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Using linked health and social care data to understand service delivery and planning and improve outcomes.

Author: Towers, Ann-Marie A.Towers@kent.ac.uk

University of Kent - CHSS

CC202 Cornwallis Central University of Kent, Canterbury Kent CT2 7NF

United Kingdom of Great Britain and Northern Ireland

University of Kent - Centre for Health Services Studies (CHSS)

Cornwallis Central, University of Kent, Canterbury Canterbury CT2 7NZ

United Kingdom of Great Britain and Northern Ireland

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Key points:

- The COVID-19 pandemic has highlighted the need for reliable, routinely collected, shared care data.
- Existing linked data sets are not comprehensive enough to accurately predict demand for long-term care in England.
- The DACHA study will pilot linking health and social care data for service planning and delivery.

Adult social care provides short or long term support with many essential activities of daily living, such as washing, dressing, getting enough food and drink and feeling safe. It provides a vital safety net for many hundreds of thousands of people and their unpaid carers across the UK. However, use of long-term, publicly-funded adult social care is determined by more than individual's needs. Access to long-term care is also associated with the level of informal support that the individual receives, the constraints of local service capacity (supply) and, unlike the NHS, a financial means test. Demand far exceeds supply, in 2019-20, local authorities in England, who have a legal responsibility to assess people's needs and eligibility for support, received the equivalent of 5,290 requests for support per day [1]. Despite expenditure on adult social care increasing, the number of older people (aged 65 and over) receiving long-term care has decreased year on year [1], because those who are eligible, require intensive packages of support. Publicly funded care is now reserved for those with the highest needs and lowest assets.

Nakubulwa and colleagues (2022) argue that there is a need to better predict the demand for long-term care to inform service planning and development and note that existing, linked health and social care data for this purpose in England is not easily accessible. Using a longitudinal, retrospective cohort design, Nakubulwa et al. used de-identified, routinely available data derived from clinical electronic health records to explore factors associated with accessing publicly-funded,

long-term social care amongst older adults (age 75 and over), and build a predictive risk model forecasting future service use.

The Northwest London Discover Database used in the research links primary, secondary, and tertiary care, community and mental health care, emergency departments and social care. The linked data contains rich information of participants' socio-demographic characteristics and health conditions. However, its power to accurately predict demand and access to adult social care is limited by a lack of data on key indicators, such as availability of informal support, (whether or not the person lived alone was missing for 82% of the sample), the individual's socio-economic status and if they were funding their own social care. Unsurprisingly, the study found that individuals were more likely to receive long-term, publicly-funded adult social care if they were older, lived in areas with higher socio-economic deprivation and had a pre-existing mental health or neurological condition (which are likely to be associated with loss of function and independence in old age). The lack of high quality shared care data on this population meant that accurate individual-level prediction was not possible.

Their study completed in December 2019, just two months before the start of the COVID-19 pandemic. Since then, the need for reliable, routinely collected shared-care data has become both obvious and urgent [2,3]. The Department of Health and Social Care's *Shared Care Records programme* is committed to bringing individuals' health and social care information together in one digital record. To do this, they first have to accelerate the uptake of digital care records in the adult social care sector. Approximately 30% of social care providers are still using entirely paper-based systems, with another 30% using a combination of approaches [3]. However, this landscape is rapidly changing and there is now growing recognition amongst providers of the potential of digital care records to reduce duplication of recording, capture real-time information, and ultimately improve the needs and outcomes of the people using their services. Given that social care providers are often the only organisations holding information about the needs and characteristics of self-funders (those who do not meet the criteria for public funding), being able to match this data to NHS data will address an important and long-standing evidence gap.

The utility of anonymised data drawn from linked NHS and social care records, alongside local authority and regulatory data, to inform care delivery and improve outcomes is being explored in an on-going study to develop and test a minimum data set (MDS) for care homes in England [4,5]. The DACHA study (Developing research resources and minimum data set for care homes' adoption and use) is working with digitally-enabled care homes to collect resident-level data from care records and match this to native data held about them (e.g. in hospital and GP data) and the care home in which they live (e.g. CQC data). It is also exploring the acceptability and feasibility of collecting comparable information about older people in receipt of domiciliary care services.

Clearly, for an MDS to have predictive power and be used to project demand for future long-term care on an individual, regional or national level, we need an comprehensive MDS for health and social care. Any data collected for the purposes of populating such a data set must also be of importance to individuals and serve to ultimately improve their outcomes, including their quality of life. Successful implementation requires that care providers benefit from the information collected and are able to use that data to demonstrate their impact, improve quality and inform people's care [5].

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