

REVIEW

Health system responses for type 1 diabetes: A scoping review

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Abstract

Aims: The focus of health system interventions for noncommunicable diseases and diabetes focus mainly on primary health care responses. However, existing interventions are not necessarily adapted for the complex management of type 1 diabetes (T1DM). We aimed to identify and describe health system interventions which have been developed to improve the management of T1DM globally.

Methods: We conducted a scoping review by searching MEDLINE, Embase, and Global Health using OVID for peer-review articles published in either English, Spanish, Portuguese or French in the last 10 years. We classified the intervention strategies according to the Effective Practice and Organization of Care (EPOC) taxonomy for health system interventions and the World Health Organization (WHO) health system building blocks.

Results: This review identified 159 health system interventions to improve T1DM management. Over half of the studies focused only on children or adolescents with type 1 diabetes. Only a small fraction of the studies were conducted in low-and-middle income countries (LMICs). According to the EPOC taxonomy, the most frequently studied category was delivery arrangement interventions, while implementation strategies and financial arrangements were less frequently studied. Also, governance arrangements domains were not studied. The most common combination of intervention strategies included self-management with either telemedicine, use of information and smart home technologies.

Conclusions: There is a need to expand potential interventions to other EPOC strategies to assess their potential effect on health outcomes in people with T1DM, as well as to involve more LMIC settings as the impact may be greater in these settings.

KEYWORDS

health care delivery, type 1 diabetes

1 | INTRODUCTION

The World Health Organization (WHO) states that a health system includes all ‘activities whose primary purpose is to promote, restore and maintain health’¹ and have as their objectives to: improve the health of the populations they serve; respond to the populations’ expectations; and provide financial protection against ill-health. Much of the focus on diabetes and noncommunicable diseases (NCD) and the delivery of care focuses on the role of primary health care (PHC). The WHO has developed its Package of Essential NCD (PEN) interventions for PHC in low-resource settings which is ‘a prioritized set of cost-effective interventions that can be delivered to an acceptable quality of care, even in resource-poor settings’.²

The current focus on PHC health system responses for diabetes is not necessarily adapted for the complex management of type 1 diabetes mellitus (T1DM),³ given the current weaknesses of PHC in managing NCDs and diabetes,^{4,5} especially in low- and middle-income countries (LMIC). Management of type 1 diabetes in high-income countries (HIC) and LMIC may differ.^{6,7} While in HIC care for type 1 diabetes might be provided at PHC, in LMICs T1DM remains a condition managed by doctors in hospitals in large urban areas.^{8–10} As an example, a study assessing clinical outcomes in children living with T1DM found that the mean HbA1c levels in children were lower in HIC (66.4 mmol/mol or 8.23%) compared to those in low-income countries (87.0 mmol/mol or 10.11%).¹¹ Thus, an adapted health system response is needed to ensure that care is accessible as well as provided by qualified health personnel.

Studies in LMICs have identified various health system barriers to care for T1DM.^{8,9,12,13} All these factors are related to the capacity of the health system to provide the different components needed as defined by the WHO’s health system building blocks, namely¹⁴: service delivery, health workforce, health information systems, access to essential medicines, financing and leadership/governance. These weaknesses in the health system result in major differences between the delivery of T1DM care between LMICs and HICs¹⁵ impacting on outcomes among people with T1DM.

In order to develop tailored health system responses, an overview of existing interventions at different levels of the health system is needed. Therefore, the aim of this scoping review was to identify and describe existing interventions developed to improve the management of T1DM globally.

2 | RESEARCH DESIGN AND METHODS

We conducted a scoping review to systematically map health systems interventions for T1DM management as

What’s new?

- Many health system interventions for noncommunicable diseases focus on primary health-care responses; but existing interventions are not necessarily adapted for the complex management of T1DM.
- A small fraction of studies were conducted in low- and middle-income countries. Interventions varied widely regarding strategy implemented. Most of the interventions were based on the delivery arrangement and had multiple strategies. Self-management and information and communication technology were the most common combination of strategies.
- There is a need to expand interventions to assess their potential effect on health outcomes in people with T1DM.

well as to describe the interventions’ characteristics and identify potential gaps in existing evidence such as understudied components of interventions.

A scoping review was conducted rather than a systematic review as it allowed us to map the existing evidence and to identify and analyse knowledge gaps, rather than providing a summary of the evidence around an specific question.¹⁶ The reporting of the results followed the PRISMA Extension for Scoping Reviews (PRISMA-ScR).¹⁷

2.1 | Eligibility criteria

We included all studies that assessed health systems interventions through quasi-experimental or experimental designs, whose full-text articles were available in English, Spanish, Portuguese or French. We defined health system interventions as ‘those that address barriers and constraints at different levels of the health system with the overall goal of improving health outcomes’ according to the WHO guidelines.¹⁸ Thus, we included complex interventions aiming to improve the health system performance (delivery of care, financial or government arrangement and implementation strategies)¹⁹ and excluded studies focusing solely on drugs or medical technologies’ efficacy.

2.2 | Search strategy

To identify potentially relevant scientific articles, we searched the following databases: MEDLINE, Embase, and Global Health using the OVID searching engine in the

last ten years (from the 1st January 2010 to the 1st January 2021). The search was last updated the 12th January 2021 to verify our ten-year search. The search strategy included terms related to T1DM and health systems interventions such as telehealth, financing, insurance coverage, among others (See details in Table S1). The results from the search were compiled by one author who removed duplicates and uploaded results to Rayyan,²⁰ an open-source software that allows for collaboration when screening and selecting studies for systematic and scoping reviews.

2.3 | Selection of sources of evidence

Selection of scientific articles was conducted by two independent researchers after having discussions and standardize procedures on how to identify health systems interventions and the inclusion criteria. After that, two reviewers screened titles, abstracts and full text of all the publications identified in the search. Disagreements on study selection were solved by consensus and discussion with other reviewers if needed.

2.4 | Data charting process

A data-charting form was developed in Excel by one author and reviewed by the other authors to determine which variables to extract. This chart was pilot tested and further improved before the data extraction process. Two independent researchers extracted the following characteristics from the studies: first author, year of publication, country, and the description of the intervention using the Template for Intervention Description and Replication (TIDieR) checklist, and the outcomes reported.²¹ The interventions were further categorized to facilitate presentation of results and analysis using two categorizations (1): the Effective Practice and Organization of Care (EPOC) taxonomy of health systems interventions: delivery arrangements, financial arrangements, governance arrangements and implementation strategies,¹⁹ and (2) the WHO framework's six health system 'building blocks'.¹⁴

The outcomes were classified according to the core outcomes set (COS) for clinical trials of interventions for people with T1DM.²² COS are 'the agreed standardized sets of outcomes that should be measured and reported in all clinical trials for a specific health condition',²³ and have been proposed as a tool that can consistently promote usage of prioritized outcomes allowing results from different studies to be compared.

Disagreements were solved by discussion and consensus between the authors.

2.5 | Synthesis of results

We summarized the intervention components according the EPOC taxonomy and WHO's health system building blocks using absolute and relative frequencies. Additionally, to assess the composition of the interventions in terms of the EPOC taxonomy categories and subcategories, we constructed a network visualization approach using the Gephi software.²⁴ To assess the combinations of components, we conducted a network analysis using nodes and edges. Nodes are circles that represent each component based on the EPOC taxonomy whose size is determined by the number of components that specific component is connected to (degree). Edges, on the other hand, are lines that connect two nodes whose width represent the frequency both components are present in an intervention. Thus, thicker edges show that those components have been used together in more studies when contrasted to thinner edges.

3 | RESULTS

We identified a total of 1487 records through the database search and included 171 records that reported results on 159 interventions (See Figure 1); 60 quasi-experimental (QE) and 99 randomized trials (RT).

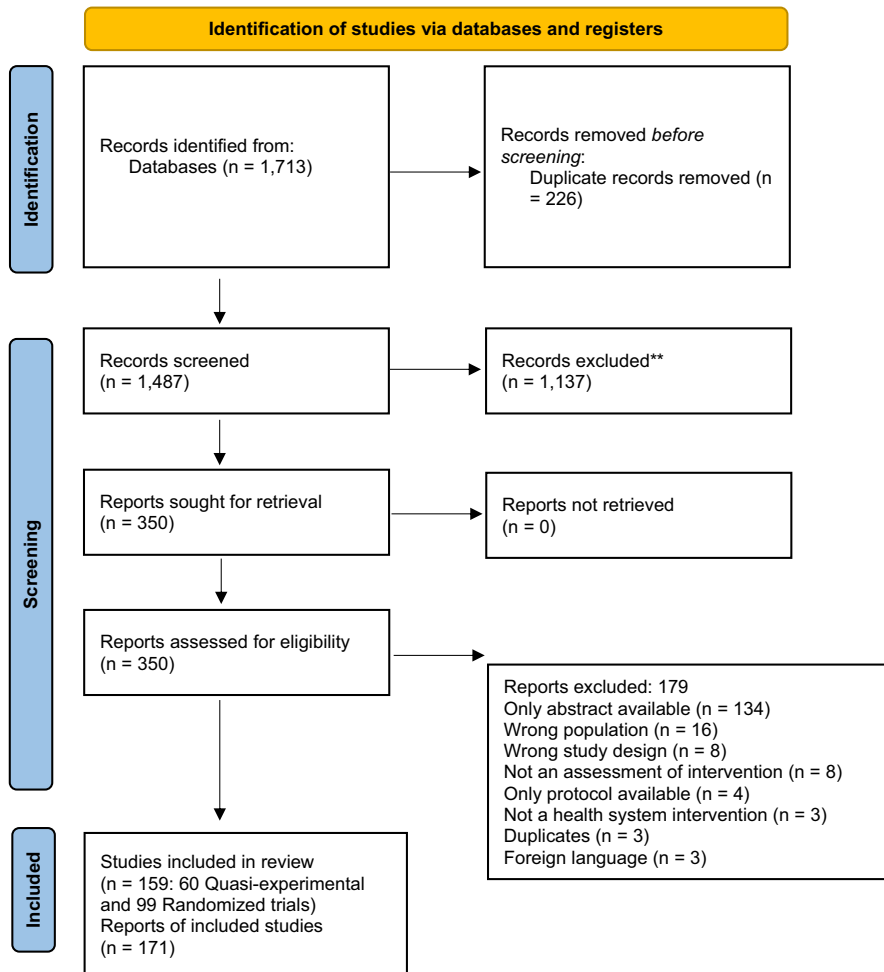
Most of the studies, 129 (84.3%) were conducted in HICs; 48 of them were QE and 87 were RT. As for the studies conducted in LMICs, 12 were QE and 12 were RT. A list of the included studies, year of publication, country and study year, and a brief summary of the interventions can be found in Table S2 (Quasi-experimental) and Table S3 (Randomized trial). See also Tables S4 and S5 for more detailed information.

3.1 | Interventions

Interventions varied widely in terms of the target population and the intervention components. Most of the studies focused only on children and/or adolescents (80, 48.2%), while fewer included adult patients with T1DM (70, 42.2%). Additionally, some studies targeted other populations such as parents or families (10, 6.2%), and more rarely, child care centres, camp counsellors or health care professionals.

Interventions were composed of different intervention strategies that were classified according to domains, categories and subcategories of the EPOC taxonomy. We found that 117 (74.1%) of the interventions used at least two strategies, while 41 (25.9%) used only one. Only 1 intervention could not be categorized using the taxonomy as it involved education using a human patient simulator for diabetes knowledge and self-efficacy in a 2-week diabetes camp stay.²⁵

FIGURE 1 PRISMA flowchart



3.2 | Description of interventions using the EPOC taxonomy

Using the EPOC taxonomy, we found that most of the interventions (157, 98.7%) included a strategy classified within the Delivery Arrangements domain focused on the category ‘who provides care and how the healthcare workforce is managed’, the most frequent category (142, 89.3% of all the included studies), followed by ‘information and communication technology’ (ICT) (88, 55.4%), ‘where care is provided and changes to health environment’ (30, 18.9%), ‘coordination of care and management of care process’ (26, 16.4%), and ‘how and when care is delivered’ (22, 13.8%). Only 11 (7%) of the studied interventions included implementations strategies and 2 (1.3%) financial arrangements domains.^{26–28}

3.3 | Delivery arrangements—Who provides care and how the healthcare workforce is managed

For the most common category ‘who provides care and how the healthcare workforce is managed’, self-management was the most common subcategory (149,

93.7%). The actions included structured education programs for patients or self-monitoring of blood glucose and provision of equipment such as glucometers and/or continuous glucose monitoring devices. Some studies included patients using insulin-pumps and provided education on how to assess the parameters and feedback related to the use of this device. The education programs aimed to enhance knowledge and self-efficacy so patients and parents become capable of conducting day-to-day diabetes care. Role expansion or task shifting subcategories were less frequent (4, 2.5%)^{29–33} and included task shifting to specialized nurses or community health care workers.

3.4 | Delivery arrangements—Information and communication technology

ICT interventions were the second most common category of interventions and included telemedicine (55, 34.6%) with the intervention either using SMS, phone or video calls to provide educational content, reminders to conduct self-monitoring or to get medical appointments,

follow-up consultations to modify treatment, among others. This subcategory was followed by the use of information and communication technologies subcategory (52, 32.7%) which included apps or websites where patients could upload their self-monitoring information and receive feedback from health care professionals, and access to educational material or discussion forums with peers and health care providers. Finally, smart home technologies subcategory (33, 20.8%) included glucose meters, continuous glucose monitoring systems, insulin pumps, and smartphones with apps.

3.5 | Delivery arrangements—Where care is provided and changes to health environment

As for interventions related to the category ‘where care is provided and changes to health environment’, we found articles that assessed changes in the site where care is delivered (26, 16.3%) including usage of online platforms, home or school visits, diabetes camps, family houses within the hospital premises, among others, and outreach services (8, 5.0%) which included offering retinopathy screening through different communication channels, T1DM awareness campaigns in the community, among others.^{26,34–40}

3.6 | Delivery arrangements—Coordination of care and management of care process

Within the ‘coordination of care and management of care process’ category, the following subcategories were present: disease management (7, 4.4%), communication between providers (6, 3.8%), shared decision making (5, 3.1%), case management (4, 2.5%), integration (4, 2.5%), referral systems (3, 1.9%), teams (2, 1.3%), transition of care (2, 1.3%), continuity of care (1, <0.1%)⁴¹; patient-initiated appointment systems (1, <0.1%)⁴²; and package of care (1, <0.1%).⁴³ Interventions were usually multicomponent and included a wide range of modification of the system from disease management programs that included improvement of communication between providers, teams and integration of services (e.g. adding psychological support through coaching or cognitive behavioral therapy on top of usual endocrinologist-led care) to shared-medical appointments (different health care professionals and one patient and/or family), to interventions related to transition of care (education and reminders to follow-up medical appointments) targeting adolescents transitioning to adult care.

3.7 | Delivery arrangements—How and when care is delivered

The category of ‘how and when care is delivered’ included the following subcategories: group versus individual care (8, 5.0%), coordination of care amongst different provider (6, 3.7%), quality and safety systems (5, 3.1%), and triage (2, 1.3%). Interventions were heterogeneous and included group-based education, coaching or psychological support, coordination between paediatric and adult diabetes care, among others.

3.8 | Implementation strategies

As for the ‘implementations strategies’ category, we found one intervention that aimed at organizational culture (1, <0.1%) through training for primary care personnel in diabetes management.⁴⁴ Additionally, ‘interventions targeted at healthcare workers’ category included audit and feedback (3, 1.9%), educational materials (2, 1.3%), routine patient-reported outcome measures (2, 1.3%), monitoring the performance of the delivery of healthcare (1, <0.1%)⁴⁴; educational outreach visits (1, <0.1%)⁴⁵; clinical practice guidelines (1, <0.1%)⁴⁶; patient-mediated interventions (1, <0.1%)⁴⁷; tailored interventions (1, <0.1%)⁴⁸; and interventions targeted at health conditions (1, <0.1%).⁴⁴

3.9 | Financial arrangement

Financial arrangement was the least frequently studied domain and included two subcategories; co-payments for retinopathy screening (1, <0.1%),²⁶ and conditional cash transfers related to complying with self-monitoring (1, <0.1%).²⁷ We did not find studies focusing on interventions tackling governance arrangements.

3.10 | Network of intervention strategies

The network analysis is presented in [Figure 2](#). Self-management was the subcategory which was combined with others most frequently, followed by telemedicine, use of information and site of service delivery, represented by the largest nodes. Subcategories included within the financial arrangements and implementation strategies domain (e.g. educational materials, outreach and meetings) were seldomly combined with other intervention strategies. Also, some subcategories included within the delivery arrangements categories such as referral systems, continuity of care, patient-initiated appointments or transition of care were also rarely combined with others.

Additionally, we found that the most common combinations of intervention subcategories included self-management with either telemedicine, use of information and smart home technologies, represented by the thicker edges. Financial arrangement interventions were somewhat neglected. As an example, co-payment for retinopathy screening was combined with outreach services and conditional cash transfer were combined with self-management, smart home technologies and telemedicine.²⁶

3.11 | Description of interventions using the WHO building blocks

When categorizing the studies using the WHO health system building blocks, the vast majority 137 (86.2%) involved service delivery, 11 (12.0%) health information systems, 6 (3.8%) health workforce, and 1 (0.6%) financing. While, 4 interventions were not classified within the building blocks. Service delivery changes were mainly related to transferring care to patients (self-management), using telemedicine or moving care to places different than

the specialist consulting room (primary health care level, community settings such as schools, etc.), thus changing the place, the way or who delivers a service.

Interventions that included the information systems block used electronic medical records to improve communication between providers, but also apps or web platforms to facilitate exchange of information between patients and healthcare providers which was mostly related to self-monitoring of glucose. As for health workforce, interventions aimed to increase awareness of T1DM in healthcare professionals and community members (e.g. school teachers) and involve them in the care of patients with T1DM. Finally, only one intervention aimed to modify the financing block by introducing co-payment of care,²⁶ and we did not find interventions focusing on access to essential medicines or leadership/governance.

3.12 | Outcomes

Studies assessed several outcomes: 125 (78.6%) studied glycated haemoglobin, 73 (45.9%) self-management, 53

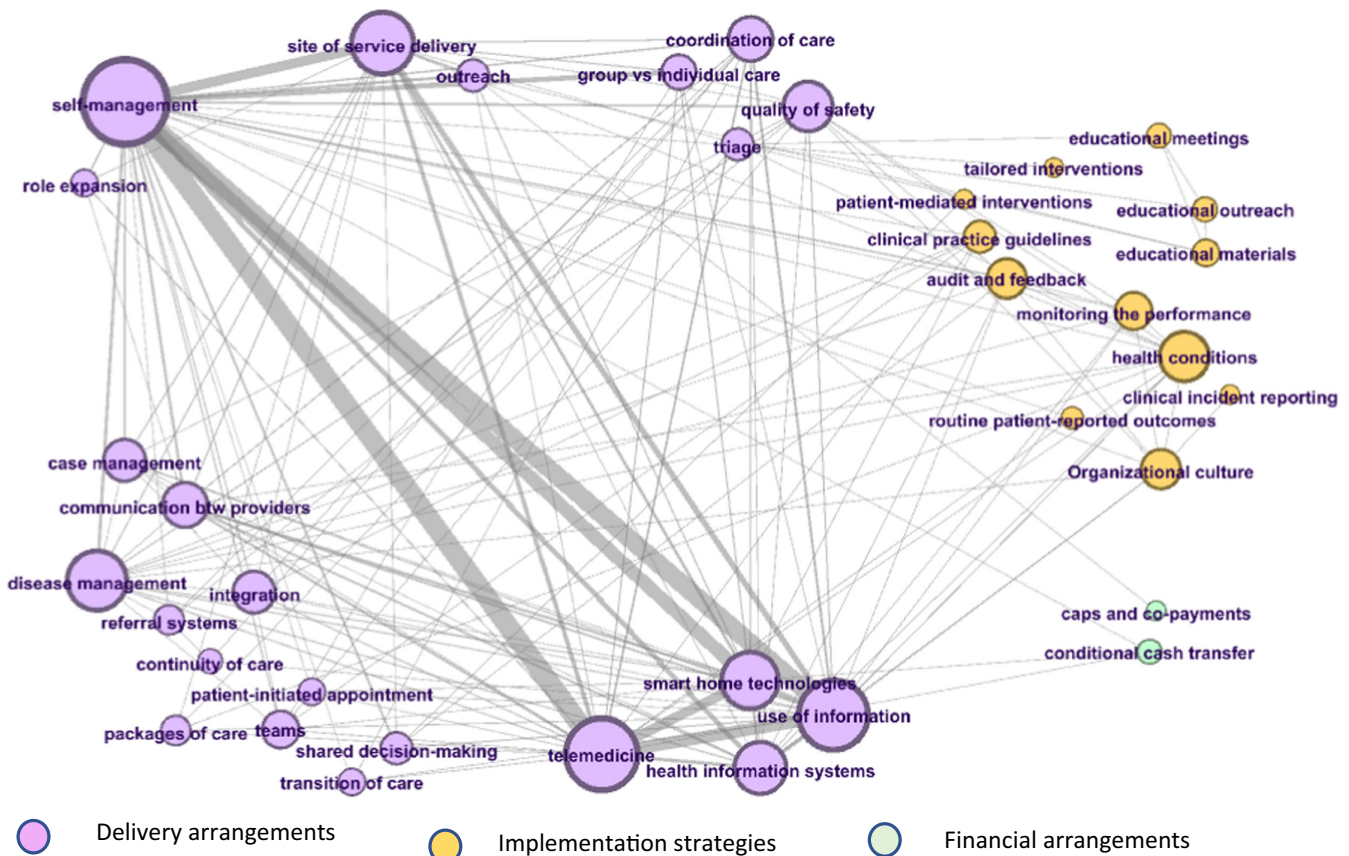


FIGURE 2 Network of intervention subcategories according to the EPOC taxonomy. The figure presents a network of the intervention strategies. Each circle represents a subcategory based on the EPOC taxonomy, the size of the circle is determined by the degree which is the number of subcategories that specific subcategory is connected to, and the width of the edges represent the frequency both subcategories are present in an intervention

(33.3%) diabetes-related quality of life, 30 (18.9%) diabetes distress and burden, 27 (17.0%) severe hypoglycaemia, 24 (15.1%) perceived control over diabetes, 17 (11.7%) clinic engagement and 12 (7.6%) diabetes ketoacidosis. Most studies, 109 (68.6%), assessed two or more outcomes while 44 (27.7%) assessed only one and 6 (3.8%) assessed other outcomes not included in the COS for T1DM interventions.

4 | DISCUSSION

This review identified 159 health system interventions to improve T1DM management. Over half of the studies focused only on children or adolescents with type 1 diabetes. Only a small fraction of the studies was conducted in LMICs, mainly in countries like Brazil or China. This poses a concern given that interventions developed and implemented in HICs might not be necessarily suited or financially viable for LMICs. Moreover, the socioeconomic environment in which people with T1DM live might also impact on the final outcomes and therefore the effectiveness of interventions. According to the EPOC taxonomy, interventions varied widely with regards to the strategy implemented. The most frequently studied category was delivery arrangement interventions, while implementations strategies and financial arrangements the less frequently studied. Moreover, we did not find studies using governance arrangements domains.

Most of the interventions had multiple interventions strategies and self-management and ICT (either telemedicine, use of information and smart home technologies) were the most common combination of strategies. As for the composition of the studied interventions, most of them included self-management with some ICT support. The rationale of these interventions was patients with chronic conditions such as T1DM should be able to manage their disease, including self-monitoring and modification of insulin doses based on glucose measures. Thus, several of the self-management interventions included structured education programs facilitated either through face-to-face, virtual platforms and app coupled with self-monitoring. Additionally, some of the interventions included apps or virtual platforms to keep track of glucose measures and share the results with physicians. It is left to explore how to best adapt educative interventions for low-literate communities and to assess whether is it possible to couple ICT in resource constrains settings were internet access is sometimes an issue.

Studies assessing financial arrangements and some implementation strategies focused on health care professionals were less frequent. In the case of financial arrangements, they were focused on monetary incentives

for self-monitoring of glucose.^{26,27} Little to no information was found regarding insurance coverage of insulin or glucose monitoring devices which might be an issue in resource constrained settings. We then suggest the reporting and publication of the assessment of implementation and clinical outcomes for interventions involving financial arrangements, governance arrangements and implementation strategies as this information could facilitate decision making processes in different contexts.

We also found that around one fifth of the interventions included people with either T1DM or T2DM, which suggests that some interventions might be suitable for both populations when treating adults with diabetes or that the number of people with T1DM is small so researchers decided to combine both populations. On the other hand, some interventions were developed exclusively for children or adolescents with T1DM targeting special issues such as self-monitoring or hypoglycaemia recognition and management (e.g. using interactive platforms or forums to exchange experiences with people their age). Thus, depending on the intervention's objective, tailoring according to the type of diabetes or the age group might be needed.

4.1 | Strengths and limitations of the review

We used a systematic approach to search, select and extract the information which allowed us to have a better understanding of what health systems interventions have been studied. Moreover, we used the EPOC taxonomy which has been validated and widely used, and the WHO health system building blocks that allowed us to identify which blocks of the health systems have been targeted in recent studies. However, when using a taxonomy such as EPOC, we face the taxonomy's limitations such as the variable level of detail provided for each category and the confounding of content, delivery mode and provider for some of the categories.⁴⁹ For this reason, we opted to describe the intervention in detail using the TIDieR and this information can be accessed by the readers (see Tables S4 and S5). Finally, we used a COS for DM to systematically classify outcomes.

Our study has some limitations related to study selection as we excluded gray literature such as governmental reports which might contain information related to implemented strategies. However, we do not consider this may affect our results because we aimed to find and describe existing interventions which may be implementable in different settings. In addition, usually interventions are published in manuscripts. We excluded studies published in a language other than English, Spanish, Portuguese or

French. This might have prevented us from finding studies published in other commonly spoken languages and conducted in other regions with different health system interventions that might have been of interest for the scoping review.

4.2 | Implications of results

Based on the findings of the scoping review, the following evidence gaps have been identified. Firstly, very few studies focusing on health system interventions have been conducted in LMICs. Although in both HIC settings and LMIC settings financial barriers to care exist,^{12,15,50} very few studies focused on financial arrangements. In looking at the outcomes few studies provide information on patient-reported outcomes.

COS are relevant as they propose outcomes relevant for important stakeholders to be consistently measured so that evidence can be used for decision-making such as deciding whether or not to implement an intervention.²³ In the case of studies assessing health systems interventions to improve T1DM care, we found that most of the studies focused on glycated haemoglobin and only a small fraction measured patient reported outcomes such as quality of life or disease-related burden. This prevents decision-makers from considering the impact of interventions in outcomes other than glycated haemoglobin when developing and implementing a health system intervention for this condition. A potential consequence of this may involve health systems not responding to the needs of subjects with T1DM, but focusing only on clinical outcomes, which can, in turn, impact on the continuity of care of T1DM patients. Additionally, severe hypoglycaemia was measured in less than a fifth of the studies, being one of the most important complications of T1DM, it is expected that health systems interventions include strategies to prevent it.

The launch of the Global Diabetes Compact⁵¹ and the World Health Assembly Resolution, “Reducing the burden of noncommunicable diseases through strengthening prevention and control of diabetes”⁵² specifically make reference to addressing the needs of people with T1DM, in parallel to improving access to insulin and care. From this review in developing health system interventions for T1DM management, two important issues need to be carefully assessed: tailoring of the intervention (related to the type of intervention and to the age group of the target population) and the need to include multiple intervention strategies. Therefore, in order to have successful interventions a good understanding of the context should guide the development of the intervention and the inclusion of intervention strategies as well as focusing on how to integrate the

perspective of those who will implement and benefit from the intervention.

In summary, we conducted a scoping review of health system interventions for T1DM and found that most of the more recent interventions are in HICs compared to LMICs despite the burden of T1DM is greater in resource-constrained settings. Most of the interventions are focused on delivery arrangements strategies, with special emphasis on self-management and technology use. Additionally, the most common combination of intervention strategies included self-management with either telemedicine, use of information and smart home technologies. We conclude that there is a need to expand potential interventions to other EPOC strategies to assess their potential effect on health outcomes in T1DM subjects, as well as to involve more LMIC settings as the impact may be greater in these settings.

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CONFLICT OF INTEREST

No potential conflict of interest relevant to this article exist.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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