EVALUATING POST-PANDEMIC PLANS
FOR SOCIAL CARE DATA INFRASTRUCTURES

Cian O'Donovan iD

Department of Science and Technology Studies, University College London,
United Kingdom

c.o'donovan@ucl.ac.uk

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ABSTRACT

COVID-19 exposed long standing neglect in UK social care. This neglect cost lives. It underpinned failings in preparedness within the sector and failures in immediate responses by governments. Data, and the infrastructures that produce and mediate data, are implicated in both. At the start of the pandemic for instance, the UK government did not know who was in care homes, or even where those care homes were. Moral costs and consequences follow the absence from data of people, their interests and what they value. Interventions that bring benefits to certain people or groups may be unfairly distributed, and harms discounted.

Problems also arose in how existing data came to categorise and value some individuals and groups while neglecting others. Furthermore, the pandemic amplified existing inequalities of epistemic power – the ability to use data was conferred at times to already well-represented groups while others were made ever less visible.

These problems cannot be solved through the production of more data alone. Post-pandemic plans for digital transformation must attend to the effects of such enduring issues in addition to expanding data infrastructure. In this chapter I scrutinise some of these issues and their relationship to data through three theoretic-analytic lenses: complexities within social care systems; the human values which shape what the data measure and the decisions they inform; and the multiple scales at which data matter. I then use this framework to offer brief commentary on prospects of emerging policy promises in England.

Keywords: data; digital transformation; infrastructure; governance; policy; social care

INTRODUCTION: THE LIVES DATA SAVES

"Suspected Covid" was the cause stated on Michael Gibson's death certificate. Mr. Gibson died at the age of 88 at the care home where he lived in Bicester, Oxfordshire, on April 3rd 2020 after that care home took in a patient discharged from a hospital with coronavirus (COVID-19) (BBC News, 2022). Exactly four weeks later, Donald Harris, 89, died in Alton, Hampshire, after an outbreak of coronavirus in his care home (PA, 2022). The deaths of Gibson and Harris were preceded on March 17th by orders from central government to discharge from hospital more than 24,000 older and clinically vulnerable people, many of whom ended up in care homes. Across these two months more than 20,000 older people died of coronavirus-related causes in England. And through the pandemic's first wave, coronavirus was the greatest cause of death in care homes, and deaths in care homes occurred at greater frequency than in any other institutional setting (Dyer, 2022).

The pandemic exposed the long-standing neglect of care homes and wider social care infrastructure throughout the United Kingdom. In this chapter, I outline features of the data infrastructure that existed prior to the pandemic, scrutinising these features through three theoretic-analytic lenses: complexities within social care systems; the human values which shape what data measure and the decisions they inform; and the multiple scales at which data matter. I aim to show that a renewed infrastructure for producing and using social care data is urgently needed. Not least because such data will play a useful role in evaluating the impacts of policy interventions, or indeed further neglect, across the sector. However, I also argue that with more data come further burdens on the people who collect it; tensions between those in the social care system who pay for data infrastructure and those who realise the value of the data; and sometimes difficult choices over how data comes to categorise and value some individuals and groups, while neglecting others. My aim with this commentary is to offer insight into how improved social care data infrastructure might distribute these benefits and costs, and more importantly, be tuned to measure what matters most to people throughout our care systems.

Returning to the early days of the pandemic, how many care home deaths can be attributed to the mass discharge of elderly and clinically vulnerable people from hospital into care homes remains a matter of intense debate. But one thing has been resolved by the English High Court: the discharge decision itself was unlawful. In a case brought by the daughters of Michael Gibson and Donald Harris against the Secretary of State for Health and Social Care and Public Health England, presiding judges Lord Justice Bean and Mr Justice Garnham held that "the drafters of the [discharge] documents of March 17 and April 2 simply failed to take into account the highly relevant consideration of the risk to elderly and vulnerable residents from asymptomatic transmission" (PA, 2022), concluding that this was "not an example of a political judgment on a finely balanced issue" but a failure of decision-making ('Gardner & Harris -v- Secretary of State for Health and Social Care', 2022).

The judgement highlights at least two failures. The first is a failure of process. Lord Justice Bean and Mr Justice Garnham write: "the decision to issue the April 2nd admission guidance in that form was irrational in that it failed to take into account the risk of asymptomatic transmission, and failed to make an assessment of the balance of risks" *(Moore and Graham, 2022)*. Aggravating this failure of process was a long enduring failure across the English social care sector: a failure in the data infrastructures critical for keeping the health of social care service users under review, for regulating providers of social care services, and for holding to account decision makers, planners and providers when things went wrong.

These failures are linked. In assessing the balance of risks for individuals, two things must be known at a population level. First, who, exactly, is at risk, and second, the degree to which that risk can be mediated, whether through action or by doing nothing. In practice, this arithmetic is complicated by a huge range of factors. For instance, co-morbidities that vary across age, place, region and groups such as Black and Minority Ethnic people. Or the influence of environmental factors such as the quality of people's living conditions, whether in care homes, in sheltered housing or in their own homes (Apea *et al.*, 2021; Katikireddi *et al.*, 2021). However, even two years into the pandemic, no UK country could routinely identify care home residents, recipients of social care at home, care home workers or those providing care to people living at home (O'Donovan, Smallman and Wilson, 2021). Moreover, comprehensive data on the case mix and needs of residents was still absent. Simply put, even as the pandemic recedes, the government *still does not know who is in care homes, where they are or what risks they face* (Burton et al. 2022, emphasis added). This is not only a failure of data: it is a failure of political and ethical responsibility too.

This chapter deals with two aspects of these data failures. First, I show that Michael Gibson, Donald Harris and other residents of UK care homes were *invisible* in national social care datasets, and I point to immediate causes and consequences of missing social care data during the pandemic. Missing data in terms of data that has not been created - it simply isn't there. But also data that, colloquially, misses the point. For instance, routine health data that record clinical care may in the context of care homes neglect what matters most to residents themselves (Todd *et al.*, 2020). Second, I use these stories to challenge already emerging narratives about pandemic data use. By the summer of 2021, a story of data's unalloyed successes in mitigating coronavirus was starting to be promoted by expert advocates of clinical data research. Pandemic rules that reduced information governance burdens and increased interlinkage between huge sets of data meant they could compile and analyse health research faster and at greater scale than ever, and their compelling story about data was one of lives saved (Department of Health and Social Care, 2021a; O'Donovan *et al.*, 2021). The real story is more complicated than that. Data, and the political and ethical decisions about who and what is data-fied, is also implicated in jobs and lives that were made more vulnerable, and stressful, and in lives that were lost.

THE DENOMINATOR PROBLEM IN CARE HOME DATA

Accurate data and effective data infrastructures are critical for decision making and planning at scale in representative democracies such as the United Kingdom. Data, and the scientific methods that underpin their production, allow politicians and civil servants to make decisions about citizens at a distance, and (should) enable those citizens to hold decision makers to account when things go wrong (Ezrahi, 1990). But in March 2020, as UK leaders watched television reports full of death and fear in Italian hospitals, there was no reliable dataset they could query to inform life and death choices about whether to prioritise vulnerable people already occupying hospital beds in England, or to discharge them and make room for the thousands of COVID-19 patients predicted to flood National Health Service (NHS) wards. On March 17, the government did not understand who was in care homes, where those care homes were or for what duration of time people stayed in them (O'Donovan, Smallman and Wilson, 2021).

One major issue is what health system experts call a denominator problem, after the bottom number in a fraction (Lucas and Zwarenstein, 2015). This, in the care home context, is the number that represents the total population of people in care homes. Denominator problems often flow from issues of indicator construction, where indicators are categories of real things, such as beds or people, especially when estimated numbers are crude or out of date. Statisticians choose to count particular indicators in order to build models that facilitate regulation, prediction or control. Decisions about what indicator to choose often hinge on what can be counted easily (for instance, tallying beds is more straightforward than counting the wellbeing of the people occupying them), or what is being counted already. In the case of social care, for example, surveys instigated by the regulator might be used. Where secondary data sources are available, their use can be cheaper or quicker than gathering new data, but the downside is that secondary data often arrives stripped of the context for which it was originally produced.

Problems can arise in social care when indicators acting as static variables, again bed numbers are a good example, are incorrectly used to model dynamic population sizes and distributions of people *actually* moving – say patients moving between hospital and community care, or between jurisdictions. Over time inaccuracies can lead to substantial measurement issues. When decision makers don't know the denominator, they quickly end up with problems in

basic calculations and false precision in the evaluation of services and, thus, the evidence base for policy.

These errors cost lives. When the denominator does not accurately represent the actual population of care home residents, reporting accurate segments of that population, or tracking homes that provide special kinds of care services, such as for residents over-80, or with dementia, fair and useful allocation becomes impossible (Burton et al., 2020). Even if we have a good sense of the care provided to the population overall, we have no idea about the care given to any one individual – or even a 'typical' individual.

The denominator problem exists because health and care infrastructures are not measuring all that really matters to residents, staff, and care home operators. These problems are social as well as technical. For instance, the Capacity Tracker is an example of data infrastructure that was expanded rapidly during the early months of the pandemic in order to collect data about care home residents and make that data useful for decision makers (NHS Vale of York Clinical Commissioning Group, 2021). The tracker was designed for efficiently allocating people being discharged from hospitals to care homes or other community care settings (ibid.). One major problem was that the tracker counted stocks of beds and resources, but during a public health emergency what planners really need is information about risk and virus spread. For this, what crucial is knowing the number of residents in each home, where they have come from and how healthy are they are. However, the Capacity Tracker was intended to solve an *allocation* problem within a care sector constructed to function like a market. That's a necessary task, but one that is useful only in narrow terms.

The quality and comprehensiveness of care home data is made worse by other social and technological factors. The diverse settings of care homes make collecting standardised data difficult. Collection and maintenance of data is made more difficult still by poor digital infrastructures within many individual care homes. Regulatory incentives prioritise data gathering for monitoring *systems* and neglect data for evaluating impacts on *human residents*. And complex market arrangements and financial worries are disincentives for care home operators to share data within the sector, and between social care and NHS data systems. A major problem is that there are few trusted third-party data intermediaries who could increase trust in the sector and foster relationships between data providers based on common interests.

WHY SOLVING THE DENOMINATOR PROBLEM IS IMPORTANT

The absence of these crucial data meant that adequate appraisal was impossible when it came to decisions about the March 2020 discharge. Further, the absence of sufficient data was of critical importance for ongoing planning during the pandemic. As is detailed elsewhere in this volume, gathering and sharing data became vital when decisions about allocation of personal protective equipment, enforcing action on care home staff and restricting visitors were being made, not least because care homes were housing and looking after residents who were typically older and less healthy than the general population, and so were more vulnerable to the most severe effects of coronavirus (Smallman *et al.*, 2023). These points are of ongoing importance for anyone involved in operational and planning decisions in UK social care sectors.

This also matters because missing data contribute to a lack of public visibility and erode the ability of the individuals affected by such systematic underrepresentation to use the epistemic power of data to advocate for themselves in the public square. The lack of visibility for people in care flows from a lack of attention to, and resources for, the care sector – a fact which is not down to a single or specific institution but implicates a range of policies, institutions, and practices over time. In short, the arrival of the coronavirus amplified existing inequalities of

epistemic power, such that the power of data often benefited already well-represented groups while others were made ever less visible.

This continues to matter greatly because comprehensive data about the population that relies on well-functioning social care services like care homes remain patchy. Shockingly though, what we do know is that between March and July 2020, care home residents represented almost half of all coronavirus deaths and, by the end of December 2021, more than 26,935 residents of English care homes had contracted the virus and died (Curry and Oung, 2021).

These arguments are important because together they make the case that the denominator problem is not just a technical issue to be solved by collecting ever more data in care homes or by instigating deeper surveillance of communities. Rather, these issues expose a wider problem across social care - that data come to categorise and value some individuals and groups while neglecting others. Moreover, these issues are not confined to care home data. Across social care more denominator problems exist. People who pay for their own care for instance, as well as adults in need of home care. In the first phase of the pandemic, more than 2,600 people with learning disabilities died in England, far in excess of deaths in the overall population (Kavanagh *et al.*, 2021). Solving denominator problems across health and social care must be a priority for transformation agendas across the care sector.

UNDERSTANDING CARE DATA INFRASTRUCTURES IN CONTEXT

Analysts of care home data know how to solve the denominator problem. Clinical data expert Dr. Jenny Burton and colleagues have proposed seven technical and social interventions aimed at governments and health services (Burton et al. 2020). These are:

1) providing reliable identification of care home residents and their tenure
2) creating common identifiers to link data sources from different sectors
3) creating individual-level, anonymised data that include mortality, irrespective of where death occurs
4) investing in capacity for large-scale, anonymised linked data analysis within social care, working in partnership with academics
5) recognising the need for collaborative working to use novel data sources, working to understand their meaning and ensure correct interpretation
6) better integrating information governance rules and cultures to enable safe access for legitimate analyses from all relevant sectors
7) creating a core national dataset for care homes, developed in collaboration with key stakeholders

These solutions, or versions of them, have been discussed for years so what makes them so hard to implement? Three features of the social, physical and political environments in which care homes operate are worth considering here. These are the complexity of the social care system itself; the diverse norms of data infrastructures, and the values around which, data infrastructures are built; and the different scales at which data is produced, used and made to matter.

Complexity

Care homes, like many other places in English society, are already data rich environments, full of smart phones, smart meters, monitoring equipment and digital technologies. And yet systematically producing data that are useful to and usable by organisations like local authorities has not been possible. To understand why, we need to consider the broader social care sector in which care homes operate. There is no single policy, funding or service stream that is widely understood as social care. Rather, social care is how society orders practices of

care and distributes responsibilities and obligations for these practices between markets, the welfare state, voluntary sectors and communities and families (Daly and Lewis, 2000). The processes and practices that constitute social care thus take place across a hugely diverse and dynamic set of locations including, but not limited to, care homes. In the UK, care that is administered outside of hospitals and GP surgeries takes place in a patchwork of communities, small and medium enterprises, a small number of very large housing firms and charities – around 19,000 providers in all (The King's Fund, 2019). Approximately 1.6 million staff, managers, administrators and others are involved in delivering this care (Skills For Care, 2021). Responsibility for policy, legislation, standards and the allocation of funding is devolved to the four nations of the UK. The delivery of services is the responsibility of 152 local authorities in England, 22 in Wales, 32 in Scotland and 5 in Northern Ireland, each separately elected and responsible to their own local populations (Gray and Birrell, 2013).

In recent decades, this institutional and organisational complexity has served to obscure political neglect. Government policies since the turn of the century have created quasi-markets underpinned by a ideologies of patient choice (Glendinning, 2016; Baxter, Heavey and Birks, 2020). These politics and policies have failed (The Health Foundation, 2020; Allen and Tallack, 2021). They have resulted in the wide dispersal of key obligations, such as responsibility for funding care services and accountability when things go wrong, and the dilution of agency within the system to direct care to where it is needed most. By the time the pandemic hit in 2020, resources such as data, a skilled workforce and even beds were not there in the numbers required. In addition, funding was both insufficient and not getting through to where it was needed most (National Audit Office, 2018; Blakeley and Quilter-Pinner, 2019).

Data are especially important within this complex sector because decision-makers need information to resolve the significant issues that currently exist. They need to be able to identify problems in the social care system as a whole, and then come to an understanding of what would count as an improvement. The Adult Social Care Outcomes Framework (ASCOF) in England is a standardised collection of tools, rules, categories and data built for this purpose. Over the course of every year ASCOF aggregates data from a range of national and local surveys and databases, which is then used by central government for policy planning and monitoring, and by local authorities and councils with Adult Social Services Responsibilities (CASSRs) for measuring local performance and for benchmarking against other CASSRs (O'Donovan, 2022). However, people who are excluded from or unable to access local authority funded care services are invisible in ASCOF data. Thus the annual reports produced using ASCOF data do not contain information that accurately reflects the quality of life of people receiving and delivering care (Jones and Meyer, 2021) and, crucially during the pandemic, data with which to assess and hold accountable in close to real time the delivery of care, the state of organisations providing care, and decision makers directing resources.

System complexity is further increased by the constantly changing and dynamic nature of the system itself and what experts call system performativity (Wilson, 2021). Performativity is important because interventions in the present can and will impact the future of the system, and it is the evolving framing or shaping of the system itself that can influence these changes. System designers know this, and frameworks such as the Adult Social Care Outcomes Framework (ASCOF) are designed, at least in part, to performatively drive behaviour across multiple levels of governance. Scholarship on improving accountability in social care notes the importance of good mechanism design within frameworks like ASCOF to protect against unintended consequences (Naylor 2018).

The principal role care infrastructure plays in people's lives changed rapidly during the peak of the pandemic. At the time the top priorities for many staff were minimising virus

transmission, infections, and deaths. Capacity Tracker data designed to allocate beds were now being used to make decisions about distributing personal protective equipment. With the provision (or lack) of equipment, staff were adapting their work practices to new realities on the ground. At the same time, policy makers learned more about the risks posed to residents by the virus and came under increasing scrutiny for their delayed response to coronavirus in care homes. In response, government legislated to require all care home staff to receive a vaccination (Department of Health and Social Care, 2021b). Discussing the efficacy and ethics of vaccine mandates are beyond the scope of this chapter, save that the controversy highlights important ethical implications for data infrastructure: for any data system or set of indicators, however carefully constructed, what counts as a breach of a duty of care or a violation of privacy is not something that can be described once and for all. Rather, what constitutes a violation is partly constituted by individual expectations and sectoral norms, which will themselves change in response to external crises and government action. Taking performativity in systems seriously means rethinking the assumption that there is a static ethical reality, which can accurately be mapped and modelled with ethical concepts and theories. Thus system design needs also to be attentive to the potential for values to change with circumstances.

Values

Data plays an important role in clarifying the relationship between an idealised concept of how care in homes should be delivered and the lived realities of people's lives as measured by specific variables. In doing this, data are imprinted with the value judgements of those choosing what data to collect, and those giving consent for that collection. These value judgements are not universal. What is valued in data can and often does differ significantly across health and social care settings. For instance, values guiding data collection and interpretation in hospitals often differ from those prioritised in care homes. Moreover, individual care homes are themselves complex settings, within which a vast milieu of human values, interests and normative concerns combine.

So, what values matter within social care data infrastructures and where can we find these? First, ideas and values about how care *should* be delivered and measured do not form separately from understandings already present in policy debates, within local authorities and on the ground which are often institutionalised as rules, regulatory frameworks, and best practices. For instance, the Adult Social Care Outcomes Framework (ASCOF, Measure 1L) reports 'the proportion of people who use services or carers who reported that they had as much social contact as they would like' and this is recorded via the annual Adult Social Care Survey (NHS Digital, 2021). Indicators in surveys like these typically stage individuals and their rights as service users as the ethical unit of analysis. This staging is itself a design choice that has implications for how care is assessed and delivered in society.

In addition to the hundreds of value judgements made during the construction of individual measures and indicators, there are overarching logics driving data design and use. One major issue is the focus by local authorities commissioning services on measures of *time and task* (a measure of resource efficiency) rather than on individual or community outcomes which are most more difficult and costly to count. Also, the survey methods used to produce data tend to discount people who fund their own services and aren't recorded in local authority figures. Is this because these people are not deemed important enough to be data-fied, or do they subsequently become unimportant because they are missing from data? Whatever the rationale, the implications are significant. Because of the quasi-market organisation of care services, accountability is structured through consumer choice. Thus excluding segments of the population from data effectively excludes their voices from governance in the sector completely.

Of course, care itself is also a value. One that directs attention to neglected things and devalued doings (Puig de la Bellacasa, 2011) such as the hidden labours of care workers (Lutz, 2013), or the marginalised groups being excluded from social services. Recognising the value and potential of care in this way, socially and relationally as well as economically, depends on a different understanding of what care actually is: not as a bundle of market-based services but as a set of relationships that depends on human connection (Cottam, 2021). Relational values of care are notable in their commitment to egalitarian practices and the affording of agency to those receiving care (Arora *et al.*, 2020). This means that processes for measuring and directing care should extend beyond counting resources and indicators of services and, in so doing, usefully report on the heterogeneous relationships that make up caring practices. Yet, insofar as these relations and aspects of everyday lives are captured at all by existing measures and methods in data infrastructures, is seems system designers have not thought them worth knowing.

Even in this brief discussion, then, it is clear that there are tensions between decentralised logics of how data encodes what matters to people and groups on the ground; market orientated logics of accountability and governance across the sector; and imperatives for centralised command and control logics that might allow the government take a firm grip in public health crises like coronavirus.

Multiple scales

These tensions between conflicting values can be mapped across the different scales at which data infrastructures operate. For instance, in the early days of the pandemic, decisions about health and care were rapidly centralised within government departments and at the level of national administrations. Thus a critical part of assessing data infrastructure is understanding and addressing the conflicts and tensions that come from putting data to use across different scales.

Our assessment of these ethics and politics is guided by Melanie Smallman (2022) who offers a set of questions that heuristically guide our investigation. These include, for instance, questions that address tensions between comprehensive coverage of populations and over-surveillance of groups and communities. As discussed above, the initial production of care home data usually focuses on the level of individuals, through the work of care home staff or residents filling out surveys. During the pandemic, many staff members worried about the increased data collection responsibilities imposed by the Capacity Tracker. As well as increasing the burdens on staff members, this amplified existing problems of low pay and time scarcity (Jones and Meyer, 2021; O'Donovan, 2021b) and is an example of the tensions that can exist between local, institutional and system-level demands. In this case, the benefits for local authority and central decision makers of collecting care home data versus the burdens on the care staff.

At the individual scale, there are also important questions of who benefits and who is burdened by data. For instance, what kind of accountability processes are in place to ensure that rights to privacy surrendered by individuals are duly matched by gains from increased pandemic surveillance. Similar questions arise at the scale of groups and communities. We know that existing social, economic and health inequalities were made much worse by the pandemic and contributed to unequal outcomes, including higher death rates, amongst people from Black, Asian and Minority Ethnic communities compared with the general population (Health and Social Care, and Science and Technology Committees, 2021). We also know that increased exposure to COVID-19 as a result of people's housing and working conditions played a significant role in unequal outcomes for people working in health and care jobs (*ibid.*) Data

that fails to convey the heightened risks at these group and community scales to the level of national decision making further exacerbates racist and unequal structures across care sectors.

Time also matters. As the crisis stage of the pandemic ends in the UK, a comprehensive review of the temporary pandemic data measures is now in order. Measures brought in during crises have a way of becoming permanent and of being applied in situations beyond those used to justify them. Infrastructures lock-in routines and practices which, once established, can be difficult to alter. For instance, obligations on care staff to collect data as part of the Capacity Tracker programme is one such issue. Another issue is concerns around data governance arrangements that have reduced information governance burdens to allow researchers and planners more quickly access and analyse population health data (O'Donovan, 2021a). Researchers will be reluctant to let these measures go. But this stance risks overlooking dramatic shifts in public attitudes around how data are collected and used, driven by huge overspends on NHS Test and Trace, ongoing scandals relating to the procurement of PPE and the opaque nature of deals with large technology firms for enterprise data systems (Bharti *et al.*, 2021). Given that timescales of pandemics are rarely certain at the start, it is critical, then, that as the crisis evolves into something else, data infrastructures and the manner in which they shape organisational, institutional and social arrangements across a range of scales are revisited and reassessed.

POLICY FOR SOCIAL CARE DATA

So what can an approach that foregrounds complexity, values and multiple scales tell us about the prospects for emerging responses and long term plans that aim to transform data use in social care? What's most curious about transformation policies and reports is that already the pandemic response has been hailed as a victory for accelerating data use in health and care, and for scaling up data infrastructures that support these uses. Take Data Saves Lives, the UK government's first major consultative study on data use in health and social care during the pandemic (Department of Health and Social Care, 2021a). The consultation's title neatly foreshadowed its findings, focussing in the main on how health data played a significant role in decision making and planning associated with mitigating and adapting to the virus (Department of Health and Social Care, 2022b).

The Goldacre Report, a parallel consultation sponsored by the Department of Health and Social Care, intensified a focus on large-scale digital research infrastructure and the imposition of flexible information governance regimes that accelerated clinical research on the virus (Goldacre, 2022). These reports praised pandemic changes in data governance, and the practices and infrastructures that supported rapid data use in health and social care sectors. But they contained little discussion about the complexity of social care, the unintended consequences of increased data gathering in care homes, or the impact of data beyond clinical research, for instance, how data shapes and obscures who is made accountable in the sector.

Data Saves Lives and the Goldacre Report are important because they form the rhetorical and evidentiary basis of subsequent white papers, strategic plans and policy proposals for addressing long-term neglect in English social care. For instance, the 2021 Social Care white paper (Department of Health and Social Care, 2021c) recognises the that transformation in the sector is urgently needed, and, specifically, that this must include improving data infrastructures. But, in relying so much on Data Saves Lives and the Goldacre Report, the 2021 white paper replicates their neglect of certain people, places and issues. The white paper also

advances and anticipates commitments relating to a series of subsequent consultations.[1] Across these strategies, there are at least three significant proposals for digital transformation in social care. The first proposal is renewed attention to evolving and improving the Adult Social Care Outcomes Framework, including efforts to link health and care records across organisations and institutions. This is to be welcomed, at least to the degree to which this project will embed and make explicit the diverse ways in which social care services, service users and outcomes can be measures and valued.

The second proposal revolves around the integration of a wide variety of services, procurement, and operational strategy at a local, place-based level. The creation of Integrated Care Systems (UK Government, 2022) has led to a major reorganisation and convergence of NHS systems and services in the first instance with the integration of social care often a secondary concern. Cresswell, Sheikh, and Williams (2022) identify three key issues with convergence: a lack of clarity on exactly what systems are to converge and at what scale; open questions about how to conceptualise convergence and concerns that more important than identifying single systems for interconnection is a job of aligning cultures and practices of care across complex setting; and the need to develop a sense of shared direction towards a future state – questions about how future integrated systems will be maintained and evolved remain open.

Ignoring these issues risks reinforcing concerns about top-down management. Indeed, a worry reported in informal conversations amongst social care staff and decision makers is that the NHS will continue to take precedence in the allocation of resources, marginalising or alienating social care services and users (O'Donovan, 2021b). As far as data use is concerned, the technical job of linking data between organisations and institutions must, in my view, be preceded by an ethical analysis of the reasons for, and the terms on, which data is used in different settings and at different scales. It is not sufficient to consider the political, personal and ethical implications during design and build phases of data infrastructure. Procedures that ensure ongoing accountability for residents, staff and informal carers are critical for good governance.

The third proposal is concerned with accelerating the construction of digital research infrastructure such as the trusted research environments (TREs) championed in the Goldacre Report (2022). TREs are technical platforms and standardised data practices designed to enable access to sensitive data for authorised projects and researchers only, thereby minimising risk of data release or exposure. Social care data analysts are making use of TREs, especially in work that makes use of interlinked healthcare data (Burton, Ciminata, et al. 2022; Burton et al. 2019). But given the relative immaturity of social care data infrastructure compared with those of hospital and GP patient data, advocates of health data research are likely to steer the agenda for investment in TREs in the immediate term.

CONCLUSIONS: WHAT SOCIAL CARE DATA NEED TO MEASURE

So what's missing from forward plans and policy? First, policies might better recognise heterogeneity in social care systems, in term of individuals, groups, organisations and the institutional players with a stake in the sector. Planners must acknowledge that different groups will benefit from data differently and, given the drive towards further interconnection and convergence, the assumptions on which plans are based must be spelled out. The benefits of

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[1] Consultations and strategies reviewed for this chapter include 'Health and Social Care Integration: Joining up Care for People, Places and Populations' (Department of Health and Social Care, 2022c), and the 2022 Cavendish Report (Cavendish, 2022) as well as a specific digital strategy for health and social care (Department of Health and Social Care, 2022a) which in turn builds on the 2021 Adults Social Care Technology and Digital Skills Review (Blake *et al.*, 2021)

data cannot be taken to be the same in different parts of social care system. Plans must then clearly distinguish between how different groups in society interact with health and social care data, and experience data-informed decisions. Finally, the attention to TREs is a welcome step in acknowledging that public perception of data infrastructure matters. But the issue of building public trust in the wider health and social care system, while at the same time broadening data use, cannot be addressed through technical specifications alone.

Problems with data about care homes often result from choices in design, or from neglect. In both cases, these things offer opportunities for re-designing the system, and maintaining it differently (and better). At the level of individual care homes for instance, it will be important to consider how to design and implement a data-informed, data consent system that is appropriate for a cohort of people who are not digital natives. Approaching these challenges from a systemic perspective, the key question is not so much how best to measure the system on a static snapshot basis (the how many beds approach), but rather requires a strategic analysis. This is a bigger-picture question of how to structure institutions, networks, incentives and accountabilities in ways that maintain and strengthen how the system distributes obligations like care and accountability over time (Wilson, 2021). And given that there is no universal and enduring measure of what we mean by *care* in care homes, it is, in my view, better to adopt a pluralist approach. This means acknowledging that the problems revealed by data are historical, contextual and differ from place to place and, further, that solving one problem may often contribute to worsening others. Because of these factors, different kinds of data, and the expertise to gather and use those data, are required.

The greatest challenges in UK social care today are tackling cost pressures and demographic needs, ensuring people currently excluded from services get the help they need, building staff capabilities, and improving the quality of services and outcomes for users. These challenges are urgent and have been for years. Improving data infrastructures is a pre-condition to the design and operationalisation of post-pandemic strategies that aim to tackle these issues and evaluate their impacts. Failure to do so risks making things worse.

But perhaps too there exists an opportunity for a more radical agenda for data in social care. Backed by a series of white papers in 2021 and 2022 the English government again promised major reform of the social care sector (Department of Health and Social Care, 2021c). But by April 2023 a major roll-back was underway as hundreds of millions of pounds of funding for workforce training and housing adaptation was postponed (Bottery, 2023). The most useful progress towards meeting the challenges that this chapter describes, then, might not start with the data. Rather, the first step should be to ensure that social care cultivates the kind of political capital across society as well as within the sector that makes breaking these promises impossible. This is a fundamental pre-requisite to ensuring that staff who work with data in care homes and across the social care sector are empowered to lead satisfying work lives, on terms that align with best practice and shared values. Recognising the value of social care, and of the relations of care that underpin the sector, will afford both staff and people who depend on social care status and respect in society and within the infrastructures through which we know them in data.

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Orcid: 0000-0003-4467-9687

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