Factors influencing effective data sharing between health care and social care regarding the care of older people: a qualitative evidence synthesis

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Scientific summary

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Scientific summary

Background

Globally, and in the UK, the population is ageing, with implications for health and social care services. Older people are more likely to have multiple or long-term conditions. Care provision for patients with multiple conditions can be complex, requiring co-ordination and integration between health and social care organisations and professionals. The potential benefits of integrated care, which include improved clinical outcomes, patient and carer experiences, and cost-effectiveness, are recognised in the UK in policy and practice for example, the development of Integrated Care Systems, which are supported by the NHS Long Term Plan.

However, barriers exist to integrated working: information technology and data-sharing have consistently been identified as issues. Data-sharing has interorganisational and interprofessional aspects, with specific conditions (e.g. policy, legal and ethical frameworks) needing to be in place to allow individual professionals to share information about service users. Professionals can share data in a number of ways, including shared electronic records systems and multidisciplinary team meetings, which are often complementary. Different professional groups differ in terms of their information needs (e.g. content and format of data) as well as their usage and contribution to the data-sharing system (e.g. collecting and updating information). Further factors affecting data-sharing between professionals include their professional relationships, the usability of electronic systems, and concerns around confidentiality.

The provision of information systems that support data-sharing across organisational and professional boundaries is a long-standing policy objective in the UK. Further understanding is needed on how to ensure effective data-sharing.

Objectives

We aimed to answer the research question: what are the factors perceived as influencing effective data-sharing between health care and social care, including private and voluntary sector organisations, regarding the care of older people?

Our specific research objectives were to:

- identify factors that could potentially influence effective data-sharing between healthcare and social care **organisations**, including those in the private and voluntary sectors, relating to the care of older people
- identify factors that could potentially influence effective data-sharing between **care professionals** who work in health care, social care or other organisations providing care for older people
- identify factors that affect the successful adoption or implementation of initiatives to improve data-sharing between health care and social care organisations and/or care professionals

Methods

Our protocol was registered on PROSPERO (CRD42023416621). We searched MEDLINE, Social Policy and Practice, EMBASE, HMIC (Ovid), ProQuest Dissertations and Theses Global (ProQuest), CINAHL (EBSCO*host*), Web of Science (Clarivate) and Google Scholar for qualitative and mixed-methods studies, in March 2023. Relevant websites were also searched and citation-chasing completed on included studies.

Included studies focused on data-sharing, defined as the transfer of information between healthcare and social care organisations or care professionals, regarding an individual patient (e.g. an electronic patient record). The service user population of focus was older people, as defined by the study, while study participants could be health and social care professionals as well as older people and their carers. Studies were included where they focused on factors perceived as influencing effective data-sharing relating to the care of older people, or influencing the successful adoption or implementation of initiatives to improve data-sharing. We included only studies conducted in the UK.

A large number of studies met the inclusion criteria (*n* = 49). This is a problem in qualitative evidence syntheses because if the volume of qualitative data is too large to allow familiarity with the content, this can reduce the quality of the synthesis. Purposive sampling was used to select a final set of studies containing the most relevant information for analysis and ensure the broadest possible range of settings and populations were included. The process of obtaining this sample involved mapping the included studies, for example, recording their aims and the richness of the data in the study. Richness of data was defined as 'thin' where studies had very little, and often only descriptive, qualitative data relating to our review objectives, while 'rich' studies had a large amount and depth of qualitative data relating to our objectives. All data 'rich' studies were included in the review (*n* = 24).

For the included studies, data were extracted on their characteristics, for example, aims, method of data-sharing and main findings relating to data-sharing. Studies were analysed using framework synthesis, with an initial framework based on sociotechnical systems theory (which emphasises the importance of social factors, e.g. working practices, alongside technical factors in the successful implementation of new technologies). Quality appraisal was conducted using the Wallace criteria. Stakeholder and public and patient involvement groups were consulted throughout the project.

Results

The bibliographic database and website searches, along with citation-chasing, retrieved 13,404 records. Following deduplication, we double-screened 8165 records, identifying 192 reports for assessment at full text. Of these, 49 studies met our inclusion criteria and, after purposive sampling, 24 were included in the analysis. The primary reasons for exclusion were that the population of focus was not older people or that the topic was not data-sharing.

Of the 24 studies included in the review, most studies scored highly on the quality appraisal checklist, although some questions were consistently answered 'no', for example regarding author reflexivity. Just over half (*n* = 13) of the studies used a mixed-methods approach, and 11 were solely qualitative, with interviews being the most commonly used method of data collection.

Studies tended to focus on populations of older people with complex needs such as people with multimorbidity; some were conducted in specific populations, including people with dementia (two studies), people with Parkinson's disease (one study), hip fracture and stroke patients (one study), people at end of life (four studies) or people living in care homes (two studies). In 11 studies, study participants were health and social care professionals; 11 studies included patients and carers as well as professionals; in 1 study, participants were not clearly reported, while 1 study was conducted solely with older people.

A range of professionals were involved in data-sharing. From the social care sector, these were most likely to be social workers or care home staff, while nurses and doctors were the professionals most involved in data-sharing from the healthcare sector, although a greater range of healthcare professionals shared data, including paramedics, physiotherapists and occupational therapists, among others. Data were shared in multiple ways; some studies focused on one method of data-sharing, such as shared records systems (two studies), paper-based records (two studies) or multidisciplinary team meetings (one study). Other methods included e-mails, telephone calls and face-to-face conversations, with multiple (but not all) methods of data-sharing used in most studies.

Findings were organised into four main themes derived from the sociotechnical framework we used as a starting point: *Goals* (the specific purpose and context of data-sharing), *Relationships* (between individual professionals as well as organisations), *Processes and procedures* (intra- and interorganisational), and *Technology and infrastructure* (the methods and means of data-sharing).

Some of the factors affecting data-sharing identified in the themes were more general and occurred across settings and populations (e.g. interprofessional relationships); others were context-specific and easier to analyse when studies were grouped together around the specific purpose and context of data-sharing (e.g. patients' and carers' perceptions of electronic record systems used in palliative care). Within *Goals*, we found five such purposes of data-sharing: joint (health and social care) assessment (eight studies); integrated case management (eight studies); transitions from hospital to home (seven studies); for residents of care homes (six studies); and for palliative care (six studies). Studies were grouped into five clusters based on these purposes of data-sharing (which had some overlap). Studies were analysed in these clusters throughout the review, cutting across the other three high-level themes: *Relationships*, *Processes and procedures*, and *Technology and infrastructure*.

In terms of factors that affected data-sharing which occurred in all clusters of studies:

In *Relationships*, interprofessional relationships were important in supporting data-sharing. Certain methods of data-sharing, such as multidisciplinary team meetings, offered opportunities for professionals to build trust and respect and gain knowledge of each other's roles. Professional prejudice and hierarchies, leading to mistrust and misunderstanding, hindered data-sharing.

Within *Processes and procedures*, data-sharing was supported by the wider policy and service delivery context, for example, the provision of integrated care, which could be used by organisations to build a shared vision of care. This created a context for formal agreements, for example, detailing mechanisms for data-sharing or the use of standardised assessment tools, which could then be translated into working practices. Failure to support new working practices, for example by not providing the necessary resources, led to a disconnect between policy ambitions and day-to-day reality.

There were two main factors that influenced effective data-sharing in the theme of *Technology and infrastructure*. Firstly, it was important that technology was considered as a tool that could be used to support data-sharing, for recording and retrieving data, and often in addition to other methods of data-sharing, rather than a solution to all problems with data-sharing. This required consideration of how professionals interacted with the technology and with each other. Secondly, awareness of the care delivery system as a whole among professionals, in terms of the information needs of others and their use of information, also supported data-sharing.

There were specific factors influencing data-sharing in each of the five clusters of studies. In the joint assessment and integrated case management clusters, cultural differences between organisations and professionals, and occupational boundaries, were often an issue. Data-sharing in the context of patients transitioning from hospital to community was affected by the different priority and value placed on this process by hospital and community-based professionals. Professional status was a particular problem in the care home cluster, with care home staff often provided with little information by healthcare professionals, while the lack of legal frameworks to enable data-sharing was a key factor in the area of palliative care.

There were some limitations to the review. While purposive sampling was necessary, it may mean some data were missed. Data-sharing was usually discussed in the context of wider initiatives in the included studies, for example integrated care, which meant the information provided on data-sharing specifically was often limited. There were also some gaps in the evidence. For example, the COVID-19 pandemic had significant impacts on ways of working but the qualitative studies in this review did not reveal whether they are enabling or preventing data-sharing as no studies were found of data-sharing during or after the pandemic. We also found few studies which investigated patient or carer experiences of data-sharing.

We identified the need for further research in several areas. Technology is advancing rapidly, facilitating innovations which may support more effective data-sharing. Research is needed to ensure the successful use of different types of technology; for example, our findings suggest that the use of electronic records may be particularly beneficial in providing palliative care. Evaluating the implementation of electronic systems in these contexts could inform the effective implementation of electronic systems more widely. As noted above, new technologies and ways of working have been adopted as a result of the COVID-19 pandemic, and research is needed to ensure that they are achieving their intended outcomes. Additionally, further research should explore patient experience, and social and demographic factors among professionals that might influence effective data-sharing, to prevent digital exclusion.

Conclusions

Our findings have implications for initiatives to improve data-sharing between health and social care. They indicate that no single factor or change is enough to facilitate effective data-sharing, instead suggesting that a combination of approaches is needed, alongside consideration of the whole care management and delivery process (i.e. a systems perspective). While agreements between organisations on governance relating to specific aspects of data-sharing were necessary, organisational support for relationship-building was more important, which has implications for policy regarding effective data-sharing. In terms of practice, initiatives to improve data-sharing need to ensure that professionals are able to share information in multiple ways, and that these methods of data-sharing allow relationship-building and the development of knowledge and understanding, whether of different professional roles or of processes and ways of working. Additionally, our findings suggest that it is important to consult staff when designing new initiatives.

Overall, the review indicates the importance of building interprofessional relationships, wider support for data-sharing at a policy and organisational level, and ensuring that professionals have access to multiple methods of data-sharing.

Study registration

The protocol was registered on PROSPERO CRD42023416621.

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