

## Do diabetes mHealth and online interventions evaluate what is important for users?

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### Abstract

Research often presents patient needs from perceptions of healthcare professionals and researchers. Today, patients can formulate tailored questions and seek solutions for what they need to self-manage in many ways. We aimed to compare reported outcomes of mHealth and online intervention studies for diabetes self-management to patient-reported needs, from a systematic review and a literature review respectively. Although we found similarities between the reported outcomes and the patient-reported needs, research has yet to meet all patient needs. Comprehensive methods for development and testing of interventions should be explored to meet the specific needs of patients.

### Keywords

mHealth, diabetes, online, evaluation, patients, needs.

## 1 INTRODUCTION

Evidence for models of diabetes self-management focus on medical devices and clinically relevant measures, and not those that are reportedly relevant for the patients who are the intended users [1,2]. Technology such as mHealth and online tools and services intend to aid patients' diabetes self-management (SM) and provide additional support and information to that from traditional diabetes care and medical technology. In fact, patients with diabetes, have expressed impatience and dissatisfaction with the medically approved technology-based solutions, leading to the rise of the Do-It-Yourself (DIY) movement of hacking technologies to provide the functions and support that patients need [3]. However, the tradition within health intervention research has been to mostly focus on addressing and reporting clinical evidence and outcomes such as change in hemoglobin A1c and cholesterol levels, and not so much on other patient-relevant factors [2]. This raises the question: to what extent is mHealth and online intervention research targeting what is important for the patient and their needs in diabetes care?

"Patient needs" are often described in scientific literature as activities or actions that patients have to take to achieve good diabetes health. In other words, it is often focused on what healthcare professionals (HCPs) and researchers, not patients, perceive as patient needs [4]. When reported, patient needs are usually inferred from patients' feedback about their experience with mHealth or online interventions as part of an intervention study [5,6]. However, these do not comprehensively cover the overall needs for aiding their self-management.

## 2 METHODS

We compare results from two reviews: Review 1 identified reported outcomes of mHealth and online intervention studies for diabetes SM, and Review 2 identified patient-reported needs and facilitating factors for diabetes SM. While performed separately, categorization of the results for each review were discussed and agreed upon by all co-authors.

### 2.1 Search strategy for Review 1 - reported outcomes of mHealth and online interventions

The first review was a systematic literature review, with the overall aim of identifying methods and evaluation criteria used during mHealth and online interventions for diabetes SM. Several categories of information were extracted from the resulting literature. However, for the purpose of this paper, we will focus on reporting only a selection of the extracted data, i.e. reported outcomes. The following are examples of terms within titles and abstracts of literature found in CINAHL, EMBASE, MEDLINE and Web of Science, and published between Jan 1, 2015 and June 21, 2018 for the search strategy: *[mHealth or web-based] AND [self-assessment OR self-care] AND [assessment OR guidelines]*. The detailed search strategy is published along with the protocol of the systematic review in PROSPERO (Registration number: CRD42018115246). Articles were included if: they reported a relevant framework, guideline, questionnaire or other relevant criteria for evaluating mHealth or online interventions for patients – with all types of diabetes. Articles were excluded if: the evaluation only included medical measurements or did not include patients. Articles with only abstracts available, reviews, and dissertations were also excluded. Data extraction was performed by two co-authors (PR, MB). The main author (DL) performed inductive qualitative analysis and grouping of the outcomes. All stages from search strategy to data extraction and synthesis were contributed to and approved by all co-authors.

### 2.2 Search strategy for Review 2 - patient-reported needs

The second review was a literature review aimed at identifying patient-reported needs related to the facilitation and performance of SM activities, including but not limited to those based on the use of mHealth technologies and online SM aids. Our search strategy included combinations of the following terms in titles and abstracts searched within Google (grey literature search) and PubMed that were published between Jan. 1, 2015 and August 17, 2019: *[patient-reported needs OR want OR information needs OR*

needs OR unmet needs] AND [patients] AND [diabetes OR mHealth OR online]. Literature, news articles and other resulting publications were included if they reported needs and wishes for SM and SM aids by patients with diabetes. Literature was excluded if the feedback was from non-patients, or from patients during development or testing of a specific app or online intervention only. This is because we aimed to identify unbiased feedback about needs for SM and factors that facilitated SM, without the context of development or testing of an app for a purpose that was chosen by the researchers, not the patients. Data extraction included patient-reported needs and facilitating factors related to diabetes self-management. Co-author (MB) performed inductive qualitative analysis and grouping of the needs.

### 2.3 Comparison of reported outcomes vs. patient-reported needs

We performed a comparison based on the individual topics, i.e. reported outcomes and patient-reported needs, independent of the previously established categories. Comparison of the individual topics was discussed and agreed upon by all co-authors. By comparing individual reported outcomes and patient-reported needs, we were able to identify which patient needs are addressed by intervention studies and which still need to be addressed in the future.

## 3 RESULTS

### 3.1 Results from Review 1 – reported outcomes of mHealth and online interventions

The search strategy resulted in the identification of n=1681 mHealth and online intervention studies. After removing duplicates, most were excluded because no evaluation was reported, the focus of the study was not on diabetes or apps and online interventions, was not in English, not peer-reviewed or published before 2015. The selection process is described in Figure 1.

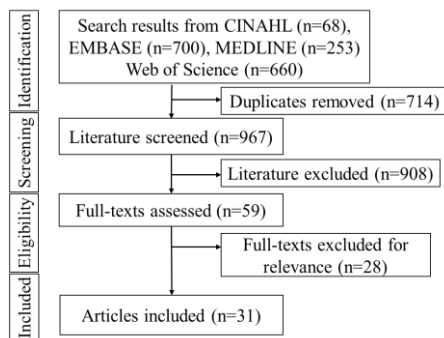


Figure 1 is a PRISMA flow chart diagram of Review 1.

The analysis of mHealth and online interventions studies resulted in six categories, each with outcomes reported from evaluations. The *Usability and Suitability of apps and interventions* category (see Table 1) had the most reported outcomes. Of these, the most commonly reported outcome was the Features and functions of an mHealth or online intervention. The Features and functions included the different types of tools for self-management such as diabetes diaries and glucose monitors, their characteristics and the users’ experiences with these tools. mHealth and

online interventions tend to focus on their effect on self-management, self-efficacy and autonomy, and clinical health measures such as hemoglobin A1c and blood pressure. See Table 1 for the full list of reported outcomes.

Reported Outcomes	Refs
<i>Usability and Suitability of apps and/or online interventions</i>	[5, 7-32]
<ul style="list-style-type: none"> <li>• Tailorability</li> <li>• Features and functions</li> <li>• Ease-of-use</li> <li>• Challenges of use (from HCPs and patients)</li> <li>• Suggestions for development and improvement</li> <li>• Feasibility of integration into care practice</li> <li>• User interface design</li> </ul>	
<i>Effect on patient empowerment and engagement</i>	[5-7, 10-12, 14, 17-20, 22, 25-29, 31, 33-35]
<ul style="list-style-type: none"> <li>• Self-management</li> <li>• Self-efficacy and autonomy</li> <li>• Motivation</li> <li>• Usage patterns</li> <li>• Adherence</li> </ul>	
<i>Effect on clinical health measures</i>	[6, 7, 9, 12, 14, 16, 18, 20, 22, 26, 29, 34]
<ul style="list-style-type: none"> <li>• Quality of life</li> <li>• Psychological symptoms</li> <li>• Physical symptoms</li> <li>• Clinically measured data</li> <li>• Changes in patient-recorded health measures</li> </ul>	
<i>Data protection</i>	[11, 13, 15, 17, 22, 32]
<ul style="list-style-type: none"> <li>• Security and privacy</li> <li>• Security regulations (or national standards)</li> </ul>	
<i>Support from and access to</i>	[6, 9-11, 13, 14, 17, 18, 20, 24, 25, 27-29, 31, 33, 35]
<ul style="list-style-type: none"> <li>• Peers</li> <li>• Family</li> <li>• Coordinated healthcare services</li> <li>• Relevant diabetes information</li> </ul>	
<i>Other</i>	[9, 28]
<ul style="list-style-type: none"> <li>• Cost of development</li> <li>• Recommendation of technical solutions to patients by HCPs</li> </ul>	

Table 1 Results of Review 1, reported outcomes from mHealth and online interventions.

### 3.2 Results from Review 2 - patient-reported needs

The search strategy in PubMed and Google resulted in 160 manuscripts with references to “patients’ needs” for diabetes self-management. Review of the titles, abstracts and brief descriptions, followed by review of full texts, resulted in the exclusion of 139 manuscripts, largely because the needs were not directly reported by patients, or were not related to diabetes. Figure 2 details the identification and selection of included literature.

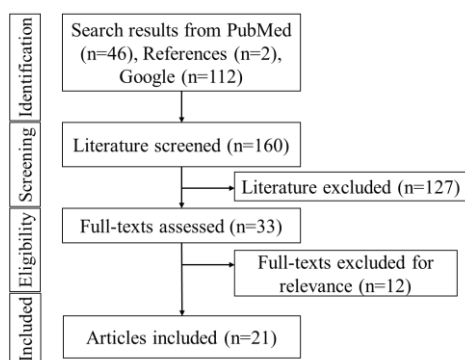


Figure 2 is a PRISMA flow chart diagram of Review 2.

Four categories of needs were identified from the qualitative assessment of reported patient needs. The most commonly reported needs were related to *Support and access to services*, including both Emotional and practical tailored support from family, peers and HCPs to encourage and guide SM. The second group of most common needs were related to *Coping, patient engagement and empowerment*. Patients saw the importance of being motivated and having confidence in their ability to perform SM tasks. This included being able to determine the best action in different situations, e.g. vacation, or if they needed to adjust how they managed their disease, e.g. because their metabolism and other factors changed as they grew older. While patients reported that they needed routines and more structure in their SM, they also wanted more relaxed and less strict SM goals, e.g. they did not like to feel ashamed or defeated by not reaching a diabetes-related goal. Because this review focused on general SM needs and facilitators of SM, fewer articles (n=6) described needs specifically related to mHealth or online interventions.

Further, many of the reported needs were inter-related. For example, patients wanted information about how their lifestyle choices affected their diabetes health, and vice versa. This information could be provided by HCPs’ feedback about their SM performance, or from visualization of previously registered lifestyle and health data in an app (seen under *Support and access to services* and *Technology needs*, respectively, in Table 2). Table 2 provides more detail of the categorized needs that patients reported.

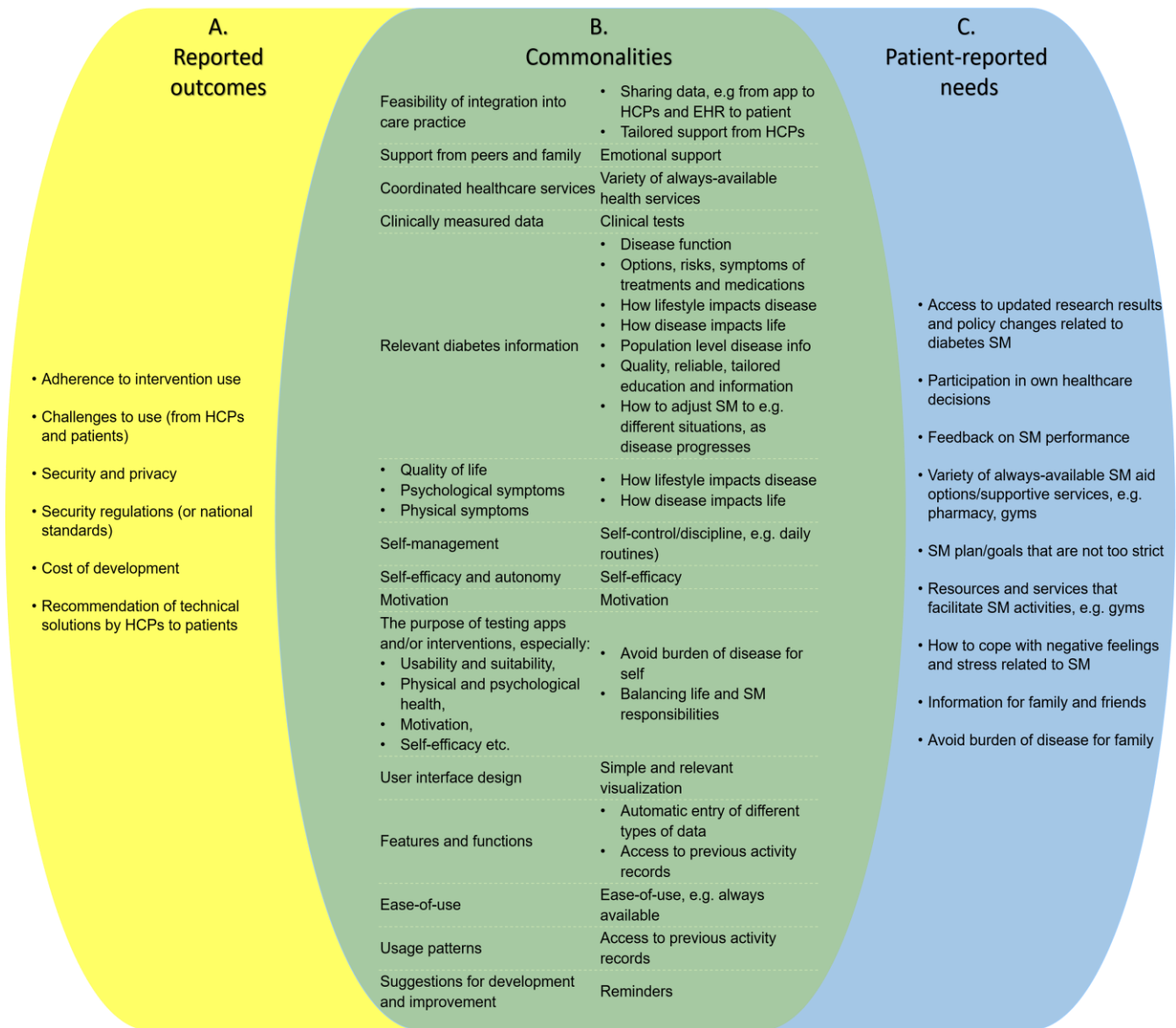
### 3.3 Comparing review results: Research foci vs. patient needs

When comparing the topics of the reported outcomes of mHealth and online interventions and the patient-reported needs (see Venn diagram, Figure 3), we found many commonalities. The green section of the Venn diagram (B) illustrates these commonalities, with some individual topics such as Relevant diabetes information, and Feasibility of integration into care practice, reported as outcomes of interventions covering a variety of individual topics from the patient-reported needs.

The yellow section of the Venn diagram (A) illustrates only reported outcomes from the mHealth and online interventions such as Cost of development, and Challenges to use from both HCPs and patients. The blue section of the Venn diagram (C) which illustrates only patient-reported needs, include individual topics such as Access to updated research results and policy changes related to diabetes SM, and How to cope with negative feelings and stress related to SM.

Patient-reported needs	Refs
<b>Information needs</b>	[36-46]
<ul style="list-style-type: none"> <li>• Clinical tests and disease function</li> <li>• Options, risks, symptoms of treatments and medications</li> <li>• How lifestyle impacts disease</li> <li>• How disease impacts life</li> <li>• Population level disease info</li> <li>• Information for family and friends</li> <li>• Quality, reliable, tailored education and information</li> <li>• Awareness of updated research and healthcare policies</li> </ul>	
<b>Support and access to services (HCPs, peers, family) needs</b>	[36-45,47-56]
<ul style="list-style-type: none"> <li>• Sharing data, e.g. from app to HCP, and from electronic health records to patient</li> <li>• Emotional and practical tailored support</li> <li>• Feedback on SM performance and reminders</li> <li>• Variety of always-available health services/SM aid options</li> <li>• Resources and services that facilitate SM activities, e.g. gyms</li> </ul>	
<b>Coping, patient engagement and empowerment needs</b>	[37, 39-42, 44-46, 49-53]
<ul style="list-style-type: none"> <li>• Participation in own healthcare decisions</li> <li>• Motivation</li> <li>• Self-efficacy</li> <li>• Self-control/discipline, e.g. daily routines</li> <li>• SM plan/goals that are not too strict</li> <li>• How to adjust SM to e.g. different situations, as disease progresses</li> <li>• How to cope with negative feelings, stress, insecurity about disease</li> <li>• Avoid burden of disease for self and family</li> <li>• Balancing life and SM responsibilities</li> </ul>	
<b>Technology needs</b>	[36, 41, 47, 48, 50, 56]
<ul style="list-style-type: none"> <li>• Simple and relevant visualization</li> <li>• Automatic entry of different types of data</li> <li>• Access to previous activity records</li> <li>• Ease-of-use, e.g. always available</li> </ul>	

Table 2 Results of Review 2, patient-reported needs.



**Figure 3** Venn diagram comparing results of both reviews, based on individual topics: **A.** topics that only appeared in reported outcomes, **B.** topics that appeared in both reported outcomes and patient-reported needs, and **C.** topics that only appeared in patient-reported needs.

## 4 DISCUSSION

The reported needs of patients and the reported outcomes of research did overlap a lot. There are still however, patient-reported needs that research has yet to address in order to optimize the self-management of diabetes patients.

### 4.1 Patients want to share data

The patients' need to share their own gathered health data from apps with HCP has little representation in research outcomes. Only recently have technology developers, health authorities and researchers accepted the need to address both patients' and healthcare practitioners' use of these technologies, for example in consultations [57]. As a new and emerging field, patient-generated health data integration faces challenges in the every-day clinical setting, as well as from continuous development and use [58]. In addition to its significant effect on patients' health, patient-generated data integration improves communication between HCPs and patients [58]. With input from HCPs

about this shared data, patients could receive more supportive and tailored services, e.g. medication advice, and tools for coping with emotional and psychological distress. With the continuous advancement in technology, more of the already existing and future diabetes interventions could incorporate this function to help improve SM activities. This is especially true for diabetes, which is the fastest growing target audience for both individual and integrated mHealth systems [59].

### 4.2 Patients want more information

The patient-reported need for Awareness of updated research and healthcare policies is among those needs not well-represented in the reported outcomes from mHealth and online intervention studies. Considering the importance that some categories of patients place in the digital sources of information [60], patients must be given the opportunity to access and understand research that pertains to their disease condition. We must also acknowledge that because

this information is published in a language and platform, e.g. scientific journals, that target researchers, not patients, it is understandable that patients do not feel that they have access to this information. If researchers would be more active in their production of popular science articles, participation in social media or blogs, this information could be more accessible and understandable for patients.

Patients also reported a strong need for evidence, information and support. Some important questions to ask regarding these topics are: for which patient group is the evidence, i.e. reported outcomes, relevant? And, are there factors or needs that precede patients' needs for SM? For example, Majeed-Ariss et al. report the needs of a group of British-Pakistani women who struggle with receiving health information and recommendations in English [51]. In this case, there was a fundamental barrier, i.e. communication, which needed to be overcome before these women could be expected to perform recommended SM activities, let alone to achieve diabetes health goals.

### 4.3 Involving Patients in SM interventions

Platforms or devices addressing the majority of the patient needs in mHealth and online interventions should be a priority for researchers. Similarly to Majeed-Ariss et al. [51], Berkowitz et al. [54] report that, in addition to healthcare services, patient needs include community resources and access to gyms that serve to lower the barriers to performing SM activities. Because patient needs relate to both medical and non-medical factors, research should involve patients from the beginning of SM aid-development to the identification and organization of a preventative or related service and support network, e.g. family and peers. Designing mHealth or online interventions that allow for personalization or tailoring based on each individual's needs at their stage of SM or disease progress, can be another way for research to significantly address patient-reported needs for SM.

### 4.4 Limitations

Based on experience in the field of mHealth development and evaluation, which iteratively involves patients, we know that data and personal security and privacy, as well as clinical efficacy of SM aids are both important to patients [61]. However, because Review 2 focused on general SM needs reported by patients, with less emphasis on needs from mHealth or health technologies, these were not included in the extraction of patient-reported needs.

Due to the differences in aims and the kind of data we hoped to extract from the two reviews used in this paper, the time span of the searches, the databases accessed, and the type of review (systematic versus non-systematic review) were different. In addition, the reviews were limited to articles published in English language.

## 5 CONCLUSION

There are many patient-reported needs not addressed in today's diabetes mHealth and online intervention studies. In order to meet the needs of patients, facilitate the expectations and treatment goals of care teams and improve overall health and wellbeing for those living with diabetes, comprehensive interventions and methods for developing and testing mHealth and online interventions should be further explored. With today's technologies, it is more feasible and possible to realize the potential of patient

empowerment and improved self-efficacy via mHealth and online interventions. Patients' desire to share information with their HCPs can reinforce the potential of collaborating with their healthcare teams as opposed to only following directions. Therefore, the more we know about the challenges that patients face, the specific needs for patients' self-management, and the ability of health services to support these needs, the more effectively we can develop tools and services, and provide relevant interventions for both patients and HCPs.

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## 7 ACKNOWLEDGEMENT

This paper is a product of the "Design and validation of instruments to assess efficacy, effectiveness and safety of apps and online resources aimed at Norwegians with diabetes" project, funded by Helse Nord (HNF1425-18).