

Issues and options for UK social care data policy

A report from the LCTcovid.org webinar:

[What policy for UK social care data needs to do now](#)

18th October 2021

Cian O'Donovan, UK Pandemic Ethics Accelerator



On October 18th, the Ethics Accelerator hosted a public panel on present and future needs for data-use in social sectors across the UK. We wanted to know what should happen to data systems newly built or scaled up during the pandemic - now that alert levels have been lowered and jabs, boosters and public health interventions such as vaccine mandates have been deployed. Commitments by the UK government to increase spending on health and social care sectors, funded through the Health and Social Care levy, make these questions especially timely.

To get some answers, the Ethics Accelerator brought together a panel of leading practitioners and academics from different parts of social care and across the UK.

Summary points

- Lessons about social data use during the pandemic are not agreed by everyone. For instance, data infrastructure such as the adult social care capacity tracker has had unforeseen consequences such as increased burdens on staff. These are often unacknowledged in plans for future data policy.
- The continued lack of data on people who pay for their own care or do not receive services from local authorities remains a priority issue across social care.
- Tensions between conflicting desires for *private data*, *more data*, *minimal data* and *no data* must be addressed in future policy plans if trust in public social care data is to be built.
- New tensions have arisen due to decisions that are being made with the data today that were not agreed with the providers from the start.
- At the same time, robust data infrastructures are a prior condition of wider reform across UK social care, critical for anticipatory appraisal, ongoing monitoring and evaluation of innovation in services and practices.
- Opportunities for optimism include building social care data that is designed around the wellbeing of people in communities – such data would go beyond the existing principles and values of population data in health to report on the relationships and values that matter for care.
- For this, new measures with which to assess data quality and new ways of assessing and improving data operations within councils will be needed

Seminar report

[Previous Ethics Accelerator research has shown](#) that data systems that were expanded to monitor and protect care homes during covid-19 have been a valuable short-term fix, but these changes are not sufficient to ensure adequate care and inform decision making on an ongoing basis. For instance, critical data about the health and well-being of residents of UK care homes is invisible in national datasets. And people outside of care homes, or who pay for their own care remain absent entirely.

One example frequently mentioned in the webinar was the [Adult Social Care Capacity Tracker](#) in England. The capacity tracker was originally a voluntary tool designed to help local authorities and commissioners in England find suitable places for people who needed to move into a care home setting. During the pandemic the tracker was rapidly scaled-up. Ultimately it became *the* pandemic data capture tool and was regularly amended and iterated, with many additional questions designed to collect a wider range of data on adult social care.

In the [proposed strategy](#) for data use in health and social care published by the UK government during the summer, the capacity tracker was cited as an exemplary success story. But [the real story is more complicated](#). Liz Jones, head of policy at the National Care Forum, told the [LTCcovid.org webinar on data policy](#) that despite reported benefits, increased data collection has put further burdens on care home staff at a time when staff shortages continue and staff stress is high.

There has also been an incremental creep in terms of the purposes for which the data are used. Decisions are being made with the data today that were not agreed with the providers from the start. The danger here being the erosion of trust between staff and service operators on the ground, and centralised decision makers using the data.

At first glance, this seems like a good problem to have. After all, a feature of reports on 'lessons learned' from the pandemic that are now emerging has been [the poor state of data use, practices and infrastructure in the sector](#) in the years before covid-19 hit. But Liz Jones made a powerful point: the Capacity Tracker might have been the best public data infrastructure we could muster in the early months of the pandemic. But it is not the basis from which to build a meaningful data strategy for the health and social care sector.

It's time for a serious conversation about what's worked and for whom. Not least because short of a full inquiry into the pandemic response, important lessons risk being missed in pursuit of health and social care data infrastructure building that [neglects specific needs of a diverse and complex social care sector](#).

So, from what basis should data practices, strategies and infrastructures in social care be rebuilt? That was a motivating question behind the LTCcovid webinar. As we move into our second full winter with covid-19, the session examined the prospects for immediate action, and what needs to happen now to make sure long-term transformations in data infrastructures, practices, and capabilities are designed to benefit those who need them most. The expert panel and experienced audience discussed the implications of September's announcement of the Health and Social Care levy in England, the evolving Data Saves Lives Strategy, as well as recent reports on data initiatives from researchers throughout the UK.

Revealing missing people across social care data

The most urgent issue remains the need to understand who's included in the data we have on social care and who is not. For instance our inability to know exactly [who was in what care homes](#) during the pandemic. But data on care homes is only part of the problem. Powerful contributions were made from the panel and from audience members about the continued neglect in data of people who pay for their own care or do not receive services from local authorities. Working age adults with learning disabilities for example, people receiving domiciliary care, and people spending personal budgets on goods and services critical for their well-being, but which don't constitute as care services and therefore aren't measured.

In recent weeks the Office for National Statistics has announced [experimental data about people who pay for their own care](#), but provisional nature of the data set serves only to underline the urgency of the issue for any forward looking data strategy.

These issues are not just about better measurement. They raise a set of uncomfortable ethical and political questions for practitioners, policy experts and academics. Why exactly are some people still missing from social care data? Are those missing considered not important enough to be *datafied*? Or is it that they are not important enough to policy makers *because* they are not included in data? Put more sharply, did relatively few people outside the sector care about covid deaths in care homes because residents were invisible, or because there was no data?

These are tricky questions that get to the heart of how data, care and public benefits are related. Addressing them should force policy makers to acknowledge the possibility that while improvements are both urgent and achievable, working out the total population of people who need care may be impossible. Social care ultimately needs systems and services that acknowledge and deal with uncertainty rather than provide care only where the data directs attention. These are problems of system design rather than simply adding more data or interlinked data and confronting them on these terms is critical as we proceed along the long tail of the pandemic.

Conflicting views and tensions

These questions also give way to ongoing tensions in the sector, some of which are visible in the above example of the capacity tracker. Tensions between the benefits and burdens of practices imposed on staff for instance. And tensions between the centralised use of data for regulators and the Department of Health and Social Care versus data that can be seen to benefit local users and services directly.

There were also conflicting views on desires for minimum data on social care situations, and those who would prefer no data at all. Concerns were raised about increased surveillance of people and communities, particularly those made more vulnerable by pandemic responses. The difficulty of squaring these concerns with calls for more data was not lost on contributors. For some, part of the problem was the production of open public data which removed valuable context. For instance, Jenni Burton from the University of Glasgow talked about how the (mis)use of freedom of information requests has added to distrust among care providers. Rankings of care homes produced using data from such requests often failed to include essential context about the data such as age or health profiles of the people who lived there. Rather than aiding understanding, explanation or accountability, this kind of data adds up to a backward step for data sharing.

The discussion then revealed countervailing views between valuing data in terms of their contribution towards market-based services and seeing aggregated public data as a collective and public good. Discussants acknowledged how conversations amongst service providers can turn quickly from 'how do we know who is in care homes' to 'who can we sell this data to'. For policy, the point - for now at least - is not that commerce and care should not mix. Rather, that there remains deep confusion in the sector about just how to value data in social care. Perhaps here there is an opportunity for targeted work by data intermediaries – an [Understanding Patient Data](#) for social care for example, that could carry out vital engagement work building trust and trustworthiness within the sector, and between the sector and the public.

Locating opportunities for success

Despite robust discussions on tensions and troubles, cause for optimism did emerge. The aim for social care, according to Charles Tallack from The Health Foundation, should be to build data infrastructures and practices that are at once complementary to those that exist in healthcare, but at the same time different - and here's the opportunity for social care - ultimately better. Health system data designed around principles and values of population health tend not to report on individual outcomes of people in communities. This is an area in which social care can excel, he said.

In this task, local authorities play a critical role. And following the proposals that accompanied the Health and Social Care levy, in England, councils and local authorities are going to be at the heart of the action.

The regulatory and statutory foundations needed to support this data infrastructure are already in place. For instance, guidance on the Care Act 2014 promotes “the kind of outcomes that matter most to people in their lives”, and is [unambiguous when it says](#) “local authorities must promote wellbeing when carrying out any of their care and support functions in respect of a person”. But data practices and data use on the ground are lagging.

Reforms to the [Adult Social Care Outcomes Framework](#) would help. These were already due before the pandemic. Local authorities also need to find ways of blending evaluation data on traditional needs-based approaches with measures of emerging forms of care such as [strength-based approaches](#).

Webinar participants advocated two further interventions. New measures with which to assess data quality. But just as important is the development of methods to evaluate data systems and operations. These are required to better target capability and capacity building within local authorities. Put simply, new methods and measures require new skills and competencies which in turn require investment in people and training. This is about organisational innovation and renewed focus on data and research infrastructures as much as increasing the amount of data available.

What was made clear in the webinar is that improved data in social care should not be viewed as an outcome of reform in the sector. It is a necessary pre-condition for targeting and evaluating success.

What’s more, these questions are relevant beyond social care. In health care systems too, questions need to be answered about what comes next. In the summer, millions of people in England opted out of sharing their GP data indicating that there is much work to be done by the NHS to build trust in public health data systems. These issues will become more pressing with the expiration of emergency regulations that have relaxed rules about how public health data is shared.

Over the coming months the [UK Pandemic Ethics Accelerator](#) along with colleagues at the [International Public Policy Observatory](#) and [LTCcovid.org](#) are going to continue to work on the ethical and policy dimensions of data use in social care. If you have comments, suggestions or would like to talk, contact [Cian O’Donovan here](#).

Acknowledgements

The expert panel consisted of Dr. Jenni Burton, University of Glasgow; Professor Claire Goodman, University of Hertfordshire; Dr. Caroline Jones, Office for Statistics Regulation; Jonathan Kilworth, Harrow Council; Liz Jones – National Care Forum; Owen Davies – Social Care Wales; Charles Tallack – The Health Foundation.

The Ethics Accelerator and the LTCcovid teams thank all the panellists and more than 40 attendees from social care think tanks, government, research, and practice.

Further information can be found at: <https://ltccovid.org/2021/10/06/ltccovid-webinar-what-policy-for-uk-social-care-data-needs-to-do-now-18-october-2021-2pm-bst/>

About this report

Dr. Cian O'Donovan is a Senior Research Fellow on the UK Pandemic Ethics Accelerator, based at the Department of Science and Technology Studies, University College London.

This report was supported by the UK Pandemic Ethics Accelerator, grant number AH/V013947/1 as part of the Accelerator's Data Use workstream. For further details contact Cian O'Donovan at the Department of Science and Technology Studies, UCL, Gower Street, London, WC1E 6BT. Email c.o'donovan@ucl.ac.uk.

The UK Pandemic Ethics Accelerator is a UKRI/AHRC-funded initiative that aims to bring UK ethics research expertise to bear on the multiple, ongoing ethical challenges arising during pandemics. We provide rapid evidence, guidance, and critical analysis to decision-makers across science, medicine, government and public health. We also support public debate on key ethical challenges. See <https://ukpandemicethics.org>.