National Health and Care Data Strategy – Response

National Care Forum (NCF) and Future Care Capital (FCC) are delighted to respond to the draft health and social care data strategy, recognising the significance such a strategy could have to improve the lives of people engaging with care services and care providers who continue to deliver high quality care across England.

About the National Care Forum

NCF is the voice of not-for-profit care and support providers across social care. We are dedicated to representing members and voicing member concerns to decision makers on a local, regional and national scale. We ensure member interests are represented at all levels and are in constant contact with government departments, politicians and the media to ensure advocacy for the sector. NCF supports its members to improve social care provision and enhance the quality of life, choice, control and wellbeing of people who use care services.

About Future Care Capital

FCC is a charity which undertakes research and engages in practical projects to advance ideas that will help shape future health and social care policy and deliver better outcomes for individuals living in the UK. Beginning life as the National Nursery Examination Board in 1945, the charity has evolved throughout its 70-year history and we continue to have Her Majesty the Queen as our Royal Patron. Future Care Capital is a registered charity, charity no. 036232.

Our work

FCC has produced several publications which explore how the UK might better harness the value of health and care data, as well as legal and regulatory considerations for data and data driven technology in health and care, including: Taking Next Steps to Harness the Value of Health and Care Data (2019)[1]; Research and Commercial Use of Healthcare Data (2020)[2]. We have also launched a programme of work to review the landscape of technology providers in adult social care starting with Home Care (2021)[3] and Mental Health Care (2021)[4], addressing learning disability and residential care technology later in the year. We also lead on the Community of Practice for Social Care Data Analytics with support from the Health Foundation. The community brings together data analysts, researchers, policy-makers and other practitioners from across the private, public and charitable sector, as well as people with lived experience of social care with the aim of sharing ideas, building links and exchanging good practice.

NCF's Hubble project helped care providers to understand the benefits of technology to improve the quality of their care. It articulated how to successfully introduce, use and evaluate CareTech. Over three innovation hubs care providers articulated their own journey – clearly highlighting the reality of the relationship between CareTech, the positive impact it had on the quality of care they provide, the improved experience of staff using the tech and the time it freed to spend more time on care. They also highlighted the value of data analysis and insight, as well as effective and supportive change management within the social care provider space. The on-going learning from this programme provides NCF with in depth, detailed and pertinent insight towards the National Health and Care data strategy.

NCF is also part of the DACHA study (Developing research resources And minimum data set for Care Homes' Adoption and use) which is a collaboration between the Universities of Hertfordshire, Cambridge, East Anglia, Newcastle, Leeds, Nottingham, Kent, Exeter, Glasgow; The Health Foundation; and the National Care Forum; led by Professor Claire Goodman, University of Hertfordshire (Chief Investigator). This study aims to stablish what data need to be in place to support research, service development and uptake of innovation in care homes and to synthesise existing evidence and data sources with care home generated resident data to deliver a minimum data set (MDS) that is usable and authoritative for different user groups (residents, relatives, business, practitioners, academics, regulators and commissioners). It is highly relevant to the draft data strategy and is referenced on the document as a case study.

Summary:

We are responding on behalf of the care sector, from the perspective of care providers as well as those developing data analysis solutions and products. We welcome the draft strategy, which is timely and will be launched in a rapidly changing health and care context. The final strategy will be published as the Health and Care bill is scrutinised in parliament, and there is an opportunity for beneficial change with integrated care systems (ICSs) being a key driver of improvement and innovation, if implemented in the right way.

Firstly, we set our reflections to the strategy, secondly, we provide a specific comment on chapter 4. dedicated to adult social care, and finally, we outline a series of principles to be used when developing the next iteration of the strategy.

1. Reflections on the strategy

A data strategy that connects and recognises the pivotal role social care plays in creating vital and life enhancing data is absolutely welcomed. Data that is created, recorded, documented and shared across all ecosystems in a clear, coherent and safe manner enriches care delivered to people and to society more broadly. The COVID 19 pandemic has highlighted the significance and value of 'data' in its broadest sense, but also how social care data is fundamental to an effective and functioning health and care system.

We welcome a strategy that brings people closer to their data and sets out intentions to reduce the burden of data collection to a workforce already under-resourced and experiencing over 112,000 staff vacancies on any given day. Additionally, we welcome a strategy that refers to the expanding use of care technologies and an increased onus on the use of digital and shared care records. Equally, we also recognise the importance of information governance as a mechanism to transfer, and maintain, said data safely and securely.

Nonetheless, having consulted widely with members across the not-for-profit sphere there are several recurring themes and concerns that arise as a result of reviewing the Health and Care Data draft strategy.

Firstly, a central proposition of the strategy is '*data saves lives'* which embodies a health centric view of data, manifested throughout the strategy. In contrast, the essence of social care data allows people to live their lives to the full, thus articulating a *much broader narrative* than the strapline suggests. As such data does not just save lives, but data also enriches lives - ***Data to live well rather than just data saves lives***.

Secondly, although a dedicated chapter on Adult Social Care (ASC) data (chapter 4) is welcomed, ***the absence of social care data elsewhere in the strategy is a missed opportunity*** to weave ASC data throughout the document. This strategy presents the opportunity to illustrate a sense of connectedness, alignment and clear aspirations around integration (i.e., the notion that health benefits from social care data as much as social care benefits from health data). Our current reading suggests that rather than being put on equal footing, social care data is valuable insofar as it benefits the health system.

Thirdly, there is a lack of clarity within the strategy as to its overall scope when thinking about social care. ***As a sector, social care isn't homogenous*** - it covers a huge breadth of care and support services, both CQC registered and not, both accommodation based and community based as well as in individuals' homes. The label of 'social care data' is problematic in and of itself. We could find very little meaningful definition in the strategy as to ***what data collection and analysis will look like for different forms of care***. It is also unclear how 'non CQC' registered services are included within this strategy. Any data strategy must understand and address that social care is fundamentally different but no less valuable than health in terms of its data.

Fourthly, the draft strategy seems silent on how data will be collected, managed and analysed to produce useful insights for care providers. Data needs to be well managed in order to secure the robustness of any insights derived from it and the analysis of robust and resilient data is central to good data collection and analysis. Data standards are welcome as is a data framework, but at present it all feels rather vague. While we know that efforts are underway to create a care provider minimum data set, it is ***essential that we have a much better, co-created approach to the overall data architecture*** here, as well as an efficient, resourced set of data systems to support the ambitions.

Our fifth concern relates to the social care workforce; the draft strategy emphasises the need to build analytical and data science capability for health, while for social care the references are to a digital skills framework and training, this does not seem sufficient to us. The ***social care workforce must be equally trained and empowered to deliver effective data analysis*** - this is important to drive business intelligence and our workforce, like the health workforce, needs to understand what to do with the data it captures and have the data literacy needed to interpret derived insights.

Our sixth observation relates to regulation. Although the CQC are referenced throughout the strategy what remains unclear is the role of regulators within the strategy both from an organisational and individual perspective. ***We suggest further consultation around the implications on registered professionals handling data (NMC, Social Work England, HCPC)*** is required in addition to discussions with CQC more broadly.

Our seventh observation – we welcome the commitment to reduce the burden of duplicate data collection; any effective data strategy for social care must address the notion of ***a 'single version of the truth'*** and the simplest, least burdensome way to achieve that. The final strategy must aspire to reduce the competing requests for the same data by commissioners and regulators is vital. Similarly, when we establish data collection mechanisms, a functioning data strategy should articulate its plans to **allow data to be captured 'at source'** which in turn reduces the burden and the potential for mistakes - and to allow the notion of a 'single version of the truth' to be reality.

As we have all learned from the Capacity Tracker, data input is burdensome, time consuming and expensive, whereas data flow can be achieved much more seamlessly if as much emphasis is put on this as the data itself. ***We are therefore pleased to see the focus on tech adoption particularly as a mechanism for data collection***. We would further champion the use of simplified tools to make collection easier, as an example "drag and drop" functionality to suit a time constrained workforce would be welcomed.

The strategy seems silent on the learnings from the Capacity Tracker [5]; the Tracker represents an amalgamation of emergency pandemic data collection, built on short-term requests for pieces of data to answer urgent pandemic related policy questions. It is not the basis from which to build a meaningful data strategy for the health and social care sector. It has been incredibly burdensome for providers to complete and there have been a range of other challenges, including:

- The 'relentlessness' of responding to daily information submission requirements which absorbs significant valuable staff time
- Duplication of data requests by different commissioners who do not share information with each other or access the Tracker data properly which again absorbs valuable staff time
- Interpreting frequently changing requirements for data collection and communicating these changes to staff, service users and their families
- Receiving additional, frequent and unscheduled phone calls requesting the data already asked for in the Capacity Tracker.
- Little perceived benefit to sharing data, as it often did not result in any tangible advantage for providers

This draft strategy, and the minimum data set it will create, offer an opportunity for a fundamental rethink of the aim and purpose of data collection; the opportunity here is very real and exciting, but the key to success is to question and agree what purpose the data strategy is serving. Are we seeking to inform future national policy or local commissioning of health and social care? Are we using it to monitor services or for quality improvement purposes? How will these data impact quality of life and quality of care for those using care and support services? How will they ensure better partnership working across the health and social system? Whose data are they and what permission do we have to share with others?

Ninthly, it is important to recognise that there are still providers who are at the beginning of their digital journeys. ***The draft strategy is entirely silent on the support - both financial and resource-led*** - which the implementation of the strategy requires; without this, the strategy will be essentially meaningless and will lead to a wholly uneven, disconnected and disenfranchised health and care system.

The opportunity of research within the strategy is alluded to, but not enough in our view. Our engagement with members and wider bodies suggests that the strategy currently misses the opportunity ***to embed research around data in social care*** as a viable field of study. Particularly around the creation of research datasets and record capturing, given the sector is far from homogeneous, funding around research would provide welcomed clarity and understanding for social care's standing across the whole ecosystem.

The final data strategy must look beyond a centralised data collection for DHSC and ensure that those using care and support services also benefit. It also needs to be mindful of the different 'data philosophies' in the health and social care sectors. ***The sorts of data desired by NHS commissioners and clinicians will be very different to that desired by local***

authority commissioners and the regulator which is again different to that desired by independent social care providers and by people using care and their families. We must ensure that meaningful data is captured and that it is of benefit to all. Data burden must be balanced with data benefit and a clear indication of how the effort needed for data flows will be resourced. Ultimately it must add value not only to national and local policy makers, but also, to the people who use care and support services and those who provide it.

2. Chapter 4, ‘Improving data for adult social care’.

We are offering our feedback on specific points within the strategy relating specifically to Adult Social Care (chapter 4), entitled, ‘Improving data for adult social care’.

- Reference to client level data for local authorities is positive however what is unclear is whether the same expectation and therefore burden is expected of care providers. ***We suggest that more information to define client level data should be included***
- What is the benefit for social care providers? There is concern that the commitments outlined in the strategy only benefit commissioners. ***The data strategy must embed the flows of data to ensure any insights and learning is used to improve person-centred care.***
- Good data analysis requires a good digital skills framework. To which, training in and of itself is far from enough. ***The strategy must also deliver funding for tech adoption and training staff is fundamental for improving data within adult social care.***

Integrating health and social care data

The draft strategy makes reference to interoperability with Shared Care Records by 2024. It is unclear whether this refers to the use of data warehouses to compare data from different systems or data interfacing between all systems. Members have also pointed out that this concept appeared much narrower in scope than the narrative earlier in the document suggested.

The notion of a ‘Shared Care Record’ is complex and has seen a number of iterations. There have been multiple attempts to build Shared Care Records, with the foundational learning from these engagements being that social care is not homogenous. The draft data strategy must consider and address this reality - acknowledging the diverse services social care covers and its constituent parts which all capture data on a daily basis

We are unclear on what ‘a data framework for adult social care & data standards’ actually means, both in terms of what the content of these standards is and who is creating them. PRSB and others have made progress here already and it is unclear where previous work relates and how much novel work is to be scheduled.

We welcome further clarity as to what the phrase ‘to continue to build the foundations needed to support care providers in accessing the information they need to deliver high quality care for people’ actually means, in the final strategy the foundations should be defined and specifically identified.

Expanding the use of care technologies

It is encouraging to see reference to a competitive ‘CareTech marketplace’ being proposed within the strategy, but it isn’t clear what this will include, the registration (CQC, MHRA, or otherwise) required or the type of technology that will be included. Given the vast range of technologies currently being used within the sector, clarity on this point is essential.

At present our members would observe that it remains relatively easy for anyone to write software and sell it into social care. Whilst we understand the existence of NHSx’s dynamic purchasing system for care providers, the standards defined must not be prescriptive on innovation and choice.

3. Fundamental principles to underpin the Health & Care Data Strategy

Following our extensive consultation with members/ community of practice and having reflected on the content of the strategy as a whole, the following principles must be seen as fundamental - underpinning the final version of the health and social care data strategy.

1. Consult and communicate with the sector regularly to co-design and implement specific parts of the strategy, using the principles described here.

2. Engage with the CQC and wider regulatory environment (including those responsible for both organisations and regulated professionals) for social care to facilitate ongoing communication.

3. Social Care should have a stand-alone chapter, as well as being integrated throughout the strategy.

4. Data driven products and services are key innovations in the sector. However, there is an urgent need for the improvement of data capture systems to reduce the burden for the sector and provider higher quality data for analytics and service management.

5. Must be based on what matters to people in receipt of care

6. Focus should be to drive improvement in quality & provision of care & support

7. The strategy needs to acknowledge that data is not free, to collect or maintain

8. The burden of data collection must be balanced by the benefit of doing so

9. Data providers must benefit from the data – the Capacity Tracker has clearly taught us this

10. Absolute clarity on purpose and function of data collection is essential

11. The data produced needs to be of a high quality and analysis needs to be suitably robust to drive sufficient decision making

12. Clear terms of engagement with the sector on providing data, use of data, and access to data is vital

13. The data strategy needs to hold the voice of social care as foundational - embedding it into the data strategy development & implementation timeline

14. Supporting relevant research for social care, prioritised by social care

15. Clarity as to the alignment of CQC within the strategy – to what extent will the regulator act in relation to these proposals? And how will the non-CQC regulated sector be considered?

Thank you for the opportunity to feedback suggestions through the workshops and survey. We hope that these further clarifications and suggestions are helpful, both for the present strategy work and future design of initiatives bridging health and social care.

Sincerely,

The National Care Forum	Future Care Capital
On behalf of the Membership	On behalf of The Community of Practice for Social Care Data Analytics

References:

[1] https://futurecarecapital.org.uk/research/22nd-may-2019-taking-next-steps-to-harness-the-value-of-health-and-care-data/

[2] https://futurecarecapital.org.uk/research/research-and-commercial-use-of-healthcare-data

[3] https://futurecarecapital.org.uk/research/care-tech-landscape-review/

[4] https://futurecarecapital.org.uk/research/mental-health-tech-landscape-review/

[5] Skills for Care commissioned research ‘How social care providers have dealt with data demands during the COVID-19 pandemic’ https://wm-adass.org.uk/media/1408/data-collection-asc-final-report-sfc-jan-21.pdf