Data governance and management in health: a scoping review protocol

Fernanda Farinelli (a), Márcio Victorino (a), Amanda Damasceno de Souza (b), Yoris Linhares de Souza (c), Ana Luisa Ferreira de Lima Bonifácio (a), Jessica Caroline Dos Santos Brito (a), Cláudio Vaz Torres (d), Thiago Gomes Nascimento (e)

(a) Faculdade de Ciência da Informação, Universidade de Brasília (UnB), Brasília, Brazil
(b) Programa de Pós-graduação em Tecnologia da Informação e Comunicação e Gestão do Conhecimento (PPGTICGC), Universidade FUMEC, Belo Horizonte, MG, Brazil
(c) Programa de Pós-Graduação em Administração, Universidade de Brasília (UnB), Brasília, Brazil
(d) Instituto de Psicologia, Departamento Processos Psicológicos Básicos, Universidade de Brasília (UnB), Brasília, Brazil
(e) Programa de Pós-graduação Profissional em Administração Pública, Universidade de Brasília (UnB), Brasília, Brazil

Abstract

Health systems increasingly depend on reliable, interoperable, and secure data to support care, management, planning, and public policy. However, evidence on how Data Governance and Data Management are structured, implemented, and assessed in health organizations remains dispersed. This scoping review protocol describes the planned methods for mapping scientific and technical literature on Data Governance and Data Management in Health. The review will follow the Joanna Briggs Institute methodology and will be reported according to PRISMA-ScR. Searches will include scientific databases and grey literature sources. Study selection and data extraction will be conducted by at least two reviewers. The review is expected to identify models, practices, actors, barriers, benefits, and research gaps.

Key words: *data management; health information systems; scoping reviews as topic; information management; hospital information systems.*

Introduction

The digital changes of health systems have increased the volume, diversity, and strategic value of clinical, administrative, and institutional data. Health organizations depend on data to support care delivery, planning, regulation, surveillance, evaluation and decision-making. In this context, Data Governance and Data Management have become relevant fields for ensuring that data are available, reliable, secure, interoperable, and ethically used [1-3].

Data Governance refers to the structures, principles, policies, roles, responsibilities, and decision-making mechanisms that guide the use and management of data in organizations. Data Management concerns the planning, execution, and control of practices related to data throughout their life cycle [3-5]. Although these concepts are distinct, they are closely related: governance defines direction, responsibilities and rules, while management operationalizes these definitions through processes, standards, technologies, and monitoring mechanisms [3, 6, 7].

In the health sector, the need for effective Data Governance and Data Management is intensified by the sensitivity of health data, the coexistence of multiple systems, the demand for interoperability, and the growing importance of digital health strategies [1, 2]. Poor data governance may affect data quality, information security, privacy protection, service integration, and evidence-based decision-making. In Brazil, the expansion of digital health initiatives, including the National

Address for correspondence: Amanda Damasceno de Souza, Universidade FUMEC, R. Cobre, 200, Cruzeiro, Belo Horizonte, MG, 30310-150, Brazil. E-mail: amandasd81@gmail.com.

Health Data Network, has also reinforced the importance of data integration, interoperability, and institutional coordination in the health sector [8, 9].

Several frameworks, maturity models, and guidelines address Data Governance and Data Management, including DAMA-DMBOK, the Data Governance Institute framework, the Data Management Maturity Model, and international recommendations on health data governance [3-7, 10]. However, the literature remains dispersed regarding how these models and practices have been applied, assessed, and sustained in health organizations.

This protocol presents the methodological planning of a scoping review on Data Governance and Data Management in Health. A scoping review is appropriate because the topic is broad, interdisciplinary, and marked by conceptual and methodological diversity [11]. The proposed review will map the available evidence, describe how the subject has been addressed in different institutional contexts, and, in addition, will identify models, practices, actors, barriers, benefits, and research gaps.

Objective and review questions

The objective of this scoping review is to map and analyze scientific and technical literature on Data Governance and Data Management in Health, identifying models, frameworks, practices, instruments, institutional actors, assessment mechanisms, barriers, benefits and research gaps.

The main review question is: *How have Data Governance and Data Management been addressed and implemented by entities operating in the health context?*

The specific questions are: What models, frameworks, methodologies, instruments and implementation roadmaps have been used? What principles, policies, roles, responsibilities, processes and standards support Data Governance and Data Management in Health? What types of institutions and organizational contexts have been addressed? What indicators, assessment mechanisms or maturity models have been used? What barriers, benefits, gaps, and implementation factors are reported?

Methods and analysis

This scoping review will be conducted according to the Joanna Briggs Institute methodology for scoping reviews [11] and will be reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews, PRISMA-ScR [12]. The protocol is registered in the Open Science Framework, available at https://osf.io/m384a. Any methodological changes made after registration will be described and justified in the final review.

Study design

The methodological flow of the review is presented in *Figure 1*, and it is organized into six sequential stages. First, the search stage comprises the retrieval of records from scientific databases and grey literature sources. Second, reference management involves importing all retrieved records into Rayyan® [14] and removing duplicates. Third, screening consists of title and abstract assessment to identify potentially relevant records based on the eligibility criteria. Records clearly outside the scope of the review will be excluded. Records considered included, or potentially eligible

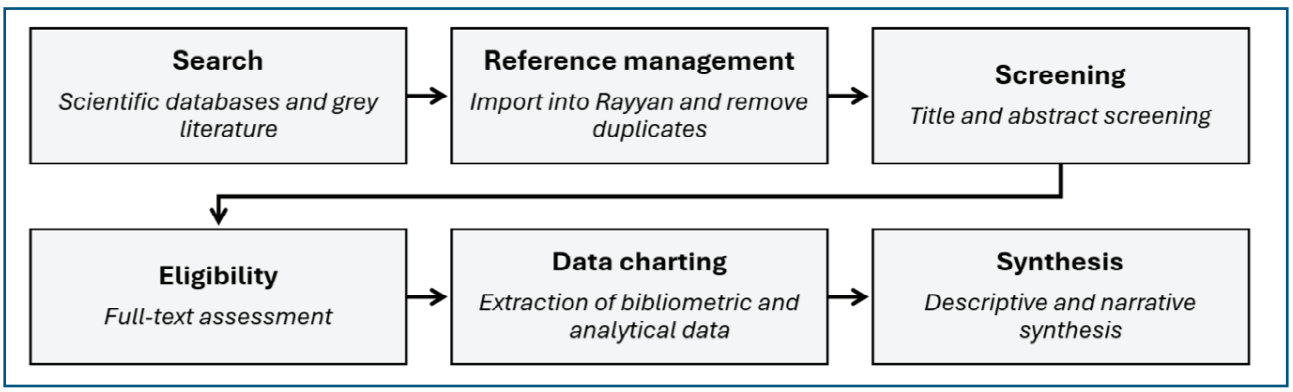

Figure 1. *Methodological flow of the scoping review.*

when there is insufficient information in the title and abstract, will proceed to full-text assessment. Fourth, the review will consist of full-text assessment of records retained after screening. At this stage, the eligibility criteria will be applied in greater detail to confirm final inclusion or exclusion. Reasons for exclusion at the full-text stage will be recorded and reported in the final review. Fifth, data charting will involve the extraction of bibliometric and analytical data from the included sources. Finally, synthesis will comprise descriptive analysis and narrative integration of the evidence mapped in the review.

Information sources and search strategy

The search strategy was developed according to the PRESS guideline [13] and the Joanna Briggs Institute recommendations for scoping reviews [11]. It was structured around three conceptual blocks derived from the Participants, Concept, and Context framework: health organizations, Data Governance, Data Management, and the health context. The general search logic combined terms related to these blocks using Boolean operators, as follows: ("data governance" OR "data management") AND (organization* OR institution* OR hospital* OR clinic* OR laborator* OR "health insurance" OR "health department*" OR "health agenc*" OR "Ministry of Health") AND (health OR healthcare OR "health care").

This generic strategy was adapted to the syntax, field tags, controlled vocabulary, truncation rules, and filtering options of each database and information source. Searches were conducted in PubMed/MEDLINE, the Brazilian Virtual Health Library (BVS) database, Web of Science, Scopus, SciELO, SPELL, Oasisbr, and BASE. Grey literature was searched in Google Scholar, the Brazilian Digital Library of Theses and Dissertations, the CAPES Theses and Dissertations Portal, the Brazilian Ministry of Health website, and the ARCA/FIOCRUZ Institutional Repository.

The searches identified a total of 5,445 records. After importing the records into Rayyan, 1,281 duplicates were detected and removed, leaving 4,164 records for title and abstract screening. The complete search strategies for each database and grey literature source are available in the Open Science Framework as supplementary material. Reference lists of included studies will also be examined to identify additional relevant sources.

Eligibility criteria

Eligibility criteria were defined using the Participants, Concept and Context (PCC) framework, as recommended for scoping reviews [11]. The Participants component includes institutional entities operating in the health sector, such as hospitals, clinics, laboratories, health insurance providers, health departments, health agencies, ministries of health and other public or private health organizations. The Concept component includes Data Governance and Data Management, considered separately or in an integrated way. The Context component is the health sector, including public, private, and mixed health systems, at local, regional, national or international levels.

The review will include journal articles, full conference papers, theses, dissertations, technical reports, guides, manuals, institutional documents, and relevant grey literature. Publications in English and Portuguese, published from 2000 onward, will be considered. Eligible sources must explicitly address policies, structures, roles, responsibilities, processes, standards, instruments, frameworks, maturity models, assessment mechanisms or implementation practices related to Data Governance and/or Data Management in Health. The main inclusion and exclusion criteria are summarized in Table 1. These criteria will guide both title and abstract screening and full-text assessment.

Screening and eligibility screening procedure

All records retained after duplicate removal will be screened in Rayyan® [14]. The selection process will be conducted in two stages: title and abstract screening, followed by full-text eligibility assessment. Both stages will be performed by pairs of reviewers, independently and blinded to each other's decisions.

In the first stage, titles and abstracts will be assessed in Rayyan® based on the eligibility criteria summarized in *Table 1*. Each reviewer will classify records as Include, Exclude, or Maybe. Records classified as Include or Maybe will be retained for full-text assessment. Records classified as Exclude, after comparison of reviewers' decisions and resolution of disagreements, will not proceed to the eligibility stage. When the information available in the title and abstract is insufficient to determine eligibility, the record will be classified as Maybe and retained for full-text assessment.

Element	Inclusion criteria	Exclusion criteria
Participants	Health institutions, hospitals, clinics, laboratories, health insurance providers, health departments, health agencies, ministries of health and other public or private health organizations.	Studies focused only on clinical, biomedical, epidemiological or laboratory analyses without an organizational or strategic approach to data.
Concept	Studies addressing Data Governance and/or Data Management, including policies, roles, responsibilities, processes, standards, frameworks, maturity models, instruments or assessment mechanisms.	Studies using "governance" or "data management" only generically, or focused only on software, algorithms or databases without institutional arrangements.
Context	Public, private or mixed health systems, at local, regional, national or international levels.	Studies outside the health context with no explicit comparison or adaptation to health organizations.
Types of evidence	Journal articles, full conference papers, theses, dissertations, technical reports, guides, manuals, institutional documents and grey literature.	Editorials, letters, interviews, opinion articles, comments, abstracts without full text and duplicates.
Limits	English and Portuguese; publications from 2000 onward.	Publications in other languages or before 2000.

Table 1. *Eligibility criteria based on participants, concept and context.*

After screening, the full-text files of records classified as Include or Maybe will be retrieved and imported into Rayyan® for eligibility assessment. In this second stage, the full texts will be assessed by pairs of reviewers using the same eligibility criteria, applied in greater detail. No data extraction will be performed at this stage. The assessment will verify whether each source explicitly addresses Data Governance and/or Data Management in an institutional health context, meets the eligibility criteria, and provides information relevant to the review questions.

The final decision for each full-text source will be recorded in Rayyan®. These records will support the preparation of the PRISMA-ScR flow diagram in the final review [12].

Data extraction/charting

Data extraction, also referred to as data charting in scoping reviews, will be performed after the full-text eligibility assessment. Only sources included after the eligibility stage will proceed to data charting.

Data will be charted using two complementary forms developed by the review team. The first form will collect bibliometric and descriptive data, including study identification, title, authorship, year of publication, document type, source title, database or source of retrieval, language, country or region, institutional affiliation, DOI or URL, author keywords and field of knowledge.

The second form will collect analytical data related to the review questions. Extracted information will include the objective of the study, problem or motivation, methodological approach, type of health institution or entity, organizational context, geographic scope, definitions of Data Governance and Data Management, models, frameworks, methodologies, instruments, implementation roadmaps, principles, policies, guidelines, processes, standards, roles, responsibilities, assessment mechanisms, maturity models, institutional actors, barriers, challenges, benefits, gaps and factors associated with implementation.

Data charting will be conducted by reviewers trained

in the use of the extraction forms. The extracted data will be checked for consistency, and disagreements or uncertainties will be resolved through discussion among the review team. When needed, an additional reviewer will be consulted. The final charted data will support both the descriptive characterization of the included sources and the narrative synthesis of findings.

Data synthesis

The extracted data will be synthesized descriptively and narratively. Bibliometric and descriptive variables will be summarized using absolute and relative frequencies, when applicable. Analytical data will be organized according to the review questions, with emphasis on models, frameworks, practices, institutional actors, assessment mechanisms, barriers, benefits and gaps related to Data Governance and Data Management in Health.

The synthesis will support the development of the Data Governance Implementation Guide for DATASUS and will also inform future articles reporting the findings of the scoping review. Results may be presented in tables, charts, figures and narrative summaries, according to the nature of the evidence identified.

Expected contribution

This scoping review is expected to provide an overview of how Data Governance and Data Management have been addressed, structured, implemented and assessed in health organizations. By mapping scientific and technical literature, the review may identify recurring models, frameworks, practices, institutional actors, assessment mechanisms, barriers, benefits and research gaps.

The findings may contribute to health information and library professionals by clarifying how data are treated as institutional information assets and how governance and management practices support data quality, interoperability, security, privacy, access and evidence-informed decision-making.

The synthesis will support the development of the Data Governance Implementation Guide for DATASUS, providing evidence to inform recommendations, organizational arrangements and implementation strategies. It will also inform future articles reporting the findings of the scoping review and discussing specific dimensions of Data Governance and Data Management in Health.

Ethics and dissemination

Ethical approval is not required because this review will use published literature and publicly available documents. The findings will be disseminated through publication in a peer-reviewed journal, conference presentations and the Open Science Framework.UID/00057/2025.

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Conflict of interest statement

The author declares no conflict of interest.

Statement on the use of AI

The generative artificial intelligence, ChatGPT-5.5 Instant, was used to support language revision, text organization, and refinement of search strategy wording. All methodological decisions, analyses, and final content were reviewed and approved by the authors, who take full responsibility for the manuscript.

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