

School for Social Care Research

Data on Adult Social Care

Derek King and Raphael Wittenberg

Scoping Review



Improving the
evidence base for
adult social care
practice

The School for Social Care Research

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

About the authors



PSSRU
Personal Social Services Research Unit

Dr Derek King is Assistant Professorial Research Fellow within the Personal Social Services Research Unit at the London School of Economics and Political Science. Derek's areas of expertise are mental health policy and economics, the demand and financing of long term care and cost-effectiveness analysis. He has previously worked in the areas of private medical insurance, priority setting in health care, pharmaceutical policy and development of quality of life instruments. He is currently involved in a number of cost and cost-effectiveness studies of health and social care interventions.

Raphael Wittenberg is Associate Professorial Research Fellow within the Personal Social Services Research Unit at the London School of Economics and Political Science. He is also Deputy Director of the Centre for Health Service Economics and Organisation (CHSEO) at the University of Oxford. At PSSRU, Raphael leads research on direct payments in residential care and on community care for older people as well as modelling work for the MODEM study on care for people with dementia. He was for many years a Senior Economist at the Department of Health, where he led a team of DH analysts providing analysis on social services and mental health services.

NIHR School for Social Care Research
London School of Economics and Political Science
Houghton Street
London
WC2A 2AE
Email: sscr@lse.ac.uk
Tel: +44 (0)20 7955 6238
Website: www.sscr.nihr.ac.uk

This report presents an independent review commissioned by the Department of Health's NIHR School for Social Care Research. The views expressed in this publication are those of the authors and not necessarily those of the NIHR School for Social Care Research or the Department of Health, NIHR or NHS.

© School for Social Care Research, 2015

CONTENTS

Introduction	1
Coverage	2
Methods	2
Findings	3
Data linkage	6
Recent and planned changes to the surveys and data collections	6
Scope for further research	7
About the rest of this report	8
References	8
Glossary	9
Data Collections and Surveys	10
Adult Social Care Activity Data	11
Adult Social Care Survey	13
Adults With Learning Difficulties In England	16
British Household Panel Survey	18
Census	21
The Office for National Statistics Longitudinal Study	25
English Longitudinal Study of Ageing	28
Family Resources Survey	32
General Household Survey	35
Health Survey for England	41
National Minimum Data Set for Social Care	44
Personal Social Services Expenditure and Unit Cost Data	47
Personal Social Services Survey of Adult Carers in England	49
Survey of Carers in Households	52
Understanding Society – The UK Household Longitudinal Study	54
Other Sources of Data on Adult Social Care	57

ABSTRACT

Despite the importance of adult social care in promoting the well-being of several million people in England, data on adult social care is considerably more limited than data on other welfare state services such as health or social security. This report reviewed the range of available quantitative data on adult social care in England, concentrating on 14 main datasets, ranging from the Adult Social Care Survey to the Understanding Society – UK Household Longitudinal Study. Its purpose was to highlight the available quantitative data on adult social care and the scope for making more use of these data in addressing research questions.

The review provides a focused commentary on the broad coverage and quality of the data and practical details about how to access them, as well as plans for future data collections or changes to current collections. Examples are included of how the data have been used in existing studies with a summary of key findings derived from the data. Suggestions are also made about how the data could be used in future research studies. This review also includes some discussion of the issue of linking social care and other data and some of the challenges and opportunities this would present.

It covers national data sources which include information on, for example, need for care, in terms of severe disability; provision of unpaid care from family and friends; numbers of users of care services and volumes of care received and indexes these topics to data collections, and vice versa. Other topics include: characteristics of recipients of unpaid, publicly funded and privately funded care services; expenditure on adult social care; unit costs and payments for care; outcomes of adult social care; numbers and characteristics of providers of formal social care services; and the social care workforce.

The intention is that this review will be updated periodically.

KEYWORDS

datasets, adult social care, research

ACKNOWLEDGEMENTS

The authors would like to thank the key providers of data they approached, especially the Health and Social Care Information Centre (the IC) and the National Centre for Social Research (NatCen). They would also like to thank the reviewers for their comments on this review, as well as the Office for National Statistics and Skills for Care for their comments.

INTRODUCTION

Social care affects the daily lives of several million people in England, who require help with everyday activities including personal care. Around 5.4 million people provide unpaid care to family and friends, according to the 2011 Census. 1.5 million people work in the adult social care sector, providing formal care (Skills for Care 2013). Some 900,000 people receive care arranged by their local authority (Health and Social Care Information Centre 2014, data for 31 March 2014); and it is estimated that at least a further 250,000, possibly more, buy care privately.

Yet, despite the importance of adult social care in promoting the well-being of so many people, data on adult social care is considerably more limited than data on other welfare state services such as health or social security. This is perhaps partly because responsibility for social care is more de-centralised, with responsibility for arranging and funding resting not with central government but with 152 local authorities in England. Moreover, there is a mixed economy of supply and of financing. Social care is provided by many thousands of providers, most of them in the independent sector and many of them small businesses, by a growing number of personal assistants employed by the person they care for and by 5.4 million unpaid informal carers. It is funded by local authorities for those with limited wealth, subject to means tested user contributions, and by users themselves for those with greater wealth. This means that no single agency holds administrative data for all social care in England and that there is no single comprehensive source of data on social care.

Research priorities are often set principally in the light of the most pressing priorities for better evidence to inform the development of social care policy and practice. The availability of data is, however, also inevitably important. Where data are not available for a study and new primary data need to be collected, this clearly impacts on the study's cost and duration. Where data are available it is important that the design and execution of the study ensures that it is used to greatest effect.

This report sets out the main findings of a scoping study commissioned by the National Institute for Health Research School for Social Care Research (NIHR SSCR) from the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE). The aims of the review were to set out clearly:

1. what quantitative data are available on adult social care in England;
2. examples of how the data have been used in existing studies;
3. what the existing data show in terms of key findings from existing studies;
4. some suggestions about how the data could be used in future research studies; and
5. any plans with regard to these existing data sets for future data collections or changes to current collections.

The purpose of this report is to raise awareness of the available quantitative data on adult social care and of the scope for making more use of these data in addressing research

Data on Adult Social Care

questions on adult social care in England. It provides a focussed commentary on the broad coverage and quality of the data and practical details about how to access them.

COVERAGE

The report concentrates on:

- Adult social care, and does not extend to children's social care or other care and support services, other than mentioning when data sets cover both social care and other services: this is in line with the remit of the NIHR SSCR;
- National data (e.g. Health Survey for England, English Longitudinal Study of Ageing) rather than data available only for individual councils;
- Official data available from the Information Centre for Health and Social Care and data from surveys and other sources;
- Data for England and does not extend to Scotland, Wales and Northern Ireland except for mentioning when similar data are available for those countries;
- Quantitative data rather than qualitative data.

It covers data sources which include information on:

- Need for care, in terms of severe disability;
- Provision of unpaid care from family and friends: numbers and characteristics of carers;
- Numbers of users of care services and volumes of care received;
- Characteristics of recipients of unpaid social care, publicly funded social care services and privately funded social care services;
- Expenditure on adult social care, unit costs and payments for care;
- Outcomes of adult social care;
- Numbers and characteristics of providers of formal social care services;
- Social care workforce: numbers and characteristics of care staff.

It includes some discussion of the issue of linking social care and other data and some of the challenges and opportunities this would present.

METHODS

The authors discussed data availability and plans for any new data collections with key providers of data, especially the Health and Social Care Information Centre (the IC) and the National Centre for Social Research (NatCen). The authors reviewed select relevant recent papers on social care data and examined recent reports of social care data

Data on Adult Social Care

published by the Information Centre and recent reports of relevant national surveys. It was not part of the remit of this study to conduct a systematic review of data sources or to conduct fresh secondary analyses of data.

FINDINGS

The findings of this review in respect of each data collection and survey are set out in annexes to this report. The intention of the NIHR SSCR is that these annexes will be updated periodically. A glossary of terms is also annexed. The rest of this report covers context and some general issues.

The great majority of nationally available data on adult social care in England derives from two types of sources: local authority administrative data collated and published by the IC and data from a range of surveys of the population or subgroups of the population. These data are mostly updated annually.

The administrative data provided by local authorities to the IC take the form of aggregate statistical returns (other than the National Minimum Data Set – Social Care): individual service user level data are not available on a national basis, but are held by individual local authorities. The data cover numbers of assessments and reviews, numbers of service users including numbers of carers receiving support, expenditure on adult social care, unit costs of care and user experience of services. The data are limited to services funded by local authorities and do not extend to services purchased privately without local authority involvement (i.e. by people who are sometimes referred to as ‘self funders’ of their care and support¹). Tables setting out the aggregate numbers are available in reports published by the IC on their website www.hscic.gov.uk/ and through the National Adult Social Care Intelligence Service (NASCIS) whose website is <https://nascis.hscic.gov.uk/>. It should be noted that the statistical returns have been reviewed and will be substantially reformed from 2014/5 as explained below.

The survey data are individual level data collected in most (but not all) cases as part of a survey with a wider remit than social care alone. This means that in many cases it is possible to cross-tabulate variables on needs for, or receipt of, care or on provision of care with variables on other issues such as age, gender, marital status, ethnicity, housing, education, social security and employment. For many of the surveys the data are available from the UK Data Service at www.ukdataservice.ac.uk.

Each data source is described in detail in the annexes, which summarise their purpose, coverage, key findings etc. To assist identification of relevant sources for specific topics, Table 1 shows sources by topic, for example adult social care workforce, and Table 2 provides a more detailed topic guide for the surveys.

¹ See Baxter and Glendinning's NIHR SSCR-funded scoping review on self funders (www.sscr.nihr.ac.uk/PDF/ScopingReviews/SR11.pdf).

Data on Adult Social Care

Table 1: Main topics by key sources of data

Topic	Main data sources
Disability among older people (age 65+)	Census 2011; General Household Survey (periodically to 2001); Health Survey for England (from 2011); English Longitudinal Study of Ageing; Family Resources Survey; Understanding Society (and British Household Panel Survey); Adults with Learning Difficulties in England
Cognitive impairment among older people	Cognitive Function and Ageing Studies; English Longitudinal Study of Ageing; Family Resources Survey
Disability among younger adults (18 to 64)	Census 2011; Understanding Society (and British Household Panel Survey); Adults with Learning Difficulties in England
Provision of unpaid care	Census 2011; English Longitudinal Study of Ageing (age 50+); Family Resources Survey; General Household Survey (periodically to 2000); Health Survey for England (from 2011); Personal Social Services Survey of Adult Carers in England; Survey of Carers in Households; Understanding Society (and British Household Panel Survey)
Receipt of unpaid care by older people (age 65+)	British Household Panel Survey; English Longitudinal Study of Ageing; Family Resources Survey; General Household Survey (periodically to 2001); Health Survey for England (from 2011);
Referrals and assessments	Adult Social Care activity data (local authority return)
Receipt of residential care	Adult Social Care Combined Activity Return; Census 2011
Receipt of community-based care	Adult Social Care activity data (local authority return); Health Survey for England (from 2011, older people only)
Payment for care	Health Survey for England (from 2011, older people in the community only); Personal Social Services expenditure and unit cost data (local authority return, user charges)
Expenditure and unit costs	Personal Social Services expenditure and unit cost data (local authority return); Laing & Buisson surveys (care home fees)
Adult social care workforce	National Minimum Data Set for Social Care
Adult social care providers	National Minimum Data Set for Social Care; Laing & Buisson surveys
User experience, outcomes	Adult Social Care Survey, Personal Social Services Survey of Adult Carers in England; Survey of Carers in Households; Adults with Learning Difficulties in England

Data on Adult Social Care

Table 2: Data on adult social care – topic guide to collections and surveys

List of data collections and surveys	Topics
Adult Social Care activity data	Referrals and assessments; receipt of residential care; receipt of community-based care
Adult Social Care Survey	User experience and outcomes
Adults with Learning Difficulties in England	Experiences of adults with learning difficulties (in relation to housing, work, education and training, financial situation, social involvement and support, and health and well-being)
Census	Disability among older people (age 65+); disability among younger adults (18 to 64); provision of unpaid care (2011); receipt of residential care
English Longitudinal Study of Ageing	Disability among older people; cognitive impairment among older people; provision of unpaid care; receipt of unpaid care by older people
Family Resources Survey	Disability among older people (age 65+); cognitive impairment among older people; provision of unpaid care; receipt of unpaid care by older people (age 65+)
General Household Survey	Disability among older people (age 65+) (periodically to 2001); provision of unpaid care (periodically to 2000); receipt of formal and unpaid care by older people (age 65+) (periodically to 2001)
Health Survey for England	Disability among older people (age 65+); provision of unpaid care (from 2011); receipt of community-based care (from 2011, older people only); payment for care (from 2011, older people in the community only); receipt of unpaid care by older people (age 65+) (from 2011)
Laing & Buisson surveys	Expenditure and unit costs (care home fees); adult social care providers
National Minimum Data Set for Social Care	Adult social care workforce; adult social care providers
Personal Social Services expenditure and unit cost data	Payment for care; expenditure and unit costs
Personal Social Services Survey of Adult Carers in England	Provision of unpaid care; user experience and outcomes
Survey of Carers in Households	Provision of unpaid care; user experience and outcomes
Understanding Society – The UK Household Longitudinal Study (and British Household Panel Survey)	Disability among older people (age 65+); disability among younger adults (18 to 64); provision of unpaid care; (receipt of unpaid care by older people (age 65+) in BHPS)

DATA LINKAGE

Linkage between different data sources has the potential to increase greatly the value of data sets and pave the way to a wider range of analyses to address important research questions. The scope for linkage of national data on adult social care is, however, limited.

The Census is linked to death and cancer registrations in the context of the Longitudinal Study, which is a linked data set of 1 per cent of Census records from successive censuses with data on death and cancer registrations incorporated. This enables studies to be conducted of survival rates of care home residents and of unpaid carers. The Health Survey for England (HSE) and English Longitudinal Survey of Ageing (ELSA) data are linked to the Hospital Episode Statistics (HES). This enables data on receipt by older people of community care services, collected in the HSE and ELSA new social care module, to be linked with data on their use of hospital services.

Information from the official local authority returns cannot be linked with health care or other individual level data since the returns are not at individual level. Local authorities and their partner Clinical Commissioning Groups, however, can locally link individual data using NHS numbers. The Nuffield Trust has conducted studies using such linked data (Bardsley *et al.* 2012) but the preparation of linked data sets is not currently routine and such data are not available nationally.

RECENT AND PLANNED CHANGES TO THE SURVEYS AND DATA COLLECTIONS

A team of researchers at PSSRU at the London School of Economics and Political Science and University of Kent, University of East Anglia and NatCen developed a module of questions on need for care and receipt of care by older people living in the community, on payment for care and on provision of unpaid care. A shorter version of this module was included in the HSE for 2011 and 2012. A longer version was included in the HSE for 2013 and in ELSA wave 6. Details are available at www.natcen.ac.uk.

Some of the statistical returns discussed below were subject to substantial changes from 2014/15. The IC conducted a 'zero-based review' of their statistical collections for adult social care, which has resulted in major changes to these collections. The Referrals, Assessments and Packages of Care return (RAP) and Adult Social Care Combined Activity return (ASC-CAR) adult social care activity returns (see below for a discussion of these), which provided data on social care activity such as numbers of assessments, numbers of users of community-based services and numbers of supported residents in care homes, have been replaced from 2014/5 by the new *Short and Long Term Collection (SALT)*. This data collection comprises two main sections, short-term and long-term support.

Data on Adult Social Care

The Personal Social Services Expenditure and Unit Costs Return (PSS-EX1) has been replaced from 2014/5 by the new *Adult Social Care Finance Return (ASC-FR)*. It reflects important aspects of the principles underpinning the transformation of social care. The new financial reporting framework includes the following: Long Term Support; Short Term Support; Social Support; Assistive Equipment and Technology; Expenditure on Social Care Activities; Information and Early Intervention; Expenditure on Commissioning and Service Delivery.

A new *Equalities and Classification* form has been introduced from 2014/5 for use alongside the new SALT and ASC-FR returns as well as the Safeguarding Adults Return (SAR). For the SALT return, for example, it sets out the definitions to be used for a breakdown of the data by accommodation, age, ethnicity, gender, health condition, mechanism of support delivery, outcomes of support, paid employment, primary support reason, routes of access to services, sequels, service types, significant event, support from carer and support setting. The sequels to a request for support include short-term support to maximise independence, long-term services (residential care or community-based care), end of life care, on-going low level support, other short-term support, universal services, or no services provided. This does not, however, mean that the data will be available at individual level: the new returns will continue to provide data by local authority.

Details about the new collections are available at www.hscic.gov.uk/socialcarecollections2015

Previous NIHR SSCR scoping studies

The NIHR School for Social Care Research has commissioned a wide range of methods reviews and scoping studies. The reports are available at www.sscr.nihr.ac.uk/scopingreviews.php and www.sscr.nihr.ac.uk/methodsreviews.php respectively. Of particular relevance to this study is a methods review on the use of 'large scale datasets' in UK social care research (Hussein 2011). Among its recommendations are that social care researchers should accredit the potential value of existing datasets that are relevant to social care practices and invest in identifying available datasets that are relevant to their research questions to produce more robust research findings.

SCOPE FOR FURTHER RESEARCH

The new questions on provision of informal care in the HSE from 2011 onward, in the 2011 Census and in ELSA wave 6, offer opportunities for further studies of unpaid caring with up-to-date data. In particular, for co-resident care of older people, the HSE now provides scope to examine relationships between the characteristics of the carer, the characteristics of the care-recipient, the nature of the caring tasks and the impact of caring on the carer's health and employment.

The new questions on payment for care in the HSE from 2011 onward, with more detailed

Data on Adult Social Care

questions in the HSE for 2013 and 2014, provide scope for the first time to investigate user payments for community-based care of older people.

ABOUT THE REST OF THIS REPORT

The rest of this report details the quantitative data sets that have been identified as especially relevant to researching adult social care in England. Each is discussed with regard to the aim of this study, e.g. some key findings from analyses of the data, to highlight some ways in which the data have been used, etc. The report then discusses each data set in turn. References to some key literature are provided for the data sets.

The following Tables 1 and 2 provide overviews of the data sets included in the report.

REFERENCES

Bardsley M, Georghiou T, Chassin L. *et al.* (2012) Overlap of hospital use and social care in older people in England, *Journal of Health Services Research & Policy*, 17, 3, 133–139.

Health and Social Care Information Centre (2014) *Community Care Statistics: Social Services Activity, England 2013–14, Final release*, available at www.hscic.gov.uk/catalogue/PUB16133

Hussein S (2011) *Methods Review 5: The Use of 'Large Scale Datasets' in UK Social Care Research*, NIHR School for Social Care Research, London.

Skills for Care (2013) *The size and structure of the adult social care sector and workforce in England, 2013*, available at: www.skillsforcare.org.uk/Document-library/NMDS-SC,-workforce-intelligence-and-innovation/Research/Size-and-structure-2013-vweb2.pdf

GLOSSARY

Cross-sectional survey: An observational study in which a sample of the population is drawn at a specific point in time and information collected from the sample once only (although this may involve a combination of actions, for example a face-to-face interview and a nurse visit). If the survey is repeated, a different sample is drawn on each occasion, which means that individuals cannot be followed over time. Also, if the survey is repeated, on each occasion the sample would be drawn using the same methodology in terms of any clustering, stratification etc, to allow samples to be comparable.

Data linkage: This applies where data collected in one survey can be linked, through a common identifier, with data collected through another vehicle, generally administrative data such as death registrations or Hospital Episode Statistics.

Longitudinal survey: An observational study in which the same sample of people is repeatedly observed over a period of time. The same data, or at least much of the same data, is collected from the sample on each occasion. This can also be referred to as Panel data.

Observational study: A study which draws inferences about the possible effects of a treatment on subjects, where the assignment of subjects into a treated group versus a control group is outside the control of the investigator(s).

Panel survey: See 'longitudinal survey' above (NB. The terminology can be used differently, but is used as defined here in the social care surveys summarised here). One distinction is that typically a longitudinal survey collects data at a few time points only, whereas in a panel survey data is typically collected at several times over equally spaced time points (e.g. monthly or quarterly).

Non-response bias: Occurs in a survey if there exists a characteristic that is associated with response (or non-response) to the survey. For example, in a survey about educational attainment, those without educational qualifications may be less likely to complete the survey.

Harmonized data: Requires that survey questions and outputs are identical. This may relate to the study design, sampling, questionnaire, data coding, and/or documentation.

Data Collections and Surveys

ADULT SOCIAL CARE ACTIVITY DATA

Aim of the data collection: The Referrals, Assessments and Packages of Care return (RAP) and Adult Social Care Combined Activity return (ASC-CAR) collect data from councils with social services responsibilities in England about their adult social care activity. The data are used by Central Government for public accountability, policy monitoring and national accounts, and by Local Authorities to assess their performance in relation to their peers.

Coverage: These two data collections cover all adult age groups and all user groups and include data on numbers of contacts from new clients, assessments for new clients, reviews for existing clients, people receiving services across the year and people receiving services on 31 March.

Date and frequency: The data collections are conducted annually. The most recent data available relate to the period 1 April 2013 to 31 March 2014. The data are provided by local authorities to the Health and Social Care Information Centre which publishes a report and tables setting out the findings.

Most of the RAP forms seek data for the full year, but a few forms relate to a snapshot on the last day of the period (i.e. as at 31 March 2014). The returns are concerned with adults aged 18 and over, except returns relating to carers, some of whom may be aged under 18 but caring for an adult aged 18 or over.

Sample size and response rate: All councils provided RAP and ASC-CAR data in 2013/14, albeit there are missing data items for a small number of councils. 144 (95 per cent) councils provided full data for all proformas and less than 0.3 per cent of requested data items were missing from the final data set submitted by councils. All missing data items have been estimated to create national totals.

Headline messages:

- The number of contacts from new clients in 2013/14 was 2,163,000 (up four per cent from 2012/13). Of these, 994,000 required a further assessment or commissioning of ongoing service (an increase of three per cent from 2012/13) while 1,168,000 were dealt with at the point of contact (Health and Social Care Information Centre 2014).
- There were 599,000 assessments for new clients in 2013/14 (down less than one per cent from 2012/13 and down 14 per cent from 2008/9). Following assessment, 65 per cent of these clients went on to receive services as a result of their assessment (a decrease of two percentage points from 2012/13).
- There were 843,000 completed reviews for existing clients in 2013/14 (four per cent less than in 2012/13 and 39 per cent less than in 2008/9).
- The total number of people receiving services in 2013/14 was 1,273,000 (down four per

Data on Adult Social Care

cent from 2012/13 and down 29 per cent from 2008/9). Of these, 1,052,000 received community-based services (a fall of five per cent from 2012/13), 204,000 received residential care (a fall of two per cent from 2012/13) and 85,000 received nursing care (which is two per cent down from 2012/13).

- The number of people receiving self-directed support was 647,000 (up six per cent from 2012/13). 153,000 of them received a direct payment – up seven per cent from 2012/13.
- Of those receiving community-based services not in the form of direct payments in 2013/14, 470,000 received home care, 358,000 equipment, 195,000 professional support, 128,000 day care, 66,000 short term residential care (excluding respite care), 32,000 meals and 75,000 other services.
- The number of carers in receipt of services was 353,000 (down less than one per cent from 2012/13). 49 per cent of them received a carer specific service and 51 per cent received information only.
- Councils funded 186 million contact hours of home care during 2013/14 (a one percent reduction on 2012/13, but a decrease of seven per cent from 2010/11).
- 684,000 clients were recorded as receiving community-based services on 31 March 2014 (a decrease of five per cent from March 2013). The majority of them (58 per cent) were aged 65 and over..
- The number of supported residents as at 31 March 2014 was 213,000 (a decline of one per cent since March 2013 and of 22 per cent since 2004). The number of supported residents in independent residential care was 148,000, and the number in independent nursing care was 56,000.

Caveats: The data on receipt of services include people receiving council funded services following an assessment of their care needs. They do not include people receiving services funded by the council which are not part of a care plan following an assessment or those receiving services which bear no resource cost to the Social Services Department (e.g. people funding their own care or people whose care is funded by the NHS).

Important uses of the data:

- Central government uses the data to: inform policy monitoring; briefings for Ministers; Parliamentary questions; national reporting and accounting for public funding.
- Local government uses the data for: benchmarking against other councils; measuring/monitoring local performance; policy development; service development, planning and improvement; management information, local reporting, accountability; informing business cases; identifying any immediate priorities/areas for concern.

Data on Adult Social Care

Access to reports and tables: The final report of the 2013/14 survey and tables with findings for individual councils are available on the Information Centre website at www.hscic.gov.uk/social-care

Data at regional and council level are available (together with a wealth of other social care data) from the online National Adult Social Care Intelligence Service (NASCIS). NASCIS provides a set of analytical, querying and reporting options, and can be accessed at <https://nascis.hscic.gov.uk/>

Changes to the data collection: The RAP and ASC-CAR activity returns will be replaced by the new Short and Long Term Collection (SALT) return from 2014/15. Guidance for the SALT collection can be found on the 2015 collections web page www.hscic.gov.uk/socialcarecollections2015

ADULT SOCIAL CARE SURVEY

Aim of the survey: The Personal Social Services Adult Social Care Survey (ASCS) for England aims to learn more about whether or not adult social services are helping service users to live safely and independently and the impact on their quality of life. The survey is also used to populate some of the measures in the Adult Social Care Outcomes Framework (ASCOF).

The ASCS is an annual survey which was introduced in 2010/11 and took place for the third time in 2012/13. It replaced an earlier social services User Experience Survey which covered (in different years) home care for older people and community equipment. The ASCS 2010/11 was the first of its kind to cover all service users aged 18 and over receiving services funded wholly or in part by local authority social services.

This survey was developed to understand at national level how well state provided services are meeting user needs, to inform service delivery locally and to monitor and develop standards. It provides a significant pool of personal outcome information for those receiving adult social care and is an important resource for accounting for what has been achieved for local people, for supporting local services and enabling people to make better choices about their care.

The main purpose of the survey is to provide assured, benchmarked local data on outcomes to support local services to think about ways of improving outcomes in a challenging financial climate. The survey is constructed so that an individual outcome can be disaggregated into constituent groups. So, as well as providing an overall quality of life index, the survey provides intelligence on whether specific groups experience better outcomes and whether services are meeting all outcome needs. There are also plans to develop a method for calculating the value added by social services.

Data on Adult Social Care

Coverage: The survey covers all adult age groups and all user groups and includes supported residents in care homes as well as users of community-based services. It asks several questions around quality of life, including an overarching question about the service users' quality of life, as well as questions about satisfaction with care and support received and general health. The quality of life questions are based on those used in the Adult Social Care Outcomes Toolkit (ASCOT) developed by the Personal Social Services Research Unit (PSSRU).

Date and frequency: The survey has been conducted annually since its inception in 2010/11. The data are provided by local authorities to the Health and Social Care Information Centre which publishes reports setting out the findings. Local authorities sent questionnaires to service users for the 2012/13 survey during January to March 2013.

Sample size and response rate: Councils are asked to send questionnaires to a stratified random sample of services users who were receiving services funded wholly or partly by the council on the date of extract from council systems. The response rate to the 2011/12 survey was 40per cent and to the 2012/13 survey, 39per cent.

Headline messages:

- 28 per cent of respondents in 2012/13 reported their quality of life was so good it could not be better or very good (up 1 percentage point from 2011/12), 31 per cent reported it was good, 30 per cent reported it was "alright", 6 per cent reported their quality of life was bad and the remaining 3 per cent reported their quality of their life was very bad or so bad it could not be worse.
- The average score for the Social Care Related Quality of Life was 18.8 (compared with 18.7 in 2011/12) out of a maximum possible score of 24. This is a composite measure calculated using a combination of questions which cover eight different outcome domains relating to quality of life.
- Nearly two-thirds (64per cent) of respondents were extremely or very satisfied with the care and support services they receive (up from 63per cent in 2011/12), 26 per cent were quite satisfied, 6 per cent were neither satisfied or dissatisfied, and the remaining 4 per cent were quite, extremely or very dissatisfied.
- 32 per cent reported they have as much control as they want over their daily life (up 2 per cent points from 2011/2), 44 per cent reported they have adequate control, 19 per cent reported they have some control but not enough and 4 per cent reported they had no control.

Caveats: Some service users are not included, for example:

Those receiving preventative services through grants or service agreements from another party which is funded by the CASSR.

Data on Adult Social Care

Those receiving services funded by the CASSR which are not part of a care plan following a Community Care Assessment such as a reablement service.

Those receiving services which bear no resource cost to the Social Services Department (e.g. people funding their own care or people whose care is funded by the NHS).

Those who lacked the capacity to consent to take part in the survey were not included in the sampling frame but were included in the eligible population to which the results were weighted.

Important uses of the data: Results from the survey are used to populate 6 of the measures in the Adult Social Care Outcomes Framework (ASCOF). These are:

- 1A Social care related quality of life.
- 1B The proportion of people who use services who have control over their daily life.
- 3A Overall satisfaction of people who use services with their care and support.
- 3D The proportion of people who use services and carers who find it easy to find information about services.
- 4A The proportion of people who use services who feel safe.
- 4B The proportion of people who use services who say that those services have made them feel safe and secure.

The definitions for these outcome measures can be seen on the DH website at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/261281/Handbook_of_definitions_v8_0__2_.pdf

The data are also used by among others:

- The Department of Health, for example to inform policy monitoring;
- Local authorities, for example to develop policy, monitor local performance and benchmark against other councils, service development etc;
- The PSSRU for a range of studies (within the work programme of the Quality and Outcomes Research Unit), including studies to examine the factors influencing nonresponse to the survey; the role of factors beyond the control of councils in determining outcomes for service users; the role of factors within the control of councils in determining outcomes for older people living in the community;
- The National Centre for Social Research, to explore satisfaction with social services among different ethnic groups.

Data on Adult Social Care

Access to reports and tables: The final report of the 2012/13 survey and tables with findings for individual councils are available on the Health and Social Care Information Centre website at www.hscic.gov.uk/searchcatalogue?productid=13851&topics=1%2fSocial+care%2fUser+experience&sort=Relevance&size=10&page=1#top

ADULTS WITH LEARNING DIFFICULTIES IN ENGLAND

Aim of the survey: The White Paper 'Valuing People' was published in 2001 and in it, the then government made a commitment to help people with learning disabilities 'to live full and independent lives as part of their local communities' (Department of Health 2001). The government also committed to carrying out a survey to determine what life is like for people with learning difficulties, what support they receive and what do they want and need? It aimed to involve people with learning disabilities at all stages of the research.

Coverage: The survey included individuals living in private households and supported accommodation. Individuals in private households were identified by a private social research company that had a role in conducting the survey and through Social Services Departments. Individuals in supported accommodation were identified by sampling from lists of recipients of housing provided under the 'Supported People' programme, in registered residential care homes or hospitals and residential homes run by the NHS.

The survey uses the term 'learning difficulties', as opposed to 'learning disabilities' as this was the preference of survey participants. In the report, 'people with learning difficulties' is defined as people who since they were a child had a real difficulty in learning many things. It excludes people who have a specific difficulty in learning, such as dyslexia.

The survey collected demographic data and data on the lives of respondents in relation to their housing arrangements and support needs; employment; education and training; financial situation; families, friends and relationships; community involvement; health and well-being; and support.

Date and frequency: The survey was the first national survey of individuals with learning difficulties in England. Survey interviews were conducted between July 2003 and October 2004. The survey has not been repeated.

Survey method: The survey was conducted using face-to-face interviews.

Sample size and response rate: A total of 2,898 interviews were conducted with people with learning difficulties. Private households were screened for inclusion of an individual with learning difficulties. Supporting accommodation facilities that were thought to support people with learning difficulties were contacted. An appendix to the report on the survey does set out analysis done to validate the sample (www.hscic.gov.uk/catalogue/PUB01760/adul-lear-diff-eng-03-04-apx-2.pdf).

Data on Adult Social Care

Headline messages:

- People with learning difficulties were more likely to live in poor and deprived areas.
- Only one in six people with learning difficulties who were of working age were in paid employment. Two-thirds of those unemployed said they would like to be in employment.
- 19 per cent of people with learning difficulties had no contact with family members, and 31 per cent said they had no contact with friends. These rates are higher than in the general population.
- A quarter of the sample had friends who did not have learning difficulties.
- One-third of the sample reported feeling unsafe either in their homes, their local area or using public transportation.
- 20 per cent of the sample were aware of a self-advocacy group in their area, however, only 3 per cent of the sample regularly attended self-advocacy groups.

Caveats:

Because an access sample approach was used to identify individuals to take part in the survey, it cannot be assumed to be a random sample of all individuals with a learning difficulty in England. Analysis conducted by the research team, however, indicates good validity of the sample.

The survey data is now over 10 years old and while considerable information is collected by government departments on the lives of people with learning disabilities, these data does not address many aspects of the lives of people with learning difficulties (e.g. social participation), so it is not possible to determine how these may have changed over time.

Important uses of the data:

- Emerson and Hatton (2007) reported on the social determinants of the health status of individuals with mild or moderate intellectual disabilities. They found that indicators of socioeconomic disadvantage were significantly associated with health status within this population. There was not, however, any association between social participation and health status.
- Emerson and Hatton (2008) used the data to assess the association between indicators of subjective well-being and the personal characteristics, socioeconomic position, and social relationships of adults with intellectual disabilities. Among their results were findings that there was no association between marital status and well-being for men; and relationships with friends who also had intellectual disabilities appeared to be protective against feeling helpless.

Data on Adult Social Care

Access: The data from the survey can be accessed via the UK Data Service at <http://discover.ukdataservice.ac.uk/catalogue/?sn=5293&type=Data%20catalogue>

References:

Department of Health (2001) *Valuing People – A new strategy for learning disability for the 21st Century*. Available online at (accessed 5th June 2015): www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

Emerson E, Hatton C (2007) Socioeconomic disadvantage, social participation and networks and the self-rated health of English men and women with mild and moderate intellectual disabilities: cross sectional survey, *European Journal of Public Health*, 18, 1, 31–37.

Emerson E, Hatton C (2008) Self-reported well-being of women and men with intellectual disability, *American Journal of Mental Retardation*, 113, 2, 143–155.

BRITISH HOUSEHOLD PANEL SURVEY

Aim of the survey: The British Household Panel Survey (BHPS) (www.iser.essex.ac.uk/bhps) began in 1991 and followed a representative sample of individuals in Britain for a period of 18 years. It has been subsumed into the new Understanding Society survey. The BHPS was carried out by the Economic and Social Research Council UK Longitudinal Studies Centre with the Institute for Social and Economic Research at the University of Essex. The BHPS collected information on household organisation, employment, accommodation, tenancy, income and wealth, housing, health, socio-economic values, residential mobility, marital and relationship history, social support, and individual and household demographics.

The aim of BHPS was to collect panel data that can be used to understand social and economic change at the individual and household level in Britain (and from wave 11 the UK). The data has been used to model these change, with the aim of identifying their causes and consequences

Coverage: The BHPS surveys individuals residing in private households. Every adult (age 16 or over) member of sampled households was interviewed for the survey. A Youth Questionnaire existed for respondents between the ages of 11 and 15.

An initial sample of 10,300 individuals, from 5,500 households across Britain, was interviewed for the first BHPS panel survey in 1991. A sample of 2,000 households in Northern Ireland was added in 2001.

The BHPS asked about provision of unpaid care, receipt of formal services and level of disability.

Data on Adult Social Care

It asked about provision of unpaid care to individuals, both within and outside their household, who were sick, handicapped or elderly. The survey asked about the number of people cared for, the relationship of the first two mentioned cared-for persons to the respondent and the total number of hours spend caring (in bands i.e. 5 to 9 hours per week).

The Survey asked if respondents received formal services such as home help, meals on wheels or a social worker. The questions relating to level of disability were limited to a small number of Activities of Daily Living (ADLs). The questions relating to levels of disability were expanded in Wave 7 (1997). Respondents age 65 and over were asked about more ADLs and were asked in more detail about their level of difficulty with these tasks.

Wave 16 of the BHPS (2006) in addition to the previously questions on receipt of unpaid care, included additional questions on receipt of unpaid care from children.

It is also possible to determine receipt of co-resident unpaid help as the individual providing the help was asked to identify the person number of the cared-for person if they resided in the same household.

Proxy interviews were conducted in the BHPS. If an eligible respondent was in hospital or temporary care for the whole of the fieldwork period. From wave 4, proxies were also used if the eligible respondent was physically or cognitively impaired. Only adults (aged 16 and over) were considered as potential proxy informants.

Respondents in institutions were interviewed if they had previously been in the sample as residents of a household within the sampling frame in a previous wave.

Date and frequency: The British Household Panel Survey began in 1991 and was conducted annually until 2008. Individuals who participated in the final wave of the BHPS were invited to participate in the survey which replaced the BHPS, Understanding Society.

Survey method: The BHPS utilised both face-to-face interviews and self-completed questionnaires in each wave.

Sample size and response rate: The initial sample of households approached to take part in the BHPS sampled 8,217 addresses. The initial wave of the BHPS included data from 5,500 households, a response rate of 67 per cent. The sample for Wave 2 and beyond consisted of all eligible adults in all households where at least one interview was obtained in Wave 1. Also non-responding households from Wave 1 were approached for participation in Wave 2 if the residents of the household remained the same. Original sample members who subsequently entered institutions (other than prisons) were approached to participate in subsequent waves.

Sample sizes in BHPS fluctuate from one wave to the next due to attrition, and the addition of new households or individuals.

Data on Adult Social Care

Headline messages:

- The BHPS Wave 12 (2002) included 3,006 individuals age 65 and over. Of these, n=224 (7.5 per cent) received home help. This figure breaks down into 116 who received free home help, 102 who paid for home help, and 6 who received both free and paid home help. In terms of source of home help, 133 received home help through NHS or SSD, 83 received private or voluntary home help, and 6 received both.

Caveats: As with any longitudinal study, there is attrition from one wave to the next in BHPS. In an analysis of factors associated with non-response in the BHPS, Uhrig (2008) found that of the 10,264 individuals interviewed at Wave 1 (full or proxy), only 45 per cent were interviewed at Wave 14. Non-response was associated with the interviewer's ease of access to the interviewee's place of residence, and age and number of hours worked by the interviewee.

Linked data: The BHPS sought consent from all adult respondents to link the BHPS with health data and health service use data from the National Health Service, the Department of Health, the General Registration Office and the Office for National Statistics.

Important uses of the data:

- Della Giusta and Jewell (2014) used data from two waves of the BHPS to investigate the effect of the intensity of care provision to elderly parents on the supply of carers and their well-being. They also assess the extent to which care tasks performed differ between women and men.
- Bell and Rutherford (2013) used Wave 16 of the BHPS to look at the prevalence of care networks – that is spousal care, care from children and/or formal care - and the impact of levels of disability on care networks over time.
- Forder and Fernández used the BHPS to pool data to populate the Personal Social Services Research Unit's dynamic micro-simulation model. Results from the model are used to make projections based on alternative long-term care funding options (Humphries *et al.* 2010).
- Heitmueller and Inglis (2007) used data from BHPS waves 3 to 12 to look at the earnings of informal carers to determine wage differentials between carers and non-carers and the opportunity costs in the form of forgone wages and wage penalties.
- Hirst (2004) used data from Waves one to ten of the BHPS to measure, monitor and evaluate health inequalities associated with the provision of unpaid care. This includes assessing the cumulative impact of caregiving on health inequalities by relating variations in health in carers and former carers to the timing, duration and intensity of caregiving.

Data on Adult Social Care

- Windle *et al.* (2009) used Waves 16 and 17 of the BHPS as the source for a comparison sample in a study of the effectiveness of community-facing services for older people which aimed to promote their health, well-being and independence and preventing or delaying their need for higher intensity or institutional care. BHPS respondents who reported limitation with one or more activity of daily living were used as a quasi-control sample.

Access: All waves of the BHPS can be accessed via the UK Data Service (<http://ukdataservice.ac.uk/>).

References:

Bell D, Rutherford A (2013) Individual and geographic factors in the formation of care networks in the UK, *Population, Space and Place*. DOI: 10.1002/psp.1792.

Della Giusta M, Jewell S (2014) Unpaid work and conformity: Why care?, *Cambridge Journal of Economics*. DOI: 10.1093/cje/beu061.

Heitmueller A, Inglis K (2007) The earnings of informal carers: Wage differentials and opportunity costs, *Journal of Health Economics*, 26, 821–841.

Hirst M (2004) *Health Inequalities and Informal Care: End of Project Report*, Social Policy Research Unit, University of York, York.

Humphries R, Forder J, Fernandez JL (2010) *Securing Good Care for More People – Options for Reform*, The King's Fund, London.

Uhrig SCN (2008) *The Nature and Causes of Attrition in the British Household Panel Survey*, Institute for Social and Economic Research, University of Essex, No. 2008–05.

Windle K, Wagland R, Forder J, D'Amico F, Janssen D, Wistow G (2009) *National Evaluation of Partnerships for Older People Projects*, Personal Social Services Research Unit, Canterbury, Kent.

CENSUS

The modern UK Census began in 1801 and has been conducted at ten-year intervals since then. In addition to the main Census data, the Office for National Statistics Longitudinal Study (LS) links data for 1 per cent of census respondents with event data such as data on births, cancers and deaths. The LS is described separately below.

THE UK CENSUS

Aim of the survey: The Census provides a detailed snapshot of the population and its characteristics. It is used in determining funding allocations in the provision of public services. The most recent Census was conducted in 2011. The 2011 UK Census questionnaire was sent out to every home and communal establishment in the UK. It was run by the Northern Ireland Statistics & Research Agency, National Records of Scotland, and the Office for National Statistics (for both England and Wales). Prior to 2011, the next most recent census took place in 2001.

The aim of the census is to provide information on the population that helps the government develop policies and to plan and run public services such as health and education.

Coverage: The 2011 Census data includes information on whether or not individuals have a long-term health problem or disability and whether or not they provide informal care. The census defines a long-term health problem or disability as one that limits a person's day-to-day activities and has lasted, or is expected to last, at least 12 months. Included in this are problems related to old age. Provision of unpaid care is defined to include looking after or giving help or support to family members, friends, neighbours or others because of long-term physical or mental ill health or disability, or problems related to old age. The census asks about the number of hours of unpaid care provided. As the census aims to get information on the entire population, it has good data on the provision of unpaid care by children and young people.

The question on unpaid care provision was first asked in the 2001 Census. The question was modelled on questions in the General Household Survey.

In the 2011 Census, the item non-response for the question on health problems or disability was 3.2 per cent and 3.2 per cent of values were imputed (across England and Wales). The item non-response for the question on unpaid care provision was 3.5 per cent and 3.5 per cent of the values were imputed (across England and Wales).

Individuals in care homes were asked the same questions as those in households except that they were not asked about their relationship to others within the household. They were also asked about their status within the establishment. The managers of communal establishments were asked about the type of establishment it is, including questions on the age group and population catered for, and management responsibility.

More detailed data on the provision of unpaid care is available from the 2011 Health Survey for England.

Date and frequency: A UK Census is conducted every ten years with the most recent census conducted in 2011.

Data on Adult Social Care

Survey method: UK Census data is collected via a questionnaire. Hard to reach groups were approached to participate. Address lists were prepared to support special enumeration in over 30 different types of establishments and communities (e.g. homeless people, day centres, night shelters, hospitals).

Census questionnaires were hand delivered to care homes. The questionnaires were then collected by special enumerators (and transferred to the census processing site via the census coordinator) or care home residents could complete the census questionnaire online.

Sample size and response rate: The census does not sample from the population but instead seeks to collect information on all individuals within the population. The 2011 Census achieved a person response rate of 94 per cent for England and Wales overall. That is, of the estimated usual resident population in England and Wales, 94 per cent of individuals returned a questionnaire. The household response rate was 95 per cent. Invalid data and non-responses were imputed using complex algorithms specifically designed for census data. Detailed information on this imputation can be found for the 2011 census in the ONS report '2011 Census Item Edit and Imputation Process' (available at: www.ons.gov.uk/ons/guide-method/census/2011/census-data/2011-census-user-guide/quality-and-methods/methods/index.html) and in the Evaluation Report for the 2001 census (available at: www.ons.gov.uk/ons/guide-method/census/census-2001/design-and-conduct/review-and-evaluation/evaluation-reports/edit-and-imputation/index.html).

Data from the 2011 UK Census on health problems or disability and on provision of unpaid care have not, as yet, been released.

The UK Data Service (<http://discover.ukdataservice.ac.uk/catalogue?sn=7205>) made available to registered users a 3 per cent sample of individuals from across the UK in its Individual Licensed Sample of Anonymised Records of the 2001 Census. This constituted a sample of 1,843,525 individuals. Plans for releases of individual and household 'microdata' from the 2011 Census can be found at: <http://census.ukdataservice.ac.uk/get-data/microdata/2011-micro-plans.aspx>.

Headline messages:

- Data from the 2011 UK Census is being released in stages throughout 2013. To date, the data shows that of responders to the question on provision of unpaid care (n=1,8225,595) in the 2001 Census, 182,664 (10 per cent) report providing unpaid care. 2.4 per cent of people in England and Wales provide 50 or more hours of unpaid care per week. There has been a 0.3 per cent increase in the proportion of the population providing unpaid care between 2001 and 2011.
- In England, there are 3.1 million women and 2.3 million men providing unpaid care. This represents 11.8 per cent and 8.9 per cent of the female and male populations respectively. In Wales 210,000 women (13.8 per cent) and 160,000 men (10.6 per cent) provide unpaid care.

Data on Adult Social Care

- The proportion of people providing 20 to 49 hours of unpaid care per week was highest in Wales (2 per cent) and lowest in the South East of England (1 per cent). Wales also had the highest proportion of people providing 50 or more hours a week of unpaid care at 3 per cent. London had the least at less than 2 per cent. In total 12 per cent of people in Wales reported provision of unpaid care, the highest across England and Wales. The prevalence of provision of unpaid care was lowest in London. When compared to 2001, the data for 2011 indicates that the largest increase in the percentage of people providing unpaid care has taken place in the South West of England.

Caveats: The rate of response to the census was lower for some specific groups of individuals within the population. For example, men in same-sex civil partnerships and some ethnic groups were less likely to have completed the census.

Important uses of the data:

- The Office for National Statistics have posted on their website some results (including tables and figures) relating to inequality in the provision of unpaid care in England and Wales (that is, inequality relating to age, region and economic activity). This can be found at: www.ons.gov.uk/ons/rel/census/2011-census/detailed-characteristics-for-local-authorities-in-england-and-wales/sty-unpaid-care.html.
- *The ONS also published a report titled, 'Changes in the Older Care Home Population at Local Authority Level between 2001 and 2011' (ONS 2014a), in which they looked at changes in the number of people aged 65 and over residing in care homes between 2001 and 2011 at regional and local authority level across England and Wales.*
- Another ONS report '*Unpaid Care Expectancies across NHS Clinical Commissioning Groups, England 2010–12*' (ONS 2014b), used data collected at the 2011 Census to estimate the average lifespan spent occupying an unpaid carer role at three distinct ages (age 15, age 50 and age 65) across NHS Clinical Commissioning Groups in England.
- Young *et al.* (2005) used the 2001 Census data, among other data, to investigate the prevalence of unpaid caregiving and geographic variation in the characteristics of unpaid carers in England and Wales. They found that there were geographic variations in the provision of unpaid care, even after controlling for other factors that may impact on the propensity to provide unpaid care. Unpaid care was found to be more prevalent in Wales and the North of England. Further, the authors found that poor health and deprivation – both at the area and individual level – were independently associated with greatly likelihood of providing unpaid care.

Data on Adult Social Care

- Dahlberg *et al.* (2007) used the Individual Sample of Anonymous Records from the 2001 UK Census to study the age and gender characteristics of unpaid carers in the UK. They concluded that informal caregiving was most prevalent amongst those individuals who were most at risk of being placed under strain by the provision of informal care – the elderly and middle-aged women who may have multiple caring roles.
- Del Bono *et al.* (2009) also conducted analysis on the Individual Sample of Anonymised Records from the 2001 UK Census. They sought to disentangle the role of gender and partnership status in the care commitments of individuals aged 65 years and over. They found that gender differences in the provision of unpaid care among older people disappeared once marital status is controlled for and adjustment is made for the presence of other household residents affected by a limiting long-term illness.

Access: The census data can be accessed via the UK Data Service (<http://ukdataservice.ac.uk/>). Census data tables and statistical bulletins and releases are available online at: www.ons.gov.uk/ons/guide-method/census/2011/index.html.

THE OFFICE FOR NATIONAL STATISTICS LONGITUDINAL STUDY

Aim of the survey: The study is conducted and coordinated by the Office of Population Censuses and Surveys with the NHS Central Register having a key role of providing NHS data via their computerised database.

The LS was started in 1974. Data from the original 1971 Census sample have been linked to information from the 1981, 1991 and 2001 Censuses. Among the reasons given for starting the LS was the opportunity to improve the analysis of occupational mortality, to provide better information on fertility and birth spacing and migration.

Coverage: LS data is held for England and Wales. It covers health and mortality, fertility, ageing, family formation, ethnicity and migration.

Date and frequency: The original 1971 LS sample included Census data for people born on one of four selected dates in a calendar year. Updates to the sample at the 1981, 1991 and 2001 Censuses to add new members (through births and immigration) also used these four dates.

Survey method: No additional surveying is done for the 1 per cent of the census respondents who are included in the LS study. The UK Census data is collected via a questionnaire

Sample size and response rate: Over the 30 years it has been running, the LS has data on approximately one million people in England and Wales. At each census, data is collected on approximately 500,000 sample members.

Data on Adult Social Care

Individuals can be lost to follow-up if they are not enumerated at a census; if information on their death is not recorded on the NHS Central Register; or if they have left the country and are living elsewhere temporarily or permanently; or if there are inconsistencies between dates of birth or other information used to establish the census-to-census link. The rate at which data for one census is successfully linked to the subsequent census does not considered valid exits from the study as a loss to follow-up. Deaths or recorded absence at a census due to having left the country are considered valid exits.

The linkage rate between the 1971 and 1981 LS sample was 91.3 per cent. The linkage rate between the 1981 and 1991 LS samples was 90.1 per cent. The linkage rate between the 1991 and 2001 LS samples was 88.0 per cent.

Several factors have been found to be associated with unsuccessful linkages in the LS from one census to the next. These include:

- being young and male
- being born outside of the UK
- being a member of an ethnic minority
- living in a communal establishment
- being single or divorced, or living in a lone-parent family
- being unemployed, a student or being economically inactive
- being in the armed services

In addition to loss to follow-up, the LS data is affected if NHS central Register data cannot be traced for a LS sample member. Unsuccessful tracing can occur if the respondent has not been registered with a doctor or inconsistent names or dates of birth have been used. The rates at which NHS data has been successfully traced for the LS sample were 96.8 per cent, 98.8 per cent, 98.4 per cent and 99.3 per cent in 1971, 1981, 1991 and 2001 respectively. Individual characteristics associated with unsuccessful tracing of NHS data were similar to those associated with loss to follow-up.

Headline messages:

- The LS data, updated to include the 2011 Census data for the original sample, has not as yet been made available publicly.
- In 2001, the LS included data on 110,464 individual between the ages of 40 and 59.5 per cent of these individuals provided 20 or more hours per week of unpaid care.

Caveats: As noted above, loss to follow-up in the LS study is associated with several characteristics. Therefore, the sample available for analysis may not be reflective of certain subgroups within the population.

Data on Adult Social Care

Important uses of the data:

- Grundy (2011) used the LS to look at transitions from private households to residential care in the age 65 and over population over time. They found that over 7 per cent of older people moved from private households to communal establishments between 1991 and 2001. After combining the data of transitions between household/family types from 1971 to 1982, 1981 to 1991 and 1991 to 2001, the authors performed multinomial regression analysis to determine the factors significantly associated with transitions into institutions. For both men and women, the transition was most significantly associated with the individual never having married, the individual being widowed or divorced, and the individual having lived at the start of the period in rented accommodation.
- Grundy and Jitlal (2007) using the LS data found that, among women, transitions from living in private households in 1991 to institutions in 2001 were, among women, strongly associated with being childless, living at the start of the period in rental accommodation, and being unmarried at the end of the period.
- Young and Grundy (2008) used the LS to examine associations between unpaid care provision for 20 or more hours per week, and employment history and marital status among those aged 40 to 59 in England and Wales. Men with a history of lower levels of employment were significantly more likely to become caregivers. Similarly, among women, a history of non-employment was associated with caregiving. Also, women in public sector jobs and those previously in employment with a caregiving dimension were 20–30 per cent more likely than other working women to provide unpaid care.

Access: An application to the LS team must be made to access the data. If access is granted, users of the data are required to sign an LS Licence describing how they must hold and use the data. Aggregate data in the form of tabulations can be sent to LS users. All analysis of individual-level LS data must take place at the LS safe setting in London.

References:

Dahlberg L, Demack S, Bambra C (2007) Age and gender of informal carers: a population-based study in the UK, *Health and Social Care in the Community*, 15, 5, 439–445.

Del Bono E, Sala E, Hancock R (2009) Older carers in the UK: are there really gender differences? New analysis of the Individual Sample of Anonymised Records from the 2001 UK Census, *Health and Social Care in the Community*, 17, 3, 267–273.

Grundy E (2011) *Transitions from independent to supported environments in England and Wales: examining trends and differentials using the ONS Longitudinal Study*, Presentation at: Census 2011: impact and potential, Manchester, UK, 7–8 July 2011.

Grundy E, Jitlal M (2007) Socio-demographic variations in move to institutional care 1991–2001: a record linkage study from England and Wales, *Age and Ageing*, 36, 424–430.

Data on Adult Social Care

ONS (2014a) *Changes in the Older Care Home Population at Local Authority Level between 2001 and 2011*, Office for National Statistics, 5 December 2014.

ONS (2014b) *Unpaid Care Expectancies across NHS Clinical Commissioning Groups, England 2010–12*. Office of National Statistics, 11 June 2014.

Young H, Grundy E (2008) Longitudinal perspectives on caregiving, employment history and marital status in midlife in England and Wales, *Health and Social Care in the Community*, 16, 4, 388–399.

Young H, Grundy E, Kalogirou S (2005) Who cares? Geographic variation in unpaid caregiving in England and Wales: evidence from the 2001 Census, *Population Trends*, Office for National Statistics. No 120 (Summer 200), 23–34.

ENGLISH LONGITUDINAL STUDY OF AGEING

Aim of the survey: The aim of The English Longitudinal Study of Ageing (ELSA) (www.ifs.org.uk/ELSA) is to collect longitudinal multidisciplinary data from a representative sample of the English population aged 50 and over. The study measures outcomes across a wide range of domains to provide data that can be used to look at the causes and consequences of outcomes of interest.

ELSA began in 2002/3 and is conducted every two years on a longitudinal sample of individuals aged 50 and older in England. It collects a range of measures relating to health and disability, biological markers of disease, economic circumstance, social participation, networks and well-being.

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. The sample is selected from people who have previously responded to the Health Survey to England. Partners of original sample members and new partners who have moved into the household since HSE 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.

ELSA covers the following topics:

- Health trajectories, disability and healthy life expectancy
- The determinants of economic position in older age
- The links between economic position, physical health, cognition and mental health
- The nature and timing of retirement and post-retirement labour market activity
- Household and family structure, social networks and social supports
- Patterns, determinants and consequences of social, civic, and cultural participation
- Predictors of well-being

Data on Adult Social Care

The ELSA questions on disability and functioning collect data on ADLs/IADLs, mobility aids, incontinence and health behaviours including smoking, alcohol and physical activity. In all waves the self-reported mobility questions have been complemented by a timed walking-speed test. A nurse visit was added in wave 2 and repeated in Waves 4 and 6. Other modules collect data on aspects of cognitive functioning, such as memory and language.

The ELSA Waves 1 and 2 questionnaires asked if help with ADLs/IADLs was received from family, a volunteer, privately paid employee, social or health service worker, friend or neighbour and whether the sources of help met their needs. Respondents were also asked about mobility aids and experience of incontinence. In Wave 3 respondents were asked about which help was received for each ADL/IADL that they report having a difficulty with. The response options were also added to with options to report home help arranged by social services or privately, nurse, or someone else from health or social services. Additionally, since Wave 3 ELSA has asked if respondents had ever used a lunch club, day care centre, meals on wheels, and if so, the frequency of use of each. In Wave 4 the list of source of help was expanded to include staff in a care/nursing home.

ELSA wave 6 included an expanded module of questions on social care which will also be repeated in Wave 7. The module included questions on receipt of care by respondents and provision of care. More specifically the topics covered are:

- Need for and receipt of care
- Who provides care – formal and informal
- Hours of care provided
- Patterns of care (frequency, days of week, time of day)
- Payment for care (including the amount paid)
- Use of services, aids and equipment
- Whether provide informal care
- Characteristics of people cared for
- Hours of care provided
- Effects of caring

In each wave of ELSA, questions on care provision are asked. Unlike other surveys, these questions are asked about all care provided, so that the person cared for is not necessarily sick, disabled or elderly. Changes to the questions in wave 6 allow people who care for someone who is sick to be identified.

Proxy interviews were conducted in waves 1 to 3 if an eligible respondent was in hospital or temporary care for the whole of the fieldwork period. From wave 4 proxies were also used if the eligible respondent was physically or cognitively impaired. Only adults (aged 16 and over) are considered as potential proxy informants.

Data on Adult Social Care

Date and frequency: The English Longitudinal Study of Ageing began in 2002/3 and is conducted every two years. The original ELSA Wave 1 sample was drawn from respondents to the Health Survey for England in the years 1998, 1999 and 2001, aged 50 years or over at the time they were sampled for ELSA.

Refreshment samples were added in ELSA wave 3 (2006/7) and ELSA wave 4 (2008/9) to ensure that individuals aged 50 to 54 were represented in the sample as the original sample aged. In Wave 4 there was also a more general boost to the sample including people aged 50–74 to maintain sample numbers. At Wave 6 (2012/13) there was a further refreshment sample of those aged 50–55. As with the original sample, refreshment samples were drawn from the HSE.

Survey method: Face-to-face interviews and self-completion forms are used in each wave of ELSA. In addition, in waves 2, 4 and 6 there was a nurse visit. In wave 3, on a separate occasion from the main interview, all respondents were asked to participate in a life-history interview.

Sample size and response rate: Sample sizes in ELSA fluctuate from one wave to the next due to attrition, refreshment and the addition of new partners.

The overall sample size for each wave of ELSA are as follows:

Wave 1 = 12,099

Wave 2 = 9,432

Wave 3 = 9,771

Wave 4 = 11,050

Wave 5 = 10,274

Wave 6 = 10,632

Headline messages:

ELSA wave 6 is the most recently collected data currently available publicly. The fieldwork took place between May 2012 and June 2013. Among the findings were the following (www.elsa-project.ac.uk/uploads/elsa/docs_w6/ELSA%20Wave%206%20report.pdf):

- Among men age 50 and over, 16.0 per cent report one or more limitations with ADLs and 15.7 per cent report (independently) one or more limitations with IADLs. The corresponding rates for women are 19.4 per cent and 23.0 per cent for ADLs and IADLs respectively.
- A higher proportion of women than men have difficulties with ADLs and IADLs across the age ranges above 50 years of age
- The prevalence of ADL and IADL limitations decrease with increasing wealth

Data on Adult Social Care

In ELSA Wave 5 (www.elsa-project.ac.uk/reportWave5)

- 10.9 per cent of men and 15.1 per cent of women report caring for someone in the last month. Provision of informal care was most prevalent between the ages of 52 and 64 years.

Caveats: As with any longitudinal study, there is attrition from one wave to the next in ELSA. For example, of the 'core members' interviewed at Wave 1, 82 per cent completed an interview at wave 2. By Wave 5 the number of original core members retained was 6,242 (51.6 per cent of original sample). Weir *et al.* (2011) found that there is a bias in more recent waves of ELSA that under represents the prevalence of cognitive impairment in these samples. That is, individuals with cognitive impairment are more likely to be excluded and without proxy responses (added for individuals with cognitive impairment in Wave 4) the sample becomes less representative over time.

Linked data: ELSA is harmonized with the Survey of Health, Ageing and Retirement in Europe (SHARE) and the US Health and Retirement Study (HRS). Also, ELSA is linked to the Hospital Episode Statistics.

Important uses of the data:

- Soleauro and Crimmins (2014) used the third wave of ELSA, along with the 2006 Survey of Health, Ageing and Retirement in Europe and the 2006 USA Health and Retirement Study, to analyse the prevalence of incapacity in performing activities of daily living; the associations between household composition and availability of family members to provide unpaid care; and receipt of unpaid care among older adults in Spain, England and the United States.
- Grundy and Read (2012) used data from Waves 1 and 2 of ELSA to investigate whether number of children and, among parents, having a daughter is associated with older people's likelihood of at least weekly face-to-face social contact and later receipt of help if needed. They found that childless women were more likely than mothers to receive help from friends but had lower odds of receiving help from any informal source.
- Vlachantoni *et al.* (2011) used ELSA Wave 4 data to examine the prevalence of unmet need for support among older people with social care needs.
- Details of further publications using ELSA are listed at www.elsa-project.ac.uk/publications/case/related

Access: ELSA Waves 1 to 5 can be accessed via the Economic and Social Data Service (ukdataservice.ac.uk). The ELSA Wave 6 report is available at www.elsa-project.ac.uk/uploads/elsa/docs_w6/ELSA%20Wave%206%20report.pdf.

Data on Adult Social Care

References:

Grundy E, Read S (2012) Social contact and receipt of help among older people in England: are there benefits of having more children?, *The Journals of Gerontology: Physiological Sciences and Social Sciences*, 67, 6, 742–754.

Soleauro A, Crimmins E (2014) Who cares? A comparison of informal and formal care provision in Spain, England and the USA, *Ageing and Society*, 34, 3, 495–517.

Vlachantoni A, Shaw R, Willis R, Evandrou M, Falkingham J, Luff R (2011) Measuring unmet need for social care amongst older people, *Population Trends*, 145, 1, 60–76.

Weir D, Faul J, Lnaga K (2011) Proxy interviews and bias in the distribution of cognitive abilities due to non-response in longitudinal studies: a comparison of HRS and ELSA, *Longitudinal and Life Course Studies*, 2, 2, 170–184.

FAMILY RESOURCES SURVEY

Aim of the survey: The Family Resources Survey (FRS) is sponsored by the Department for Work and Pensions (DWP). It 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. The fieldwork for the survey is currently managed in Great Britain by the Office for National Statistics and NatCen Social Research, and in Northern Ireland by the Department for Social Development (and carried out by the Northern Ireland Statistics and Research Agency).

The FRS aims to (i) support the monitoring of the social security programme; (ii) support the costing and modelling of changes to National Insurance contributions and social security benefits; and (iii) provide better information for the forecasting of benefit expenditure. These functions are important to meet the information requirement of the DWP. Prior to the launching of the FRS, the Department for Work and Pensions had relied on the Living Costs and Food Survey and the General Lifestyle Survey for this information.

Coverage: The FRS is an annual cross-sectional survey. It targeted samples of 25,000 households each year, until 2011/2 when the target was reduced to 20,000 households. It now covers all of the UK having been expanded to include a sample in Northern Ireland in April 2002.

The sample size of the FRS allows for analysis of data for sub groups, such as for regional breakdowns and recipients of certain benefits (DWP 2014).

The FRS asks questions about disability across nine areas of life: mobility, lifting/carrying, manual dexterity, continence, communication, memory/concentration/learning, recognising when in danger, physical coordination and other. The number of areas that

Data on Adult Social Care

have been asked about has changed over time and did so again in 2012/13.

The FRS includes questions on both the receipt and provision of unpaid care. This extends to individual household members who provide help to someone outside the household. There are also questions on who provides/receives help and the frequency of care. Up until 2010/11 the FRS included a question on how long care had been provided.

Proxy responses were accepted under restricted circumstances only.

Date and frequency: The FRS began in 1992 and is conducted annually. The most recent data from the Family Resources Survey is for 2012/13.

Survey method: The data in the FRS is collected through face-to-face interviews of all adults in each sampled household. 'Adults' were defined as those age 16 and over excluding those aged 16 to 19 if they were unmarried and still in full-time education or unwaged training.

Sample size and response rate: In 2012/13 33,774 eligible households were sampled. Of these, 60 per cent fully co-operated (that is, all eligible adults were interviewed and no more than 12 questions in the monetary amount questions were unanswered), 2 per cent partially co-operated (that is, a full interview was obtained from the Household Reference Person's benefit unit) and 33 per cent refused to be interviewed. In 4 per cent of cases the assigned interviewer was unable to make contact with anyone in the household.

Headline messages:

- The prevalence of disability in the adult working age population in the UK is estimated to be 16 per cent. Forty-three per cent of adults over State Pension reported some level of disability. The estimated percentage of the population who were disabled had remained consistent over time at around 19 per cent. The overall number of people living with a disability has increased, however, because of increases in the size of the overall population (DWP 2014). The prevalence of disability is highest in the North East (25 per cent) and Wales (24 per cent) regions. London (14 per cent) has the lowest prevalence of disability.
- Approximately 5.6 million individuals in the UK provide care to a family or friend. This represents 9 per cent of the population. Among working age adults, 11 per cent were carers and among adults above State Pension age, 12 per cent were carers. The percentage of carers by age has remained broadly stable over time (DWP 2014).
- Across the UK, approximately 7 per cent of benefit units receive the care component of the Disability Living Allowance (DLA) and 6 per cent receive the mobility component of DLA. One per cent of respondents across the UK report receipt of Carer's Allowance. 10 per cent of pensioner couples across the UK receive Attendance Allowance (AA). Among single pensioners, AA is received by 9 of males and 14 per cent of females.

Data on Adult Social Care

Caveats: The FRS does not sample from individuals in nursing or retirement homes. This means that statistics relating to the most elderly individuals may not be representative of the individuals of within this age group in the UK more generally.

Some important subgroups may be underrepresented in the FRS. Data can be combined across years to increase the sample size of small groups, though this may complicate the use of the sample weights.

The disability questions in the FRS have changed over time. Thus it is not possible to conduct comparisons over time with respect to specific disability measures.

Relative to administrative records, the FRS has been found to under-report benefit receipt (DWP 2013).

In asking about the financial resources of households and benefit units, the FRS asks a large number of questions requiring recall on very detailed financial information. Therefore, understandably, household surveys are thought to underestimate income; particularly income from self-employment and investment income.

The DWP suggests treating data relating to savings and investments with caution (DWP 2013). The questions relating to these have the lowest response rate of all questions in the survey. The survey also does not capture information on non-liquid assets such as property and accruing pensions.

The rate of reporting provision of unpaid care is lower in the 2009/10 FRS than that reported in the PSS Survey of Carers in Household (also 2009/10).

Linked data: Linking FRS data with administrative data from DWP is important as the administrative data can be used to correct for measurement error resulting from misreporting of information – a common problem with respect to the reporting of individual or household financial data. Permission from respondents must be obtained before the data can be linked.

Important uses of the data:

- Hancock *et al.* (2007) used three years of data from the FRS in modelling personal spending of older people on care home fees or home care. This model is used to assess the distribution effects of alternative long-term care charging regimes.
- Hancock *et al.* (2012) used the FRS to compare the economic circumstances of Attendance Allowance and Disability Living Allowance recipients in the older population.
- Blackburn *et al.* (2010) conducted analysis of the 2004/5 Family Resource Survey data to estimate the prevalence of childhood disability and describe the social and household circumstances of disabled children.

Data on Adult Social Care

- McKay (2010) compared different strategies to constructing an overall measure of deprivation for older people, based on data from the 2008/9 Family Resources Survey.

Access: The DWP's report on the 2012/13 FRS data and results can be accessed online at: www.gov.uk/government/statistics/family-resources-survey-2012-to-2013.

FRS data can be accessed via the UK Data Service (<http://ukdataservice.ac.uk/>).

References:

Blackburn CM, Spencer NJ, Read JM (2010) Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey, *BMC Pediatrics*, 10, 21. doi:10.1186/1471-2431-10-21.

DWP (2014) *Family Resources Survey – United Kingdom, 2012/13, July 2014*, Department for Work & Pensions. Accessed online at: <https://www.gov.uk/government/statistics/family-resources-survey-2012-to-2013>

Hancock R, Wittenberg R, Comas-Herrera A, Pickard L, Juarez-Garcia A, Malley J, King D (2007) Winners and losers: assessing the distributional effects of long-term care funding regimes, *Social Policy and Society*, 6, 3, 375–395.

Hancock R, Morciano M, Pudney S (2012) Attendance Allowance and Disability Living Allowance claimants in the older population: is there a difference in their economic circumstances?, *Journal of Poverty and Social Justice*, 20, 2, 191–206.

McKay S (2010) *Using the New Family Resources Survey Question Block to Measure Material Deprivation among Pensioners*. Department for Work and Pensions, Working Paper No 89.

GENERAL HOUSEHOLD SURVEY

There were two social care related modules in the General Household Survey (GHS):

- A module of questions to older people only about their needs and receipt of care, which was most recently included in 1994/5, 1998/9 and 2001/2; and
- A module of questions to all adults about provision of unpaid care, included every fifth year from 1985 to 2000/1.

The survey was conducted by the Social Survey Division of the Office for National Statistics. The GHS later became known as the General Lifestyle Survey (GLS). The GLS was discontinued in 2012 having transitioned from cross-sectional to a longitudinal format in 2005.

THE GENERAL HOUSEHOLD SURVEY – MODULE ON PROVISION OF UNPAID CARE

Aim of the survey: The GHS/GLS collected data on a range of topics from people living in private households in Great Britain with the aim of these data being used by government departments and other organisations for planning, policy and monitoring purposes. Further, the survey data presented a picture of households, family and people in Great Britain. The GHS includes core questions (household information, migration, ethnicity, employment, pensions, education, health etc) and additional modules. A module of questions to all adults about provision of unpaid care was included every fifth year from 1985 to 2000/1. The purpose was to provide data on the prevalence of unpaid caring in Britain and the characteristics of the unpaid carers.

Coverage: The module of questions relating to provision of unpaid care asked about care provided to someone with long-term physical or mental ill health or disability, or problems related to old age. The 2000/1 questions on informal care asked about the effect of caring on the respondent's health and social life for the first time.

The core set of questions in each annual GHS did include a question on provision of unpaid help if not economically active but otherwise did not cover unpaid caring. Other subjects covered in each annual GHS were health status, use of health services, receipt of benefits and pension arrangements.

Date and frequency: The General Household Survey (GHS) last asked questions relating to provision of unpaid care in 2000/1. The data for the 2000/1 GHS was collected between 1 April 2000 and 31 March 2001. Although the GHS was an annual survey, questions relating to provision of unpaid care were not asked each year. Prior to 2000/1, questions relating to unpaid care provision were asked in the 1995/6, 1990/1 and 1985 editions of the survey. The 1996/97 GHS included a module on young (age 8 to 17 years) carers.

Information on unpaid caring has more recently been collected in the 2009 survey of carers in households (www.hscic.gov.uk/pubs/carersurvey0910), the 2011 Census and the Health Survey for England for 2011 onward.

Survey method: The GHS data was collected in face-to-face interviews. The GHS used a multi-stage sample design, which involves both clustering and stratification. GHS interviewers aimed to interview every adult (aged 16 years and over) in each sampled household. Proxy responses were allowed.

Sample size and response rate: The 2000/01 GHS identified a sample of 12,393 eligible addresses, and were able to conduct interviews at 8,221 of these – a response rate of 67 per cent. These interviews provided data from 14,096 adults.

Data on Adult Social Care

Headline messages:

- Sixteen per cent of respondents aged 16 and over report that they provided unpaid care to a sick, disabled or elderly person. This was an increase of 3 per cent from the 1995 GHS (Maher and Green 2002).
- Women were more likely to be carers than men (18 per cent compared to 14 per cent). This difference was greatest in the 45 to 64 age group. Within this age range, 27 per cent of women identified themselves as carers as compared to 19 per cent of men. Among the over 65s, men were more likely than women to be providing care (18 per cent compared to 15 per cent).
- The North East of England had the highest prevalence of caring in Britain at 20 per cent of respondents. The lowest prevalence of caring was observed in London (11 per cent).
- Among those spending 20 or more hours per week providing unpaid care, 45 per cent were caring for their spouse or partner, 18 per cent were caring for a child and 41 per cent were caring for a parent or parent-in-law.

Caveats: The main caveat with regards to the GHS data is that it is now more than ten years since it was collected. It can serve, however, as a comparator to current estimates on aspects of the provision (and receipt) of unpaid care (for example, from the Health Survey for England). Another general caveat is that the nature of the sample design means that the precision of survey estimates is reduced. The GHS utilises a clustered sample design. Clustering can lead to a substantial increase in sampling error if the households or individuals within the PSUs are relatively homogenous but the PSUs differ from one another. Although this effect is reduced by the use of stratification it is nevertheless a limitation of the survey.

The GHS asks about help provided to a sick, disabled or elderly person but does not ask about specific tasks. There is a risk that there are some tasks for which help is provided where the carer does not recognise as provision of care, and as such the respondent may not recognise themselves as a carer.

Important uses of the data:

- Pickard *et al.* (2010) included the 2000/1 GHS data in a review of questions on provision of informal care.
- Parker and Clarke (2002) used data from the GHS on carers in 1985, 1990 and 1995 to show that over this period there was little change in the services going directly to the people carers support.

Data on Adult Social Care

- GHS data are used in Social Trends (www.ons.gov.uk/ons/index.html?vlnk=13675) which is published annually in the spring. Social Trends draws together social and economic data from various sources to paint a broad picture of British society today, and how it has been changing.
- GHS data are also used in Regional Trends (<http://webarchive.nationalarchives.gov.uk/20140721132900/www.statistics.gov.uk/hub/regional-statistics/index.html>). Regional Trends is a comprehensive regular source of official statistics for the Statistical Regions of the United Kingdom. It includes a wide range of demographic, social, industrial and economic statistics, covering aspects of life in the regions.

Access: GHS data can be accessed via the UK Data Service (<http://ukdataservice.ac.uk/>). Reports of the findings are available in the ONS publication, 'Carers 2000' (Maher and Green 2002).

THE GENERAL HOUSEHOLD SURVEY – MODULE OF QUESTIONS TO OLDER PEOPLE ON RECEIPT OF SOCIAL CARE

Aim: The GHS/GLS collected data on a range of topics from people living in private households in Great Britain with the aim of this data being used by government departments and other organisations for planning, policy and monitoring purposes. Further, the survey data presented a picture of households, family and people in Great Britain. The GHS includes core questions (household information, migration, ethnicity, employment, pensions, education, health etc) and additional modules. A module of questions to older people only about their care needs and receipt of care was most recently included in 1994/5, 1998/9 and 2001/2

Coverage: The module of questions relating to older people covered the following topic areas: ability to perform a wide range of personal care and domestic tasks, receipt of unpaid help with these tasks, receipt of formal services (including frequency of receipt), and contact with family and friends. The questions in the module were asked of individuals age 65 and over. Proxy respondents were not asked these questions. The questionnaire also includes a small number of questions on mobility aids. These questions were asked of all respondents.

The core set of questions in each annual GHS did include some questions regarding health status (self-reported general health and long-standing illness), use of health services (but not social services), receipt of benefits and pension arrangements. With regards to IADL tasks, respondents in the GHS were not asked if they found each task difficult; only if they could or could not perform the task.

Individuals in care homes were not included in the GHS.

Data on Adult Social Care

Date and frequency: The General Household Survey (GHS) last asked questions relating to social care in 2001/2. The data for the 2001/2 GHS was collected between 1 April 2001 and 31 March 2002. Although the GHS was an annual survey, questions relating to social care were not asked each year. Prior to 2001/2, social care questions were asked in the 1991/2, 1994/5, and 1998/9 editions of the survey. The GHS later became known as the General Lifestyle Survey (GLS). The GLS was discontinued in 2012 having transitioned to a longitudinal format in 2005.

Information on older people's ability to perform personal and domestic care tasks, receipt of unpaid help, receipt of care services and payment for care have more recently been collected in the Health Survey for England for 2011 onward.

Survey method: The data was collected in face-to-face interviews. GHS interviewers tried to interview every adult (aged 16+) in each sampled household.

Sample size and response rate: The 2001/2 GHS has data on 3,356 adults age 65 years or older. The sample weights are constructed to compensate for non-response. The documentation of the GHS does not provide data on the response rate of the survey.

Headline messages:

- Of the 3,221 older individuals who were asked about their level of disability, 600 (18.6 per cent) reported difficulty with one or more activity of daily living (ADL) task. 650 (19.4 per cent) reported that they could not perform one or more instrumental activity of daily living (IADL) task.
- Four per cent of all respondents report receipt of home care and 10.4 reported receipt of private help. Of those who report difficulty with one or more ADLs, 13.7 per cent and 16.1 per cent received home help and private help respectively.
- Of those reporting difficulty with one or more ADLs, 84 per cent receive informal (unpaid) help with domestic tasks. Of these, about 40 per cent were receiving informal help from their spouse. Among those reporting difficulty with one or more ADLs, 8.6 per cent of respondents reported receipt of Attendance Allowance.
- The GHS 2001/2 data includes 299 respondents age 85 and over. Of these, 42.3 per cent report difficulty with one or more ADLs. In the 85 and over age group, 87 per cent of those with difficulty on an ADL receive informal care.

Caveats: Key caveats of the GHS module on older people are that the sample is small, and the number of older people with one or more disabilities and the number of service users are small. It is also likely that people with severe disability are under-represented in the GHS.

The wording of the questions on receipt of formal services were such that it may not have been clear to respondents whether questions about local authority home care and private help referred to the sector of the funder or of the provider.

Data on Adult Social Care

Important uses of the data:

- The GHS data were used to develop the formulae for allocating resources for social care equitably between councils (Bebbington and Darton, 1995)
- Personal Social Services Research Unit researchers have used the GHS data in their long-term care finance macrosimulation model (Wittenberg *et al.*, 1998)
- Vlachantoni *et al.* (2011) used the 2001/2 GHS data, along with Wave 4 of ELSA and Wave 18 of the BHPs to investigate the extent and nature of unmet need for social care in later life.
- Pickard *et al.* (2007) used the 2001/2 GHS data in showing that, based on projections of receipt of informal care by disabled older people, care by spouses is likely to increase substantially, while care by children will need to increase by 60 per cent by 2031 to meet the demand for informal care.
- GHS 2001/2 data were used in the 2005 'Focus on Older People' report published by the ONS and DWP (www.ons.gov.uk/ons/rel/mortality-ageing/focus-on-older-people/2005-edition/index.html).
- Broese van Groenou *et al.* (2006) used the 2001/2 GHS data to show that within Britain, socio-economic status was negatively associated with use of informal care, even after adjusting for differences in age, health and marital status.
- GHS data are used in Social Trends (www.ons.gov.uk/ons/index.html?vlnk=13675) which is published annually in the spring. Social Trends draws together social and economic data from various sources to paint a broad picture of British society today, and how it has been changing.
- GHS data are also used in Regional Trends (<http://webarchive.nationalarchives.gov.uk/20140721132900/www.statistics.gov.uk/hub/regional-statistics/index.html>). Regional Trends is a comprehensive regular source of official statistics for the Statistical Regions of the United Kingdom. It includes a wide range of demographic, social, industrial and economic statistics, covering aspects of life in the regions.

Access: GHS data can be accessed via the UK Data Service (<http://ukdataservice.ac.uk/>). A report on the results of the GHS module on older people was published by the ONS and is entitled, 'People aged 65 and over: results of an independent study carried out on behalf of the Department of Health as part of the 2001 General Household Survey' (Bridgwood 2000).

References:

Bebbington AC, Darton RA (1995) *Alternatives to Long-term Hospital Care for Elderly People in London*, PSSRU Discussion Paper 1139, PSSRU, University of Kent.

Data on Adult Social Care

Bridgwood A (2000) *People aged 65 and over: Results of an independent study carried out on behalf of the Department of Health as part of the 2001 General Household Survey*, Office for National Statistics, Social Survey Division, The Stationery Office, London.

Broese van Groenou M, Glaser K, Tomassini C, Jacobs T (2006) Socio-economic status differences in older people's use of informal and formal help: a comparison of four European countries, *Ageing & Society*, 26, 745–766.

Maher J, Green H (2002) *Carers 200*, Office for National Statistics, Social Survey Division, The Stationery Office, London.

Parker G, Clarke H (2002) Making the ends meet: do carers and disabled people have a common agenda?, *Policy & Politics*, 30, 3, 347–359.

Pickard L, Wittenberg R, Comas-Herrera A, King D, Malley J (2007) Care by spouses, care by children: Projections of informal care for older people in England to 2031, *Social Policy & Society*, 6, 353–366.

Vlachantoni A, Shaw R, Willis R, Evandrou M, Falkingham J, Luff R (2011) Measuring unmet need for social care amongst older people, *Population Trends*, 145, 1, 60–76.

Wittenberg R, Pickard L, Comas-Herrera A, Davies BP, Darton RA (1998) *Demand for Long-term Care: Projections of Long-term Care Finance for Elderly People*, Personal Social Services Research Unit, Kent.

HEALTH SURVEY FOR ENGLAND

Aim of the survey: The Health Survey for England (HSE) (www.natcen.ac.uk/series/health-survey-for-england) began in 1993 and is conducted annually. It monitors the health of individuals resident in England. Data from the HSE are used by the NHS and the Department of Health to inform health policy and track progress towards health targets. The HSE is funded by the Health and Social Care Information Centre.

The HSE aims to record trends in health and estimate the prevalence of health conditions and their associated risk factors.

Coverage: The HSE covers a core set of topics which are asked about each year. These include general health, smoking and drinking and objective measures such as height, weight and blood pressure. In addition to these topics, each year the survey includes a module of questions asking about specific health issues such as cardiovascular disease or physical activity.

The 2005 HSE asked about use of local authority home help, private help, district nursing, health visitors (or other kinds of nurses), meals on wheels, lunch club, and day centre services. For each, the frequency of use was also asked. For home help and private help,

Data on Adult Social Care

respondents were asked the number of hours per week that were used. Respondents were also asked if they received and/or provided informal help. The questionnaire did not ask for information about the person(s) involved, however.

The 2011 HSE was expanded to include a module of questions on social care. The topics covered in this module were 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:

- Need for and receipt of care (including Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), and Barthel index)
- Who provides care – formal and informal
- 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 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 were meals, lunch club and day centres.

The questions on provision of care are asked where the person cared for has long-term physical or mental ill-health, a disability or problems relating to old age. Respondents can report on up to three people they care for. For each person cared for the respondent is asked for the relationship of the person cared for, whether or not they live in the same household, the number of hours per week of care provided, the activities they help with and the age and sex of the cared for person.

Further questions on social care were included the 2013 HSE. An expanded module of questions on social care was included, with additional questions on:

- Patterns of care receipt (frequency, days of week, time of day)
- Amount paid for care
- Aids and equipment

The HSE samples from the population living in private households. It does not survey individuals living in institutions. An attempt was made to interview all adults aged 16 years and over at each randomly sampled household. Proxy respondents are not used for

Data on Adult Social Care

individuals who lack capacity or are in hospital, or otherwise unavailable, at the time of the HSE interview.

Date and frequency: The HSE began in 1993 and is conducted annually.

Survey method: HSE data is collected in a face-to-face interview and if participants agree, they also have a nurse visit.

Sample size and response rate: A total of 5,416 eligible households were sampled for the 2013 HSE, a 64 per cent response rate.. The response rate at the individual level was 58 per cent among adults. Of the 8,795 adults interviewed, 2,235 were age 65 years or over.

Headline messages:

- Twenty-three per cent of men aged 65 and over reported a need for help in the last month with at least one ADL and (independently) 22 per cent with at least one IADL. For women the corresponding figures were 33 per cent and 35 per cent. Getting up and down stairs and having a bath or shower were the ADL tasks most often cited as requiring help amongst those aged 65 and over.
- Nineteen per cent of men and 29 per cent of women who reported having difficulty or needing help with at least one ADL task did not receive any help with that task in the last month.
- Among those aged 65 and over, 80 per cent of men and 69 per cent of women did not currently use any form of mobility aid.
- The majority of older people who received help with ADLs or IADLs received this help from informal helpers only (88 per cent of men and 71 per cent of women).
- A summary of the results from the questions on social care in the 2011 HSE can be found in Chapter 2 of the official Information Centre report, *Health Survey for England 2013* (www.gov.uk/government/statistics/health-survey-for-england-2013).

Caveats: The Information Centre's report on the 2013 HSE identifies the following limitations (Information Centre 2014):

- (i) The sample size is relatively small and thus subject to inaccuracies which sampling may introduce
- (ii) Due to the small sample size, data is not available at Local Authority level
- (iii) Due to difference in methodologies and questionnaire design across other health surveys in the rest of the United Kingdom and Europe, there are limitations in the comparability of the results

A further caveat of the HSE is that it does not include data on those who lack capacity to give consent to be interviewed. Individuals who are judged to lack capacity are more likely to need help with ADL and IADL tasks.

Data on Adult Social Care

Linked data: Respondents to the HSE are asked for their consent for their data to be linked to the NHS Central Registry for information about their mortality and cancer and to the NHS Hospital Episode Statistics. An individual's name, address and date of birth are used to find their NHS number. As of May 2014, the linked data was not, as yet, available.

Important uses of the data:

- There exists the possibility to link the HSE data with health outcomes data from the Hospital Episode Statistics and/or cancer and death registries (Information Centre 2012).
- Ismail *et al.* (2014) used data from the 2011 and 2012 Health Survey for England to describe the scale and nature of reductions in publicly funded social care for older adults in England following the financial crisis of 2008.

Access: The HSE data can be accessed via the UK Data Service (<http://ukdataservice.ac.uk/>). The 2013 data are currently available from the UK Data Service. The main report on the HSE 2013 results can be found at the Health and Social Care Information Centre's website at www.hscic.gov.uk/catalogue/PUB16076.

References:

Information Centre (2012) *Health Survey for England – 2011, Health, Social Care and Lifestyles*. Available online at: www.hscic.gov.uk/catalogue/PUB09300 accessed: 3rd June 2013.

Ismail S, Thorlby R, Holder H (2014) *Focus On: Social Care for Older People – Reductions in Adult Social Services for Older People in England*, The Health Foundation and Nuffield Trust, London.

NATIONAL MINIMUM DATA SET FOR SOCIAL CARE

Aim of the data collection: The National Minimum Data Set for Social Care (NMDS-SC) is managed by Skills for Care on behalf of the Department of Health. It collects information on the social care workforce in England. Given the recent and current changing policy around social care and the current economic crisis, the NMDS-SC aims to provide detailed information that can be used by government, strategic bodies, employers and individuals to make decisions relating to the social care workforce that will improve outcomes for users of adult social care services. For example, the data can be used for national and local level workforce planning. The NMDS-SC can also be used to compare information on various aspects of employment conditions, such as pay rates and qualification levels, across social care providers.

Data on Adult Social Care

Coverage: The NMDS-SC currently has data on around 750,000 workers. Data are collated at establishment level with analysis available at local authority (LA), local education and training board, regional and national levels. The dataset includes information of worker demographics such as gender, age, ethnicity, nationality and disability; and information on pay, work experience, and qualifications. There is also information on the main service provided by establishment type, size of establishment and service types including data on overall capacity and utilisation. The NMDS-SC's coverage of adult social care in England reflects data collected to date and does not include data on the entire social care workforce in England, though 100 per cent of LA workforce data is captured.

Date and frequency: The NMDS-SC is an ongoing resource. Organisations that employ social care workers register with the NMDS-SC and are asked to update the information pertaining to their organisation and workforce when changes occur.

Survey method: The data is collected online at www.nmds-sc-online.org.uk. Advice is given as to how to submit NMDS-SC information for those organisations that do not have internet access.

Sample size and response rate: The NMDS-SC currently has information on around 750,000 individuals working in the social care sector. Skills for Care estimate that there are 1.63 million jobs in the adult social care sector in England. Some individuals will do more than one job in the sector. As such, the estimated rate of coverage of the NMDS-SC is approximately 50 per cent of the social care workforce in England.

Headline messages:

- Skills for Care produces an annual report on the size and structure of the adult social care sector and workforce in England. The 2014 report was published in September 2014 (available at: www.skillsforcare.org.uk/Document-library/NMDS-SC,-workforce-intelligence-and-innovation/NMDS-SC/Size-and-structure/SFC-SIZEANDSTRUCTURE-NEW-MASTER-DY.pdf). Much of the data for the analysis provided in the report came from the NMDS-SC. It found that an estimated 17,300 organisations were involved in providing or organising adult social care in England in 2013 and 38,900 establishments employed adult social care staff. 214,000 adults, older people and carers were receiving direct payments from councils as at 2013, an increase over the previous year of 11 per cent.
- Skills for Care also produced a report in 2013 of the characteristics of the workforce in the social care sector (produced once every two years). This was titled, 'The State of the Adult Social Care Sector and Workforce in England, 2014' (available at: www.skillsforcare.org.uk/NMDS-SC-intelligence-research-and-innovation/NMDS-SC/Workforce-intelligence-publications/The-State-of-the-Adult-Social-Care-Sector-2014.aspx).

Data on Adult Social Care

- Some of its findings were that one in five of the adult social care workforce is aged 55 or over, suggesting an older workforce. Eighty per cent of the workforce are women. Also, Black and minority ethnic groups make up 20 per cent of the workforce. The data also indicated an overall turnover rate of 25 per cent. The report presents further results on the pay, qualifications and training of the adult social care workforce.

Caveats: The data collected at establishment level is skewed but Skills for Care use these data in combination with data from the Care Quality Commission, the Inter-Departmental Business Register and the Health and Social Care Information Centre to arrive at their published workforce estimates.

Important uses of the data

- The NMDS-SC is used by strategic stakeholders to inform policy making. The Department of Health and the HSC Information Centre use the data for decision making around funding, resources and policy. The Care Quality Commission (CQC), by accessing the NMDS-SC, removes the burden on employers to provide data to the CQC. The Migration Advisory Committee uses the data to provide evidence on the importance of migrant workers to the social care sector.
- Further, local authorities can use the data to obtain information on the workforce in their local area, helping them to develop their own Workforce Strategies and meeting the aims of the Putting People First initiative. Also Health Education England, responsible for leading on the new education and training system for the health and public health workforce, use the NMDS-SC to inform commissioning decisions on numbers of qualified staff in any particular area.
- Chester *et al.* (2014) used a subset of the NMDS-SC data to compute local authority-level measures of turnover and vacancy level in independent-sector care homes and domiciliary care organisations in England. The extent to which turnover and vacancy levels were influenced by local authority commissioning and contractual arrangements in the two settings was also examined.
- Hussein and Manthorpe (2014) used NMDS-SC data for December 2009 to investigate the impact of employment sector and individual characteristics on pay levels and pay differentials in the English long-term care sector.

Access: The data are accessible directly from the online system via dashboard reporting and downloadable excel files. In addition Skills for Care upload anonymised data files to the NMDS-SC site and to Data.gov. Skills for Care share raw anonymised data with stakeholders if they sign up to their Data Sharing Agreement.

References:

Chester H, Hughes J, Challis D (2014) Commissioning social care for older people: influencing the quality of direct care, *Ageing and Society*, 34, 6, 930–950.

Data on Adult Social Care

Hussein S, Manthorpe J (2014) Structural marginalisation among the long-term care workforce in England: evidence from mixed-effect models of national pay data, *Ageing and Society*, 34, 1, 21–41.

Lynn P, Burton J, Kaminska O, Knies G, Nandi A (2012) *An initial look at non-response and attrition. Understanding Society Working Paper 2012–02*, University of Essex, Colchester. <http://research.understandingsociety.org.uk/publications/working-paper/2012-02>.

PERSONAL SOCIAL SERVICES EXPENDITURE AND UNIT COST DATA

Aim of the data collection: The Personal Social Services Expenditure and Unit Cost Return (PSS-EX1) collects data from Councils with Adult Social Services Responsibilities (CASSRs) in England and reported on gross and net current expenditure on adult social care. The data are used by Central Government for public accountability, policy monitoring and national accounts, and by Local Authorities to assess their performance in relation to their peers.

Coverage: The data collection covers all adult age groups and all user groups and includes expenditure on assessment and care management as well as on residential, community-based services and direct payments.

Date and frequency: The data collection has been conducted annually since 2000/1. The most recent data available relate to the period 1 April 2013 to 31 March 2014. The data are taken from councils' administrative systems used to record personal social services expenditure and income and provided to the Health and Social Care Information Centre which publishes annually a report and tables setting out the findings.

The most recent report looks at overall expenditure and associated income in 2013/14, trends in expenditure over the last five years, and expenditure by the type of provision, such as day and domiciliary care or residential services. It also includes some information on grants. Activity and expenditure data are combined to provide information on Unit Costs of service provision.

Sample size and response rate: All councils have provided PSS-EX1 data in 2013/14, albeit there are missing data items for a small number of councils (0.1 per cent).

Headline messages:

- Gross current expenditure (GCE) spend by councils on adult social care in 2013/14 was £17.2 billion. This is an increase of half of one per cent in cash terms but a decrease of one per cent in real terms since 2012/13. Over the five years between 2008/9 and 2013/14, real terms expenditure decreased by three per cent and, over the ten years between 2003/04 and 2013/14, increased by 8 per cent (but see caveat below) (Health and Social Care Information Centre 2014).

Data on Adult Social Care

- Over half (51 per cent) of gross current expenditure in 2013/14 was on older people (those aged 65 and over). People aged 18–64 with a learning disability accounted for 31 per cent of expenditure, while those aged 18–64 with a physical disability accounted for nine per cent, and those aged 18–64 with mental health needs for six per cent. There was a slight shift in shares of expenditure between 2012/13 and 2013/14 from older people and people with mental health issues to people with learning disabilities.
- The proportion of expenditure on residential care has decreased over the five year period 2008/9 to 2013/14, from 44 per cent to 43 per cent. Over the same period the proportion of expenditure on day and domiciliary care has increased from 43 per cent to 46 per cent. The remaining 11 per cent of expenditure in 2013/14 was spent on assessment and care management.
- Expenditure on Direct Payments was £1.4 billion in 2013/14 compared to £610 million in 2008/09, an increase of around 125 per cent in cash terms or 103 per cent in real terms.
- Net current expenditure on adult social care in 2013/14 was £14.7 billion, only marginally higher in cash terms than the 2012/13 figure of £14.6 billion, and £2.6 billion was contributed by users in charges for their care in 2013/14 compared with £2.5 billion in 2012/13.
- The average cost per week for each adult supported in residential care, nursing care or intensively in their own home was £597 in 2013/14, a decrease of three per cent in real terms from 2012/13.

Caveats: There have been transfers of responsibilities between councils, the NHS and the social security systems on various occasions since 2000/1. Most recently, as part of the Valuing People Now initiative, funding has transferred from the NHS to CASSRs, so the money is no longer included as income from the NHS and netted off gross current expenditure. Further, additional monies have been given to CASSRs via the NHS for spending on social care services which will also benefit the NHS. When Valuing People Now and NHS transfer resources are included, net total expenditure in 2013/14 was £15.5 billion, three per cent higher than the £15.1 billion spent five years previously (2008/9).

In some years some of the unit costs submitted by individual councils appeared very high or low compared to those for the generality of councils of the same type. Councils have provided various explanations including difficulty in attribution of expenditure between "own provision" and "provision by others"; difficulty in attribution of expenditure between "nursing care placements" and "residential care placements"; difficulty in attribution of expenditure between client groups.

Data on Adult Social Care

Important uses of the data:

- Central government uses the data to: inform policy monitoring; briefings for Ministers; Parliamentary questions; national reporting and accounting for public funding.
- Local government uses the data for: benchmarking against other councils; measuring and monitoring local performance; policy development; service development, planning and improvement; management information, local reporting, accountability; informing business cases; identifying any immediate priorities and areas for concern.
- The PSS-EX1 data are used within a large number of research projects conducted by Personal Social Services Research Unit (PSSRU) and the Quality and Outcomes of Person - centred Care Policy Research Unit (QORU), Economics of Social and Health Care Research Unit (ESHCRU) and Policy Innovation Research Unit (PIRU).

Access to reports and tables: The final report of the 2013/14 survey and tables with findings for individual councils are available on the Health and Social Care Information Centre's website at: www.hscic.gov.uk/social-care

Data at regional and council (CASSR) level are available (together with a wealth of other social care data) from the online National Adult Social Care Intelligence Service (NASCIS). NASCIS provides a set of analytical, querying and reporting options, and can be accessed at <https://nascis.hscic.gov.uk/>

Changes to the data collection: The new Adult Social Care Finance Return (ASC-FR) will replace the Personal Social Services Expenditure and Unit Costs Return (PSS-EX1) from 2014/15. Information about it is available at: www.hscic.gov.uk/socialcarecollections2015

References:

Health and Social Care Information Centre (2014) *Personal Social Services: Expenditure and Unit Costs, England: 2013–14*. Final release, 9 December 2014.

PERSONAL SOCIAL SERVICES SURVEY OF ADULT CARERS IN ENGLAND

Aim of the survey: Since 2001, Councils with Adult Social Services Responsibilities (CASSRs) in England have been required to conduct surveys of users' experience of social services. User experience surveys (UESs) offer councils information about how users perceive the services they receive and how they might improve local services. UES data was collected by CASSRs and centrally collated by the Health and Social Care Information Centre. Until 2009, carers' views have been sought only as an adjunct to those of service users.

Data on Adult Social Care

The development of the 2009/2010 The Personal Social Services Survey of Adult Carers in England (PSS SACE; Fox *et al.* 2010) drew heavily on previous work carried out by Personal Social Services Research Unit (PSSRU) for Kent County Council in 2008 (Holder *et al.*, 2009). The sample included carers who were looking after people with a range of needs including: dementia, problems connected to ageing, learning disability or difficulty, physical impairment, sensory impairment, mental illness, difficulties with drugs or alcohol, long-term illness and terminal illness. The heterogeneity of the sample population necessitated that the survey design was responsive to the varied experiences and needs of carers.

A strategy for carers (Department of Health 2008) was introduced by the then government in 2008. It identified four key outcomes to be achieved by 2018:

- Carers will not be forced into financial hardship.
- Carers will be supported to stay mentally and physically well and treated with dignity.
- Carers will be able to have a life of their own alongside their caring role.
- Carers will be respected as expert care partners.

The Department of Health planned to monitor the impact of the new strategy using a variety of methods. One approach was the collection of baseline information about carers' experiences and outcomes with a view to repeating the survey at intervals in the future to monitor the impact of the strategy over time. The questionnaire was developed in consultation with the Social Services User Survey Group and the Strategic Information Group on Adult Social Care. The survey was carried out by CASSRs under the guidance of the NHS Information Centre for Health and Social Care.

Coverage: The 2009/10 PSS SACE was voluntary and 90 CASSRs participated. The survey included carers aged 18 and over who had been assessed or reviewed by social services during the previous year and, in some CASSRs, carers identified from the records of service users (known as 'carers by association'). The 2012/13 Survey of Adult Carers in England was mandatory. Data was collected between 1 April 2012 and 31 March 2013.

In addition to basic demographic information, the survey asks about health conditions of the cared-for person, their use of formal services, support or services received by the carer, the work and social situation of the carer, whether or not caring has affected the health of the carer and the type of help given by the carer to the cared-for person.

Date and frequency: The survey was conducted in 2009/10 on a voluntary basis. From 2012, the Personal Social Services Survey of Adult Carers in England is conducted biennially and is compulsory for CASSRs.

Survey method: The survey was a self-completion postal survey. Some councils offered face-to-face interviewing and telephone interviewing as completion options but these account for only 1 per cent of responses.

Data on Adult Social Care

Sample size and response rate: Out 125,950 carers of users of social care invited to participate in the 2012/13 survey 57,810 responded. This represents a response rate of 46 per cent.

Headline messages:

- Thirty-six per cent of carers reported that they were extremely or very satisfied with the support and services they and the person they care for received from Social Services in the last 12 months. Twenty-nine per cent reported being quite satisfied; 11 per cent were neither satisfied nor dissatisfied; 5 per cent were quite dissatisfied and 4 per cent were very or extremely dissatisfied. Sixteen per cent of the sample reported that neither they nor the person they cared for had received any support in the last 12 months.
- Half of the sample reported that it was either very or fairly easy to find information and advice about support for themselves in their caring role. Thirty-two per cent said they always felt involved or consulted as much as they wanted to be, in discussions about the services provided to the person they care for.
- Control of their daily lives was reported by 29 per cent of carers; 12 per cent reported no control over their daily lives. Based on a composite measure of quality of life which combined the responses on six difference domains, an average carer quality of life score of 8 (maximum score 12) was observed.

Caveats: While the response rate is in line with what would be expected from a postal survey, it is low. This may lead to non-response bias. That is, the answers of those that responded may differ from the full range of responses that would be answered if the sample included those that did not answer the survey. Further, the response rate differed for certain subgroups. For example, it was 34 per cent for carers known by association, but 46 per cent for carers assessed separately and 40 per cent for those that had a joint assessment with the person they care for. This may be because the basic information on carers known by association may not be up to date, resulting in non-response.

Twenty-two councils did not achieve a sample size such that any estimates from the survey have a 95 per cent confidence interval of less than + or – 5 per cent.

To maximise returns, respondents were allowed to have help completing the questionnaire. Approximately 10 per cent of carers reported receiving help.

Because not all carers included in the survey will have had an assessment or received services, as a result, some basic demographic information is missing for a sizeable proportion of the respondents.

Important uses of the data:

- Malley *et al.* (2010) used the PSS SACE data to inform the choice of appropriate and robust carers' experience performance indicator.

Data on Adult Social Care

- Emerson *et al.* (2011) used data from the PSS SACE to report key statistics on the carers of people with a learning difficulty or who are learning disabled.
- Ismail *et al.* (2014) report data from the 2012/3 PSS SACE to report on perceptions of quality of life among unpaid carers in England.

Access: The 2012/13 data (provisional) and a provisional report of the results can be accessed at: www.hscic.gov.uk/catalogue/PUB10963.

References:

Emerson E, Hatton C, Robertson J, Roberts H, Baines S, Evison F, Glover G (2011) *People with Learning Disabilities in England 2011: Services & Supports*. May 2012. *IHAL 2012–04*. Improving Health and Lives: Learning Disabilities Observatory. Available at: www.improvinghealthandlives.org.uk/publications/1063/People_with_Learning_Disabilities_in_England_2011 (accessed on 14 June 2013).

Ismail S, Thorlby R, Holder H (2014) *Focus On: Social Care for Older People – Reductions in adult social services for older people in England*, The Health Foundation and Nuffield Trust, London.

Malley J, Fox D, Netten A (2010) *Developing a Carers' Experience Performance Indicator*, PSSRU Discussion Paper 2734, Personal Social Services Research Unit, Canterbury, Kent.

SURVEY OF CARERS IN HOUSEHOLDS

Aim of the survey: The Survey of Carers in Households (SCH) was commissioned by the Department of Health as part of the Government's Carers' Strategy programme. The survey was undertaken by the Health and Social Care Information Centre. The survey was also part funded by the Department for Work and Pensions.

A new Carers' Strategy was launched in June 2008. "Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own" set out goals for the role, respect and quality of life of carers. As part of the strategy the SCH was commissioned. The survey would aim to go beyond the usual questions about carers and the health and social services they receive and will ask questions about employment, income and housing. It would act as a means to assess how progress was being made to achieving the goals of the Carers' Strategy.

Coverage: The survey targets unpaid carers in private households in England. Individuals who provide care in a professional capacity were excluded. The carers' questionnaire was based largely upon the General Household Survey (GHS) module on unpaid cares. The survey collected demographic information as well as data on support given to the main person(s) cared for (up to seven persons), support for carer, access to specific services for the carer, impact of care-giving on the carer in terms of their health and employment.

Data on Adult Social Care

With respect to care provided, the survey asks about tasks helped with, the frequency with which help is provided for each task, and the total number of hours providing care across all cared for persons. The survey also asks about what formal services the cared-for person receives, reasons why formal services were not used, whether or not the carer has had a carer's assessment and whether or not the carer receives any services.

Date and frequency: The survey was conducted in 2009/10.

Survey method: The method of selecting addresses was designed to replicate that of the GHS. Households across England were screened using a stratified clustered two-stage probability design. The first stage involved selecting 528 postcode sectors as primary sampling units (PSU). In the second stage, addresses were randomly selected from each (PSU). An initial sample of carers was identified via a short screening 'prevalence' questionnaire, completed by over 25,000 individuals aged 16 and over. For the full survey, at each household where contact was made, interviewers used a short questionnaire to collect data on all adults aged 16 and over in the household.

Sample size and response rate: The response rate for the household screening was 77 per cent. The response rate amongst eligible respondents was 76 per cent. 2,401 carers were interviewed for the SCH.

Headline messages:

- The data found that 15 per cent of households contained a carer and, among individuals aged 16 and over, 12 per cent were looking after or giving special help to a sick, disabled or elderly person. Of this twelve per cent, half were looking after someone in the same household and half were looking after someone who lived in a separate household.

Caveats: The data in the survey is self-reported and is not corroborated by the cared-for person.

The NHS Information Centre, in their overview of the SCH, compared the age-standardised prevalence of the provision of unpaid care in England observed in the SCH with that in the 2000 GHS, 2001 Census, FRS (2004/2005 and 2005/2006) and BHPs 2007. They found that in the SCH and other surveys (Census, FRS) where questions on unpaid care were asked of one respondent on behalf of the household, the prevalence of unpaid care provision was lower than in those surveys where the questions on unpaid care provision were asked of all adults in the household. The rates of reporting of higher-intensity caring (20 or more hours a week) were similar across surveys regardless of the survey method, however, suggesting that recall of the caring responsibility of others in the household was better if that person provided unpaid care for 20 or more hours a week.

Data on Adult Social Care

Important uses of the data:

- Milne *et al.* (2012) used data from the SCH to show that few carers are aware of their right to request flexible working.
- Yeandle and Joynes (2012) looked at the rate of employment of women at different levels of intensity of caring from the SCH to corroborate data from Leeds.

Access: The Survey of Carers in Households data can be accessed via the UK Data Service (<http://ukdataservice.ac.uk/>).

Documentation on the survey is available at the UK Data Service website:

<http://discover.ukdataservice.ac.uk/catalogue/?sn=6768&type=Data%20catalogue#documentation>

References:

Milne A, Brigden C, Palmer A, Konta E (2012) The intersection of employment and care: Evidence from a UK case study, *European Journal of Social Work*. DOI:10.1080/13691457.2012.724388.

Yeandle S, Joynes V (2012) Challenges in combining work and care: Evidence from investigating women's work in Leeds, *Local Economy*, 27, 8, 816–830.

UNDERSTANDING SOCIETY – THE UK HOUSEHOLD LONGITUDINAL STUDY

Aim of the survey: Understanding Society replaced the British Household Panel Survey (BHPS). It is the main UK household longitudinal survey. The first wave of Understanding Society took place in 2009/2010. Household members are surveyed at each wave to collect information on changes to their household and individual circumstances. The survey is funded by the Economic and Social Research Council with additional funding from multiple government departments. The survey is designed and managed by the Institute for Social and Economic Research at the University of Essex.

The aim of Understanding Society is to provide high quality longitudinal data about subjects such as health, work, education, income, family, and social life to help understand the long term effects of social and economic change, as well as policy interventions designed to impact upon the general well-being of the UK population (McFall 2011).

The overall study has multiple sample components. There is (i) the General Population Sample, with a subset General Population Comparison Sample, (ii) the Ethnic Minority Boost Sample, and (iii) participants from the British Household Panel Survey. The Ethnic Minority Boost sample was undertaken to produce enough cases to analyse household and individual from five major ethnic groups. Former BHPS sample members were added

Data on Adult Social Care

to the Wave 2 Understanding Society sample.

Coverage: The Understanding Society sample is made up of adults (age 16 and over) residing in private households in the United Kingdom.

Wave One included 50,994 individuals from 30,169 households. The individual level data includes responses from proxies. The breakdown of the sample is as follows: 43,674 individuals in the General Population Sample and 7,320 in the ethnic minority boost sample.

In addition to demographic information, the dataset covers questions on the provision of unpaid care. Unpaid care is defined as caring for someone who is sick, disabled or elderly. The provision of care questions includes data on number of hours spent caring, relationship to cared-for person and whether caring prevents the respondent from being in paid employment.

The long term content plan for Waves One to Ten of Understanding Society is available at: www.understandingsociety.ac.uk/documentation/mainstage.

Date and frequency: Each wave within Understanding Society is collected over a 24 month period with each sample member within participating households interviewed yearly. The data for Wave One was collected between January 2009 and January 2011 and for the second wave between January 2010 and January 2012. The sample from the British Household Panel Survey was added to become part of Understanding Society from Wave Two onwards. The former-BHPS sample includes respondents to the Northern Ireland Household Panel Survey which started in 2001. Wave 4 of Understanding Society became publicly available in November 2014.

Survey method: Data collection for Understanding Society takes place through face-to-face interviews.

Sample size and response rate: A total of 45,325 households were included in the General Population Sample in Wave One of Understanding Society. This represented a response rate of 57.6 per cent. The Ethnic Minority Boost sample included data from 10,111 households (52 per cent of those sampled).

The household response rate at Wave Two for those included in Wave One was 77.0 per cent. The response rate from the former-BHPS sample was 77.8 per cent. The response rate at Wave Two for the Ethnic Minority Boost sample was 67.5 per cent.

Headline messages:

- A total of 7,990 respondents (unweighted) report their number of hours spent providing unpaid care in Wave One. The number of hours caring was reported in categories. Of those not reporting varying number of hours caring, 39.5 per cent were caring for 10 or more hours per week and 25.3 per cent were caring for 20 or more hours per week.

Data on Adult Social Care

Caveats: As with any longitudinal study, there will be attrition from one wave to the next in Understanding Society. If the rate of loss to follow-up from Wave One to Wave Two, approximately 20 per cent, persists the sample for longitudinal analysis will be substantially reduced and this may also impact on the longitudinal weights provided in the data. The rate of loss to follow-up was slightly greater for the former BHPS sample members, and higher still for the Ethnic Minority Boost sample. Lynn *et al.* (2012) conducted an analysis of the data to look at whether or not individual characteristics were associated with non-response.

More detailed data on the provision of unpaid care is available from the 2011 Health Survey for England.

Linked data: There are places to link the data from Understanding Society with several other data sources. The current linkages are: geographic identifiers, administrative data linkage and organisations. Consent for use of linked data is requested from all respondents to the main survey.

The Health Survey for England has considerable data on provision of unpaid care (number of individuals cared-for, amount of time spent caring) that can be compared to the Understanding Society data.

Important uses of the data

- The main findings document based on the first two years of the survey is available at: www.understandingsociety.ac.uk/research/publications/findings/2012.
- Details of further methodological publications about Understanding Society are listed at: www.understandingsociety.ac.uk/research/publications/working-papers.

Access: Waves One and Two of Understanding Society can be accessed via the UK Data Service (<http://ukdataservice.ac.uk/>).

The user guide for Waves One to Four of Understanding Society is available at: www.understandingsociety.ac.uk/documentation/mainstage.

References:

Lynn P, Burton J, Kaminska O, Knies G, Nandi A (2012) An initial look at non-response and attrition. *Understanding Society Working Paper 2012–02*, University of Essex, Colchester. <http://research.understandingsociety.org.uk/publications/working-paper/2012-02>.

McFall SL (2011) *Understanding Society – The UK Household Longitudinal Study, Wave 1, 2009–2010, User Manual*, University of Essex, Colchester.

OTHER SOURCES OF DATA ON ADULT SOCIAL CARE

The Safeguarding Adults Return (SAR) is a collection of tables of data supplied by councils to the Health and Social Care Information Centre. It replaced, from 2013/14, the previous Abuse of Vulnerable Adults (AVA) return. It covers data on the number of individuals for whom there have been safeguarding referrals, the number of concluded referrals and the number of serious case reviews and includes information on the victim, alleged perpetrator and alleged offence.

The Cognitive Function and Ageing Studies (CFAS) are large UK-based longitudinal multi-centre studies, funded by the Medical Research Council, looking at health and cognitive function in older people. The first study (CFAS I) started in the late 1980s with the initial aim of investigating dementia and cognitive decline in a representative sample of more than 18,000 people aged over 65 years in the community and in care homes. New cohorts (CFAS II) based in England and Wales started in 2008, building on the design and infrastructure of CFAS I. The surveys collected data on demographic characteristics, lifestyle health status, disability, cognitive function, social support, hearing and vision, and receipt of services. Data from the surveys have been used for a wide range of studies. Information about the surveys, publications from studies using the data and how to access the data is available on the CFAS website www.cfas.ac.uk

The Labour Force Survey (LFS) is a large survey of the employment circumstances of the UK population living at private addresses, student residencies or NHS facilities. Each household which is selected to participate is included for five successive quarters giving the survey a longitudinal element. It includes among other topics data on employment status, industry, occupation, hours of work, employment patterns, training and earnings. It can be used to examine the characteristics of employees working in the social care sector, subject to caveats about how far social care jobs can be robustly identified within the Standard Occupational Classification and Standard Industrial Classification.

The Annual Survey of Hours and Earnings (ASHE) is a large UK sample survey of employee jobs. It provides annual data on the distribution of earnings and hours by age, gender, region, industry and occupation. It can be used to examine the distribution of earnings of employees working in the social care sector, subject to caveats about how far social care jobs can be robustly identified within the Standard Occupational Classification and Standard Industrial Classification.

The British Retirement Survey 1988/9 and 1994 contains a range of longitudinal information on the family, social and economic circumstances of people aged 55 to 69 (and their spouses). There are however just two waves of data, for 1988/9 and 2004, with considerable attrition between them. The survey includes employment, partnership and parenthood histories, which enables analyses to be conducted of the relationship between these histories and receipt and provision of care by older people. Glazer and Grundy (2002) used this survey to investigate the relationship between class, caring and disability.

Data on Adult Social Care

References

Glazer K, Grundy E (2002) Class, caring and disability: evidence from the British Retirement Survey, *Ageing and Society*, 22, 325–342.

Glazer K, Tomassi C, Racioppi F, Stuchbury R (2006) Marital disruptions and loss of support in late life: a longitudinal study of the United Kingdom, *European Journal of Ageing*, 3, 207–216.

School for Social Care Research

Phase I (2009–2014) of the NIHR School for Social Care Research (SSCR) was a partnership between the London School of Economics and Political Science, King's College London and the Universities of Kent, Manchester and York. Phase II (2014–2019) of SSCR is a partnership between the London School of Economics and Political Science and the Universities of Bristol, Kent, Manchester and York, and is part of the National Institute for Health Research (NIHR) www.nihr.ac.uk/.



NIHR School for Social Care Research
London School of Economics and Political Science
Houghton Street
London
WC2A 2AE
020 7955 6238
www.sscr.nihr.ac.uk
sscr@lse.ac.uk