Improving data-sharing between health and social care

Protocol for a synthesis of qualitative evidence

Version 4

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PROSPERO registration number	

Table of Contents

1 Background

This review of research and other evidence has been commissioned by the NIHR HSDR programme on behalf of Health & Care Research Wales. It is primarily intended to inform the development and operation of health, social care and other care and support services for older people in Wales.

The overall topic and area of uncertainty that the review focuses on was identified as a priority within a James Lind Alliance (JLA) research prioritisation project (ref: Project Update, Health & Care Research Wales, Feb 2021). The overarching topic of the research prioritisation exercise was: *How can we best provide sustainable care and support to help older people live happier and more fulfilling lives?* The third of the 'Top 10' research priorities, prioritised by care workers, carers and older people, was:

> How can social care and health services, including the voluntary sector, work together more effectively to meet the needs of older people?

This was viewed as a priority in order to ensure:

1. care workers and health professionals know about all the care and support available in their area and can signpost older people and their families to services
2. assessments in health services lead to the provision of appropriate social care and someone takes responsibility to check that all needs are met
3. funding and resources are distributed across all sectors to avoid voluntary services being forced to provide social care "on the cheap"
4. social care workers are members of multi-disciplinary teams caring for older people in hospital
5. voluntary sector services are valued and respected for the essential care they provide
6. health professionals and care workers coordinate their care successfully to provide the best possible care for the older person
7. health and social care services communicate with each other, refer older people to each other's services and provide seamless care

Of these more specific goals of working together more effectively, goal 1 – about signposting to appropriate services - relates to the topic of a realist review that has been conducted by the HSDR Evidence Synthesis Centre at ScHARR, University of Sheffield (ref: PROSPERO 2022 CRD42022348200). Goals 6 and 7 both relate to improving communication between services in an area and the people who work in them.

Interestingly, the researchers involved in the priority-setting project “felt there is a large existing evidence base (and several evidence syntheses) on integrated working but it is hard for practitioners to make sense of it. The key question is how to mobilise existing knowledge about integrated working … not just amongst health and Local Authorities, but also social care providers”. Overall, the project therefore concluded that:

> “A new evidence synthesis is also needed on the mechanisms / interventions that local areas implement to improve communication between health services, social care services and social care providers.”

The planned review (evidence synthesis) described in this protocol aims to address one aspect of this need. Initial scoping searches found a wide-ranging body of evidence regarding communication and data-sharing between health and social care, including strategies aimed at organisations and individual professionals. Consultation with key stakeholders was used to focus the review on a specific aspect of communication: data-sharing.

1.1 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 are to:

- Identify factors that may influence effective data-sharing **between health care and social care organisations**, including private and voluntary sector organisations, relating to the care of older people.
- Identify factors that may 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.

2 Methods

2.1 Identification of studies

2.1.1 Searches

The bibliographic database search strategies will be developed using MEDLINE (via Ovid) by an information specialist (AB) in consultation with the review team. The search strategy will use both controlled vocabulary when available and relevant (e.g. MeSH in MEDLINE) and free-text searching. Search terms will be partly derived from search strategies of pre-identified systematic reviews on improving communication in health and social care as well as the titles, abstracts, keywords and controlled vocabulary from relevant papers already identified from the extensive scoping already undertaken. Relevant qualitative search filters may be used. Initially we will search only for UK-based studies, as detailed in the inclusion criteria. Results will be limited to English and Welsh language studies.

We plan to search the following bibliographic databases:

- CINAHL Complete (EBSCOhost)
- Embase (Ovid)
- MEDLINE (Ovid)
- Web of Science Core Collection (Clarivate)
- Scopus (Elsevier)
- PEDro
- OTseeker
- HMIC (Ovid)
- SPP (Ovid)
- Proquest Dissertations and Theses Global (if we're including theses)

A provisional search strategy for the MEDLINE (Ovid) bibliographic database can be seen in Appendix A.

Other search techniques detailed below will also be utilised

Website searching either by browsing publication lists or using site search functionality. The websites will include:

- Age UK (https://www.ageuk.org.uk/) and Age Cymru (https://www.ageuk.org.uk/cymru/)
- Older People's Commissioner for Wales (https://olderpeople.wales/)
- NHS Professionals (https://www.nhsprofessionals.nhs.uk/)
- British Association of Social Workers (https://www.basw.co.uk/)

- Royal College of General Practitioners (https://www.rcgp.org.uk/)
- BMA (https://www.bma.org.uk/)
- Health Foundation (https://www.health.org.uk/)
- Nuffield Trust (https://www.nuffieldtrust.org.uk/)
- NHS Confederation (https://www.nhsconfed.org/)
- Care Quality Commission (https://www.cqc.org.uk/)
- Care Inspectorate Wales (https://www.careinspectorate.wales/)
- Social Care Wales (https://socialcare.wales/)
- NHS Wales (https://www.nhs.wales/)
- NHS England (https://www.england.nhs.uk/)
- THIS Institute (https://www.thisinstitute.cam.ac.uk/)
- Association of Directors of Adult Social Services ()
- ADSS Cymru (https://www.adss.cymru/)
- Public Health Wales (https://phw.nhs.wales/)
- IMPACT Centre (https://impact.bham.ac.uk/)
- Centre for Care (https://centreforcare.ac.uk/)
- Skills for Care (https://www.skillsforcare.org.uk/Home.aspx)

Google searches will be undertaken using domain limits (eg wales.gov) when relevant

Expert consultation from the other team members and Health & Care Research Wales.

Google scholar searches using publish or perish

Citation chasing (both forwards and backwards) on included papers from database searching

2.1.2 Inclusion and exclusion criteria

Below we detail the inclusion and exclusion criteria which will be applied to the studies identified through the search strategy.

Table 1. Inclusion and exclusion criteria

	Include	**Exclude**
Population	Older people, as defined by individual studies. We will include studies of populations where it is reasonable to assume that the focus is on older people (e.g. people with dementia, multi-morbidities, people in residential care homes). Studies will be included if data-sharing relates to care or services for the above population. If the study focused on a mixed population, will include it if the results for older people are reported separately.	Studies focusing on other age groups or not reporting the results for older people separately.
Study participants	Health and social care professionals, volunteers, older people, and their families and carers.	Focusing on professionals who are sharing data within a single type of organisation, e.g. within primary and secondary healthcare.
Topic	Data-sharing, defined as: • Information held by an organisation about an individual patient or client (e.g. an electronic patient record or hand-written notes), • Which is transferred or made available between organisations or care professionals belonging to different organisations, where this is across the health care and social care boundary.	Studies not focusing on data-sharing, or investigating data-sharing within: • the same organisation, or • between different NHS/healthcare organisations e.g. between primary and secondary care, or • between different social care organisations e.g. between social workers and care home staff. Informal data-sharing e.g. conversational sharing of knowledge about patients or their care. Sharing of aggregated and anonymised data.

	Include	**Exclude**
Study focus	Description or analysis of factors perceived as influencing effective data-sharing relating to the care of older people OR Description or analysis of factors perceived as influencing the successful adoption or implementation of initiatives to improve data-sharing.	All other outcomes.
Study design	Qualitative studies or mixed methods studies with a qualitative component designed to identify, explore and/or understand factors influencing effective data-sharing *or* the implementation of data-sharing improvement initiatives.	Other study designs. Relevant systematic reviews will be excluded from the review but will be used to identify additional titles and will be listed in an appendix.
Context	Studies focusing on data-sharing between UK care organisations and care professionals will be considered first. If necessary (e.g. only a small number of relevant studies identified), this criterion will be expanded to include studies conducted in other countries with similar health and social care systems. This is to ensure that the results from the review are relevant to Health & Care Research Wales who commissioned this work.	Non-UK studies unless only a small number of UK studies have been identified. The decision on whether non-UK studies need to be included to complement the UK-based evidence will be made through discussion with the stakeholders. If there are specific gaps in the UK evidence, we will conduct focused searches for relevant non-UK studies.
Publication type	Only studies reported in English or Welsh will be included. If the number of hits exceeds our capacity, we will restrict the inclusion to studies published in the most relevant time period, defined after discussion with our stakeholder groups. Both journal articles and grey literature (e.g. evaluation reports) will be included, but we will exclude conference	Studies not reported in English or Welsh.

	Include	**Exclude**
	abstracts or similarly short publications which do not provide sufficient information on the methods and results of the study.	

2.1.3 Process for applying inclusion criteria

Once the search results have been obtained, all reviewers will independently apply the inclusion and exclusion criteria to a representative sample of citations (e.g. n=100). Decisions will be compared and discussed in a group meeting to ensure consistent application of criteria. This will allow us to clarify the inclusion and exclusion criteria, and refine their definitions where necessary, enabling more consistent reviewer interpretation and application of the criteria.

After the initial calibration exercise has been completed, two reviewers will independently apply the inclusion and exclusion criteria to the title and abstract of each identified citation. We will obtain the full text of papers where either reviewer judges it to meet the inclusion criteria. Two reviewers will assess the full text of each record independently for inclusion, with disagreements settled through discussion with a third reviewer. The study selection process will be detailed using a PRISMA-style flowchart, with a reason reported for exclusion of each record assessed at full text (1).

2.2 Data extraction

We will extract data: 1) on the characteristics of the included studies (e.g. study reference, aim, methods, type of patient/service user, types of organisation/professionals/care settings, types of data or information being transferred, and findings) and 2) data on specific themes identified during the analysis (passages from the papers associated with the identified themes, including participants' accounts and the author's interpretations). To capture correctly the characteristics of the included studies, we will develop and pilot a data extraction form. The form will be based on templates developed by the National Institute for Health and Clinical Excellence (NICE) and summarise contextual and methodological information as identified above (2, 3). After any refinements are made to the form, one reviewer will perform data extraction. Their data will be checked by a second reviewer, with disagreements being settled through discussion and, if necessary, involvement of a third reviewer. Since the extraction of data related to specific themes is part of the data analysis, we detail this in the Data analysis and presentation section below. The full texts of all included studies will be uploaded into NVivo v12 and all data extraction tasks will be managed using this software.

2.3 Study quality assessment strategy

The methodological strength and limitations of the included studies will be assessed using the Wallace criteria for qualitative studies (4), as adapted by Gwernan-Jones et al. (5). The criteria are prompts which cover a range of domains, including theoretical perspective, data analysis, and ethics, so can be used to assess any qualitative research methodology. Further adaptations will be made if necessary, as studies included in the review may come from a range of disciplines and use differing approaches (6).

Quality assessment will be performed by one reviewer and checked by a second, with disagreements settled by discussion and, if required, a third reviewer.

Studies will not be excluded based on quality. However, the methodological quality of the included studies and the quality of reporting will be considered in the interpretation of results (7, 8). If time and data permits, the overall confidence in the individual findings of the review will be assessed using the GRADE-CERqual tool and presented in a Summary of Qualitative Findings table created using the related ISoQ tool (9).

2.4 Data analysis and presentation

Framework analysis is a systematic method of analysing primary qualitative data (10); this method has been further developed for application in systematic reviews, where it is known as framework synthesis (11). It offers a highly structured approach to data analysis and can be used to map and compare the concepts under study, to identify associations between themes (11, 12).

Conducting framework synthesis involves five distinct stages (8):

- familiarisation with the topic;
- development of a framework;
- indexing, where studies are screened and data extracted using the initial framework;
- charting, where themes are derived from data in the studies; and
- mapping and interpretation.

In the initial stages of the synthesis, we will construct an initial framework to analyse the data (11). This will involve identifying research detailing relevant theories and conceptual models (in conjunction with searching for studies for inclusion in the review) as well as consulting with stakeholders (as detailed in section 3).

After identifying and screening studies as detailed above (section 2.1), we will move to the indexing and charting stages of the synthesis. We will code data from included studies against the initial framework and conduct thematic analysis of the data, using the same principles as for primary qualitative data, but applied to the data (defined in section 2.2) in the included papers (8). An iterative approach to data analysis will be taken (2), with new themes generated to capture relevant data not covered by the original framework, and constant comparison of themes across studies (8). The initial framework will serve as a starting point for organising and coding data, but will be developed and changed to accommodate new data and evolving understanding of the phenomenon under study. Coding of included studies will be shared between reviewers, with coding of each study check by a second reviewer, and discussion of data and themes within the team (13).

Finally, we will map and interpret the synthesis. We will compare the final framework, developed using the iterative process described above, to the original framework, recognising additional themes identified from the data, and examining relationships between themes (13). We will map the themes in the form of a chart to aid interpretation (11).

The Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) will be used when reporting the methods and results of the review. This will ensure that all relevant information on the conduct of the review is included, enabling understanding of the development of the synthesis (14). We have used the NIHR-INCLUDE guidelines (15) to reflect on Equality, Diversity and Inclusion (EDI) whilst designing the protocol. The review focuses specifically on older people, with age being a PROGRESS-Plus characteristic that has been identified as being associated with discrimination; implications for addressing health inequalities raised by the synthesis will be considered in the final report (16, 17). We will also aim to capture and reflect upon any exclusion criteria related to PROGRESS-Plus characteristics in included studies e.g. older old (>80 years), language or cognitive impairment.

3 Stakeholder and patient/public involvement

The focus of this review – data-sharing between social and health care organisations and professionals in relation to the services they provide to older people – is naturally fraught with tensions and controversies. This is evidenced by the long history of local and national initiatives seeking to improve collaboration between health and social care organisations. The results from the current review are intended to be of value to and impact on the lives and/or professional practices of various stakeholder groups, including older people and their carers, health and social care professionals, voluntary organisations, healthcare commissioners, social care commissioners, and policy makers.

As commissioners of the research, Health and Care Research Wales are a key stakeholder but to ensure we fully understand the complexity of the topic and consider different perspectives and interests, we plan to consult a Patient and Public Involvement Advisory Group (PPIAG) and a Professional Stakeholders Advisory Group (PSAG).

The PPIAG will include representatives of the target population – older people and their families and carers. Members of the group will be recruited through relevant contacts in Wales and England following advice and support from the ARC South West Peninsula Patient and Public Engagement Group (PenPEG) (https://arc-swp.nihr.ac.uk/patient-public-involvement-engagement/. We will aim to recruit at least 5 representatives of the target population, with different backgrounds and experiences.

The PSAG will include representatives of health and social care organisations (e.g. social workers, care workers, doctors, nurses, managers, commissioners) focusing on those operating in Wales. Members of the group will be recruited through relevant contacts in Wales. We will aim to recruit at least 6 stakeholders – including at least three healthcare and three social care representatives – with different professional backgrounds and experiences.

We will also seek to involve academic researchers with relevant experience in evaluating programmes or synthesising research evidence relating to the improvement of data-sharing between organisations.

The two advisory groups will meet (separately, most likely online via MS-Teams or Zoom) twice during the lifespan of the project to discuss progress and provide input to the following:

- An understanding of data-sharing between health and social care organisations in Wales and how the review could provide impact.
- The framework for analysis and results of the review.
- Peer review of the final report /Plain English summary.

- Involvement in the dissemination of results.

4 Dissemination plans

The dissemination plan will be finalised after discussion with the two advisory groups. The key findings of the review will be disseminated according to the following:

Aim: To provide stakeholders with evidence-based insights and actionable findings to improve current data-sharing practices.

Audience: The findings will be of interest to the stakeholder groups listed above who can use them to:

- Discuss and challenge current practice (e.g. older people and their carers).
- Suggest improvements to current practice (e.g. health and social care workers and voluntary sector).
- Design new interventions that take account of the factors identified in the review.

Products and channels:

- An (Open Access) Health and Social Care Delivery Research report in the NIHR Journals Library that describes in full the methods and results of the project.
- An Evidence Briefing (4-page summary as downloadable pdf).
- A blog or podcast.
- A publication in a relevant peer-reviewed journal identified as being relevant to stakeholders for this review.

Outputs will also be disseminated and promoted via the Exeter HSDR Evidence Synthesis Centre webpage and social media.

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Appendix 1 Search strategy

Database: Ovid MEDLINE(R) ALL <1946 to March 07, 2023>

UK terms

1 exp United Kingdom/ (388603)

2 ("national health service" or nhs).ti,ab,in. (260214)

3 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. (48240)

4 (gb or "g.b." or britain or (british not "british columbia") or uk or "u.k." or united kingdom* or (england not "new england") or northern ireland* or nothern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in. (2405575)

5 (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in. (1708882)

6 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in. (68641)

7 (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in. (251789)

8 (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in. (32940)

9 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 (3018117)

10 (exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp great britain/ or europe/) (3295923)

11 9 not 10 (2858092)

Qual terms

12 (("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (discussion* or questionnaire*)).tw,kf. (36908)

13 (focus group* or qualitative or ethnograph* or fieldwork or field work or key informant* or interview*).tw,kw. (667263)

14 Interviews as Topic/ (66807)

15 Focus Groups/ (35344)

16 Narration/ (9993)

17 exp Qualitative Research/ (80131)

18 12 or 13 or 14 or 15 or 16 or 17 (718664)

Data sharing terms

19 ((share* or sharing or integrat*) adj2 (data or organisat* or organizat*)).tw. (26495)

20 (integrat* adj2 (care* or health*)).tw. (27399)

21 ((interprofession* or inter profession* or organisat* or organizat* or interagency* or agenc*) adj2 (communicat* or share* or sharing or integrat*)).tw. (4668)

22 ((data or digital*) adj2 (link* or system* or access or information* or exchange*)).tw. (86093)

23 interdisciplinary communication/ (18127)

24 *"Delivery of Health Care, Integrated"/ (10678)

25 *interprofessional relations/ (22423)

26 *interdisciplinary communication/ (6687)

27 (electronic* adj2 record*).tw. (57094)

28 (patient* adj2 record*).tw. (64397)

29 (share* or sharing or integrat* or access*).tw. (1659487)

30 (((electronic* adj2 record*) or (patient* adj2 record*)) adj2 (share* or sharing or integrat* or access*)).tw. (1995)

31 (information adj2 (share or sharing)).tw. (8576)

32 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 30 or 31 (192839)

33 11 and 18 and 32 (3109)

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