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Navigating blindfold in a blizzard:
the invisibility of social care in routine data

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What is the problem?

Adult social care is a key element of the health and social care system but care home residents and those receiving care-at-home are poorly represented in routine data. This reflects the wider marginalisation of the social care sector and the people who need social care.[1] COVID-19 has brutally revealed the consequences of invisibility and marginalisation, with a large minority of COVID-19 related deaths happening in care homes and minimal information about the impact of COVID-19 on those receiving care-at-home. People in receipt of adult social care are among our most vulnerable citizens, but we cannot systematically improve their care without understanding their needs and current patterns of care.

What do we know about it?

The social care data gap reflects and reinforces the relative invisibility of adult social care in policy and public debate. In policy, adult social care is largely talked about as a problem of funding, rather than the quality or effectiveness of care. In public discourse, much less attention is paid to social care than to the NHS, and there is little recognition of the challenges faced by the sector or emphasis on the need to systematically invest in quality and safety improvement.

The initial response to COVID-19 highlights this. The focus was on 'protecting the NHS', with the impact in care homes only apparent when larger care home providers themselves reported multiple outbreaks with large numbers of deaths. Even catastrophic outbreaks were largely invisible because of the minimal testing in the community early in the pandemic, but also because there was (and is) no routine dataset in any of the four UK countries which identifies who is resident in care homes, or who is in receipt of care-at-home.

There still isn't a national dataset that reliably identifies who is in receipt of adult social care.[2,3] All UK countries have implemented various workarounds to improve our understanding of COVID-19 outbreaks in care homes (for example, by using 'whole home' resident and staff COVID-19 testing as a measure for who lives and works in a care home). However, these workarounds will be less effective as COVID-19 wanes, and they do not improve the visibility of care-at-home.

What helps?

Data is not a panacea, but good data and improved understanding are key building blocks in making social care better, and a necessity for health and social care integration.

Making better use of existing data today

We can make better use of existing data now. Public health and social care systems routinely record people's addresses, for example in GP registration. There is increasing focus on using address data to identify where people live. Address matching

Key points

- We were late to recognise and respond to the catastrophic impact of COVID-19 in care homes in large part because social care data is relatively poor and highly fragmented.

- This reflects a wider marginalisation of the social care sector, the people who work in it, and the people who use it.

- We need better social care data that can be linked to health and other data to improve our understanding of the needs of some of our most vulnerable citizens.

- Better data and understanding are critical, but have to be used effectively to improve the quality, safety and experience of care in later life. Data is not a panacea, but good data and improved understanding are key building blocks in making social care better, and a necessity for health and social care integration.

methods, in particular, have been applied to identifying care home residents,[4-6] but can also identify other vulnerable groups, including people living in sheltered housing or hostels. A key limitation of such methods is that people with rapid or temporary changes of address are not easily identified, including people living in care homes temporarily after hospital discharge for example. Although very valuable for multiple purposes, such methods are a stopgap rather than an alternative to more systematic social care data development[7].

Improving data for tomorrow

Although there are many things we can do now to make better use of existing data, closing the social care data gap requires system-wide change.[1-3] Box 1 lists some of the key requirements, including: (1) Reliable identification of users of social care; and (2) Use of a shared unique identifier to allow data linkage.

The only reliable way to know who is a care home resident is to ask the care home. We would never attempt to measure who was admitted to hospital by looking GP or ambulance records. We get hospitals to record who is admitted. We need the equivalent **Care Episode Statistics**, implemented in a way which is secure and protects privacy. The absolute minimum data needed simply includes who is a care home resident, whether they are a permanent or temporary resident, and uses a unique identifier like NHS Number or Community Health Index (CHI) Number to allow linkage to other existing data. A further absolute minimum requirement is that the burden of data collection on care homes has to be minimised, and all data collection has to provide value to the care home itself.

For care-at-home, the obvious place to start is to identify people in receipt of publicly funded personal care, which is already accurately known to local authority payers. There are plans for federating such data for secondary use (Client-Level Data in England which was delayed by the pandemic, SOURCE data in Scotland), but making these plans a reality is a priority.

Once these foundations are in place, then support will be needed to develop analytical capacity, to develop core datasets, and to support implementation and interoperability of electronic care records in social care. A potential model for this is general practice, where private businesses (general practices) are contracted to deliver public services (primary health care) on behalf of the NHS. GPs have long enjoyed subsidised clinical IT systems which are required to be designed to common standards and be interoperable with other NHS systems. General practices are also commonly financially incentivised to record core data in a standardised way, supporting both direct delivery of care and secondary data use. There is much that can be learned from other countries about minimum datasets for social care, and the ongoing DACHA study (Developing research resources And minimum data set for Care Homes' Adoption and use) in the UK will provide key learning to inform core dataset design and implementation[8].

Box 1: Key requirements to close the social care data gap (adapted from Burton et al[2])

1. Reliable identification of care home residents and those in receipt of publicly funded social care-at-home (including short-stay residents and short-term recipients)

2. Use of a shared unique identifier to facilitate linkage of data from different sources and sectors (e.g. NHS Number, CHI Number)

3. Access to individual-level, anonymised data to inform policy and planning and for research, including integration of information governance to enable rapid, secure access to legitimate users

4. Investment in capacity for large-scale, anonymised linked data analysis of social care data, including support for collaborative working to develop meta-data

5. Development and integration of a core national dataset for care homes and care-at-home developed in collaboration with key stakeholders to support integrated care delivery, service planning, commissioning, policy and research

What will the ACRC do about it?

The ACRC has multiple areas of work which will improve data infrastructure and extend our understanding of health and social care. A key element of our data infrastructure work is working with the Lothian DataLoch and the Data Driven Innovation (DDI) team to make linkage of health and social care routine, and to link NHS address data to the Unique Property Reference Number which will allow us to better examine how need and service use varies in different types of households (including care homes and sheltered housing) and in different neighbourhoods. Our linked work to understand the experience of later life and of care using sophisticated qualitative and quantitative methods will inform what kinds of data health and social care systems should regularly collect. New care technologies which we are developing and evaluating will create rich new datasets, but also raise challenges for privacy which need careful consideration. Our new models of care work will build on these insights and technologies to examine how health and social care can most effectively use data to improve quality and safety.

The ACRC will also continue to advocate for improved social care data. Better data itself will not improve the experience of later life and of care, which is why we are collaborating with residents and families, care providers, regulators, the NHS, government and researchers to maximise the value of data while protecting privacy and supporting dignity and independence.

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