the target audience for the survey, and taking into account concerns raised by participants about some of the topics, dual approach with **a paper questionnaire sent out initially together with details for completing online** seems more appropriate than a push-to-web approach (which only sends a paper questionnaire at a reminder mailing). The advantage of sending a paper questionnaire out initially alongside the option to complete online is that it would allow everyone to consider the questions before having to answer them.

Moreover, many participants mentioned they would likely complete the survey jointly with someone else (usually their carer or the person they were supporting) – something which a mixed online and paper mode would allow. This was the case among all groups of participants, whether they had care needs or were caring for a family member.

> **"I know the first thing she would say [if she got this survey in the post would be], 'Will you do it for me?' [But] I involve her in anything that I think is going to keep her brain working."**
>
> **Unpaid carer**

Participants should be encouraged to submit the information online where possible but the paper questionnaire would ensure that those for whom paper is the only option or is preferable would still be able to complete the survey.

The other advantage of an online option, compared with paper, is that it allows ‘textfills’: in an online survey the question wording can be different according to whether the person completing it is the person with care needs or their carer (a question can be asked about this at the start of the survey and the response is then used to ensure the remaining questions are addressed to the carer or to the person with care needs). In a paper survey the wording has to be standardised to cover both carers and people with care needs, which can make the questions wordy.

In addition to a self-completion mode, a telephone helpline was considered important, to allow respondents to clarify or check anything they were unsure about, ask questions about the survey when deciding to take part, as well as to provide reassurance about the survey more generally:

> **“Online or on telephone, I think it'd be easier, and then on the phone if there was a question I didn't quite understand, I feel like I could ask the person what it means.”**
>
> **Person with care needs**

5.1.3 Telephone interviews

Participants were split as to whether a telephone interview would be an appropriate way to administer the survey.

Those in favour of a telephone completion mode explained that they were better able to express their feelings in a conversation, and would also feel more comfortable speaking to someone about the information required.

> **“On a piece of paper, you don't always know. You don't always get what they're trying to get at, whereas over the phone, you can, sort of, make those extra questions to find out in detail what the person wants.”**
>
> **Person with care needs**

In contrast, other participants suggested that an unannounced phone call might make them feel uncomfortable and uncertain about providing sensitive information over the phone to a stranger. They were very wary of scams and being asked to provide information on income and assets over the phone would make them suspicious.

> **“I wouldn't want to do it over the phone to anybody, no. They've already tried, they've all tried to scam me twice, it's not very nice.”**
>
> **Unpaid carer**

A number of participants mentioned that they would not have the required financial information readily available and would need to find this either from others or look at their papers, meaning unplanned telephone interviews would not be the best way to capture accurate financial data.

5.1.4 Disseminating the survey

Reflecting their concerns about scams, participants emphasised the importance of the survey being sent out by a reputable and trusted source. Mentions included government departments, local authorities, care providers, charities and well-established research organisations. Knowing where the survey invitation was coming from, and being able to check that the survey was indeed coming from the named organisation, were important for reassuring participants that the survey was genuine. Regardless of the mode of administration, and because of the concerns expressed by participants, sending a letter about the survey through the post will be important as a letter is likely to come across as more legitimate than an e-mail.

5.2 Acceptability of collecting information from a family member – views of people with care needs

Participants with care needs thought that asking a close family member to complete the survey on behalf of someone unable to provide the information themselves was acceptable, providing that the person responding to the survey (who would act as a consultee) knew the person with care needs very well.

Participants with care needs actually mentioned that if they received a survey about their care needs and finances, they would discuss it or complete it with a close family member supporting them. Things they would check included whether the survey was genuine, whether taking part was worthwhile, the accuracy of some of their responses, and asking them for some of the information required. Involving a close family member was something many participants did regularly for various things in their daily life, and they thought it brought them peace of mind and reassurance, though in some cases they missed the ability to do things independently.

People with care needs thought it was important that anyone completing the survey on behalf of someone lacking mental capacity knows the person well, and their wishes and feelings regarding sharing personal information. In practice, this means that the survey should seek to involve personal as opposed to nominated consultees in case where the person with care needs lacks mental capacity.

> **"I would have 100% faith in my wife [completing the survey] on my behalf."**
>
> **Person with care needs**

5.3 Acceptability of collecting information from a family member – views of carers and people with Power of Attorney

Carers and people with Power of Attorney were supportive of the idea of people in their situation being invited to complete the survey on behalf of people with care needs who were unable to do it for themselves. Those with Power of Attorney were most likely to think this was acceptable.

> **‘‘Because me and my dad have got lasting power of attorney, she's given us that permission as it were, so I think they'd be no issues.’’**
>
> **Unpaid carer**

However, several points were raised about how this should be approached. First, it was felt that the survey should still be addressed to the person with care needs, giving them the chance to complete it themselves, with decisions about who is the person best placed to complete it taken on a case-by-case basis depending on the circumstances and the mental capacity of the person with care needs.

> **"It all depends on the condition, what they're suffering with. I mean if it's someone with Alzheimer's who couldn't remember much or anything, then I think it would have to be the person with Power of Attorney deciding whether it's appropriate or not."**
>
> **Unpaid carer**

Second, when prompted they thought the wishes of the person with care needs should be taken into account – and being asked about this led some carers to refine their response about taking part on behalf of a family member. The consensus was that family members should not answer questions about the care needs, assets and income of the person who lacks mental capacity if they know they would not like this. This is something that should be made clear in the communication to family members.

> **"It depends on the circumstances, doesn't it? My mum wouldn't mind [me sharing information about her]…"**
>
> **Unpaid carer**

> **''Yes [it is appropriate for someone else to complete the survey on behalf of someone else] … It all depends on families, how close they are.''**
>
> **Unpaid carer**

Regardless of this, carers and people with Power of Attorney said they would involve the person they supported in their decision to take part in the survey or not, and in choosing response options, as much as possible. The exception was where this could confuse or worry them unnecessarily, or if they the person supported always lacked mental capacity.

> **"I think it would have to be discussed with my mum. I mean, the fact that she's got mild dementia, but you'd have to discuss it. I'd discuss it anyway, even though I have power of attorney."**
>
> **Unpaid carer**

6 Conclusions and next steps

This section focuses on the implications of the findings for the cognitive testing phase, and for the set-up of the survey.

6.1 Implications for cognitive interviews

To encourage completion of the questionnaire, it will be important to:

- explain that all questions being optional, to encourage at least partial completion and submission. This means that all questions should ideally include a ‘prefer not to say’ answer code
- carefully consider the ordering of the questions, starting with topics which participants are most comfortable answering and then ask about more sensitive areas to minimise participants dropping out earlier on in the survey

Considering questions on care and support needs specifically, the survey should:

- collect the minimum amount of information about care and support needs that DHSC require
- not include questions about intimate care needs as these questions are considered intrusive and are not considered to be justified in light of the purpose of the survey
- frame questions in a way that makes them easy to respond to without respondents having to look for information or health records

When asking about finances, income and assets, we recommend the following:

- use financial ranges when asking about property values and benefits
- for questions on property value, collect post code and append average property value for that area, or ask about home ownership as an indication of financial assets
- proxy measures could be considered to collect information on income, pension and savings e.g., whether participants are in receipt of a state pension and/or a private pension. This is because participants were more concerned about providing information on these, which they regarded as more sensitive information
- consider inclusion of questions on the affordability of care services in particular scenarios as an indication of participants’ financial assets

The questions tested during cognitive interviews should be designed for a self-completion approach. For cognitive testing they would be on paper. Preferred mode (paper or online) and how people would respond to a dual mailing (with paper questionnaire and online link) should be explored in the interviews.

Finally, the sample for the cognitive interviews should involves a small number of people caring for a family member who lacks mental capacity to explore issues related to third-party responses and the viability of this option. These interviews would not aim to collect any information about the person lacking capacity but focus on the practicalities of proxy responses.

6.2 Wider implications for the survey

The findings from these 20 in-depth interviews clearly show the risks associated with this survey. These include:

- generating worries among the target audience, including retrospectively once people have completed and returned their questionnaire. These concerns constitute an ethical issue that requires robust mitigating measures to be implemented ahead of REC approval being sought for the survey. Concerns are likely to include:
    - scam and fraud and whether the survey is genuine,
    - data storage/leak and the ability of the survey provide and the client to handle the data securely,
    - access to and use of the identifiable personal data provided (which organisations),
    - use of the data to make decisions about their individual care (based on information provided on their care needs or finances),
    - how the information could be used for policy making and whether any resulting changes in policy could be detrimental for people with care and support needs and their carers
- a low response rate, if the information provided about the survey is not considered sufficiently reassuring or the purpose not clear or convincing
- partial survey responses, if questions are considered unnecessarily intrusive for the stated purpose. This has implications for the ordering of the questions (intrusive questions early on could put off people from taking part), for the answer codes provided (they should include a ‘prefer not to say’ option), and for the way the survey is communicated (explaining that partial survey responses would still be valuable)

In light of these risks, it is recommended that the information which would be provided about the survey, e.g. the cover letter and Q&A which would be sent alongside the questionnaire, are thoroughly tested, with the aims to explore people’s understanding and reactions to the information provided, whether the purpose of the survey is clear and sufficiently convincing, and if the content addresses all the concerns that the target audience may have. Phase 2 of WS4 will involve testing messages about the survey, but more thorough testing will be required once the survey materials are fully designed.

The survey invitation letter and Q&A documents about the survey should cover the following points:

- the purpose of the survey, how the data will be used and by whom, what impacts this survey may have on people with care and support needs and their carers in the future and whether people will benefit from taking part
- information on confidentiality and anonymity, and the process to anonymise/depersonalise the data collected, reassuring participants that their answers will not be linked back to them nor combined with other information they may have provided to another organisation
- information about what data will be shared with DHSC, and who will have access to identifiable data more generally

- explanation about data-sharing, to help people to understand why the survey is necessary and that DHSC does not have access to this data already

Concerns over the authenticity of the survey, and the potential for scams and fraud, need to be examined carefully. Mitigating actions could include:

- providing a survey helpline with a freephone number and an e-mail address
- providing contact details of a named person withing DHSC and within the organisation appointed to conduct the survey
- setting up a website explaining what the survey is about and what it will involve. To avoid this website being used by fraudsters to legitimise scams the website would need to specify key details such as the fieldwork period, content and look of the questionnaire, method of data collection, freepost address etc. This web site should also be tested with the target audience

Participants with care needs often mentioned that they would seek support from a family member to complete the survey. Some carers also explained that the family member they support would most likely ask them for help or ask them to complete the survey on their behalf, or would not be able to do anything if they received the survey because they lacked mental capacity. In terms of GDPR, if the legal purpose for the survey is to collect data in the public interest, then it is possible to collect proxy information without the consent of the individual. A DPIA would be required, which would need to balance the rights and interests of the people who lack capacity with the benefits of the research. There is however another ethical implication: the Mental Capacity Act (MCA) requires research involving adults lacking capacity in England to be approved by a REC under the MCA. The interviews showed that participants found it acceptable to ask a family member to complete the survey on behalf of a person with care needs who lacks capacity, if certain conditions are met, and this will help make the case for proxy responses when applying to the REC. Seeking REC approval under the MCA has implications for how the survey is presented to family members of people with care needs who lack mental capacity. They would act as ‘personal consultees’ under the Mental Capacity Act and the REC will typically expect ‘a consultee declaration form’ to be provided alongside the questionnaire. How this would work in practice will need to be considered ahead of the pilot and the REC application.

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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
http://twitter.com/IpsosUK

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