

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

Workstream 2 report: In-depth interviews
with adult social care stakeholders

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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 2 which involved in-depth interviews with 21 care providers, local authorities and other key informants, to explore different ways that data on the characteristics, income and assets of people with care and support needs are currently recorded and collected. The interviews also explored participants' views on additional data collection activities. Please note that these interviews were conducted prior to the 2022 Autumn Statement announcement that the implementation of the charging reforms would be delayed.

The results of these interviews build upon the findings of the rapid evidence review at workstream 1, by exploring in more depth the strengths and limitations and practical considerations of existing large-scale surveys. The findings from these interviews are summarised below.

1.1 Existing data held by care providers

Care providers collect detailed information about the care needs of the people they support but hold minimal financial information on them. No financial data are collected about people whose support is fully funded by their local authority, or who are in receipt of continuing health care funding. For self-funders, financial assessments of those in receipt of home care are uncommon. For people entering care homes, financial assessments are informal and detailed data on income and assets are not usually recorded – instead care providers just check the family's ability to pay care home fees for the next few years.

There is very limited scope for the data care providers hold to be shared because it is not held in a suitable format or there would be concerns about data sharing.

1.2 Existing data held by local authorities

In contrast, local authorities hold robust financial data about people with care and support needs who qualify for funded care services. These data are collected from care users or their families through a thorough financial assessment used to decide about eligibility for local authority-funded care. The type of financial information collected is consistent across local authorities as it is guided by a national framework. Data are regularly updated and digitally recorded. Local authorities collect little or no information on self-funders and those receiving continuing health care, although this will change for self-funders who choose to meter their spend against the cap when the charging reforms are introduced.

Before data held by local authorities can be shared a number of issues need to be resolved regarding data protection, the impact on local authorities' privacy notices, consent from the people the data relate to, the exact data required by DHSC, the level of granularity needed, and whether the data can be fully anonymised. These would need to be considered and approved by the Health Research Authority (HRA) ethics committee and Confidentiality Advisory Group.

Additional practical considerations were raised regarding local authority capacity to prepare a data return and the frequency at which it would be required, the purpose of the data collection, how this would be aligned with changes put in place for the charging reforms, and the need for a rigorous ethical review.

1.3 Conducting a survey with people receiving care

An alternative option could involve collecting data on income and assets through a survey. This was thought to have some advantages: it would enable DHSC to collect data about all people in receipt of paid care regardless of funding status, reduce the burden on local authorities, and reduce data sharing considerations. 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. The challenges mentioned related to trust and respondents' willingness to provide detailed information on their income and assets, privacy, how the survey is communicated to people, the accuracy of the data collected, participant burden (especially if similar information has recently been provided to a local authority or care provider), the administration and cost of the survey. Asking a small number of high-level questions could mitigate some of these challenges. 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, some of whom might not know the full details on the income and assets of the person in receipt of paid care.

Looking at ways a survey could be administered, a survey run locally by care providers and local authorities would help with the dissemination and ownership of the survey which would improve response rates. However, capacity and workload issues would make it challenging for care providers and local authorities to conduct a survey on behalf of DHSC. A centrally administered survey would minimise the burden on care providers and local authorities but it would require them to share the contact details of the people they support with DHSC's appointed contractor and important data sharing issues would need to be resolved beforehand.

1.4 Using existing general population surveys

Another option for collecting data on the income, assets and care needs of people in receipt of paid care could involve using existing, well-established surveys such as the English Longitudinal Study of Ageing (ELSA), the Family Resources Survey (FRS), Understanding Society (UK Longitudinal Household Survey: UKHLS), or the Adult Social Care Survey (ASCS). The samples for these surveys do not cover all the groups needed or have large enough sample sizes for other groups of interest, so compromise would need to be made in terms of coverage or the sampling approach would need to involve sample boosts. None of the existing surveys looked at include all the information needed but the quality of financial data, where collected, is felt to be good. Still, as with administrative data and standalone surveys, data quality relies on the information participants are able and willing to provide. Despite this, it was thought that some of the limitations of the samples and information provided could be overcome analytically using analysis experience and existing modelling.

Participants suggested additional options to collect data on income and assets, such as making better use of information, which is already known, for example information held by the land registry, HMRC and DWP, to reduce burden and avoid duplication of effort. This would come with information governance challenges regarding data sharing and linking. It was also pointed out that developments taking place in relation to social care financial reforms may offer future opportunities to collect the information needed. Examples included using a national system for local authorities and care providers to collect standardised information from people accessing care services (whether local authority or self-funded) or extending the activities of the trailblazers that had been chosen to pilot the charging reforms in some local authorities when the fieldwork took place.

Overall, it is likely that a combination of options will be needed if data are needed by in the short to medium term and if in the longer term the data gathered is to be as robust as possible while minimising the burden on people with care and support needs, carers, local authorities and care providers.

2 Introduction

2.1 Background and objectives

This report presents findings from workstream 2 of this project about the feasibility of collecting data about income and assets. 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). Workstream 2 looks to explore the views of stakeholders in the adult social care (ASC) sector. They 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 data collection activities.

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 future implementation of the charging reforms. DHSC is interested in data which could be collected or analysed in advance 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 Other workstreams

Workstream 2 is one of several workstreams forming part of this research. The 5 workstreams were conducted mostly iteratively between December 2021 and October 2023:

Workstream 1: CPEC at LSE have 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 will provide 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 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, 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 the charging reforms 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. 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 the charging reforms.

2.3 Methodology

A qualitative approach was undertaken to ensure an in-depth and well-rounded view of the key issues and considerations of the data currently held on the income and assets of people with care and support needs and the feasibility of future data collection or linkage activities.

Overall, 21 in-depth interviews were conducted. Each interview lasted up to one hour and took place via Microsoft Teams or by telephone between January and February 2022. Interviews were carried out with a variety of participants to understand current data collection practices and what would be feasible in the future. This included those working in care providers, local authorities and key informants (other key organisations involved in ASC and data collection).

The sample for care providers was developed using the publicly available list of registered care providers on the CQC website. Only providers working in ASC were included in the sample, this included care home providers, homecare providers, extra care housing, supported living services and other types of providers. Quotas were set by number of settings (one, two or more), regions within England, and types of service provided.

Local authorities were purposively selected and recruited through DHSC, Ipsos and CPEC networks with the support of the Association of Directors of Adult Social Care Services (ADASS). DHSC were blind to the final selection. Similarly, key informants were also purposively recruited through existing networks to ensure a range of experience and knowledge across ASC were reflected, this included:

- academics
- strategy consultants
- ethics and data governance leads
- ASC policy leads
- ASC finance leads
- analytics and data leads

Table 1 outlines the number of interviews completed across the three key groups.



Table 1: In-depth interviews

Interview type	Number of interviews
Care providers	4
Local authorities	4
Key informants	13
Total	21

2.4 Notes about the interpretation of findings

This report presents the data from interviews with care providers, local authorities and key informants. As mentioned, in-depth interviews were conducted with participants as they 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 on what participants as a whole are thinking, 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. All quotes used throughout this report are taken from the qualitative interviews unless otherwise stated. Where there is a risk that a comment might identify an individual the inclusion of their quote has been checked with them.

Acknowledgements

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

3 Using existing data held by care providers and local authorities

This chapter explores what existing administrative data on income and assets is held by care providers and local authorities; whether and how this data could be shared with DHSC or organisations working their behalf; and the practical considerations for this option. It is important to note that these interviews were conducted prior to the 2022 Autumn Statement announcement that the implementation of the charging reforms would be delayed.

Key findings

Care providers hold limited financial information about the people who pay for their services, and they do not collect financial information about people receiving local authority funding or NHS Continuing Healthcare (CHC).

Local authorities hold robust data about people with care and support needs who qualify for funded care services, and they use software to collect and record information. However, they currently collect little or no information on self-funders and those receiving CHC, although this will change when the charging reforms are introduced and local authorities start to collect information of self-funders who choose to meter towards the cap.

As care providers do not generally hold any financial data which they would be willing or able to share, there is very limited scope for them to take part in data sharing.

Participants felt that local authorities would be best placed to share data and information and if DHSC wanted to make use of existing data, the most consistent and robust data on income and assets for those eligible for support would be held by local authorities.

How data is anonymised and aggregated, and how appropriate consent is obtained, would be key considerations for any future data sharing. This would include any data sharing to be reviewed and approved by the HRA ethics committee and Confidentiality Advisory Group.

Other practical considerations highlighted by participants included the capacity of local authorities to collate and prepare any data which could be shared; the need for clear messaging and buy in from local authorities; and how this data sharing can be aligned with changes to local authority systems and processes ahead of the charging reforms being introduced.

3.1 Data and information held by care providers

Care providers hold minimal financial information on the people they support.

Participants were asked what information is collected about people when they first contact and start using care services. Most of the information collected is related to the health and wellbeing of the person with care and support needs. For example, care providers will receive their medical history, or an assessment carried out by the local authority social services in cases where the person is local authority funded. Other care providers will also carry out their own health and wellbeing assessment to ensure the

care they provide meets the needs of the person; this may also include more holistic information. For example, one care provider who offered dementia care services collected information from friends and family on the person's life story.

“We ask the family for a life story so we can understand the person's care needs and make sure the home is appropriate place for them.”

Care provider

However, data on income or assets of the person they are providing care services to was not collected by care providers in a detailed or consistent way. Financial assessments were informal and varied in detail between care providers. Often, if financial information was requested by the care provider, it was for self-funders entering residential care, and was required to check and confirm if the person or their family could pay for care services over the next few years. Care staff would then make a note that they had made this check rather than recording or keeping any detailed financial information.

“We ask the family to show us their funds. We don't keep anything on file, it's just so we've witnessed that they have enough to sustain them being here. This could be bank statements, property ownership, savings. For data protection and everything like that, we don't want anything on file.”

Care provider

These checks are also often conducted with family members, or with their assistance, rather than directly with the person with care and support needs. The format of any data also varied, with some providers still carrying out initial assessments by paper. A record of the overall financial situation may be kept by providers as a reminder to check in whether the person needs to move over to local authority support at a future date when their capital has been depleted but this would not be detailed information, more an estimation of how long their financial resources might last. For people purchasing home care services there was usually no financial information collected by providers.

It was suggested by participants that care providers do not collect this information or have inconsistent approaches to data collection as there is no statutory duty to conduct financial assessments. As such, they do not have the processes, policies or trained staff to carry out financial assessments or credit checks.

“Care home managers are amazing people at managing care, providing care. They are not always financially savvy and financially diligent. So, it's a very different skill set to ask accounting information...care home managers don't have the time, capacity, knowledge or the capability [to collect financial information].”

Key informant, umbrella organisation

Care providers interviewed did not collect financial information about people receiving local authority funding or NHS Continuing Healthcare.

Participants said care providers did not collect financial information about people they support if they were receiving local authority funding or NHS Continuing Healthcare (CHC) payments as there was need to do so. For people who were funded by CHC, there was no need to do an assessment as the care would be fully funded based on decisions by the local CCG. Similarly, financial data was not generally collected if the person with care and support needs was being funded by the local authority. This is

because the person's finances would already have been assessed by the local authority and had no bearing on their ability to sustain their care.

“The majority of the people come to us already assessed and ready to go, so most of our clients just make a contribution to their care and support that's sorted out by the Local Authority and their financial assessment.”

Care provider

Care providers did state that some financial information would be discussed with people with care and support needs, for example to help them manage their benefits or to budget their money over time. However, this tended to be more support and advice rather than a process which would collect data.

“When you first meet somebody, to make a judgement on whether they can decide something as large as where they would like to live and agree to pay all that money, it was more a part of that assessment of the decision making rather than the finances itself.”

Care provider

Care providers working with people with a learning disability would help explain financial information and support them to access financial services e.g., visiting a bank, looking through bank statements or to count money. A record may be kept of their cash at home (to ensure that it could all be accounted for when care workers come and go) or their latest benefit statement (keeping a record on their behalf) but this is not held in a way which could be shared.

3.2 Data and information held by local authorities

Local authorities hold robust data about people with care and support needs who qualify for funded care services.

Participants were also asked about the information that local authorities collect as part of assessing people for care and support. Both those working in local authorities and those working in other sectors felt that local authorities hold the most detailed and consistent financial data on those who qualify for state funding, as financial information is collected in order to make an assessment of eligibility for funded care services. The collection of these data is guided by a national framework and so there is consistency between local authorities.

As part of their assessments, participants suggested local authorities ask for information on savings, investments, property, bank statements, benefits and pensions. Participants said that local authorities had dedicated systems, processes and specialist staff to collect this information in order to carry out their assessments.

“We collect as much information as we can, this includes savings, pensions investments, and property owned. We can then assess their entitlement.”

Local authority

The financial information local authorities require to carry out their assessments is collected from a variety of sources. Participants said this could include family members, friends, carers, solicitors or legal representatives with responsibility for managing a person's estate. They may or may not have power of attorney. Documentary evidence would be sought for the information provided. The person asked to provide information typically depends on the type of care services required. For example, one participant

suggested that they usually speak with family or friends for nursing care services, whereas they would speak to the person requiring support for residential care services.

“For nursing provision we’re talking to a family member. Residential, it’s probably the individual themselves.”

Local authority

Participants suggested that most financial assessments were carried out once a person requiring support had contacted the local authority and an assessment may only be updated once there is a significant change in a person’s financial circumstances. However, people with care and support needs can request a review at any time if they feel it is needed. There are also circumstances where local authorities will assess a person’s historical payments for care when moving from self-funding to local authority funding.

“They may come to us as a ‘capital depletor’. So, if they bought their own personal care 5 years ago, and have now run out of money, we assess them for continuation of that care. Sometimes we get into a debate with the provider because the person who was private is now going state funded, and the amount the state would pay is less, and then we get into a negotiation with the provider in order to continue that care. It becomes particularly relevant if you’re in a residential home where you’ve been for 3 or 4 years. We try to keep people in situ.”

Local authority

Although local authorities collected the best data about the financial circumstances of those they are assessing, even here there are limitations, as they are reliant on people sharing this information. Complex or sensitive financial circumstances involving trusts, multiple properties or deliberate deprivation of assets can affect the accuracy of data provided. Carrying out reassessments or keeping track of people’s finances can also be a time-consuming process.

“Obviously there are laws about deprivation of assets and things like that where people aren’t supposed to sell their assets in order to avoid paying for care and that sort of thing...but it can be difficult to track or record depending on when the assessment is carried out.”

Key informant, local government

Local authorities use online platforms to collect and record financial information.

When conducting financial assessments, participants suggested local authorities did this via online platforms and recorded and stored information digitally. However, different systems may be used within a local authority, for example, the system which records social care needs and other medical information may be separate from the online system which collects financial information. Participants suggested that it may be difficult for local authorities to link these data sets for research purposes, mainly as they may not be interoperable.

“They’d obviously have to extract the data from systems that weren’t designed to extract that data from...it would depend on the system providers.”

Key informant, local government

Participants also highlighted that local authorities across England may be using different systems to record and store data on people with care and support needs, which may have implications for whether

and how this information could be shared with DHSC in the future. Interoperability of data and the burden on local authority staff to collate information may be a barrier. However, it seems that there are about six different systems used across most local authorities and there is potential for software providers to set up some standard reports for those systems which would generate consistent information from different systems to a common specification. It was suggested that it would be easier for software providers to do this than for individual local authorities to set up and run the reports.

Local authorities currently collect little or no information on self-funders and those receiving continuing health care, although this will change when the charging reforms are introduced and they start to collect information of self-funders who choose to meter towards the cap.

Participants also highlighted the financial data which local authorities hold is mostly focused on those who qualify for funded care services, as these are the people the local authority have a statutory duty to support. As CHC funding or self-funding is not means tested and does not fall into the remit of the local authority, they collect minimal information or none at all on these groups of people.

Participants felt that this lack of data for self-funders would change in the near future though, when the charging reforms are introduced¹ (a lifetime cap on the amount people will need to spend on personal care and an increase in the capital limits in the means test for local authority financial support) as local authorities will need new data collection processes in place for self-funders who choose to ‘meter’ their spend against the new cap and deal with the larger volume of people coming into contact with them. They did suggest this would have implications for their resourcing and questioned whether they had the capacity to carry out as many assessments as will be needed.

“They’re [local authorities] going to end up with a lot more assessments to carry out as well because these funding reforms mean that they’re going to have to do assessments for self-funders. So further data will be picked up and recorded but what that looks like in practice is still unclear.”

Key informant, local government

3.3 Data sharing, governance, and ethics

Care providers do not hold any financial data which could be easily shared, and care providers interviewed were sceptical of this idea in general.

Participants were asked if and how care providers and local authorities could provide an anonymised or aggregated version of the data they currently hold on the income and assets of people with care needs to DHSC (or another central government body such as NHS Digital).

As mentioned, participants stated that care providers did not hold detailed, robust or consistent financial data on the people they support which could be shared. Therefore, participants did not see care providers as a viable source of information for DHSC. However, care providers interviewed also highlighted that they would be unwilling to share this type of information in the future (if they did hold financial data), as there was some scepticism around why DHSC or another government body may need it. This suggests there would need to be a clear need and reasoning to back up a programme of financial data returns from care providers.

¹ <https://www.gov.uk/government/publications/build-back-better-our-plan-for-health-and-social-care/adult-social-care-charging-reform-further-details>

“I just don’t see it happening, I wouldn’t want to do it because they might reduce people’s entitlement or change policies, so people get even less.”

Care provider

Local authorities would be best placed to share data and information.

Participants felt that if DHSC wanted to make use of existing data, the most consistent and robust data on income and assets would be held by local authorities. They also stated that local authorities provide aggregated data returns to other external bodies such as NHS Digital which would suggest that a similar process could be put in place. Some local authorities also have agreements with Department of Work and Pensions (DWP) so that they can access and verify benefits related income, suggesting that information governance procedures between local authorities and central government departments are feasible.

All local authorities also provide NHS Digital with aggregated data on the costs of care they fund. Within this data, costs can be broken down to specific client types (such as learning disability), and demographic characteristics e.g., age.

“A local authority would tell us how much they have spent on clients aged 18 to 64, in nursing accommodation or in a residential home. That’s then broken down further by the reason why they were getting that support, so for example it might be, clients with a learning disability, aged 18 to 64 in a residential care home, but that’s as low as the level of granularity goes.”

Key informant, data and analytics lead, central government

As NHS Digital already collects and collates data from local authorities on DHSC, this may suggest they would be well positioned to collect additional information on the income and assets of people with care needs.

“NHS Digital may be seen as a more independent (or less risky) organisation to be collecting this type of data”

Key informant, data and analytics lead, central government

However, it should be noted that the information currently provided by local authorities to NHS Digital is aggregate and concerns local authority spend, rather than the assets of individuals. The issues involved in sharing individual level personal financial information are discussed below.

How data is anonymised and aggregated, and how appropriate consent is obtained, would be key considerations for any future data sharing.

Participants felt that local authorities sharing anonymised and aggregated data on the income and assets of people with care and support needs was possible. But the practical processes of how consent would be obtained, the level of anonymity needed, and the level of granularity required from the data would need to be clearly set out.

In terms of anonymisation and aggregation of data, participants were concerned that this may be quite difficult to achieve. For example, even if no names or addresses were included in a data set, the combination of care needs and financial data may mean it’s possible to trace the identity of an individual.

“At an individual data level, even without names, it may be possible for individuals to be identified, especially if information on care needs is appended to financial data. The more aggregated the data is before it is shared, the better.”

Local authority

Overall, participants were in favour of data being as aggregated as possible, to prevent the identification of individuals and suggested a similar level of aggregation to the current data returns to DHSC would be appropriate.

“Don't give people the individual lines of all the users with names and addresses deleted but what you do is say in aggregate to say we have this many people, there are this many people in this category or that category, there are this many people who have housing wealth, there are this many people who are entitled to benefits.”

Key informant, local government

A minority of participants were, however, concerned about the concept of creating a data set of people with care and support needs which also included details on their income and assets, as they felt it could be targeted by fraudsters or would be open to abuse. This would suggest that there would need to be a strong security protocol in place for the sharing of any data set.

Participants were also unsure about whether current privacy policies and consent policies were in place to allow for the sharing of financial information between local authorities and a central government body. They suggested that they would need to update their privacy policies and may need to ask for specific consent for the data to be shared. In some cases, this may mean that local authorities would not be able to share the data they currently hold but could share future data if consent was obtained. The issues of a loss of capacity at some point in the future would also need to be explored further, as well as how local authorities would judge capacity and keep track of this if people lost the capacity to consent.

Obtaining consent for sharing of the data may also have ethical implications if people approaching the local authority feel their information may be shared. It was suggested that it could affect their willingness to approach the local authority for the support they need. Making consent opt-in so it is clear it is optional and would have no impact on decisions about funding their care would help but could affect the representativeness of the resulting shared data.

3.4 Other practical considerations

The exact requirements and reason for data sharing, and the ability of local authorities to collate information will be important practical considerations.

Participants raised a number of practical issues which will need to be considered by DHSC. These included:

- **Local authority capacity:** Participants stated that local authorities are working under considerable pressure and will continue to be leading up to the reform of ASC charging policy. This may limit their time to engage with the process and would require clear guidelines on what data is needed and when, and what would be involved in collating this information. If they felt it was burdensome, they would also expect compensation for their time.

- **Clear messaging and communication about the purpose of the data collection:** Local authorities are more likely to buy in to the process of collating and providing this information if it is clear why DHSC needs it and how it will be used to inform policy development. If local authorities could also get something out of the processes such as local level modelling, they may be more willing to assist.
- **How can this be aligned with changes for the charging reforms:** Participants suggested it may be easier to produce data returns if it was built into the systems and processes local authorities are putting together to track people's spend on care services. For example, it could be a report set up on an online platform.
- **Any process would need to be subject to rigorous ethical consideration and approval:** This would involve review by a HRA ethics committee and the Confidentiality Advisory Group at the HRA.

4 Conducting a survey with people receiving care

This chapter outlines participants' views of carrying out a survey on the income and assets of people receiving care. This includes practical and ethical considerations and the strengths and weaknesses of different approaches to sampling, survey administration and data collection.

Key findings

Participants felt that a survey conducted on a yearly basis could provide up to date and relevant data. This would allow DHSC to capture changes and build up a longer-term view of the financial situation of people using care services.

But there were several difficulties with collecting financial information through a survey. This included trust, privacy and communication about the survey; burden on participants to provide detailed and sensitive information about their finances; the accuracy of the data; and administration and cost of a survey. However, participants did suggest that asking a small number of high-level questions could mitigate some of these challenges.

Participants felt that any data collection activity would need to ensure participants had the mental capacity to consent to taking part. The sensitivity of financial arrangements and the role of family and friends would also need to be an ethical consideration.

Participants were asked about constructing a sample and how the survey could be administered. They were asked about two options: care organisations (care providers or local authorities) distributing a survey on behalf of DHSC; and care providers or local authorities sharing contact details of people with care and support needs and their families with an organisation appointed by DHSC to conduct the survey.

Participants felt that care organisations administering a survey could encourage local ownership and improve response rates. However, they also suggested that capacity and workload issues would mean care organisations would not be able to administer a survey successfully.

Participants stated that care providers would not be willing to share the contact details of the people they support and this would be a major challenge to any centrally administered survey. Local authorities may be in a better position to do this.

4.1 Conducting a survey among people receiving care

4.1.1 Benefits of conducting a survey

Participants felt there would be benefits to collecting financial information through a survey.

Participants were asked for their views on the possibility of conducting a survey with people with care and support needs aged 18+ in England about their income and assets. The survey would aim to be representative of people with care and support needs regardless of their funding status, with the survey potentially repeated over time.

Participants noted a survey would enable the collection of financial data about all people in receipt of paid care, not just those who are receiving local authority funded care. The data collection could also be **designed to meet the needs and requirements of DHSC which may mean analysis is more useful.**

“You could be more prescriptive in what you want, and it could be designed to cover all the things they need to get.”

Key informant, strategy consultancy

A survey conducted on a yearly basis could provide up to date and relevant data.

During the in-depth interviews, participants were asked how often a survey should be conducted to ensure the information is relevant and up to date. Generally, participants thought that conducting a survey on an annual basis would be a good time frame for capturing changes and building up a longer-term view of the financial situation of people using care services. However, participants suggested that the frequency of the survey may need to be tailored to different audiences. They felt that carrying out a survey with people of working age (18-64) who use care services yearly would be unnecessary as their circumstances may not change much from year to year. But the circumstances of older people who use care services may change more rapidly and it would be useful to measure this via a survey.

“In terms of frequency, someone who is older, with health and care needs, those needs are going to change quite quickly, they know that those things escalate quite quickly, so you'd need quite a high frequency. Younger adults you could do with much less frequently. So, maybe some sort of tailored approach around that would be helpful.”

Key informant, strategy consultancy

4.1.2 Challenges of conducting a survey

But there were several difficulties with collecting financial information through a survey.

Participants stated there were a number of challenges to collecting financial information through a survey with people using care and support services which would affect the response, representativeness and quality of data. These included:

- **Trust, privacy and communication:** Participants suggested that people would be unlikely to complete a survey asking about financial information as this is a highly sensitive topic. People may worry about the survey being a scam, who this information is shared with and whether they can trust who is asking for it. Linked to this, it would be unclear what the benefits of providing their financial information would be for participants. This indicates that any survey would need to have a clear purpose and messaging around why people should take part. The survey would also need to come from a trusted source to be considered legitimate.
- **Accuracy of the data collected:** Linked to challenges around trust, privacy and communication, participants felt that people would not provide accurate data as they would be concerned about anonymity or information being shared with other agencies or government bodies. Identifying the correct person to take part in the survey would also be challenging as those in receipt of care services may not be fully aware of all their financial arrangements and their family, friends or carers may not be willing to take part. This would also limit the accuracy of the data.

- **Participant burden:** Participants also suggest there would be a risk of overburdening people who have recently been through a financial assessment with a local authority or applied for benefits, as they would possibly need to provide similar information in a survey.
- **Administration and cost of the survey:** Participants were asked about the best mode for the survey. They suggested that previous studies on this topic collected information by using specialist interviewers or researchers in a face-to-face setting, who were skilled in asking about financial arrangements. However, participants felt this would be a resource intensive way to collect survey data and would require a large amount of project management and scheduling with care providers.

Participants suggested that asking a small number of high-level questions could mitigate some of the challenges mentioned.

Those who were experts in data collection and analysis said that high-level data could be collected which could then be used to make estimations about the income and assets of people with care and support needs. It was suggested that this would avoid asking detailed questions about income and assets that may cause people to be worried and reduce the risk of them providing inaccurate information by instead focussing on simpler questions which people know the answers to. This approach might also require a less resource intensive method of data collection (e.g., self-completion survey).

“The main issue could be the precision of, or specificity of the financial data that you would be requesting. It absolutely terrifies some of the participants, because if I get a letter from the state saying, show me the extent of your income and assets, I'm just going to go, well, it's not your business, I'm not telling you. So, I'd have to be-, I think it's quite tricky to ask that of people, and so, I suppose the other thing you can think about doing high level questions, just a few that would be more general and could be used for estimation, modelling and inferring.”

Key informant, local government

This could include asking people to provide their postcode (to then attribute property value), where their income or investments fall within a particular band and whether they need support with day-to-day activities.

“You could use proxies such as home ownership and indirect measures. For example, area level data on wealth, housing tenure, receipt of benefits that sort of indirect indicator, rather than actual information. In my work I'm always looking at other indicators than actual money because people are not good at giving you money information.”

Key informant, academic

4.2 Ethical issues

Participants were asked about the ethical and data protection implications of conducting a survey with people with care and support needs.

Any data collection activity would need to ensure participants had the mental capacity to consent to taking part.

Participants in the in-depth interviews highlighted capacity to understand the purpose of the research and the ability to give consent to taking part as a key issue. The research would be with a population who may lack mental capacity to take part or consent or who have cognitive impairments which make

taking part in research difficult. In order for information to be collected on behalf of someone who lacks mental capacity, specific procedures and approvals are needed. Where data is being collected from a family member, friend or carer of a person with support needs, it would be important to establish whether the person taking answering survey questions is legally and ethically able to provide financial information (either because they have power of attorney or correct procedures for involving personal consultees have been followed).

"Ethically, you need to make sure that the person you're asking to provide the information is legally able to talk about that person's finances. That is very important because if you don't have authority to speak to the daughter or the son about the mother's finances, then you legally cannot talk to them about their finances."

Key informant, umbrella organisation

The survey would also need to be approved under and comply with the Mental Capacity Act 2005. As part of this, any data collection would need approval from the HRA research ethics committee. One participant did suggest that the data collection could be considered as non-research and potentially classified as an economic evaluation, which would mean it would not need research ethics committee approval. However, they felt this was a borderline case and would most likely need to follow a structured ethics review process. This suggests this option would need further exploration to determine how the data collection should be classified.

The sensitivity of financial arrangements and the role of family and friends would also need to be an ethical consideration.

Participants suggested that the financial arrangements of a person in receipt of care services can be complex, and family and friends may not be aware of some assets and income they have. It would therefore be important to consider the effect survey question may have on family dynamics and how it may be used.

"There're some sensitive family issues buried in all of this care stuff. It's complicated, one side of a person will feel happy their mum has sold the house and going into care, but the other half may be quite concerned that their inheritance is to be compromised. So, there are some quite complicated family scenarios. That may mean that the care user may not have shared all their financial details with their family members. So, there are those ethical concerns that one might need to consider as well."

Key informant, local government

4.3 Care organisation administered survey or shared sample and centrally administered survey

In the in-depth interviews participants were asked about constructing a sample and how the survey could be administered. They were asked for their views on two options: care organisations (care providers or local authorities) distributing a survey on behalf of DHSC; and care providers or local authorities sharing contact details of people with care and support needs and their families with an organisation appointed by DHSC to conduct the survey.

4.3.1 Care organisation administered

Care organisations administering a survey could encourage local ownership and improve response rates.

Participants could see some benefits to a survey administered by care providers or local authorities. One of the main benefits would be that it would help encourage local ownership of the survey as they would be directly involved with the administration. However, a few participants mentioned that this would require that the data was available to, and useful for, care organisations.

“It definitely needs local ownership...it's how that data is packaged up and given back in a way that they can make great use of. If it's a one-way flow, again, it'll feel quite hard.”

Key informant, strategy consultancy

Linked to the issue of trust in the survey, people with care and support needs and their carers may also be more likely to trust a survey if it was provided by a care provider or local authority. For example, one participant mentioned the possibility of care staff taking a tablet round to residents and asking them to complete the survey.

“It would be better for the care home to facilitate the collection. They could take an iPad round to residents.”

Key informant, umbrella organisation

However, participants felt capacity and workload issues would mean care organisation would not be able to administer a survey successfully.

Participants in the in-depth interviews stated that main barrier to this option would be the workload and pressures care providers and local authorities are working under. They felt care staff would be too busy to share a questionnaire, support people to complete it and follow up with people who had not completed it.

“Right now, I'm amazed that any care home joins in any study. They're under such stress and they wouldn't have any time to chase it up either.”

Key informant, academic

Similarly, participants also said local authorities would be too stretched responding to COVID-19 and implementing the processes required as part of adult social care charging reform to administer and manage a survey. They may also be less interested in managing a survey as they already hold detailed financial information which will increase in the future (as discussed in Chapter 2).

“Local authorities are in a different position because they already have detailed financial data. And they're going to end up with a lot more of it as well because these funding reforms mean that they're going to have to do assessments for self-funders as well. I don't think this [LAs or care providers administering a survey on behalf of DHSC] is a terribly practical proposition, in all honesty, the way things currently are.”

Key informant, umbrella organisation

4.3.2 Shared sample and centrally administered

The second survey option participants were asked for their views on was the possibility of care providers and local authorities sharing the contact details of people with care and support needs with DHSC or a third-party contractor so they could conduct the survey.

Participants stated that care providers would not be willing to share the contact details of the people they support.

Most participants suggested that care providers would be unwilling to share contact details with any government or third-party organisation for the purpose of a survey. This is because they would be concerned about GDPR regulations and how this data would be used.

“They wouldn't share contact details. Absolutely no way. They only hold the information they need to, and it wouldn't be shared with anyone.”

Key informant, policy lead, umbrella organisation

Local authorities and care providers were also concerned about the involvement of third-party contactors and whether survey participants would trust them (as discussed earlier in this chapter). But they thought an organisation like NHS Digital may be more trusted and could possibly be involved in the administration of a survey.

"In terms of public trust in what's going to happen to their data, maybe from an NHS Digital point of view and a DHSC point of view, they have confidence. If they see contractors, that's when it starts - 'Are you selling off my data? Or is it third parties that are going to have this? Are they going to be subject to the rigorous safeguarding of our data, the disclosure and so on?'"

Key informant, data and analytics lead, central government

5 Collecting data through existing general population surveys

Key findings

Another option for collecting data on the income, assets, and care needs of people in receipt of paid care could involve using existing, well-established surveys, such as the English Longitudinal Study of Ageing (ELSA), the Family Resources Survey (FRS), Understanding Society (UK Longitudinal Household Survey: UKHLS), or the Adult Social Care Survey (ASCS).

The samples for these surveys do not cover all the groups needed or have large enough sample sizes for other groups of interest, so compromises would need to be made in terms of coverage or the sampling approach would need to involve sample boosts.

None of these surveys include all the information needed but the quality of financial data, where collected, is felt to be good. Still, as with administrative data and standalone surveys, data quality relies on the information participants are able and willing to provide.

Some of the limitations of the samples and information provided could be overcome analytically using analysis experience and modelling.

This chapter outlines the different general population surveys which could be used to collect financial information on people with care and support needs; the content, samples and implications for analysis if these surveys were used to collect data. This builds upon the rapid evidence review at workstream one by providing further insight into the strengths and limitations of these population surveys, how well they capture the information DHSC requires and provides practical considerations for modelling.

5.1 Surveys mentioned during interviews

The following surveys were mentioned by participants when asked about existing surveys during the interviews:

- **Family Resources Survey (FRS)** was mentioned as a source of data on income and assets which can be used to model future spending on income and assets, using data from a general population sample
- **Understanding Society (UK Longitudinal Household Survey, UKHLS)** is a longitudinal study of general population which takes place annually
- **English Longitudinal Study of Ageing (ELSA)** is a longitudinal study of people aged 50 and over which takes place every 2 years
- **Adult Social Care Survey (ASCS)** is a survey of people in receipt of local authority funded care in England, which was also mentioned, though it is not a general population survey

5.2 Samples

The samples for general population or existing social care surveys may not cover all the groups needed or have large enough sample sizes for other groups of interest.

The advantage of general population surveys is that there is consistent data to compare people receiving social care (non-residential) with the rest of the population. However, there are limitations in the small number of people receiving the care in the sample and the fact that in not all surveys include all working age people (ELSA). In a survey such as ELSA, which is of the general population aged 50 and over, only some will have care needs and only some will receive any support for their needs. Among those who do, only some will be self-funders. This means only a relatively small sub-set of the sample are people for whom the new social care charging policies apply.

“One limitation is simply that you don't get many people in the surveys that are receiving social care.”

Key informant, academic

One option would be a sample boost of people receiving or needing social care, especially those of working age, who are a small proportion of the overall population.

The surveys are also based on people living in private households, not institutions. ELSA does follow participants into care homes but has small numbers in this group. It was suggested that this is because following sample members into care homes relies on there being a sample member left outside the care home which means people already living alone (who are the ones most likely to go into care homes) may not be followed. The Understanding Society survey may be extended into care homes in future but could face similar issues.

If surveys do successfully follow people into residential care, it was suggested that the information on assets would need to be collected at the point they start using this care, before their assets are depleted. This led to the suggestion that information would be better collected from people at the point of entering care, rather than from these general population surveys.

There are existing surveys of people receiving care such as the Adult Social Care Survey (ASCS), but the limitation is that it doesn't cover people who are self-funded. However, this and other surveys which already take place in social care settings were felt to be an option if one could get a representative enough sample from them.

5.3 Content

The surveys may not include all the information needed but the quality of financial data is felt to be good.

Among those who were not very familiar with the surveys a question was raised of whether they would give the right information or enough detail. However, as they are established it was felt they provided good quality data. Across these surveys the quality of data on income was felt to be good by those with expertise in using the data.

“Of course, there are problems with income, but between the various surveys, there's quite a lot of experience in how you ask about incomes.”

Key informant, academic

The surveys contain valuable information but do vary in the quality of asset data and they do not include all the questions required by this research. For example, they do not provide information on how people are using their income and wealth to pay for care. Although some of the surveys are longitudinal, they are not frequent enough to provide data on the spending over time.

Another issue is that in order to manage content, surveys rotate modules between waves. This means the combination of questions needed for analysis are not all asked in the same way everywhere and every wave.

“The wave in which you have detailed asset data might be different from the wave in which you have expenditure on social care data. My feeling is that you would need observations much closer together than just annually or bi-annually.”

Key informant, academic

There was discussion about adding new questions to surveys to meet the information needs. An example would be adding questions about care to surveys such as FRS which have income and assets data or data on income and assets to a survey such as the ASCS which currently asks about care. However, there are risks associated with adding to existing surveys because they are already long and complicated, with repetition and overlap within questions. These long and complex surveys place burden on participants and this should be considered when adding questions. Other challenges with adding questions include the need for ethics approval and cognitive testing before questions can be added to surveys.

5.4 Ability or willingness to respond

As with administrative data and standalone surveys, data quality relies on the information participants are able and willing to provide.

Even on these established surveys there are issues associated with people’s ability to answer the questions. For example, several of the surveys (including ELSA and HSE) include questions about the amount of personal budget received and the amount contributed by the person themselves. However, not everyone can answer this, meaning that to avoid missing data, assumptions and imputations have to be made in the analysis.

If the surveys collect income and assets data from people with care and support needs, there may be challenges in identifying a family member or friend to provide financial details if the participant cannot. There could be sensitivity for the participant in involving others and those others may not recognise themselves as carers with any responsibility to provide this information. This was mentioned in the context of the ASCS but could also apply with a boost of people with care needs in a general population survey. Questions were also raised about the willingness of family and friends to respond to a survey.

Even if people are willing to respond, some uncertainty was expressed about whether people would be motivated to tell the truth in the survey, with impacts on the accuracy of data.

5.5 Modelling and analysis

There is analysis experience and existing modelling which would enable some of the limitations of the samples and information provided to be overcome analytically.

Analysis and modelling of the survey data is needed to deal with missing data at an individual level and model information which is not included at all. For example, where people are unable to provide

information on the overall spending on care, this can be calculated from information which is available, such as the hours of care they receive, assumptions about cost for different types of care, and potentially some information about their own contribution to care costs.

The surveys do not provide information on the way in which income and assets are spent on care, but these can be modelled based on assumptions because for local authority funded residents in care homes there is relatively little flexibility in how they pay for their care.

“They [local authority funded residents] have to put all their income, apart from their small personal-expenses allowance towards it.”

Key informant, academic

“The assumption is that people use their income first, then their non-housing wealth, and then they were draw on the housing wealth. Now, that may or may not be true, but I guess that for sort of the modelling questions we're looking at, that's a kind of reasonable starting point.”

Key informant, academic

This approach means that with key information such as income, assets and the value of property before needing care, modelling of the spending on care is possible with existing survey data.

A question was raised about the extent to which it is possible to predict who will enter residential care from among those in the general population surveys. It was pointed out that individuals will not know this themselves.

“...most people will think, 'Well I won't need to go into residential care, so I'm not the right person to answer that question'.”

Key informant, local government

This means that analysis would need to rely on assumptions about who would need residential care in the future and should therefore be included in the analysis of how assets and income are spent down by care users.

“If you're projecting forward in time, then it's actually people who are in the household population that are relevant. So, one question is, how important is it to get a picture of the situation now or is it that you want something which will help you to predict the future, in which case, you might not worry too much about the current care home population.”

Key informant, academic

6 Other options for data collection

Key findings

Additional options to collect data on income and assets were suggested: making better use of information, which is already known, for example information held by the Land Registry, HMRC and DWP.

This would reduce burden and avoid duplication of effort but would come with information governance challenges regarding data sharing and linking.

Developments taking place in relation to social care financial reforms may offer future opportunities to collect the information needed. Examples included using a national system for local authorities and care providers to collect standardised information from people accessing care services (whether local authority or self-funded) or extending the activities of the trailblazers that had been chosen to pilot the charging reforms in some local authorities when the fieldwork took place.

This chapter outlines the other data collection options mentioned in the interviews for workstream 2. This includes standardising information gathered by local authorities, linking central government data, a smaller scale survey to provide proxy measures and qualitative research.

6.1 Introduction

During the interviews a range of alternatives to existing data held by local authorities or care providers, existing or new surveys were suggested. It should be noted that these do not always explore how they would work in practice.

An important point was raised that the best way of collecting the data depends on the purpose for which it is being collected and the timing. This is necessary so that people who need to provide the information 'can buy into it as an idea' and are reassured that it is going to be collected safely. The burden on participants or informants is also important as people may query why they are providing information which they have already given to someone else, or which they think is already known. Therefore, there was a strong theme of the importance of using data that was already held as well as possible. Legacy infrastructure, lack of scale and lack of skills were felt to limit the use of existing data and it was suggested that a strategy to address these could enable greater use of existing data or data that might be collected in the future for other purposes. However, existing pressure on local authorities may limit what is possible.

6.2 Standardised information gathered by local authorities or care providers

Developments taking place in relation to social care financial reforms may offer future opportunities to collect the information which is needed.

A suggestion was made by one person of a national system used by local authorities and care providers to collect standardised information from people accessing care services (whether local authority or self-funded). This could be used by local authorities for assessments and for care providers in assessing ability to pay. It was felt that by providing a system which enabled care providers to do this more easily would be appreciated by them and make things easier for them, while providing nationally consistent data. However, this same person had already observed the lack of financial expertise among many people working in care homes.

It was suggested that there is a technology workstream with a trailblazer pilot for local authorities which might offer a suitable approach, as an extension of current activities. This pilot involves local authorities gathering financial information in partnership with care providers in relation to the social care cap.

“If you're thinking about this as an ongoing data collection, well it'll be collected via the financial assessments that have to be done when people come forward for the cap.”

Key informant, local government

“The trailblazers are going to start collecting information from self-finders in the not-too-distant future, so why wouldn't you use that as the opportunity to collect that data?”

Key informant, local government

It was also suggested that trusted assessors who are already used to collecting this kind of information for local authorities might be able to assist with any additional data collection such as a survey.

6.3 Data linkage with central government data

Better use could be made of information which is already known, to reduce burden and avoid duplication of effort but this comes with information governance challenges.

It was suggested that central government already holds data which would provide some of the information needed, either directly or through assumptions. For example, land registry holds information about property, DWP holds information about benefits and HMRC hold information about taxes paid (which could indicate levels of savings). Data about income and assets could be simulated from this information and it was suggested that organisations such as the Institute for Fiscal Studies already do this type of analysis.

“HMRC knows what your birth date is, they know your National Insurance number, they know what you're filing in your tax returns...HMRC would certainly have your address, so that could be matched to postcode.”

Key informant, umbrella organisation

“Because all of that data actually exists in the state's records somewhere. And then they have to think about whether or not they have the analytical capability and the strategic sensibilities to actually unpick that and understand that well, and process that so that they can report upwards.”

Key informant, strategy consultancy

As indicated in the quote above, there was uncertainty about whether the government has permission for this, how to get hold of this information and who has the analytical capacity to make full use of it. Interviews with local authorities showed that at least some do have links with DWP and permission to access benefit data already via the Searchlight system. However, it was observed by someone with experience with surveys with data linkage permission, that linking data or accessing linked data is challenging and involves ‘hoops and security issues to jump through’.

It was also unclear to participants whether the government knows who is in a care home, and this and other important information about care is missing from the central government data. This would limit its usefulness for DHSC's needs without linkage to information from local authorities about care needs.

6.4 Smaller scale survey for development and analytical purposes

There was a general feeling that if a survey of people with care needs was conducted, simple proxy measures should be used as far as possible to minimise burden and maximise the accuracy of data (see Chapter 3). In order for this to be effective, analysis of these high-level proxy measures against more detailed high-quality measures of income and assets would be needed. This could potentially be done using existing general population surveys such as FRS, but another option would be a smaller scale standalone survey on which suitable proxy measures are developed. Following this, larger scale ongoing surveys discussed in chapter 4 could be used, as well as any new survey of people using care services (as described in chapter 3).

6.5 Qualitative methods

It was suggested that a focus group could be used to explore the issues in more depth. Little information was given about this and the issue of confidentiality when discussing sensitive financial information in a group setting was not addressed.

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