The aim of the Round Table on care data was to define the data we need to inform the critical debate on how we can sustainably arrange and pay for social care in the future. Although the provision of paid and unpaid care is vital to the wellbeing of millions of adults in the UK, data collection on aspects of care lags behind other areas of welfare state activity.

The three main areas of interest for social care researchers are: local authority data collected by NHS Digital, large national population surveys, and sector and workforce data: agencies, sector bodies and the regulators. Important related datasets include: demographic and population data; labour market and other economic data; housing data; social attitudes data; pensions and cash transfer data; and health records.

The Round Table discussed the limitations of existing data and suggested a number of avenues for future development of datasets and collaboration around existing data collection. Round Table participants and experts outlined urgent needs: for a multi-pronged survey on care, care-recipients and carers in the UK; for information on care to flow between different sets of organisations; and the importance of contextualising such information on care with theory. Care is often presented as simple problem to solve, but is in reality a complex interaction of institutions and norms.
How best to inform the collection and use of care data in the UK is an urgent current issue. It was one of the topics chosen for a series of Re-Imagining Care Round Tables, held in London and Birmingham in 2018, bringing experts, practitioners and members of the Sustainable Care team together to discuss issues crucial for the sustainability of care arrangements in the UK. At a time when social care is high on the policy agenda and a growing focus of much public debate, the round tables were designed to inform the development of the Sustainable Care research programme and to guide the Sustainable Care team’s advice to policymakers.

Government has promised a Green Paper on Social Care, and working carers feature in the priorities for this, set out by former Secretary of State for Health and Social Care, Jeremy Hunt. In a speech on 20 March 2018, he stated the importance of sharing data across health and care systems to ensure a joined-up service for citizens: “...the risk is that too often an individual and their family are passed from pillar to post, giving the same information repeatedly without receiving joined up, personalised care that makes them feel like a valued human being and not just another task on someone else’s to do list.”

KEY ISSUES

Data in Adult Social Care

Although the provision of paid and unpaid care is vital to the wellbeing of millions of adults in the UK, data collection on care lags behind other areas of public services activity. Social care is a broad phenomenon, and therefore requires the compilation of a broad range of data sets to facilitate research and evidence-based policy. Important data for social care includes:

- need for care and unmet need
- carers’ characteristics
- number of care recipients
- the volume of care provided
- characteristics of care recipients
- expenditure and unit costs of adult social care
- outcomes of adult social care
- numbers and characteristics of providers of formal social care services
- the social care workforce.

Most data relating to adult social care in the UK are compiled from administrative returns by local government and by employers. In addition, a number of surveys of population groups and subgroups most likely to receive care (for example the various longitudinal studies of ageing) are collected. Finally, data are collected about the registered social care market and its employees by sector organisations, regulators and market information companies.

This complex picture of data and sources is a reflection of a sector which is hard to quantify: covering the statutory activity of local government, the informal activity of families and a sprawling, fragmented private sector. Our debate focused on the potential role for coordination and compilation for use in evidence-based policy.

Data from local authorities

Although data are collected in slightly different ways across the four nations, reflecting the divergent organisational makeup and priorities, there are a few central themes for collection:

- Activity: referrals and assessments, receipt of certain types of care for people who have been in contact with local authority services (including carers).
- Outcomes: surveys measuring the impact of local authority provided or commissioned care and support services (including carers).
- Financial returns: showing expenditure by local authorities and reflecting their priorities, particularly in times of financial retrenchment.
- Safeguarding: monitoring safeguarding activity, activity related to deprivation of liberty, mental capacity, and activity related to the Mental Health Act (1983).

In England, data are collected by NHS Digital (see the Adult Social Care Activity and Finance Report and Safeguarding Adults Collection). In Scotland it is collected by ISD Scotland, in Wales by Social Care Wales (see the National Social Care Data Set for Wales) and in Northern Ireland data are collected centrally by the Department of Health (NI).

National Surveys

A number of surveys, again with national differences in the UK, are collected covering a range of variables vital to social care research including:

- disability among older people
- disability among younger adults
provision of unpaid care
• cognitive impairment among older people
• provision of unpaid care.

These surveys include: the Census, General Household Survey, Longitudinal Studies of Ageing (ELSA: in England), the NICOLA study in Northern Ireland; Family Resources Survey; Understanding Society and the British Household Panel Survey.

Workforce and provider data
The adult social care sector is growing rapidly across the UK. It is vital that researchers and policymakers can access evidence about its size, scale and composition. Information about the sector is collected by a number of different agencies throughout the UK, including arms-length bodies such as Skills for Care in England, the social care regulators in each country, industry bodies and government departments.

Vital aspects of this sector data include:
• number of adult social care organisations
• number of adult social care establishments
• individual employers
• direct payment recipients employing staff
• number of adult social care jobs
• number of full-time equivalent adult social care jobs
• number of people working in adult social care.

Complementary data
Of course, ‘care’ is more than what is easily measured in surveys. In order to understand the complexities of care provision and receipt, it is not sufficient to study the composition of state and/or market bodies, but it is vital to explore the indicators of gender and family norms, the migration rules as well as employment and social rights related to care work.

Research into social care therefore requires an understanding of a number of complex datsets and sources, including:
• demographic and population data
• labour market and other economic data
• housing data
• social attitudes data
• pensions and cash transfer data
• health records.

The available data can shed light on issues that affect carers: data can dispel myths, illustrate changes over time and provide insights on diversity and differences.

Round Table discussion
Our discussion in the Round Table focused on the necessity of coordinating the use of data across the UK’s four nations for research and evidence-based policy making. There is a huge range of organisations that collect data, some of which provide accessible overviews of the data they collect (the National Minimum Dataset in England). None attempt to summarise the state of the whole sector (the informal, the formal, and underlying social determinant aspects of care). This should be explored, to ensure that data can be used quickly and effectively in research, policy and commissioning.

Another aspect of our discussion was the potential ‘blind spot’ of data collection on the informal cash economy of care in the UK. There is a lack of available information about the amount of care delivered on a ‘cash in hand’ basis. As the grey economy grows around the world, the UK must understand the role of migrant and other informally employed workers in the provision of care.

There also remains unknowns in national data collection regarding ‘self-funders’. While there have been interesting attempts to estimate the size of the ‘self-funding’ economy and the role of cash transfers, including Attendance Allowance and pensions, there remains a lack of clear and usable data about this key part of our care economy and culture.

Measures such as the CPI (Consumer Price Index) and RPI (Retail Price Index) attempt to capture the costs of living. Currently, payments such as pensions and benefits are linked to the RPI, and while the CPI takes into account residential and Local Authority care fees along with home care assistant fees, the RPI does not consider any financial aspects of care or caring. Additionally, many NHS data sets focus only on patients and ignore the role of carers.

In many cases, we ‘don’t know what we know’. The collection and collation of data by multiple organisations and by the four UK nations, without data flow between them, has hampered our understanding of the care situation. The Digital Economy Act 2017 granted the Office for National Statistics (ONS) sharing powers, including...
Care data: the scope and quality of data on care

from Local Authorities and commercial organisations, which will allow them to better link and interrogate datasets— an example being expanding the analysis on student suicides to include Higher Education data as well as official suicide statistics. Better statistics can lead to better decisions, and the ONS is hoping to re-ignite longitudinal studies, leveraging their unique ability to link datasets to uncover new insights surrounding care and carers.

A new Data Science Campus at ONS is expected to become a centre for artificial intelligence (AI) and big data analysis, with projects in the field of health and social care a key part of this work. The aim is to move from policy-based evidence towards evidence-based policy interventions.

**Key Issues**

- Absence of an accessible and comprehensive statistical overview on social care in the UK, outlining regional and national differences on a number of key measures
- Lack of coordination of information between institutions and associations, experts, policymakers, and service providers
- Unknown areas: the grey economy and self-funders.

**RECOMMENDATIONS**

Round Table participants felt these major issues called for policy and research responses.

**For policymakers:**

1. Establish a coordinating body for adult social care data in the UK to coordinate and summarise data trends for policy and research use.
2. Focus on improving data collection in under-researched areas: the informal economy of care and self-funding.

**For the Sustainable Care research team and partners:**

1. Familiarise ourselves with the plethora of datasets and organisations and build links in order to make the most of available information.
2. Link with the ONS and Department for Health and Social Care, to drive the changes needed in order to improve data gathering and interpretation around social care issues.

**Footnotes**

1. Mental Health Act 1983
4. Data in Scotland is collected by the Information Services Division, part of NHS National Services Scotland.
5. Data in Wales is collected by Social Care Wales, in the National Social Care Data Set for Wales.
6. In Northern Ireland, social care statistics are collected by the Department of Health (NI).
7. ELSA is the English Longitudinal Study of Ageing; see website for details.
8. NICOLA, the Northern Ireland Cohort for the Longitudinal Study of Ageing, is the first large scale longitudinal study of ageing in Northern Ireland, carried out by researchers at Queen's University Belfast.
9. The four social care regulators are: the Care Quality Commission (CQC); Social Care Wales; the Northern Ireland Social Care Council; and the Scottish Social Services Council (SSSC).
11. Digital Economy Act 2017, an amendment to the Statistics and Registration Service Act 2007, gave ONS permission to receive data from all public authorities and Crown bodies, in addition to some UK businesses.

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The recommendations in this Policy Perspective are from the Sustainable Care team, and do not necessarily reflect the personal and/or collective opinions of those taking part in the Round Table or the ESRC.

**ABOUT THE RESEARCH**

The Sustainable Care: connecting people and systems programme explores how care arrangements can be made sustainable with wellbeing outcomes. It studies the systems, work and relationships of care in the context of changes in technology and mobility and aims to support policymakers, the care sector and academics to conceptualise sustainable care as about ethics, justice and the distribution of resources. The programme focuses on adults living at home with chronic health problems or disabilities and their families, carers and paid workers. Funded by the ESRC, it is delivered by eight universities and Carers UK, led at the University of Sheffield by Professor Sue Yeandle. This Policy Perspective was prepared by Camille Allard and Patrick Hall. Policy Perspectives were designed by Kelly Davidge.

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