



Office for
Statistics Regulation

Adult Social Care Statistics in England

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Contents

Executive Summary	3
1. Introduction	5
Why this matters.....	5
Our unique perspective	5
What we hope to achieve	6
Our approach	6
This report	7
2. Overview of Adult Social Care in England	8
Policy context	8
Data landscape	8
3. System-wide issues	10
Leadership and infrastructure	10
Data Gaps	11
4. Existing statistics.....	15
Accessibility.....	15
Coherence and Insight	16
Quality	17
Timeliness	17
Granularity.....	18
5. Conclusion and next steps	19
Annex A: Organisations that we spoke to during this review	20
Annex B: Summary of statistics on Adult Social Care	21
Official statistics.....	21
Other statistics.....	22

Executive Summary

This report sets out the findings from our review of adult social care statistics in England. Adult social care is a large and important area which requires strong evidence to support effective policy development, delivery of care and personal choice. Latest [figures](#) from HM Treasury show that public expenditure on personal social services in England (table 10.1 of that report) amounted to £24.5 billion in 2017/18, and this does not include the significant private expenditure on social care. For comparison, £72.5bn was spent on education and £120.5bn on health. Our review finds that this important sector of public policy is very poorly served by data.

The need for good data to support delivery of adult social care should not be underestimated. While there is rightly a focus on delivery, a scarcity of funding has led to under investment in data and analysis, making it harder for individuals and organisations to make informed decisions. This needs to be addressed. The need for information is increasing as society evolves and the demands on social care services over coming years look set to increase. Improved data matters in solving problems, supporting efficiency and maximising outcomes. It is also important to inform decisions made by individuals about the care they receive or provide for themselves and their families.

We have grouped the issues we've identified into three areas: leadership and collaboration; data gaps; and existing official statistics.

Better leadership and collaboration

There are many different organisations involved in the process of publishing official statistics on social care. To make improvements will require collaboration across traditional boundaries: across government departments; across local authorities; and between public and private sector providers. There needs to be a strong voice to champion statistics that meet a range of user needs and strong leadership to implement the required changes.

In line with the [introduction of new technologies](#) to assist healthcare, we want to see progress made with proposed infrastructure that will support the integration of health and social care data so that there is a better understanding of the interaction between health and care and an individual's experience. We welcome plans set out in the government's [vision for digital, data and technology](#) in health and care and hope the establishment of NHSX, a body to 'progress digital transformation of the NHS', will allow government to deliver on this ambition while considering data needs. There is also potential for ONS to support the sector through innovative approaches to data analysis, such as data linking, and use of provisions in the Digital Economy Act.

Addressing Data Gaps

There are significant gaps in what adult social care data currently measures. These include:

- **Delivery of social care outside statutory control:** Statistics on social care activity are primarily sourced from data provided by Councils with Adult Social Services Responsibilities (CASSRs). The established assessment criteria mean that many individuals privately funding care or receiving informal care have little or no contact with a local authority. CASSRs can therefore only measure part of the picture. These limited data have to act as a proxy for the whole social care sector. The information on unmet need and future demand is also limited.
- **Funding outside statutory control:** There are gaps in understanding of the scale of household expenditure on privately funded care and the value of unpaid care. There is no

official estimate of the value of unpaid care provided by family and friends, but unofficial estimates that do exist vary between [£100bn](#) and [£132bn](#) per year, far exceeding HM Treasury spending, giving a sense of the unacknowledged value of this support.

- **Individual experiences and quality of care:** There is little information on pathways and transitions between health care and social care - new infrastructure is required to effectively address this. There is also little information on the quality of care and outcomes for those who experience social care.

The gaps identified are significant and need to be addressed in order to support effective delivery and facilitate improved outcomes for those who experience social care. There is public and policy interest in knowing about social care activity and spend wherever it happens, whether in the home, in a residential home or nursing home. The traditional route of relying on data collected by local authorities to complete official statistics is not enough.

Improving existing official statistics

There are improvements which should be made to the existing official statistics, around accessibility, coherence, quality, timeliness and granularity of the data. This would improve insight and allow the existing data to better meet user needs. We welcome ONS proposals for a portal to signpost users to existing social care statistics and want to see all producers of social care statistics take on the recommendations we have set out in letters to the relevant Head of Profession for Statistics following our detailed review of official statistics outputs as part of this review.

We will continue to work with a range of organisations to make the case for improvements to social care statistics. We hope to raise the profile of the issues highlighted in this report and work towards parity of esteem between health and social care statistics.

Improved statistics can support policy makers who are developing proposals to reform the funding and delivery of adult social care as well as individuals who will be able to hold government to account and make better informed decisions about issues which impact the lives of themselves and their families.

1. Introduction

Why this matters

Adult social care is an area of significant public and private spending which affects the lives of millions of individuals. Latest [spending figures](#) from HM Treasury show that public expenditure during 2017/18 on personal social services in England (table 10.1 of that report) amounted to nearly £24.5 billion. For comparison, £72.5bn was spent on education and £120.5bn on health. There were more requests for social care ([1.9 million](#)) in the year than there were people receiving social care (approximately 840,000). This review, which focuses on adult social care, will demonstrate that this important sector of public policy is very poorly served by data.



In 2018/19, gross current expenditure on adult social care by local authorities was £18.7 billion.



There were 841,850 clients receiving long term care in 2018/19

Source: [NHS Digital Adult Social Care Activity and Finance Report 2018-19](#)

Adult social care stands out as a major public policy area with significant data limitations, particularly when compared to the data rich health system. NHS Digital only collects and publishes expenditure information on long term care, for example. Good data is essential to support effective delivery and help individuals make decisions about their lives.

Adult social care is most commonly defined as the provision of social work, personal care, protection or social support services to adults in need or at risk. It helps people to live as independently as possible, with support offered in individuals' homes, residential or nursing homes and other community settings. In many cases social care provision is dependent on assessment of an individual's needs and financial resources.

Our previous review of [health and care statistics](#) focused on health statistics, but highlighted that adult social care has not been measured or managed as closely as health. For example, there are more comprehensive, useful statistics on hospital activity in the NHS, than on the entirety of social care.

While there is rightly a focus on delivery of social care, a scarcity of funding has led to under investment in data and analysis, making it harder for individuals and organisations to make informed decisions. This needs to be addressed if social care is going to evolve to support a changing society and meet the increasing demands expected over coming years. [Requests for support](#) have been rising since 2015/16, with the number for working-age clients rising faster than the number for people aged over 65.

Our unique perspective

As the Office for Statistics Regulation (OSR) we regulate official statistics in the UK. Our vision is statistics that serve the public good, and is underpinned by the three pillars of the [Code of Practice for Statistics](#):

- Trustworthiness - Confidence in the people and organisations that produce statistics;
- Quality - Data and methods that produce assured statistics;
- Value - Statistics that support society's needs for information.

We want to see statistics that provide a robust evidence base for national and local policy development and decision making. We also champion the need for statistics to support a much wider range of uses, including, by charities, community groups and individuals. They should allow individuals and organisations to reach informed decisions, answer important questions, make the case for change or hold government to account.

As an independent regulator, we are in a unique position to take a broader look at issues of importance to society and make the case for improved statistics. This is supported by our ability to convene, influence and highlight best practice from other sectors.

What we hope to achieve

Through our review we hope to raise the profile of social care statistics. We want to highlight why it is important to have good statistics on social care and make the case for investment in the skills and infrastructure needed to support good data. We hope this will lead to improvements to social care statistics.

We want to see stronger leadership and greater visibility for social care and associated statistics. This should raise awareness of often invisible aspects of social care, such as working age adults, unpaid care and privately delivered or funded social care. It is essential that there is a coordinated approach to tackling issues around social care, and we want to see a cross-departmental commitment to improving the data.

We want statistics to drive improved public debate and more informed decision making, including individuals' decisions about how they fund their care, how they get the right care and where they go for care. Through better data we hope to see better information on how social care is delivered and what the most cost-effective interventions are. Better information about provision of social care should also support better regulation, including the ability to more effectively target key interventions which support improving standards.

Alongside this report we will continue to engage with a range of organisations to make the case for improved data and statistics on adult social care in support of these aims.

Our approach

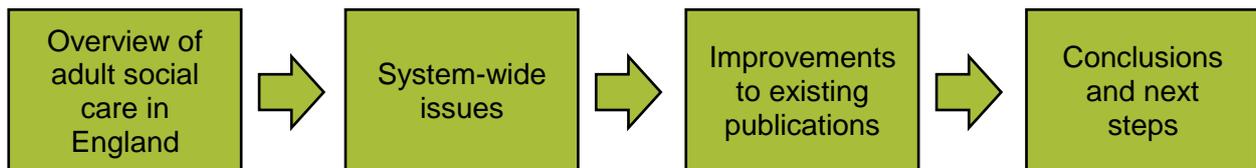
Adult social care is a devolved policy, and responsibility for the funding and delivery of adult social care lies with the devolved administrations in each country of the UK. Our review has looked at issues in each of the four countries separately to reflect the different environments in which the statistics are produced and used. This report focuses on England and will be followed by reports for Scotland and a GB summary later in 2020. These follow publication of a [blog and summary of user views](#) in February 2019 and our [report for Wales](#), published in June 2019.

To inform our review, we spoke to users of adult social care statistics from organisations across England. These users represented a range of local and national government, charitable, regulatory, think tanks and academic organisations. We also met with statistical leads working in NHS Digital, NHS England, the Department of Health and Social Care (DHSC) and the Ministry of Housing, Communities and Local Government (MHCLG). A full list of organisations we spoke to during this review is provided at Annex A.

Using the [Code of Practice for Statistics](#) as our benchmark, we also reviewed the quality and value of publicly available national data and statistics about adult social care in England. We focused on official statistics but have also reviewed some additional outputs where they have been highlighted by those we spoke to. A summary of statistics we considered is set out at Annex B. We also reviewed written materials such as academic papers, blogs, reports from regulators and submissions to parliamentary enquiries.

This report

The rest of this report sets out the findings from our review of adult social care in England. Section 2 summarises the social care landscape, sections 3 and 4 outline our findings in relation to system-wide issues and improvement to existing publications respectively. Section 4 sets out our conclusions and next steps.



2. Overview of Adult Social Care in England

From our conversations with users of adult social care statistics and reviews of reports on the topic, it is clear there are a range of significant and well documented challenges facing the social care sector. These include, but are not limited to:

- Rising care needs from an ageing population with increasingly complex conditions;
- Increasing costs to providers of adult social care;
- Constrained public funds to meet rising demand;
- Lack of insurance or safety net for those who pay for their own care;
- Challenges in recruiting and retaining good quality staff;
- The risks and instability of the care provider sector.

Statistics that can be trusted and that accurately reflect the adult social care sector play a vital role in informing public debate and developing effective public policy within the context of these challenges. This section provides context for the current policy environment and data landscape in England.

Policy context

During the financial year 2018/19 there were [1.9 million requests](#) for adult social care support from 1.3 million new clients, equivalent to 5,245 requests for support received per day by local authorities, an extra 195 requests per day over the previous year. This compares with 841,850 individuals receiving long term care in 2018-19.

Social care needs are currently being met through a range of approaches including paid and unpaid care. Where there is a need for paid care this could be delivered and funded by local authorities or privately, or a combination of the two. However, data on privately funded and unpaid care is limited, so it is hard to ascertain the scale of the sector. While there is no official estimate of the amount or value of unpaid care provided by family and friends, unofficial estimates of value that do exist vary between [£100bn](#) and [£132bn](#) per year, far exceeding the HM Treasury spending of [£25.5bn](#) on all personal social services, which gives a sense of the unacknowledged value of unpaid care.

The size and scale of expenditure on adult social care by people who self-fund is also difficult to estimate, because there is no official data source to obtain this information. An unofficial source of data, the Skills for Care Report [Economic Value of the Adult Social Care Sector in England](#), estimates that the total expenditure to provide adult social care in 2015/16 (table 4.2 of that report) was just over £30 billion, with nearly £11 billion self-funded and just under £20 billion public and co-funded.

Data landscape

In England, statistics on social care are produced by a range of organisations, with many different bodies involved in collecting and submitting data for aggregate analysis and publication. Annex B lists the datasets we considered as part of the review. It includes

some outputs, that, although free, are not official statistics, but were highlighted to us as meeting an important need that could not be met through the existing official statistics.

Official statistics currently provide basic activity and financial information related to care delivered or commissioned by the state sector and are largely based on datasets provided by Councils with Adult Social Services Responsibilities (CASSRs). However, CASSRs can only measure part of the activity picture, because the established financial and care needs assessment criteria mean that many individuals privately funding care or receiving informal care have no contact with a local authority. Therefore CASSRs do not collect data on these individuals. For example, Official statistics [*Personal Social Services Staff of Social Services Departments*](#) published by NHS Digital only measure the social care workforce working for CASSRs, which is estimated to be nearly 7 per cent of the total workforce in the sector (table 1.1 of that report).

3. System-wide issues

Adult social care is a major public policy area being developed in the absence of adequate statistics. Users of care data have many unanswered questions. A review such as this could focus solely on the existing outputs, highlighting examples of good practice and recommending improvements (see section 4). However, for adult social care, this would not be sufficient as the issues we have identified require system wide changes and strong leadership. Better data infrastructure and outputs which address the gaps in existing data are essential.

Leadership and infrastructure

The scale of the challenge to improve social care statistics is huge. To be successfully addressed will require cross-departmental collaboration and clear leadership.

Many different organisations are involved in the collection, analysis and dissemination of statistics on adult social care, with many more involved in the delivery of social care services. For example, DHSC have responsibility for social care policy, but MHCLG have oversight of local authorities which, as outlined in section 2, hold much of the relevant data and information. There are also a range of other organisations which can have an impact or interest in social care, but do not have a strong voice in the sector, for example DWP manage benefits such as disability living allowance, personal independence payments and attendance allowance and BEIS have an interest in flexible working, which can be an important factor in supporting unpaid care. Currently, the Care Quality Commission is fulfilling a key leadership role in trying to drive up the quality of care provided, but without cross-government working to improve the data collections, it will be unable to comprehensively monitor and measure improvements to care.

This disparate landscape can create challenges around leadership and development of statistics, and in ensuring there is a strong voice to champion statistics that meet user needs.

It is essential that there is good collaboration and effective leadership in order for social care statistics to undergo the critical development required of them.

We judge that the most significant long-term solution to improve the coverage and quality of social care statistics is transformation of the social care data collection and analysis systems, bringing them onto a par with hospital data. Strong leadership and coordination across government is essential for this to be achieved. We heard about ambitious plans to evolve social care data collection and analysis. In 2014, the Department of Health had formed a body responsible for transforming the capture, storage and analysis of health and social care data, called the National Information Board (NIB). The NIB's framework for action titled [Personalised Health and Care 2020](#) outlined much-needed improvements to enable data to be collected across health and social care; and the NHS Information Centre (now NHS Digital) was set up to operationalise this work. This work is still in progress and, in a letter to Directors of Adult Social services dated September 2019, DHSC restated [plans](#) for the implementation of a client level dataset for adult social care, which should enable CASSRs to submit client level data to NHS Digital, to be mandated for financial year 2021/22.

While progress has not been as quick as it should have been, NHSX, a body to ‘progress digital transformation of the NHS’, was set up in 2019. Steps are also being taken by some regions of England to pilot a single health and social care record. The future of healthcare provides some successful case studies, most notably, the development of a person-centred health and social care record by Greater Manchester Health and Social Care Partnership.

We will work with senior leaders of NHS England, NHS Digital and NHSX to ensure that plans to progress client-level data are progressed and that data are collected to provide national coverage to maximise all their possible uses, from the care of individuals to planning services, all the way to their aggregated secondary uses, such as for published research and official statistics.

In parallel to the work NHSX are taking forward, there is potential for the Office for National Statistics to play an important leadership and coordination role on statistics in social care. Chapter 7 Part 5 of the Digital Economy Act amended the Statistics and Registration Service Act 2007 to provide the UK Statistics Authority (and ONS as its executive office) with greater and easier access to data held within the public and private sectors.

As well as progressing the existing plans for joining up health and social care data from the state sector, there should be greater collaboration between a range of data suppliers to build a more complete picture of the landscape of adult social care.

Data Gaps

Our conversations with users of social care statistics highlighted the inability of long-standing official statistics to address questions they want to know the answers to. The key gaps are summarised in the table below.

Delivery		Value		Individual Experiences		
Activity that is provided or funded without involvement by the local authority	Unmet need and future demand	The value of privately funded care (household expenditure on care)	The value of unpaid informal care provided by family or friends	Pathways of adult social care activity	Outcomes	Quality of care

Delivery

Statistics on social care activity are primarily sourced from data provided by Councils with Adult Social Services Responsibilities (CASSRs). The established financial and care needs assessment criteria mean that many individuals privately funding care or receiving informal care have little or no contact with a local authority. CASSRs can therefore only measure part of the activity picture and even when they are involved in the assessment, procurement or delivery of care, they do not collect comprehensive data on the outcomes of that care.

There is a lack of robust official statistics about the economic market of private care providers. The instability of this care market, with providers closing businesses, is

highlighted by CASSRs as a cause for concern, because they would need to find alternative accommodation for people at short notice. CASSRs would appreciate having an understanding of the risk of closure of their local providers, that better and more timely data would give them. Public money is used to purchase social care from private care providers and it is important that this market is understood through comparable and timely data.

The official statistics collections have not kept pace with the changes to service delivery, which means that data from a relatively small pool of state-funded social care activities are acting as an unrepresentative proxy for a wider range of social care activities.

Some of these gaps can be filled outside official statistics, for example, stakeholders told us they rely heavily on Skills for Care data on workforce. Skills for Care's report [The size and structure of the adult social care sector and workforce in England](#) provides information on independent providers, as well as the state sector. Skills for Care curates a national minimum dataset to provide information about the adult social care workforce and the provider landscape in England. Whilst annual completion of this is mandatory for CASSRs, it is not mandatory for other types of providers and the response rates for registered providers are about 50 per cent.

There are no official statistics about the potential number of people who could be eligible for social care, but who don't yet receive it. Stakeholders told us this is an important area to try to measure to help them with planning workforce and services for the future. Innovative approaches, such as analysis of unstructured data, are likely to be needed to address this gap, ONS or others may consider building models to assist Councils with Adult Social Services Responsibilities (CASSRs) with planning or investigating the possibility of using unstructured data to predict unmet need.

Another key knowledge gap for policy makers is understanding future changes in social care needs. For example, the demands on adults who are caring for children and elderly relatives at the same time and how this will impact on the amount of informal care they can provide, their economic activity and that impact on their future economic situation e.g. pension contributions. Stakeholders told us that they would like to understand what drives people to choose to provide informal care or seek formal care, and how this impacts on their income and living situation.

Value and scale

There is published information on the expenditure on social care by CASSRs and the extent of publicly funded personal social services for the whole country, but this still leaves significant gaps in the overall understanding of how different aspects of social care are funded and the value of those alternative contributions. For example, in areas such as:

- Value of privately funded care (household expenditure on care);
- Value of unpaid informal care provided by family or friends.

Until the next Census in 2021 captures nation-wide data about the extent of unpaid care, there is no consistent question about unpaid care that is asked across government surveys. This lack of understanding of issues around funding and the scale of unpaid care limits effective decision making and planning at the organisational and individual level. Individuals are unlikely to be able to fully understand the impact on them if they have future care needs.

The limitations of official statistics on funding of adult social care means other sources of information are filling some of these gaps. For example, the [Personal social services research unit: Unit Costs of Health and Social Care 2018](#) provides useful information about

the cost of nursing home care and can be used by commissioners, planners and people needing to estimate the costs of care of a family member, but rely on expert knowledge to utilise. Many of the areas identified do not have a reliable alternative source of data to provide the relevant information.

Individual experiences

There is very limited information on the pathways and transitions into and out of adult social care activity. Stakeholders told us that the complexity of care is such that defining what is adult social care and medical care is difficult and, in many cases, the lines demarcating adult social care and medical care are blurred and vary between providers. It would be beneficial to understand how often and why people move between hospital care and social care.

Currently, there are no official statistics to measure this because, nationally, England has yet to join up health records and social care records. Work has started on a client-level data project and this should allow linking of individual level records for analysis. It is important that work to share social and health care data from multiple settings is progressed. In the meantime we can gain some insight through the Care Quality Commission (CQC) report titled [Beyond barriers: how older people move between health and care in England in July 2018](#). This is an insightful document analysing how people switch between needing the health service and needing social care.

There is also limited information on the quality of care funded by CASSRs and no information about the quality of unpaid or voluntary care given to this vulnerable client group. National estimates of the quality of care come from two surveys whose results are published by NHS Digital:

- *Personal Social Services Adult Social Care Survey (ASCS)*: It asks people who are over 18 and who are receiving long-term support services funded or managed by social services about their experiences.
- *Personal Social Services Survey of Adult Carers in England (SACE)*: SACE seeks unpaid carers' opinions about their experience of support and information received.

Limited further statistics on this topic are available from other sources, for example, the Local Government and Social Care Ombudsman publishes an [annual report](#) about complaints and the Care Quality Commission publishes an [annual report](#) about Health and Social Care in England.

Finally, there is a lack of statistics and data available on the outcomes of social care interventions. Unlike health, where the effectiveness of interventions is a priority research area, in social care there is very little understanding of the most cost-effective intervention and what the impact of each intervention is. In order to ensure people are getting appropriate care, comparable linked data on spending on care packages, the needs being met and the individual outcomes is needed.

The gaps in data identified in this report are significant and need to be addressed in order to support effective delivery and facilitate improved outcomes for those who experience social care. It will not be possible for analysts to solve these issues in isolation. It will require recognition of the importance of data from senior leaders in a range of organisations and strong leadership across government. Work by NHSX to deliver on the government's vision for digital, data and technology in health and care will be a critical factor. There is also potential for ONS

to support the sector through innovative approaches to data analysis and use of provisions in the Digital Economy Act.

4. Existing statistics

As part of the review we looked at existing statistics on adult social care. Our focus was on official statistics, but we also considered a small number of other publications which were highlighted by users we spoke to. Using the Code of Practice for Statistics as our benchmark, we reviewed the quality and value of the statistics. A full list of the statistics we considered is provided at Annex B.

Looking across all these statistics, we found some good examples of insightful analyses. However, there were many instances where we identified that improvements were necessary. The improvements identified come under five broad themes:

- Accessibility;
- Insight and Coherence;
- Quality;
- Timeliness;
- Granularity.

We have written separately to each of the main producers of statistics on social care (NHS Digital, NHS England and MHCLG) as well as to the Office for National Statistics (ONS) setting out our findings in more detail in relation to their publications and seeking improvements. The key findings in each broad theme, along with some examples of good practice and areas for improvement are summarised below.

Accessibility

While there are some significant gaps in the available data (as set out in section 3), there is still a lot of data available, but it is often hard to find. Users were sometimes unaware of existing data which would meet their needs and the difficulties finding available data means that the statistics that do exist are not being fully utilised.

There are examples of official statistics producers working to make data more accessible, for example Public Health England (PHE).

Public Health England Fingertips Dashboard

Statistics from various sources are gathered by Public Health England (PHE) and presented as National Public Health Profiles on the [Fingertips dashboard](#). Information is presented by local authority and searches by, for example, social care, reveal a variety of information, allowing the expert user to benchmark the performance of local authorities or clinical commissioning groups.



We welcome ONS' proposals to develop a portal to signpost users to existing social care statistics and hope this will support better access for a range of potential and existing users of social care statistics.

Coherence and Insight

Many of the publications we reviewed did not clearly answer the key questions of most interest to society. Users of social care statistics identified many areas which were not addressed through the statistics available (see gaps in section 3) and where data do exist it is not always presented in a way that maximises insight or answers questions of greatest interest. For example, because of the slow pace of change to national data collections, mandated data from NHS Digital's [Adult Social Care Activity and Finance Report](#) tends to be based on national policies that have changed by the time the data is published and so, therefore, does not effectively support understanding of local issues or how effective current delivery is.

Some organisations outside government have shown leadership by pulling together summary reports which support interpretation of the available data, such as the Kings Fund [Social Care 360](#) or the Institute for Government's [Performance Tracker](#). There are also examples within government, such as the MHCLG report on the Improved Better Care Fund.

Improved Better Care Fund

In October 2018, [MHCLG published](#) research and statistics about the impact of the Improved Better Care Fund. This management information voluntarily complies with the Code of Practice for Statistics. The release has insightful commentary, linking policy and funding with operational delivery choices made by CASSRs, providing a broader context about adult social care and the care market and their interfaces with the NHS.



Another example of recent improvements are expenditure data from MHCLG and NHS Digital. Many users highlighted difficulty understanding differences between the two sources of expenditure data and as a result were unable to gain a clear picture of the key messages around social care expenditure. A working group of analytical officials in MHCLG, DHSC and NHS Digital evolved following meetings in March and May 2018. Its purpose was formalised as: to identify, and understand, differences in expenditure data and to seek consistency where possible. It has steered a series of workstreams to clarify, explain and, where possible, reconcile data. In particular, there have been a series of actions designed to reconcile the two sources of annual net current expenditure data on adult social care, MHCLG's revenue outturn return, and NHS Digital's ASC-FR return, including improved guidance, validations within the return to ensure data is consistent, and data sharing agreements to allow additional checks on returns. It is anticipated that the known differences between these two returns ought to reduce in future years as a result of the work of this cross-government initiative.

Statistics producers should strive for more insightful commentary to provide a clear narrative and help users interpret the data to answer the questions they most care about.

Quality

There are quality concerns about the comparability of data over time and across different geographies. For example, operational definitions may vary across councils and providers meaning the figures submitted are not consistent across different areas, which has implications for aggregate data and benchmarking. Time consuming manual processes can create challenges and introduce errors. This has been exacerbated by staffing cuts in local authorities which have led to lost expertise and limited resource.

There are also data quality concerns with some of the survey data relating to adult social care, for example the [Personal Social Services Adult Social Care Survey](#).

Adult Social Care Survey

In 2018-19, nearly 80 per cent of respondents reported having help to complete the Adult Social Care Survey questionnaire. While NHS Digital do not recommend that assistance is provided to respondents as they complete the questionnaire, allowing such assistance is considered essential if the survey is to be representative of as many service users as possible.

This support is likely to impact on the results of the survey. The NHS Digital [Data Quality Statement](#) provides detailed information on some of the potential issues. It shows that in 2018-19 those who had help from a care worker to answer the questionnaire reported higher levels of satisfaction compared to all other service users. This raises concerns about the quality of the survey and leaves some users sceptical about the results.



There are some possible approaches to addressing quality issues, such as raising concerns with data suppliers and explaining the uses for the statistics more clearly, but the issues are not straightforward to resolve and will require cross-government leadership and investment to address effectively.

Timeliness

Our discussion with users highlighted the limitations of data that is not timely. For example, NHS Digital's Activity and Finance Report data does not get published until seven months from reporting year end and the activity data is twelve months out of date. This was considered too slow to support planning the operational decisions for CASSRs.

Another example is that data published by NHS Digital in [Personal Social Services Staff of Social Services Departments](#) are collected as a 'snapshot' each October and are published four months after the collection period. The lack of timeliness was an issue for stakeholders, as they needed to be able to respond to workforce issues much sooner.

Granularity

All of the users we spoke to wanted more granular data, including the characteristics of the person, their needs and the setting of care, for example. Many of the current data collections do not collect data at a level of detail that allows these breakdowns as part of publication as official statistics. Collection of specific data items can vary even for the same survey, for example, SACE does not always include demographic data such as ethnicity and religion, as these data fields are not mandatory. We anticipate that the project to request client-level data from CASSRs for the compilation of more granular statistics will improve information in the medium term.

To maximise public value, statistics producers should be seeking to make statistics accessible, insightful, reflective of the needs of a range of users and uses. They should be innovative so that the statistics keep pace with a complex and changing world.

We do not underestimate the complexities involved, however, we do expect producers of statistics on social care to consider the recommendations set out in letters to them in order to improve the insight offered by the existing data and statistics relating to adult social care in England.

5. Conclusion and next steps

Adult social care has not been measured or managed as visibly as hospital care. The ongoing public and policy debates around social care would be assisted by more comprehensive and better data. We want to see improvements to the existing statistics as well as more fundamental changes, this will require a cross-government commitment to improvements.

We strongly encourage the implementation of joined up data across health and social care to understand how the two systems interact, and what drives the best outcomes. This information could also improve data to inform care, personal decision-making and national debate.

As we note in this report, there is public and policy interest in knowing about **all** social care activity and spend. Now that a much wider service is being delivered, the traditional route of relying on aggregated data collected only by local authorities is not enough and statistical producers must expand and transform their data collections.

In addition to the system-wide improvements we want to see, we have written to each of the main producers of social care statistics, encouraging them to build on the examples of good practice we have seen and encouraging improvements to existing statistical releases.

We will continue to convene key parties, for example, by holding a workshop with interested parties to highlight issues raised in this report and help build consensus to ensure long term data transformation is progressed. We will also work closely with senior leaders of NHS England, NHS Digital and NHSX to ensure that plans to progress client-level data are progressed and that data are collected that provide national coverage to maximise all their possible uses, from care to planning services, all the way to their aggregated secondary uses, such as for published research and official statistics.

We need to push data to the front of the agenda because reliable and comprehensive evidence is vital for evaluating delivery and informing policy decisions, which can lead to improved outcomes and support individual choice.

Annex A: Organisations that we spoke to during this review

We would like to thank all those that gave up their time to contribute to this Review.

Age UK	Hertfordshire Council	NHS Digital
Association of Directors of Adult Social Services	House of Commons Library	Nuffield Trust
British Geriatrics Society	Independent Age	Office for National Statistics
Care Quality Commission	Institute for Fiscal Studies	Public Health England
Department of Health and Social Care	King's College London	Richmond Group
Devon County Council	King's Fund	Royal College of Physicians
Doteveryone	Local Government Association	Skills for Care
Full Fact	Ministry for Housing, Communities and Local Government	Sue Ryder Care
Future Care Capital	MS Society	Wirral Council
Greater Manchester Combined Authority	National Audit Office	
Health Foundation	Neurological Alliance	

Annex B: Summary of statistics on Adult Social Care

Official statistics

Producer organisation	Publication	Coverage	Status	Frequency
Ministry of Housing, Communities and Local Government	Local Authority Revenue Expenditure and Financing	Local Authorities in England	National Statistics	Twice a year
	Improved Better Care Fund Quarterly and Year End Reporting	England	Management Information	Quarterly
NHS Digital	Adult Social Care Activity and Finance Report	CASSRs in England	National Statistics	Annual
	Personal Social Services Staff of Social Services Departments	Local Authorities in England	National Statistics	Annual
	Personal Social Services Adult Social Care Survey	England	National Statistics	Annual
	Personal Social Services Survey of Adult Carers in England	England	Official Statistics	Every two years
	Measures from the Adult Social Care Outcomes Framework	England	Official Statistics	Annual
	Safeguarding adults	CASSRs in England	Experimental Statistics	Annual
	Guardianship under the Mental Health Act	CASSRs in England	National Statistics	Every two years
	Mental Capacity Act 2005, Deprivation of Liberty Safeguards	CASSRs in England	Official Statistics	Annual
NHS England	Delayed Transfers of Care	England	Official Statistics	Monthly and Annual
	Better Care Fund Quarterly Reporting	England	Official Statistics	Quarterly
Office for National Statistics	Public Service Productivity: Adult Social Care	England	Official Statistics	Annual

There are a number of other sources of data that may of wider interest for research into social care, however, they are not always presented to allow a user to maximise insight. We welcome ONS' plans to plans to make social care statistics more accessible, it would also be helpful if ONS considered how to draw links between datasets to encourage greater insight.

HM Treasury's statistical series [Public Expenditure Statistical Analysis](#) (PESA) publishes expenditure under the relevant function 'social protection' (item 10), which includes the following sub-functions with personal social services:

- Sickness and disability (10.1)
- Old age (10.2)
- Family and children (10.4)
- Unemployment (10.5)
- Social exclusion (10.7)

In the PESA release, it is not clear which sub-function(s) can be related to 'adult social care'.

Information about caring can be found using the [official statistics](#) published by DWP using the results of the Family Resources Survey, for example. Latest statistics noted that seven per cent of respondents were giving care on an informal basis. Thirty-two per cent of informal carers cared for parents living outside their household, with a further seven per cent caring for parents within their household. For twenty per cent of informal carers, the care was provided to a spouse, partner, or cohabitee within the same household.

Other statistics

In addition to our review of the official statistics outlined above we also considered a small number of key reports highlighted to us through our stakeholder engagement. These are summarised in the table below.

Producer organisation	Publication	Frequency
Personal Social Services Research Unit	Unit Costs of Health and Social Care 2018	Ad hoc
Skills for Care	The state of the adult social care sector and workforce in England	Annual
Public Health England	National Public Health Profiles	Ad hoc
	Quality Matters	Ad hoc

Care Quality Commission	Beyond barriers: how older people move between health and care in England	Ad hoc
	State of Care reports	Annual
Local Government and Social Care Ombudsman	Complaints data and reports	Ad hoc