

Better Evidence for Better Care

How can data improve the
social-care system in the UK?

Giselle Cory for Doteveryone 2019

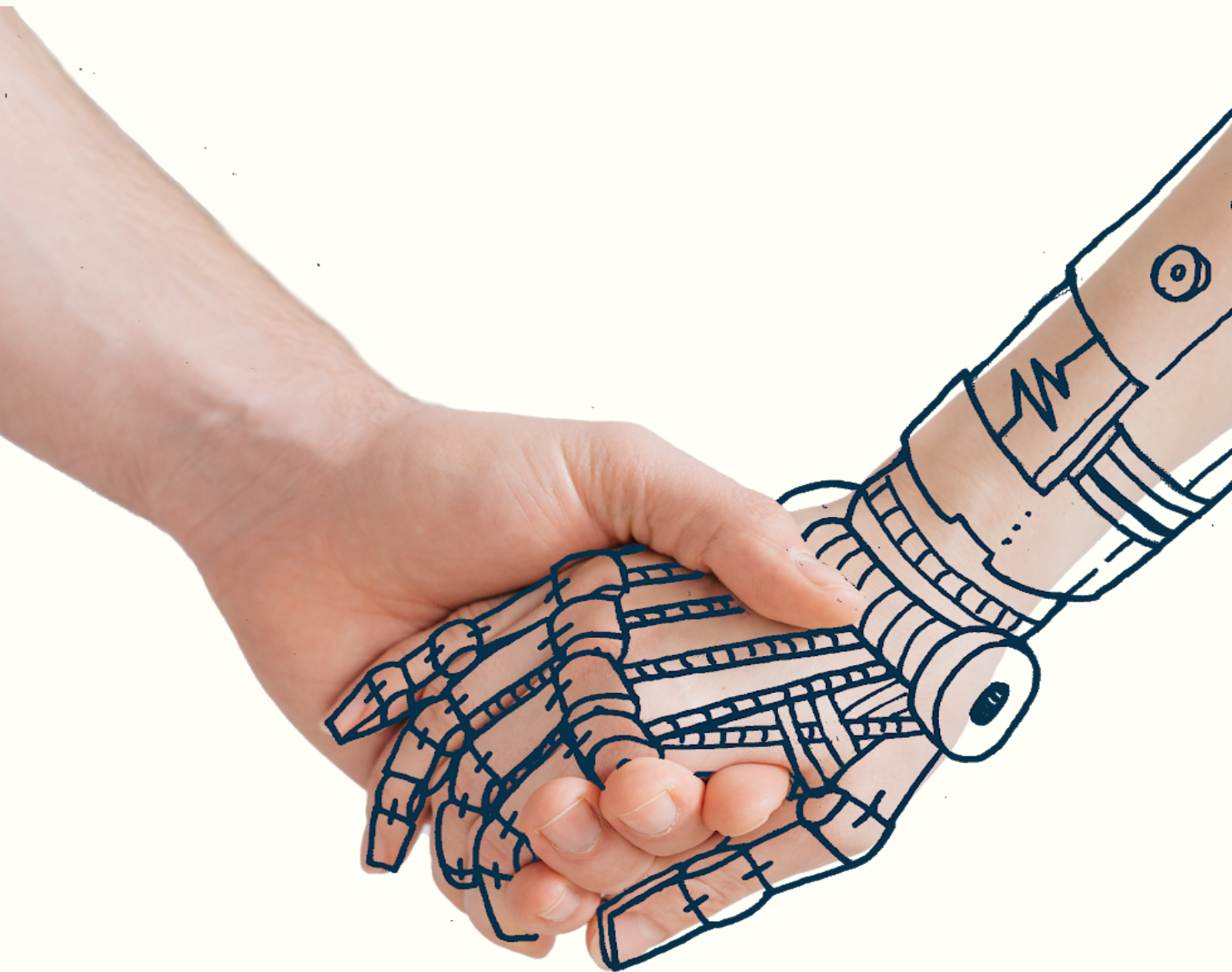


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Executive summary

By Lydia Nicholas

The UK needs a better evidence base for social care.

The bedrock of all future innovation is data. Sustainable innovation for UK social care cannot happen without a comprehensive, person-centred evidence base.

Doteveryone commissioned Giselle Cory, Executive Director of DataKind, to review the social-care data landscape and found current data collection to be inadequate. Insufficient data is collected on the areas that matter most, including the outcomes for people who receive care. This fragmentation means it is not possible to understand what is happening across the social-care sector and inside the systems it's made up of.

It also means that policymakers, commissioners and providers are not able to make robust decisions to improve the lives of people who receive care. Future innovation will be developed on the basis of the current, inadequate metrics, resulting in biased and uninformed decisions.

It is in the interests of the entire social-care sector to support a better care evidence base. While this may lead to costs in the short term, this investment will ensure future care expenditure is truly cost effective. This paper outlines the actions needed to make this change, based on two recommendations:

Committing to understanding the whole care ecosystem

Right now data is siloed in different services. We need to connect metrics across health and care and related public services. This will help produce a holistic picture of what works for people, and how well communities are supported to thrive by the services they pay for.

Measuring outcomes, not process

We measure what we value. But currently the majority of metrics across health and social care focus on narrowly defined issues of process, not outcomes for the individual, family or community. This needs to change if we truly value the lives of care recipients. Currently we are unable to see the whole person, discover what matters to them and tackle the root causes of problems. We need to develop a shared vision of wellbeing outcomes for individuals and communities that take into account developing their skills, capacity and resilience.

Section 1: What data exists on social care at a local level?

Indicators of social care inputs – users, funding and workforce.¹

On social care users

The **number of people receiving support** from adult social care services at a local level can be defined as the number of older people (65+) supported, including those in community care, residential care and nursing home care, received for any duration, at any time throughout the year.²

This can be broken down by the **nature of support needed**: the number of people receiving long term support, and the number of completed *instances* of Short Term Support.³

On social care funding

It is not known exactly how much money is spent on adult social care in England. Though there is comprehensive data on public funding, exact figures for private spending are unknown.

On public funding

Data on **public spending** by Local Authorities for adult social care is provided in the NHS Digital [Adult Social Care Activity and Finance Report](#).⁴

¹ See Appendix B for an overview of available data

² Health and Social Care Information Centre and ONS population estimates, available through the PHE [Fingertips](#).

³ NHS Digital Adult Social Care Activity and Finance Report; Previously NHS Digital Community Care Statistics, Social Services Activity.

⁴ For unit costs see NHS Digital [Personal Social Services: Expenditure and Unit Costs](#). This data contains information on the annual expenditure and unit costs of CASSRs with Adult Social

For the minority of care that is funded by the NHS, figures can be found in the NHS Continuing Healthcare and NHS-funded Nursing Care datasets, available quarterly at CCG (Clinical Commissioning Group) level from [NHS England](#). This dataset also tells us the proportion of patients whose care costs are fully funded (in comparison to those whose are partially funded) at a CCG level.

Recommended Action:

Develop a metric that exposes the large disparity in per capita funding between areas ([Health Foundation](#)).

Alert: NHS England data is provided at CCG level. Adult social care spending by Local Authorities (LAs) is at LA level. CCGs and LAs do not uniquely map onto each other (one CCG covers many LAs, but LAs may be split between multiple CCGs) and so summing LA and NHS spend to get total social care spend at LA is likely to be challenging, if not impossible.

On private funding

Data on **private funding** (where those receiving care are self-funders) is not collected by the Government. We do know the proportion of service users who buy additional care or support⁵ and instances of deferred payments,⁶ however the amount they spend and what they spend it on is unknown.

The best we have on overall private spending are macro-level estimates and privately-run surveys.

A survey of the care market is conducted by non-government organisation Laing and Buisson,⁷ however this is behind a paywall. Though the [National Audit Office](#) have made their own estimate of privately bought care, they comment that there is no “*reliable national estimate of the number of people who pay for their care in their own home*”.

Services Responsibilities in England, including by whether long or short term support, by primary reason for support, and also income by type (i.e. including from individuals or public sources).

⁵ NHS Digital, [Personal Social Services Adult Social Care Survey](#)

⁶ NHS Digital [Deferred Payment Agreements](#)

⁷ [Care of older people](#) market report

On the social care workforce⁸

The shape of the care sector is fairly well understood. The Government's [National Minimum Dataset for Social Care \(NMDS-SC\)](#) provides survey data on the sector, including the number and type of services provided and the size and shape of the workforce (including qualifications, employment terms, sickness, pay and turnover, estimates of the number of hours worked) at Local Authority level.

The dataset is managed by Skills for Care on behalf of the Department of Health and Social Care, and used as the adult workforce data return for councils.⁹ A visualisation of the data is available from [Skills for Care](#). This includes data that can be used as proxies for the state of the social care labour market, such as vacancy rate, turnover rate and sick day rate.¹⁰

Alert: The NMDS-SC does not provide a complete picture. Data submission is not mandated by the Government for independently run services. In 2017, the dataset included around half of the workforce and just over half of all Care Quality Commission (CQC) regulated social care establishments.

Recommended Action:

Create a combined metric of these indicators to give an indication of the state of the social care workforce for each local area.

⁸ Note that unpaid carers, a major element of support for those in need of care, are discussed in Section 3.

⁹ More information on [NHS Digital](#)

¹⁰ Further information: NHS Digital [Personal Social Services: Staff of Social Services Departments](#)

Section 2: What data exists on outputs and outcomes?

An overview of the Government's Adult Social Care Outcomes Framework, and a look at what measures are important beyond the framework. Includes a note on measuring efficiency, productivity and collaboration in the sector.

The Adult Social Care Outcomes Framework

The Adult Social Care Outcomes Framework ([ASCOF](#)) “*measures how well care and support services achieve the outcomes that matter most to people.*”¹¹ The measures are grouped into the following four domains:

1. Enhancing **quality of life** for people with care and support needs
2. Delaying and **reducing the need** for care and support
3. Ensuring that people have a **positive experience** of care and support
4. **Safeguarding adults** whose circumstances make them vulnerable and protecting from avoidable harm

Below, the measures relevant to adult social care are listed.¹²

In the following, ASCS refers to NHS Digital [Personal Social Services Adult Social Care Survey](#) and SALT refers to the Short and Long Term Services data collection, published in the NHS Digital [Adult Social Care Activity and Finance Report](#).

¹¹ Further information: [NHS Digital](#) (2018) Measures from the Adult Social Care Outcomes Framework.

¹² *Other outcomes within the framework that are less relevant here:* The proportion of adults with a learning disability in paid employment; Proportion of adults in contact with secondary mental health services in paid employment; The proportion of adults with a learning disability who live in their own home or with their family; Proportion of adults in contact with secondary mental health services living independently, with or without support; Long-term support needs of younger adults (aged 18-64) met by admission to residential and nursing care homes, per 100,000 population

Domain 1: Quality of life

Social care-related quality of life score (ASCS)

This takes into account eight measures asked within the ASCS:

1. Control over daily life
2. Personal care
3. Food and Nutrition
4. Accommodation (clean and comfortable)
5. Safety
6. Social participation
7. Occupation (how you spend your time)
8. Dignity (how the way you are helped and treated makes you think and feel about yourself)

Adjusted social care-related quality of life – impact of Adult Social Care Services (ASCS)

This is a weighted version of the metric above.

The proportion of people who use services who:

- have control over their daily life (ASCS)
- receive self-directed support (SALT)
- receive direct payments (SALT)
- reported that they had as much social contact as they would like (ASCS)

The proportion of carers who:

- receive self-directed support (SALT)
- receive direct payments (SALT)

Domain 2: Reducing need

Long-term support needs of older people met by admission to residential and nursing care homes (SALT).

The proportion of older people who:

- were still at home 91 days after discharge from hospital into reablement/rehabilitation services (SALT)¹³
- received reablement/rehabilitation services after discharge from hospital (SALT/[HES](#))
- received a short-term service during the year where the sequel was either no ongoing support, or support of a lower level (SALT)¹⁴

¹³ Further information: [NHS England](#) and PHE [Fingertips](#)

¹⁴ Formally called ‘The outcome of short-term services: sequel to service’. Further information on [NHS Digital](#)

Note: this is perceived as a good outcome, as it is either delaying dependency or supporting recovery

- Delayed transfers of care from hospital:
 - per 100,000 people
 - that are attributable to adult social care, per 100,000 population
 - that are jointly attributable to NHS and Social Care, per 100,000 population

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Domain 3: Positive experiences¹⁶

- Overall satisfaction of people who use services with their care and support (ASCS)
- The proportion of people who use services who find it easy to find information about support (ASCS)

Alert: The survey only includes people who have successfully accessed Local Authority services. The data will not include experiences of those who are not able to access Local Authority support, and so is unlikely to capture the degree of unmet need.

Alert: Due to changes in survey methodology, satisfaction cannot be compared over time

Domain 4: Safeguarding

- The proportion of people who use services who feel safe (ASCS)
- The proportion of people who use services who say that those services have made them feel safe and secure (ASCS)

¹⁵ [NHS England](#)

¹⁶ *Note on the data source:* The ASCS is an annual national survey conducted by Councils with Adult Social Services Responsibilities (CASSRs), of service users aged 18 and over in receipt of long-term support services funded or managed by social services. Data is collected from a sample of 65,020 service users and used to make estimates for the whole population of 645,940 service users. (Further information: NHS Digital, [Personal Social Services Adult Social Care Survey](#)).

Beyond the Framework

The Framework aims to capture crucial outcomes and impacts of social care: quality of life, control, safety and social contact, sustainability of outcomes, satisfaction with care, access to information. It also seeks to measure the success of the health and social care interface, by counting whether people are staying at home after discharge from hospital, whether that discharge was delayed, and whether they have access to rehabilitation services.

These measures are important - each offers an important insight into the performance of the care system and the experience of its users - but they are incomplete. In particular, they do not include many of the elements of high quality social care as identified by [NICE](#), such as the importance of carers building rapport, the consistency of care and ensuring home care visits are of a sufficient length.¹⁷

With respect to measurement in social care, the other crucial element is the CQC inspection roster. CQC inspections are framed around [five key elements](#): is the care provider safe, effective, caring, responsive to need and well-led?

CQC inspections and the [ratings](#) that they result in are, at present, the main lever by which Government can affect the quality of social care.¹⁸ However, there remain concerns around the Commission and its inspection regime.¹⁹

In attempting to find a balance between rigour and acceptable inspection burdens, it can be argued that the Framework doesn't cover many of the areas that care users have been told to expect from good quality [at-home](#) and [care home](#) support.

Measuring, and optimising for, the 'wrong' things can have a significant negative impact.

The impact of using current data and assessment frameworks, in particular, the ACS framework and the CQC assessment framework, to assess outcomes means that only the views of (a sample of) those who are in contact with the council are taken into account.

This is particularly worrying given the increase in rationing and more people being turned away for support. Similarly, optimising for the overall number of people who receive support can result in rushed, poor quality care and neglect, which are at present poorly captured (if at all) by the current outcomes framework.

Below, we explore additional data that can be used to understand the social care system, keeping our focus on direct outcomes and experiences of care. Externalities will be discussed in the next section.

¹⁷ NICE home care [guidelines](#)

¹⁸ CQC also publish their ratings [collated by LA](#), however, they do not make a single assessment of quality across **all** providers by LA or assess LA social care departments

¹⁹NAO (2017) [Care Quality Commission – regulating health and social care](#); Public Accounts Committee (2015) [Care Quality Commission Inquiry](#)

Broadening data on satisfaction

In assessing the experiences of those within the care system, the Framework includes one measure of satisfaction of care users. However other metrics would be insightful here, including views of **unpaid carers**, such as the percentage of carers who were satisfied with support and services they, and the person they cared for, received.²⁰

The views of the **general public** would also be useful. As the [Institute for Government](#) notes,²¹ “....user satisfaction does not reflect the views of those who do not receive social care. Public concern with social care provides a proxy for overall satisfaction with social care.” The British Social Attitudes survey asks respondents whether they are satisfied with social care.

Though our focus here is on adult social care services, users are likely to be reliant on elements of the health system as well. To get a more holistic understanding of the experiences of care users, include data on the health system.

Recommended Actions:

- When assessing the quality of care using satisfaction measures, take into account multiple perspectives - in addition to those receiving care - including unpaid carers and the general public.
- Explore the British Social Attitudes survey to assess whether regional/local level analysis of public concern with social care is possible.
- When assessing the quality of the care system, build in satisfaction and quality of other elements of the health and care system, for example, satisfaction and confidence in care received from GPs ([GP Patient Survey](#), NHS England)

²⁰ NHS Digital [Personal Social Services Survey of Adult Carers](#)

²¹ Performance Tracker 2018

Incorporating complaints and safeguarding enquiries

The [Local Government Ombudsman](#) publishes headline statistics on the number and nature of complaints at a local level, including what proportion are upheld. The parallel rises in user satisfaction (as described above)²² and complaints to the ombudsman suggest that satisfaction should be taken into account when complaints are referenced.

²³

Another important metric for system failure is safeguarding enquiries. The number of Section 42 safeguarding enquiries - which are more common among older people than younger - are provided by NHS Digital [Safeguarding Adults](#) statistics.

Recommended Action:

Incorporate data on complaints into assessments of quality at a local level.

Measuring the availability of care

The Framework does not attempt to capture the availability of care. Though it is not straightforward to quantify, there is an abundance of data that can be used to understand this, including:

1. Public funding per head

Availability can be indicated by funding, i.e. the adult social care budget per older person with a self-reported need.

This can be calculated from NHS Digital [Personal Social Services: Expenditure and Unit Costs](#) or NHS Digital [Adult Social Care Activity and Finance Report](#), and NHS Digital [Health Survey for England](#) for the number of older people with a self-reported need.²⁴

Recommended Action:

Publish this availability data, as well as a relative measure that highlights outliers (particularly those with below average spending).

2. Assessment of sufficiency

²² NHS Digital [Personal Social Services Adult Social Care Survey](#)

²³ The King's Fund note that ASCS findings that most users are satisfied "contrasts with rising levels of complaints to the ombudsman about adult social care – up by 18 per cent since 2013; 55 percent of claims were upheld." (King's Fund (2016) Social care for older people: Home truths)

²⁴ Related to funding per head is the sustainability of services. The Association of Directors of Adult Social Services survey LAs to understand the number and distribution of care home providers that have ceased trading or handed back a contract ([ADASS Budget Survey](#)).

The sufficiency of care is assessed by Local Authorities themselves and accessed through Freedom of Information (FOI) requests. These are reported on by the non-government organisation, Coram Family and Childcare in their [Older People's Care Survey](#).²⁵

Recommended Action:

This data should be collected consistently, regularly, & be incorporated into data on our understanding of the availability of social care.

3. Local Authority support thresholds

The Local Authority eligibility threshold for support (low, moderate, substantial, critical) is indicative of availability.

Data collection by the [NAO](#) (2014) and [Age UK](#) provide us with a national picture²⁶; however no consistent, up to date data exists at a national level with an indication of how they have changed over time.

Recommended Action:

Collect data on eligibility thresholds and how they changed over time

4. Survey responses on need and support

NHS Digital [Health Survey for England](#) asks about both the need for help with daily activities and the receipt of this help, among older people in the last month.²⁷

Responses to these questions allow for calculation of the gap in provision of social care but we recommend exploring the survey further to see whether it allows for local level analysis.

Recommended Action:

Explore if the Health Survey for England allows for local level analysis

²⁵ Note that sufficiency is reported on using a binary measure, i.e. whether an area reports having sufficient or insufficient amount of care available for older people.

²⁶ Age UK: In 2011-12, only 3 councils provide social care to people falling in to all eligibility criteria bands

NAO: Most adults (87 per cent) now live in LAs that set the eligibility threshold for substantial or critical needs only

²⁷ [The Health Foundation](#)

5. The number (and response to) LA requests for support

The number of requests for adult social care support at a local level is provided by NHS Digital [Adult Social Care Activity and Finance Report](#).²⁸ We also know the proportion of requests for support made to councils by outcome, including those that resulted in no direct support from the council. A ‘no direct support’ outcome could mean that the person was redirected to universal services or signposted elsewhere or the council did not identify any unmet need.

Recommended Action:

Assess responses to requests for support at a local level to see if these are outliers, and if so explore the reasons behind this.

6. Waiting times

For social care provided by, or through, the Local Authority, waiting times (i.e. between assessment and receipt of care) are not centrally collected nor is there an enforced maximum waiting time.²⁹ Though waiting time data has been collected in the past, the indicator was scrapped in 2010.

For NHS-provided care (continuing healthcare funding in England), data on the proportion of applicants who received a decision within the recommended 28 days is available from [NHS England](#). It should be possible to collect and publish data on waiting times for LA social care assessments and care.

Recommended action:

Collect data on waiting times for LA social care assessments & care

7. Delayed Transfers of Care (DTOC)

Another measure of availability is the number of bed days due to Delayed Transfers of Care (DTOC). According to The King’s Fund,³⁰ a rise in DTOC is the “*most visible manifestation of pressures on health and social care budgets.*”

²⁸ previously by NHS Digital [Community Care Statistics, Social Services Activity](#)

²⁹ In the absence of a target, the Local Government Ombudsman (LGO) identifies waits of up to six weeks as reasonable when investigating complaints about delays.

³⁰ [Social care for older people: Home Truths](#) (2016)

This data is available from [NHS England](#) at a CCG level, with DTOC categorised as either attributable to social care; jointly attributable to NHS and social care; or the total number irrespective of cause. All three categories are captured in the ASCOF.

Recommended action:

Incorporate data on availability of care into assessments of the care market at a local level

8. Number of unpaid carers

The number of unpaid carers is taken from the Census.³¹ This is a vital measure, indicating both the access to care and the potential demand for support for unpaid carers.

Recommended action:

Explore whether the ONS will share detailed LA-level tables of unpaid caring from the 2011 census

9. Choice

Feeling empowered and in control is an important element of user's experiences, and the metric above ('have control over their daily life') is a welcome part of the Framework. In addition to this metric, control (or the presence of choice) can be indicated by the proportion of older people dying in their usual place of residence.³² As the [Nuffield Trust](#) report: *'Survey data suggest that many people would, given the choice, prefer to die at home, with few wishing to die in hospital. The proportion of deaths in usual place of residence is a key indicator for end-of-life care and acts as a proxy quality marker for choice and access.'*

Recommended action:

To understand choice and control from a care user perspective, consider the proportion of deaths in usual place of residence, alongside the ASCOF metric of control in daily life

³¹ Latest data available: 2011; for example, see ONS [2011 Census analysis](#): Unpaid care in England and Wales, 2011 and comparison with 2001. NB: The Government-run [Family Resources Survey](#) can also be used to analyse the number of unpaid carers; however the data will not allow for LA-level analysis.

³² PHE [Fingertips](#). (Note that this includes care homes if that is the person's residence at the time of death.)

A note on efficiency, productivity and collaboration

Though data on efficiency, productivity and collaboration are out of the scope of this essay, we take a brief detour to make a note of these elements.

The ONS attempts to capture public sector productivity of the social care workforce.³³ Efficiency is hard to measure in care, given the outcomes are poorly measured themselves and some are entirely missing from the data. Shifting from outcomes to outputs does not make the task easier. As the [Institute for Government](#) notes:

“....difficulties measuring exactly what care is being purchased and provided with public money mean that it is not possible to say whether adult social care is more efficient now [2018] than in 2009/10.” (Performance Tracker 2018)

Though we do not seek to stray into performance management here, it is interesting to note that the CQC recommend that: *“There should be a single, joint, nationally agreed framework for measuring the performance of how organisations collectively deliver improved outcomes for older people.”*³⁴

In order to understand the degree to which collaborative working improves the outcomes of older people in care, data on collaboration and outcomes at a local level are vital.

³³ [measuring adult social care productivity](#)

³⁴ [Beyond Barriers](#), 2018

Section 3: What data exists on the externalities of care?

Here we discuss the externalities of care on those using care, on unpaid carers, and on paid carers.

Relating to care users

These are threefold, relating to the nature and quantity of care provided; care users' health and wellbeing; and their community participation and cohesion.

1. Nature and quantity of care provided

Care packages

Current data collection does not provide any insight into the *amount* of care hours provided across local areas in England.³⁵ Before 2014-15, data was collected on Referrals, Assessments and Packages of Care (RAP). This included the amount of planned community care that care users were entitled to each week.³⁶

As the strain on the social care system grows, there are risks of (a) declining numbers of people being supported, and (b) of those who do receive care getting poor quality and/or insufficient care.

Given these risks, there is a strong case to collect data on the nature of care packages, as well as the number of people receiving support.

³⁵ Note that a survey by Unison (2016) [Suffering alone at home](#), found that the majority of councils commission home care visits in 15-minute time slots, with 1 in 7 home care visits in these areas now being just 15 minutes long. The Care and Support Alliance (CSA) conducted a survey asking about difficulties with essential activities, paid carers rushing visits and care packages being reduced ([The Health Foundation](#) (2018) What's the problem with social care, and why do we need to do better?). In both cases, sample sizes are small and non-representative, and therefore not directly useful for further analysis.

³⁶ See e.g. National Archives, NHS Digital [Community Care Statistics. Social Services Activity. England - 2013-14](#); [Institute for Government](#) Performance Tracker 2018.

Recommended action:

Collect this data, or something similar, to allow for the understanding of the type of care packages being provided.

2. Health and wellbeing

Mental health: Though the ASCOF incorporates social isolation³⁷ (service users having as much social contact as they would like), there is no more direct inclusion of mental health.

Recommended action:

In addition to social isolation, take into account:

- (a) anxiety or depression levels reported by service users³⁸
- (b) the suicide rate of all people 65+ years, not just service users³⁹

Wellbeing: Average wellbeing by age are available from the Government-run Annual Population Survey. Given the fairly large sample size of the survey, it may be possible to get Local Authority breakdowns for the 65+ population.

Recommended action:

Explore possibility of using APS wellbeing data at a local level

Preventable illness/death: The quality of the care system can be in part be measured by the instances of preventable illness and death among older people. In addition to the ASCOF data on whether the care user is still at home 91 days after discharge, other data on preventable illness or death can be used.

³⁷ Age UK have modelled likelihood of older people being lonely, to create local level '[loneliness maps](#)'. Age UK state "*The relative risk of loneliness is based on the Census 2011 figures for the factors: marital status; self-reported health status; age; household size. These four factors predict around 20% of the loneliness observed amongst older people 65 and over as represented in the English Longitudinal Study of Ageing (ELSA).*" Given the modest predictive power of this modelling, and the lack of robust data to back up their assumptions, I would not advise using or replicating this approach.

³⁸ NHS [Digital Personal Social Services Adult Social Care Survey](#)

³⁹ PHE [Fingertips](#) using ONS data)

Recommended action:

Incorporate data on preventable ill health, such as hip fractures in people aged 65 and over, and preventable sight loss. Incorporate data on preventable deaths, such as excess winter deaths for those aged 85+ (PHE [Fingertips](#))

Avoidable emergency admissions to hospital could be better understood at a local level. Data exists on avoidable emergency admissions for acute conditions (NHS [Outcomes Framework indicator 3a](#)), on the number of emergency admissions for injuries due to falls⁴⁰ among older people in by local area (Available from PHE [Fingertips](#), data from NHS Digital), and on emergency admissions related to dementia ([NHS England](#); PHE [Fingertips](#)). However, data that directly addresses social-care related preventable admissions as a whole is not available.

According to [The Health Foundation](#) (2018) What's the problem with social care, and why do we need to do better?: *“When the Alzheimer’s Society asked hospital trusts for numbers of dementia patients they admitted as emergencies with diagnoses of falls, delirium, chest infections, urinary tract infections and dehydration, 65 trusts reported over 50,000 patients in 2016/17.”*

This data could be of great use to councils, to understand the quality of their social care offer and to incentivise better integration of health and social care.⁴¹

Recommended action:

Collect data on preventable admissions as relevant to social care

Nutrition: The NHS Digital [Personal Social Services Adult Social Care Survey](#) asks those in receipt of care about their satisfaction with the food and drink they have ('Thinking about the food and drink you get, which of the following statements best describes your situation?'). This indicator could be helpful in addressing the high levels of dehydration and poor nutrition among older people admitted to hospital.

Recommended action:

⁴⁰ Among older people, falls are the most common cause of emergency admissions

⁴¹ For further discussion, see: The Health Foundation (2018) [Emergency hospital admissions in England - Which may be avoidable and how?](#); and The Health Foundation (2018) [What do we know about the effects of cutting public funding for social care?](#)

Take satisfaction with food, and issues with dehydration and nutrition into account when assessing the quality of care.

Movements through health and social care services

There is no way of currently identifying people with social care needs at person-level in NHS data, which makes it hard to measure links between hospital admissions and social care. Though, for example, “...analysis by the IFS has suggested a correlation between emergency hospital attendances amongst the over 65s and areas affected by the biggest reductions in social care spending” ([The Health Foundation](#) (2018) What’s the problem with social care, and why do we need to do better?), it is impossible to understand in more detail what is going on, where people are falling through the gaps and how this can be corrected.

Recommended action:

Link data at a person-level, to allow analysis (anonymised or pseudo-anonymised) of movements through the health & social care system

3. Participation and cohesion

Cohesion: [Understanding Society](#), a large-scale longitudinal study, provides data on the proportion of people who feel people in their local area can be trusted; are willing to help their neighbours; feel they belong to their local area and regularly stop and talk to people in their neighbourhood.⁴²

Recommended action:

Explore whether this data can be analysed at a local level, and if possible, by care user status

For a deeper understanding of safety, Police recorded crime data can be used for the proportion of people who have been victim of crime by age group and local area. Perceptions of the likelihood of being a victim, whether people feel safe in the local area during the day and after dark, and safe in their own home at night can be found from the Crime Survey for England and Wales (Further information: [ONS](#); also see [PHE Fingertips](#)). In addition to the metrics in the ASCOF (the proportion of service users who feel safe, and who say that those services have made them feel safe), an additional NHS

⁴² For further information, see [Inequalities in Social Capital by Age and Sex](#), Office for National Statistics, July 2015

Digital metric can be used: the proportion who report feeling as safe as they *want* (NHS Digital [Personal Social Services Adult Social Care Survey](#)).

Civic society: Understanding the nature of civic society in the local area is a proxy for the degree to which there is an active community of older people. However current data is patchy and not particularly accessible to non-technical users. Structured data on civic society - such as the number and nature of groups available to join, assessed by whether they are aimed at older people, those with caring needs, carers or none of these groups - would be valuable.

Recommended action:

Scope out sources of data on local groups, such as the Charity Commission, National Council for Voluntary Organisations and AgeUK

Participation: Though detailed survey data on volunteering and community participation are available from longitudinal surveys ([Understanding Society](#) or [ELSA](#)) and annual surveys ([Community Life Survey](#)), no local analysis has been done of participation among older people.

Recommended action:

Explore whether these datasets can be analysed at a local level (and ideally for those experiencing care) to understand participation by age

Internet access: The Annual Population Survey tells us the proportion of people who have internet access by age group (ONS [Internet access - households and individuals](#)).

Recommended action:

Explore whether this data can be analysed at a local level, and ideally by care status

Relating to unpaid carers

Here we discuss four areas with respect to unpaid carers: availability of support for carers; their health and wellbeing, community participation and labour market participation.

1. Availability of support for carers

We can assess the degree of support and respite care offered to carers using the NHS Digital [Adult Social Care Activity and Finance Report](#). This gives the number of carers and, of those, the number who receive direct support; instances of respite or other support and instances of a review or assessment of need for that carer. [DWP](#) Benefits statistics tell us how many informal carers are in receipt of carers allowance and the average amount awarded.

Recommended Action:

Explore if the Health Survey for England allows for local level analysis

Alert: This survey takes into account only those who are or have been in contact with the council

Recommended Action:

In addition to data on the instance of unpaid care, also incorporate data on the support for carers into consideration of the quality and coverage of the care system

The Nuffield Trust data toolkit, [Understanding carers: a guide for local authorities](#), provides a useful overview of data on support for carers, as well as data on demographics and experiences.

2. Health and Wellbeing

Depression, stress and other health conditions: The NHS Digital [Personal Social Services Survey of Adult Carers](#) (carried out every other year), provides data on the experiences of carers aged 18 or over who are caring for a person aged 18 or over.⁴³ Responses include the proportion of carers who reported feeling depressed, having ‘a general feeling of stress’, had developed their own health conditions and felt socially isolated. Looking at

⁴³ Further detail on the impacts on unpaid carers of caring can be found in the Health and Social Care Information Centre [Survey of Carers in Households](#) (2009/10). However, this does not allow for local level analysis.

carers more broadly (i.e. all carers rather than those in contact with the council), [Carers UK](#) explored the impact of caring on the health of the carer at a local level using the 2001 Census. In addition, Carers UK run an annual [State of caring](#) survey with a much smaller sample than the Government-run version. This survey asks whether carers feel their LA need assessment had properly considered their need for support to look after their own physical and mental health.

Recommended actions:

- Incorporate statistics about the health and wellbeing of unpaid carers into consideration of the quality of the care system.
- Repeat the Carers UK analysis for 2011 census data (if others have not done so).
- Though the Carers UK survey is too small a sample to allow for local-level analysis, explore whether the wording of these questions is more useful than those in the Government-run carers survey, and the potential implications of this
- Explore if the Health Survey for England allows for local level analysis

3. Labour market participation

Though much has been written on the topic of older people's labour market participation (e.g. ONS [Living longer: Fitting it all in – working, caring and health in later life](#)) it is difficult to ascertain the direct *impact* of social care quality and availability on the employment status of carers at a local level.

However, we do not know the number of people dropping out of labour market to care for others, at a local level. This could be estimated by using the instance of unpaid care as reported in the Census (2011) combined with national-level studies that give an estimate of the proportion of unpaid carers would have stopped work to care.

Care responsibilities as a barrier to work can cause or exacerbate financial difficulties for the household. Carers financial concerns are surveyed in the NHS Digital [Personal Social Services Survey of Adult Carers](#).

Recommended Action:

Collect, compute and analyse data on the labour market impact on unpaid care at a local level. Additional analysis of how the financial impacts (both in terms of individual households and the macro-level tax/benefit impact) can contribute to the case for better investment in care.

Relating to paid carers

1. Health and wellbeing

Given qualitative data on the experiences of paid carers, as well as high vacancy and turnover rates, it is likely that working conditions are challenging and may be resulting in poor physical and mental health. Yet no reliable quantitative data exists on the wellbeing, physical and mental health of paid carers at a local level.

Recommended Action:

Collect data on the wellbeing, physical and mental health of paid carers that can be analysed at a local level

Conclusion

As summarised by the Health Foundation, there is a strong case for better data on the fundamentals of social care in England:

“....a major problem is a lack of data. Good data on the quantity and type of care received by older people are rarely available to policymakers and researchers. Indeed, due to changes in the way the data are collected and reported, it is impossible to know with certainty even how the number of people receiving public social care across the country has changed in the last few years, let alone who is receiving this care or what it includes. If policymakers are serious about understanding the issues involved with social care then this needs to change, and the sooner the better. (The Health Foundation (2018) [What do we know about the effects of cutting public funding for social care?](#)).”

Though steps to improve the fundamental data offer are necessary, this essay suggests that we go beyond those fundamentals to understand the impact of social care on the lives of those receiving it, their loved ones and paid care workers. This essay contains 33 actions to achieve this. They range from incorporating additional metrics into our assessment of the quality, coverage and accessibility of the care system, to collecting data to better understand the externalities of care at a local level. Note that all data analysis should include contextual data, some recommendations for which are given in appendix A.

In trying to assess the quality of our social care system, we are fumbling in the dark if we do not also try to understand its outcomes not only in terms of outputs and narrow outcomes, but more broadly, taking into account the broader impacts on people's everyday lives, their health and wellbeing and our communities.

Appendices

(A) Contextual data

Any data analysis of outcomes and externalities at a local level should be done taking into account relevant contextual data. The following provides some suggested contextual data, at a local authority level unless otherwise stated.

Describing the local area

- Deprivation, both the overall IMD score as well as more specific elements ([MHCLG](#), and can also found in [PHE Fingertips](#))
- Internal migration in and out of the area ([ONS](#))
- Distribution of household types, including instances of single pensioner households and multi-generational living ([ONS](#))
- Population by age ([ONS](#), also found in [PHE Fingertips](#))
- Health inequality - Local basket of inequality indicators ([NHS Digital](#))
- Coverage of health service routine functions, e.g. the proportion of the population aged 40-74 who received an NHS Health check; vaccination coverage for the Flu (aged 65+) ([PHE Fingertips](#))
- Coverage of health screening programmes, i.e. breast cancer screening ([NHS Digital](#))

Describing the local older population

- Proportion of people aged 65+ receiving winter fuel payments ([PHE Fingertips](#))
- People aged 65+ in receipt of Attendance Allowance ([PHE Fingertips](#))
- Proportion older people with health problems ([PHE Fingertips](#))
- Recorded prevalence of Dementia among those aged 65+ ([NHS England](#), [PHE Fingertips](#))
- Life expectancy and disability-free life expectancy at 65 ([ONS](#); [PHE Fingertips](#))
- Rate of deaths from Cardiovascular Disease/Cancer/Respiratory Disease among people aged 65 years and over ([PHE Fingertips](#))
- Permanent admissions to residential and nursing care homes per 100,000 aged 65+ ([PHE Fingertips](#))
- Access to transport: this is available at local level from the Census 2011

(B) Social care datasets

A summary of the data collects relating to adult social care can be found on NHS Digital [here](#). For only datasets that are able at a local level, see NHS Digital local [search](#).

The NHS Digital social care collection contains the following:

- Adult Social Care Outcomes Framework (ASCOF)
- National Minimum Data Set for Social Care
- Personal Social Services Survey of Adult Carers in England
- Personal Social Services Adult Social Care Survey, England
- Short and Long Term Support (SALT)
- Summary of the Registers of People who are Blind or Partially Sighted (SSDA902)
- Adult Social Care Finance Return (ASC-FR)
- Deferred Payments Agreements (DPA)
- Safeguarding Adults Collection (SAC)
- Deprivation of Liberty Safeguards (DoLS) Return [Mental Capacity Act 2005]
- Guardianship [Mental Health Act 1983]

A summary of relevant datasets can also be found on the Government Statistical Service [Health and Care statistics landscape for England](#). Public Health England also have a useful portal, [Fingertips](#), which contains an older people's health and wellbeing section.