



RAPID ETHICS REVIEW

MAKING OLDER PEOPLE VISIBLE: SOLVING THE DENOMINATOR PROBLEM IN CARE HOME DATA

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In the UK today, the government does not understand who is in care homes, where they are and for what duration of time. Critical details about the population of people in care homes is missing or is not accurate.

While covid-19 has accelerated the pace and broadened the scope of data gathering in the UK care sector homes, **comprehensive data on the case mix and needs of residents is still missing.**

One major issue is what health system experts call **a denominator problem**, after the bottom number in a fraction. This is the number that represents the population of people in care homes. When decision makers don't know the denominator, they quickly end up with errors in assessment, in the evaluation of services, and in the evidence base for policy. These errors can cost lives.

Because of this, the denominator problem is a critical ethical issue in care homes today.

Transformations in care home data infrastructures are urgently needed. Researcher Jennifer Burton and colleagues have suggested seven priorities that will help

get the basics right. These priorities, which would go a long way towards solving the denominator problem in care home data, are endorsed by this review.

At the same time, further measures are needed to build and maintain resilient, sustainable data infrastructure in the sector. To this end, this review complements the Burton priorities and makes further proposals on how to overcome structural, institutional and policy barriers.

The aim of this Rapid Ethics Review is to:

1. Highlight state-of-the-art research on the reasons for the denominator problem in care home data.
2. Show how ethical arguments are critical in helping decision-makers understand the values and issues at play in designing better data infrastructures, and the urgency with which these infrastructures must be rolled out.

Paying attention to these concerns and underlying values will help decision-makers responsible and accountable for care homes plot a route forward.

OVERVIEW

- Residents of UK care homes are invisible in national datasets.
- This is a serious problem because covid-19 is particularly harmful to older people, and because of the increased risk of transmission from communal living even amongst younger care home residents.
- Data infrastructures expanded to monitor and protect care homes during covid-19 have been a valuable short-term fix. These changes are not sufficient to ensure adequate care and inform decision making on an ongoing basis.
- The challenge of producing accurate and timely data across the care home sector is increased by the lack of digitalisation within care homes and the difficulty of connecting with NHS data.
- Gaps can be addressed through data analysis methods such as data linkage and service integration.

- Seven specific challenges and solutions are recommended based on work by Burton and colleagues.
- Further interventions are also needed to change motivations and practices amongst care home operators that currently prevent the right kind of data being gathered and shared.
- Data linkage needs ethical diligence to ensure the values and interests of care home residents, staff and operators are commensurate with whatever work the data is put to.
- Opportunities to debate the terms of data linkage and the kinds of policy and sectoral interventions that are needed could be missed.
- Detailed plans and timings for broader reform in social care are still absent from the government's political agenda, but changes in care home data infrastructure don't need to wait.

1. WHAT IS THE DENOMINATOR PROBLEM IN CARE HOME DATA AND HOW DOES IT AFFECT WHAT WE KNOW ABOUT RESIDENTS?

Summary points

- Residents of UK care homes are invisible in national datasets.
- Existing data do not accurately report who is in and out of care homes at any given time, and information about their health and wellbeing.
- This *denominator problem* leads to inaccurate basic calculations, and uncertain assessments, evaluations and evidence base for policy.
- This long-standing problem has been exacerbated by covid-19.
- This problem reduces the effectiveness of measures designed to combat covid-19.

1.1 Why data on care home residents matters

Care home is used by us as an umbrella term to describe regulated services offering 24-hour care. Care homes are diverse settings, with many in the UK providing services for a diverse set of adults, not just older people.

Residents of UK care homes are invisible in national datasets (Burton et al., 2020). Problems with these datasets include patchy information on the overall population of residents in care and service demographics and difficulties identifying the

population from routine data. Data on the case mix and needs of residents are often missing.

Missing data, problems with using the data that do exist, and poor infrastructure for gathering data, has been a problem for research and evaluation in this sector for years. These problems have been exposed and amplified by covid-19.

More seriously, they have hampered efforts designed to combat covid-19. For instance, the problem meant that when Public Health England wanted to work out how patients released from hospitals might have seeded covid-19 outbreaks in English care homes, they had no quick and easy way of finding out. Using data-linkage techniques, it took analysts almost a year to find out (Public Health England, 2021).

1.2 Explaining the denominator problem

At the heart of the data problem is what health systems experts call a *denominator problem* (Lucas & Zwarenstein, 2015). This is the bottom number in a fraction, the number that represents the total population in terms of which statistical values are expressed.

If decision makers don't know, or don't have certainty in the denominator, they quickly end up with problems in basic calculations, and false precision in the evaluation of services and the evidence base for policy.

Problems start when the denominator does not accurately represent the actual population of care home residents. This means that 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, 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.

1.3 Technical and social reasons for the denominator problem

The denominator problem exists because we are not measuring everything that matters to residents, staff, and care home operators in the right way. These problems are social as well as technical.

For example, the *Capacity Tracker* is an existing piece of data infrastructure that was rolled out rapidly during the early months of the pandemic (see Box 1). The Tracker is a market instrument designed to efficiently discharge people leaving primary care settings and entering community care (NHS Vale of York Clinical Commissioning Group, 2021). One major problem is that the tracker counts stocks of beds and resources, but what we really need to know is the number of residents in each home, where they have come from, and how healthy are they are.

What is happening is that static measures are being used to assess flows in a dynamic care system. This results in measures of system performance being used as indicators of residents' health and wellbeing. These measures are imprecise and not appropriate to accurately assess health risks due to covid-19 and other co-morbidities.

One major reason why this happens is because it's relatively easy and cheap to measure beds and homes which tend not to move about. Much more difficult is measuring people, who do. There are constant flows of people between private dwellings, stays in care homes, and visits to hospitals.

Existing data infrastructures focus on measuring static resources such as beds or even aggregate counts of deaths. For instance, the Care Quality Commission in association with the Office of National Statistics publish total number of deaths in care homes on a weekly basis. But on their own, the number of deaths at a care home during the pandemic does not prove an accurate assessment of quality or safety (Care Quality Commission, email newsletter, 11 May 2021). Measures that would complement these data, for example by accurately tracking flows, do not exist (Bell et al., 2020).

Box 1. The capacity tracker

In a matter of weeks, the NECS Capacity Tracker developed by North of England Commissioning Support Unit became the de-facto way of monitoring thousands of care homes in England and Wales. Built to help administrators, case workers and families find available beds from an often-bewildering choice of thousands of residential care providers, in the early months of covid-19, the tracker was adapted to monitor bed capacity and levels of infection nationally.

The Capacity Tracker is a self-reporting survey tool. Care home managers use it to make regular reports on indicators such as bed availability.

This data influenced decisions about how resources such as protective equipment were distributed to care homes in England and Wales (Healthy London Partnership, 2021)

2. WHAT FACTORS MAKE THIS PROBLEM WORSE?

Summary of factors which contribute to the problem

- The diverse settings of care homes make collecting standardised data difficult.
- Poor digital infrastructures within care homes and at local and national level.
- Regulatory incentives prioritise data gathering for monitoring systems and neglect data for evaluating impacts on residents.
- Complex market arrangements and financial worries are disincentives for care home operators to share data.
- 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.

The pandemic played out against a backdrop of political neglect in the wider social care sector (The Health Foundation, 2020b). Three major and longstanding issues are relevant to this review. First, the problem of money and budgets which have rapidly shrunk in real terms over the last decade. Second the problem of how care is paid for. And third, problems in the way that thousands of care homes are organised and regulated in a quasi-market arrangement makes implementing change difficult (Allen & Tallack, 2021). These structural issues impact the provision, creation and use of data in the sector in the following ways.

2.1 Poor digital infrastructures and data-use that monitors but does not evaluate

The challenge of producing accurate and timely data across the care home sector is increased by limited digitalisation within care homes: roughly three in four care homes are still paper-based (Say, 2019). Also, while residents are known to GP systems, information stored on paper, or in free text digital records, cannot be linked to data held centrally by NHS Digital, nor made available to inform local authority or national level decision-makers.

These factors mean that data infrastructures cannot reliably provide accurate and timely data on transfers of patients from hospital and into care homes, data on testing of residents and staff and infection rates in the care home local area, and care home level covid-related mortality data (Bell et al., 2020).

Another problem is that national level data infrastructures built before covid-19 were not keeping pace with how local areas understand and manage

care home provision. These over-emphasised tasks of monitoring system indicators while they neglected to evaluate outcomes for residents (Naylor, 2018).

For instance, national-level measures tend to focus more on 'late-stage' indicators of social care with an emphasis on safeguarding. One example of this is Delayed Transfers of Care (NHS England, 2021c), which tracks the delays in moving people on from their current hospital-based care due to non-clinical reasons – the problem the *Capacity Tracker* was designed to address. Because of this, there tends to be a greater focus on getting people out of hospital than preventing them from going into hospital in the first place.

By contrast, local decision-makers increasingly understand their duty as being to promote wellbeing more generally which often means supporting people to thrive throughout their lives. For these tasks, the evaluation of specific programmes and interventions is required but is often missing.

The picture is strikingly similar when we look at how *NHS Test and Trace* was monitored during 2020. Again, the focus was on monitoring system performance and not evaluating outcomes. Dunn and colleagues show how government reporting focused on 48 high-level statistics on the number of tests carried out among care home residents and staff. But these data did little to tell us how the testing programme was actually meeting the social care system's needs for testing (Dunn et al. 2021).

The House of Commons Public Accounts Committee recently reported that the NHS Test and Trace system publishes "a lot of performance data but these do

not demonstrate how effective test and trace is at reducing transmission of covid-19” (House of Commons Public Accounts Committee, 2021).

2.2 Care in diverse settings, discrimination and the undervaluing of care

Many UK care homes provide services for a diverse set of adults, not just older people. There is also diversity in where they are located and how they operate. Numerous providers are running different business models across the country – from large private equity-owned providers and state-run facilities, to thousands of small family-run care homes with a handful of residents.

A major problem is identifying adults who finance their own care as opposed to receiving support from local authorities or other third parties. This is because there is currently no requirement for care providers or local authorities to collect data on these individuals (John, 2020). This leaves a significant gap in the evidence of understanding how care is funded and the impact on the sector.

These factors make quality assessment and regulation that relies on standardised indicators of care difficult.

A series of workshops by The Health Foundation and Future Care Capital in July 2020 showed that difficulties faced by staff and residents in care homes were bound up with wider structural issues such as discrimination against older people and disabled

people and the undervaluing of care wherever it happens throughout society (Steventon et al., 2020). Combined with poor governance in the sector, even in a crisis-situation, it was often difficult to compel change quickly.

2.3 Complex market arrangements, disincentives to share data and few trusted intermediaries

Difficulties in gathering nationally standardised data in care homes are compounded by the large but fragile provider market, and the complex and distributed nature of care in the UK. For instance, an estimated 410,000 older people currently live in approximately 11,000 long term care facilities (LTCFs) in England (Bell et al., 2020). Complex and ongoing flows of residents between acute, primary, community and informal care settings mean tracking individuals is impossible given existing infrastructure.

Staff conditions such as poor pay and limited time contribute to workforce shortages and further mitigate against the collection of data.

Finally, care home operators are often reluctant to share data that might have consequences on their finances (Curry & Oung, 2021). Unlike the health care sector, there are few trusted third party intermediaries, who could play a role both aggregating and sharing data, as well as establishing relationships between data providers based on trust and common interests.

3. WHY SHOULD ADDRESSING THE DENOMINATOR PROBLEM BE A PRIORITY FOR POLICY?

Summary points

- Covid-19 is particularly harmful to older people, and communal living brings increased risk of transmission. There is much at stake for care home residents.
- A lack of data has been a significant factor in shaping policy response.
- Vaccination drives or even mandatory vaccination is not enough. Vaccines are not 100% effective, and not all residents of staff will receive vaccines.
- A failure to understand and represent the dynamics of care homes will increase the number of deaths due to covid-19 next winter.
- Solving the denominator problem will be a key plank in addressing ongoing shortcomings in the broader social care sector
- Quality care home data will contribute to national data infrastructure which is needed for emergencies and for everyday use.

3.1 Outbreaks of Covid-19 in care homes have killed thousands

The care home sector has been harder hit than any other institutional setting (The Health Foundation, 2020a, 2020c).

According to the Office of National Statistics, there have been 173,974 deaths amongst all care home residents in England and Wales since the beginning of the pandemic through to 2 April 2021 (Office for National Statistics, 2021). This is an increase of 19.5% compared with the five-year average, suggesting that there may have been 28,414 excess deaths in this population. Of the total number of care home residents' deaths, 42,341 involved covid-19, accounting for 24.3% of all deaths of care home residents.

A recent study of excess deaths in care homes in the first 23 weeks of the pandemic suggests that the odds of experiencing covid-19 attributable deaths were significantly higher in homes providing services to older people or those with dementia (Morciano et al., 2021).

Another study shows that both covid-19-related and non-covid-19-related excess deaths in this sector were concentrated in care homes with a confirmed outbreak of covid-19. This suggests that such outbreaks may have had a direct effect on care for other conditions in the homes affected (Burton et al., 2020).

3.2 Vaccination drives and mandates are not enough to protect care home residents

Vaccinating care home residents and staff is seen as a major intervention in reducing the spread of transmission and reducing the risk of death following infection. The Scientific Advisory Group for Emergencies (SAGE) has suggested an 80% uptake threshold for older adult care home staff, and a 90% uptake threshold for residents in these homes.

According to NHS England statistics as of 30 May 2021, 289,229 (95.2%) residents in older adult care homes in England have been reported as receiving at least one vaccine dose (NHS England, 2021a). 89.6% of residents have had a second dose. More than 8 in 10 eligible staff in older adult care homes are reported to have been vaccinated with at least one dose (394,163; 83.5%), and 67.4% of eligible staff had had a second dose.

At a population level, the vaccination programme has been successful. However, at the level of individual older adult care homes, NHS statistics show only 53% of homes in England currently meet the SAGE guideline thresholds for both staff and residents. But even if plans to mandate all care home staff are brought forward, issues remain (O'Donovan et al., 2021): Vaccination is not 100% effective at preventing infection or transmission. Even if vaccination is mandated, exemptions will be given to some residents and staff, and, given the fractured nature of the care home sector (Curry & Oung, 2021), it is unlikely every care home can be monitored and policed to ensure unvaccinated staff are entirely prevented from coming into contact with residents.

3.3 Better quality data needed to prevent excess deaths next winter, to appraise alternative policies and to underpin broader reforms

According to The Health Foundation, a lack of data has been a significant factor in shaping policy responses to date (Dunn et al. 2021) and will continue to be so. Timely data on infection rates and deaths amongst people using social care services, and support staff availability, are critical to the monitoring, and the targeting of support to, at-risk populations such as care home residents (Comas-Herrera et al., 2020). A failure to understand and represent the dynamics of care homes will increase the likelihood of further excess deaths due to covid-19 next winter.

Quality data is also critical in appraising the likelihood of success of interventions in social care, and evaluating their actual outcomes (Crellin et al., 2021). The appraisal of prospective social care programmes is required by the Care Act 2014 in order to compare expected outcomes from alternative proposals (Naylor, 2018).

Appraisal usually involves a comparison of a range of options to identify the preferred one. Evidence to support appraisal requires data on understanding the fundamentals of a system to properly intervene. This applies at national and local level, for instance when considering alternative funding regimes or the relative strengths of proposed programmes. Without this knowledge, decision-makers only have a limited ability to plan effectively, allocate resources wisely and design and implement new modes of care.

Solving the denominator problem will likely have positive spill-over effects across the broader care sector. It will improve the ability to do research on

issues that matter to people on the ground and contribute to evidence bases that can help us better understand the causes of mortality.

Future care interventions and policies are going to need accurate and robust data, supported by reliable, well-maintained data infrastructures. Quality care home data will also contribute to national data

infrastructures which are needed for emergencies and for everyday use. Because of this, solving the denominator problem will be a key plank in addressing ongoing shortcomings in the broader social care sector.

4. WHAT ARE PROMISING DIRECTIONS FOR IMPROVING DATA INFRASTRUCTURES FOR CARE HOMES?

Summary points

- Feasible ways to close gaps in data have been suggested by researchers and are currently being trialled.
- These must be complemented by different kinds of data, rethinking how data quality is assessed and new ways of gathering data.
- New forms of research and innovation are already being trialled. Successes should be fast-tracked into practice and data infrastructures.
- Third-party data intermediaries that can build trust within the UK's system of care homes do not currently exist but might be important in the future. Lessons can be learned from NHS data governance efforts.

4. Investment in capacity for **large-scale, anonymised linked data analysis** within social care working in partnership with academics
5. Recognition of the need for **collaborative working to use novel data sources**, working to understand their meaning and ensure correct interpretation
6. Better **integration of information governance**, enabling safe access for legitimate analyses from all relevant sectors
7. **A core national dataset for care homes developed in collaboration with key stakeholders** to support integrated care delivery, service planning, commissioning, policy and research

Some of these priorities are being addressed in ongoing research projects. Trials for minimum data sets (Hanratty et al., 2020) are testing how to produce data in care homes in ways that matter to residents and their carers (Musa et al., 2020) and are building frameworks for collating and interpreting these data (Akdur, 2020) that directly address many of the suggestions made by Burton and colleagues.

These priorities, which would go a long way towards solving the denominator problem in care homes, are endorsed by this review. They are necessary measures to solve the denominator problem, and achieving them will ensure the basic conditions for ethical data gathering and data use in care homes can be met.

At the same time, further measures are needed in order to build and maintain resilient, sustainable data infrastructure in the sector, and to address structural and institutional problems discussed in this review. To this end, this review complements the Burton priorities

4.1 How gaps in data can be closed

Burton and colleagues call for changes within care homes and within infrastructures, for increased collaborative work between sector experts and academics, and for changes to the rules and regulations that govern the sector. They list seven priorities (Burton et al., 2020):

1. Reliable **identification** of care home residents and their tenure
2. Common identifiers to facilitate **linkage** between data sources from different sectors
3. Individual-level, anonymised **data inclusive of mortality irrespective of where death occurs**

and sets out further proposals on how to overcome structural, institutional and policy barriers.

4.2 Adding different kinds of data, rethinking data quality and innovating ways of gathering data to better understand the needs of residents, staff and care home operators

First, new *kinds* of data are also needed to fully solve the denominator problem. A group of social care researchers at the London School of Economics call for better quality and different kinds of data to inform policy (Bear, 2020). They use ideas from anthropology to redefine data quality to include the following factors: the context in which care is provided; how clinical data is understood differently in non-clinical settings like care homes; and issues that currently hamper the sector, such as low pay, high churn and blocks on migration. They suggest methods that combine existing forms of ONS and public health data with systematic evidence-gathering in communities and across different social groups using ethnographic methods.

Experimental testbeds like Care City (Crellin et al., 2021) and research projects like Supporting Adults Social Care Innovation (SASCI, 2020) show how innovation in care practices and procedures, coupled with wider organisational and institutional changes in the sector, make data useful and usable to staff and residents on the ground.

These approaches further add to the idea of what better care data should be like by complementing static measures of performance with data on the context of care in the community. They do this by interpreting population and clinical data in these contexts and contributing data on low pay, high staff churn and blocks on migration that currently hamper the sector; and making these data useable for statutory responses to inequality and deprivation.

4.3 Complementing new data with improving the infrastructure and social conditions in which care home data is gathered

The recent white paper from the Department of Health and Social Care frames proposed changes to broader health and social care systems in terms of innovation and integration (Department of Health and Social Care, 2021a). It has surprisingly little to say about the specifics of care homes.

Social, political, and institutional hurdles remain. Critical will be aligning advances in care home data with broader transformations across health and social

care, such as service integration (Pollock et al., 2020) between health and social care (Alderwick et al., 2021) and further inter-linking of datasets across public sectors and local authorities. An integrated system would allow detailed monitoring of staffing levels, sickness levels and other data points for care staff and residents.

Issues of trust and unwillingness to share data must be also addressed in ways that are fair to care home operators, staff and residents and address concerns that the public has about the discriminatory impact of some covid-19 related apps and technologies (The Health Foundation, 2021). The point here is that technological solutions such as apps also contribute to widening a digital and data divide (Ada Lovelace Institute, 2021).

One suggestion is that care home commissioners and regulators learn from recent initiatives in how NHS data is shared. For example, the work that the Understanding Patient Data project does to engage with stakeholders and patient groups and develop trusted approaches to data gathering and data use (Understanding Patient Data, 2021).

Third-party data institutions that might build trust within the UK's system of care homes do not currently exist but might be important in the future. There is some indication that enhanced social care collaboration has emerged during the crisis, but according to Ian Trenholm, chief executive of the Care Quality Commission, "those areas that have performed the best during the covid-19 period have largely been characterised by good joint working between the NHS, local authorities and the individual care home providers." (Rudgewick, 2021).

But these solutions on their own don't deal with the institutional settings and the misaligned motivations and trust. Capacity building is required in research so that collaborative approaches between clinicians, data scientists and epidemiologists can contribute to and learn from routine data research in care home settings and amongst care home resident populations. (Todd et al., 2020).

5. HOW ETHICS CAN INFORM DATA STRATEGIES AND DECISION MAKING FOR UK CARE HOMES

Summary points

- The denominator problem is an ethical problem.
- Problems with data on care homes are not naturally occurring. They often result from choices in design or result from neglect. This means they can be designed and maintained differently.
- Care homes operate in a complex, dynamic system. The ethical implications of how care home data is gathered and used look different depending on whether you are focusing on the individual, groups or communities and whether data is used in clinical or care settings.
- When commissioning new data infrastructures, it is important that decision-makers consider the implications for using data at these different scales.
- Because data is understood and used differently at different scales, simply collecting *more data is not sufficient* to solve the denominator problem in care home data.
- This has implications for data linkage, interconnection and integration agendas across health and social care. The technical job of data linkage must be accompanied by ethically appraising the terms on which data is used in different settings.
- It is not sufficient to consider ethical implications only during design and build phases of data infrastructure. Procedures that ensure ongoing accountability for residents, staff and informal carers are critical for good governance.

How should data infrastructure measure and respond to the denominator problem in care homes and what factors should an ethical assessment of data use consider?

This review has shown the care home system is complex and exists across several scales: national, local authority and community settings as well as individuals. At these scales there are thousands of care homes, and hundreds of thousands of residents with distinct combinations of risk factors and needs. There are many variables that can be measured, and ways in which these variables can be counted. Given the systemic interconnection between variables, making a situation 'better' in some ways will make it 'less good' in others.

5.1 Taking a complex systems perspective

Pragmatically, decision-makers need to decide what to do given how things currently are. They need to be able to spot deficiencies in care, and an understanding of what would count as an improvement.

Approaching these challenges from a systemic perspective, the key question is not so much how to best measure the system on a momentary basis. Rather, it is the strategic question of how to structure institutions, networks and incentives in ways that maintain and strengthen how the system distributes care over time (Wilson, 2021).

There is no one measure of care in homes that matters equally to everyone, so it is better to adopt a pluralist approach. This means acknowledging that the ethical problems are historical, contextual and differ from place to place and that solving one problem may often contribute to worsening others. Because of these factors, different kinds of data, and expertise to gather and use that data are required.

We discussed several promising avenues for progress on gathering new kinds of data in new ways Section 4.

5.2 Solving problems of dynamic systems by iterating and evaluating

One major factor that contributes to making people invisible in care home data, is the constantly changing

and dynamic nature of the system. This review has shown how data is used in decision-making for assessment, monitoring and evaluation, but with an over-emphasis on monitoring static resources. This kind of simplistic surveillance underplays how the system changes over time and the role that dynamic data can play in improving outcomes.

One way of thinking about what's really going on is to consider how data are used in the care home sector to measure and ultimately allocate the distribution of care. During the peak of the covid-19 crisis, care was understood most starkly as **minimising transmission, infections, and deaths**. Data were used to measure changes in the distribution of care and allocate protective equipment accordingly.

Two factors were constantly changing in this view of care homes. First, the people in care homes: in Section 3 we reviewed why it is important to address this problem and make people visible in the data. Second, as policy makers learned more about what was happening in care homes, and risks posed by the virus, ideas about the kind of care that should be provided also changed. And so, decision-makers and data system designers must pay attention to feedback loops that change ideas about what constitutes good care. This feature of complex systems is what experts call *system performativity* (Wilson, 2021).

The important lesson is this: ideas 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. Data here plays a critical role in clarifying the relationship between an idealised concept of how care in homes should be delivered and the lived realities of individuals' lives as measured by more specific variables.

Because of this, interventions within complex systems need to be iterative rather than one-off. Data infrastructure decisions made by policy-makers today are not likely to be silver bullets, and they may in the future need to address shortcomings and unforeseen negative outcomes.

Data will be critical in building evidence to support iterative interventions and must be gathered and re-gathered accordingly. And because of system dynamism, performativity and the need for ongoing maintenance, getting institutional structures and social processes right is the only plausible way of ensuring sustained and systematic improvements for those whom systems are currently failing.

5.3 Paying attention to values when interconnecting and interlinking data and infrastructures

Given this complexity, scale and dynamism, this review suggests the need for a more socially engaged set of data strategies than currently exist. Given this complexity, scale and dynamism, this review recommends a more socially engaged set of data strategies than currently exist.

Factors from a broad set of domains that affect the health and well-being of individuals, communities, populations and the economy should be opened up for ethical analysis. This analysis must pay attention to technical data infrastructures, social processes – such as how data gathering actually happens – and the mutual interactions of people and data from these domains.

The policy push for increased integration between health and social care systems may offer some fruitful opportunities here. But the technical task of interlinking datasets, a trend accelerated during covid-19 (Centre for Data Ethics and Innovation, 2021), needs ethical diligence to ensure the values and interests of care home residents, staff and operators are in agreement with whatever work the data is put to.

This is important because data are imprinted with the value judgements of those choosing what data to collect, and those giving consent for that collection. Also, values guiding data collection and interpretation in clinical settings often differ from those prioritised in care homes.

The risk today is that opportunities to debate the terms of interlinking could be missed. For instance care sector data was largely absent from the terms of reference of the Goldacre review, (Department of Health and Social Care, 2021b) which aimed to continue recent momentum in health data interlinking. But momentum is a function of speed *and* direction. As we adapt to living with covid-19, there is an opportunity to steer the benefits of these transformations so they are equally directed at health and social care settings.

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About this review

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About the UK Pandemic Ethics Accelerator

The UK Ethics Accelerator is a UKRI/AHRC-funded initiative that brings UK ethics research expertise to bear on the multiple, ongoing ethical challenges arising during a pandemic emergency. We provide rapid evidence, guidance, and critical analysis to decision-makers across science, medicine, government, and public health. We also facilitate public stakeholder deliberation around key ethical challenges.