

The Use Of Information Standards In Health Management In The Care Of Patients With Diabetes Mellitus In Australia: A Scope Review

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ABSTRACT

Objective: To map the evidence on using health informatics standards in caring for patients with Diabetes Mellitus in Australia. Method: Scope review, based on the method described in the JBI (Joanna Briggs Institute) and PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses – Scoping Reviews) Manual, containing academic articles published between 2017 and 2022 of 2 databases. A guiding question for the study was determined using the mnemonic PCC (Population, Concept, and Context). The articles were independently evaluated by two reviewers who carried out the screening and selection steps of the studies according to the guiding question and the criteria determined by the team. Descriptions of the characterizations of the studies included in the analysis are presented in figures and tables. It then ended with narrative syntheses, discussion, and conclusions. Results: The database search resulted in 459 articles. After the screening and selection steps, five articles were analyzed in this scoping review. The analysis of these articles revealed that the use of standardization standards in health information technology is still a challenge, an essential obstacle to the interoperability of systems. This lack of interoperability can result in different problems for health systems, such as difficulty managing resources and programs due to unreliable indicators, difficulty researching due to poor data collection, or even an obstacle to adherence to good guidelines. Clinical practice, among others. It was also possible to verify the use of some strategies to improve data quality. Conclusion: The lack of standardization of regulations in health systems is a frequent and current problem that must be increasingly combatted with policies of use, education, and research into solutions that can lead to true interoperability of digital health systems in Australia.

Keywords: *Diabetes Mellitus, digital health, e-health, EHR, SNOMED, HL7, FHIR, medical informatics*

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I. INTRODUCTION

Health management has been a challenge that many countries have faced under different circumstances and determining factors, as shown by studies by Marcus and Marcus (2015), Liu et al. (2019), Rehman et al. (2022) and Fang et al. (2020), among others. The challenges seem to have their impacts multiplied in adversities and unwanted effects regarding chronic diseases (Sørensen & Kristensen, 2023; Calcaterra et al., 2023; Rani et al., 2023). Moreover, among chronic diseases, diabetes stands out (Sun & Li, 2023; Wang et al., 2023; Khunti et

al., 2023), mainly due to the need for monitoring (Ghardashi et al., 2023; Lee et al., 2022; Zhu et al., 2022), due to the complications it can generate, the almost always high costs and the family impacts it causes.

In countries like Australia, there is a concentrated effort on several scientific fronts to generate valid and reliable knowledge that allows diabetes to be tackled with a high chance of success. This concern is because disease cases have grown, often overloading health systems, especially public ones, as in Brazil. In countries with less financial capacity to bear the costs of the disease, the multiplication of cases compromises the system's functioning. Generating knowledge and information about diabetes has been crucial to more efficient coping methods and procedures. Unfortunately, the existing stock of knowledge has not yet allowed the development of successful action schemes for this purpose, even with artificial intelligence. In this sense, this study aimed to map the research carried out in the standardization of data in IT that could identify gaps in diabetes knowledge and practice based on the Australian experience through a scoping review.

II. LITERATURE REVIEW

Worldwide, chronic non-communicable diseases (NCDs) are the leading causes of disability and death, accounting for 41 million deaths (71% of all deaths) annually (Australian, 2023), with 77% of these occurring in countries of low and middle-income (Marrero et al., 2012). The growth of NCDs may be related to several factors, such as increased life expectancy of the population, rapid and unplanned urbanization, and factors related to lifestyle (for example, physical inactivity, unhealthy diets, and tobacco and alcohol consumption (Beaglehole et al., 2008). If current trends continue, the estimated cumulative deaths from NCDs will reach 52 million by 2030 (Beaglehole et al., 2008). The economic burden related to NCDs is estimated to be US\$47 trillion between 2010 and 2030 (Capizzi et al., 2015).

Diabetes mellitus is a chronic disease that imposes a tremendous socioeconomic burden not only on patients and their families but also on society. In 2017-2018, the National Health Survey reported that 1.2 million Australians have diabetes, a rate that has doubled over the past 30 years ("National Health Survey", 2018). Additionally, type 2 diabetes (T2DM) has been ranked as the 13th most common cause of disease in Australia. In 2015-2016 (Australia, 2023), total healthcare costs for people with diabetes were estimated at A\$2.7 billion (2.3% of total healthcare costs). In this context, providing information about diabetes was considered a national priority (Australia, 2023).

The diabetic patient is a chronic patient who requires constant monitoring, and the disease has an essential characteristic of being silent and multiorgan. Due to this reason, there is a need for integration for agile care if necessary (Australia, 2023). The patient care process can be diverse and complicated, including numerous processes that can be improved with standardization (Shortliffe & Cimino, 2021). A lack of agreement on terms and meanings complicates clinical data's capture, storage, and use in computer systems. In recent years, there has also been a growing recognition that standardizing the terms and codes used in medicine is insufficient to enable interoperability. The structure or form of medical data provides essential context for the computable understanding of the data. Terms and codes need to be interpreted in the context of clinical information models. The many terminologies and detailed modeling activities were developed to facilitate the communication of codified medical information (Shortliffe & Cimino, 2021).

Progress towards interoperability has been slow-paced due to its inherent complexity. Efforts to date have resulted in overly complex technical standards that are not always fit for purpose, clinical cultures in which information sharing has not been the default position, vendor business models that do not support interoperability, and other factors that impede the definitive implementation of an interoperable model. Interoperability in the healthcare sector is more complicated due to the many concepts in the area compared to other sectors, the lack of standardization of care models, and the lack of approved processes to facilitate and leverage the exchange of healthcare information. Interoperability is one of the Australian Digital Health Agency's seven strategic priorities. This reflects its importance in promoting equity, care coordination, and health security (Australia, 2017).

Although there are studies on the standardization and standardization of health terminologies, no satisfactory model has resolved this issue. Studies that use artificial intelligence models, archetypes, and multiple databases have shown themselves promising but are still far from the ideal result, requiring constant updating and continued mapping of new evidence that supports advances in this area. Because of this, we aimed to map the evidence on the use of standards in health informatics in diabetic patients in Australia to understand and establish the level of evolution in that country. In this sense, this scoping review was carried out to map the research on data standardization in health informatics and identify existing gaps in knowledge and practice. The following research question guided this study: "What is the recent literature evidence on using standardization standards in health informatics in caring for patients with Diabetes Mellitus in Australia? "

III. METHODS

This is a scoping review conducted based on the methodological framework developed by the Joanna Briggs Institute (Aromataris & Munn, 2020) and the Preferred Reporting Items for Systematic reviews and Meta-

Analyses extension for Scoping Reviews checklist (Tricco et al., 2018). According to the proposed methodological basis, this review was developed in five stages (Aromataris & Munn, 2020; Tricco et al., 2018): (1) identification of the research question; (2) bibliographical survey to search for relevant studies; (3) selection of studies, according to the criteria defined in this review; (4) data mapping; and (5) presentation of results.

For the first stage, identifying the research question, the mnemonic PCC (Population, Concept, and Context) (Aromataris & Munn, 2020) was used: the letter P (Population) was defined as patients with Diabetes Mellitus, the first letter C (Concept) was defined as the use of Standardization in Health Informatics and the second C (Context) was established as Australia. Therefore, the guiding question of this article was the following: What is the evidence in recent literature on the use of standardization standards in health information technology in the care of patients with Diabetes Mellitus in Australia?

The authors determined the creation of the query (step 2) based on an initial search in the Pubmed database. The search strategy was built with specific words related to the topic in natural language and Boolean operators AND and OR to obtain a broad spectrum of results in different databases. The searches took place on August 29, 2022, in the Pubmed and Scopus databases. In the databases researched, the structuring presented in Table 1 was used.

Table 1 - Search strategy table used for document retrieval.

	Population	Concept	Context
Extraction	Chronic patients with Diabetes Mellitus	Use of Standardization Standards in Health Informatics	Australia
Conversion	Diabetes Mellitus, except for Gestational Diabetes	Standardized Data in Health Informatics	Australia
Construction	diabetes [Title/Abstract] OR diabetic [Title/Abstract] OR "diabetic patient"[Title/Abstract] NOT (gestalt*[Title/Abstract] OR pregn*[Title/Abstract])	"Digital health"[Title/Abstract] OR "ehealth"[Title/Abstract] OR "e-health"[Title/Abstract] OR "electronic health"[Title/Abstract] OR "telehealth"[Title/Abstract] OR "EHR"[Title/Abstract] OR "health informatics"[Title/Abstract] OR "SNOMED"[Title/Abstract] OR "HL7"[Title/Abstract] OR "FHIR"[Title/Abstract] OR "medical informatic*"[Title/Abstract] OR "terms"[Title/Abstract] OR "standard*"[Title/Abstract] OR "terminology"[Title/Abstract] OR "ontology"[Title/Abstract] OR "record linkage"[Title/Abstract] OR "record exchange"[Title/Abstract] OR "health information system*"[Title/Abstract] OR "biomedical informatic*"[Title/Abstract] OR "Systematized Nomenclature of Medicine"[Title/Abstract] OR "electronic health"[Title/Abstract] OR "medical information systems"[Title/Abstract] OR "interoperability"[Title/Abstract] OR "LOINC"[Title/Abstract]	"Australia"[Title/Abstract] OR "New South Wales"[Title/Abstract] OR "Victoria"[Title/Abstract] OR "Queensland"[Title/Abstract] OR "Australian capital territory"[Title/Abstract] OR "Northern Territory"[Title/Abstract] OR "Tasmania"[Title/Abstract] OR "South Australia"[Title/Abstract] OR "Western Australia"[Title/Abstract]
Pubmed Base Final Consultation	((diabetes[Title/Abstract] OR diabetic[Title/Abstract] OR "diabetic patient"[Title/Abstract]) NOT (gestalt*[Title/Abstract] OR pregn*[Title/Abstract]) AND ("Digital health"[Title/Abstract] OR "ehealth"[Title/Abstract] OR "e-health"[Title/Abstract] OR "electronic health"[Title/Abstract] OR "telehealth"[Title/Abstract] OR "EHR"[Title/Abstract] OR "health informatics"[Title/Abstract] OR "SNOMED"[Title/Abstract] OR "HL7"[Title/Abstract] OR "FHIR"[Title/Abstract] OR "medical informatic*"[Title/Abstract] OR "terms"[Title/Abstract] OR "standard*"[Title/Abstract] OR "terminology"[Title/Abstract] OR "ontology"[Title/Abstract] OR "record linkage"[Title/Abstract] OR "record exchange"[Title/Abstract] OR "health information system*"[Title/Abstract] OR "biomedical informatic*"[Title/Abstract] OR "Systematized Nomenclature of Medicine"[Title/Abstract] OR "electronic health"[Title/Abstract] OR "medical information systems"[Title/Abstract] OR "interoperability"[Title/Abstract] OR "LOINC"[Title/Abstract])) AND ("Australia"[Title/Abstract] OR "New South Wales"[Title/Abstract] OR "Victoria"[Title/Abstract] OR "Queensland"[Title/Abstract] OR "Australian capital territory"[Title/Abstract] OR "Northern Territory"[Title/Abstract] OR "Tasmania"[Title/Abstract] OR "South Australia"[Title/Abstract] OR "Western Australia"[Title/Abstract])		
Scopus Base Final Consultation	TITLE-ABS-KEY ("primary care" OR "primary healthcare" OR "primary health care" OR "general practice" OR "family medicine" OR "family practice") AND TITLE-ABS-KEY ("primary care informatic*" OR "primary health care informatic*" OR "primary healthcare informatic*" OR "Digital health" OR "ehealth" OR "telehealth" OR "EHR" OR "health informatics" OR "SNOMED" OR "HL7" OR "FHIR" OR "medical informatic*" OR "term*" OR "standard*" OR "terminology" OR "ontology" OR "record linkage" OR "record exchange" OR "health information system*" OR "biomedical informatic*" OR "Systematized Nomenclature of Medicine" OR "electronic health" OR "medical information systems" OR "interoperability" OR "LOINC") AND TITLE-ABS-KEY ("chronic disease*" OR "diabetes mellitus") AND TITLE-ABS-KEY ("Australia" OR		

	"New South Wales" OR "Victoria" OR "Queensland" OR "Australian capital territory" OR "Northern Territory" OR "Tasmania" OR "South Australia" OR "Western Australia") AND (LIMIT-TO (PUBYEAR , 2022) OR LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018))
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Source: prepared by the authors.

As eligibility criteria for this scoping review, the following were established: publications on care for people with Diabetes Mellitus (excluding studies related to Gestational Diabetes) carried out through digital technologies in the last five years, written in English, related to Australia and in which the use of Standardization Standards in Health Informatics was addressed. Regarding the type of study, primary and secondary, empirical, quantitative, and qualitative research of any design or methodology was chosen, excluding reviews. Book articles, letters to the editor, summaries in event annals, incomplete articles, and studies without definitive results were excluded. After the search, the retrieved articles were exported to the Zotero reference manager. Data from this manager were exported to a Microsoft Excel spreadsheet to select the studies to be included in this review, as described in step 3.

Duplicates were then removed. The two authors screened the remaining articles; based on the titles and abstracts, articles that answered three questions were selected: (1) this article has patients with Diabetes Mellitus as one of its main subjects. (2) does the article discuss health care in Australia? (3) does it meet the inclusion criteria? Moreover, (4) Does the article mention the use of Health Informatics Standards in any way? If the reference in question met these criteria, it was considered chosen for the next study phase. The two authors analyzed the data as independent reviewers, blinding each reviewer's interventions, and disagreements and doubts were resolved by consensus after discussion.

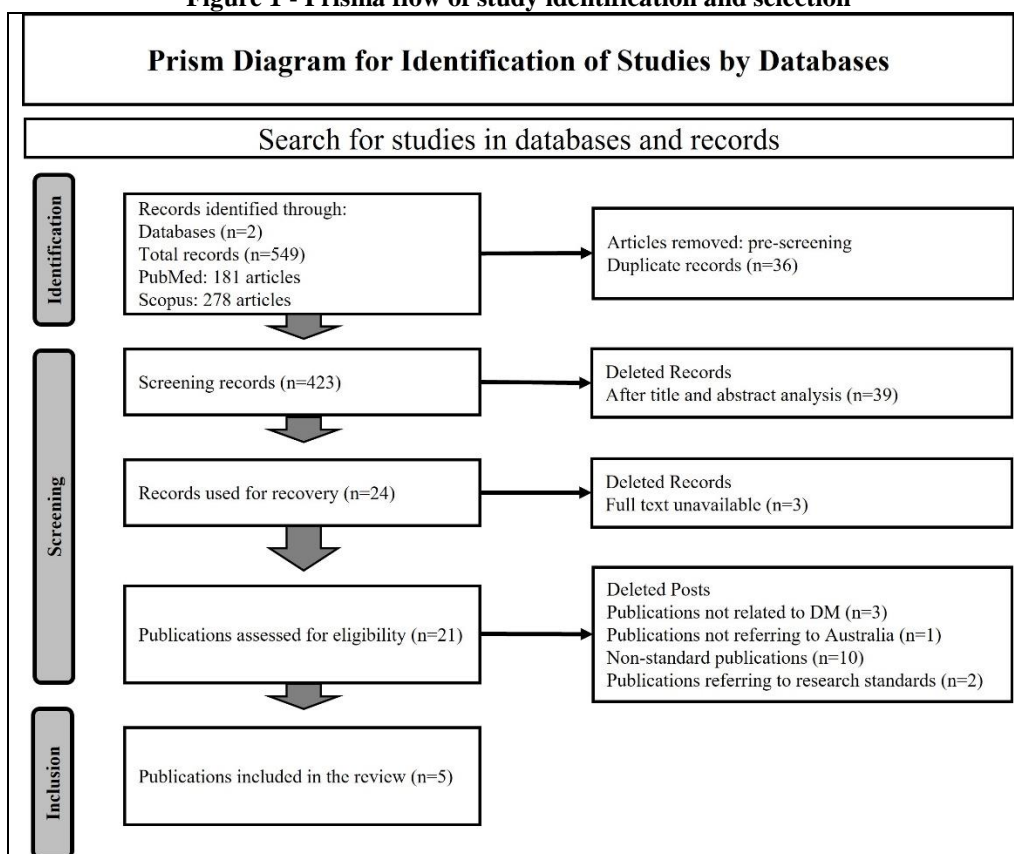
Table 2. Mapping to characterize the articles included in the review.

No.	Journal	Authors	Title	Base	Year	Design	Sample
1	PLOS ONE	Wubishet et al.	Age and cohort rise in diabetes prevalence among older Australian women: Case ascertainment using survey and healthcare administrative data	Scopus	2020	Survey longitudinal	26146 women (12432 cohort 1921-1926 and 13714 cohort 1946-1951)
2	BMC Public Health	Morrell et al.	Changes in proportional mortality from diabetes and circulatory disease in Mauritius and Fiji: possible effects of coding and certification	Scopus	2019	Survey longitudinal	12105 people (9559 from Mauritius and 2546 from Fiji)
3	Journal of Pediatric Psychology	Laurens et al.	Chronic physical health conditions, mental health, and sources of support in a longitudinal Australian child population cohort	Scopus	2019	Longitudinal cohort	21304 Australian children
4	BMJ Open	Sezgin et al.	Compliance with pathology testing guidelines in Australian general practice: Protocol for a secondary analysis of electronic health record data	Scopus	2018	Quantitative Observational Retrospective	Not specified. A large number of patients from 350 clinics between 2018 and 2019
5	Journal of Medical Systems	Wu et al.	iT2DMS: A standard-based diabetic disease data repository and its pilot experiment on diabetic retinopathy phenotyping and examination Results Integration	Scopus	2018	Pilot Study	120 patients with Type 2 Diabetes in Australia

Source: data collected by the authors.

The texts of the chosen studies were then retrieved in total. Studies in which it was impossible to obtain the entire manuscript were discarded. The studies retrieved in full were then analyzed by reading the texts by both researchers. A rigorous relevance analysis was then applied regarding the criteria chosen during this analysis of the completeness of the chosen studies. The reasons for selection or discard were noted in the Excel spreadsheet exclusively by each researcher. Differences were then resolved by consensus after a case-by-case discussion. The final selection of articles included for the definitive writing of this review then took place. Those selected were then mapped (step 4) in a table by Article Number, Periodical, Authors, Title, Database, Year of Publication, Study Design, and Sampling, as shown in the data contained in Table 2.

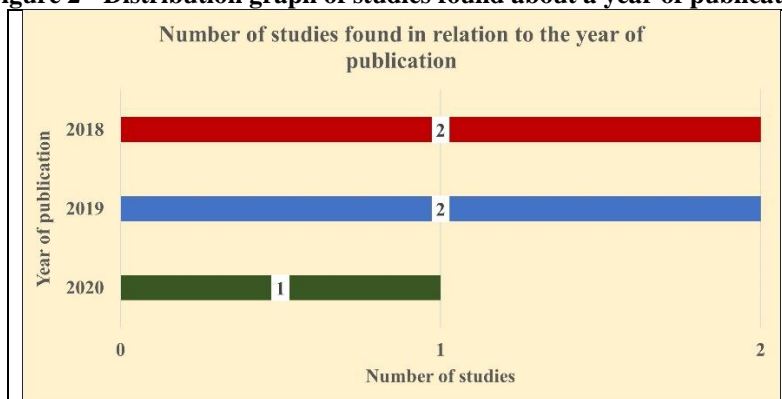
Figure 1 - Prisma flow of study identification and selection



Source: prepared by the authors.

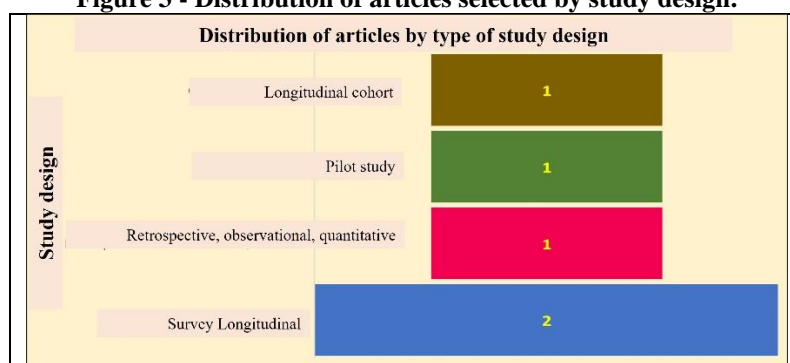
Figure 1 demonstrates the identification, screening, and inclusion process of studies by Prisma-ScR (prisma) recommendations and was developed by the authors according to the template proposed by Prisma-ScR. After selection, the results were tabulated for the characterization analysis of the selected studies (Table 2). Distribution analyses by year and study design type were performed (Figures 2 and 3).

Figure 2 - Distribution graph of studies found about a year of publication



Source: data collected by the authors

Figure 3 - Distribution of articles selected by study design.



Source: data collected by the authors.

A summary table of the mapped articles was assembled according to the main results and standards identified in Diabetes Mellitus care in Australia. After reading the articles in full and selecting them, a manual search was carried out for the data items that comprised this article's objective and were by the selection criteria. These results were then synthesized with the following information: Number, Authors, Year of Publication, Objectives, and Results relating to the subjects chosen by the team for this scoping review (Table 3).

Table 3. Summary of articles mapped according to the main results and patterns identified in Diabetes Mellitus care in Australia from 2017 to 2022.

No.	Authors	Year	Goals	Results
1	Wubishet et al.	2020	To understand diabetes cases and estimate prevalence in middle- and older-aged women through the simultaneous use of a longitudinal survey and multiple sources of administrative health data.	The simultaneous use of multiple data sources improved the validity of diabetes case ascertainment. Applying this methodology in future studies could bring significant benefits, including estimating disease burden, health service needs, and resource allocation with greater precision.
2	Morrell al.	2019	Compare secular trends in diabetes deaths with cardiovascular disease mortality in Mauritius and Fiji and the ICD versions used for derivation and coding of the underlying cause of death.	Significant and abrupt changes in proportional mortality from diabetes and circulatory disease in Fiji and Mauritius coincided with the local introduction of ICD-10 coding in different years. These artifacts can hinder accurate monitoring of the cause of death to assess the effectiveness of prevention and control, especially mortality from circulatory diseases, which is proven to be reversible in populations.
3	Laurens et al.	2019	Examine associations between chronic physical health conditions (identified in hospital records) and children's emotional, behavioral, and social functioning during childhood	...A positive finding of this study was that children with hospital records containing diagnoses of various chronic physical health conditions, regardless of the type of disease, were comparable to their peers without hospital records...
4	Sezgin et al.	2018	Define how pathology tests are used in general practice and investigate how test ordering practices align with evidence-based pathology guidelines.	Laboratory testing plays a vital role in general practice... A limitation of using EHRs is that recording clinical data is not always well standardized, resulting in variations and inconsistencies in the information available. Problems can arise due to free text data without standard formatting and the absence of recorded comorbidities and diagnoses or missing data, addressed by prioritizing standardized terms and adopting strict criteria to define variables. The POLAR program already encodes and organizes significant amounts of extracted data, and LOINC and SNOMED, both available, provide standardized pathological examination and diagnostic data.
5	Wu et al.	2018	Evaluate the phenotyping performance of the proposed system, a novel standards-based T2DM data repository framework. This repository can integrate data from multiple sources. It would be a standardized record for later data transfer and integration.	...To date, difficulties in obtaining patient data from EHR software have made it challenging to study the ordering of pathology tests in general practice. This study will be one of the first in Australia to extensively investigate the impact of best practice guidelines on clinicians' testing standards.

Source: data collected by the authors.

IV. RESULTS

The search identified 459 potentially relevant studies in the two databases consulted, Pubmed and Scopus, of which 36 were removed as duplicates; 423 records were then analyzed by title and summary using pre-

established criteria, with 399 articles being eliminated at this stage. The next step was the recovery of the complete manuscripts of the remaining 24 articles; in this step, three articles could not be recovered and were eliminated. The remaining 21 articles were read independently by the two researchers and were classified as eligible or not. At this stage, 16 articles were discarded, leaving five selected for this analysis to compose the sample (Figure 1). All articles were written in Australia. All were in English and distributed over time: 2 articles in 2018, 2 in 2019, and 1 in 2020 (Figure 3).

As for the journals, they were not limited to those specific to the areas of endocrinology and diabetes or Health Informatics. The journals cited were the following: Plos One (Wubishet et al., 2020), BMC Public Health (Morrell et al., 2019), Journal of Pediatric Psychology (Laurens et al., 2019), BMJ Open (Sezgin et al., 2018) and Journal of Medical Systems (WU et al., 2018) showing the multifaceted characteristic of Diabetes Mellitus. The studies were of the Longitudinal Survey type (n=2), Longitudinal Cohort (n=1), Retrospective Observational Quantitative (n=1), and Pilot Study (n=1). In all these studies, we could objectively infer the participation of 59,625 people in the sum of the samples from the selected studies, some with Diabetes Mellitus and others not (one study declared a large sample but did not describe the number) (Table 2). In Table 3, the evidence synthesis was mapped in summary form for an overview of the results.

V. DISCUSSION OF RESULTS

In this scoping review, we identified five studies addressing evidence from recent literature (2017-2022) on using health informatics standards in caring for patients with Diabetes Mellitus in Australia. Our findings indicate a lack of research specifically focused on the issue of approaching standardization standards aimed at interoperability and studies on implementation in this area.

These studies are essential due to the interoperability and integration of current systems and aim to implement Health 5.0, which has this integration as an imperative (Ahmad et al., 2022). It was also possible to observe the practical implications directly impacting health management due to the lack of standardization, such as coding the underlying cause of death (Morrell et al., 2019). A strategy of simultaneous use of multiple data sources, both medical records and administrative data, can increase the reliability of the numbers obtained and thus provide better results for the health system (Wubishet et al., 2020).

Major problems in this sense arise from data that are usually transcribed in free text, such as laboratory exams, and fragmented data, such as ophthalmological exams (Sezgin et al., 2018; Wu et al., 2018), making interoperability and use of this data even in the implementation of care standardization guidelines. In one of the studies, the similarity of results in data recovery from both hospital and outpatient systems was cited, leaving doubt as to whether both are satisfactory or deficient (Laurens et al., 2019). Based on the data analyzed, some strategies have been used to reduce the problems caused by the lack of interoperability. The use of more than one database for the collection (recall) of prospective data has been used as an alternative to improve data quality (Sezgin et al., 2018; Wu et al., 2018; Wubishet et al., 2020), approaches to strengthening the standards already established by more rigorous policies in demanding their use (Sezgin et al., 2018) and less conventional, but no less promising, approaches, such as the use of archetypes and digital phenotyping (Wu et al., 2018).

The consequences of the lack of interoperability in a digital health system can be diverse and vital. For example, simply changing the version of the International Disease Code (ICD) from version 9 to 10 had a brutal impact on the causes of death in two different locations (Morrell et al., 2019); this type of mismatch in indicators harms monitoring the causes of death, focusing on actions to prevent and control chronic non-communicable diseases (NCDs) that can be avoided in essential quantities, this fact alone may have been decisive for the increase in mortality in the places covered in this study (Morrell et al., 2019). The lack of interoperability can also limit the use of clinical guidelines and good clinical practices, such as laboratory tests in diabetes mellitus, impacting the results of patient control (Sezgin et al., 2018).

VI. CONCLUSION

This study showed a lack of objective studies regarding using standardization standards in health informatics in patients with diabetes mellitus. Due to the importance of this pathology, both in public health and in economic terms, more studies are necessary to implement effective management that can generate practical results for patients and the country's health system. The lack of evidence regarding the use of these standards represents an essential challenge for everyone involved in health care. This review aimed to identify the current situation and check whether there are gaps in knowledge in the chosen area. The small amount of evidence in this regard means that more studies can be carried out on the use of standardization in the care of diabetes mellitus in Australia, as well as some actions that can consolidate this type of objective, which is a national priority in managing diabetes mellitus.

These actions include education and training of professionals and patients, development of interrelationships between the main actors in the area (industry, state, and professional body, for example), and objective implementation and evaluation policies that can also be actions that promote this data integration. We

consider new studies with systematic reviews, meta-evaluations, and new evaluative studies, both local and international, to be fundamental, which can stimulate and evaluate the implementation of programs and actions already implemented, access to all levels of care, effectiveness, coverage, and the impact of the political and economic context of the use of standardization standards in health information technology to promote integration between the different services, which are essential for the increasingly better use of computerized health systems.

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