



Department
of Health &
Social Care

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

Workstream 1 report: Review of past studies and data sources

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Contents

Glossary of key terms.....	3
1. Executive Summary.....	4
2. Background	5
3. Rapid review of past studies.....	8
4. Relevant data sources.....	10
5. Summary and conclusions.....	27
References	29
Appendix 1.....	30
Appendix 2.....	35
ELSA – Individual income and asset variables.....	35
Appendix 3.....	38
UKHLS – Individual income and asset variables	38

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.

Glossary of key terms

1. **Activities of Daily Living (ADLs):** Activities of daily living (ADLs) is a term used to collectively describe fundamental skills required to independently care for oneself. It is used as an indicator of a person's functional status. ADL tasks are as follows: bathing, dressing, toileting, transferring (i.e. getting in and out of a chair or bed without assistance), continence and feeding.
2. **Benefit unit:** a single adult or a married or cohabitating couple and any dependent children. This distinguishes from households in that a benefit unit does not include adult non-dependent children, older family members living with adult children and unrelated household members.
3. **Cross-sectional survey:** an observational survey that takes place at one particular point in time. Cross-sectional surveys cannot be used to determine causality.
4. **Instrumental Activities of Daily Living (IADLs):** Instrumental activities of daily living (IADLs) are those activities that allow an individual to live independently though not necessary for functional living. IADL tasks are as follows: using the telephone, shopping, food preparation, housekeeping, laundry, mode of transportation (i.e. manages personal travel independently), managing medication and managing finances.
5. **Longitudinal survey:** a survey that is repeated at two or more points in time with the same questions asked at each time point.
6. **Panel survey:** see Longitudinal survey above.
7. **Personal Budget:** The amount of money a local council or local authority determines that someone needs to pay for the care and support they need after conducting a needs assessment and assessing their financial situation to determine eligibility for council/local authority support.
8. **Proxy respondent:** a survey respondent who provides responses on the characteristics or activities of another individual, where the person on whose behalf they are providing responses is a member of the survey sample and typically, not able or unwilling to respond on their own behalf.

1 Executive Summary

This summary outlines the findings of Workstream 1 led by CPEC which consisted of a rapid evidence review of past studies on the income and assets of people with care needs. It also looked at existing large-scale population datasets and bespoke surveys of people receiving care and support and their carers which collect financial data. This included the English Longitudinal Survey of Ageing (ELSA), the Family Resources Survey (FRS), the Health Survey for England (HSE), and the UK Household Longitudinal Study (UKHLS). The aim of Workstream 1 was to find out the extent to which these existing surveys could provide the data DHSC needs.

1.1 Review of past studies

The review of past studies identified one relevant paper 'The characteristics of residents in extra care housing and care homes in England' conducted in 2010 by the University of Kent. In this paper (Darton et al. 2012) presents findings on the characteristics of residents of 19 extra care housing schemes and findings of a comparable study of residents who moved into care homes providing personal care. The residents in extra care were more likely to have been owner-occupiers and less likely to have lived in privately rented accommodation than those who moved into care homes.

1.2 Review of existing population surveys

The ELSA, FRS, HSE, and the UKHLS are all large data collections with significant potential contributions to examining the income and assets of social care service users. However, they are all limited in their sample frame, as they do not routinely include people in residential care. Each of the datasets offer the potential for boost samples, follow-ups or linking with administrative data. ELSA and UKHLS have more comprehensive data collected on the assets of respondents, compared to the other two datasets. The opportunity exists to compare the data on income and assets of social care service users with non-users and potentially to combine the data across these studies to generate a large sample on which the data could be analysed.

Analysis of the data from these four surveys was important to determine their feasibility as approaches to collecting representative data on the income and assets of individuals receiving social care, whether in their current form or with adaptations.

2 Background

This report presents the findings of a rapid review of past studies and a review of relevant data sources of care needs, income, and assets, which forms the first part of the feasibility study. This review aims to inform the rest of the study, indicating possible data collection approaches and where further information is required.

This work has been undertaken by Care Policy and Evaluation Centre (CPEC) at LSE and Ipsos on behalf of the Department of Health and Social Care (DHSC). The project was commissioned by DHSC as there is currently a lack of robust data about the income and assets of the population using care services, as well as other information such as demographics and spending on care. The collection of this data can be complex and sensitive with important ethical implications. The overall project therefore looks to explore the different options for data collection and their benefits and drawbacks. This will help DHSC to have a better understanding of the different options available to them and what these options may look like.

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

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

Improved data on the income, assets and wealth of people using care services will help DHSC to better understand the impacts of government policy and inform work to shape the implementation of charging reforms. DHSC is interested in data which could be collected or analysed in advance of the introduction of charging reform, 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.

2.1 The five workstreams

This report focused on workstream 1 is one of 5 workstreams forming part of this research. The 5 workstreams were conducted mostly iteratively between December 2021 and October 2023:

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 ELSA and UKHLS. The objective was to identify how well these questions in ELSA and UKHLS capture the financial information they are designed to capture. In the options appraisals, Ipsos looked at the different data collection options available. Three groups of options were considered, and their benefits and drawbacks identified. Each option was appraised on a range of topics including: coverage of the target population, information that the option would provide and whether this would meet DHSC needs, impact on people with care needs, impact on carers and families, required involvement of organisations, technical and practical considerations and, data analysis and use. Findings from Workstreams 1 and 2 and from CPEC's secondary data analysis fed into the options' appraisal. This options' appraisal was conducted prior to the 2022 Autumn Statement announcement that the implementation of charging 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, which are included in this report. Once finalised these questions were cognitively tested during the second phase of WS4.

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

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

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

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

3 Rapid review of past studies

Searches were conducted in December 2021 for papers published from 2010 onward in English on the National Center for Biotechnology Information (NCBI) database (which links to PubMed and Medline) and Social Care Online. Papers were considered relevant for this study if they presented data on the financial circumstances of users of adult social care in England, where financial circumstances covered incomes, savings, housing tenure or receipt of means-tested social security benefits.

Only one relevant paper published since January 2010 was found - Darton et al 2012, which presents data on the housing tenure, but not on the incomes or savings, of 601 older people admitted to new extra care housing schemes in around 2005 and 499 older people admitted in 2005 to care homes providing personal care.

3.1 NCBI database search

First search:

(income[Title/Abstract])) OR (saving[Title/Abstract]) OR (wealth[Title/Abstract]) OR (Asset[Title/Abstract]) OR (Housing tenure[Title/Abstract])

AND

((long term care) OR (residential care)) OR (domiciliary care)) OR (home care)) OR (social care)

AND

((England) OR (UK)) OR (United Kingdom)

737 abstracts identified, but none are relevant

Second search:

((Survey) AND (residential)) AND (England)

122 abstracts identified, but none are relevant

Third search:

((Survey) AND (home-care)) AND (England) AND (income)

43 abstracts identified, but none are relevant

3.2 Social Care Online Search

First search:

Survey AND residential AND England

90 items identified for 2010-2022, but only 1 is relevant (Darton et al 2012)

Second search:

Survey AND homecare AND England

10 items identified for 2010-2022, but none are relevant

Third search:

Survey AND home-care AND England

226 items identified for 2010-2022, but only 1 is relevant (Darton et al 2012)

3.3 Conclusion from searches

These searches yielded only one relevant paper published since January 2010 - Darton et al 2012. It presents findings from a study conducted by the Personal Social Services Research Unit (PSSRU) at the University of Kent. The paper provides data on the housing tenure, but not on the incomes or savings, of 601 older people admitted to new extra care housing schemes in around 2005 and 499 older people admitted in 2005 to care homes in England providing personal care. A summary of findings drawn from this paper and an earlier report - Darton et al (2006) - about the financial circumstances of the sample of care home admissions is in Appendix 1.

The 2005 PSSRU survey followed earlier PSSRU surveys of the admissions of older people to care homes in England. PSSRU conducted a longitudinal survey of publicly-funded residents admitted in 1995 – see Bebbington et al (2001) - and a survey of self-funded residents admitted in 1999/00 – see Netten et al (2002) and PSSRU (2002). Summaries of these papers are in Appendix 1.

4 Relevant data sources

Four data sources were examined to assess their value in calculating the incomes, assets and source of funding of service users. These are commonly used for analysis of social care receipt because they survey nationally representative samples and include a significant number of questions on the need for social care, the sources of social care, and in some cases, how the social care received by individual respondents is paid for. They are the English Longitudinal Survey of Ageing, the Family Resources Survey, the Health Survey for England, and the UK Household Longitudinal Study (Understanding Society).

In each source, questions on income and assets were asked of all respondents and respondents were asked separately about their need for and receipt of social care. Analysis of these data would be necessary to assess the completeness of responses to the questions on income, assets and sources of funding by users of social care.

The focus in these surveys is on social care for older people, aged 65 and over (although ELSA asks the questions of those aged 50 and over). The focus on older people is because the prevalence of disability among working age adults and therefore the potential need for social care support is much lower than among older adults (19% compared with 44%).¹ The proportion of younger adults in the general population who receive social care would be lower than the prevalence of disability, such that very few younger participants in national surveys would receive social care even if the surveys asked about social care among younger adults. Moreover, among younger adults the majority of public social care funding for working age adults was for learning disability² which means that general population surveys may not be the best way of gathering information from many younger adults anyway. There are also relatively few self-funders among working age adults.

4.1 English Longitudinal Study of Ageing (ELSA)

4.1.1 Coverage

The ELSA sample is made up of people aged 50 years or over, living in a private household in England at the time of joining the sample. Partners of original sample members and new partners who have moved into the household since the survey base are also included. Respondents in institutions are interviewed if they had previously been in the sample as residents of a household within the sampling frame in a previous wave. If respondents move out of a household and into an institution, their household identifier is kept the same so that their data can be connected to their previous records, as well as the

¹ Kings Fund: Key facts and figures about adult social care. <https://www.kingsfund.org.uk/audio-video/key-facts-figures-adult-social-care>

² Kings Fund: Key facts and figures about adult social care. <https://www.kingsfund.org.uk/audio-video/key-facts-figures-adult-social-care>

data of members of their former household. Core ELSA sample members who move into a residential care home after their first ELSA interview are still eligible for interview. Data is collected from a longitudinal sample of individuals every two years. At the point of review, the most recent data available was from Wave 9 of ELSA for which data collection took place in 2018-2019. The social care module was introduced in wave 6 (2012-13).

4.1.2 Methodology

Sample members are drawn from respondents to the Health Survey for England (HSE). The first wave of ELSA was conducted in 2002. The original ELSA sample was drawn from individuals who participated in the HSE in 1998, 1999 and 2001 (a combined total of 23,132 households). Households which did not contain an adult of age 50 or above (as of 1st March 2002) who had consented to be re-contacted were removed from the sampling frame for ELSA Wave 1, resulting in an eligible sample of 18,813 individuals in 11,578 households. The study sample was replenished from HSE at waves 3, 4, 6, 7 and 9.

Participants have a face-to-face interview, followed by a self-completion questionnaire. Every other wave there is a nurse visit to collect biomedical data. All of the questions relating to social care need and use, as well as those on income and assets are contained in the face-to-face interview.

4.1.3 Proxy responses

Proxies are used if the eligible respondent is physically or cognitively impaired; in hospital; or temporarily in care for the whole of the fieldwork period. Only adults (aged 16 and over) are considered as potential proxy informants. Proxy interviews are also conducted if a sample member refuses to take part in a face-to-face interview but agrees to someone else taking part in the interview on their behalf. Interviewers identify potential proxy informants from those who know enough about the respondent's circumstances to be capable of providing the requested information. Where a participant is co-resident with someone that person would be approached about being a proxy. ELSA also collects 'stable' contact details as well as proxy nominations and these could also be used if needed. After completing a household grid (if someone is co-resident with another ELSA member), a question is asked about whether a proxy is needed and information is provided about the reason for this. These include:

9. "Mentally incapacitated/impaired"
10. "Physically incapacitated"
11. "In hospital"
12. "Away or no contact with respondent"

13. "Refused personal interview"
14. "Language difficulties"
15. "Other reason". Language difficulties is not permitted as a reason and in this case the proxy interview would not be allowed.

From wave 5 to 8 a Mental Capacity Act form³ was used where the reason for needing a proxy was "Mentally incapacitated/impaired". This enabled personal consultees to confirm that in their opinion the ELSA participant would want to take part in ELSA at this time. This enabled proxy interviews to be done when the participant no longer had capacity to give their own consent for a proxy interview. No information is available from wave 9 onwards about whether the Mental Capacity Act form was still in use.

Proxy interviews do not include questions about attitudes or expectations. "In cases where no-one else in the same financial unit was eligible for interview, the proxy interview included the Income and Assets module. If two proxy interviews were needed for a couple, the Income and Assets module would only appear in one of the interviews (asking about both their finances). For couples comprising of one person who was interviewed in person and another who needed a proxy interview, the former would automatically be asked the Income and Assets module on behalf of the couple".⁴

The documentation of the fieldwork for ELSA does not mention incentives to participants and it is assumed that these are not provided. In the past ELSA branded gifts have been given to participant (e.g. an alarm clock).

4.1.4 Data on social care need and/or use

A social care module,⁵ funded by the Department of Health and Social Care and the Nuffield Foundation and developed in a collaboration between researchers at NatCen, the London School of Economics, the University of Kent and the University of East Anglia, was introduced in Wave 6 (2012-13) of ELSA and has been included in subsequent waves. The topics covered in this module are need for care, receipt of care and payment for care among people aged 65 and over and provision of care by all adults. More specifically, the social care module covers:

³ https://www.ucl.ac.uk/drupal/site_iehc/sites/iehc/files/elsa_mental_capacity_consent_w8.pdf

⁴ https://www.ucl.ac.uk/epidemiology-health-care/sites/epidemiology-health-care/files/5050_elsa_waves_1-9_interviewer_data_user_guide_v1.pdf (section 2.4)

⁵ Full details of the module and its development can be found here: Blake, M., Gray, M., Balarajan, M., Darton, R., Hancock, R. Henderson, C., King, D., Malley, J., Pickard, L., Wittenberg, R (2010) 'Social Care for older people aged 65+, questionnaire documentation'. <https://natcen.ac.uk/our-research/research/social-care-questions-for-over-65s/> (accessed 12/01/2022). Versions of this module with adaptations to fit with existing survey set up are used on ELSA, HSE and UKHLS.

- need for and receipt of care (including Activities of Daily Living (ADL),⁶ Instrumental Activities of Daily Living (IADL) 2, and Barthel index)⁷
- who provides care – formal and unpaid (family or friend)
- hours of care provided
- payment for care
- use of services
- provision of informal care
- characteristics of people cared for
- hours of care provided
- effects of caring

The social care questions on who provides care are linked to specific tasks. More than one provider can be identified for each task. Respondents are also asked the amount of time each provider spends helping them per week. Additionally, the questionnaire asks about receipt of Direct Payments and Individual Budgets. The care services asked about are residential care, meals on wheels, day centres, lunch clubs and Local Authority Handy Man service.

4.1.5 Data on income, assets, housing wealth and paying for care

In each wave respondents are asked questions on their financial and physical assets. Financial assets include investments and inheritances; physical assets include housing wealth (and mortgage debt). Based on these data, the ELSA study team have created a number of derived variables. All are derived for the benefit unit. These are as follows:

⁶ Activities of daily living (ADLs) is a term used to collectively describe fundamental skills required to independently care for oneself, such as eating, bathing and mobility. It is used as an indicator of a person's functional status. Instrumental activities of daily living (IADLs) are those activities that allow an individual to live independently though not necessary for functional living. Example IADLS are cooking, cleaning, laundry and managing finances. See Katz S. Assessing self-maintenance: activities of daily living, mobility, and instrumental activities of daily living. *J Am Geriatr Soc.* 1983 Dec;31(12):721-7.

⁷ The Barthel Index consists of 10 items that measure a person's daily functioning, particularly personal care tasks required for an individual to care for themselves and mobility. The items include feeding, transfers from bed to wheelchair and to and from a toilet, grooming, walking, going up and down stairs, dressing, continence of bowels and bladder. See Mahoney FI, Barthel D. Functional Evaluation: The Barthel Index. *Maryland State Medical Journal* 1965; 14, 56-61.

- income – including employment, state benefit, state pension, private pension, asset income and other income
- total savings
- total investments
- gross financial wealth (savings + investments)
- financial debt
- net financial wealth (gross financial wealth – debt)
- net physical wealth (e.g. second homes, art, etc)
- total gross non-housing wealth (savings + investments + physical wealth)
- total net non-housing wealth (total gross non-housing wealth – debt)
- gross housing wealth (value of owner-occupied primary housing before mortgage debt is subtracted)
- net housing wealth (value of owner-occupied primary housing after mortgage debt is subtracted)
- mortgage debt
- net total wealth (savings + investments + physical wealth + net housing wealth – financial debt)

ELSA also includes questions on the likelihood of needing care and to pay for care in the future, as well as views and respondent's expectations of their current and future financial circumstances.

Further details of ELSA individual income and asset variables are in Appendix 2.

4.1.6 End of Life interview

In waves 2 (2004), 3 (2006), 4 (2008), 6 (2012) an 'End of Life' survey was included to collect data on those who had died since the previous wave of the survey. This included their care needs prior to death and financial circumstances at death. ELSA sample members were identified as having died from sample updated in the field or between waves or mortality data from the NHS Central Register database. Individuals were contacted about conducting an End of Life interview on behalf of an ELSA sample members if that sample member had died since the previous wave of ELSA and contact

details for an appropriate End of Life Interview informant were available.⁸ The End of Life questions were asked of a close friend or relative of a deceased ELSA sample member. Informants were prioritised in the following order: (1) potential informant identified by interviewer; (2) another ELSA sample member in the household; (3) proxy nomination.

The interview asked:

- where the deceased ELSA sample member died (including if in a nursing home or care home)
- frequency and length of deceased's stays in place of death
- frequency and length of stays in nursing home or care home in the two years prior to death
- need for help with ADLs in the three months prior to death, and if yes, length of time help had been needed
- receipt of formal help for ADL prior to death (including from a home care worker)
- number and type of pensions held by deceased
- share of home owned by deceased and current value of home (and amount of any outstanding mortgage)
- any other property, other than their main home, owned by deceased

Unfortunately, these data were not collected after wave 6 and the first year for the social care module was wave 6 so there would be no sample member for whom both the social care module and had end of life data were collected. However, if the End of Life interview was included again, with a focus on those who had previously responded to the social care module and with some additional questions, it may be possible to look at links over time between care needs and assets.

4.1.7 Definition of key variables

Each member of the benefit unit is assigned a total benefit unit level income. Housing wealth is assigned only to the person or people named on the property and their partner. Individual items in the ELSA questionnaire pertaining to income and wealth (see

⁸ Prior to ELSA wave 6, it was determined that 562 sample members had died since the wave 4 data collection. Of these, an End of Life interview request was sent to 326 family members or friends. Interviews were obtained in 240 cases (74% response rate).

Appendix 2) are, in some cases, available at the individual level or for the respondent and their spouse/partner.

Individual questions on savings and investments, income, state pension and financial commitments are asked of the respondent and their spouse. Individual questions on private pensions and payment for care are asked of the respondent only.

4.1.8 Strengths and limitations

The main strength of ELSA as a source of data is that it is longitudinal. This would allow analysis to determine if changes in need for and receipt of social care impact on income and assets.

The limitation of the dataset is that it does not include data on individuals in residential care unless the sample member was previously a part of the sample drawn from individuals and households living in private accommodation. Documentation for wave 8 (2016) of ELSA indicates that participants in residential care are asked the same questions as participants in households, apart from two important differences. Firstly, if an individual is single, fewer questions are asked about their income, assets and housing. Secondly, the social care module is not asked as it is intended for people living in their own home. The sample size for those who move into institutions and continue to participate is small. At Wave 8 (2016), of the 7,223 core sample members who participated, 15 took part in an institution interview in person and 43 were proxy institution interviews.

In addition, there was an 'end of life' module asked to the relative of an ELSA sample member who had died since the previous survey. However, the limitation of this is that the focus is on the three months before death, nonetheless it could provide some information on the assets of households where someone needs care before death.

The survey is also limited in that the sample is aged 50 and over so it would provide only partial information on people of working age with care needs. Further, the sample for the survey is subject to attrition over time. The sample is refreshed at regular intervals (last refreshed in the 2018/19 wave).

A strength is that the survey collects detailed data on social care service use as well as income and assets. For those receiving care in their own home there is good quality data on these topics.

4.2 Family Resources Survey (FRS)

4.2.1 Coverage

The FRS collects data on the living conditions and resources of individuals and private household (and benefit units) across the United Kingdom. The FRS began in 1992. For the first ten years the survey covered Great Britain, with Northern Ireland included from 2002/3. It is an annual cross-sectional (that is, data collected at one point in time only) survey. The current target sample is 20,000 households. At the point of review, the most recent reporting of results was for the financial year 2019/20. Data for the 2020/21 financial year is due to be released in March 2022.

The sample does not include people living in institutions so no one in a care home is included.

4.2.2 Methodology

The Great Britain sample is drawn from the Royal Mail's small users Postcode Address File (PAF).⁹ These are grouped into 1,417 postcode sectors and within each, a sample of addresses is selected. The sample in Northern Ireland is identified using the POINTER address database.¹⁰ A random sample of addresses are drawn from this database.

Each selected address is sent a letter explaining that they have been chosen for the survey and emphasising that information given in the interview will be used for research and statistical analysis purposes only. Potential participants sent an information letter about the survey and receive a £10 Post Office voucher included with the letter to encourage participation.

Interviews are conducted face-to-face. A report on the background and methodology of the FRS 2019/20 (the most recent reporting financial year at the point of review) details that the mean interview length in Great Britain was 52 minutes. The household part of the interview is conducted with one adult and asks household level information. The individual schedule is asked of each adult (age 16 and above unless classed as dependent children) in the household.

The FRS accepts proxy response if a household member is unavailable for interview.

⁹ The small users PAF is limited to addresses which receive, on average, fewer than 50 items of post per day and which are not flagged with Royal Mail's "organisation code".

¹⁰ The POINTER is the most comprehensive address database in Northern Ireland with approximately 737,000 address records available for selection.

4.2.3 Data on social care need and/or use

The FRS identifies individuals with a disability by asking respondents if they have any physical or mental health condition or illness that lasts or is expected to last 12 months or more, and which limits their ability to carry out day-to-day activities. If they respond that they do, they are asked if they receive care from paid care workers or unpaid care from family members or friends. The type of care received is not linked to specific tasks.

4.2.4 Data on income, assets, housing wealth and paying for care

FRS asks respondents about income, benefits, pensions, savings and investments. It does not capture information on non-liquid assets such as physical wealth. It also does not collect data on expenditure (except for housing costs).

The data collected are as follows:

1. Income: gross of tax, national insurance and any other deductions from wages.
2. Benefits: in most cases at the benefit unit level.
3. Pensions: including state, individual and employer pensions. The data includes type of pension, amount of last payment, amount of tax and other deductions, how pension wealth is received (e.g. regular payment, lump sum).
4. Savings and investments: asked at a benefit unit level. Respondents are asked which of several bands the total amount of their benefit unit savings and investments are in. Based on the amount reported and type of savings, respondents are either asked about the amount in current and basic bank accounts, the amount of interest that accrues from each account and asset, or the value of each account and asset.
5. Housing tenure/wealth: respondents are asked whether they rent (Council/Housing Association/Private) or whether the property they live in is owned outright or owned with a mortgage. If owned they are asked the purchase price, year bought, mortgage amount, and mortgage term. It may be possible to combine these data with geographic data to estimate the current value of the respondent's home.

4.2.5 Definition of key variables

Income data is collected at the individual level, as is pension information. Benefits and savings and investments data are collected at the benefit unit level. Housing tenure and housing wealth is determined at the household level.

4.2.6 Strengths and limitations

A strength of the FRS is that interviewers ask respondents to check payslips, tax returns and other financial paperwork at the time of the face-to-face interview. The 2019/20, individuals who were employees consulted their latest payslips for 32% of jobs they reported and 54% of households in Great Britain consulted a Council Tax bill or statement in answering questions on their Council Tax payments. This reduces the impact of difficulty of recall. Despite this, the FRS study team note that they think household surveys underestimate income from both self-employment and investments due to the difficulty in recall of detailed financial information and tendency to forget to include one or more income source.

If a household or individual does not know the answer to certain questions or refuses to answer them, this creates a problem for deriving key variables such as total household income. To make the best use of the data available, missing values are imputed. Additionally, prior to publication FRS data are put through several stages of validation and editing to ensure that the final data presented are as accurate as possible.

The FRS study team reports that the data under-reports the number of people on benefits relative to administrative records from the Department for Work and Pensions. Data comparisons suggest that both benefit caseload and receipt are under-reported as some respondents do not know or do not have the necessary information to answer specific questions about individual benefits which makes it difficult to collect accurate information.

The sample does not include people living in institutions so no one in a care home is included.

The data is cross-sectional, so it is not possible to look at associations between changes in social care service use and changes in income and assets over time. Because the data is cross-sectional, however, it can be argued that recent samples will be more representative of the national population than longitudinal samples such as in ELSA and UKHLS which rely on booster sampling to improve representation in their samples to reflect changes in demographics that occur over time and mitigate the impacts of attrition.

A limitation of the survey is that information on social care need and receipt of support is limited. The focus of this survey is on financial information, but housing wealth information is limited.

4.3 Health Survey for England (HSE)

4.3.1 Coverage

The HSE is an annual cross-sectional household survey. Each household member aged 16 and over is sampled. At the point of review, the most recent data collection was from

2019. The sample is of people living in private households and so usually excludes people living in residential care, except in 2000 when the survey focussed on older people and included a care home sample. The care home sample in HSE 2000 consisted of 2,500 care home residents across 677 care homes. Care home residents who were capable of completing a full interview were interviewed in person; other residents were interviewed by proxy.

4.3.2 Methodology

Like the FRS, the sampling for the HSE uses the small user Postcode Address File. From these, a random sample of primary sampling units is selected. Then within each primary sampling unit, a random sample of postal addresses is drawn. Addresses that do not contain private households are excluded. At addresses at which there is more than one dwelling unit, one is selected at random by the interviewer to be included in the survey.

All adults aged 16 and over at each household are interviewed. Interviews are conducted face-to-face and is followed by a nurse visit (for taking biological measurements).

Proxy respondents are not used for individuals who lack capacity or are in hospital, or otherwise unavailable, at the time of the HSE interview.

A £10 voucher is enclosed with the advance information letter sent to each household to encourage participation. Verbal consent is sought (but not recorded) for taking part in the survey. Written consent is sought for specific elements of the survey (such as taking of biological measurements and storing blood samples for future use).

4.3.3 Data on social care need and/or use

Questions asking about the receipt of social care are asked of respondents who are age 65 or older.

The 2011 HSE was expanded to include most of the module of questions on social care. Prior to this, respondents were asked if they had a long-standing illness, disability or infirmity and if so, did their condition require them to cut down on things they do around the home. However, there were limited questions on the support received as a result.

The social care module used in HSE asks about use of meals, lunch club and day centre services.

The social care module of questions in the HSE was expanded in 2013 with additional questions on:

- patterns of care receipt (frequency, days of week, time of day)

- amount paid for care
- aids and equipment

The questions on social care in HSE are very similar to those included in ELSA and UKHLS data and so can be compared. Thus, HSE can provide population level prevalence data to compare with ELSA and UKHLS which are longitudinal.

4.3.4 Data on income, assets, housing wealth and paying for care

Data is collected on household income, disability benefits received, housing tenure and payment for social care.

1. Income: including employment, state benefit, state pension, private pension, interest from savings and investments and any other regular allowance from outside the household (e.g. maintenance, rent). Respondents are asked to report total household income, in bands, in the household interview and the combined income for themselves and their spouse/partner before deductions for income tax, National Insurance, etc in income bands.
2. Disability benefits: respondents are asked if they receive Attendance Allowance, Disability Living Allowance - mobility component, Personal Independence Payment - daily living component, and/or Personal Independence Payment - mobility component; and the amount received for each benefit.
3. Housing tenure: as part of the household interview, respondents are asked if their home is owned outright, owned with mortgage, shared ownership, rented or other. Little information is collected that would allow for valuation of the property (number of rooms only).
4. Payment for care: respondents are asked if they receive a Personal Budget and, if yes, amount received; whether they contribute in user charges or top-up for the Personal Budget; whether they receive care paid for by the council or local authority and, if yes, amount paid; and any private payments for social care.

4.3.5 Definition of key variables

Income, disability benefits and housing tenure are asked at the household level. Payments for care, including receipt of Personal Budgets, are asked at the individual level.

4.3.6 Strengths and limitations

The HSE does not have data on assets. The questionnaire asks for total household income in bands – specific income amounts are not asked for. These less granular data

may be less preferable to having specific amounts and amounts at the individual or couple level. Asking about income in ranges may, however, improve the willingness of respondents to provide income information.

The questions on social care are very similar to those asked on ELSA so it can provide useful comparative data on prevalence as context for analysis of the longitudinal but less representative data on ELSA.

The data is cross-sectional so it is not possible to look at associations between changes in social care service use and changes in income over time. Because the data is cross-sectional, however, it can be argued that recent samples will be more representative of the national population than longitudinal samples such as in ELSA and UKHLS which rely on refreshment samples to increase representation in their samples to reflect changes in demographics that occur over time. The sample excludes those living in residential care or other institutions.

4.4 UK Household Longitudinal Study (UKHLS; Understanding Society)

4.4.1 Coverage

The UKHLS sample is made up of adults (age 16 and over) residing in private households in the United Kingdom. The UKHLS is a panel survey. It began in 2009 and annually collects data from household members. At the point of review, the most recent wave for which data is available is wave 11 (fieldwork in 2020; results published in 2021). The individual questionnaire which asks questions on income and assets is completed by household members aged 16 and above. The social care module is asked of those aged 65 and over.

4.4.2 Methodology

The overall study has multiple sample components. There is the (i) General Population Sample, with a subset General Population Comparison Sample, (ii) the Ethnic Minority Boost Sample in 2009/10 (undertaken to produce enough cases to analyse household and individual from five major ethnic groups), (iii) the Immigrant and Ethnic Minority Boost

Sample in Wave 6 (2015) and (iii) participants from the British Household Panel Survey (BHPS)¹¹ and the Northern Ireland Household Panel Survey (NIHPS).¹²

Sample members are sent an advance mailing shortly before the start of fieldwork explaining that an interviewer will be contacting them. Additionally, to encourage people to keep their contact details up to date, there are between wave mailings and emails to sample members to feedback findings from the study.

Early waves of the survey employed face-to-face interviews only. Online interviewing was used for the first time at Wave 7. Since then, an increasing proportion of households are encouraged to complete the survey online. Due to the Covid-19 pandemic, and the restrictions that prevented any face-to-face interviewing, this was changed to online and telephone completion for those sample members who had not yet been interviewed by the middle of March 2020.

Proxy interviews are offered for adults that are unable or unwilling to complete a full interview (e.g. studying away from home, in institution, on holiday, temporarily unwell etc).

With the exception of individuals that are in prison, sample members who have moved into an institution remain eligible for interview at their new address. Interviewers are instructed to attempt to interview participants where possible but briefed about the need to contact gatekeepers in advance in some circumstances, and also about allowing for sensitivities relating the reasons for the participants moving into an institution such as a nursing home.

An incentive of a gift voucher is either included in the advance letter or handed out by interviewers at the end of the interview. The amount and administration are assigned as summarised in table 1 below.

Table 1: Gift voucher groups

Group	Incentive
Previous wave responding adults and those who have turned 16 years of age since last wave in households surveyed at the previous wave	£10 gift voucher

¹¹ The BHPS was a panel survey that preceded UKHLS. It began in 1991 and followed the same representative sample of individuals in 18 subsequent waves. As part of wave 18, BHPS participants were asked if they would consider participating in the new, larger and more wide-ranging survey Understanding Society (UKHLS).

¹² The NIHPS was an extension of the BHPS which ran in Northern Ireland from 2001 to 2008. As with BHPS, sample members were recruited to participate in the UKHLS.

Group	Incentive
Adults that did not take part at the previous wave but are in household that were surveyed	£10 gift voucher handed out by interviewer at the end of the interview (or posted for web and telephone respondents)
Adults in household that did not take part at the previous wave	£20 gift voucher handed out by interviewer at the end of the interview (or posted for web and telephone respondents)
New entrant adults to households that had taken part at the previous wave	£10 gift voucher handed out by the interviewer at the end of the interview (or posted for web and telephone respondents)
New entrant adults to households that had not taken part at the previous wave	£20 gift voucher handed out by interviewer at the end of the interview (or posted for web and telephone respondents)

4.4.3 Data on social care need and/or use

An adapted version of the social care module asked in ELSA and HSE is included in the UKHLS in some waves (waves 7 (15-16), 9 (17-18), 11 (19-20)) and asked of household members aged 65 and over. The ADL and IADL tasks included are:

- managing stairs,
- getting around the house,
- getting in and out of bed,
- cutting toenails,
- bathing/showering,
- walking down road,
- toileting,
- eating,
- washing face and hands,

- getting dressed,
- managing medication,
- shopping,
- doing housework or laundry, and
- doing paperwork or paying bills.

Questions on who provides help distinguish help for ADLs and IADLs and whether the help is provided by a formal care provider (home care worker, member of reablement team, etc) or an unpaid carer.

4.4.4 Data on income, assets, housing wealth and paying for care

Data is collected on household income, benefits received, saving and investments, housing wealth and payment for social care.

1. Income: including employment income, state benefit, state pension (and State Earnings Related Pension Scheme, private pension, income from savings and investments, and any other payments (e.g. maintenance or alimony, rent from any other property, etc). Respondents are asked to report both total household income and share of joint income with another household member. If the respondent is not retired, they are asked to identify the sources of income they expect to use to provide for their retirement.
2. Disability benefits: respondents are asked if they receive Attendance Allowance, Disability Living Allowance, Personal Independence Payment, but not the amounts received.
3. Housing tenure: as part of the household interview, respondents are asked if their home is owned outright, owned with mortgage, shared ownership, rented or other. The value of their home, if it is owned by them or another household member, and the amount outstanding on any current mortgage.
4. Payment for care: respondents are asked if they pay for all or part of their care received (if partly, asked the proportion total cost of care paid). They are also asked if they receive a Personal Budget and, if yes, amount received; whether they contribute user charges towards, or top-up, their Personal Budget; and whether they receive care paid for by the council or local authority and, if they do, the amount paid by the council or local authority.

Further details of UKHLS individual income and asset variables are in Appendix 3.

4.4.5 Definition of key variables

Within the UKHLS, income is estimated at both the household and individual levels. Saving and investment data are collected at the individual level in each wave, while household investments were asked about in Waves 4, 8 and 12. Respondents are asked in detail about payments for the cost of their own care but are also asked if a family member contributes.

The questionnaire asks respondents who live in an owner-occupied home, which household member owns the house. Therefore, housing wealth can be attributed to that individual or the household. Further information as to contributions by family members to the cost of social care received is also collected, so it should be possible to know if the homeowner, if not the respondent, is contributing to the cost of care received by the respondent.

Proxy respondents are asked a limited number of questions that includes whether or not the individual has a long-standing illness or disability and income but not the more detailed questions on social care need and receipt and the different sources of income asked in the main questionnaire.

4.4.6 Strengths and limitations

The UKHLS interviews every member of a sampled household, so that relations between generations and couples with respect to income and assets can be explored. Proxies are used with sample members who are absent throughout the field period or too old or infirm to complete the interview themselves, including those who may have moved into residential care.

As with any longitudinal study, there is attrition – that is, those lost to follow-up due to being uncontactable (e.g. change of address) or refusal to participate further - from one wave to the next. If attrition persists the sample for longitudinal analysis will be substantially reduced and this may also impact on the longitudinal weights provided in the data.

Although the sample covers people of all ages in households, the detailed information on social care is only collected from people aged 65 and over.

As in ELSA, UKHLS respondents are asked about their plans or expectations regarding the cost of future care needs. The Ethnic Minority Boost and Immigrant and Ethnic Boost samples are also unique in allowing for analysis of contributions to the cost of social care for immigrant and ethnic subgroups within the UK population.

5 Summary and conclusions

The four datasets reviewed are all large data collections with significant potential contributions to examining the income and assets of social care service users. They are all limited, however, in their sample frame, as they do not routinely include people in residential care. Each of the datasets offers the potential for boost samples, follow-ups or linking with administrative data.

Detailed information is obtained on the incomes of respondents in each of the surveys, including income from benefits, state and private pensions. ELSA and UKHLS have more comprehensive data collected on the assets of respondents, compared to the other two datasets. ELSA, HSE and UKHLS all include a version of the module of social care questions with adaptations to fit with their existing survey set up. For example, the social care module is asked of respondents who are aged 50 and over (ELSA) or aged 65 and over (HSE and UKHLS). The opportunity exists to compare the data on income and assets of social care service users and potentially to combine the data across these studies to generate a large sample on which the data could be analysed.

There are only two examples found of data collection at point of entry into care. Both were carried out before the new GDPR regulations. More details are found in Appendix 1.

Core ELSA sample members who move into a residential care home after their first ELSA interview are still eligible for interview. In UKHLS, sample members who have moved into residential care institution are eligible for interview allowing for sensitivities relating the reasons for the participants moving into an institution such as a nursing home. Consideration is needed about how those approaches could be adapted for data protection and Mental Capacity Act legislation.

Analysis of the data from these four surveys is important to determine their feasibility as approaches to collecting representative data on the income and assets of individuals receiving social care, whether in their current form or with adaptations. In particular, it is important to understand the degree to which survey respondents are able to answer specific questions on a range of financial questions to allow users of the data to get a complete picture of the financial situation of respondents. Non-response to questions asking about multiple sources of income and a potentially wide range of investments will make the data less reliable. Analysis that seeks to take advantage of the longitudinal design of ELSA and UKHLS to assess the relationship between changes in need and receipt of social care and changes in income and assets must consider the potential impact of any attrition that has occurred.

Table 2: Characteristics of the ELSA, FRS, HSE and UKHLS

	ELSA	FRS	HSE	UKHLS
Type	Longitudinal	Cross-sectional	Cross-sectional	Longitudinal
Sample size (most recent available data pre Covid-19) ¹³	8,736 individuals (2018-19)	19,175 households (2018-19)	10,250 individuals (2018-19)	49,685 individuals (2017-19)
Sample frame	Follow up from HSE - private households but follows into care homes	Private households	Private households except for care home sample in 2000	Private households with some proxy information on people in care homes
Social Care information	50+ social care module	All adults but limited	65+ social care module	65+ social care module
Income	Detailed	Detailed	Detailed	Detailed
Assets	Detailed	Only financial, not property	Only financial, not property	Detailed
Paying for care	Detailed	Not included	Detailed	Detailed
Additional features	End of life module (but not since 2012 when social care module was introduced)	Focus on financial resources		Large immigrant and ethnic boost sample

¹³ Pre-Covid estimate provided to reflect typical sample sizes as opposed to those potentially distorted by restrictions put in place at the start of the pandemic.

References

Bebbington, A., Darton, R. and Netten, A. (2001) Care Homes for Older People: Volume 2. Admissions, Needs and Outcomes. The 1995/96 National Longitudinal Survey of Publicly-Funded Admissions. Personal Social Services Research Unit, University of Kent at Canterbury

Darton, R., Bäumker, T., Callaghan, L., Holder, J., Netten, A. and Towers, A-M (2012) The characteristics of residents in extra care housing and care homes in England. *Health & Social Care in the Community*, 20 (1). pp. 87-96

Darton, R., Forder, J., Bebbington, A., Netten, A., Towers, A. and Williams, J. (2006) Analysis to Support the Development of Relative Needs Formulae for Older People: Final Report. PSSRU Discussion Paper No. 2265/3. Personal Social Services Research Unit

Netten, A., Darton, R., & Curtis, L. A. (2002). Self-Funded Admissions to Care Homes. Funded/commissioned by: Department for Work and Pensions, Research Report No. 159. Personal Social Services Research Unit.

Personal Social Services Research Unit (2002) Self-funded admissions to care homes: summary of findings, March 2002, Personal Social Services Research Unit, University of Kent

Appendix 1

Previous surveys

The characteristics of residents in extra care housing and care homes in England

In this paper (Darton et al. 2012) present findings on the characteristics of residents of 19 extra care housing schemes and findings of a comparable study of residents who moved into care homes providing personal care. The people who moved into extra care were younger and much less physically and cognitively impaired than those who moved into care homes. However, several of the extra care housing schemes had a significant minority of residents with high levels of dependence on the Barthel Index of Activities of Daily Living. In contrast, levels of severe cognitive impairment were much lower in all extra care housing schemes than in care homes, even among schemes designed specifically to provide for residents with dementia.

The paper presents data on the housing tenure, but not on the incomes or savings, of 601 older people admitted to new extra care housing schemes in around 2005 and 499 older people admitted in 2005 to care homes providing personal care. The residents in extra care were more likely to have been owner-occupiers and less likely to have lived in privately-rented accommodation than those who moved into care homes. 33.5% of the extra care residents were owner-occupiers, 56.7% were local authority or housing association tenants and 9.9 lived in privately rented accommodation (after excluding 92 missing data or not applicable). 26.5% of the extra care residents were owner-occupiers, 57.1% were local authority or housing association tenants and 16.5% lived in privately rented accommodation (after excluding 105 missing data or not applicable).

Darton, R., Bäumker, T., Callaghan, L., Holder, J., Netten, A. and Towers, A-M (2012) The characteristics of residents in extra care housing and care homes in England. *Health & Social Care in the Community*, 20 (1). pp. 87-96

Survey of older publicly funded admissions to care homes and home care users

This earlier report (Darton et al. 2006) provides more information on the 2005 survey of older publicly funded admissions to care homes and a 2005 survey of older publicly funded home care users. It presents information on the financial circumstances of these samples of older social care users combined with other data. Tables C1 and C3 in the report set out the following information.

	Care home	Home care
Tenure		
Owner-occupier	33%	47%
Renting from LA/HA	52%	45%
Renting privately	15%	7%
Other	0%	1%
Savings		
Up to £12,250	77%	59%
£12,251-£20,000	15%	6%
Over £20,000	3%	9%
Did not know	5%	15%
Refused to respond	-	11%
Receipt of Pension Credit		
Yes	66%	45%
No	22%	40%
Did not know	12%	15%
Income per week		
Up to £105	20%	20%
£106-£160	57%	34%
£161-£250	20%	32%
£251+	3%	14%

Note: Missing responses are not included except where indicated

Darton, R., Forder, J., Bebbington, A., Netten, A., Towers, A. and Williams, J. (2006) Analysis to Support the Development of Relative Needs Formulae for Older People: Final Report. PSSRU Discussion Paper No. 2265/3. Personal Social Services Research Unit

The Survey of Self-Funded Admissions to Care Homes

The Personal Social Services Research Unit (PSSRU) at the University of Kent in 1999-2000 conducted a DWP funded survey of self-funded admissions to residential and nursing homes. The survey aimed to establish, among other issues, whether self-funded people in care homes differed in terms of financial assets and informal support from older people in private households.

The survey collected information on 921 care home residents. For 331 of them information was also obtained from relatives or friends. Information about home ownership was available for 848 of the 921 residents, 81% of whom were homeowners prior to admission. Around half of the residents had sold their property by the time of interview, with three-quarters of sales taking place to fund the resident's care.

The levels of assets and incomes among admissions to self-funded care were higher than among the general population of older people living in private households. There was no clear relationship between levels of income and levels of assets for the residents in the survey. A third of the residents had assets of £60,000 or less, but nearly two-fifths had assets in excess of £100,000.

Information on residents' average weekly income was available for 309 residents. Their mean and median incomes were £184 and £150 per week respectively. Information about assets and income was combined to identify the distribution of people across different income and asset groups, with £200 per week income and £50,000 assets used as cut-off points. Slightly over a third (35%) of the residents were in the low-income high-asset group, over a quarter (26%) in the relatively low-income-low assets group, around a third (32%) in the high-income-high-asset group and only 7% in the high-income-low-asset group.

Nine per cent of admissions received Income Support, compared with 15% per cent of the general population in this age group. Nine per cent of residents paid their care home fees with help from their spouse or relative. In the remaining 91% of cases, the resident was either solely responsible for paying the charges or was paying with assistance from the (then) Department of Social Security. Sixteen per cent of residents had a weekly income that exceeded the charge for their care. Around 70% of residents had a weekly income that was insufficient to meet the charge for their care but had assets of more than £16,000.

Netten, A., Darton, R., & Curtis, L. A. (2002). *Self-Funded Admissions to Care Homes*. Funded/commissioned by: Department for Work and Pensions, Research Report No. 159. Personal Social Services Research Unit.

Personal Social Services Research Unit (2002) Self-funded admissions to care homes: summary of findings, March 2002, Personal Social Services Research Unit, University of Kent

The 1995/96 National Longitudinal Survey of Publicly Funded Admissions

The Personal Social Services Research Unit (PSSRU) at the University of Kent in 1995 conducted a DHSC funded survey of local authority funded admissions to residential and nursing homes to identify factors associated with the risk of admission to a care home, to provide data to use in the development of the formulae used to distribute central grant for adult social care to English local authorities. The survey was extended to include longitudinal follow-up over 42 months of this sample of admissions. The objective of the follow-up was to examine the health outcomes for people who enter homes and the total cost consequences to local authorities.

The sample was recruited in 18 local authorities, which were broadly nationally representative in terms of a range of socio-demographic indicators and statistics of care home provision. The survey included 2,573 older people assessed for admission to a residential care or nursing home in the last three months of 1995. Each person in the survey was followed up after one, six, 18, 30 and 42 months, unless they had died or withdrawn.

The information collected at admission and one month follow-up was provided by social services staff. In the other follow-ups, care home managers were asked to complete a questionnaire to record the location of the individual and provide information on their level of dependency. At each follow up consent was sought from the individuals or their families for use of their personal information for research.

The questionnaire at admission, but not the questionnaire at follow-up, included questions about the household's housing tenure and the person's receipt of housing benefit and income support before admission, the person's total income, total capital and net value of any property, and their agreed contribution to the cost of their care, as well as weekly contributions by others.

The great majority of the sample had low incomes implying that they relied on state benefits. Although nearly half had some savings, only 1 per cent had savings above the threshold for claiming income support. 53% received income support, 53% received housing benefit and 61% received attendance allowance (but note that the criteria for these benefits have changed since 1995). Their housing tenure prior to care home admission was 30% owning (including with mortgage), 58% renting from local authority or housing association, 9% renting privately and 3% other.

Bebbington, A., Darton, R. and Netten, A. (2001) Care Homes for Older People: Volume 2. Admissions, Needs and Outcomes. The 1995/96 National Longitudinal Survey of Publicly-Funded Admissions. Personal Social Services Research Unit, University of Kent at Canterbury

Appendix 2

ELSA – Individual income and asset variables

Data on private pensions are as follows:

- adjusted to take account of inflation?
- period last payment covered
- amount received (if amount not known, asked if within set ranges based on period covered)
- is amount before or after tax?
- is pension paid by current employer?
- any withdrawals (single/multiple/none)?
- amount of withdrawal(s) (if amount not known, asked if amount is within set ranges)
- current remaining value of pension fund (if amount not known, asked if within set ranges)

Data on income are as follows:

- any paid work in the past year by yourself or spouse
- amount of wage and salary income received before taxes and other deductions (if amount not known, asked if within set ranges)
- any non-pension annuity income?
- if respondent, spouse or both?
- if received annuity, what amount after tax (if amount not known, asked if within set ranges)

Data on state pension income are as follows:

- received by respondent only, spouse or partner only or both?

- amount received and period covered (if amount not known because paid with benefits, asked for total amount received; if not known for other reasons, asked if within set ranges)

Data on health or disability benefits are as follow:

- type of benefit
- amount received and period covered (if amount not known, asked if within set ranges)

Data on other benefits (includes Pension Credit, Widow’s pension, winter fuel payment)

- type of benefit
- amount received and period covered (if amount not known, asked if within set ranges)

Data on savings and investments are as follows:

- type of saving or investment (e.g. current account, savings account, ISA, Bonds, Stocks or Shares, etc) held by respondent or spouse
- amount held (if amount not known, asked if within set ranges)
- interest or income received last year after tax from investments (if amount not known, asked if within set ranges)

Data on other assets (not including own home) are as follows:

- type of asset (e.g. house, holiday home, inheritance, art or collectibles)
- value of asset
- any income received from asset in the last year?
- amount received (if amount not known, asked if within set ranges)

Data on any other regular payments from people outside household in past year

- type (e.g. loan repayment, maintenance or alimony, royalties etc)
- amount and period covered (if amount not known, asked if within set ranges)

Data on financial commitments are as follows:

- type (e.g. overdraft, personal loan, etc)
- amount and period covered (if amount not known, asked if within set ranges)

Data on housing wealth are as follows:

- current value (if amount not known, asked if within set ranges)
- if mortgage or loan outstanding
- number of years left on the mortgage
- {additional data that may allow for estimate of value (e.g. number of rooms, when built; features etc)}

Data on how care is paid for are as follows:

- in receipt of a direct payment or local authority manages money?
- has a Personal Budget?
- do you or spouse partner pay for formal and/or unpaid care received?
- if yes, amount and period covered (if amount not known, ask if within set ranges)
- if yes, does payment cover all or some of total cost of help received?
- how do you pay for formal and/or unpaid care? (personal income/savings/pension or benefit/Direct Payment/Personal Budget/other)
- does anyone else contribute to pay for formal or unpaid care received (local authority or social services/family member/other/nobody else pays)
- amount paid from Personal Budget for formal and/or unpaid care (and period covering; if amount not known, asked if within set ranges)
- if had residential care home stay, amount paid for this (if amount not known, asked if within set ranges)

Appendix 3

UKHLS – Individual income and asset variables

Data on income are as follows:

- income, income components (investment, miscellaneous, pension, other), amount each component including benefits (PIP, child tax credit, housing benefit, working tax credit, etc), sources of income recorded at previous wave but not in current wave, income reported pre or post tax
- any joint income (person number of joint recipient, last amount received, period covered by last amount received)
- gross earnings (amount, period), total monthly personal income gross, total monthly labour income gross
- gross household income in month before interview, share of imputed household income
- total income from benefits and other sources including alimony; payments from family member not living with you; rent from lodgers (not family members) living with you; rent from any other property
- pension drawdown amount, period covered and whether before or after tax
- annual income from savings and investments, annual
- source of retirement income: savings or investments; state pension; equity release in your home; renting out another property; sale of another property other than your main home; inheritance in the future; earnings from part-time/freelance work; financial support from partner or family; occupational or personal pension; other; none of the above
- interest and dividends reported within set bands

Data on asset are as follows:

- savings and investments
- largest investment asset

Data on housing wealth are as follows:

- housing tenure
- person number of household member owning accommodation
- value of property (amount in £)
- how home came to be owned outright (cash/mortgage/inherited/other)
- original purchase price of property (amount in £)
- year mortgage began
- amount borrowed at purchase
- years left to pay on mortgage
- type of mortgage
- total amount secured against property
- last total monthly mortgage payment

Data on how care is paid for are as follows:

- if they pay for care privately and if so the amount and period
- if yes, they are asked how payments are managed (Direct Payment, Council managed or neither of these)
- if they or their spouse paid towards care, the amount paid and period covered
- the proportion of care cost covered by respondent's payment
- source of respondent's payment for care: (i) personal income, savings, pension or benefit OR (ii) Direct Payment, Personal or Individual Budget from local authority or Council OR (iii) some other source
- other contributors to payment for care: Council or local authority, family member or other
- method of payment of other contributors: Council or local authority social services pay directly, or paid through Direct Payment or Personal or Individual Budgets

- amount paid via direct payment to care provider and period covered
- if received Personal Budget, amount and period covered
- proportion of Personal Budget taken as a Direct Payment
- amount of user cares for social care received
- if contributes to top up Personal Budget, amount and period covered
- if receives care paid for by council or local authority, amount and period covered