Exploring Literature on Data Governance in the Healthcare of Older Persons: A Scoping Review

Angely Garcia, Ayra Mae Sierra Balingbing, Yves Yalung Palad

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Abstract

Background: Health data is growing rapidly and the processing of such data is evolving. Research on data governance in older persons' healthcare is unexplored, providing little guidance for practice and future studies.

Objective: This scoping review aimed to synthesize available information on data governance in the context of older persons' health based on evidence from literature.

Methods: The study followed the methodological framework of Arksey and O'Malley and PRISMA extension for scoping reviews. Online databases namely PubMed, Cochrane, Ovid, ACM, IEEE Xplore, and Google Scholar were searched by two independent reviewers for studies on older persons' health data governance published from January 2000 to April 2024. The independent reviewers performed the search, screening, data extraction, and review of full text articles. A third reviewer made the final decision for unresolved discrepancies between the first two reviewers. The framework by the WHO Pan American Health Organization, a high-level framework for planning and implementing data governance in public health, was utilized in the data extraction and analysis. Descriptive statistics were employed, and a descriptive approach was used to summarize the results of the scoping review.

Results: A total of 9,847 titles were identified and 57 articles were included. Of these, 35 (61.4%) focused on technology, 19 (33.3%) on processes, and 3 (5.3%) on people. Data controller, processor, researchers, data subject/patient (including family/relatives), and relevant organizations are involved in older persons data governance. Data governance frameworks are designed and implemented by reviewing the current evidence, involving the stakeholders from planning to implementation and defining their roles, obligations, accountabilities, and the system, implementing specific processes, and testing and monitoring. Processes such as collection of older persons' health data, aggregating these data to inform the assessment, diagnosis, and care management, and implementing such processes to address certain health issues, as well as the use of innovative approaches contribute to the improvement of older persons' health.

Conclusions: The review underscores the importance of the involvement of relevant stakeholders and the use of various innovative tools and approaches in governing data related to the health of older persons. Meanwhile, research specifically addressing data governance for older persons' health conditions is limited. To enhance health outcomes for older persons, effective data governance is essential, alongside further research on relevant policies and practices. Clinical Trial: Not applicable

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Conclusion: The review underscores the importance of the involvement of relevant stakeholders and the use of various innovative tools and approaches in governing data related to the health of older persons. Meanwhile, research specifically addressing data governance for older persons' health conditions is limited. To enhance health outcomes for older persons, effective data governance is essential, alongside further research on relevant policies and practices.

Keywords: older persons; health; data governance; scoping review

Introduction

Data governance is a management discipline and an emerging data management approach in healthcare. It is defined within the context of information technology as specifying the framework for decision rights and accountabilities to vitalize desirable behavior in the use of data [1]. Data governance highlights the responsibilities of those with authority in the organization [2], internal and external stakeholders [3], such as data stewards [4], civic society, public bodies [5], professional bodies [6], and the individuals who contributed their data [4], in managing data through its life cycle to generate quality information that can inform decision-making. Data life cycle begins with the capture or collection to the processing, use, storage, and disposal of data [7].

Data governance is also important in health systems as it is considered by many organizations as a promising method of maintaining health data [8]. Health data is considered an important asset to improve health through its utility in public health, epidemiology, and health informatics [9]. Governance of such data allows health organizations to successfully manage, protect, maintain, and use data to generate information that improves healthcare quality, health outcomes, and health system performance [10].

Real-time generation and efficiency in obtaining knowledge are possible when data governance principles are applied in healthcare [3]. In contrast, the absence of data governance could lead to failure in decision-making and effectively addressing the individual needs of the public sector [11]. Literature underscores the impact of data governance on a nation's healthcare system, and the need to collect the right data, effectively process them to generate quality information for evaluating the health system and identify where and when it is not functioning well [12]. Available evidence calls for the need to establish, streamline, and institutionalize a strong and comprehensive data governance process [5,13-19].

Data governance is essential in digital transformation initiatives of organizations as it improves data quality and accuracy and facilitates real-time data exchange [20]. One of the principles of the global health sector's digital transformation is accelerating progress toward inclusive digital health with emphasis on the most vulnerable populations [15]. These vulnerable populations include the older persons. The potential of data governance in the field of elderly care has been highlighted by the World Economic Forum by presenting a new approach to data governance [21]. It emphasized that the combination of caregiver skills, for example, with the older persons' data such as their specific care needs, can result in better and more precisely tailored care for older persons.

The state of research on data governance in the healthcare of older persons is unexplored locally and internationally. This leaves little guidance for its application in practice and for future research on the topic. Thus, this scoping review aimed to map out the available literature on data governance in the context of older persons' health. Specifically, this review sought to answer the following questions: who is involved in the planning and implementation of data governance *(people),* how are data governance frameworks designed and implemented, what are the governance processes that lead to the improvement of older persons' health *(process)*, and what tools and technologies are used to effectively govern data *(technology)*?

Methods

Study design and framework

This scoping review followed the methodological framework of Arksey and O'Malley, 2005 [22] and Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) extension for scoping reviews [23]. The review questions were informed by the data governance framework in public health by PAHO, a high-level framework for planning, implementing, and continuously improving data governance [10]. The framework highlights the involvement of three components: *people*, *processes*, and *technology*. The *people* component includes establishing decision-making structures (i.e., both the executive decision-making and technical bodies), defining roles and responsibilities of those involved in the management of data throughout its lifecycle, communicating these roles and responsibilities, data-related decisions, policies, and processes, and ensuring transparency on adherence to standards. *Processes* include managing data assets, enabling processes and standard operating procedures, and establishing processes for policy management and ensuring standards. The *technology* component pertains to identifying and implementing tools and technology required to manage data such as hardware and software, ensuring quality, availability, and security of information systems, and ensuring performance of the tools [10].

Aside from the framework for planning and implementing data governance, the data governance functions throughout the data lifecycle also guided this scoping review. Data governance should address and include defining accountabilities, prioritizing investment requirements, establishing policies, implementing processes, setting standards, managing risks, and monitoring performance related to data throughout its lifecycle. The data lifecycle are as follows; data collection, data aggregation, data quality assurance and monitoring, data storage, data protection, data access, use, and disclosure, and data retention and destruction [10].

Sources of information

Six (6) databases namely PubMed, Cochrane, Ovid, IEEE Xplore, Association for Computing Machinery (ACM), and Google Scholar were searched. Pubmed, Ovid, and Cochrane contained a vast collection of health literature. IEEE Xplore and ACM digital libraries contain resource materials from the fields of electrical engineering, information technology, computer science, and electronics which capture the technology-related aspect of this review. Google Scholar indexes the full text or metadata of scholarly literature and contains a wide variety of disciplines and sources.

Search strategy

The strategy was developed in consultation with an academic librarian and the search terms used were: "data governance", "health data governance", "older person", "older people", "older adult", "elderly", "senior citizen", and "aged". Boolean operators were used to filter search results (see Supplementary material 1. Search terms used by database).

This review also included evidence from non-research sources [24] such as reports, projects, and economy papers from Google Scholar. Moreover, experts in data governance, eHealth, and geriatrics were consulted to explore additional literature sources. The experts were identified through the existing networks of the investigators and organizations relevant to digital health. Searching the reference list of the identified data governance literature was also conducted.

All literature searched through the online databases, digital libraries, consultation with experts, and reference listing were uploaded in a shared Google Drive folder accessible only to the reviewers using their official university email addresses. The titles were encoded using Google Sheets to identify and remove duplicates.

Selection process

Considering that data governance was introduced in 2000 and literature on the topic started to be published around the same time [1,2,25], the search was filtered by publication dates between 1 January 2000 and 22 April 2024. The articles that meet the following criteria were included: 1.) the topic is related to data governance including *people*, *processes*, or *technology*, 2.) the topic is relevant to older persons' healthcare, 3.) peer-reviewed publications, reports, policies, programs, policy briefs, and 4.) in the English language. Resources that were not related to data governance and older persons' health, conference abstracts, and published in languages other than English were excluded.

Following the eligibility criteria above, two reviewers (APG & AMSB) independently searched databases, screened articles for eligibility, reviewed the full texts, and extracted data from the included studies (see Figure 1). If the reviewers are unable to screen articles based on the title alone, abstract screening was done to check whether the articles are related to health, data governance, and older persons. Initial data extraction from the abstracts was done to document the topic they covered using a data extraction form.

The reviewers independently documented the search yields and listed the titles obtained per online database using Google Sheets. The search yields of each reviewer per online database were compared as a form of initial validation. To ensure consistency among the reviewers, the procedures from searching to data extraction were pilot tested using 10 randomly selected samples. Reviewers proceeded with the next phases only upon reaching 75% agreement [24].

For each phase of the review, the reasons for exclusion were documented and the reviewers settled discrepancies by discussing them throughout the selection process (Figure 1). The reviewers met online and conferred about the discrepancies, which led to an amendment of the eligibility criteria. Based on the initial assessment of the abstracts and available full texts, there were various articles with mixed populations as their study samples (e.g., 18 years and above). Considering the focus of this review, the reviewers decided to only include articles with older persons explicitly stated in their titles and/or abstracts or representing more than 50% of the study sample. Meetings between the reviewers were conducted to discuss which of the articles will be included in the review.

Data extraction

Once the list of included studies was finalized, the two reviewers independently extracted the relevant information using an extraction tool in Google Sheets. Information such as authors, citation, publication year, type of publication, research design, setting of care, population, data governance function and component, and outcomes of the study and the technological intervention, among others, were extracted for further analysis. The reviewers conducted regular meetings to discuss and reconcile differences in the extracted data. Any disagreements that remained unresolved were discussed with a third reviewer (YYP) to arrive at a consensus. The third reviewer made the final decision for the unresolved disagreements between the first two reviewers.

Data management and analysis

The search results and study selection process are documented in this scoping review report and presented using a PRISMA flow diagram (Figure 1). All data were documented in a Google Sheets document and exported into an Excel file after the entire process ended. For the unstructured texts in the data extraction form, a qualitative content analysis was conducted to describe how data governance is planned and implemented in the care of older persons. The data were coded according to the framework components involved namely *person*, *processes*,

and *technology* and data governance functions. A descriptive approach was used to summarize the result of the scoping review. Numerical or categorical data were presented using counts and proportions. Tables and a figure were used to present the extracted data for each extraction category.

Ethics clearance

The study was monitored and classified as exempt from ethics review (UPMREB 2023-0864-EX) by the University of the Philippines Manila Research Ethics Board.

Results

A total of 9,847 titles were identified from six databases, consultation with three experts, and reference listing (Figure 1). Duplicates and all articles not related to older persons, health, and data governance, and those with mixed populations were removed during the screening phase, leaving a total of 259 articles assessed for eligibility. Of these articles, 202 were removed due to the unavailability of full texts, non-English language, and lack of specific data governance components. A total of 57 (22%) papers met the criteria for inclusion in the synthesis.
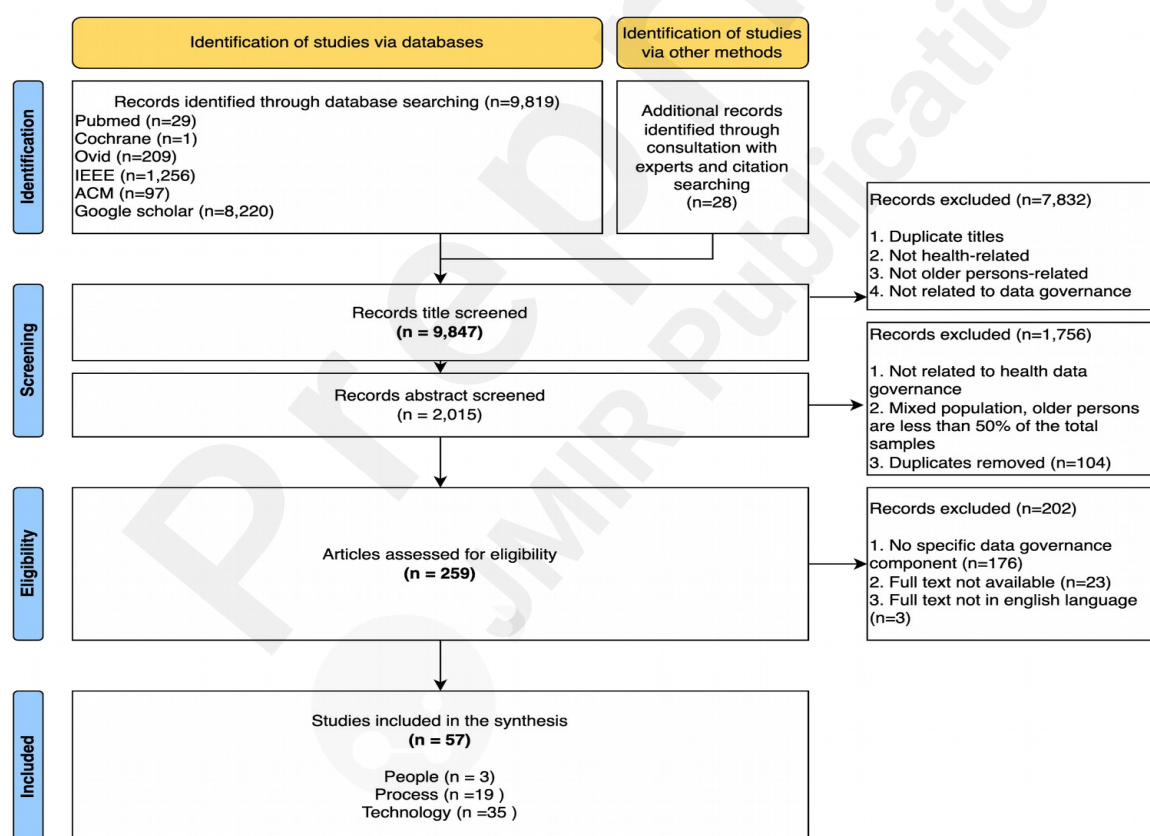
Figure 1. PRISMA diagram

Description of Included Studies

The included studies were published between 2003 to 2024; 56.1% of these were published in the year 2020 onwards. Majority (56.1%) of the included studies were from the IEEE digital library. Most (82.5%) were journal articles, followed by conference proceedings (12.3%). These conference proceedings were peer-reviewed full papers from IEEE and ACM (Table 1).

Table 1. Profile of included studies

Description	Included studies	
	f	%
N of cases	57	100.0
Data sources		
IEEE	32	56.1
Google scholar	15	26.3
ACM	4	7.0
PubMed	4	7.0
Ovid	2	3.5
Expert consultation	0	0.0
Publication year		
2000-2009	4	7.0
2010-2019	21	36.8
2020 and onwards	32	56.1
Publication type		
Journal article	47	82.5
Conference proceeding	7	12.3
Thesis	1	1.8
Review	1	1.8
Economy paper	1	1.8
Study design		
Observational	21	36.8
Experimental	17	29.8
Technology development	15	26.3
Randomized controlled trial	2	3.5
Review (e.g., systematic review, scoping review)	3	5.3
Not specified	16	28.1
Study settings		
Home	11	19.3
Multiple settings	9	15.8
Hospital	5	8.8
Long-term care setting	5	8.8
Community	4	7.0
Others: research lab/special facility for experiment, University, office	4	7.0
Not specified	19	33.3
Geographic coverage		

Europe	12	21.1
Asia	6	10.5
Australia and Oceania	3	5.3
North America	2	3.5
Multi-country/continent sites	6	10.5
Not specified	28	49.1
Age of older persons in study sample		
Specified (age covered/mean/range)	38	66.7
Minimum age		18
Maximum age		104
Not specified	19	33.3
Sample size		
Specified	39	68.4
Minimum sample size		1
Maximum sample size (data sets)		591,726
Not specified	18	31.6

In terms of study design, 36.8% were observational followed by 29.8% classified as experimental studies. These experimental studies are subdivided into two groups, namely: technology development and randomized controlled trials. About 30% of the studies did not specify their design.

The studies were conducted mostly in home settings (15.8%), followed by those conducted in multiple settings of care such as home and hospital, community and hospital, hospital and long-term care facilities. More than 30% of the included studies did not specify their study setting. In terms of geographic coverage, most were conducted in Europe followed by Asia and those with multi-country sites. There were no included studies that covered the following continents: Africa, Middle East, and South America (Table 1).

Sixty-seven percent (67%) of the included studies provided information about the study population particularly, the age group, mean age, or age range they covered. Although 33.3% did not indicate the specific age of their study population, the technology or the data governance component being relevant to older persons was explicitly stated in the title, abstract, and full text. Due to the variation of available information on age and unavailability of other information, the overall mean age cannot be computed.

About 70% of the included studies specified the sample size. A study had 1 older person sample which was about a novel cloud-based framework for the elderly healthcare services [26]. The largest sample size among the included studies was 591,726 electronic health records of primary care patients aged 65 years and above [27].

Data governance components and functions

A majority (61.4%) of the included studies were largely related to *technology*, tools and technology, in particular (Table 2). This is followed by *processes* (33.3%) which are mostly

centered on enabling processes and standard operating procedures. Only 3 articles were focused on *people* particularly roles and responsibilities and decision-making structure.

Table 2. Data governance components and functions of included studies

	Included studies	
Data governance	f	%
N of studies	57	100.0
Data governance component		
People	3	5.3
None	54	94.7
Roles and responsibilities	2	3.5
Decision-making structure	1	1.8
Communication and transparency	-	-
Process	19	33.3
None	37	64.9
Enabling processes and SOPs	11	19.3
Data asset management	8	15.8
Standards and policy management	-	-
Technology	35	61.4
None	22	38.6
Tools and technology	33	57.9
Tools and technology and performance	2	3.5
Availability and security	-	-
Performance	-	-
Data governance function		
Implement processes	47	82.5
Monitor performance	4	7.0
Define accountability	3	5.3
Set standards	2	3.5
Manage risks	1	1.8
Prioritize investment	-	-
Establish policy	-	-

Interestingly, there were no included studies on communication and transparency under the *people* component, standards and policy management in the *process* component, availability and security, and performance alone in the *technology* component (Table 2).

Table 2 also showed that the data governance function of the included studies mostly focused on implementing processes while only a few covered monitoring performances [27-30], defining accountability [31-33], setting standards [34,35], and managing risks [36].

Designing and implementing data governance

The identified actors involved in designing and implementing data governance related to the health of older persons include data controllers, processors, and subjects. Specific data controllers identified in this review include a hospital [32], researchers [33], and a steering committee [37]. The data subjects were patients [32], persons with dementia [33], nursing home residents [37], friends or relatives [32], legally authorized representatives [33], and hospital staff [32]. The data processors were a platform service provider [32], research team members [33], and privacy, scientific expert, and data access committees [37].

All included studies on the *people* component of data governance highlighted the crucial roles of relevant stakeholders (e.g., controllers, processors, and subjects) in planning, designing, and implementing data governance [32,33,27]. Moreover, the composition, roles, and accountabilities of these stakeholders vary depending on the settings (e.g., hospital, research, nursing home).

A total of ten (10) articles provided information on how frameworks related to data governance of older persons' health data are designed and implemented [26,32,33,35,37-42]. Conceptual content analysis of the methods using the PAHO framework emphasized the involvement of relevant stakeholders, implementation of specific processes, conduct of literature review, demonstrating the feasibility or testing of the developed framework, and defining the roles and accountabilities of the actors/stakeholders (see Supplementary material 2. Summary of extracted entries from the included studies).

Data governance processes, tools, and outcomes

A total of 19 articles provided information on the specific processes or interventions relevant to older persons' health [26,30,34,35,38,39,41-53]. Majority focused on implementing processes pertaining to data collection, aggregation, and access, use, and disclosure. One study covered six data lifecycles, from data collection up to disclosure [43]. There were no articles that covered the process of defining accountability, managing risks, prioritizing investment, and establishing policy (Table 2).

Several tools and technologies were identified and used for data governance throughout the data lifecycle. A total of 35 articles provided information on the specific technologies relevant to older persons' health [27-29,36,40,54-82]. Most of the identified technologies focused on implementing processes while only a few were related to use of technology in monitoring performance, defining accountability, and managing risks. Furthermore, these technologies are mostly involved in data collection.

In implementing data governance processes, various tools and technologies are used in collecting data for the assessment and monitoring of health needs, assessment of fall risk and detection of fall, identification of mental health-related issues such as mild cognitive impairment (MCI), dementia, stress, loneliness, and depression, and improvement of lifestyle and health (see Supplementary material 2. Summary of extracted entries from the included studies).

In terms of specific outcomes of the *technology* component of data governance, a total of 34 articles provided information on these. Most of the outcomes were process-related such as efficient data access, quality control, communication and care support, recognition, detection, and prediction of various conditions, monitoring, and others (see Supplementary material 2.

Summary of extracted entries from the included studies).

Discussion

Principal results

This scoping review aimed to synthesize available information on how data governance is planned and implemented in the context of older persons' health based on evidence from literature. Specifically, it aimed to answer the following questions: who are involved in the planning and implementation of data governance *(people),* how are data governance frameworks designed and implemented, what are the governance processes that lead to the improvement of older persons' health *(process)*, and what tools and technologies are used to effectively govern data *(technology)?*

Findings show that available studies related to the health of older persons covered mostly data governance components related to *technology* and *process.* Moreover, data governance is designed and implemented by initially examining the current evidence and existing regulatory frameworks, involving all relevant stakeholders and defining their roles and accountabilities, implementing specific processes following the focused issue, and testing and monitoring the governance framework. Various data governance processes, tools, and technologies are utilized and contribute to the improvement of older persons' health. The use of these mostly leads to process outcomes.

This review emphasizes the involvement of stakeholders, particularly in technology development and testing process [40-41], sharing perspectives on digital transformation of public health services [39], and mapping of service users [42]. Moreover, the accountability of data controllers, processors, and subjects were outlined [32,33,37]. This underscores the data governance responsibilities of those with the authority in the organization [2] (data controller), the internal and external stakeholders (data processors and subjects) [3-6], and ultimately, the data subjects who contributed their data [4], in managing data through its lifecycle to inform decision making.

Limitations

This review only included literature on data governance relevant to older persons published from the past two decades and those peer-reviewed publications, reports, policies, programs, or policy briefs written in English language. Identified studies eligible for review but without full texts were excluded from the synthesis. Despite the efforts of the reviewers and consultant librarian in accessing the articles, 23 full texts were not retrieved. These articles were mostly from ACM and Google Scholar, published 2021 and beyond, include conference proceedings, and focused on the *technology* component of data governance.

Many included studies did not specify the study design, setting, geographic coverage, age of the study population, and sample size. It would be helpful if this information were available to provide a complete description of the state of data governance literature for older persons. Moreover, the assessment or appraisal of the included studies for methodological rigor was not performed as this review only aimed to describe information on data governance in the context of older persons' health.

Various processes and technologies aimed to contribute to the improvement of older persons' health based on their objectives and purpose were identified. However, since most of the included studies are related to technology and at their preclinical stage of technological development, limited information on the actual health outcomes of data governance specific to older persons was collected.

Comparison with Prior Work

Studies related to health information systems included in this review [27,60,79] also support data governance as an important player in the health system, a promising method of maintaining health data [8], and recognize its potential in the field of elderly care [83,84]. Various processes, tools, and innovative approaches in governing health data of older persons were explored in this review. Available evidence suggests that the use of these tools and technologies supports data governance, leading to positive health outcomes and better processes [27,31,61-63,68,75-77].

In terms of processes, findings in this review are consistent with Cave (2017) [85] where strategies for implementing data governance were explored through a qualitative case study. These strategies include structured oversight with committees and boards, obtaining stakeholder buy-in, and benchmarking and standardization. Benchmarking and standardization through review of current evidence and existing regulatory frameworks were identified to be important steps in planning and implementing data governance [32,33,35,38,39,42].

Strategies for effective and strategic communications and compliance with regulations were not adequately covered in this review due to the lack of studies on this topic. Communication and transparency as well as compliance with standards and policies should be considered in implementing data governance. This is to ensure the protection of people, promotion of health value, and prioritization of equity which are the key health data governance principles [86]. Moreover, although there were no articles that covered the processes of defining accountability and managing risks, these were discussed in the literature in terms of the role of persons involved in data governance and as integral components of designing and implementing data governance.

Various geriatric syndromes, such as falls and fall risk [54,55,65,69,71,73,74], MCI and dementia [33,42,53,64,66,75,82], frailty [29,80,], loneliness, social isolation, and depression [56,57] were the focus of the studies included in this review. However, there were no included studies related to other geriatric syndromes such as functional decline, incontinence, delirium, pressure ulcers, polypharmacy, malnutrition, sleep problems, and others. These geriatric syndromes are common health conditions among older persons [87-90], often having multifactorial causes, and may have a major impact on their quality of life and disability [90]. Data governance covering these conditions can also generate information on strategies to address the needs of older persons and provide quality care to improve their health and quality of life.

Only one article explicitly proposed a data governance framework specific for older persons which was published a decade ago [38]. The proposed framework was drawn from the Data Management Body of Knowledge (DMBoK) of the DAMA International, Inc. [2,91] and the work of Cleven and Worktman (2010) [92]. Dalhberg's (2014) [38] motive for proposing this specific governance framework was the fragmentation of older persons' data and the necessity to

consolidate this data to make it more useful. The article defined the types and sources of data that exist about older persons, and how these can be integrated into a comprehensive framework. It suggested defining the data categories, attributes, and sources of data first to improve data governance of older persons. There is no evidence that the framework has been validated. Hence, testing this framework is essential to determine its value in data governance for older persons.

The need for data governance in general [14] and in the care of older persons has been highlighted by the reviewed articles specifically on dementia research [42,53], healthcare applications for geriatric clinical care [49], and nursing homes for quality improvement [37]. New paradigms on the use of big data in dementia research and clinical care [42] as well as international dementia care mapping require data governance [53]. Likewise, the standardization of machine learning approaches tailored to healthcare applications is required to evaluate whether these applications improve clinical care for older persons [49]. In nursing homes, literature suggests the need for enhancing transparency, specifically in presenting understandable information to the residents and their representatives on which data will be used, how it will be used, and for what purposes [37].

Findings agree with other articles not included in this review such as the call for institutionalizing a strong and comprehensive data governance process [5,10,12-19,93-95], a national health data governance framework to ensure availability and use of personal health data for public interest [96], and data governance for learning health systems to reduce concerns about privacy and trust in the system [97,98]. The included studies were analyzed according to the data lifecycle, data governance function, and components they covered to identify research gaps. The *people* data governance component only covered data access, use, and disclosure. How people are involved, their roles and responsibilities, and communication and transparency during data collection, aggregation process, quality assurance, storage, data protection, retention, and destruction are lacking. In terms of the *process* component, limited studies were related to data quality, storage, and protection and none for defining accountability and managing risk. Meanwhile, no tools and *technology* were identified from the studies that covered data aggregation, data quality, data protection, and setting standards.

Studies on data governance in healthcare of older persons are largely focused on various forms of *technology* followed by *process*. The major research gap across all data governance components was the lack of included studies on data retention and destruction, prioritizing investments, and establishing policy (see Supplementary material 3. Research gaps on data governance in the healthcare of older people). Findings and gaps that were identified from this review inform future research directions and practices of older persons' health data governance.

Conclusions

This review highlighted the importance of benchmarking, involvement of relevant stakeholders, and the use of various innovative tools and approaches in governing data related to the health of older persons. However, studies that are explicitly centered on data governance of older persons' health data, their common health conditions, or other geriatric syndromes, are limited. Likewise, identified research gaps include the lack of studies on data retention and

destruction, establishment of policy, prioritizing investment, and communication and transparency.

Available studies on the health of older persons covered mostly *technology* and *process* data governance components. Only a few focused-on *people* which were identified to have crucial roles in designing governance frameworks, planning, and implementing data governance. In order to optimize the utility of data in improving the health and quality of life of older persons, a well-designed process that considers the essential data governance components, functions, and principles should be developed and implemented.

Recommendations
Effective governance of older persons' health data requires a multisectoral approach. Benchmarking, utilization of innovative tools and approaches, and collaboration between relevant stakeholders including policymakers, program planners, health facility administrators, healthcare providers, ICT and digital health experts, data privacy and legal experts, and ultimately, the older persons and their families are essential in designing and implementing data governance.

In establishing health data governance policies or incorporating them into the national standards, legislations, and organizational policies, the key governance principles, components, functions, and data lifecycle should be considered. In practice, health settings and personnel should ensure the involvement of the patients (including their families and relatives) in collecting and processing their data.

Further studies on the governance of data on common health conditions of older persons, health data retention schedules and destruction methods, and data governance policies and investments are recommended.

and offices.

Conflicts of Interest

The authors declare no potential conflicts of interest regarding the research, authorship, and publication of this article.

Abbreviations

ACM: Association for Computing Machinery
ICT: Information and communication technology
IEEE: Institute of Electrical and Electronics Engineers
PAHO: Pan American Health Organization
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses
WHO: World Health Organization

Multimedia Appendices

Supplementary material 1. Search terms used by database
Supplementary material 2. Summary of extracted entries from the included studies
Supplementary material 3. Research gaps on data governance in the healthcare of older people

Data availability statement

Supplemental materials containing further study data are submitted with this manuscript.

References

1. Weill P, Ross JW. IT governance: how top performers manage IT decision rights for superior results. Boston: Harvard Business School Press; 2004. ISBN:9781591392538
2. Data Administration Management Association. The DAMA guide to the data management body of knowledge: DAMA-DMBOK guide. First edition. Mosley M, Brackett M, Earley S, Henderson D, editors. Bradley Beach, NJ: Technics Publications, LLC; 2010. ISBN:9780977140084 9781935504023
3. Hovenga EJS, Grain H. Health data and data governance. Stud Health Technol Inform; 2013; (193):67-92. PMID:24018511
4. Rosenbaum S. Data Governance and Stewardship: Designing Data Stewardship Entities and Advancing Data Access. Health Serv Res; 2010 Oct;(45)5 Pt 2:1442-1455. PMID: 21054365
5. Micheli M, Ponti M, Craglia M, Berti Suman A. Emerging models of data governance in the age of datafication. Big Data & Society; 2020;(7)2. doi:10.1177/2053951720948087
6. Hovenga E, Grain H. Quality data, design, implementation, and governance. Roadmap to Successful Digital Health Ecosystems Elsevier; 2022; p. 209–237. doi:10.1016/B978-0-12-823413-6.00013-6 ISBN:9780128234136
7. Oachs PK, Watters A, American Health Information Management Association, editors. Health information management: concepts, principles, and practice Sixth edition. Chicago, Illinois: AHIMA, American Health Information Management Association; 2020. ISBN: 1584267259
8. Ngesimani NL, Ruhode E, Harpur P-A. Data governance in healthcare information systems: A systematic literature review. S Afr j inf manag; 2022 Aug 18;(24)1. doi: 10.4102/sajim.v24i1.1475
9. Dickens A. From Information to Valuable Asset: The Commercialization of Health Data as a

Human Rights Issue. Health Hum Rights, 2020 Dec;(22)2:67–69. PMID:33390695

10. Pan American Health Organization. Data Governance in Public Health. Digital Transformation Toolkit; 2022; Available from: https://iris.paho.org/handle/10665.2/56576

11. Benfeldt Nielsen O. A Comprehensive Review of Data Governance Literature. Selected Papers of the IRIS, Issue Nr 8 (2017); 2017 Dec 31; Available from: https://aisel.aisnet.org/iris2017/3

12. Hovenga EJS. Impact of data governance on a nation's healthcare system building blocks. Stud Health Technol Inform; 2013;(193):24–66. PMID:24018510

13. American Health Information Management Association (AHIMA). Healthcare Data Governance; 2022; Available from: https://www.ahima.org/media/pmcb0fr5/healthcare-data-governance-practice-brief-final.pdf

14. OECD. Recommendation of the Council on Health Data Governance, OECD/LEGAL/0433; 2025; Available from: https://legalinstruments.oecd.org/public/doc/348/348.en.pdf

15. Pan American Health Organization. From the Evolution of Information Systems for Health to the Digital Transformation of the Health Sector. IS4H Conference Report; 2021; Available from:
https://iris.paho.org/bitstream/handle/10665.2/53364/PAHOEIHIS210006_eng.pdf

16. Paparova D, Aanestad M, Vassilakopoulou P, Bahus MK. Data governance spaces: The case of a national digital service for personal health data. Information and Organization; 2023; (33)1:100451. doi: 10.1016/j.infoandorg.2023.100451

17. Zayas-Cabán T, Chaney KJ, Rucker DW. National health information technology priorities for research: A policy and development agenda. Journal of the American Medical Informatics Association; 2020 Apr 1;(27)4:652–657. doi: 10.1093/jamia/ocaa008

18. World Health Organization Regional Office for the Western Pacific (WHO WPRO). Meeting On Strengthening Health Information Systems For Sustainable Development Goals And UHC Monitoring In The Western Pacific Region; 2019; Available from: https://iris.who.int/handle/10665/325941?locale-attribute=fr&show=full

19. Williamson K, Nimegeer A, Lean M. Navigating data governance approvals to use routine health and social care data to evidence the hidden population with severe obesity: a case study from a clinical academic's perspective. Journal of Research in Nursing; 2022; (27)7:623–636. doi: 10.1177/17449871221122040

20. World Economic Forum. Good Data: Data Sharing, public trust and willingness; 2021; Available from: https://www.weforum.org/publications/good-data-sharing-data-and-fostering-public-trust-and-willingness

21. World Economic Forum. Why we need to leverage data for healthy ageing; 2021; Available from: https://www.weforum.org/agenda/2021/10/we-need-to-leverage-data-for-healthy-ageing/

22. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology; 2005;(8)1:19–32. doi: 10.1080/1364557032000119616

23. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, Moher D, Peters MDJ, Horsley T, Weeks L, Hempel S, Akl EA, Chang C, McGowan J, Stewart L, Hartling L, Aldcroft A, Wilson MG, Garritty C, Lewin S, Godfrey CM, Macdonald MT, Langlois EV, Soares-Weiser K, Moriarty J, Clifford T, Tunçalp Ö, Straus SE. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med; 2018 Oct 2;(169)7:467–473. doi: 10.7326/M18-0850.

24. Peters MDJ, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, McInerney P, Godfrey CM, Khalil H. Updated methodological guidance for the conduct of scoping reviews. JBI

Evidence Synthesis; 2020;(18)10:2119–2126. doi: 10.11124/JBIES-20-00167

25. Nooteboom B. Learning by Interaction: Absorptive Capacity, Cognitive Distance and Governance. Journal of Management & Governance; 2000 Mar 1;(4)1:69–92. doi: 10.1023/A:1009941416749

26. Liu Y, Zhang L, Yang Y, Zhou L, Ren L, Wang F, Liu R, Pang Z, Deen MJ. A Novel Cloud-Based Framework for the Elderly Healthcare Services Using Digital Twin. IEEE Access; 2019;(7):49088–49101. doi: 10.1109/ACCESS.2019.2909828

27. Joseph RM, Knaggs RD, Coupland CAC, Taylor A, Vinogradova Y, Butler D, Gerrard L, Waldram D, Iyen B, Akyea RK, Ashcroft DM, Avery AJ, Jack RH. Frequency and impact of medication reviews for people aged 65 years or above in UK primary care: an observational study using electronic health records. BMC Geriatr; 2023 Jul 14;(23)1:435. doi: 10.1186/s12877-023-04143-2

28. Pradhan A, Kuruganti U, Chester V. Biomechanical Parameters and Clinical Assessment Scores for Identifying Elderly Fallers Based on Balance and Dynamic Tasks. IEEE Access; 2020;(8):193532–193543. doi: 10.1109/ACCESS.2020.3033194

29. Papoutsi C, Poots A, Clements J, Wyrko Z, Offord N, Reed JE. Improving patient safety for older people in acute admissions: implementation of the Frailsafe checklist in 12 hospitals across the UK. Age and Ageing; 2018 Mar 1;(47)2:311–317. doi: 10.1093/ageing/afx194

30. Daniels H, Hollinghurst J, Fry R, Clegg A, Hillcoat-Nallétamby S, Nikolova S, Rodgers SE, Williams N, Akbari A. The Value of Routinely Collected Data in Evaluating Home Assessment and Modification Interventions to Prevent Falls in Older People: Systematic Literature Review. JMIR Aging; 2021 Apr 23;(4)2:e24728. doi: 10.2196/24728

31. Fang L, Wu Y, Wu C, Yu Y. A Nonintrusive Elderly Home Monitoring System. IEEE Internet Things J; 2021 Feb 15;(8)4:2603–2614. doi: 10.1109/JIOT.2020.3019270

32. Bernsmed K. Accountable Health Care Service Provisioning in the Cloud. 2014 IEEE/ACM 7th International Conference on Utility and Cloud Computing London, United Kingdom: IEEE; 2014; p. 902–907. doi: 10.1109/UCC.2014.147

33. Thorogood A, Mäki-Petäjä-Leinonen A, Brodaty H, Dalpé G, Gastmans C, Gauthier S, Gove D, Harding R, Knoppers BM, Rossor M, Bobrow M, Global Alliance for Genomics and Health, Ageing and Dementia Task Team. Consent recommendations for research and international data sharing involving persons with dementia. Alzheimer's & Dementia; 2018;(14)10:1334–1343. doi: 10.1016/j.jalz.2018.05.011

34. Kiefer R, Abid M, Steen J, Ardali MR, Amjadian E. A Catalog of Public Glaucoma Datasets for Machine Learning Applications: A detailed description and analysis of public glaucoma datasets available to machine learning engineers tackling glaucoma-related problems using retinal fundus images and OCT images. 2023 the 7th International Conference on Information System and Data Mining (ICISDM) Atlanta USA: ACM; 2023; p. 24–31. doi: 10.1145/3603765.3603779

35. Billis AS, Papageorgiou EI, Frantzidis CA, Tsatali MS, Tsolaki AC, Bamidis PD. A Decision-Support Framework for Promoting Independent Living and Ageing Well. IEEE J Biomed Health Inform; 2015;(19)1:199–209. doi: 10.1109/JBHI.2014.2336757

36. Chung-Chih Lin, Ping-Yeh Lin, Po-Kuan Lu, Guan-Yu Hsieh, Wei-Lun Lee, Ren-Guey Lee. A Healthcare Integration System for Disease Assessment and Safety Monitoring of Dementia Patients. IEEE Trans Inform Technol Biomed; 2008;(12)5:579–586. doi: 10.1109/TITB.2008.917914

37. Wieland-Jorna Y, Verheij RA, Francke AL, Tomassen M, Houtzager M, Joling KJ, Oosterveld-Vlug MG. Setting up a Governance Framework for Secondary Use of Routine Health Data in Nursing Homes: Development Study Using Qualitative Interviews. J Med Internet Res; 2023 Jan 25;(25):e38929. doi: 10.2196/38929

38. Dahlberg T. A framework for and issues in the management and governance of data on elderly citizens (ongoing res.). Proceedings of the 8th International Conference on Theory and Practice of Electronic Governance Guimaraes Portugal: ACM; 2014; p. 296–299. doi: 10.1145/2691195.2691295

39. Zhou S, Ni Z, Ogihara A, Wang X. Behavioral Patterns of Supply and Demand Sides of Health Services for the Elderly in Sustainable Digital Transformation: A Mixed Methods Study. IJERPH; 2022 Jul 5;(19)13:8221. doi: 10.3390/ijerph19138221

40. Zhang T, Sodhro AH, Luo Z, Zahid N, Nawaz MW, Pirbhulal S, Muzammal M. A Joint Deep Learning and Internet of Medical Things Driven Framework for Elderly Patients. IEEE Access; 2020;(8):75822–75832. doi: 10.1109/ACCESS.2020.2989143

41. Lin D, Yao C, Min W, Han Q, He K, Yang Z, Lei X, Guo B. A Novel Fall Detection Framework With Age Estimation Based on Cloud-Fog Computing Architecture. IEEE Sensors J; 2024 Feb 1;(24)3:3058–3071. doi: 10.1109/JSEN.2023.3334555

42. Khalid S. Towards Data Governance for International Dementia Care Mapping (DCM). A Study Proposing DCM Data Management through a Data Warehousing Approach; 2011 Nov 18; Available from: https://bradscholars.brad.ac.uk/handle/10454/5226 [accessed Jul 22, 2024]

43. Buleje I, Siu VS, Hsieh KY, Hinds N, Dang B, Bilal E, Nguyen T, Lee EE, Depp CA, Rogers JL. A Versatile Data Fabric for Advanced IoT-Based Remote Health Monitoring. 2023 IEEE International Conference on Digital Health (ICDH) Chicago, IL, USA: IEEE; 2023; p. 88–90. doi: 10.1109/ICDH60066.2023.00021

44. Béland F, Bergman H, Lebel P, Clarfield AM, Tousignant P, Contandriopoulos A-P, Dallaire L. A System of Integrated Care for Older Persons With Disabilities in Canada: Results From a Randomized Controlled Trial. The Journals of Gerontology: Series A; 2006 Apr 1; (61)4:367–373. doi: 10.1093/gerona/61.4.367

45. Greene BR, McManus K, Redmond SJ, Caulfield B, Quinn CC. Digital assessment of falls risk, frailty, and mobility impairment using wearable sensors. npj Digit Med; 2019 Dec 11; (2)1:125. doi: 10.1038/s41746-019-0204-z

46. Lin C-H, Wang F-C, Kuo T-Y, Huang P-W, Chen S-F, Fu L-C. Early Detection of Parkinson's Disease by Neural Network Models. IEEE Access; 2022;(10):19033–19044. doi: 10.1109/ACCESS.2022.3150774

47. Shulman MA, Wallace S, Gilbert A, Reilly JR, Kasza J, Myles PS. Predicting Death or Disability after Surgery in the Older Adult. Anesthesiology; 2023 Oct 1;(139)4:420–431. doi: 10.1097/ALN.0000000000004683

48. Kim J-Y, Liu N, Tan H-X, Chu C-H. Unobtrusive Monitoring to Detect Depression for Elderly With Chronic Illnesses. IEEE Sensors J; 2017 Sep 1;(17)17:5694–5704. doi: 10.1109/JSEN.2017.2729594

49. Choudhury A, Renjilian E, Asan O. Use of machine learning in geriatric clinical care for chronic diseases: a systematic literature review. JAMIA Open; 2020 Oct 1;(3)3:459–471. doi: 10.1093/jamiaopen/ooaa034

50. Elbattah M, Molloy O. Coupling Simulation with Machine Learning: A Hybrid Approach for Elderly Discharge Planning. Proceedings of the 2016 ACM SIGSIM Conference on Principles of Advanced Discrete Simulation Banff Alberta Canada: ACM; 2016; p. 47–56. doi: 10.1145/2901378.2901381

51. Hu X, Chu D, Li Z, Dai R, Cui Y, Zhou Z, An B, Han Y, Jiang C, Ding D. Coarse-to-Fine Activity Annotation and Recognition Algorithm for Solitary Older Adults. IEEE Access; 2020; (8):4051–4064. doi: 10.1109/ACCESS.2019.2962843

52. Subbe CP, Goulden N, Mawdsley K, Smith R. Anticipating care needs of patients after discharge from hospital: Frail and elderly patients without physiological abnormality on

day of admission are more likely to require social services input. European Journal of Internal Medicine; 2017;(45):74–77. doi: 10.1016/j.ejim.2017.09.029

53. Unleashing the Power of Big Data for Alzheimer's Disease and Dementia Research: Main Points of the OECD Expert Consultation on Unlocking Global Collaboration to Accelerate Innovation for Alzheimer's Disease and Dementia; 2014 Mar; Report No.: 233. doi: 10.1787/5jz73kvmvbwb-en

54. Lin K-C, Wai R-J. A Feasible Fall Evaluation System via Artificial Intelligence Gesture Detection of Gait and Balance for Sub-Healthy Community- Dwelling Older Adults in Taiwan. IEEE Access; 2021;(9):146404–146413. doi: 10.1109/ACCESS.2021.3123297

55. Taramasco C, Rodenas T, Martinez F, Fuentes P, Munoz R, Olivares R, De Albuquerque VHC, Demongeot J. A Novel Monitoring System for Fall Detection in Older People. IEEE Access; 2018;(6):43563–43574. doi: 10.1109/ACCESS.2018.2861331

56. Schutz N, Botros A, Hassen SB, Saner H, Buluschek P, Urwyler P, Pais B, Santschi V, Gatica-Perez D, Muri RM, Nef T. A Sensor-Driven Visit Detection System in Older Adults' Homes: Towards Digital Late-Life Depression Marker Extraction. IEEE J Biomed Health Inform; 2022;(26)4:1560–1569. doi: 10.1109/JBHI.2021.3114595

57. Austin J, Dodge HH, Riley T, Jacobs PG, Thielke S, Kaye J. A Smart-Home System to Unobtrusively and Continuously Assess Loneliness in Older Adults. IEEE J Transl Eng Health Med; 2016;(4):1–11. doi: 10.1109/JTEHM.2016.2579638

58. Rajamäki J, Gioulekas F, Rocha PAL, Garcia XDT, Ofem P, Tyni J. ALTAI Tool for Assessing AI-Based Technologies: Lessons Learned and Recommendations from SHAPES Pilots. Healthcare; 2023 May 17;(11)10:1454. doi: 10.3390/healthcare11101454

59. Najafi B, Aminian K, Paraschiv-Ionescu A, Loew F, Bula CJ, Robert P. Ambulatory system for human motion analysis using a kinematic sensor: monitoring of daily physical activity in the elderly. IEEE Trans Biomed Eng; 2003;(50)6:711–723. doi: 10.1109/TBME.2003.812189

60. Elhussein L, Jödicke AM, He Y, Delmestri A, Robinson DE, Strauss VY, Prieto-Alhambra D. Characterising complex health needs and the use of preventive therapies in the older population: a population-based cohort analysis of UK primary care and hospital linked data. BMC Geriatr; 2023 Jan 31;(23)1:58. doi: 10.1186/s12877-023-03770-z

61. Manh Do H, Sheng W, Harrington EE, Bishop AJ. Clinical Screening Interview Using a Social Robot for Geriatric Care. IEEE Trans Automat Sci Eng; 2021;(18)3:1229–1242. doi: 10.1109/TASE.2020.2999203

62. Spinsante S, Poli A, Mongay Batalla J, Krawiec P, Dobre C, Bǎjenaru L, Mavromoustakis CX, Costantinou CS, Molan G, Herghelegiu AM, Prada GI, Drǎghici R, González–Vélez H. Clinically-validated technologies for assisted living: The vINCI project. J Ambient Intell Human Comput; 2023;(14)3:2095–2116. doi: 10.1007/s12652-021-03419-y

63. Bajenaru L, Marinescu IA, Dobre C, Tomescu M, Herghelegiu AM. Clinically-validated technologies for older adults' quality of life self-management: vINCI ecosystem. 2022 14th International Conference on Electronics, Computers and Artificial Intelligence (ECAI) Ploiesti, Romania: IEEE; 2022; p. 1–6. doi: 10.1109/ECAI54874.2022.9847465

64. Delmastro F, Martino FD, Dolciotti C. Cognitive Training and Stress Detection in MCI Frail Older People Through Wearable Sensors and Machine Learning. IEEE Access; 2020;(8):65573–65590. doi: 10.1109/ACCESS.2020.2985301

65. Yao L, Sheng QZ, Li X, Gu T, Tan M, Wang X, Wang S, Ruan W. Compressive Representation for Device-Free Activity Recognition with Passive RFID Signal Strength. IEEE Trans on Mobile Comput; 2018 Feb 1;(17)2:293–306. doi: 10.1109/TMC.2017.2706282

66. Moreno PA, Hernando ME, Gomez EJ. Design and Technical Evaluation of an Enhanced Location-Awareness Service Enabler for Spatial Disorientation Management of Elderly

With Mild Cognitive Impairment. IEEE J Biomed Health Inform; 2015;(19)1:37–43. doi: 10.1109/JBHI.2014.2327638

67. Andrew N, Beare R, Ravipati T, Parker E, Snowdon D, Naude K, Srikanth V. Developing a linked electronic health record derived data platform to support research into healthy ageing. IJPDS; 2023 Jun 12;(8)1. doi: 10.23889/ijpds.v8i1.2129

68. Lin Y-H, Mao H-F, Lin KN, Tang YL, Yang C-L, Chou J-J. Development and Evaluation of a Computer Game Combining Physical and Cognitive Activities for the Elderly. IEEE Access; 2020;(8):216822–216834. doi: 10.1109/ACCESS.2020.3041017

69. McManus K, Greene BR, Ader LGM, Caulfield B. Development of Data-Driven Metrics for Balance Impairment and Fall Risk Assessment in Older Adults. IEEE Trans Biomed Eng; 2022;(69)7:2324–2332. doi: 10.1109/TBME.2022.3142617

70. Wu J, Chang L, Yu G. Effective Data Decision-Making and Transmission System Based on Mobile Health for Chronic Disease Management in the Elderly. IEEE Systems Journal; 2021;(15)4:5537–5548. doi: 10.1109/JSYST.2020.3024816

71. Chen T, Ding Z, Li B. Elderly Fall Detection Based on Improved YOLOv5s Network. IEEE Access; 2022;(10):91273–91282. doi: 10.1109/ACCESS.2022.3202293

72. Doyle J, Caprani N, Kealy A, Bond R, Komaba Y, Inomata A. Healthcare Professionals Views on Technology to Support Older Adults Transitioning from Hospital to Home. Proceedings of the 30th International BCS Human Computer Interaction Conference; 2016. doi: 10.14236/ewic/HCI2016.34

73. Ayena JC, Zaibi H, Otis MJ-D, Menelas B-AJ. Home-Based Risk of Falling Assessment Test Using a Closed-Loop Balance Model. IEEE Trans Neural Syst Rehabil Eng; 2016;(24)12:1351–1362. doi: 10.1109/TNSRE.2015.2508960

74. Muheidat F, Tawalbeh LA. In-Home Floor Based Sensor System-Smart Carpet- to Facilitate Healthy Aging in Place (AIP). IEEE Access; 2020;(8):178627–178638. doi: 10.1109/ACCESS.2020.3027535

75. Kim J, Cheon S, Lim J. IoT-Based Unobtrusive Physical Activity Monitoring System for Predicting Dementia. IEEE Access; 2022;(10):26078–26089. doi: 10.1109/ACCESS.2022.3156607

76. Yu L, Chan WM, Zhao Y, Tsui K-L. Personalized Health Monitoring System of Elderly Wellness at the Community Level in Hong Kong. IEEE Access; 2018;(6):35558–35567. doi: 10.1109/ACCESS.2018.2848936

77. Van Der Meer HG, Wouters H, Teichert M, Griens F, Pavlovic J, Pont LG, Taxis K. Feasibility, acceptability and potential effectiveness of an information technology-based, pharmacist-led intervention to prevent an increase in anticholinergic and sedative load among older community-dwelling individuals. Therapeutic Advances in Drug Safety; 2019;(10):204209861880588. doi: 10.1177/2042098618805881

78. Nath RK, Thapliyal H. Smart Wristband-Based Stress Detection Framework for Older Adults With Cortisol as Stress Biomarker. IEEE Trans Consumer Electron; 2021;(67)1:30–39. doi: 10.1109/TCE.2021.3057806

79. Lutomski JE, Baars MAE, Schalk BWM, Boter H, Buurman BM, Den Elzen WPJ, Jansen APD, Kempen GIJM, Steunenberg B, Steyerberg EW, Olde Rikkert MGM, Melis RJF, on behalf of TOPICS-MDS Consortium. The Development of the Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS): A Large-Scale Data Sharing Initiative. Bayer A, editor. PLoS ONE; 2013 Dec 4;(8)12:e81673. doi: 10.1371/journal.pone.0081673

80. Lewis ET, Williamson M, Lewis LP, Ní Chróinín D, Dent E, Ticehurst M, Peters R, Macniven R, Cardona M. The Feasibility of Deriving the Electronic Frailty Index from Australian General Practice Records. Clin Interv Aging; 2022;(17):1589–1598. PMID:36353269

81. Zherebtsov EA, Zharkikh EV, Loktionova YI, Zherebtsova AI, Sidorov VV, Rafailov EU,

Dunaev AV. Wireless Dynamic Light Scattering Sensors Detect Microvascular Changes Associated With Ageing and Diabetes. IEEE Trans Biomed Eng; 2023;(70)11:3073–3081. doi: 10.1109/TBME.2023.3275654

82. Lin C-C, Chiu M-J, Hsiao C-C, Lee R-G, Tsai Y-S. Wireless Health Care Service System for Elderly With Dementia. IEEE Trans Inform Technol Biomed; 2006;(10)4:696–704. doi: 10.1109/TITB.2006.874196

83. Garcia AP, De La Vega SF, Mercado SP. Health Information Systems for Older Persons in Select Government Tertiary Hospitals and Health Centers in the Philippines: Cross-sectional Study. J Med Internet Res; 2022 Feb 14;(24)2:e29541. doi: 10.2196/29541

84. World Health Organization. Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies; 2010; Available from: https://iris.who.int/handle/10665/258734

85. Cave A. Exploring Strategies for Implementing Data Governance Practices. Walden Dissertations and Doctoral Studies; 2017 Jan 1; Available from: https://scholarworks.waldenu.edu/dissertations/4206

86. Transform Health. Health Data Governance. Health Data Governance - Homepage; 2025; Available from: https://healthdatagovernance.org/

87. Aïdoud A, Gana W, Poitau F, Debacq C, Leroy V, Nkodo J, Poupin P, Angoulvant D, Fougère B. High Prevalence of Geriatric Conditions Among Older Adults With Cardiovascular Disease. JAHA; 2023 Jan 17;(12)2:e026850. doi: 10.1161/JAHA.122.026850

88. Gómez-Ramos JJ, González-Guerra M, Dávalos-Rodríguez IP, Pérez-Ruíz ME, Peña-Durán E, Marín-Medina A. Geriatric Syndromes and Their Relationship with Mortality in a Population of Mexican Older Adults Aged 65 and Over, Admitted to the Emergency Department of a Second-Level Care Hospital. Healthcare; 2024 Jun 8;(12)12:1166. doi: 10.3390/healthcare12121166

89. Wang L-Y, Hu Z, Chen H, Tang M, Hu X. Multiple geriatric syndromes in community-dwelling older adults in China. Sci Rep; 2024 Feb 12;(14)1:3504. doi: 10.1038/s41598-024-54254-y

90. Ward KT, Reuben DB, Schmader KE, Givens J. Comprehensive Geriatric Assessment; 2024 May 17; Available from: https://www.uptodate.com/contents/comprehensive-geriatric-assessment

91. Earley S, Data Management Association. The DAMA dictionary of data management. 2nd ed. Bradley Beach, NJ: Technics Publications; 2011. ISBN:9781935504139

92. Cleven A, Wortmann F. Uncovering Four Strategies to Approach Master Data Management. 2010 43rd Hawaii International Conference on System Sciences; 2010; p. 1–10. doi: 10.1109/HICSS.2010.488

93. A. Alampay E. Open Data Governance in the Time of the Pandemic. 14th International Conference on Theory and Practice of Electronic Governance Athens Greece: ACM; 2021; p. 455–462. doi: 10.1145/3494193.3494255

94. Koltay T. Data governance, data literacy and the management of data quality. IFLA Journal; 2016;(42)4:303–312. doi: 10.1177/0340035216672238

95. Delacroix S, Lawrence ND. Bottom-up data Trusts: disturbing the 'one size fits all' approach to data governance. International Data Privacy Law; 2019 Oct 1;ipz014. doi: 10.1093/idpl/ipz014

96. Yukhno A. Digital Transformation: Exploring big data Governance in Public Administration. Public Organiz Rev; 2024;(24)1:335–349. doi: 10.1007/s11115-022-00694-x

97. Platt JE, Raj M, Wienroth M. An Analysis of the Learning Health System in Its First Decade in Practice: Scoping Review. J Med Internet Res; 2020 Mar 19;(22)3:e17026. doi: 10.2196/17026

98. Zurynski Y, Smith CL, Vedovi A, Ellis LA, Knaggs G, Meulenbroeks I, Warwick M, Gul H, Pomare C, Braithwaite J. Mapping the Learning Health System: A Scoping Review of Current Evidence. In: NHRMC Partnership Centre for Health System Sustainability. Sydney: Australian Institute of Health Innovation; 2020. ISBN: 9781741384765

Supplementary material 1. Search terms used by database

Database	Search terms
Pubmed	("older person" OR "older people" OR "older adults" OR "senior citizens" OR "seniors" OR "elderly" OR "aged") AND ("data governance" OR "health data governance")
	(((("Abstract":"older person") OR ("Abstract":"older people") OR ("Abstract":"older adults") OR ("Abstract":"senior citizens") OR

IEEE Xplore	("Abstract":"seniors") OR ("Abstract":"elderly") OR ("Abstract":"aged") AND ("Abstract":"data governance") OR ("Abstract":"health data governance")))))
ACM	Fulltext:("older person" OR "older people" OR "older adults" OR "senior citizens" OR "seniors" OR "elderly" OR "aged") AND Fulltext:("data governance" OR "health data governance")
Cochrane	((("older person"):ab OR ("older people"):ab OR ("older adults"):ab OR ("senior citizens"):ab OR ("seniors"):ab OR ("elderly"):ab OR ("aged"):ab) AND (("data governance"):ab OR ("health data governance"):ab))
Ovid	(FullText:("older person" OR "older people" OR "older adults" OR "senior citizens" OR "seniors" OR "elderly" OR "aged") AND ("data governance" OR "health data governance"))
Google Scholar	("older person" OR "older people" OR "older adults" OR "senior citizens" OR "seniors" OR "elderly" OR "aged") AND ("data governance" OR "health data governance")

Supplementary material 2. Summary of extracted entries from the included studies [*see separate file*]

Supplementary material 3. Research gaps on data governance in the healthcare of older people

	Data governance component, f		
	People	Process	Technology
N of cases	3	19	35
Data life cycle			
Data collection	0		
		12 [26], [34], [38-39], [41],[43]*, [44-49]	29 [27-28], [31,36,40,55-66], [68-71], [73-76], [78-79], [81-82]
Data aggregation	0	5 [34-25], [43]*, [50-51]	0
Data quality	0	1 [43]*	0
Data storage	0	1 [43]*	1 [27]
Data protection	0	1 [43]*	0
Data access use, and disclosure	3 [32], [33], [37]	5 [43]*, [39], [81], [42-53]	5 [58], [67], [72], [77], [80]
Data retention and destruction	0	0	0
Data governance function			

Define accountability	2 [32], [33]	0	1 [31]
Prioritize investment	0	0	0
Establish policy	0	0	0
Implement processes	1 [37]	16 [26], [35], [39,41-53]	30 [54], [40], [55], [56-59], [60-73], [74-82]
Set standards	0	2 [34], [38]	0
Manage risks	0	0	[36]
Monitor performance	0	[30]	[27], [28], [29]

a. Multiple response (covered more than 1 data lifecycle);

a. [ ] Reference number

Supplementary Files

Figures

PRISMA diagram.