Covid-19 and lack of linked datasets for care homes

The pandemic has shed harsh light on the need for a live minimum dataset

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Residents of care homes are centre stage in the covid-19 pandemic for all the wrong reasons. Home to vulnerable people with complex needs, these settings should have been an obvious focus and priority in pandemic planning.[1] Almost half of newly admitted residents in the UK are transferred from hospitals, creating a resident population with wide ranging needs spread across 450 000 beds in almost 11 000 homes.[2] [3] This is more than double the number of beds in NHS hospitals,[3] but unlike NHS facilities most homes are privately owned, with residents responsible for some or all of the costs of their care. Yet as covid-19 spread across the UK, minutes suggest that the government's Scientific Advisory Group for Emergencies (SAGE) discussed care homes only twice in the first five months of 2020.[4]

The covid-19 pandemic has placed a spotlight on how little is known about this sector, and the lack of easily accessible, aggregated data on the UK care home population. Basic information that could be used to inform service responses, such as the number of residents in homes with and without nursing care and hospital admissions and deaths among them, is difficult to locate.[5] It is not simply lack of data that is the problem; it is the number of different bodies that are collecting information, and the absence of standardisation and cross sector cooperation in how data are collated, shared, and used.

Care homes collect and use data every day on the needs, health, and wellbeing of their residents, and a growing number of homes have sophisticated information systems to monitor medications, support care planning, and much more. Health services also keep routine records about homes' residents, but these data are, rightly, difficult to access. External bodies such as the Care Quality Commission in England and the Care Inspectorate in Scotland

collect information for regulation and quality assurance, including data on deaths and disease outbreaks.[6][7] Figures on staffing are collated by managers' organisation Skills for Care and the Scottish Social Services Council.[8] None of these sources, however, provide timely information in a usable format that could inform urgent responses to the covid-19 pandemic.

Real time data

Some of the most innovative responses to the pandemic have emerged at regional level. For example, Health Innovation Manchester has a care data tracker that allows homes to provide real time information about residents to general practices and hospitals.[9] In north east England digital collection of national early warning scores and linking of routine health and social care data has accelerated during the pandemic.[10] And a capacity tracking app was introduced in England to generate data on care home bed occupancy and staffing.[11]

To date there has been no national, systematic approach in the UK to develop care home datasets or to exploit their full potential to enhance residents' care. We are collaborating on a study to design, develop, and implement a minimum dataset for UK care homes such as that developed in the US for the Centers for Medicare and Medicaid Services.[12] The learning from covid-19 will directly inform this work, and we intend that any minimum dataset built for UK care homes should be a resource to support residents' care and not just a tool for regulation or cost containment.

Longitudinal data on infections and deaths in care homes would have allowed real time monitoring from the start of the pandemic, early detection of problems, and targeted appropriate interventions. This could have yielded insights into the natural course of covid-19 in care homes, underpinned evidence based guidance, and identified triggers for service responses. As patients were discharged from hospitals to care homes after treatment, data on the health of residents would have been invaluable to develop strategies to protect people at greatest risk and minimise further spread within homes. Such data could also inform the need for bespoke surveillance systems for future pandemic waves.

Other countries have shown great interest in care home minimum datasets, but none have been adapted for or adopted into routine UK care. In the US nursing homes are federally mandated to contribute to a minimum dataset, and payments are contingent on participation.[13] Related measures, such as the Resident Assessment Instrument and Dutch National Measurement of Care Problems, are in use in Europe.[14][15] None, however, provide the comprehensive information at the individual resident, care home, or organisational levels needed for health monitoring, and all have faced challenges in implementation.

Timely and accessible data on residents' health, wellbeing, and service use could support rational planning and delivery of care tailored to residents' needs, something that UK health and social care sectors have often struggled to do. Data are also vital for research, and for monitoring equity in outcomes and access to care. Workloads are already high in care homes, though, and it is crucial that data collection is not a burden on staff.

This pandemic has focused public and political attention on the needs of people in care homes, exposing a long established gap in data intelligence and prioritisation of needs. Such information could have made the difference between rapid, effective responses and the high rates of infection and mortality that have been the hallmark of covid-19. Political decisions on the funding and organisation of social care over decades have led us to this point.[16] As societies question these choices and seek better ways of looking after our older citizens, ensuring that care homes are part of a data system that works to support and protect residents must be a priority.

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