

Use of Linked Administrative Adult Social Care Data for Research: A Scoping Review of Existing UK Studies

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Abstract

Administrative data provide unique coverage of populations using care and the use of new datasets and advancing digital technologies only contribute to this growing area. There are ongoing limitations in the linkage of administrative datasets, which for adult social care have been exacerbated by inconsistent coding and varied IT systems. The aim of this review was to provide an overview of all studies to date that have used linked adult social care administrative data in the UK. This scoping review included primary quantitative research using individual-level adult social care service or workforce data when linked with at least one other data source. The search strategy was developed systematically and two authors independently screened and reviewed full-texts for inclusion. Fourteen articles were included—a mix of national and local projects. Definitions for the adult social care population ranged, with only four including all ages. One included unpaid carers and one included the domiciliary care workforce. Where described, linkage of datasets was slow, with challenges in the governance and linkage process.

This review demonstrates that administrative data can be a rich source of information for the adult social care sector and linkage can expand its utility and impact.

Keywords: adult social care, scoping review, administrative data, social care workforce

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Introduction

The availability of administrative data from health care, education and children's social care for research has increased rapidly over the last decade (Mc Grath-Lone *et al.*, 2016; Jay *et al.*, 2019; Scourfield *et al.*, 2019; Allnatt *et al.*, 2022b; Marryat *et al.*, 2023) along with advances in digital technologies, data storage and processing power. This has enabled analysis of large datasets, including linkage with other routinely-available data (Todd *et al.*, 2020). There is considerable untapped power in these public service administrative datasets such as the application of novel machine learning techniques, new administrative data sources as well as the positive impacts for research such as improved recruitment, inclusivity of often excluded groups and the reduced burden of research on participants (Goldacre and Morley, 2022).

Nationally available administrative data in the adult social care sector have, until recently, only been returned to government departments via aggregated annual returns. Historically, local authorities and other administrative regions have assessed their population needs when legally required, but staff capacity and data-expertise (including a lack of a common coding language (Bardsley *et al.*, 2012)) have prevented them from fully exploiting the potential of their data. From April 2023 (Wales) and July 2023 (England), independent individual-level datasets have been submitted by local authorities to the Welsh Government and NHS England, respectively, for those in receipt of care and support (Department of Health and Social Care, 2023). National adult social care data, linked to data from other public services, could provide powerful insights about this population in need. Through linkage with other sectors such as health and welfare, it could provide complete coverage of those receiving or delivering services, providing new understandings of the population's outcomes and needs. Linkage of these datasets is an essential part of the wider picture of using data to 'save lives' (Department of Health and Social Care, 2022) and is included in the long-term plan for adult social care data in England (Department of Health and Social Care, 2023) but is yet to be realised. This comes at a time of austerity, where the adult social care sector is faced with severe challenges such as high staff turnover, the complexity of need across the adult social care population, an increase in the prevalence of disability amongst working-age adults (Department for Work and Pensions, 2023) and an ageing population estimating an increase in demand of 41–49 per cent by 2038 (Hu *et al.*, 2020).

Anecdotally, there is very little research published where administrative adult social care service data have been linked to other data sources

(administrative and research), at local or national levels. This is likely explained by some of the inherent limitations of administrative data, namely the granularity of the data collected, inconsistency of data collected across local authorities and the governance and practicalities of securely linking multiple datasets (Lugg-Widger *et al.*, 2018). The aim of this scoping review was to provide an overview of all studies to date that have linked routinely collected individual-level adult social care administrative data in the UK to other data sources.

Materials and methods

The study aligns with best practice guidelines for scoping reviews, namely the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Scoping Review extension (PRISMA-ScR) (Peters *et al.*, 2015; Tricco *et al.*, 2018; Peters *et al.*, 2020). A protocol was not published ahead of conducting the review.

Eligibility criteria

Adult social care across the four nations can encompass different populations and services. For this scoping review, we used the definition used by the King's fund (Kings Fund, 2023): 'people who are older or living with disability or physical or mental illness ... It can include "personal care" ... as well as wider support to help people stay active and engaged in their communities ... [it] includes support in people's own homes; support in day centres; care provided by care homes and nursing homes; "reablement" services ... providing aids and adaptations for people's homes; providing information and advice; and providing support for family carers'.

Eligibility criteria and rationale are provided in Table 1. We included primary quantitative research that used individual-level adult social care service or workforce data, linked with another data source. Both national and local studies were included if relating to UK data (this included single and multi-nation if England, Northern Ireland, Scotland or Wales). Both studies of individuals receiving care and support and studies of the care workforce were included. Research papers, reports and theses were all included. Data resource profiles that were not primary research were also included if all other inclusion criteria were met.

Search terms

The following databases were searched: Medline, Web of Science, Applied Social Sciences Index Abstracts, Social Care Online* (not updated since Jan 23), SCOPUS, PSYCHINFO, Social Services Abstract

Table 1. Eligibility criteria and description.

Criteria	Description
Primary quantitative research study OR data resource profile	Primary research studies published in peer-reviewed journals or identified in the grey literature. Includes profiles of data resources in which primary research can be undertaken.
Included individual-level adult social care service data or workforce data	Any studies/profiles that included individual-level service data on the population, carers and/or staff within the adult social care definition used by Kings fund, made available from administrative sources (not research data). Census data, health records and postcode level data were not included within this definition.
Included linkage to other data	Studies or profiles that linked, at an individual level to other individual or area level (administrative or research) data.
UK population	UK studies only; from all or any of the four nations.
Any study design	Any quantitative study design.
No date restrictions	Any studies/profiles identified.
Published in English	Only studies/profiles published in the English language.

and Social Science Research Network (SSRN). Searches were conducted (by MS and FLW) on 30th January 2024. We used keywords that represented adult social care, administrative data and data linkage, and this approach was adapted for each database as required ([Supplementary Table S1](#)). We excluded ‘adulthood’, assuming this term would be used in relation to childhood, to reduce the number of children’s social care research papers identified. Theses and policy documents were searched (by FLW) via EThOs and Overton. Additional searches were conducted (by FLW) in topic-specific websites for organisations involved in adult social care research in particular those utilising administrative data. This included: ADR UK (including ADR Wales, ADR Scotland, ADR Northern Ireland), Health Foundation, Skills for care, Centre for International Research on Care, Labour and Equalities (CIRCLE). In addition, we examined reference lists of relevant articles and reports.

Identification and selection of relevant studies

Two reviewers (MS and FLW) screened all titles and abstracts of articles identified by the searches. Full-text articles were retrieved if potentially eligible. Characteristics of the included studies were extracted by one researcher (by MS, reviewed by FLW), including (1) citation; (2) sample size; (3) population; (4) adult social care data; (5) linked data -not adult social care; (6) linkage process; and (7) summary of findings ([Supplementary Table S2](#)). We summarise findings into the following broad themes: description of the study populations included, data sources and study designs and methods such as data linkage.

Results

We identified 894 articles in total—886 from abstracts using electronic databases and eight from other sources. After duplicates were removed, there were 668 articles and reports where abstracts were reviewed for relevance. Thirty-six were identified as potentially eligible, and full texts were retrieved. Of these, fourteen met the inclusion criteria and were included in the review (Figure 1). The range of publication years for included studies is 2012–2023.

Of those fourteen, there was a mix of national and local projects, however only ever within a single UK nation. No research had linked data across the boundaries of the UK nations or included data from two separate nations. Five (three in Wales, two in Scotland) included the whole population of a nation, and the remainder were local (limited to local authority, health board or city boundaries). Seven were based in England (Bardsley *et al.*, 2012; Steventon and Roberts, 2012; Lewer *et al.*, 2018; Shand, 2020; Grimm *et al.*, 2022; Nakubulwa *et al.*, 2022; Towers *et al.*, 2023). Three were in Scotland (Evans *et al.*, 2019; Henderson *et al.*, 2021; Burton *et al.*, 2022) and four in Wales (Tingay *et al.*, 2015; Hollinghurst *et al.*, 2020; Hollinghurst *et al.*, 2022; Cannings-John *et al.*, 2023), and no

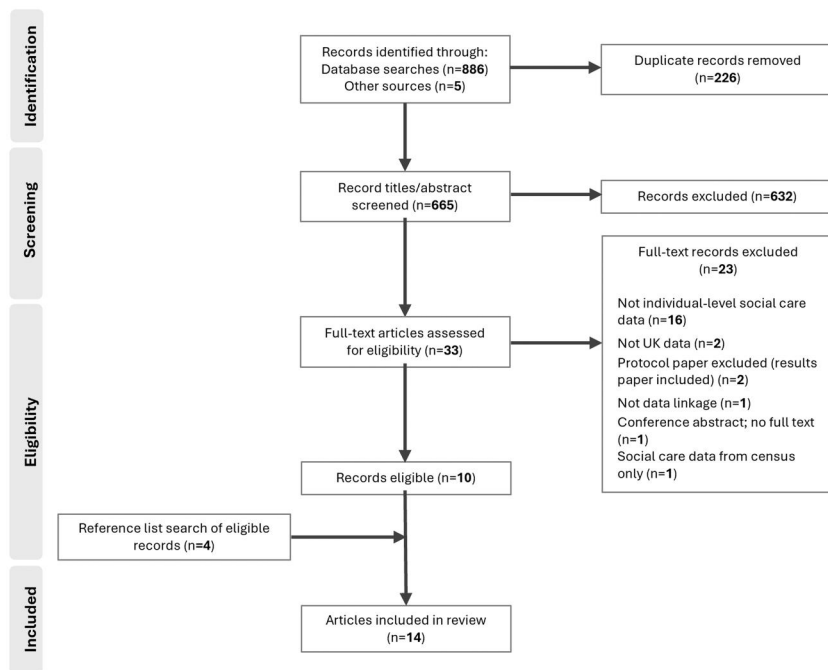


Figure 1. Consort for included articles.

papers were found based in Northern Ireland. Two resource profiles were identified (Lewer *et al.*, 2018; Towers *et al.*, 2023), and the remaining were primary research papers. The resource profiles will be described separately below. [Supplementary Table 2](#) provides an overview of the included articles in the review.

A range of definitions of the adult social care population were used to describe ‘older adults’ including, seventy-five years and over (Bardsley *et al.*, 2012; Nakubulwa *et al.*, 2022), sixty-five and over (Steventon and Roberts, 2012; Evans *et al.*, 2019; Henderson *et al.*, 2021) and sixty years and over/sixty to ninety-five years (Hollinghurst *et al.*, 2020; Hollinghurst *et al.*, 2022). Four papers contained adult populations of all ages in receipt of social care provision (Tingay *et al.*, 2015; Shand, 2020; Burton *et al.*, 2022; Grimm *et al.*, 2022), including one paper with unpaid carers identified (Shand, 2020). For the latter, it was data from the primary care records that documented whether someone had a carer or was a carer rather than the local authority social care data.

Burton *et al.* provided a breakdown of the population of adults moving into care homes over a three year period: older adults (74 per cent of homes), those with learning disabilities (16.5 per cent), mental health problems (5 per cent), physical disabilities (3 per cent) and substance misuse needs (1.5 per cent) including those living with the chronic consequences of alcohol dependency (Burton *et al.*, 2022). Grimm *et al.* describe the population of adults receiving domiciliary care packages with the majority sixty and over years of age ($n = 1736$) in contrast to $n = 305$ nineteen to fifty-nine years of age. Those with a recorded comorbidity of a learning disabilities represented $n = 24$ (1.2 per cent of the $n = 2041$ cohort in receipt of domiciliary care) (Grimm *et al.*, 2022).

Only one paper had linked adult social care workforce data (Cannings-John *et al.*, 2023). This study presented a unique opportunity to link social care work staff via their registration with regulator Social Care Wales to a large number of datasets already held within the SAIL Databank in Swansea, Wales. This was the first study to carry out such a linkage for social care staff. All staff were provided with the opportunity to opt-out of the linkage prior to data transfer. However, it was only through qualitative interviews that it was established that the staff registering as domiciliary care workers included both those providing personal and home care at home and also those working in supported shared-care living. In the context of COVID-19 risk, this was an important distinction (Prout *et al.*, 2022; Cannings-John *et al.*, 2023).

All research articles described retrospective observational study designs, two applied a case–control methodology (Hollinghurst *et al.*, 2020; Hollinghurst *et al.*, 2022), and the remaining papers described a cohort study. Hollinghurst *et al.* (2020) used a matched-control evaluation to assess the risk of care home admissions for people with different frailty levels receiving home advice and modification interventions. This

study linked data from the Welsh charity, Care and Repair Cymru ([Care and Repair Cymru](#)), and used this list of individuals and the interventions they received to create the intervention group for comparison. Frailty for the whole population was based on the electronic frailty index which uses thirty-six variables within the primary care records to produce and individually calculated score for each individual. The outcome of care home admission was based on the individual's post-code having been updated to a unique property reference number known to be a care home address. This was all carried out within the SAIL Databank trusted research environment, internationally known for its secure access and procedure for creating anonymised linking fields and split file approaches ([Ford et al., 2009](#); [Lyons et al., 2009](#); [Jones et al., 2019](#)). Using the same set-up, [Hollingshurst et al. \(2022\)](#) evaluated the impact of these interventions on emergency department admissions using a retrospective longitudinal controlled non-randomised intervention cohort study design ([Hollingshurst et al., 2022](#)).

At a more local level, and using more manual processes, [Steventon and Roberts \(2012\)](#) accessed administrative data from three local authorities in England to estimate the length of publicly funded care home stays and approximate costs of care home placements ([Steventon and Roberts, 2012](#)). Measures of social care need were inconsistent across the three local authorities, and much time was spent with local authority staff to manually identify records corresponding to residential and nursing care placements. These authors reflect on the potential of using such linked data which were limited in this study by the local authorities' ability to make their data available.

Given the challenges of social care services not consistently capturing National Health Service (NHS) number within their records, we were particularly interested in what identifiers were used to enable linkage of social care service data with other data sources. The available information on this varied across the papers—some provided little to no detail. Where NHS or Community Health Index (CHI) number was not consistently available within the social care/local authority data, data were probabilistically matched on the basis of name, address and/or date of birth ([Bardsley et al., 2012](#); [Steventon and Roberts, 2012](#); [Evans et al., 2019](#); [Shand, 2020](#)). For example, [Evans et al. \(2019\)](#) used probabilistic techniques to match name and address of people in receipt of home care services to the master patient list of CHI numbers (equivalent to NHS number in Scotland) in Glasgow. It was possible to then link to the Scottish Morbidity Record 1 for inpatient hospital records ([Evans et al., 2019](#)). This process to enable this linkage was complex and time-consuming from an ethical approval and data sharing perspective; however, the matching of records was relatively straightforward. No match rates were provided, so it is not clear if any records were lost or excluded from the analysis.

A number of linkages were already established either within local clinical commissioning groups, national data safe havens or integrated datasets, and therefore information within the manuscripts was not provided (Tingay *et al.*, 2015; Grimm *et al.*, 2022; Nakubulwa *et al.*, 2022; Cannings-John *et al.*, 2023). The ‘Care City cohort’ was such a resource with linked health and care records in the London Borough of Barking and Dagenham. Grimm *et al.* (2022) described how local authorities and NHS commissioners set up the cohort of all people aged nineteen and over living in the borough on 1 April 2018 (Grimm *et al.*, 2022). No further detail was provided on how the records were matched or if records were lost due to not-matching. 140,987 people were represented in the dataset, with 1.4 per cent having relevant records pertaining to receiving a domiciliary care package, for which associated hospitalisations were being investigated.

The adult social care service/workforce data available at an individual level included domiciliary care provision (Grimm *et al.*, 2022), home adaptation/repair provision (Hollinghurst *et al.*, 2020; Hollinghurst *et al.*, 2022), adult social care service receipt (Tingay *et al.*, 2015; Nakubulwa *et al.*, 2022) and domiciliary care workforce registration details (qualifications, employment type) (Cannings-John *et al.*, 2023).

There were a number of identified articles, initially thought to be in scope, but excluded at full-text review, and these related to individuals being identified as residing in a care home through the linkage of their post-code to the care home registry. The decision was made to exclude from this review as, other than identifying their residence as being at a care home, no other social care service data were available at an individual level (McCann *et al.*, 2011; Maguire *et al.*, 2013; McCann *et al.*, 2014; Knapp *et al.*, 2016; O’Reilly and Rosato, 2017; Santos *et al.*, 2020; Giebel *et al.*, 2021; Hollinghurst *et al.*, 2021; Morciano *et al.*, 2021; Harrison *et al.*, 2022). Only one study remained in scope, Burton *et al.* (2022), which used the Scottish Care Home Census (SCHC), an annual data collection from care homes in Scotland, containing aggregate-level data on service and individual-level data on long-stay (six and over weeks) residents (Burton *et al.*, 2022). It is worth noting that the SCHC is not a mandatory data submission with a maximum of 81 per cent of care homes returning data in the study period, authors also note the lack of nationally available primary care data as a limitation of the current landscape.

The range of data sources each study has linked to is included in Supplementary Table S2. Most have linked to health related datasets, hospital attendance or admissions, primary care consultations and prescriptions. Cannings-John *et al.* linked to COVID-19 PCR test data for the primary outcome of confirmed COVID-19 infection in domiciliary care workers (Cannings-John *et al.*, 2023). Mortality data were also accessed across a number of studies (Tingay *et al.*, 2015; Hollinghurst *et al.*, 2020; Henderson *et al.*, 2021; Burton *et al.*, 2022; Hollinghurst *et al.*, 2022; Cannings-John *et al.*, 2023).

The most varied data sources in the studies included were in the PhD thesis by [Shand \(2020\)](#) which linked not only to health data (including mental health) but also to benefits, housing and community services ([Shand, 2020](#)). This was at a borough level (Barking and Dagenham), with linkage undertaken for the purpose of the study. Individuals had an option to opt out of data sharing and a data sharing agreement was in place between the borough and the CCG. Fuzzy logic was applied when NHS Numbers were missing from records and matching was conducted using name, date of birth and postcode.

The two resource profiles identified are summarised here, as whilst not including primary research, these two articles provide insights in to the potential of the linked adult social care data. Firstly, [Lewer *et al.* \(2018\)](#) describe a local dataset for the population of Kent and Medway which includes individual-level data from Kent County Council on Care package type and Client category type, extracted from the SWIFT system ([Lewer *et al.*, 2018](#)). Linkage for 94 per cent of the records was using NHS Number. Datasets available to link to include community health services, mental health, out of hours, primary and secondary health care. One of its key strengths is the linkage to primary care data, one of ‘the richest sources of clinical information’ as well as the linkage to other health care services, not available via national data linkage platforms except in Wales. Authors acknowledge that the population and service utilisation of this population may not be generalisable to other regions and countries.

[Towers *et al.* \(2023\)](#) describe a pilot of a prototype minimum dataset of care home record data that can be linked to health and social care data ([Towers *et al.*, 2023](#)). Sixty care homes are taking part in this pilot that already have digital care software to record residents’ care. The information on the residents includes health and care needs, quality of life, vaccinations, adverse events (such as falls) as well as workforce and care home characteristics. Participating homes will receive aggregated summaries of their own data, benchmarked against other aggregated data. The aim is to develop a tool that can be used across all four nations.

Discussion

This review provides evidence of the current picture of adult social care research that uses administrative data from social care services linked to further data of interest, with twelve primary research studies and two resource profiles identified. The research presented in this review is focused largely on older adults ($n=8$) despite the search strategy and eligibility encompassing adults of all ages, workforce staff and unpaid carers. This confirms the suspicion that very little research to date has used linked adult social care data to explore unpaid carers or working

age people with care needs. Indeed, for the latter, one study actively excluded this wider population from their research (Towers *et al.*, 2023). There were only three studies that included adults of all ages and therefore by default included those of working age in receipt of social care services. Burton *et al.* (2022) and Grimm *et al.* (2022) reported that those with learning disability represented 16.5 per cent and 1.2 per cent of the cohort population (respectively), with no research questions specifically looking at this population of individuals.

Informal care plays a crucial role in supporting the adult social care population, with estimates from the 2021 Census indicating that 5 million unpaid carers are providing £162 per year of informal care across England and Wales, a substantial saving in local authority-funded social care (Petrillo and Bennett, 2023). Only one of the studies included unpaid carers with that information stored in primary care records and not in the adult social care administrative data (but was linked to adult social care data therefore included on that basis). During screening and full-text review, we noted a number of articles that included unpaid carers but were based on self-report in either the census or in primary care records, but and not as part of care and support packages from local authorities, and therefore not included. Similarly, it was noted by a number of authors that self-funders are not included in these administrative datasets and indeed are unlikely to be included in the future. This means that the adult social care population will always be underestimated without self-funders included in the data bringing unknowns such as whether someone funded their own care before accessing local authority-funded care or were newly eligible for support (Bardsley *et al.*, 2012; Grimm *et al.*, 2022; Nakubulwa *et al.*, 2022).

Where information was provided on the linkage, and where this had not already been established, authors overwhelmingly referred to slow, complex processes to enable the linkage. This included ethical approvals (Evans *et al.*, 2019) and data sharing agreements (Lewis *et al.*, 2010; Burton *et al.*, 2022), followed by often manual matching of records when NHS Number was not already associated with a record (Tingay *et al.*, 2015). The impact of subpar linkage for Bardsley *et al.* (2012) meant an underestimation of overlap between the health and social care sector (Bardsley *et al.*, 2012). Burton *et al.* (2022) detailed structural and practical challenges of undertaking data linkage for their project leading to long timelines to deliver the project (Autumn 2015 to publication in 2022) (Burton *et al.*, 2022). The use of already established trusted research environments did appear to negate some of these challenges, for example, the SAIL Databank in Swansea, Wales (Ford *et al.*, 2009; Jones *et al.*, 2019) was used for all of the Welsh-based studies and a similar data warehouse model was used for the Scottish studies (Pavis and Morris, 2015).

In light of the limited availability of datasets available for research alongside challenges in linkage, many studies opted for local rather than

national level data. Authors supported the idea of nationally collated standardised data at an individual level, suggesting benefits such as enabling researchers to track individuals who moved to another local authority within the country and producing generalisable findings (Bardsley *et al.*, 2012; Steventon and Roberts, 2012; Grimm *et al.*, 2022).

A similar scoping review of children's social care linked administrative data in the UK identified twenty-five articles for inclusion from an initial list of 1550 (Allnatt *et al.*, 2022a). Standardised data have been collected by local authorities and returned to national governments since the early 1990s for children's social care (Mc Grath-Lone *et al.*, 2016). Experiences and challenges of linkage were echoed in both scoping reviews as well as data quality and data recording across the local authorities. In contrast to that review, the datasets linked for the adult social care population for the majority were health-related whereas as only four of the twenty-five children's social care papers linked to health datasets. This likely reflects the differences in these populations and support required by local authorities in particular for older adults. The dominance of health-related linkages in adult social care risks accentuates the medicalisation of older age and highlights the need for a range of datasets that capture more diverse and holistic social care factors. For children's social care datasets, education data were most regularly linked to, enabled often through already established linkages (Jay *et al.*, 2019) again reflecting these different needs for children vs adults. Employment and welfare could be more relevant and meaningful for some of the adult social care population.

The ability to link primary care records for this population is of particular importance given the high rates of co-morbidities for older adults and the importance for assessing frailty for these individuals. Hollinghurst *et al.* (2022) assigned an electronic frailty index score using variables recorded in the primary care data, demonstrating the power of linkage in particular to primary care records. Although only one study was ultimately included that linked to care home data (Burton *et al.*, 2022), the promise of individual-level care home data in the future and linkage at a postcode level to identify admissions and residence in a care home is encouraging. Other datasets with future potential for linkage include the Adult Social Care Workforce Data Set in England, which includes workforce employment and training data at social care organisation level.

Strengths and limitations

We applied systematic review principles to this scoping review, developing a thorough search strategy, having two people screen and then review full-texts, and extracted data into an agreed template. Grey literature and reference lists were also reviewed. The criteria for datasets needing to be adult social care service or workforce data did restrict the

availability of studies that included unpaid carers. As mentioned, information on unpaid care does not seem to have been reported routinely in social care records.

Conclusion

Adults social care administrative routine data can be a rich source of information and through linkage can expand its utility and impact of research. There are few national resources available, linking to other data, and this is a real gap.

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Supplementary material

[Supplementary material](#) is available at *British Journal of Social Work* online.

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