Care data matters roadmap - response to survey

Do you think these are the right data needs themes? (optional)
- All themes are included
- Some themes are missing
- Some themes are incomplete
- I don't know

We would like to hear more from you on what data you think is needed for each of these themes if they are relevant to you. The following questions will ask for more details on each theme.

Theme 1: Population, characteristics, needs and outcomes of people who draw on care and support including self-funders
- What information and data do people who use care and support services and their carers need, in relation to population, characteristics, needs and outcomes of people who draw on care and support including self-funders? (optional)
- What information and data do care providers need, in relation to population, characteristics, needs and outcomes of people who draw on care and support including self-funders? (optional)
- What information and data does local government (including local authorities and their staff) need, in relation to population, characteristics, needs and outcomes of people who draw on care and support including self-funders? (optional)
- What information and data does national government need, in relation to population, characteristics, needs and outcomes of people who draw on care and support including self-funders? (optional)
- What information do any other people and organisations across the sector need, in relation to population, characteristics, needs and outcomes of people who draw on care and support including self-funders? (optional)
- Any other comments, in relation to population, characteristics, needs and outcomes of people who draw on care and support including self-funders? (optional)

The ability to analyse person-level data (also referred to as client-level data) and to track an individual's care 'journey' through time and across different services would be game-changing. It would support monitoring at population level and for particular cohorts of service users, and increase understanding of care outcomes across the life course. This would facilitate development of more effective prevention strategies and increase understanding of current and future population needs (NHS Digital, n.d.). The scale and challenge of this ambition is significant; mindful of this we note that some milestones in the roadmap may not be achievable within the timeframes indicated.

Analysis of person-level data across multiple adult social care data sets will be resource-intensive work (presumably for local authorities). As an example, our Centre currently works closely with Hampshire County Council as part of our research activity. This council is at a high level of digital maturity compared to many other local authorities in England, but is nonetheless finding this work (particularly the data harmonisation needed) highly complex and challenging. Without a single unique identifier (such as the NHS patient number), identifying the same person across multiple social care data sets requires matching of multiple characteristics (e.g. full name, postcode, date of birth), that can change

for individuals over time, or may have been entered differently (or incorrectly) in the various data sets. This issue reflects the current lack of digital maturity in the sector, in which some data are still collected in paper form and likely to contain errors. To achieve data harmonisation on the scale needed will require a range of data scraping techniques, and there may be a role for machine learning in accelerating this work.

A further challenge will be understanding who is excluded from available data, whether on a systematic basis (e.g. self-funders) or because they have chosen not to share their data.

Regarding 'self-funders' (an increasingly important issue); the term needs careful definition and in some usages may be a misnomer. Most people fully self-funding their residential care are not exercising a personal choice but are legally required to do this because the value of their home is taken into account (after the 12-week property disregard has elapsed). People self-funding other forms of care may be doing so because they have savings/other assets (excluding their home) over £23,250; because they do not want to be assessed or to wait to be assessed; because they do not trust or have confidence in their local authority social services department; or because they prefer a private care arrangement.

In some communities, there is evidence of high levels of mistrust about sharing data with public agencies. For example, those from racially minoritised communities often express deep mistrust, particularly in the wake of the Windrush scandal which arose from government agencies sharing personal information with devastating consequences for the individuals involved.

As Martin et al (2023) argue in the BMJ, the 'social licence' for collecting and analysing data is fragile. Public trust needs to be earned and cannot be taken for granted; as they put it: "trust in public authorities is low among some ethnic minority groups and for good reason. Recent events, including the Windrush scandal, demonstrate the malintent and racist consequences of some government data collection activities." Others have made the case, for these communities, for a 'firewall' - a commitment that personal data held by essential public services (including health and social care) will not be shared with the Home Office for immigration enforcement purposes (Liberty, 2018). This argument is based on evidence that the 'hostile environment' policy announced by Home Secretary Theresa May in 2012 led to injustices that continue to deter some people from racially minoritised communities from seeking access to services, regardless of their migration status, as they fear they will be treated with suspicion (Liberty, 2018).

Better understanding of the level of unmet need for care and support is also urgently needed. Currently there is limited evidence both on who has unmet needs and why this is. It is highly likely that people from marginalised groups who experience multiple disadvantages and may struggle to access a range of public services, including adult social care are under-represented in the data currently collected.

Collecting and analysing data on the demographic characteristics of people who draw on care and support (and those with unmet needs) is crucial for understanding the reasons behind inequalities in access to, experience of, and outcomes of care. Often, these data are collected using categories derived from those used in the Census of Population. While this has some benefits, it can be problematic. Aggregating ethnic categories, as public agencies

often do, cannot capture important variation between and within groups whose lived experience needs to inform how personal data is recorded. A further important point is that ethnicity is "socially constructed and ethnic identifications and inequalities evolve over time" (Martin et al, 2023).

Access to good data on self-funders would add significantly to understanding of people with care and support needs. The University of Birmingham's NIHR-funded Shifting Shapes research project found that self-funders remain largely invisible, with data on the numbers of people paying for care "imprecise and based on a range of estimates, with considerable variation" (Henwood et al, 2022). Self-funders are mostly either not included in the person-level data held by local authorities, or included but with very limited information. For example, the Adult Social Care Survey (ASCS) includes only people whose needs have been assessed (via a Care Act assessment). The roadmap does not currently include a mechanism for collecting data on self-funders; we think this is an important omission. The ONS recently undertook work to estimate the size of the population of self-funders, but could only do so for those living in CQC-registered care homes, as adequate data on those living in the community were not available (ONS, 2023). Currently the main source of data on self-funders is probably that held by the business intelligence company LaingBuisson, which provides intelligence on the healthcare market to ONS and sells market research reports to care sector organisations https://www.laingbuisson.com/shop-category/market-reports/). Greater clarity is needed about access to data on care provision for both public sector agencies and academic researchers. The dominant position of the independent sector in care, and growing private purchase of care services makes this an increasingly salient issue not acknowledged in the roadmap. Academics have adopted open science principles but in social care find much data is inaccessible to them as it is marketed at costs beyond academic and local authority budgets as business intelligence data.

In 2022, the Government's adult social care charging plans (set out in the Health and Care Act 2022 which amended the Care Act 2014) were postponed until 2025. These would have required local authorities to collect data for self-funders opting to exercise their new right to ask their local authority to arrange care on their behalf (either to access the typically lower rates charged to councils than to individuals, or to start a care account metering their spending on care costs). With the current Parliament due to be dissolved in December 2024, the future of these reforms is now uncertain. Analysis by the County Councils Network (CCN) warned in 2022 that the Government was seriously underestimating the cost of implementing the reforms, including the resource required to respond to self-funders. The CCN estimated an additional 105,000 Care Act assessments per year would be needed, and an additional 4,300 staff to undertake these. Data on the number of self-funders will be crucial if these reforms go ahead, to support local authorities' planning.

References
County Councils Network and Newton consultancy (2022), Preparing for reform
Henwood, M., Glasby, J., McKay, S., & Needham, C. (2022). Self-funders: Still By-Standers in the English Social Care Market? Social Policy and Society, 21(2), 227-241.
Liberty (2018) Care Don't Share. Hostile environment data-sharing: why we need a firewall between essential public services and immigration enforcement
Martin G, Mathur R, Naqvi H. How can we make better use of ethnicity data to improve healthcare services? BMJ 2023; 380 :p744 doi:10.1136/bmj.p744

NHS Digital (n.d.). [Commissioning Datasets](#)
Office for National Statistics (ONS), released 6 July 2023, ONS website, article, Care homes and estimating the self-funding population, England: 2022 to 2023
https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/carehomesandestimatingtheselffundingpopulationengland/2022to2023#cite-this-article

Theme 2: Quality of care and support (including early intervention, safeguarding and integration of health and care services)

- What information and data do people who use care and support services and their carers need, in relation to quality of care and support (including early intervention, safeguarding and integration of health and care services)? (optional)
- What information and data do care providers need, in relation to quality of care and support (including early intervention, safeguarding and integration of health and care services)?
- What information and data does local government (including local authorities and their staff) need, in relation to quality of care and support (including early intervention, safeguarding and integration of health and care services)?
- What information and data does national government need, in relation to quality of care and support (including early intervention, safeguarding and integration of health and care services)?
- What information do any other people and organisations across the sector need, in relation to (optional)
- Any other comments, in relation to quality of care and support (including early intervention, safeguarding and integration of health and care services)? (optional)

Defining 'quality' in these contexts is challenging. We suggest that a first principle to agree is that definitions of 'quality' in care and support, both in the specific contexts mentioned (safeguarding, early intervention, integration) and more generally, should be co-produced with people with care and support needs and carers and adhere to the principles set out in the Care Act 2014. The latter place the individual's wellbeing at the centre of service provision to people with care and support needs and unpaid carers. The Care Quality Commission, as the sector regulator, has published fundamental standards below which services and support should never fall and also (May 2023) published a set of 'quality statements', defining these as 'commitments that providers, commissioners and system leaders should live up to'. The CQC is clear these are applicable to 'people who use services, their families, friends and unpaid carers', and that this includes both 'people with protected equality characteristics' and 'those most likely to have a poorer experience of care or experience inequalities'. Data collected on care needs to include evidence on how the latter two groups experience care as a key priority, as at present official data on carers, older people and disabled people often cannot be disaggregated to explore differences and inequalities in how care and support is experienced, and the unfairness that results as a consequence of these.

Integration of health and social care data is a key aim of the NHS Transformation Directorate (which is both relatively new and intended to be a single body for health and social care). Differences in funding models and practices between health and social care are likely to

make implementation of its strategy challenging; as Simon Bolton, former CEO of NHS Digital, has put it, "*the link between healthcare and social care in digital is really unclear and the models are massively different […] in social care there are lots of smaller organisations who are typically, but not always, less digitally enabled*" (Say, 2022).

DHSC's 2022 policy paper states that "*to support place based organisations, ICSs [*Integrated Care Systems] *will develop digital investment plans for bringing all organisations to the same level of digital maturity*" (DHSC, 2022). Local authorities and other stakeholders have raised questions about how ICSs can deliver these, and concerns about ICS funds being funnelled towards the NHS rather than social care (LGA, 2021). It seems likely that the fragmented nature of the social care sector (compared to health) and incompatibilities in the funding models for social care and health will be ongoing challenges.

Data sharing to support integration of health and social care services will also need to involve linkages with data on (for example) education, housing and the criminal justice system. Although the roadmap does not refer to these areas, people's experiences of these have major effects on inequalities and life chances that feed into their experiences of adult social care.

References:
CQC (2023) https://www.cqc.org.uk/assessment/quality-statements
DHSC (2022) Health and social care integration: joining up care for people, places and populations, Policy Paper
LGA [Local Government Association] (2021) LGA response to 'People at the heart of care: adult social care reform White Paper.'
Say, M. (2022) NHS Digital chief calls for stronger emphasis on social care. UKAuthority

Theme 3: Supply of care services, local authority commissioning and accountability, and markets (including occupancy, capacity and discharge)
● What information and data do people who use care and support services and their carers need, in relation to supply of care services, local authority commissioning and accountability, and markets (including occupancy, capacity and discharge)? (optional)
● What information and data do care providers need, in relation to supply of care services, local authority commissioning and accountability, and markets (including occupancy, capacity and discharge)? (optional)
● What information and data does local government (including local authorities and their staff) need, in relation to supply of care services, local authority commissioning and accountability, and markets (including occupancy, capacity and discharge)? (optional)
● What information and data does national government need, in relation to supply of care services, local authority commissioning and accountability, and markets (including occupancy, capacity and discharge)? (optional)
● What information do any other people and organisations across the sector need, in relation to supply of care services, local authority commissioning and accountability, and markets (including occupancy, capacity and discharge)? (optional)

Access to granular data on the supply of care services will be needed to understand and address the problem of 'care deserts' - areas where people cannot access the care they need due to a lack of provision, including in cases where they have ability to pay for these (Age UK and Incisive Health, 2019). Analysis commissioned by Age UK in 2019 found that the situation varies hugely across the country and that 1 in 7 older people had unmet needs. Its 'Can't Wait for Care' campaign estimates that 2.6 million people over 50 are currently unable to get the care they need (Age UK, 2023).

Researchers in higher education, government departments and other organisations, need to understand the 'back office' functions of commissioning and providing care, as well as how people with care and support needs directly interact with services. Our team has experience (Shifting Shapes research project) of using the Adult Social Care Finance Return to calculate the costs of commissioning. Making sense of this data proved challenging and raised questions about its robustness. This underlines the need for those entering the data to understand the purpose and requirements of the return. This is likely to be particularly challenging for smaller providers, for whom the administrative burden is greater. There may be a need for workforce skills development related to data among providers in the sector.

References:
Age UK and Incisive Health (2019) Care deserts: the impact of a dysfunctional market in adult social care provision.
Age UK (2023) Can't Wait for Care Campaign,
https://www.ageuk.org.uk/our-impact/campaigning/care-in-crisis/#:~:text=Unmet%20need%2 0%E2%80%93%202.6%20million%20people,increasing%20pressure%20on%20unpaid%20 carers
Needham et al (2020), Shifting Shapes: how can local care markets support personalised outcomes?

- Any other comments, in relation to supply of care services, local authority commissioning and accountability, and markets (including occupancy, capacity and discharge)? (optional)

Theme 4: Social care workforce
- What information and data do people who use care and support services and their carers need, in relation to the social care workforce? (optional)
- What information and data do care providers need, in relation to the social care workforce? (optional)
- What information and data does local government (including local authorities and their staff) need, in relation to the social care workforce? (optional)
- What information and data does national government need, in relation to the social care workforce? (optional)
- What information do any other people and organisations across the sector need, in relation to the social care workforce? (optional)
- Any other comments, in relation to the social care workforce? (optional)

We believe there are ways of further improving the quality, completeness and representativeness of data collected on the social care workforce. The main data source -

the Adult Social Care Workforce Data Set (ASC-WDS) - is collected by Skills for Care (SfC) from returns provided by social care providers (not care workers themselves). The latest data was provided by almost 20,000 'care providing locations' registered with SfC, which publishes information on its data collection and analysis methods and their quality (Skills for Care, n.d.). Completion of the annual 'ASC-WDS' returns is '*mandatory for local authorities (but) … non-mandatory for the independent sector*' (SfC 2022a). The ASC-WDS thus lacks 100% coverage of adult social care.

Surveys have been undertaken since 2017 (annually, although not in 2018) to obtain information on care workers working as personal assistants (Skills for Care, 2023) and SfC's 2022 State of Social Care report included data on '*the number of filled posts working for direct payment recipients … calculated from a survey of individual employers and their personal assistants*' (SfC 2022a:30).

The methods used in compiling the ASC-WDS thus cover a large but incomplete share of the workforce. Segments of the workforce not included, or less visible, than others, are likely to be neglected in policymaking, despite the significant role they play. They include:
- Self-employed care workers;
- Community micro-enterprises which typically employ 5 staff or fewer; and
- Live-in care workers, who stay in their client's home and provide around-the-clock presence and personalised support, whose numbers are increasing.

Incentives may be needed to encourage care providers in some segments of the sector to submit data to the ASC-WDS. To reduce the risk of biases in understanding of the workforce, further efforts should focus on increasing the proportion of independent and non-regulated adult social care providers providing returns.

SfC collects data in its ASC-WDS on 29 social care job roles (SfC 2022:31), summarising these in its publications into four categories (managerial, regulated professions, direct care, other roles). It would be valuable to have data on workers in the sector who are often overlooked and about whom little is known (such as staff working in alarm receiving response centres and first responders) and on the digital gig economy platforms that match workers to people with care and support needs, including 'live-in care workers' who may be especially likely to experience precarious or exploitative working conditions.

We strongly recommend that in future data are regularly and systematically collected from care workers themselves (as well as from care employers/providers). The intelligence produced would be valuable for providers, commissioners, policymakers and researchers. The new survey collecting wellbeing data directly from the workforce (referred to in the consultation document) is a welcome development. Ensuring this collects representative data on workers at different career stages and with varying degrees of experience will be important. The 'flat' nature of the sector and its uneven progression opportunities is an important barrier to retention; understanding the views and motivations of experienced workers in entry-level positions would be particularly useful.

Crucial questions that only workers can answer include reasons for leaving or moving between jobs and/or for exiting the sector. Workers' perspectives are key to understanding not just the decision to take up a particular social care job, but also why people choose to do

care work, what influences them to take it up, and the characteristics of those who do and do not choose it.

Given longstanding concerns about the age structure of the care workforce, it will also be important to understand how younger people (e.g. those leaving school or further education, or returners to the labour force) perceive the care sector and what would make working in it attractive to them. Such data could be gathered from jobseekers (e.g. via JobCentre Plus), perhaps using methods similar to those recently used by the Work Foundation (2021).

References:

Skills for Care (n.d.) 'Our values',
https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/about-us/Our-Values.aspx

Skills for Care (2022a) 'The state of the adult social care sector and workforce in England', Leeds: Skills for Care.

Skills for Care (2022b) 'Using data and evidence to be the leading source of adult social care workforce intelligence: Statement of commitment to the UK Statistics Authority's Code of Practice for Statistics, January 2022, v1'. (Online publication.)

Skills for Care (2023) 'Individual employers and the personal assistant workforce'. (online)

Work Foundation (2021) Social Care: A Guide to Attracting and Retaining a Thriving Workforce. London: Work Foundation.

Theme 5: Population of unpaid carers
- What information and data do people who use care and support services and their carers need, in relation to the population of unpaid carers? (optional)
- What information and data do care providers need, in relation to the population of unpaid carers? (optional)
- What information and data does local government (including local authorities and their staff) need, in relation to the population of unpaid carers? (optional)
- What information and data does national government need, in relation to the population of unpaid carers? (optional)
- What information do any other people and organisations across the sector need, in relation to the population of unpaid carers? (optional)
- Any other comments, in relation to the population of unpaid carers? (optional)

Our team has been actively advocating for a new survey of unpaid carers to significantly develop understanding of this population for several years. Such a survey was promised - Action 5.3 - in the Government's Carers Action Plan 2018-20 (DHSC 2018) and the Roadmap refers to the feasibility survey for this (due to be undertaken March 2023). Since 2020, we have participated in discussions with various government departments to support this development, and can provide further details of the advice we have previously provided about the need for it, if required. Major gaps in data currently collected (in the Census, Understanding Society and the Survey of Adult Carers in England) include the level of unmet need, use and experience of services and the impact of these, and what forms of support

carers find most useful. We consider it vital that attention is paid to how to reach unpaid carers who are not connected to their local authority. A survey that captures data from carers including those NOT in touch with or using services provided following a local authority carers' assessment is vital. Currently it is impossible to know how effective different kinds of services are in helping carers avoid the negative health, financial and social isolation consequences frequently seen among the carer population, particularly those caring intensively or over long periods. The issues of public mistrust in some population groups about sharing personal data with government agencies, as described under Theme 1, also apply here.

It will also be crucial to operationalise the concept of 'unpaid care' in the survey effectively, so that it is clearly understood by people providing unpaid care. There is no commonly accepted way to do this, although it is known that many people do not readily self-identify as unpaid carers, or take some time to do so. The 2021 Census introduced some changes to the wording of the question on unpaid care (notably, the phrase '*family members, friends, neighbours or others'* was replaced by '*anyone*', in the question on looking after or providing help to others, thereby losing the prompt that support to people both within and beyond family was relevant). The 2021 Census saw an unexpected decrease in the number of unpaid carers compared to 2011, which may have arisen in part from this (Petrillo and Bennett, 2023).

References:
Petrillo, M. and Bennett, M. (2023), Valuing Carers 2021 England and Wales.

Theme 6: Contingency and infectious disease control measures - don't answer
- What information and data do people who use care and support services and their carers need, in relation to contingency and infectious disease control measures? (optional)
- What information and data do care providers need, in relation to contingency and infectious disease control measures? (optional)
- What information and data does local government (including local authorities and their staff) need, in relation to contingency and infectious disease control measures? (optional)
- What information and data does national government need, in relation to contingency and infectious disease control measures? (optional)
- What information do any other people and organisations across the sector need, in relation to contingency and infectious disease control measures? (optional)
- Any other comments, in relation to contingency and infectious disease control measures? (optional)

Do you want to comment on other themes you have specified? - don't answer
- What information and data do people who use care and support services and their carers need, in relation to adult social care in general or other themes you have specified? (optional)
- What information and data do care providers need, in relation to adult social care in general or other themes you have specified? (optional)

- What information and data does local government (including local authorities and their staff) need, in relation to adult social care in general or other themes you have specified? (optional)
- What information and data does national government need, in relation to adult social care in general or other themes you have specified? (optional)
- What information do any other people and organisations across the sector need, in relation to adult social care in general or other themes you have specified? (optional)
- Any other comments, in relation to adult social care in general or other themes you have specified? (optional)

Overall questions
Overall, what information and data is most crucial in your opinion? (optional)
The ability to analyse person-level data and track an individual's journey through time and across different services would be transformative, enabling the deeper understanding of people's care trajectories and inequalities that is vital for good policy making and planning.

Do you foresee any upcoming changes that will change the data you think is needed across any of these themes?   (optional) Please include reasons why.

- If the delayed charging reforms are implemented, local authorities will need to collect and process data from self-funders and people partially funding their care. Analysis by the County Councils Network (CNN) suggests the resources needed to do this have been seriously underestimated.
- The digital switchover will render unreliable the analogue telecare-based devices and systems, widely used in adult social care. Data on the new digital and Smart devices being introduced to replace them need to be captured and understood and have significant potential and implications for data sharing.

References:
Hamblin, K. (2020) Technology and social care in a digital world: challenges and opportunities in the UK, *Journal of enabling technologies*, 14(2): 115–25.

Chapter 4 outlines national data projects led by central government. Are there other substantial social care data, digital or technology projects or initiatives in development across the sector that you think DHSC should be engaging with? (optional)

Other projects and initiatives which take innovative approaches to adult social care data and digital technologies include our own team's work and work being done by the teams listed below:

- The Centre for Care (our own team, led by Centre Director Professor Sue Yeandle) is a research-focused collaboration between the Universities of Sheffield, Birmingham, Kent and Oxford, the London School of Hygiene & Tropical Medicine, the Office for National Statistics, Carers UK, the National Children's Bureau, and the Social Care Institute for Excellence. The Centre has Economic and Social Research Council funding (with a

contribution from the National Institute for Health Research/Department of Health and Social Care) as an ESRC flagship research centre. We work with care sector partners and leading international teams to provide accessible and up-to-date evidence on care, which we define as the support needed by people of all ages who need assistance to manage everyday life. Our work includes a major focus on 'Care Data Infrastructure'; we have team members with advanced skills in statistical analysis and data science and a strong group of PhD students (some undertaking their studies in collaboration with the Office for National Statistics). Within our wider aim of improving societal responses to people with support needs or affected by care and caring so that they can live the lives they choose, Centre for Care objectives include working to improve how social care data are collected, stored, analysed, reported and made publicly available.

- VIVALDI study, led by UCL (highlighted in roadmap)
- DACHA study, led by the University of Hertfordshire (highlighted in roadmap)
- SAIL Databank in Wales
- DataLoch in Scotland
- IMPACT - the UK centre for implementing evidence in adult social care
- TLAP (Think Local Act Personal) - undertakes work on co-production with people with lived experience (includes social care data, digital and technology projects)
- ESRC-funded Digital Good Network - which is building a research community focused on what a good digital society should look like and how we get there.
- Careful Industries - undertakes research making visible the current and future consequences of social and technical change, and designs and delivers technology policy, governance and training solutions that centre equity and social justice.
- Promising Trouble - social enterprise with a mission to ensure more people have the chance to shape, inform and create new technologies.
- Wales Community Care Integration System - aims to create shared electronic records across health and social care.
- CoDE (Centre on Dynamics of Ethnicity) led by the University of Manchester - research focused on understanding changing ethnic inequalities and identities.
- Tribe - UKRI project funded by the Healthy Ageing Challenge Fund, focused on mapping/predicting care 'dark patches' in areas where home care provision is failing.
- Work Foundation - based at the Business School, University of Lancaster.

General comments - to be submitted separately

Investment
We feel the roadmap is a really important step forward and appropriately ambitious; we consider the level of investment required for set-up and implementation is significant, with major resource and recruitment implications for local authorities and their partners.

The work set out in the roadmap will require recruitment of data scientists with the right skills. This may be challenging in the public sector as such people command high wages in the private sector. Much of the work is complex, and requires a thorough understanding of governance issues (for instance, understanding data flows in health and social care requires advanced conceptual skills.)

Diversity of the adult social care market
The adult social care sector comprises a diversity of providers working under a wide range of operating conditions. What is proportionate for one provider may not be for another. Large providers are likely to hire employees specifically in data analysis roles, but smaller providers may struggle with the administrative burden.

The challenges of collecting data from individuals employing Personal Assistants and from Personal Assistants themselves need to be recognised.

How to collect data about innovations in workforce recruitment, management and the matching of workers to individuals requiring support needs to be considered.

Building public trust
The roadmap would benefit from a set of underpinning principles on the ethical collection, management, analysis and storage of personal data related to social care. These principles are essential for developing higher levels of public trust in government agencies collecting and sharing data, and for ensuring existing inequalities are not reproduced.

The Scottish Government has explored similar issues in its Data Dialogues (The Liminal Space) project, which developed an ethical approach to data collection. This includes the right for individuals to access and correct data held about them, and transparency from the outset about how data will be used and shared.

Public mistrust of sharing data with government agencies should be acknowledged and addressed in plans to improve the representativeness of data collection, in particular how this mistrust is felt by specific communities. In the NESTA Data Dialogues Summary Report LGBTQIA+ people, young people, and people with a named health condition expressed their distrust, saying *"We worry that our data will be inaccurate, used out of context or misunderstood. We want authorship over our own healthcare information. We want our data to be used by specialists - whether in a sensitive topic or simply in avoiding bias."*

Increased digitalisation of social care can lead to care workers sometimes feeling under surveillance as they track and log their hours and visits online.

Data collection approaches should be varied and appropriate, as those that are not sufficiently inclusive can reproduce existing inequalities (Benjamin, 2019). In some cases, community groups and community researchers could support data collection. For example, the Centre on Dynamics of Ethnicity (CoDE) at the University of Manchester employed community researchers to conduct a survey with the Roma community. Findings from this fed into the EVENS (Evidence for Equality National Survey) dataset, a robust dataset featuring a sample of 14,200 participants, of whom 9,700 identify as members of ethnic and religious minority groups. This type of data collection could be expanded to social care (but would require significant and sustained investment, including in producing accessible information, recruitment and training).

A lesson from the government's approach to use of health and social care data during the pandemic is that relationships with private firms can have a negative impact on public trust,

especially if their values do not align with those expected of the health and social care system:

- NHSX produced a 'Care Workforce App' which workers were encouraged to use to access information related to Covid, learning resources, and discounts. This caused some disquiet, with the union GMB highlighting the potential for employers to access workers' smartphone webcams and access their private messages (Syal, 2020).
- Partnerships between government, the NHS and technology companies have sometimes broken existing data protection laws. (For example, in 2017, the Royal Free Hospital was found to have breached the UK Data Protection Act in its deal with DeepMind, an AI company owned by Alphabet, the parent company of Google (Whitfield et al, forthcoming). Government partnerships with corporations in the use of data have also sometimes fallen foul of ethical expectations of public bodies.

References:
Benjamin, R. (2019) Race After Technology: Abolitionist Tools for the New Jim Code, Polity.
Centre on the Dynamics of Ethnicity (n.d.) EVENS Data

Digital, Culture, Media and Sport Committee (2022) HC157 Oral evidence: Connected Tech: Smart or Sinister?
Nesta (2021) Data Dialogues Summary Report.
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