



Office for  
Statistics Regulation

**Systemic Review Programme**

# **Adult social care statistics in Scotland**

February 2020

## **Office for Statistics Regulation**

We provide independent regulation of official statistics produced in the UK. Statistics are an essential public asset. We aim to enhance public confidence in the trustworthiness, quality and value of statistics produced by government.

We do this by setting the standards they must meet in the [Code of Practice for Statistics](#). We ensure that producers of official statistics uphold these standards by conducting assessments against the Code. Those which meet the standards are given National Statistics status, indicating that they meet the highest standards of trustworthiness, quality and value. We also report publicly on system-wide issues and on the way statistics are being used, celebrating when the standards are upheld and challenging publicly when they are not.

## **Acknowledgements**

We would like to thank all the individuals and organisations that gave up their time to contribute to this Review. Their details are listed in [Annex 1](#).

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# Executive summary

The Office for Statistics Regulation has been exploring the quality and public value of adult social care statistics in the United Kingdom. This report presents the findings for Scotland.

Companion reports on [Wales](#) and [England](#) were published in June 2019 and January 2020 respectively, and a high-level summary report covering all three countries will be published in March 2020.

## Why we did this review

Social care is a central part of the lives of many people in Scotland. However, society has changed greatly over the last few decades and care needs have changed markedly. Understanding more about people who need or provide care, the impact it has on their lives, how the adult social care sector is currently delivered and how this might need to change in the future are issues of national importance in Scotland. Through our ongoing work with users of social care statistics, we heard of frustrations that the data and statistics in this area do not currently allow these issues to be fully understood and explored.

Central and local government, health and care services and other agencies can use statistics to steer policy decisions and ensure suitable budgets and workforce are in place to deliver the intervention needed at the right time. Current and future care users, and their families, also need timely and relevant statistics of an appropriate quality to help them understand the care landscape and make decisions about their lives. Statistics about children's social care and day care – service areas which have not been subject to the same level of change as adult social care – will be explored in subsequent work.

We want to support the many innovations and improvements to data capture, analysis and dissemination that are already happening, and to advocate for further developments in this area, to ensure that the statistics better reflect the lived experience of people using social care services.

## What we found

Statistics serve the public good when they enable a wide range of users to answer important questions. To do this adequately they need to:

- add **value** by covering the topics that matter to people
- have **insightful** commentary that draws out key messages
- tell a **coherent** story focused on the needs of information seekers, not providers
- be based on data of a suitable **quality**
- be published in a **timely** fashion
- be **accessible** in formats that support further analyses.

Based on our conversations with statistics users, and our own observations and research, it is clear that there are issues in all these areas that need to be addressed.

- There are gaps in the provision of statistics on social care – we don't know how many people currently need social care and whether those needs are being met, how many people might need care in future, and we don't know how well social care services

achieve their goals of helping people to live independently and maintain a good quality of life.

- There is a need for more insightful commentary, greater coherence and more timely statistics that bring together key messages about adult social care.
- Data quality is improving over time, but major challenges still remain, and re-use of social care data for research is not as extensive as it could be.

These issues affect a wide range of people and organisations who are not having their analytical needs fully met. These include: the general public, care users, care providers, Integrated Joint Boards, councils, NHS bodies, councillors and members of parliament, scrutiny and regulatory bodies, academics and researchers, and Scottish Government policy makers. The statistics users we spoke to had a strong vision of what social care statistics should be delivering.

While there is currently a large gap between this vision and what currently exists, statistics producers clearly share many of the concerns raised by users and are demonstrating a strong appetite to make improvements. The following developments are already helping to address some of these issues:

- new national data systems have been developed to improve data collection about the adult social care services delivered and funded by health and social care partnerships
- new statistics based on these data have been produced and users have been actively involved in shaping their development
- new statistics about carers will be published in 2020 that will deliver insights that are unavailable elsewhere in the UK
- new workforce statistics have been developed and plans are in place to make more use of data collected via inspections of social care services.

## Improving social care statistics in the short to medium-term

Building on these developments, we have four recommendations to support further short to medium-term improvements.

- All social care statistics producers need to work together, in consultation with health and social care partnerships and statistics users, to identify and prioritise actions to address social care data gaps – including by making better use of existing data – and meet users' information needs.
- All social care statistics producers should work together – with statistics users – to identify ways to make social care statistics in Scotland more coherent. The social care topics that matter to users should be the guiding framework for statistics presentation.
- Public Health Scotland, Scottish Government and the Care Inspectorate need to work together to identify a long-term solution that enables social care data to be shared safely and efficiently.
- Public Health Scotland and Scottish Government should convene a social care data user summit in 2020 to help inform Research Data Scotland's development and Public Health Scotland's plans for making more use of linked health and social care data.

## Longer-term transformation of social care statistics

Major transformation of adult social care statistics in Scotland will need more fundamental action. We have made recommendations in three strategic areas to support this.

### **Clearer leadership to drive analytical integration**

Integration of health and social care in Scotland is dismantling the traditional split between these services in order to make the planning and provision of care more joined-up and, ultimately, provide better outcomes for care users. The health and adult social care statistics landscape now needs to follow this lead and itself be better integrated, so it can deliver the evidence base that this new model of integrated care requires. This will require careful management to ensure that alignment is maintained with the wider social service sector, for example to avoid large discrepancies between adult and children's social care data.

Responsibility for social care statistics production is currently spread between different organisations. This can act as a barrier to the more joined-up approach to data collection and analysis that is needed to improve the public good of the statistics. Clearer responsibility for analytical leadership is required to scope and deliver the local and national level improvements outlined in this report.

### **Address the imbalance in resources for health and social care statistics**

Users and analytical leaders have clear ambitions for long term improvements in adult social care statistics, but there are improvements to existing statistics' timeliness, insight and coherence that could be delivered in the short to medium term. However, these will be difficult to deliver without addressing the imbalance between the resources available for health service statistics production and social care statistics that currently exists. This imbalance exists at all levels, from the national bodies responsible for publishing statistics down to the teams and systems supporting data collection in local areas.

### **Invest in data systems**

The biggest challenge – logistically, technically and financially – is improving the underlying data used to create social care statistics. This will involve improving the quality of existing data and identifying ways to capture new data to fill the many gaps that users have identified.

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.

# 1. Introduction

## Why this matters

Large numbers of people rely on adult social care in their daily lives, are providers of unpaid care to family, friends and others, or are employed as carers.

- 230,017 people were estimated to be receiving publicly-funded social care support in Scotland during 2017/18.
- Around 700,000 adults and children in Scotland are estimated to be unpaid carers.
- As of March 2017, around 36,000 people were living in a care home for adults.
- £3.1 billion was spent on social care in 2017/18 by local authorities.
- In 2018, just over 200,000 people in Scotland worked in the social service sector, the majority of whom provide services for adults.

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.

Our previous work with users of health and social care statistics indicated that adult social care statistics tend to be less well developed than health statistics. We heard from users that there is a growing need for better quality statistics to understand how social care operates, including topics such as waiting times, access routes, funding, effectiveness, staffing and client experiences. Such information is necessary to inform policy, workforce planning and budget allocation, as well as providing guidance for individual users for whom these matters are relevant. These are critical issues of high public interest where good statistics are vital to policy and service delivery.

In the Office for Statistics Regulation (OSR) we have been exploring the quality and public value of adult social care statistics across the UK. In December 2019 the Scottish Parliament Health and Sport Committee invited submissions to its [Social Care Inquiry](#) which is looking at the future delivery of social care and meeting future needs. A summary of the findings in this report has been submitted as evidence to help support the Committee's work.

## Our unique perspective

OSR regulates 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.

The [Code of Practice for Statistics](#) is clear that statistics add value when they support society's need 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

We want to raise the profile of social care statistics in Scotland, and throughout the UK, and highlight why good statistics are essential for the sector.

We want statistics to drive improved public debate and support more informed decision making - better informing individuals' decisions about how they fund their care, how they get the right care and where they go for care.

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.

We want to see clearer leadership and more coordination of insights about social care, leading to 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 all the social care service partners in Scotland make a commitment to improving the statistics and underlying data.

We want to make the case for more local and national investment in the skills and infrastructure to develop and support good data. Through better data we hope to see better information on how social care is delivered, what the most cost-effective interventions are, and how care contributes to people's quality of life.

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

Our review of [Adult Social Care statistics](#) across the UK began in 2018. We wanted to explore the adult social care statistics landscape across the UK to better understand its strengths and weaknesses, recognising that policy variations across the UK have led to differences in how statistics are produced. We were also keen to increase our understanding of users' needs for statistics about adult social care, and to discover and share best practice in the compilation, harmonisation, data linking potential, publication and statistical commentary of these statistics.

Responsibility for the funding and delivery of adult social care lies with the devolved administrations in each of the UK's countries. Consequently, our review mainly focused on issues specific to each country, to reflect the different environments in which statistics producers work and the policy needs resulting from this. In February 2019 we published a blog and high-level findings for all four countries. In June 2019 we held a workshop with statistics users and producers in Scotland to discuss the feedback from the first phase of

the project in more detail. This report presents our findings in more detail. Separate reports for [Wales](#) and [England](#) were published in June 2019 and January 2020 respectively. A summary report of common themes identified in all three countries will be published in March 2020.

Our research in Scotland involved individual meetings and a workshop with organisations with an interest in the adult social care and the statistics sector. We met with a wide range of stakeholders including: local and national government, inspectorate bodies, academics, third-sector organisations and care providers. In addition, we also met with the statistical leads working in this area in Scottish Government, ISD Scotland, the Scottish Social Services Council and the Care Inspectorate, followed by further meetings with the senior leaders for health and social care analysis in Scottish Government and ISD. A full list of organisations we spoke to during this review is provided at Annex A.

The initial phase of meetings took place between July and October 2018. The workshop took place in June 2019 and was timed to follow the first publication of ISD Scotland's new Insights into Social Care statistics.

## This report

The rest of this report sets out our review's findings.

- Section 2 provides an overview of the adult social care landscape in Scotland.
- Section 3 outlines our judgement of how well adult social care statistics in Scotland currently meet users' needs and highlights plans that are in place for improvements.
- Section 4 highlights the three strategic areas where action is needed to improve statistics.
- Section 5 sets out our conclusions and next steps.

# 2. Adult social care in Scotland

## Overview

The adult social care sector in Scotland comprises a wide range of different types of care, settings and funding arrangements. Not all who need care are receiving it, and many of those who receive care are not included in official estimates (either because their care is all privately funded, or is provided by an unpaid carer). Figure 1 provides a simplified overview of the social care landscape in Scotland. It highlights the complexities of social care provision which, for any individual, can take place through several settings, be they paid for (either publicly or privately), delivered by a charity or the voluntary sector or be unpaid care delivered by family and friends (some of whom may receive carers' allowance). It also illustrates the lack of information currently available for many aspects of this landscape, in particular for people with care needs that are not funded by the public sector, or whose needs are not currently met at all.

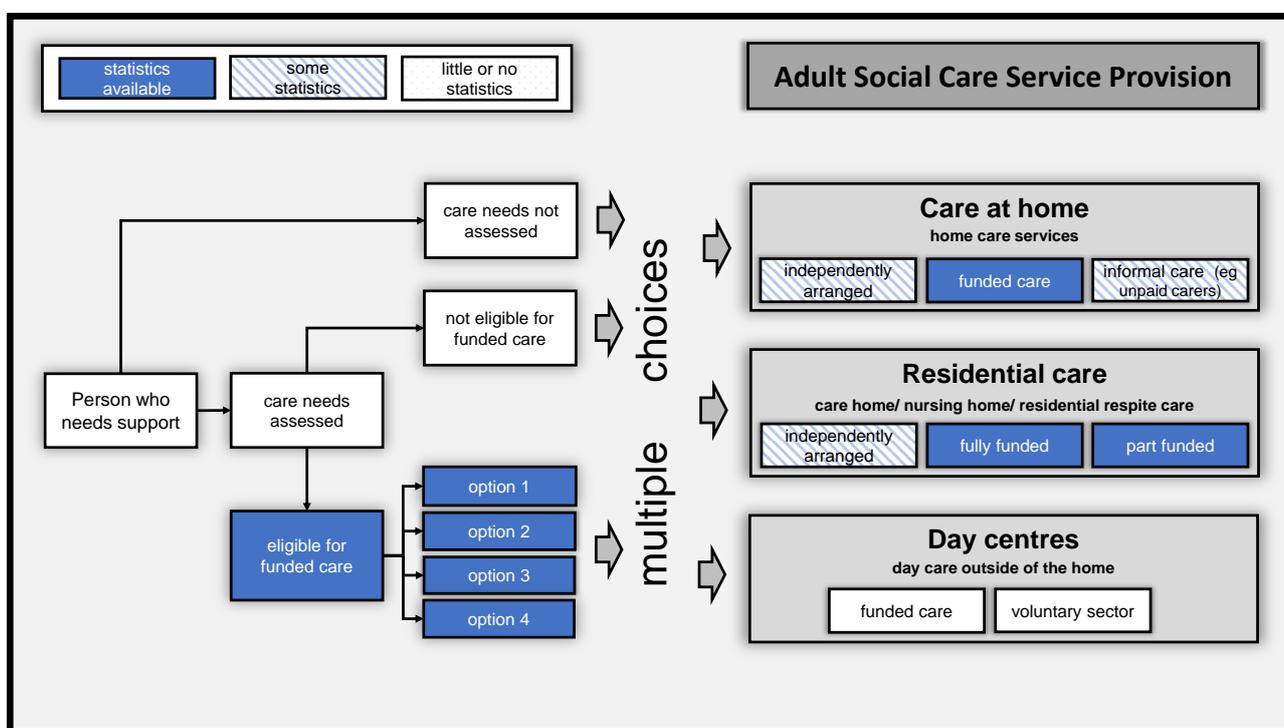


Figure 1: Simplified statistical landscape of adult social care service provision in Scotland (funded care options explained below)

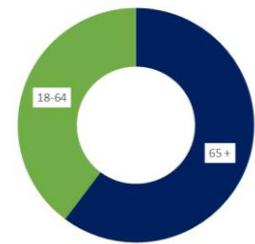
Since 2002, adults aged 65 and over in Scotland whose needs meet the eligibility criteria are entitled to free personal care<sup>1</sup> regardless of income or assets (this was extended to adults under 65 in 2019). However, many individuals self-fund their personal care if they do not meet the local eligibility criteria, want extra services beyond their entitlement or wish to 'top up' their personal budget to receive care from a specific provider. [Care home fees](#), which

<sup>1</sup> Personal care covers help with things like washing, continence management, food preparation, mobility, and household admin.

form a large element of overall social care costs for people in residential care, are means-tested, with assistance available to people with assets below certain thresholds.

Almost half of the Scottish Government's budget is allocated to health and social care. Of the £13.5 billion spent by NHS Boards and local authorities on health and social care in the 2017/18 financial year, 22% (£3.1b) was spent by local authorities on social care.<sup>2</sup> These figures relate to public expenditure, there are no published estimates of the total spend on social care, including individual private payments. Policy debates around social care often focus on the older population's care needs and costs, but 40% of this £3.1b local authority expenditure was to support working age adults.<sup>3</sup>

40% of adult social care spending supports working age adults



## Policy context

In much of the UK, social care policy debates are frequently dominated by the question of how much individuals and the state should contribute to care costs. Although Scotland has introduced free personal care for adults, funding is still at the heart of many public debates about social care, and Scotland faces many of the same challenges we heard about in the rest of the UK, for example:

- 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
- strains on the finances of those who pay for their own care
- challenges in recruiting and retaining good quality staff
- instability in the care provider sector.

The way that social care is funded, organised and delivered has changed notably in the past decade. The [2011 Christie Commission](#) set out the direction for the future delivery of public services in Scotland. This had a significant emphasis on integrated services and outcomes-focused approaches.

The Christie principles were reflected in [2014 legislation](#) which enabled the planning and provision of health and social care in Scotland to be formally integrated. From 2016 onwards, 31 Integration Authorities have been formed from partnerships between Scotland's 14 Health Boards and 32 councils (Stirling and Clackmannanshire councils are in the same Integrated Authority), IAs are commonly referred to as Health and Social Care Partnerships (HSCP). New legal bodies, Integrated Joint Boards (IJBs), have also been created with responsibility for strategic planning and commissioning services (30 IAs are also IJBs, a different model operates in Highland). This [toolkit](#) provides a guide to integration in local areas.

**Audit Scotland's** reports on the progress of health and social integration provide a comprehensive overview of this landscape. The [2018 report](#) highlighted concerns about data that are relevant to our interest in better social care statistics. It recommended the Scottish Government, Convention of Scottish Local Authorities (COSLA), NHS boards and Integration Authorities work together to:

<sup>2</sup> ISD Scotland, [Health and Social Care Expenditure Dashboard](#), 2017/18.

<sup>3</sup> Estimated based on 2016-17 figures in: Scottish Government: [Table 1A](#), Social Care Expenditure, 2016-17.

- address data and information sharing issues, recognising that in some cases national solutions may be needed
- review and improve the data and intelligence needed to inform integration and to demonstrate improved outcomes in the future. They should also ensure mechanisms are in place to collect and report on data publicly.

The **Scottish Government Ministerial Strategic Group** for Health and Community Care's final report on the progress of health and social care integration was published in February 2019. It supported all of Audit Scotland's 2018 report recommendations. While it did not contain any specific commitments for actions to address these points about data and intelligence, Scottish Government analysts provided the Group's [May 2019](#) meeting with a [briefing](#) about the availability of social care data and measurement challenges. The Group supported proposals for Scottish Government officials to work on developing better indicators of people's experiences of care.

June 2019 saw the launch of the Scottish Government's [social care reform programme](#) which is intended to:

- support integration authorities, the wider sector, and communities in planning and taking forward changes
- advise Scottish Ministers if national changes or interventions are required
- raise awareness of the role of social care support in Scotland and its social and economic value.

Evaluation, data and learning is one of the priorities for the reform programme.

As already noted, the Scottish Parliament's Health and Sport Committee is conducting a [Social Care Inquiry](#) in 2020 looking at the future delivery of social care and meeting future needs (it is not intending to replicate the work of the Scottish Government reform programme which is looking at current care delivery models and needs).

Examples of other policy initiatives aimed at improving outcomes for care users are provided in the box overleaf. Our aspiration is to see the social care statistics landscape in Scotland transformed, so that it can deliver insights about each of the many ways that people can experience social care and help to assess whether these policies are meeting their objectives.

## Examples of social care policy initiatives in Scotland

In 2013, new [legislation](#) gave care users more autonomy around the support they receive via **Self-directed Support**. This placed a duty on councils to offer people who are eligible for social care four options for how they receive their support:

- Option 1 Taken as a Direct Payment, with the person then purchasing their care services directly.
- Option 2 Allocated to an organisation that the person chooses, with the person in charge of how it is spent.
- Option 3 The person chooses to allow the council to arrange and determine their services.
- Option 4 The person can choose a mix of these options.

The Scottish Government's **Reshaping Care of Older People** (2011-2021) strategy aims to shift practice in favour of anticipatory care and prevention approaches in order to improve older people's care. Its objective is: "Older people are valued as an asset, their voices are heard and they are supported to enjoy full and positive lives in their own home or in a homely setting".

New **Health and Social Care Standards** came into place in April 2018, setting out what standards people should expect when using health, social care or social work services in Scotland. The headline outcomes are:

- 1: I experience high quality care and support that is right for me.
- 2: I am fully involved in all decisions about my care and support.
- 3: I have confidence in the people who support and care for me.
- 4: I have confidence in the organisation providing my care and support.
- 5: I experience a high-quality environment if the organisation provides the premises.

The standards are underpinned by 146 descriptive outcomes that set out what achieving each outcome looks like in practice. The Care Inspectorate and Healthcare Improvement Scotland will incorporate these into their inspections and scrutiny work.

The **Carers Act 2016** came into force in April 2018. It is designed to improve carers' rights and the support available to help them in their caring role. It has a particular focus on carers' health and wellbeing, with new provisions such as an Adult Carer Support Plan and Young Carer Statement to identify needs and outcomes, a duty on local authorities to support carers, and a requirement to provide an information and advice service for carers.



## Social care data landscape

Three bodies currently have primary responsibility for producing official statistics on adult social care in Scotland.

- **Scottish Government** - statistics about unpaid carers, free personal and nursing care, and patient experience surveys which cover social care.
- **ISD Scotland** (from April 2020 ISD will become part of Public Health Scotland) - statistics on delayed discharges from NHS services and the care home population and, from 2019, sole responsibility for collecting data and publishing statistics about adult social care provisions in health and social care partnerships (see case study below).
- **Scottish Social Services Council** - workforce statistics for the social service sector. SSSC is leading work to integrate social service and health service workforce data via NHS Education for Scotland's Integrated Workforce Data Platform.

In addition, the **Scottish Commission for Learning Disability** produce Learning Disability Statistics Scotland, which are National Statistics, and cover some issues relevant to adult social care. Annex B lists the statistics publications that each of these bodies produce and their data sources.

**The Care Inspectorate** (who regulate care services in Scotland) publish inspection data and collect data (such as the Care Home Census) which are used by other bodies to produce official statistics. They have a wealth of data about service providers in Scotland and about service users' views of their care. They do not currently produce official statistics but are planning to start doing so and will need to be involved in future discussions about developments to adult social care statistics in Scotland.

The case study below provides information about ISD's new social care data collection. There are high aspirations for these new statistics in the longer term, both locally and nationally. However, many of the users we spoke to had concerns about the quality of the data in the short term and highlighted various gaps that the new adult social care data collection cannot (and was not designed to) fill. The next section of this report provides more information about this.

## Scotland's new adult social care data collection system

Prior to 2017, both Scottish Government and ISD collected data from councils about adult social care and produced their own statistics based on this information. The Scottish Government's data collection – the Social Care Survey – has now ceased and ISD is responsible for collecting data about adult social care service provision from councils/health and social care partnerships and for publishing associated statistics.

In 2017/18, ISD developed a new data collection system to bring together these two previous social care data collections. Moving the responsibility to ISD has made it easier to link NHS health data and council/partnership social care data, which in turns helps to support some of the local and national information needs arising from the integration of health and social care.

Having a sole body collecting these data has streamlined the process for data suppliers. The data that were previously collected annually by Scottish Government are now requested quarterly, which will support more timely statistics to be produced. However, it also confers additional burdens that local data suppliers will need support to manage.

ISD's first publication based on this new data – Insights into Social Care – was published in June 2019. The publication included new analyses made possible through the linkage of the social care data to key health related data.



# 3. Are adult social care statistics meeting users' needs?

## Introduction

The Code of Practice for Statistics stipulates that statistics published by public sector bodies should be produced in a trustworthy way, be of high quality, and provide value by answering people's questions: providing accountability, informing policy and helping a wide range of users make choices. Statistics serve the public good when they enable a wide range of users to answer important questions. To do this they must:

- add **value** by covering the topics that matter to people
- have **insightful** commentary that draws out key messages
- tell a **coherent** story focused on the needs of information seekers, not providers
- be based on data of a suitable **quality**
- be published in a **timely** fashion
- be **accessible** in formats that support further analyses.

Based on our conversations with statistics users, and our own observations and research, it is clear that there are issues in all these areas that need to be addressed. A wide range of people and organisations are not having their analytical needs fully met. These include: the general public, care users, care providers, Integrated Joint Boards, councils, NHS bodies, councillors and members of parliament, scrutiny and regulatory bodies, and Scottish Government policy makers. The statistics users we spoke to had a strong vision of what social care statistics should be delivering.

While there is currently a large gap between this vision and what currently exists, statistics producers clearly share many of the concerns raised by users and are demonstrating a strong appetite to make improvements. Many of the positive developments outlined below highlight how Scotland is taking steps to capture new social care data and improve its quality. These are important and welcome developments. We want to highlight and support this positive direction of travel with the following recommendations for further actions based on our analysis of the six criteria outlined above.

## Statistics should cover topics that matter to people

When statistics fully serve the public good, they can help to answer questions about how many people have a characteristic of interest, how this might vary between groups in society, and how it is changing over time. They can also reveal insights about people's experiences and outcomes.

If statistics do not cover the topic areas that people need to know about then they will fail in their ability to serve the public good. Annex C provides examples of specific questions that users told us they couldn't answer using the statistics currently available.

There are positive developments to highlight here. Scotland is developing new data collection systems that should lead to improved insights about social care, of which ISD's new adult social data collection is a significant example.

A new data collection focused on carers in Scotland, the [Carers Census](#), has been developed by Scottish Government analysts to help monitor the implementation of the [Carers Act 2016](#) which came into force in April 2018. This kind of information is not being collected anywhere else in the UK at present and we know, from our conversations with users, that it will be highly valued information. Data is being provided by health and social care partnerships, local authorities and third sector organisations who provide support to carers, many of whom have developed new data recording systems in order to meet the requirements for this data collection. Statistics based on this data will, for the first time, be able to provide insights about the demographic characteristics of carers in Scotland, the people for whom they provide care, whether they have a care support plan / young carers statement and, if so, what support they are eligible for, need and have received. Data has been collected for 2018/19 so far and the first set of statistics is planned for April 2020.

New workforce statistics about [vacancy rates in care services](#) are now being published jointly by the Care Inspectorate and the Scottish Social Services Council (SSSC). These are not currently official statistics, but the Care Inspectorate has expressed interest in starting to publish more of their data as official statistics. A report about social service providers is also being considered to help shed light on this diverse and large sector (around 2,500 providers are responsible for over 13,000 care services in Scotland).

Despite these welcome developments, social care statistics in Scotland do not currently provide the range and depth of information needed to fully serve the public good as some fundamental gaps exist. For example, we don't know how many people currently need social care and whether those needs are being met, how many people might need care in future, and we don't know how well social care services achieve their goals of helping people to live independently and maintain a good quality of life.

As the previous chapter outlined, Scotland is moving towards a more outcomes-focused approach to public service design and delivery, as reflected in the [National Performance Framework](#) for government which has 11 outcomes supported by 81 National Indicators. It is notable that none of the nine national indicators which focus on health relate to social care. Some of the [indicators](#) used by local Health and Social Care Partnerships to monitor their performance do cover social care, but they mainly focus on perceptions of the care services received, rather than what the care provided enables people to do, how it contributes to their quality of life or helps them realise their rights.

A lack of information about outcomes for people who use social care was one of the most common frustrations we heard. Users told us that too much emphasis is placed on counting system outputs such as the number of hours of care delivered, costs of services, and numbers of staff. Instead, they would like to know about the outcomes achieved for the people using those services. As noted in the previous section, the Care Inspectorate collects data via its inspections on many of these issues and could therefore make a valuable contribution by publishing official statistics based on these data.

In recognition of these needs, and of the adult social care reform programme currently underway and the work we have been conducting in this review, Scottish Government analysts have been working to identify, map and understand the social care data landscape with a focus on data gaps. Outcomes measurement is a strong feature of this work. For

example, a scoping [review](#) was conducted on behalf of the Ministerial Strategic Group on Health and Community Care about outcomes focused data collected by Health and Social Care Partnerships. Unmet needs for care is another area identified in this work. Little is currently known about how many people are in need of social care but are not receiving any care, and new data systems will likely be required before this issue can be better evidenced. The next chapter discusses the strategic level levers that will be necessary to help realise these ambitions for better data.

**All social care statistics producers need to work together, in consultation with health and social care partnerships and statistics users, to identify and prioritise actions to address social care data gaps – including by making better use of existing data – and meet users’ information needs.**

### Statistics need insightful commentary

ISD’s [Insights into Social Care](#) publication is based on the new data collection that replaced the Scottish Government’s Social Care Survey. ISD recognise that their expertise in, and resources for, social care analysis is not as extensive as is the case for health data analysis. Users felt that this imbalance of resources was reflected in the level of insight provided in this new statistics publication. ISD has been working with users to get more detailed feedback on the statistics to help develop them further and deepen the insights and commentary provided. They are currently classed as statistics in development and there is an aspiration for them to progress to a point where they are a suitable candidate for National Statistics designation. As noted in the Case Study on page 20, they are also working to provide more insightful commentary in the Care Home Census report.

Some of the Scottish Government’s social care information is provided in spreadsheets with no accompanying commentary. For example, the data on [waiting times for client assessments and service delivery](#) – which are very important measures of service performance that matter to care users and their families – show wide variations between areas, but this publication format provides no explanations as to why these might occur. This insight is particularly needed as the differences can be quite stark: in January to March 2018, 62% of care assessments in Midlothian took more than 6 weeks to be conducted compared with just 5% in neighbouring West Lothian. Everyone assessed as requiring services in Midlothian waited more than 6 weeks to receive them, whereas in Falkirk everyone received services before their assessments had been completed. Using this information to create statistical publications with insightful commentary could help users understand why these kinds of variations exist.

### Statistics need to tell coherent stories based on users’ needs

As outlined earlier, there are multiple social care statistics producers in Scotland. This can have negative consequences for users of these statistics, as they are required to go to different sources to get all the information they need about a topic, or if different sources provide similar but not necessarily consistent information about the same issues. At present, there is no map of this statistical landscape for users to help them navigate all the different sources or a single portal to access social care information. The Scottish Government has in recent years provided information about social care statistics [publications](#) and [data](#) on multiple webpages, introducing some inconsistencies (for example, the publications page links to the 2016 Social Care Census, the data page links to the 2017 version, the former signposts to other statistics from ISD and SSSC, the latter does not). This should be resolved when the Scottish Government’s new website development is complete and there is a single location, but it has not been ideal for users in the meantime.

Coherent and consistent data definitions are another important requirement. At present, there is a lack of comparability between the workforce and service data published by the SSSC and the Care Inspectorate and some of the definitions of services captured by ISD's new adult social care data collection. A solution to this will be piloted in 2020.

This kind of incoherence can be avoided if producers work together to identify topic overlaps and agree how best to provide information in a single place with consistent definitions and terminology. Alternatively, multiple outputs could be coordinated, and their contents aligned, with clear signposting to other relevant sources so users can easily piece information together for themselves.

To illustrate the impact of this kind of incoherence on users, the diagram below looks at a small selection of questions someone interested in residential care might have. This example shows there are four sets of official statistics produced by three different producers covering varying time periods that would provide their answers. The Care Inspectorate also hold data on many of these issues. Two points stand out: for some questions there are multiple sources with the same or similar information (e.g. for care home population characteristics), while for some questions multiple sources need to be used in order to gain a complete answer (for example, to determine costs).

**All social care statistics producers should work together – with statistics users – to identify ways to make social care statistics in Scotland more coherent. The social care topics that matter to users should be the guiding framework for statistics presentation.**

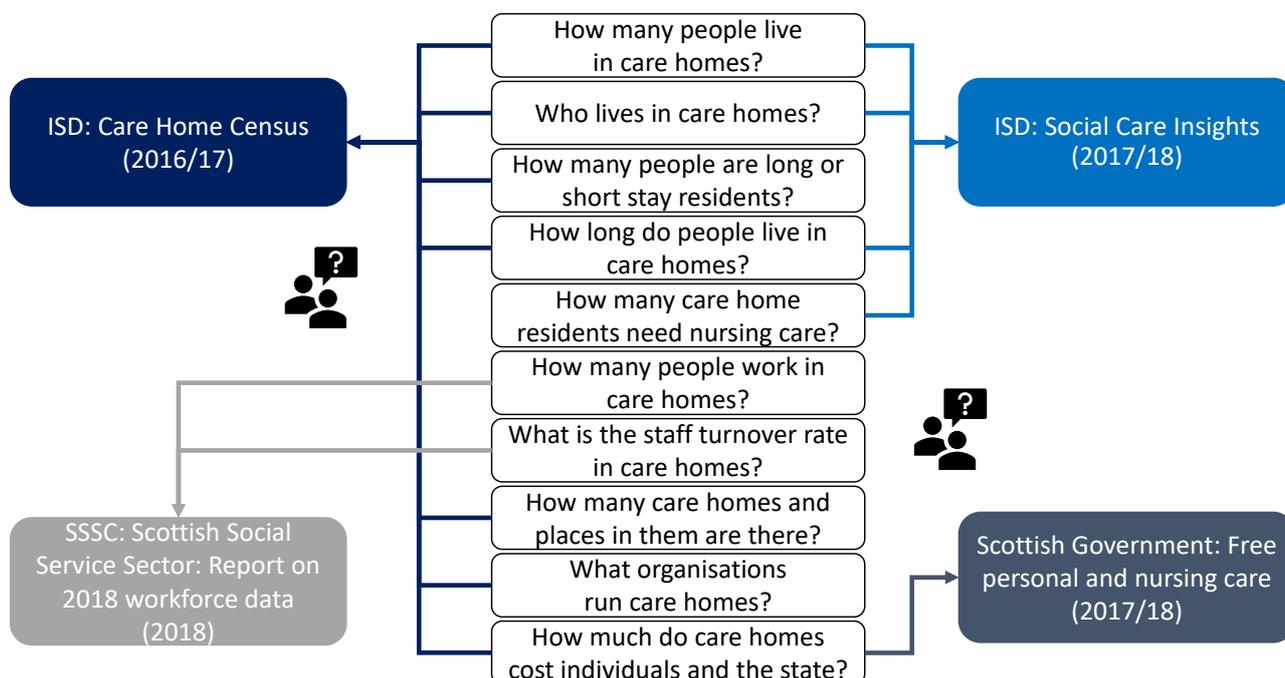


Figure 2: Sources of answers to users' questions about care homes

### Data quality needs to be improved

We heard lots of concerns about data quality issues. For example, the users we spoke to about ISD's new adult social care data collection largely supported its development and had high aspirations for the data quality improvements (and new insights) that it might deliver in the medium to long term. They recognised that the data systems it was designed to replace

had gaps in coverage and data quality problems that restricted their value for statistics and research purposes. These issues have been helpfully described in recent academic publications.<sup>4,5</sup> However, there was also concern voiced by users that the transition to the new data collection would result in some information loss and data quality problems, at least in the short term while the new system was introduced.

Users and data suppliers told us how variations in coverage and consistency of information recording by health and social care partnerships can differ by both topic area and locality – one area might have very good quality data about hours of care received but large volumes of missing data about care users' living arrangements, whereas the situation could be reversed in their neighbouring area. Any data collection system experiencing multiple and different causes of data quality problems such as these will require significant efforts to address. ISD's new data collection provides a new impetus and infrastructure for data quality improvement, but it will not happen overnight, and other investments within the data collection system will be needed to support ISD's drive to improve data quality.

The transition in 2017/18 from annual to quarterly data collection using the new platform has proved to be understandably challenging for a lot of data providers, many of whom have lost analyst and data collection staff in recent years. For the first publication in June 2019 this resulted in delays to some returns, data gaps, and problems with the data quality, as users had voiced concern about in the pre-implementation period. Because of these problems, and in line with good practice, it was necessary for ISD to make a series of adjustments to the data to address these data gaps and to highlight any limitations. However, the footnote in the chart below illustrates how making these kinds of limitations clear to readers can lead to a loss of clarity and fluency to the overall narrative. Users told us they weren't always sure how to interpret charts with lots of data gaps.

We have spoken to data suppliers who confirmed that data submissions have become faster and less resource intensive over time, but that it is still quite a burdensome process. We also understand that many of the issues highlighted above have now been addressed and data gaps and quality problems will have less of an impact on the next Social Care Insights publication.

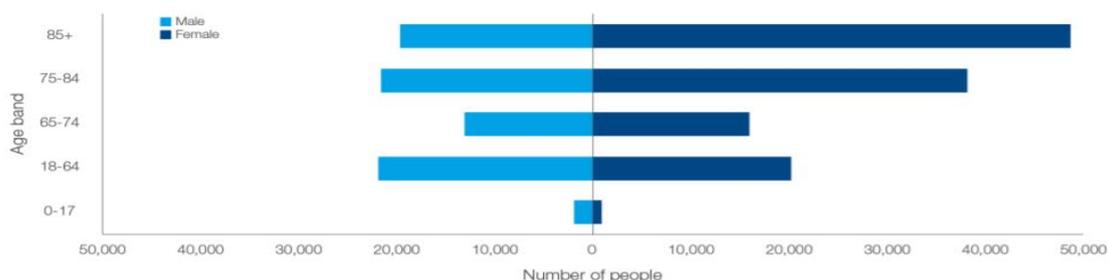
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<sup>4</sup> Lemmon, E. 2019. [Essays on the provision of long term care to older adults in Scotland](#). PhD thesis. University of Stirling.

<sup>5</sup> Henderson, D., Burton, J., Lynch, E., Rintoul, J., Clark, D., Bailey, N. 2019. [Data Resource Profile The Scottish Social Care Survey \(SCS\) and the Scottish Care Home Census \(SCHC\)](#). International Journal of Population Data Science. Vol 4(1).

Figure 3: Illustration of the impact of data gaps on clarity and insight - *Insights into Social Care*, (ISD 2019, p11)

Figure 2: Number of people supported in receiving social care support and services by age and sex for all areas submitted<sup>1,2,3</sup> 2017/18



1. Incomplete data: Self-directed support: Fife, Comhairle nan Eilean Siar (self-directed support option 3); Community alarms/telecare: Scottish Borders, South Lanarkshire, East Lothian (community alarms/telecare clients only with services that began prior to 2017/18); Housing support: North Lanarkshire, Orkney Islands, Shetland, West Dunbartonshire; Meals: North Lanarkshire; Day Care: North Lanarkshire, Orkney Islands, Argyll and Bute; Social Worker: Renfrewshire, West Dunbartonshire; Glasgow City all services and support.

## Statistics need to be timely

The publication of the first set of statistics based on ISD's new adult social care data was delayed from the end of 2018 to June 2019. The delay had many causes, including councils taking time to adjust to the new data collection system and, if necessary, to review and amend their internal recording processes.

As part of the return, new data sharing agreements were required between ISD, the 14 territorial Health Boards, 32 councils and 31 H&SCPs. Glasgow City initially opted not to sign a data sharing agreement which resulted in their data being delivered much later than other councils and available only in aggregate form (all other councils signed a data sharing agreement and provided individual level data). This issue has now been resolved and a data sharing agreement is in place, but this was a contributing factor to the overall delay in publication and impacted negatively on the presentation of results throughout the first published statistics (Glasgow City accounts for around 11% of Scotland's population).

The following example illustrates a particularly concerning situation we investigated, and highlights where users' need for timely statistics about care homes are not currently being met.

## Care Home Census (ISD)

Users have raised serious concerns about the timeliness of statistics about people who live in care homes. This important part of the care sector is facing significant pressures on its funding and staffing. Policy makers, care providers, residents and their families therefore need timely and insightful statistics to help make decisions.

This situation has arisen because of delays in signing a data sharing agreement between ISD and Scottish Government to enable ISD to continue producing the statistics. As a result of this the 2016/17 data were published in September 2018, a year after they were scheduled, and the 2017/18 results will now not be available until 2020.

These are National Statistics and such lengthy delays do not meet the high standards of trustworthiness, quality and value expected of them. We conducted a review of the statistics and published our judgement in [March 2019](#). We concluded we were content for their National Statistics designation to remain in place if the 2017/18 and 2018/19 statistics were published in autumn 2019, and the insight accompanying the statistics was improved.

ISD has made significant improvements to the statistics' presentation and accompanying insights in advance of the data arriving. However, the data sharing issues were not resolved in time to publish in 2019. Consequently, [the National Statistics designation was removed at ISD's request in February 2020](#). ISD hopes to publish the delayed statistics in 2020 and will put them forward for re-designation in 2021. All the parties involved are working to identify a solution to ensure this situation does not happen again.



**Public Health Scotland, Scottish Government and the Care Inspectorate need to work together to identify a long-term solution that enables social care data to be shared safely and efficiently.**

### Data needs to be accessible

Many researchers are keen to make more use of health and social care data. Scotland has for many years had a wealth of health data and has a strong and active research community keen to make use of it. In contrast, comparatively much less social care data exists, limited use has been made of it until very recently, and there is limited awareness about how the new ISD adult social care data will be shared with researchers. Access to the Social Care Survey, one of its precursors, is managed by Scottish Government whereas access to the new data collected by ISD is overseen by the [Public Benefit and Privacy Panel for Health and Social Care](#) Scotland, who also handle applications for the historic Social Care Survey data if researchers want to link it to health data.

Single sources of data often become more insightful when they are joined together with other data, but the potential insights that might be gained from linking social care data with other sources is very much untapped at present. Few published examples currently exist but ISD is now exploring this new potential. For example, their [Insights into Social Care](#) report used linked social care data and NHS hospital admission data to provide estimates

of emergency admission rates for people receiving care at home and people resident in care homes who were fully or partially funded by the local authority. Further linkages are now being explored. Outside of ISD, a recently completed PhD<sup>6</sup> linked the Social Care Survey and prescribing data to help estimate the prevalence of multiple long-term conditions among social care users in Scotland.

In [July 2019](#) we voiced our hopes that the launch of [Public Health Scotland](#) (PHS) in April 2020 would be used as an opportunity to create a robust legislative framework for secure and proportionate cross-sector data sharing with common information governance processes to support data linkage and efficient data access. We know that ISD, one of the bodies forming PHS, shares these aspirations and is keen to make more use of data linkage to deliver insights about health and social care. Another new body, [Research Data Scotland](#), is being created in 2020 which should help to address the data access issues that researchers currently face when seeking health, social care and other data, while also supporting greater joining up of these data.

**Public Health Scotland and Scottish Government should convene a social care data user summit in 2020 to help inform Research Data Scotland's development and Public Health Scotland's plans for making more use of linked health and social care data.**

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<sup>6</sup> Henderson, D. 2019. Multimorbidity and social care: exploiting emerging administrative datasets in Scotland. University of Glasgow.

# 4. Improving adult social care statistics

In Chapter 3 we have made recommendations for short to medium-term improvements to adult social care statistics and data collection, and have noted where plans are in place to address these. However, three strategic actions are required to support and deliver the long-term transformation in adult social care statistics that Scotland needs:

- greater clarity about who will lead the drive to improve social care statistics
- address the imbalance in resources for health and social care statistics
- sustained cross-sector investment in data systems to address data gaps and improve the quality and value of what is collected.

## A need for clearer leadership

The traditional split between health and social care services is being dismantled in Scotland. With the establishment of Integration Authorities, Scottish Government has made structural changes to ensure that these services are funded, managed and, in many cases, delivered in a way that meaningfully integrates health and social care service delivery. The health and social care statistics landscape now needs to follow this lead and itself be better integrated so it can deliver the evidence base that this new model of care requires.

Responsibility for social care statistics production is currently spread between different organisations. This is currently acting as a barrier to the more joined-up approach to data collection and analysis that is required to fully deliver statistics that serve the public good. Clearer responsibility for analytical leadership is required to scope and deliver the kinds of improvements outlined in this report. The main statistics producers, Scottish Government and ISD, acknowledge and understand this issue and are now considering options to address it. This is being undertaken as part of a wider review of responsibilities aligned with the launch of Public Health Scotland (PHS) in April 2020.

## Address the imbalance in resources for health and social care statistics

The previous chapter highlighted some improvements to existing statistics' timeliness, insight and coherence that could be delivered in the short to medium term. However, these will be difficult to deliver without addressing the imbalance between the resources available for health service statistics production and social care statistics that currently exists. The ambitions that users and analytical leaders have for these statistics will also require this. More resource is certainly needed to support PHS's social care statistics production function, and also to support the teams and systems responsible for data collection in local areas.

## Invest in data systems

The biggest challenge in improving the statistical evidence base – logistically, technically and financially – will be to improve the underlying data used to create social care statistics. This will involve improving the quality of existing data and identifying ways to capture new data to fill the many gaps that users have identified.

This will not be easy. Resourcing issues beset all aspects of social care data collection and statistics production. This includes the availability of staff to collect data and return it, the need for investment to improve its quality, the need for entirely new forms of data to be collected to better meet user needs, and the availability and capability of staff to use the data themselves to inform service development locally. We recognise that the resource implications associated with building new data systems are far greater than those associated with improving existing statistics. The drivers and funding to do this will also be largely beyond the reach of statistics producers alone.

Building data collection systems that deliver value to staff and users of social care and which yield useful population data is also difficult to do without imposing unreasonable administrative burdens. And as the landscape map in Figure 1 highlights, unlike the situation in the health service, huge amounts of social care activity takes place beyond the scope of public sector service settings and the majority of the social care workforce (around 70%) is employed by private and third-sector providers. This also makes the task of building routine data collection systems significantly harder.

Scotland is not alone in facing these challenges. Our work in the rest of the UK has identified similar demands for more and better social care information, significant resource constraints, and all the same difficulties with collecting data in disparate settings about human experiences (as opposed to flows of money or service provision). There are innovations in social care delivery and technology that might, in future, help to deliver new data. We will continue to work with interested parties across the UK to identify possible solutions to these mutual challenges.

# 5. Conclusion and next steps

There are many positives to report about the developments that have already happened in Scotland to capture new social care data and improve its quality. ISD is working with users to develop their new Social Care Insights statistics. New statistics about carers are on the horizon that will deliver insights that are unavailable elsewhere in the UK. Scottish Government analysts are working to identify ways to address data gaps such as outcomes measures for social care users. However, there are many issues that need to be addressed before social care statistics in Scotland can be said to be serving users' needs and meeting the public good.

There is high-level recognition, for example by Audit Scotland and the Ministerial Strategic Group on Health and Community Care, that better information systems and data are needed to support health and social care integration. We believe that the recommendations we have set out in this report support and extend those ambitions.

Chapter 3 contained specific recommendations for steps that statistics producers can take to address issues with existing statistics.

- **All social care statistics producers need to work together, in consultation with health and social care partnerships and statistics users, to identify and prioritise actions to address social care data gaps – including by making better use of existing data – and meet users' information needs.**
- **All social care statistics producers should work together – with statistics users – to identify ways to make social care statistics in Scotland more coherent. The social care topics that matter to users should be the guiding framework for statistics presentation.**
- **Public Health Scotland, Scottish Government and the Care Inspectorate need to work together to identify a long-term solution that enables social care data to be shared safely and efficiently.**
- **Public Health Scotland and Scottish Government should convene a social care data user summit in 2020 to help inform Research Data Scotland's development and Public Health Scotland's plans for making more use of linked health and social care data.**

Chapter 4 contained three strategic actions to help drive the transformation of social care statistics that Scotland needs.

- **Greater clarity about who will lead the drive to improve social care statistics.**
- **Address the imbalance in resources for health and social care statistics.**
- **Sustained cross-sector investment in data systems to address data gaps and improve the quality and value of what is collected.**

We will continue to use our voice to support the many innovations and improvements to data capture, analysis and dissemination that are already happening, and to advocate for further developments in this area, to ensure that the statistics better reflect the lived experience of people using social care services.

**We have asked statistics producers to publish an integrated health and social care statistics action plan by July 2020, setting out what steps will be taken, by whom, and when, to take forward the recommendations in this report.**

# Annex A: Organisations that contributed to this review

Over the course of the review we spoke to or received feedback from people in the organisations listed below.

Age Scotland	Scottish Social Services Council (SSSC)
Care Inspectorate	Scottish Commission for Learning Disability (SCLD)
City of Edinburgh Council	Scottish Government analysts and policy teams
Coalition of Care and Support Providers in Scotland (CCPS)	Scottish Human Rights Commission
East Lothian HSCP	Scottish Care
Edinburgh Napier University	Sue Ryder Care
Health and Social Care Alliance Scotland (the ALLIANCE)	University of Edinburgh
ISD (including the LIST team)	University of Glasgow
NHS Highland	

# Annex B: Data and statistics landscape

Adult social care in Scotland National and Official statistics	
ISD Insights in Social Care: Statistics for Scotland 2017/18	Experimental statistics
ISD delayed discharges	National Statistics
ISD care home census	Official Statistics
Scottish Government Scottish Health Survey questions on carers	National Statistics
Scottish Government Health and care experience survey	National Statistics
Scottish Government Local authority revenue and capital outturn expenditure	National Statistics
Scottish Government Free personal care stats	National Statistics
SSSC Scottish Social Service Sector: Report on 2018 Workforce Data	Official Statistics
SCLD Learning Disability Statistics Scotland	National Statistics

# Annex C: Questions about social care that users told us they cannot answer

Questions about people needing social care
Is social care meeting its goals of helping people to live independently and maintain a good quality of life?
What is the extent of unmet social care need in the population?
How does adult social care use vary by protected characteristics and other sub-groups of interest?
How many people are waiting for social care assessments and how long are they waiting for?
What social security benefits are social care users receiving?

Questions about adult social care service delivery
Where is there good practice locally?
Are the right services being provided?
How does service provision vary across Scotland (evidencing the postcode lottery)?
Why does Self Directed Support (SDS) use vary across Scotland?
What is the extent of adult social care input in end of life and palliative care?
What are peoples' experiences of using adult social care?
What contributions do anticipatory and intermediate care make?

Questions about the cost of social care
How much is spent on adult social care – by central government, local government, NHS boards?
What is the extent of individuals self-funding regulated and unregulated care?
How are Self Directed Support (SDS) budgets spent?