Design, evaluation, optimization, and adaptation of a web application for type 1 diabetes self-management

Li Feng Xie
School of Human Nutrition
McGill University
Montreal, Canada

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Thesis abstract

Introduction: Self-guided web applications (apps) are one of the digital solutions with the lowest long-term development and maintenance costs that can be used in the field of self-management of chronic health conditions (e.g., type 1 diabetes [T1D]). People living with T1D (PWT1D) are in a constant state of decision-making for glycemic control and to avoid short-term (e.g., hypoglycemia) and long-term (e.g., retinopathy) complications. Providing access to an online tool delivering diabetes self-management education and support (DSME/S) to PWT1D could be beneficial, especially when access to in-person specialized healthcare is challenging. However, a self-guided web app with evidence-based evaluation is lacking. This doctoral project aims to investigate the development of self-guided web apps, specifically in the context of T1D.

Methods: A systematic review was performed to understand the development of self-guided web apps for the self-management of chronic health conditions. A self-guided web app for adult PWT1D was then developed with a multi-disciplinary team and tested. A mixed-method registry-based proof-of-concept study was conducted for the web app evaluation. Self-reported questionnaires and semi-structured interviews were used. Data was collected at 6 months (user satisfaction, impact on hypoglycemia, web app engagement) with a follow-up at 12 months and analyzed using paired and independent t-tests and Person correlation tests. Interviews were conducted after 6 months of use (n=16), recorded, transcribed, and analyzed using inductive and deductive thematic approaches. The same web app was then used to explore the needs of youth for diabetes self-management (DSM) in the context of healthcare transition. Purposive sampling was used to recruit 21 youth living with T1D from the registry, social media, and word-of-mouth. After coding the transcribed interviews, themes were grouped using an inductive approach with concept mapping.

Results: Results from the systematic review (n=20 publications) demonstrated: 1) an absence of behavior change theory-based self-guided web apps for PWT1D; 2) less than half of the publications (40%, n=8) discussed the acceptability of the features; and 3) inconsistency in the definition of web app adherence. The *Support* bilingual (English and French) self-guided web app for DSME/S was then developed based on the Behavior Change Wheel and Behaviour Change Techniques. It is accessible from any device with an Internet connection. It is comprised of four learning paths based on the user's diabetes treatment with six categories of learning modules (e.g., diet and medication) and multiple features (e.g., discussion forum, videos). The web app evaluation was conducted on 207 *Support* users (mean age 49.2 ± 13.7, 35% men, 96% White). *Support* received a median [quartile 1; quartile 3] satisfaction of 40 [35;45] (/49). There was a decrease in hypoglycemia frequency and fear at 6 and 12 months; 51% of users reported an increase in confidence in preventing hypoglycemia after using *Support* for 6 months. Features facilitating access (e.g., email newsletters) and personalization of the information (e.g., personalized learning path) are the most appreciated. User engagement was measured by the number of page views related to the content and features, the median [quartile 1; quartile 3] was 54 [24;147] pages during the first 6 months and 0 [0;10] for the following 6 months. Youth (14-24 y.o.) living with T1D expressed interest in reliable, practical, and novel educational content. They also emphasized the need to increase social support from such a web app.

Conclusions: This project contributes to the field of digital health by demonstrating the development of evidence-based digital tools along with the fast pace of digital evolution and end-users needs. It also resulted in *Support*, a highly accepted self-management resource for PWT1D and provided evidence supporting its future implementation in routine diabetes care.

Résumé de thèse

Introduction : Les applications web sont des outils de santé digitale qui nécessitent un moindre coût de développement et de maintenance à long-terme et qui peuvent être utilisées pour la gestion de conditions de santé chroniques, comme le diabète de type 1 (DT1). Les gens vivant avec le DT1 sont dans un état constant de prise de décision pour la gestion glycémique. Fournir de la formation et du soutien pour la gestion de leur maladie est nécessaire. Il y a toutefois une absence d'application web autoguidée fondée sur des évidences scientifiques. Ce projet vise à investiguer leur développement, en particulier pour le DT1.

Méthodes : Une revue systématique d'applications web autoguidées pour l'autogestion des conditions chroniques a été faite. Une application web pour les gens vivant avec le DT1 a été ensuite développée avec une équipe multidisciplinaire et évaluée via une étude de preuve de concept avec approches mixtes. Des adultes du Québec vivant avec le DT1 ont été recrutés via le registre BETTER. Les données sont auto-rapportées via des questionnaires en ligne (0, 6 et 12 mois) et des entrevues semi-structurées à 6 mois. Des analyses descriptives, corrélation de Pearson, tests t indépendants et pairés ont été faits. Les entrevues (n=16) ont été enregistrées, transcrites, codées et analysées avec une méthode thématique inductive et déductive. La même application web été utilisée pour explorer les besoins des jeunes (14 à 24 ans) vivant avec le DT1. Un échantillonnage dirigé a été utilisé pour recruter 21 jeunes pour des entrevues individuelles. Après avoir codé les entrevues, les thèmes ont été regroupés avec la cartographie conceptuelle de façon inductive.

Résultats : Les résultats de la revue systématique (20 articles) indiquent: 1) une absence d’applications web autoguidées pour les gens vivant avec le DT1; 2) une faible proportion d’études discutant de l’acceptabilité des fonctionnalités (40%, n=8); 3) une inconsistance dans la définition d’adhésion aux application web. L’application web bilingue (anglais et français) *Support* a par la suite été développée avec une équipe multidisciplinaire basée sur la Roue de Changement de Comportement et les techniques de changement de comportements. Elle contient quatre parcours d’apprentissage selon le traitement suivi, six catégories d’information (p.ex. diète et médication) et plusieurs fonctionnalités (p.ex. forum de discussion et vidéos). Son évaluation a été réalisée auprès de 207 utilisateurs (l’âge moyen : 49,2 ± 13,7 ans ; 35% homme ; 96% Blancs). *Support* a reçu un score de satisfaction de 40/49 [35;45] (médiane [quartile 1; quartile 3]). La fréquence et la peur d’hypoglycémie ont diminué à 6 et à 12 mois; 51% des utilisateurs indiquaient une augmentation de leur confiance à prévenir l’hypoglycémie après 6 mois. Les fonctionnalités facilitant l’accès (p.ex. des courriels pour les bulletins de nouvelles) et la personnalisation de l’information (p.ex. des parcours différents) sont les plus appréciées. L’engagement, en terme de pages vues, était de 54 [24;147] pages pour les 6 premiers mois et de 0 [0;10] pour les 6 mois suivants. Lors des entrevues chez les jeunes, ces derniers avaient un intérêt pour des informations fiables, pratiques et originales à l’application et un accès à du soutien social directement sur l’application.

Conclusions : Ce projet contribue au domaine de la santé digitale en présentant le développement d’un outil basé sur les évidences scientifiques, à jour avec l’évolution digitale et en considérant les besoins des utilisateurs. La résultante est *Support*, une ressource web de formation à l’autogestion du DT1, appréciée par les adultes vivant avec DT1 et qui pourra être adaptée aux besoins des plus jeunes.

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List of abbreviations

Abbreviation	Full text
App	Application
BCW	Behaviour Change Wheel
BCT	Behavior change technique
BETTER	BEhaviors, Therapies, TEchnologies and hypoglycemic Risk in type 1 diabetes
CBG	Capillary blood glucose
CI	Confidence interval
COM-B	Capability, Opportunity, Motivation-Behavior
COPD	Chronic obstructive pulmonary disease
CSII	Continuous subcutaneous insulin infusion
DAFNE	Dose Adjustment for Normal Eating
DSM	Diabetes self-management
DSME/S	Diabetes self-management education and support
e-health	Electronic health
e-counseling	Electronic counseling
EMBASE	Excerpta Medica database
GDM	Gestational diabetes mellitus
HbA1c	Hemoglobin A1c
HCP	Healthcare professional/provider
HFS-II	Hypoglycemia Fear Survey-II
MeSH	Medical Subject Headings
MDI	Multiple daily injections
m-health	Mobile health
PRIMAS	Programme for diabetes education and treatment for a self-determined living with type 1 diabetes
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PWT1D	People living with type 1 diabetes
PWT2D	People living with type 2 diabetes
ORBIT	Obesity-Related Behavioral Intervention Trials
Q1;Q3	Quartile 1; quartile 3
QOL	Quality of life
RCT	Randomized controlled trial
SD	Standard deviation
SH	Severe hypoglycemia
SMBG	Self-monitored blood glucose
SMS4BG	Self Management Support for Blood Glucose intervention
T1D	Type 1 diabetes
T2D	Type 2 diabetes
URL	Uniform resource locator
y.o.	Years old
y.d.	Years of diabetes diagnosis

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Contribution to original knowledge

This doctoral project systematically explored current self-guided web applications (apps) for chronic health conditions, specifically the evaluation of adherence to web apps, selection, and evaluation of the features. It demonstrated the gaps presented in this area:

1. lack of consistency in the definition of adherence to a web app,
2. only a minority of the studies evaluated the acceptability of the features, and
3. the absence of a self-guided web app for people (≥14 y.o.) living with type 1 diabetes (T1D).

Additionally, this article summarized common features included in self-guided web apps. During this doctoral project, based on the systematic review [1], the first self-guided web app for adults living with T1D based on a behavior change theoretical framework (i.e., Behavior Change Wheel), *Support,* was developed. A description of how a scientific evidence approach was used for its development along with the involvement of a multiple-disciplinary team was provided. Following the design of this web app, a mixed-method proof-of-concept study was conducted for its evaluation and provided evidence for its optimization. This study showed that *Support* is a potential self-guided resource for diabetes self-management to decrease the burden of hypoglycemia. The method used can also be applied to the development of self-guided digital tools for other chronic diseases. In addition, this section provides a detailed explanation of how engagement was measured, which is often absent in the literature. It is also important to highlight the limited self-guided online tools for youth living with T1D using a behavior change framework that especially focuses on the transition of healthcare. From a web app that is already designed for adults (the *Support* web app), this doctoral project included a qualitative study investigating whether adaptation should be made for youth and how the modification should be processed.

Contribution of authors

This thesis includes four manuscripts that I (Li Feng Xie) am the first author written under the supervision of my supervisors Dr Anne-Sophie Brazeau and Dr Deborah Da Costa, with guidance from my committee members Dr Meranda M Nakhla and Dr Treena Delormier. The section below describes the contribution of each author listed in the respective manuscript.

Manuscript 1 (chapter 3): Understanding Self-Guided Web-Based Educational Interventions for Patients With Chronic Health Conditions: Systematic Review of Intervention Features and Adherence

Li Feng Xie: conceptualization, data collection and analysis, writing (original draft, review and editing), publication effort.

Alexandra Itzkovitz: data collection, writing (review and editing).

Amélie Roy-Fleming: conceptualization, data analysis, writing (review and editing).

Deborah Da Costa: conceptualization, data analysis, writing (review and editing).

Anne-Sophie Brazeau: conceptualization, data analysis, writing (review and editing).

Manuscript 2 (chapter 4): Development of the *Support* self-guided, web application for adults living with type 1 diabetes in Canada by a multi-disciplinary team using a people-oriented approach based on the Behaviour Change Wheel

Li Feng Xie: conceptualization, writing (original draft, review and editing), publication effort.

Amélie Roy-Fleming: project coordination, conceptualization, writing (review and editing).

Sarah Haag: conceptualization, writing (review and editing).

Deborah Da Costa: conceptualization, writing (review and editing).

Anne-Sophie Brazeau: conceptualization, writing (review and editing).

Manuscript 3 (chapter 5): Evaluation of *Support*, a self-guided online type 1 diabetes self-management education and support web application- A mixed-methods study

Li Feng Xie: conceptualization, recruitment, data collection and analysis, writing (original draft, review and editing), publication effort.

Asmaa Housni: data analysis, writing (review and editing).

Amélie Roy-Fleming: conceptualization, recruitment, data cleaning and analysis, writing (review and editing).

Aude Bandini: conceptualization, data analysis, manuscript review.

Treena Delormier: conceptualization, qualitative data analysis, and writing (review and editing).

Deborah Da Costa: conceptualization, data analysis, writing (review and editing).

Anne-Sophie Brazeau: conceptualization, data analysis, writing (review and editing).

Manuscript 4 (chapter 6): Adaptation of an adult web application for type 1 diabetes self-management to youth: use of the Behaviour Change Wheel to tailor youth needs

Li Feng Xie: conceptualization, data collection and analysis, writing (original draft, review and editing), publication effort.

Asmaa Housni: data collection and analysis, writing (original draft, review and editing).

Rosemarie Cianci: data collection, writing (original draft, review and editing).

Catherine Leroux: conceptualization, recruitment, data collection, writing (review and editing).

Meranda M Nakhla: conceptualization, data analysis, writing (review and editing).

Deborah Da Costa: advised data analysis, writing (review and editing).

Anne-Sophie Brazeau: conceptualization, data analysis, writing (review and editing).

Chapter 1- Introduction

1.1 Thesis rationale

Digital health refers to the use of mobile devices for health information, communication, and management with a highlight on the self-responsibility of individuals for their health [2]. Web applications (apps) are among digital health tools with the lowest development and maintenance costs [3]. Especially with a self-guided format (i.e., absence of individual contact or live presence of a person with the user). In addition to reducing the human cost for the developer team, it has the advantage of being more flexible and accessible compared to guided tools or an in-person approach. Type 1 diabetes (T1D) is an area where the use of self-guided web apps can be applied. People living with T1D (PWT1D) are in constant decisions in their diabetes self-management (DSM) considering multiple daily factors (e.g., diet, physical activity) to maintain their normoglycemic level [4] and need to be kept updated with the evolving information and skills in T1D self-management. However, there are limited studies on how a self-guided digital health tool targeting the needs of PWT1D in their DSM can be developed based on scientific evidence along with the fast evolution of digital technologies.

1.2 Thesis objectives

Therefore, this doctoral project aims to investigate the development of self-guided web apps for chronic disease management using T1D as an area of application. More specifically, to 1) understand how current self-guided web apps for chronic health condition self-management are developed and identify its gaps in the literature; 2) design a self-guided web app for DSM of adults ($\geq$ 18 y.o.) living with T1D; 3) evaluate this web app (i.e., acceptability, impact on hypoglycemia) and provide insights on the web app optimization; 4) investigate the needs of youth and young adults (14-24 y.o.) for T1D self-management especially focusing on the period of transition from pediatric to adult healthcare and how this web app can be adapted to their needs.

1.3 Research questions

Manuscript 1: Systematic review

Research questions: How self-guided web-based web apps were designed and evaluated? What are the most commonly selected features? How adherence to web-based self-guided interventions were defined and measured?

Scientific proposition: Since there are no laboratory experiments or statistical analyses associated with this review, only a scientific proposition was formulated. Based on evidence from previous studies [5], features related to personalization and feedback would be the most appreciated by the users.

Manuscript 2: Web app (*Support*) design

Objective: Design of *Support*, a self-guided T1D self-management web app.

No hypothesis or scientific proposition will be formulated as this is a descriptive process.

Manuscript 3: *Support* evaluation

Research questions:

Primary outcome: What will be the level of satisfaction among users after 6 months of using *Support*?

Secondary outcomes: What will be the changes in hypoglycemia (frequency and fear) after 6 and 12 months of use and changes in diabetes self-efficacy (i.e., self-efficacy in preventing hypoglycemia and glycemic management) after 6 months?

Hypothesis and scientific propositions: It was expected that *Support* would receive a satisfaction score similar to other digital interventions with a score of ≥ 75% [6] and a decrease in hypoglycemia burden (frequency and fear) after 6 and 12 months of use and an increased diabetes self-efficacy after 6 months.

Manuscript 4: *Support* adaptation

Research questions: What will be the interest and needs of youth living with T1D (14 to 24 y.o.) for T1D self-management in the context of healthcare transition? What are adaptations to *Support* required for this population?

Scientific proposition: My scientific proposition is that the format of *Support* will be positively accepted by youth, they will have similar feature preferences to adults, but the features might be presented in different ways [7], and their interest in the learning content will differ from adults.

Chapter 2: Background review

2.1 Digital health

The 2030 Agenda for Sustainable Development published by the United Nations accentuated the use of cutting-edge digital technologies for universal health coverage and highlighted the opportunities brought by digital health for the achievement of the 17 Sustainable Development Goals [8]. The concept of digital health is an extension of electronic health (e-health), mobile health (m-health), and advanced concepts of computer sciences (e.g., big data). Compared to e-health, where the focus is on the use of the Internet for the prevention and rehabilitation of health, and m-health, where the focus is on the use of mobile devices for health information, digital health aims to portray a higher degree of self-responsibility of individuals for their health [2]. Digital health refers to the development and use of digital technologies (e.g., computers, phones, electronic devices) for health-related communication and management [8, 9]. It includes products and services such as telemedicine, social media, digitized health record platforms, and health and wellness tools [10]. These can be used in areas such as diagnosis, prevention, and treatment of diseases [10].

Digital health interventions can reach a greater population, being highly interactive and personalized, delivered with greater fidelity [11], and decreasing logistical challenges (e.g., scheduling, travel time) that can be encountered with traditional face-to-face intervention delivery. Despite the opportunities provided by the use of digital health technologies, their use also creates new challenges in their implementation and monitoring [12]. Among these, we can observe 1) a variable level of digital and health literacy in the general population [13, 14]; 2) increased possibilities of creating health inequality [13]; 3) unclear end-user expectations [14-

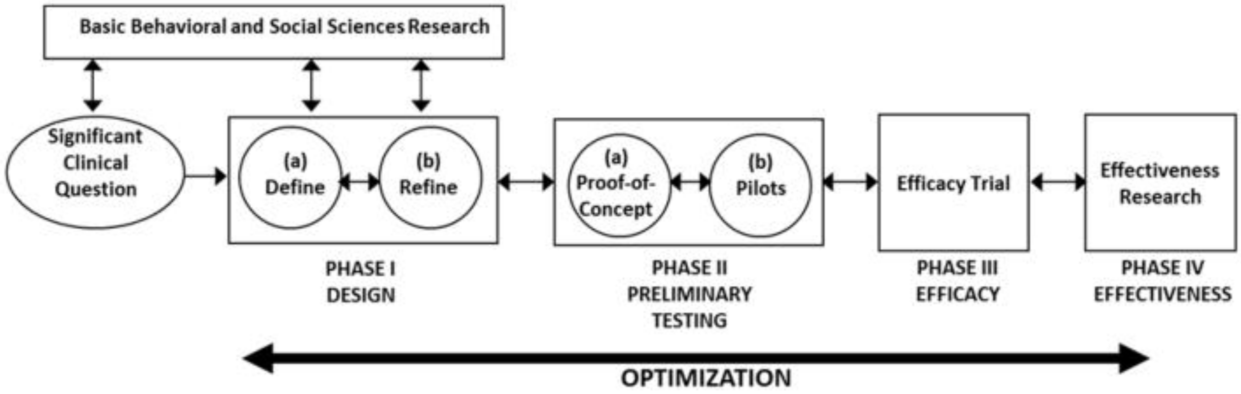
16], and engagement [15, 17]; 4) a potential spread of medical misinformation (e.g., via social media) [13]; 5) difficulties in keeping up with the latest digital technology (e.g., updating the intervention to the latest software version) [12, 17]; 6) a lack of evidence-based research on the health effectiveness [12, 13, 15, 18]; 7) a lack of acceptance from the public due to uncertainties in digital health policies and legislation [13]; and 8) data ownership and privacy concern [12, 17]. To reduce these challenges, it would be essential to provide evidence-based findings on the effectiveness of these interventions through a transparent, secure, and replicable development process, including its design, evaluation, optimization, and adaptation [8, 19].

2.2 Development of digital health interventions and the ORBIT model

The term development here is referred to as the early-phase translation of an intervention: the overall process used to realize a digital health tool before its implementation in the real world, it includes the iterative approaches of the design, evaluation, and optimization of the intervention [20]. The later-phase translation usually refers to the dissemination and implementation [21].

The use of a framework in the development phase encourages a systematic and unified approach to developing and testing interventions by bridging elements needed through various phases. It also increases the success of interventions in the implementation phase by recognizing the failures in the early process [22]. One of the proposed frameworks for developing complex digital health interventions is the use of the Obesity-Related Behavioral Intervention Trials (ORBIT) model (Figure 2.1) [22]. This model focuses on the early-phase translation of evidence-based behavior interventions for the treatment or prevention of chronic diseases and focuses more on the clinical rather than statistical significance [22, 23]. The ORBIT model highlights the translation from basic science through clinical science to implementation science. It encourages flexibility and an iterative process that facilitates refinement and optimization of the intervention [22].

Figure 2.1 The ORBIT model for behavioral treatment development



The model (Figure 2.1) starts with finding a significant clinical question based on basic behavioral and social science research and is then followed by three phases for the early-phase translation: phase I- design, phase II- preliminary testing, phase III- efficacy, and one phase (IV-effectiveness) for late-phase translation. Optimization can occur at any of these four phases. Phase IV will not be discussed as it goes beyond the scope of early-phase translation and is only included in the model to show the presence of continuity in the development process.

This model displays a general development process. It does not require the integration of all these phases and can be performed in any order. It thus offers flexibility to transdisciplinary developers to identify the specific ORBIT sections needed to support their trial. While the traditional randomized controlled trials (RCTs) still have value, this model acknowledges the use of other study designs based on the goal of each phase. In addition, dividing the developmental cycle into phases decreases the risk of abandoning premature treatments that have weak clinical outcomes due to a lack of understanding of their mechanism. The progressiveness of the development process also increases the chance of developing an intervention that is robust enough to face the diverse factors once it will be implemented in the real-world (phase IV and beyond) [22].

Based on the ORBIT model, we will discuss three key components of the early-phase translation: design (mainly at phase I), evaluation (phase IIa), optimization (throughout the development cycle), and adaptation (restart the model for a new intervention based on a developed one).

2.2.1 Design of digital health interventions

In general, the design and evaluation should be performed hand-in-hand in an iterative approach within the development cycle [24]. However, for this thesis, they will be presented separately. In our context, the design stage is referred to as the initial process of selecting the goal, components (including the content), and format of delivery of the digital health intervention (e.g., via web or mobile based). Currently, there is still a lack of standardized approaches for the design of digital health interventions [25-28]. However, two key considerations have been highlighted in the literature to design more effective interventions [29], namely 1) involvement of multi-disciplinary expertise (including end-users) and 2) integration of theoretical frameworks [17, 25].

Involvement of multi-disciplinary expertise

Digital health interventions are usually composed of multiple components and vast expertise is needed for their development. Effective collaboration and communication of an interdisciplinary team including healthcare professionals (HCPs), behavioral scientists, people who deliver (or facilitate) the intervention, engineers, computer scientists, and end-users would be suggested [17]. These strategic alliances facilitate the creation of digital health tools using new digital technologies and computation capabilities [12] and generate new ideas [24].

End-users are a key category of stakeholders to facilitate the selection of the features (i.e., functionality facilitating the learning or navigation experience of the user other than the learning content [1]), method of intervention delivery, and increase the usability and engagement of end-users [20]. They should be involved from the early design stage and continue throughout the developmental cycle [20, 25]. The incorporation of end-users can also be referred to as a people-based or people-oriented approach. This has the goal of understanding the needs of its end-users and can result in interventions accommodating their perspective. Qualitative methods are often used to identify physical, emotional, and cognitive factors influencing behaviors related to the health outcome, their expectation, reason, and method of using these interventions. Framework or guidelines regarding their role should be referred to ensure that their voice is heard and that the end-users have an equal vote around the table. For instance, the Canadian Institutes of Health Research developed a Patient Engagement Framework to encourage the participation of patient representatives in all steps of the research procedure (e.g., design of the research protocol, recruitment, and finding dissemination) to co-build projects responsive to their needs [30]. This framework highlights that people living with the disease should be adequately represented with integrations of diverse perspectives (e.g., including people from various social backgrounds, gender, and ethnicities). It also stipulates researchers respect the degree of the contribution that a patient partner is ready to offer and provide support (e.g., training, financial compensation) to ensure that they can fully participate in the decision-making [30].

Integration of theories or frameworks

When behavior changes are key to leading a change in clinical outcomes, the use of behavioral change theories or theoretical frameworks would be suggested to increase the precision and efficacy of the intervention by facilitating the understanding of mechanisms behind the target behaviors [23, 31]. However, it is often not included and interventions are frequently built on common sense [18]. In addition, the selection of the relevant theories is also challenged by the overlapping of constructs, their lack of definition, and their understanding of their interrelationships [23]. The behavior change techniques (BCTs) (e.g., goal-setting, social support, feedback) are considered the building blocks of digital health interventions implying a behavior change mechanism [32]. However, many of the existing behavior change theories are not linked to the BCTs. By breaking down factors influencing the target behavior and associating each of them with one or more BCTs, the intervention has a higher chance of directly tackling the underlying issue and increasing the intervention potency [23].

To bridge these gaps, the Behaviour Change Wheel (BCW) can be used to design digital health interventions implying behavior changes. It is a non-linear model inspired by a combination of 19 existing frameworks [18]. It has three layers with the Capability, Opportunity, Motivation-Behavior (COM-B) model at the core to guide the understanding of the behavioral mechanism; encircled by nine intervention functions (i.e., activities needed to change behavior), such as enablement, training, and education; and finish with an outer of seven policy categories (i.e., actions needed from the related authorities to enable or support interventions), such as marketing, guidelines, and legislation [18]. The use of the BCW helps to identify factors influencing the target behavior and provides the basis for systematically selecting interventions and policies. The selected interventions can be then associated with one or multiple BCTs to enhance or minimize the influence of key factors of behavior (i.e., factors identified from the COM-B model).

2.2.2 Evaluation and optimization of digital health interventions

Rigorous evaluation of digital health interventions is important for the continuous improvement of the intervention, informing the health impact, and reducing health inequalities (e.g., ensuring adequate distribution of health care resources) [9]. It should go beyond the clinical outcomes by including evaluation criteria for its stability (e.g., the intervention system works), usability, positive user experience, and effective user engagement [15, 20, 25]. The evaluation should also be performed in all phases of development iteratively, using mixed methods with a combination of subjective (e.g., perceived level of satisfaction) and objective (e.g., system usage metrics) measurements [17].

Qualitative research methods (e.g., semi-structured interviews) help to explore users' perspectives on using the intervention. These methods facilitate the understanding of different intervention components (e.g., features) and provide insight into which part of the intervention may be contributing to a positive impact and how the intervention can be improved. However, qualitative methods are often based on a small sample size which limits their generalization, and they cannot draw any conclusion on the cause-and-effect relationship [29]. In contrast, quantitative methods (e.g., quasi-experimental studies, RCT) can indicate statistical relationships and can be conducted with a larger population. These two methods complement each other by providing a triangulation of the results and similarities between the results can demonstrate the robustness of the findings [29].

When evaluating digital interventions, it would also be essential to acknowledge their specificity and adapt the research strategy accordingly. Among these, we can find:

1) Being up to date with the rapid evolution of the technology landscape

To stay with the fast pace of digital evolution, digital interventions can start with a minimum viable product (i.e., the minimum number of components needed to test the intervention idea) and then move on to evaluation for the optimization and refinement of the intervention [33, 34]. During this evaluation phase, researchers should consider the time needed from the study design to results dissemination. Development of digital technology often requires an operating system (e.g., the iOS system for iPhone), which is regularly updated for its functionality, design, and overall use. If a mobile app needs many years for its evaluation, by the time the results are published, the app might need a newer system [35, 36]. The method of evaluation should thus consider the time requirement, and whether the results remain adapted to the contextual factors once obtained.

2) Controlling the testing environment

Pre-post design is currently the most commonly used method in evaluating digital interventions with the pre-phase as control data followed by the post-phase where intervention is implemented [16]. It has an advantage over RCT as it uses fewer resources (e.g., monetary and time), but it is difficult to control for the testing environment [16]. Participants of digital intervention also tend to search information online for the same problem and this external resource finding might be difficult to be tracked in the study design [36]. The influence of these factors should be considered when analyzing the study results.

3) Identifying the key components of the intervention

Digital health interventions implying behavior changes are often considered complex interventions with many components (e.g., content, features) requiring a high development and maintenance cost. Some components might be frequently used but not considered effective (i.e., components that are causally linked with the outcome) [37]. When they are delivered as a whole, it is difficult to discern the components acting on the outcome and decide on the minimum set of components to be included. Therefore, its optimization throughout the development phase with factorial experimental design can be beneficial [36].

4) Evaluating the engagement in the intervention

In-person interventions or earlier computer-based interventions that replicated therapeutic coaching "sessions" can use the "number of completed sessions" as the measurement of the engagement [17]. However, in digital interventions, users might only use the intervention briefly every time they need to obtain information [17]. The perceived personal relevance (i.e., perception of how the intervention can be applied to their situation), motivation and expectation at the moment, social and physical environment, and methods of intervention delivery can all impact the way that the intervention is being accessed and used [37]. In addition, given the complexity of digital interventions, engagement in the intervention can be multidimensional and the traditional way of measuring engagement is no longer suitable [17].

When evaluating behavior-based digital interventions, engagement can be defined based on a combination of the one used in computer science and behavioral literature. In computer science, engagement is referred to as a subjective experience of flow, where the user is focused on the intervention and presence of a state of enjoyment [37]. In behavioral literature, engagement is referred to as the usage of the intervention related to the temporal patterns (e.g., frequency) and depth of usage (e.g., amount of information viewed) [37]. Therefore, researchers should combine subjective and objective measurements. Consideration of the aim of the intervention (e.g., target behavior), user's context (e.g., user's experience obtained via surveys, semi-structured interviews), usage of the intervention over time (e.g., frequency of log-in obtained via automatic tracking), physiological measures (e.g., cardiac activity), and psychophysical measures (e.g., eye tracking) should be made to find the valid and efficient engagement measurement combination [17]. Furthermore, researchers should also acknowledge that engagement in digital intervention is a dynamic process that varies both over time and across individuals and that the optimal dose (i.e., pre-defined level of engagement at which the digital interventions are effective) may vary depending on the user characteristics [37].

Therefore, for the purpose of this thesis, engagement is defined as the degree of interaction between the user, it can be the same parameter used to describe the digital tool usage but it should reflect the research question or the goal of using the digital tool [38]. The engagement differs from the term “adherence” as the latter would imply the presence of intended usage [39].

5) Collecting and sharing data

The large amounts of data collected by digital interventions can both be an opportunity and a challenge to their evaluation. The information can include identifiable data regarding the geographic location, and social networking of the user and be threatening to the user’s privacy [17]. While proceeding to the data collection, researchers need to be transparent about how the data is being collected, shared, and used. Information disclosed to the participants should include data ownership, protection, and commercialization [17].

These challenges thus highlight the need to adapting a pragmatic and agile approach in the evaluation of digital health interventions to support real-world behavior change by starting with a minimum viable intervention responding to the basic needs of stakeholders, being flexible in the development process, conducting the evaluation under usual conditions, and being sensible to the contextual and individual factors [33, 40].

2.2.3 Adaptation of digital health interventions

Digital health interventions have the advantage over in-person sessions of being applied on a wide scale and are flexible in their adaptation to a specific population. Studies have shown that interventions are more likely to be effective when they are tailored to the needs and goals of the population [41, 42]. Therefore, even with a slight change in the characteristics of the target population (e.g., moving to a younger group age), it would be important to reassess the social, contextual, and individual factors, and needs of the new group by reapplying the ORBIT model to ensure that the intervention can be adapted to novel contexts without compromising the fidelity and integrity.

2.3 Overview of type 1 diabetes

Digital health interventions can provide health information, education, and support as a supplement to their routine care [24]. Type 1 diabetes (T1D) is a chronic disease where self-management behaviors are key to the condition management and include behaviors such as meal planning, carbohydrate counting, performing physical activities, smoking cessation, and regular insulin administration [43]. Previous studies also reported a varied adherence rate depending on the type of behavior and the population [44-47]. People living with T1D require life-long learning in relation to their T1D self-management [48] and this can be provided with the use of digital health interventions.

A modelling study published in 2022 estimated that based on the sum of mid-year prevalence estimates of people born in 1922 up to 2021, the prevalence of people living with T1D (PWT1D) in Canada was 276 284 in 2021, including 31 601 people 19 years and lower [49]. The exact cause of T1D is currently unknown; however, potential factors include genetic predisposition, viral infections, and environmental issues [50]. T1D can be diagnosed at any age, but mainly occurs in childhood and youth (i.e. before 30 years old) [51].

T1D is often confused with type 2 diabetes (T2D) by the general public [52]. Despite the similarities they share in their symptoms (e.g., hyperglycemia), they are distinct in their pathophysiology and management [52]. PWT1D also prefer to be self-identified as “individual affected by T1D” rather than “individual affected by diabetes” (e.g., being mixed with other types of diabetes such as type 2 diabetes [PWT2D]) [53].

T1D is a chronic autoimmune disease characterized by an insulin deficiency due to the damage or destruction of beta-cells in the islets of Langerhans leading to hyperglycemia [51]. In PWT1D, insulin therapy is an essential medical treatment and is needed starting from the diagnosis. Because of the use of insulin and the early diagnosis, PWT1D are also at risk of developing many health complications [54]. In short term, among PWT1D, inadequate daily insulin administration and self-monitoring can lead to severe hyper- or hypoglycemia [55]. Long-term hyperglycemia can lead to micro- (e.g. retinopathy) and macro-vascular (e.g. strokes) complications [56], and a reduced life expectancy [55]. Thus, these complications highlight the importance of self-management in those with T1D.

The concept of “self-management” can be referred to as a day-to-day activity (e.g. healthy eating, medication adherence, regular physical activity) needed by an individual to control or reduce the impact of a disease on their health [4]. Self-management is required at the moment of the T1D diagnosis and is to be maintained for a lifelong. Diabetes self-management (DSM) (e.g. glycemic management) often encounters daily barriers such as family (e.g. taking care of others), work (e.g. lack of a routine schedule) situations, and life span events (e.g., pregnancy) [57].

Because PWT1D are often diagnosed at a very young age, many of them will experience the transition from the pediatric to the adulthood healthcare system (i.e., transition of care) [58].

Previous studies reported that over 25% of transitioned young adults felt “worried” or “apprehensive” about this change [59] and many topics (e.g., birth control) remained undiscussed or assumed by the healthcare team (from both the pediatric and adult side) [59]. In addition to having to adapt to the new healthcare environment at 18 y.o., DSM for people at this transition stage (e.g., 18 to 25 years old [y.o.]) is further challenged by changes in responsibility of the disease (e.g., taking care of their diabetes instead of their parents) and shifts in social situations (e.g., transiting from school to part-time work environment) [60, 61]. Extra time and effort have to be put in compared to pre-transition to adulthood for DSM. At this stage, DSM behaviors (e.g., blood glucose monitoring and carbohydrate counting) can be even more considered an “extra thing” and traded for school, work, and extracurricular activities [62]. Compared to other population, youth at the transitioned stage also has a higher no-show or cancellation rate for their medical appointments, and adult care clinics might have strict attendance policies which can penalize youth for their absence[63]. These social-environmental changes might further trigger insulin-induced hypoglycemia, which is seen as one of the most important barriers to blood glucose management among PWT1D and achieving optimal health behaviors (e.g. diet [64, 65] and physical activity [66, 67]) [4, 68, 69]. Furthermore, in addition to the glycemic outcomes, interventions for this age group should also target outcomes such as their readiness to transit, T1D knowledge/skills, and “ownership” of T1D self-management [70].

2.3.1 Type 1 diabetes and hypoglycemia

Hypoglycemia refers to a low plasma glucose level (<4.0 mmol/L), the development of autonomic (e.g., trembling, palpitations, sweating) or neuroglycopenic symptoms (e.g., confusion, dizziness, vision changes), and response to the consumption of carbohydrate [71]. In

2018, a Canadian report showed the rate of hypoglycemia at 128 events/adult/year [72], but the true rate is often underestimated as people do not always confirm their low blood sugar when the associated symptoms appear and some hypoglycemia is asymptomatic. Hypoglycemia occurs when there is an excessive dose of insulin administration, a mistake in the time or dose of insulin given, increased use of blood glucose, or an insufficient external glucose intake [73].

In people with functional beta cells, physiologic responses will be triggered when the plasma glucose level goes below the physiologic threshold. The insulin secretion will be decreased, and glucagon will be released to increase plasma glucose. Among PWT1D, this physiologic feedback is absent due to the lack of insulin [73]; and if no action is taken (e.g. fast glucose administration), this can progress to severe hypoglycemia (SH) (i.e., a blood glucose level usually below 2.8 mmol/L needing the help of another person [74]). Repeated hypoglycemia might decrease the physiologic threshold of an individual and cause hypoglycemia unawareness due to decreased sympathetic feedback [73]. Hypoglycemia unawareness is associated with a 6-fold increase in the risk of SH [75] and can lead to the fear of hypoglycemia. Fear of hypoglycemia correlates with the level of hemoglobin A1c (HbA1c, a measurement of blood glucose) [76]. Due to this fear, PWT1D might maintain a high level of blood glucose and in the long-term, this can increase the risk of hyperglycemia-related complications (i.e., micro- and macrovascular complications) [76]. Both hypoglycemia and fear of hypoglycemia are associated with diabetes-related anxiety, reduced health-related quality of life (QOL), and higher healthcare costs [76-78].

2.3.2 Hypoglycemia prevention using medical technologies and therapies

Prevention of hypoglycemia is key to adequate blood glucose management [73]. For this thesis, medical technologies are defined as electronic devices that can help assess the level of blood glucose or/and administration of therapies (e.g., continuous glucose monitoring [CGM] and insulin pump) [73]; and medical therapies refer to medications given for the management of blood glucose (e.g., long-acting basal insulin and nasal glucagon injections).

Despite the positive results on the potential of these technologies and therapies in improving blood glucose control (e.g., measured by HbA1c) [79] and being considered a common facilitator of DSM [4], many barriers are still present in their use. Challenges decreasing their effectiveness include a lack of adequate knowledge in their use by both PWT1D and healthcare providers (HCPs) [75, 80] and difficulty in understanding the recommendations [81].

2.4 Digital health intervention and type 1 diabetes

2.4.1 In-person type 1 diabetes self-management education and support interventions

Diabetes self-management education and support (DSME/S) interventions are cost-effective methods to improve HbA1c, QOL, and behavioral and psychological aspects of PWT1D. They provide information and strategies, on an ongoing basis, to empower people living with this condition to make decisions, engage in self-care behaviors, and encourage them to participate actively in their diabetes management [82]. DSME/S interventions include diabetes knowledge and skill transfer in various aspects (e.g., diet, physical activity, medication) guided by evidence-based research. They are also designed in a people-oriented approach based on the characteristics (e.g., health beliefs, financial status), needs (e.g., emotional concerns, cultural needs), preferences, and other factors of the target population regarding DSM [82].

Traditional DSME/S interventions have been delivered in an in-person manner such as the Programme for diabetes education and treatment for a self-determined living with type 1 diabetes (PRIMAS) and Dose Adjustment for Normal Eating (DAFNE). Those two examples are both delivered in group sessions for adults living with T1D by trained educators in diabetes but with slightly different intervention lengths and evidence-based content. The PRIMAS is delivered in 12 sessions of 90 minutes each over six weeks with support material in-between (e.g., worksheet for goal setting, the exercise of carbohydrate estimation). It aims primarily to promote diabetes empowerment through a better understanding of diabetes treatments, diet, insulin adjustment, physical exercise, and barriers in DSM (e.g., diabetes distress, lack of social support). It also tends to facilitate the detection and treatment of acute complications (e.g., hypoglycemia) and the prevention, and early detection of late complications (e.g., retinopathy). The sessions are incorporated with nutrition games to increase the interactivity, and people living with the condition were able to invite their family and friends to the tenth session of the intervention (i.e., the session on social support) [83]. Compared to the PRIMAS, the DAFNE is offering a longer length. It was initially delivered for five consecutive full days (eight hours per day) with a follow-up session after eight weeks [84]. However, due to the potential access barrier and to encourage patients to apply the information in between [85], another format was offered with one full day per week for five consecutive weeks. The curriculum is similar to the PRIMAS' with the information provided on an overview of diabetes, food and diabetes, insulin management, and hypoglycemia management. The DAFNE also contains medical and social situations for the application of learning and uses giving meals and snacks to practice carbohydrate counting and insulin adjustment [85]. However, these interventions provide an overview of insulin therapy without specifically targeting the functionalities of medical therapies and technologies.

Both interventions have been proven to have clinical effectiveness (e.g., reducing HbA1c, diabetes-related distress, and frequency of hypoglycemia [83, 86]) and this impact has been shown to last after seven years of the intervention participation [86, 87]. The PRIMAS study also reported a slightly improved self-care behavior among the control and the PRIMAS group but no precision was provided on the type of behavior [83] and people from the DAFNE study expressed a better food choice through an increased diabetes self-management knowledge and empowerment [88]. Nevertheless, there are challenges in accessing this intervention. In addition to the travel time and schedule availability, this in-person and group format delivery can become a barrier to many because of stigmatization (e.g., people would have to expose their conditions to others [89]), lack of long-term access to educational sessions [90], difficulties in recalling the information after the sessions [90], and lack of accommodation to different health literacy levels [91].

The unexpected COVID-19 pandemic also created a turning point for the format of delivering healthcare services. The stay-at-home order was imposed by many countries and in-person healthcare consultations were limited. An alternative was the use of digital technologies to deliver DSME/S interventions. The DAFNE team quickly responded by offering the intervention remotely (i.e., Remote DAFNE) which takes five weeks to complete and weekly group video support calls given by a trained DAFNE educator [84]. The effectiveness of this new Remote DAFNE intervention has not been published yet. In parallel, adding a live human component can increase the cost of intervention and decrease its accessibility (e.g., the user might need to schedule an appointment) [17]. Therefore, the use of a self-guided digital DSME/S intervention (i.e., absence of live human component or one-on-one interaction with the healthcare team) would benefit both the development team and the end-users in terms of cost and accessibility.

2.4.2 Self-guided digital intervention and social support

One concern about using the self-guided digital format for delivering health interventions is the lack of social support. A meta-analysis published in 2017 found that from the 28 studies including 5 242 participants with T1D or T2D, the perceived social support was significantly correlated with the diabetes self-care [92]. In 2020, an Australian survey performed on 1 727 people living with diabetes (T1D and T2D) showed a higher perceived social support was associated with greater self-efficacy and lower distress across both types [93].

Social support is defined as the help given to a person from his/her social bonds when they need it [94]. Perceived social support can be influenced by sociodemographic characteristics and the cultural context of an individual [92]. Social support can come from the HCPs, family, friends, peers, or institutions. Social support is further divided into emotional (e.g., sharing life experience), appraisal (e.g., providing information for self-evaluation such as constructive feedback or affirmational comments such as praise for a behavior), informational (e.g., providing guidance to address a challenge), and instrumental (e.g., providing financial or goods) [92, 94, 95]. Compared to in-person DSME/S interventions, self-guided digital interventions maintain the ability to provide informational support from HCPs. However, due to the lack of in-person contact (e.g., with HCPs and peers), there are a limited possibility of providing informational support from peers, and appraisal and emotional support in general.

To overcome the limitation of lacking social support, self-guided digital interventions can be delivered using or incorporating social media platforms (e.g., Facebook), having features such as online discussion forums, chatrooms, and game competitions to promote emotional support [96-98], and have automatic personalized feedback and motivational messages for appraisal support [95]. These methods of incorporating social support provide users with the possibility to self-express in an anonymous way, which is difficult to attain with in-person interventions [94].

2.4.3 Digital type 1 diabetes self-management education and support interventions

Internet and mobile technologies are commonly used among the general public of all ages. In 2020, the number of smartphone users in Canada reached more than 31 million [99] and the number of mobile phone users who accessed the internet via mobile phone at least once per month was more than 29 million [100]. In 2021, 96% of Canadians (36 million) accessed the Internet at least once per month and it is estimated that this number will reach 99% in 2026 [101]. There is also increased use of digital technologies among the older age group (≥ 65 y.o.) since 2010 [102, 103].

Regarding T1D, a survey conducted in 2018 in Norway showed that among 514 adults living with T1D, 87% used one or more forms of e-health (mobile apps, search engines, social media, or video services) sometimes or often during the previous year [104]. A report published by

Juvenile Diabetes Research Foundation in 2020 shows that, based on Britain source, using the Internet and online forums were among the top three methods used by PWT1D to obtain health information, along with diabetes specialist nurses and other HCPs [105]. These promising findings highlight the possibility of using digital tools to deliver DSME/S interventions.

DSME/S interventions delivered through short message service

Digital self-guided DSME/S can be delivered in a mobile or web-based format. Examples of delivering in a mobile-based format include the use of short message services and mobile apps. For instance, the Self Management Support for Blood Glucose intervention (SMS4BG) was developed for people who are 16 years and older living with poorly controlled T1D or T2D (i.e., HbA1c $\geq$ 8% in the nine months before the intervention) across New Zealand. This short messaging service delivered intervention was designed following the mHealth Development and Evaluation framework [106] based on behavior change theories with a multidisciplinary team including HCPs. The number of text messages delivered varied from 30 to 461 messages over three months with a minimum of two text messages per week. After three and six months interventions, users were able to choose if they can continue for another three months, for a total of nine months [107]. The intervention included mandatory content for general motivation and support for diabetes management (e.g., on diet and physical activity) and optional ones tailored to the user's situation (e.g., smoking or not) and the user's choice (e.g., stress management, blood glucose monitoring reminder). Users could select the timing of their message and reminder, stop or hold the intervention at any time. People were able to receive the intervention for free but when responding to the text message (e.g., sending a blood glucose value), $0.20 per message would be charged by the user's phone service provider. Users' blood glucose value was sent to a password-protected website where the information can be shared with their HCPs [107]. Based on this three months pilot study with 42 participants (T1D and T2D; age range from 17 to 69 y.o.; New Zealand European, Māori, Pacific, and Asian ethnicity) the intervention was proven to be culturally acceptable [107]. A RCT with 366 participants also showed that this intervention led to a significantly greater reduction in HbA1c and other health outcomes such as foot care behavior, and overall diabetes support compared to the control group (i.e., receiving usual care from their medical team) after nine months of intervention [107].

Delivering DSME/S intervention using a short messaging service can indeed be an easy way to operate but due to the need of using a mobile network, its delivery can only be limited to a specific region (e.g., phone network is often limited to one country and user needs to pay a long-distance fee when they change to another one). This method is also often limited to one-way communication (e.g., from the intervention platform to the user) and restricts the ability to receive the user's feedback. In addition, the content delivered has to be limited in the number of characters which contrasts with the flexibility of content delivered via other formats, such as via mobile and web apps [108].

DSME/S interventions delivered through mobile apps

A survey conducted from 2017 to 2018 with the online community of people living with diabetes (n=1 682 respondents; 63% PWT1D) found that 30% go first to Facebook group/Internet/smartphone app for assistance regarding diabetes management concerns, and 52% use a diabetes app. The use of a mobile app for DSM was also one of the factors positively associated with self-care behavior scores, along with being older, and consulting diabetes specialist teams or other HCPs [109]. However, despite the number of mobile apps for chronic health condition self-management had exponentially increased during the last decade, the lack of scientific evidence in their development, evaluation, and regulation remains an issue [35, 110, 111]. In 2018, the Agency for Healthcare Research and Quality in the United States produced a report "Mobile Applications for Self-Management of Diabetes" and found that among hundreds of mobile apps for DSM that are commercially available, only 11 apps were evaluated for impact on health outcomes, and only five showing a clinically significant reduction of HbA1c of 0.5%, including two for T1D and three for T2D. None of the included studies were considered as having high-quality research methodology due to a lack of information on randomization and allocation concealment, absence of drop-out analysis, and high rates of attrition [112]. Similarly, a meta-analysis published in 2019 by Wu et al. showed that there is inconclusive evidence on the efficacy of mobile apps for lifestyle modification in T1D [113].

In addition to a lack of evidence of their clinical impacts, mobile apps are often not based on evidence information. The American Association of Diabetes Educators Self-Care Behaviors™ guidelines form a framework for diabetes care behaviors and can be used as a standard in developing DSME/S interventions. The seven self-care behaviors include Healthy Coping, Healthy Eating, Being Active, Taking Medication, Monitoring, Reducing Risk, and Problem Solving [114]. An analysis published in 2018 found that, among the 137 eligible DSM mobile apps retrieved from iTunes and Google Play, features were not equally covering these topics [111]. Most DSM mobile apps included features related to Healthy Eating, Being Active, Monitoring, and Taking Medication but few related to Problem Solving, Reducing Risks, and Healthy Coping [111]. A study published in 2018 by Martinez-Millana et al. [5] proposed a taxonomy of ideal features to be included in a mobile app for T1D self-management (i.e., improving clinical outcomes) and explored the included ones in current mobile apps for PWT1D. They proposed that features such as data management, tips and support, reminders, rewards, support, and aspects relating to personalization should be included. Their findings showed that none of the 80 identified apps corresponded to the ideal app. They also found that the choice of features in these apps is not consistently justified [5]. The lack of regulation among diabetes management-related apps further decreases their clinical reliability. A study published in 2015 found that only 14 of the 46 English-language bolus calculator apps provided documentation for calculation formulas and 42 lacked numeric input validation [115]. Furthermore, many DSM apps were developed by small teams lacking expertise in the field and without a long-term commitment, the apps were abandoned after a certain time [116]. All these pitfalls of diabetes apps increase the challenges for both the HCPs and people living with the condition in using them for DSM.

Nevertheless, recent studies show the development of more evidence-based self-guided mobile apps for DSM. An example from a 2020 publication is the My Care Hub mobile app for PWT1D and PWT2D. This app was developed with a multidisciplinary team (including patient partners) based on behavior change theories. In addition to evidence-based learning content, it also has features such as self-monitoring (e.g., blood glucose measurements, weight), carbohydrate content in common foods in Australia, and automated motivational feedback in response to the entered glycemic values. The recommended glycemic level was adapted to the type of diabetes. This intervention was tested for its usability on 12 participants (including four people living with the condition) and was rated as appropriate for its easiness of use and recommended for other people with the condition [117]. However, clinical outcomes are still not published [117].

Indeed, there are continuous evolvements in mobile apps for DSME/S, and efforts to regularize their use were implemented by health and governmental organizations. For example, the American Association of Diabetes Educators Diabetes Advanced Network Access online technology initiative established a Review Library for finding trusted resources on diabetes apps (DANAapps.org) [118]. In 2015, the U.S. Food and Drug Administration released a guidance document defining apps that need regulation compared to ones that do not [35]. Health Canada also established a new division within the Therapeutic Products Directorate's Medical Devices Bureau to facilitate the revision of the digital health technologies [119].

Nevertheless, it would also be essential to consider the intervention aim, and the available resources of the developer team when choosing the method of intervention delivery. Mobile-based interventions can be more accessible than computer-based due to their easiness to be carried out at all times and it offers features such as notification alerts which might not be tangible otherwise [29]. Nonetheless, compared to the interactive web design format of delivery (i.e., web apps), mobile apps are more costly, time-consuming in their development, and more difficult to be updated [3]. In addition, web apps can be easily adapted to mobile screens and navigated through the mobile Internet browser, but the reverse is more difficult to realize. Especially in the field of T1D where medical treatments are evolving rapidly and where the learning content has to be regularly updated [120, 121], the use of web apps to deliver interactive DSME/S interventions can be more beneficial for both the users and the developer team.

DSME/S interventions delivered through web apps

Given the specific needs (e.g., pathophysiology of the condition, transition in healthcare) of PWT1D, digital DSME/S interventions should be tailored [52], and should provide a unique environment where PWT1D can obtain peer-to-peer support from people who live the same reality [122, 123]. Yet, based on a systematic review published in 2020, there is no literature on clinical outcomes of self-guided web apps on DSME/S interventions targeting adults PWT1D developed based on behavior change theories, and only four self-guided interventions with clinical outcomes tailored for T2D were available in the English literature [124-127]. A few examples of self-guided web apps for PWT1D without clinical impacts can however be found in the literature. The Diabetes Youth Empowerment and Support 12 weeks intervention was developed to provide Australian young adults (18-35 years old) living with T1D with education and peer support [128]. The program contained a mobile optimized educational website along with a closed online support group on Facebook for peer discussion moderated by a researcher. Evidence-based information was divided into 'Diabetes Technology', 'Exercise and Diet', 'Emotional Wellbeing', and 'Life and Diabetes' and was regularly updated based on the latest diabetes-related news and research. Based on a survey of 30 participants, the intervention was overall well-received (e.g., appreciation for the clarity of the information and the Facebook peer support group) [128]. Another self-guided web-based DSME/S intervention is the MODIAB-web, which is designed for pregnant women (≥18 y.o.) living with T1D in Sweden [129]. The website contained evidence-based information on being pregnant, labor, and childbirth; a self-care diary for self-tracking (e.g., blood glucose, insulin doses, diet), and a discussion forum for peer support [129]. However, in neither case, are results published regarding their clinical impacts. Moreover, none of the interventions specifically focus on hypoglycemia, none reported reference to a behavior change framework, and there is limited evidence on how components of these interventions (e.g., features) were chosen.

2.5 Summary

Therefore, there is a need to investigate the development of evidence based DSME/S web apps for PWT1D. This investigation also provides an opportunity to advance concepts within the field of digital health by exploring questions such as determining: 1) which features should be selected, 2) how engagement with the intervention should be measured, 3) how being up to date with the fast digital evolution while developing digital health tools.

Chapter 3: Manuscript 1- Systematic review

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Understanding Self-Guided Web-Based Educational Interventions for Patients With Chronic Health Conditions: Systematic Review of Intervention Features and Adherence

Li Feng Xie[1], Alexandra Itzkovitz[1], Amelie Roy-Fleming[1],
Deborah Da Costa[2], Anne-Sophie Brazeau[1, 3]

Authors' Affiliation:

[1] School of Human Nutrition, McGill University, Sainte-Anne-de-Bellevue, QC, Canada

[2] Department of Medicine, McGill University, Montreal, QC, Canada

[3] Montreal Diabetes Research Center, Montreal, QC, Canada

3.1 Abstract

Background: Chronic diseases contribute to 71% of deaths worldwide every year, and an estimated 15 million people between the ages of 30 and 69 years die mainly because of cardiovascular disease, cancer, chronic respiratory diseases, or diabetes. Web-based educational interventions may facilitate disease management. These are also considered to be a flexible and low-cost method to deliver tailored information to patients. Previous studies concluded that the implementation of different features and the degree of adherence to the intervention are key factors in determining the success of the intervention. However, limited research has been conducted to understand the acceptability of specific features and user adherence to self-guided web interventions.

Objective: This systematic review aims to understand how web-based intervention features are evaluated, to investigate their acceptability, and to describe how adherence to web-based self-guided interventions is defined and measured.

Methods: Studies published on self-guided web-based educational interventions for people (≥14 years old) with chronic health conditions published between January 2005 and June 2020 were reviewed following the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Statement protocol. The search was performed using the PubMed, Cochrane Library, and EMBASE (Excerpta Medica dataBASE) databases; the reference lists of the selected articles were also reviewed. The comparison of the interventions and analysis of the features were based on the published content from the selected articles.

Results: A total of 20 studies were included. Seven principal features were identified, with goal setting, self-monitoring, and feedback being the most frequently used. The acceptability of the features was measured based on the comments collected from users, their association with clinical outcomes, or device adherence. The use of quizzes was positively reported by participants. Self-monitoring, goal setting, feedback, and discussion forums yielded mixed results. The negative acceptability was related to the choice of the discussion topic, lack of face-to-face contact, and technical issues. This review shows that the evaluation of adherence to educational interventions was inconsistent among the studies, limiting comparisons. A clear definition of adherence to an intervention is lacking.

Conclusions: Although limited information was available, it appears that features related to interaction and personalization are important for improving clinical outcomes and users' experience. When designing web-based interventions, the selection of features should be based on the targeted population's needs, the balance between positive and negative impacts of having human involvement in the intervention, and the reduction of technical barriers. There is a lack of consensus on the method of evaluating adherence to an intervention. Both investigations of the acceptability features and adherence should be considered when designing and evaluating web-based interventions. A proof-of-concept or pilot study would be useful for establishing the required level of engagement needed to define adherence.

3.2 Introduction

Background

Chronic diseases contribute to 71% of deaths worldwide every year, which corresponds to 41 million deaths per year. It has been estimated that among these deaths, 15 million people between the ages of 30 and 69 years die mainly because of cardiovascular disease, cancer, chronic respiratory diseases, or diabetes [1]. Apart from mortality, the consequences of these chronic diseases include a decrease in the quality of life [2,3] and an economic burden for both households and countries [4-6]. The use of information and communication technology for health-related purposes has the potential to mitigate these consequences by offering numerous benefits for disease management, such as facilitating access to health information and helping to increase the understanding of the disease [7]. It is also considered a flexible, low-cost method for patients to obtain information in comparison with face-to-face education sessions [8]. Web-based interventions are an example of information and communication technology that has the potential to educate people living with a specific chronic disease condition and can help to improve their self-care over the long term through education and peer support [8,9]. These web-based interventions can be in a guided format by including features such as electronic counseling (e-counseling) and long-distance monitoring by health care professionals (HCPs) [10] or can be self-guided, defined in this paper as an absence of individual or face-to-face contact between HCPs and the users. Previous studies have investigated the integration of various features (eg, reminders and opportunities for social support) and the design of these web-based interventions. They concluded that the implementation of specific features and degree of adherence to the intervention are key factors in determining their success [11,12]. However, these studies do not distinguish between interventions with one-on-one or in-person contact among users with (guided) and without (self-guided) an HCP. As contact with HCPs or e-consultations can lead to a higher cost per usage and decrease the accessibility of the intervention [13], it is important to understand the inclusion of specific features and evaluation of adherence to these self-guided interventions.

The definition and measurement of adherence to self-guided interventions are still subject to debate [14,15]. Adherence is defined by the World Health Organization as “the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” [16]. However, this definition is not adapted in the context of information and communication technology; there is no prescribed dosage that users of specific web-based interventions should be using to have the expected behavioral change [12]. The difficulty in defining adherence to web-based self-guided interventions is further accentuated by the differences in which they have been measured across studies with the use of parameters, such as the number of log-ins, the content viewed, and/or the time spent on the intervention [14].

Objective

A deeper understanding of previously published evaluations of self-guided educational interventions is required. The goals of this systematic review are to investigate how web-based intervention features are evaluated to determine their acceptability and to explore how adherence to web-based self-guided interventions are defined and measured. An understanding of the specific features and standardization of the definition of adherence to web-based self-guided interventions can help increase their efficacy and help to develop future web-based interventions for disease management.

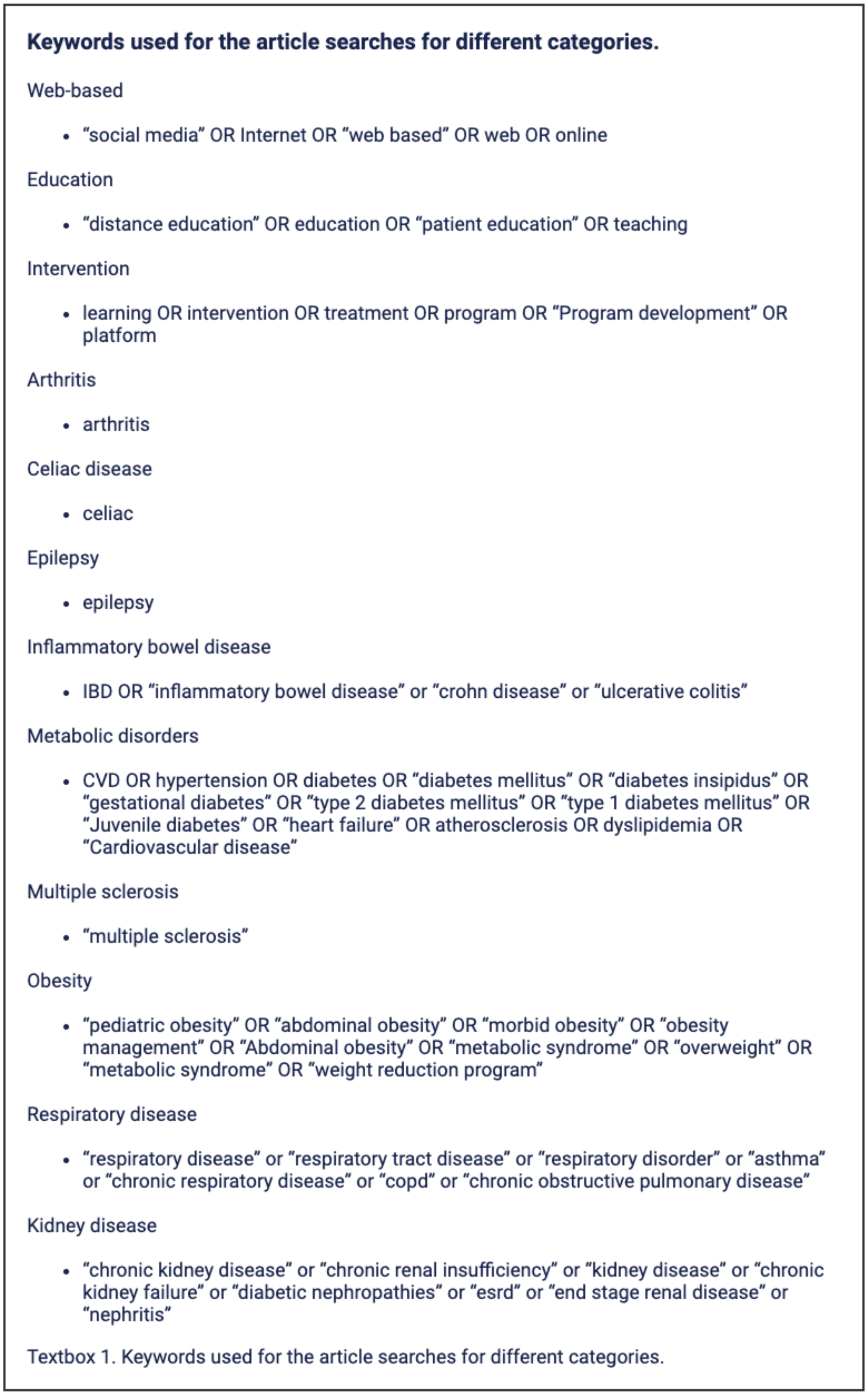
3.3 Methods

Design and Search Strategies

To achieve these objectives, a systematic review of studies investigating the acceptability of the included features in web-based educational interventions on chronic health conditions was conducted based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses framework [17]. For this review, chronic health conditions also include chronic diseases. Nine chronic health conditions were selected from a list of common chronic diseases in Canada [18]. The selection of these studies was related to the implication of a web-based educational intervention on patients' self-management and their commonality across different age groups. Cancer and mental illness were excluded from this systematic review because of the broad variety of disease and treatment methods [19-21]. The selected categories were defined as follows: (1) arthritis, (2) celiac disease, (3) epilepsy, (4) inflammatory bowel disease (including Crohn disease and ulcerative colitis), (5) metabolic disorders (including hypertension, dyslipidemia, atherosclerosis, heart failure, gestational diabetes mellitus [GDM], and type 1 and type 2 diabetes mellitus), (6) multiple sclerosis, (7) overweight and obesity, (8) respiratory disease (including chronic respiratory disease, asthma, and chronic obstructive pulmonary disease [COPD]), and (9) kidney diseases (including end-stage renal disease and nephritis).

The search method was elaborated with the help of a librarian. The PubMed, Cochrane Library, and EMBASE (Excerpta Medica dataBASE) databases were used to ensure that all articles related to the topic were covered. Keywords (Textbox 3.1), derived from Medical Subject Headings (MeSH), were searched in the titles or abstracts. The search combined each medical condition with the web-based, education, and intervention terms. A full list of the search methods is included in Appendix I: Chapter 3. If the clinical trial protocol was available, the corresponding author’s name and the study title were further searched on these databases to find the relevant publications. The reference lists of the selected articles were also screened to capture potential articles. The screening and selection of the articles were performed independently by 2 reviewers (LFX and AI), and consensus was reached through a discussion to ensure agreeability. A third researcher (ASB) was consulted for a nonunanimous discussion for the selection of the articles.

Textbox 3.1 Keywords used for the article searches for different categories



Keywords used for the article searches for different categories.

Web-based

- "social media" OR Internet OR "web based" OR web OR online

Education

- "distance education" OR education OR "patient education" OR teaching

Intervention

- learning OR intervention OR treatment OR program OR "Program development" OR platform

Arthritis

- arthritis

Celiac disease

- celiac

Epilepsy

- epilepsy

Inflammatory bowel disease

- IBD OR "inflammatory bowel disease" or "crohn disease" or "ulcerative colitis"

Metabolic disorders

- CVD OR hypertension OR diabetes OR "diabetes mellitus" OR "diabetes insipidus" OR "gestational diabetes" OR "type 2 diabetes mellitus" OR "type 1 diabetes mellitus" OR "Juvenile diabetes" OR "heart failure" OR atherosclerosis OR dyslipidemia OR "Cardiovascular disease"

Multiple sclerosis

- "multiple sclerosis"

Obesity

- "pediatric obesity" OR "abdominal obesity" OR "morbid obesity" OR "obesity management" OR "Abdominal obesity" OR "metabolic syndrome" OR "overweight" OR "metabolic syndrome" OR "weight reduction program"

Respiratory disease

- "respiratory disease" or "respiratory tract disease" or "respiratory disorder" or "asthma" or "chronic respiratory disease" or "copd" or "chronic obstructive pulmonary disease"

Kidney disease

- "chronic kidney disease" or "chronic renal insufficiency" or "kidney disease" or "chronic kidney failure" or "diabetic nephropathies" or "esrd" or "end stage renal disease" or "nephritis"

Textbox 1. Keywords used for the article searches for different categories.

Study Selection

Inclusion criteria were as follows: (1) the study included a web-based educational intervention designed for people living with this health condition (eg, transfer of knowledge to this population), (2) the intervention aimed to improve clinical outcomes defined as the result of a health care intervention, which includes a change in clinical laboratory values (eg, level of blood glucose, blood lipid profile), lifestyle behavior (eg, improvement in eating habits and level of physical activity), use of health care system (eg, use of emergency department and length of hospitalization), and quality of life [22] related to an existing chronic health condition, (3) no in-person or one-to-one contact with an HCP within the intervention, (4) only contacted the research team for technical support or an introductory meeting during the intervention (to ensure the pragmatism of the study results [23] and limit the impact of these contacts on the adherence to the intervention), (5) the included population is ≥14 years old (age cutoff where people can make their own health care decisions in Quebec, Canada [24]), (6) the articles (published or in-press, to have a full portrait of the intervention and have peer-reviewed evidence) were published between January 1, 2005, and June 15, 2020, in English or in French, (7) the articles are fully available to the researchers, and (8) no restriction on the design of the study but only original research was included.

Studies corresponding to any of the following criteria were excluded from this systematic review: (1) the intervention is for family members or HCPs only, (2) the intervention has only a purpose of prevention/assessment/screening aftercare, (3) the web-based intervention included a live session or personalized e-counseling, (4) the intervention consisted of only emails, discussion forums, and/or recording functions, (5) the study explicitly stated an inclusion of participants with severe depression, and (6) the primary target outcome was related to mental health.

Data Extraction and Analysis

For each study, the following information was collected and compared: the year of publication, country where the study took place, study design, targeted chronic health conditions, primary clinical outcomes, age group of the population, sample size, intervention given to the experimental and control groups, and length of the intervention.

In this study, a feature is defined as any functionality within a web-based educational intervention other than text-based educational modules, supporting users to have a better learning or navigation experience or to improve clinical outcomes. The term feature and functionality are used interchangeably for this review. Both analyses of acceptability of the features and adherence to the intervention were based on reported information contained in the articles or the complete protocol cited from the selected articles. The method for evaluating features and their acceptability on the outcomes of the intervention are discussed. The measurement and criteria used to evaluate adherence to the intervention were collected and compared between studies.

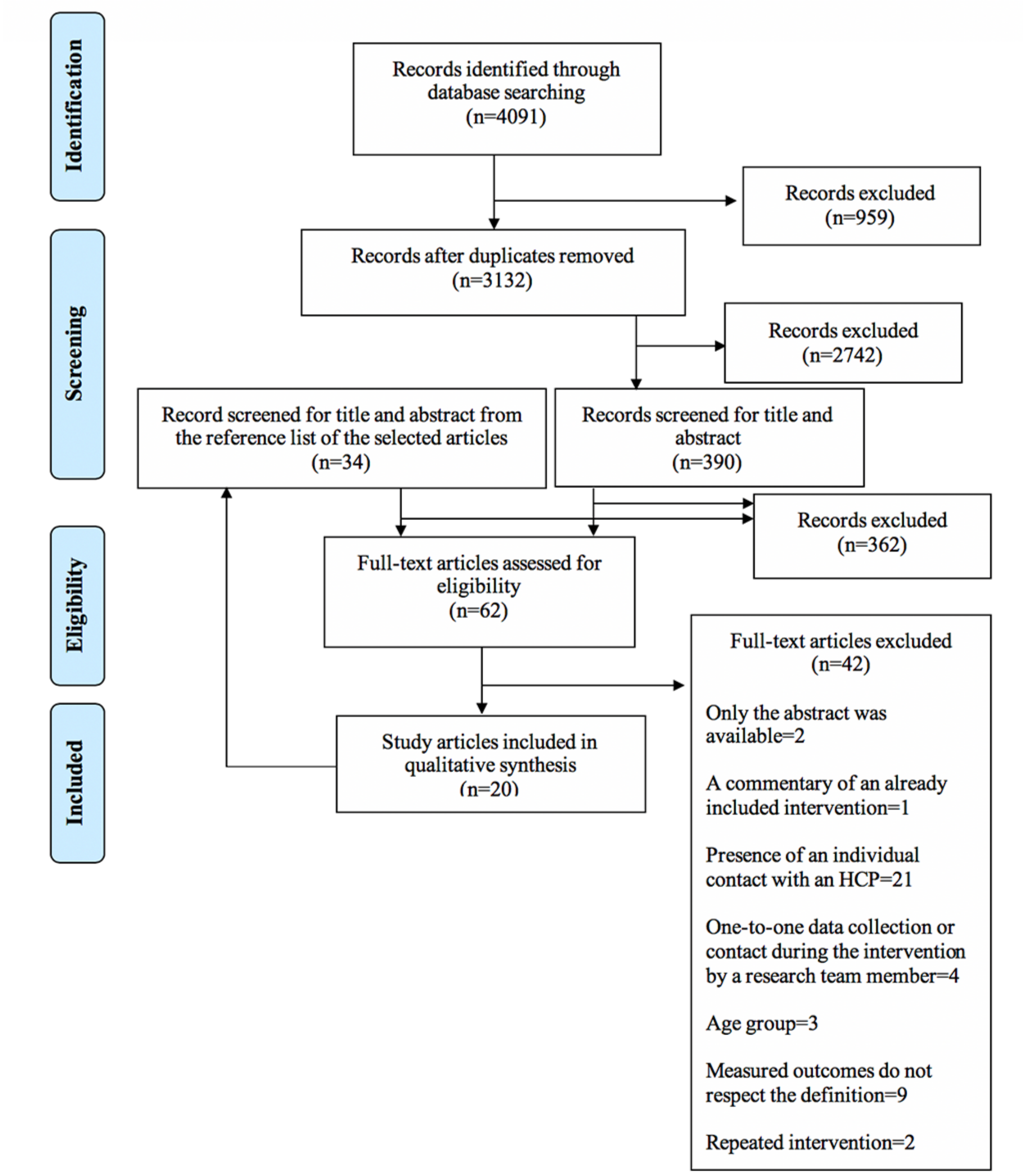
All the data were collected from information within the articles, the related published supplementary documents, or the cited references. If >1 article reported the same intervention and outcomes but had different sample sizes, then articles stating results of the acceptability of the features or adherence to the intervention were reported. If none or all the articles reported these details, the latest publication was analyzed. However, information related to the acceptability of the features and adherence was collected from all related articles. If 2 interventions within the same study correspond to the inclusion criteria of this review, the intervention with the highest number of features was analyzed. The data from each study were then grouped into themes. EndNote X9.2 for Macintosh was used to regroup the articles.

3.4 Results

Study Selection

The searches on the PubMed, Cochrane Library, and EMBASE databases resulted in 4091 potentially eligible articles (Figure 3.1). The titles and abstracts were reviewed, resulting in 390 articles. The titles and abstracts of potential articles from the reference list of the selected articles were also reviewed (n=34). After reading the full articles, 20 studies were selected.

Figure 3.1 Study selection



Study Characteristics

The study characteristics are presented in Table 3.1. The identified articles included 6 areas of chronic health conditions: arthritis (n=1) [25], celiac disease (n=1) [26], metabolic disorders other than weight issues (n=8; metabolic syndrome [27], cardiac condition [28], hypertension [29], type 2 diabetes [30-33], and GDM [34]), multiple sclerosis (n=1) [35], overweight and obesity (n=7 studies) [13,36-41], and respiratory diseases (n=2; asthma [42] and COPD [43]). No study related to epilepsy, inflammatory bowel disease, or chronic kidney disease was found. The primary clinical outcomes were mainly related to changes in weight [13,36-41]. The studies were predominantly conducted in the United States [13,27,28,31,33,39-41,43] and Australia [25,26,34,36-38,42]. All the selected studies were randomized controlled trials, except for the study by Hutchesson et al [36], which was a pre-post design, and the study by Umapathy et al [25], which had a quasi-experimental design. All selected articles were published in English.

Table 3.1 Study characteristics and description of the interventions

Study; primary clinical outcomes	Health conditions	Study design; length of the intervention	Population, sample size	Descriptions of the interventions given to the experimental group	Descriptions of the interventions given to the control group
Bosak, 2010, United States [27]; minutes of PA[a], energy expenditure per week	Metabolic syndrome	RCT[b]; 6 weeks	Adults ≥19 years; n=22	In-person introductory session, weekly new content, goal setting, self-monitoring, quiz, feedback (by email and after a quiz), use of persona, discussion board monitored by the PI[c]; general discussion question posted by the PI on the forum. Requested at least weekly participation in the discussion[d] (n=12, with 57% men)	Usual care (assessment by physicians and a consultation with a dietitian); (n=10, with 80% men)
Burns, 2013, Australia [42]; asthma control, self-efficacy, QoL[e]	Asthma	RCT; 3 months	Adults with asthma ≥55 years; n=51	Six 15-min modules, reminder email to the nonresponders[d] (with 33% men)	None
Carolan-Olah, 2019, Australia [34]; BMI, blood pressure, glycemic level	GDM[f]	RCT; ND[g]	Singleton pregnant women aged 18-45 years with recently diagnosed GDM; n=110	Standard GDM program and an additional 41-module web-based program including a one-on-one 30-min introductory session and quizzes[d] (n=52)	Standard GDM program (1.5 hours of in-person class education given by HCPs[h]; n=58)
Hansel, 2017, France [30]; change of the dietary score	T2DM[i]	RCT; 16 weeks	Adults with T2DM and abdominal obesity, 18-75 years; n=120	4 modules, videos, hotline technical support, and feedback on the self-monitoring data and pedometer outcomes; requested at least 11 weekly log-in[d] (n=60, with 33% men)	Usual follow-up with HCPs (n=60, with 33% men)
Hutchesson, 2016, Australia [36]; weight, BMI, WC[j]	Overweight	Pre-post design; 3 months	Women aged 18-30 years; n=26	Web-based quizzes to assess current health status (diet, exercise, weight) with email feedback report, goal setting, discussion forum monitored by a dietitian, smartphone app, email newsletters, text messages, graphic design reflecting the image of the population[d]	None

Jane, 2017, Australia [37]; weight	Obesity	RCT; 24 weeks	Adults aged 21-65 years; n=67	1. Leaflet group with pedometer: weight loss information contained in a booklet (n=23, with 9% men); 2. Facebook group with pedometer: same weight loss information within a booklet but with pages only accessible via the Facebook group. The group was monitored by the study coordinator and this person made a weekly post[d] (n=23, with 17% men); all the groups: 30-min introductory session	Standard care following Australian dietary and physical activity guidelines (n=21, with 19% men)
Kessel, 2016, New Zealand [35]; fatigue severity and impact	MS[k]	RCT; 8-10 weeks	Adults[l] experiencing MS fatigue; n=39	MSInvigor 8 plus: MSInvigor8 intervention with email-based support provided by a clinical psychologist for guidance and personal feedback (n=19, with 42% men)	MSInvigor8: cognitive behavior therapy–based 8 sessions with printable document, audio, and video; 25-50 min to complete; automated email reminders[d] (n=20, with 10% men)
Kerfoot, 2017, United States [31]; HbA_{1c}[m]	T2DM	RCT; 6 months	Veterans with T2DM; n=456	Team-based web game with questions related to DSME[n] and a civic booklet about American history; other features: multiple-choice questions via email or smartphone app, same questions resent in a cycled pattern, points given for the quiz answer, feedback after the quiz, team and individual financial reward (US $100 gift certificate[d]; n=227, with 95% men)	Same game format as the intervention group but with game questions on civics and a DSME booklet (n=229, with 93% men)
Leahey, 2014, United States [13]; weight	Obesity	RCT; 3 months	Adults aged 18-70 years; n=230	Group 1: the ShapeUp Rhode Island 2011 (SURI) program plus an internet behavioral weight loss program. Included a 60-min introductory session, self-monitoring, and feedback on the progress[d] (n=90, with 18% men); group 2: the previous program plus optional weekly face-to-face group sessions (n=94, with 14% men)	SURI program alone: team participation, self-monitoring, pedometer, newsletters, community workshops, and recognition for meeting goals (n=46, with 18% men)

Liu, 2018, Canada [29]; systolic blood pressure	HTN[o]	RCT; 4 months	Adults aged 35-74 years with HTN; n=128	1. Web expert-driven group with a prescribed weekly exercise and diet plan (n=43, with 51% men); 2. web user-driven group with weekly email where participants can choose their exercise and diet goals[d] (n=42, with 48% men); in both groups, the same contents are under video and text format	Weekly email newsletter on HTN management only (n=43, with 57% men)
Morgan, 2011, Australia [38]; weight	Obesity	RCT; 3 months	Men aged 18-60 years; n=65	75-min face-to-face introductory session, self-monitoring, goal setting, feedback, and online forum weekly monitored by the research team[d] (n=31)	60-min face-to-face introductory session and a weight loss program booklet (n=34)
Moy, 2016, United States [43]; HRQoL[p]	COPD[q]	RCT; 4 months	Veterans with COPD, n=239	Goal setting, self-monitoring, feedback for the self-monitoring data, reminder, discussion forum, technical support, and pedometer[d] (n=155, with 95% men)	Pedometer with 12-month delayed access to the web intervention (n=84, with 92% men)
Noh, 2010, Korea [32]; postprandial glucose, HbA_{1c}	T2DM	RCT; 6 months	Adults with T2DM aged 18-80 years; n=40	6-module program, adaptation to smartphones[d] (n=20, with 80% men)	Same educational content in a printed booklet (n=20, with 75% men)
Richardson, 2007, United States [33]; steps	T2DM	RCT; 6 weeks	Nonpregnant adults with T2DM; n=35	Basic intervention with automated step goals based on the previous weekly total accumulated steps[d] (n=17, with 29% men)	Basic intervention (60-min introductory session, pedometer, access to web-based educational information, tailored motivational messages, feedback for the performance) with step goals based on walking bouts >10 min with at least 60 steps per minute (n=13, with 62% men)
Rothert, 2006, United States, [39]; weight	Overweight and obesity	RCT; 6 weeks	Adult with BMI 27-40 kg/m^2; n=286	Tailored expert system: automated personal weight management plan delivered at 1, 3, and 6 weeks of the study; reminders and choice of encouragement message via email[d] (n=1475, with 17% men)	Information-only: standard Kaiser Permanente weight loss website (n=1378, with 13% men)

Sainsbury, 2013, Australia [26]; gluten-free diet adherence	Celiac disease	RCT; 8 weeks	Patients ≥16 years with biopsy-confirmed celiac disease (n=189, with 13% men)	Six 30-min modules[d] (n=101)	Access to the intervention after 8 weeks of randomization (n=88)
Tate, 2006, United States, [40]; weight	Overweight and obesity	RCT; 6 months	Adults (20-55 years) with a BMI 27-40 kg/m^2; n=122	1. Basic intervention with an additional website that includes electronic diary, message board, additional weekly reminder emails, weekly automated email feedback[d] (n=61, with 13% men); 2. same intervention as in 1 but email feedback was given by a human counselor (n=64, with 16% men)	Basic intervention: introductory face-to-face group session, diet and energy expenditure goal, access to Slim-Fast website, meal-replacement coupon, optional web matching with another participant, weekly report, email communications (n=67, with 18% men)
Thomas, 2015, United States [41]; weight	Obesity	RCT; 3 months	Adults aged 18-70 years; n=154	60-min introductory session, video, animation, quiz, self-monitoring, weekly feedback about participant's progress, reminders, and recognition for meeting the goals[d] (n=15, with 20% men)	Introductory session, printable newsletters with educational information on diet and physical activity; requested at least weekly log-in (n=16, with 21% men)
Umpathy, 2015, Australia [25]; heiQ[r]	OA[s]	Quasi-experimental study; 12 months	Adults with self-assessed hip and/or knee OA; n=195	My Joint Pain: educational modules (text or video) with self-assessment tools[d] (n=104, with 24% men)	No intervention was provided from the study (n=91, with 20% men)
Widmer, 2017 2015, United States [28,44][t]; CV-related ED visits[u] and rehospitalizations	Cardiac condition	RCT; 3 months	Eligible patients to a regular cardiac rehabilitation; n=80	Regular cardiac rehabilitation with digital health: 30-min introductory session, accessibility via a smartphone app, technical support, and reminders[d] (n=40, with 78% men)	Regular cardiac rehabilitation for 36 weeks (weekly in-person meeting) (n=40, with 85% men)

[a]PA: physical activity. [b]RCT: randomized controlled trial. [c]PI: Principal Investigator. [d]Interventions with a d superscript are the ones analyzed in this review. [e]QoL: quality of life. [f]GDM: gestational diabetes mellitus. [g]ND: nondisposible. [h]HCPs: health care professionals. [i]T2DM: type 2 diabetes mellitus. [j]WC: waist circumference. [k]MS: multiple sclerosis. [l]Adults refer to 18 years and older unless specified. [m]HbA_{1c}: hemoblogin A1c. [n]DSME: diabetes self-management education. [o]HTN: hypertension. [p]HRQoL: health-related quality of life. [q]COPD: chronic obstructive pulmonary disease. [r]heiQ: health education impact questionnaire. [s]OA: osteoarthritis. [t]The selected article was Widmer et al, 2017 [28] and additional information about the interventions were collected from Widmer et al, 2015 [44]. [u]CV-related ED visit: cardiovascular-related emergency department visit.

Study Population

In the selected studies, 19 included an adult population (age 18 years) [13,25,27-34,37-43] and 1 included an adolescent/adult population aged 16 years [26]. The sample size varied from 22 to 456 participants. Seventeen studies included both genders [13,25-33,35,37,39-43]. The intervention length ranged from 8 weeks to 12 months, and in 1 article, the length was not specified [34].

Web Educational Components

The web-based interventions are summarized in Table 3.1.

Features and Acceptability

The main features included in the web-based educational intervention and their acceptability are summarized in Table 3.2. None of these main features were identified in the studies by Noh et al [32] and Sainsury et al [26].

Only 8 studies (8/20, 40%) discussed the acceptability of the features. Acceptability was evaluated based on feedback from the users [33,36,38], their association with clinical outcomes [13,31,33,38,40,41,43], or device (eg, pedometer) adherence [43]. The features that reported positive, negative, or mixed acceptability in the studies are presented with a "+," "−," or "±" symbol in Table 3.2.

Table 3.2 Main features included in the web-based educational intervention and their acceptability

Articles and features	**Introductory session**	**Goal settings**	**Self-monitoring**	**Quiz**	**Feedback**	**Reminder**	**Online community**
Bosak, 2010, United States [27]	✓[a]	✓	✓	✓	✓	x[b]	✓
Burns, 2013, Australia [42]	x	x	x	x	x	✓	x
Carolan-Olah, 2019, Australia [34]	✓	x	x	✓	x	x	x
Hansel, 2017, France [30]	x	✓	✓	x	✓	x	x
Hutchesson, 2016, Australia [36]	x	–[c]	✓	+[d]	+	x	–
Jane, 2017, Australia [37]	✓	✓	✓	x	x	x	✓
Leahey, 2014, United States [13]	✓	✓	+	x	✓	x	x
Liu, 2018, Canada [29]	x	✓	x	x	x	x	x
Morgan, 2011, Australia [38]	✓	✓	±[e]	x	±	x	–
Moy, 2016, United States [43]	x	+	✓	x	+	✓	+
Richardson, 2007, United States [33]	✓	±	+	x	+	x	x
Rothert, 2006, United States [39]	x	x	x	x	x	✓	x
Kessel, 2016 and 2012, New Zealand [35,45]	x	x	✓	✓	x	✓	x

Articles and features	**Introductory session**	**Goal settings**	**Self-monitoring**	**Quiz**	**Feedback**	**Reminder**	**Online community**
Kerfoot, 2017, United States [31]	x	x	x	✓	✓	x	+
Tate, 2006, United States [40]	✓	✓	✓	x	+	✓	✓
Thomas, 2015, United States [41]	✓	✓	+	✓	✓	✓	x
Umpathy, 2015, Australia [25]	x	x	✓	x	✓	x	x
Widmer, 2015 and 2017, United States [28,44]	✓	x	✓	x	x	✓	x

[a]✓: Features presented in the study but without evaluation of its acceptability. [b]x: data not available.[c]–: features reported having negative acceptability.[d]+: features reported having positive acceptability.

Introductory Session

Face-to-face introductory sessions varying from 15 to 75 min were offered in 9 of the studies [13,27,28,33,34,37,38,40,41]. Among these, the study conducted by Carolan-Olah et al [34] specified that it was offered individually, and the study conducted by Tate et al [40] mentioned that it was offered in groups of 25 participants. The format was not specified in the other studies. The purposes of these sessions were mainly to introduce the study and provide instructions about navigating the website [28,33,34,37,38,40,41]. This session also allowed the development of personal goals, teach skills (eg, food intake self-monitoring), and provide the required material (eg, printed documents or meal supplement coupons) for the intervention [13,38,40,41]. In the selected articles, no information was provided on the usefulness or acceptability of this feature.

Goal Setting

Among the selected studies, goal setting (n=11) and self-monitoring (n=13) were frequently reported. The participants were able to select their goal from a predetermined area (eg, physical activity or dietary habits) [27,29,36-38] or the goal was provided by the research team at the beginning of the intervention [13,29,30,40,41,43]. The predetermined topics were chosen according to clinical guidelines [13,29,37,41] based on participants' self-reported physical activity baseline information (eg, number of steps) [30,43] or self-reported performance from the previous week [33,46].

Three studies reported inconsistent acceptability of goal setting [33,36,43]. Participants in the study by Hutchesson et al [36] considered this feature as one of the least used. This could be related to the technical difficulty of not knowing where to find this feature. Richardson et al [33] highlighted that more structured goals were associated with a lower level of satisfaction and adherence to the intervention among participants. However, Moy et al [43] reported that the goal-setting feature might lead to higher device (eg, pedometer) use.

Self-Monitoring

The term self-monitoring and self-assessment are used interchangeably in 2 studies [25,35]. Studies led by Umpathy et al [25] and Kessel et al [35] mainly used the term self-assessment to describe health-related risk assessment and information tracking (eg, pain, weight, use of medication). Ten other studies [13,27,28,30,33,36-38,41,43] used the term self-monitoring and referred only to the tracking function. As most of the studies used the term self-monitoring, *self-monitoring* was employed for this review.

Among all the studies with the tracking function, 6 studies requested daily self-monitoring throughout the [13,27,28,38,41,43] intervention. Other studies requested self-monitoring for a specific period (eg, participants need to complete the self-monitoring module in 1 week before going to the other modules [30,37] or by completing the module [35]), weekly, or longer self-monitoring for specific parameters (eg, weight change) [25,33,36,38,46]. The majority of the self-monitored data were entered directly into the intervention website [13,25,27,28,30,35,38,41,43,46], and one study used a smartphone app that was not designed by the research team [36]. In the study by Hutchesson et al [36], self-monitoring was captured in a quiz format where questions allowed participants to track their weight, eating habits, and physical activity level.

The acceptability of self-monitoring was evaluated in 4 studies [13,33,38,41]. Studies found that a greater frequency of self-reporting correlated with better clinical outcomes [13,38,41], increased mindfulness in food choices [38], or higher satisfaction with the intervention [33]. However, the participants in the study conducted by Morgan et al [38] expressed that it was difficult to use this feature and to remember the food eaten. These barriers might also explain the low compliance (<50%) in this study. However, the embedded *save favorite meals* feature was reported to simplify the recording process.

Quiz and Feedback

Quizzes were used in 6 studies [27,31,34-36,41]. They were mainly embedded within the web-based intervention, except in the studies by Hutchesson et al [36] and Kerfoot et al [31], where the questions were sent to participants by email or via a smartphone app. In addition to being used as a tracking method [36], the quizzes had the objective of introducing the learning material

[31], learning reinforcement [27,34,35], and increasing participants' engagement [27,41]. Quizzes were included within the educational module [34,45] or sent periodically to the participants [27,31,36].

Feedback was used to reflect the progress of self-monitoring [13,25,30,33,38,40,41,43,46], the responses of the quizzes [27,31,36], and/or used as email communication with physicians [41]. In 8 of the studies, a report format was used either weekly [13,27,30,33,40,41,43,46] or periodically [38] as a follow-up to the self-monitoring data. Tate et al [40] also provided an automated weekly feedback report on the general performance of the participants for those who submitted their self-monitoring entries. In addition to summarizing the progress toward the goal [13,27,36,38,41,43], the report could also include recommendations [25,36,38,40,41], praise for achieving the goal [33,40,41], anecdotes [38], or the amount of virtual points/diamonds accumulated [36] or provide a personalized menu [30]. Among these, the use of an algorithm for generic messages or a standardized email based on the performance of each participant was used to build this report [13,25,27,33,38,40,41] and was specified in 7 of the studies. Rothert et al [39] noted the optional *buddy* feature where participants can receive email encouragement. However, no information was given on its specificity or the email content.

For feedback related to the quizzes, the correct answer and an explanation were often given immediately following the participants' responses [27,31]. The intervention led by Kessel et al [35] used the term *interactive tasks* and *homework* for the quiz feature. In this study, the completed quizzes were discussed in the following module, but the presence or absence of feedback to the participants' answers was not specified. Communication letters to physicians were used in 1 study and sent to the referring physician at 3 time points during the intervention [41].

The quiz feature was considered by the participants in 1 study as useful for providing information and feedback [36]. A similar observation was found in the study led by Richardson et al [33], where participants expressed their support for feedback on their step performance using a graph format. Morgan et al [38] explored the effect of the feedback feature, and the opinion was shared among participants. Some users positively highlighted its usefulness in helping people to realize their possible dietary issues, but others found that the feedback lacked personalization. In the study by Tate et al [40], the authors discussed that the feedback provided by both the automated computer program and the human counselor can lead to greater weight loss. This potential positive impact of the feedback feature on clinical outcomes was also reported by Moy et al [43].

Reminder

Seven studies included a reminder (eg, by email) to increase the intervention usage [35,39-42] or to recall the upload of self-monitoring data [28,38]. The frequency of sending the reminder varied between studies: weekly reminder emails to participants not using the web intervention only [41], occasional reminders to participants who did not recently log-in [28], weekly automatic reminders to all participants to upload their self-monitoring data [40,43] or the use of the intervention [35], reminder emails sent before the release of each management plan [39], or 1 reminder email midway of the intervention [42]. In addition to the email reminders, Widmer et al [28] also included reminders within the intervention to recall the completion of daily tasks and educational material. Other than reminding people participating in the intervention, Sainsbury et al [26] noted that email and text messages were used to manage participants' progress toward the goal, but the study did not explicitly use the term reminder to qualify this function. No information was provided on the usefulness or acceptability of reminders in the selected articles.

Online Community

An online community was used in 7 studies [27,31,36-38,40,43]. Online communities included discussion forums [27,36,38,42,43], social media groups [37], game competitions [31], and buddy matching (optional pairing with another participant) [40]. The objectives of an online community were to increase social support between the participants [36,37,40,43], overcome barriers in behavioral change [27], answer questions [27,38,43], and/or increase a sense of competition [31]. The discussion forums were mainly operated by a research team member and divided into topics [27,36-38,43]. Jane et al [37] used a Facebook group to both deliver learning materials and encourage peer exchange. Tate et al [40] provided the option to the participants to be matched with another person and communicate through the web page. Kerfoot et al [28] used a game format to create an online community in which participants were grouped based on their geographic region and competed against each other by answering questions. A leaderboard displaying individual and team scores was used to increase the sense of competition.

Kerfoot et al [31] found that the positive change in mean hemoglobin A_{1c} among the participants was potentially related to participants' engagement in the online community and through competition with others. Its positive effect was further supported by a correlation between patient empowerment and game engagement, reflected by the number of earned points. The benefit of using an online community was also reported in the study by Moy et al [43]. The researchers compared the number of step counts in a population with COPD between the intervention group (access to the web intervention) with a control group having only the pedometer and a self-monitoring log. The results showed that the intervention group had significantly better device adherence, which suggested the potential benefits of the included features (discussion forum, educational content, goal setting, and feedback). In addition, more than half of the participants (67/121, 55%) expressed that the online community forum helped them learn information on their chronic condition. However, the use of the discussion forum was negatively rated in a study on weight loss among men [38]. In this study, the acceptability of the feature was based on qualitative feedback collected from the participants. Users of this discussion forum considered that weight loss was a personal issue and participants were unlikely to participate in the forum. Users also expressed a preference for having more face-to-face contact with the instructor. This negative comment was also reflected in an acceptability questionnaire in a study targeting weight loss in women [36].

Other Features

In addition to the previously mentioned features, others were presented in the studies, such as the use of a pedometer, reward, adaptation of the website intervention for smartphones, and technical support.

A pedometer was provided by 7 studies as a component of self-monitoring to increase step counts [13,27,29,30,33,37,43].

The use of rewards was mentioned in 3 studies. A social reward included praise in a weekly report to participants who reached their goal [41] and the use of online rewards (eg, virtual diamonds) [36] indicated participants' progress toward the goal. Only 1 study reported the use of material rewards [31], such as a US $100 certificate was given for the top 30% of participants based on their game points. It was also mentioned that the reward feature was included in the intervention led by Widmer et al [28], but no description was provided.

The adaptation of the website to mobile devices was specified in 3 studies [28,31,32].

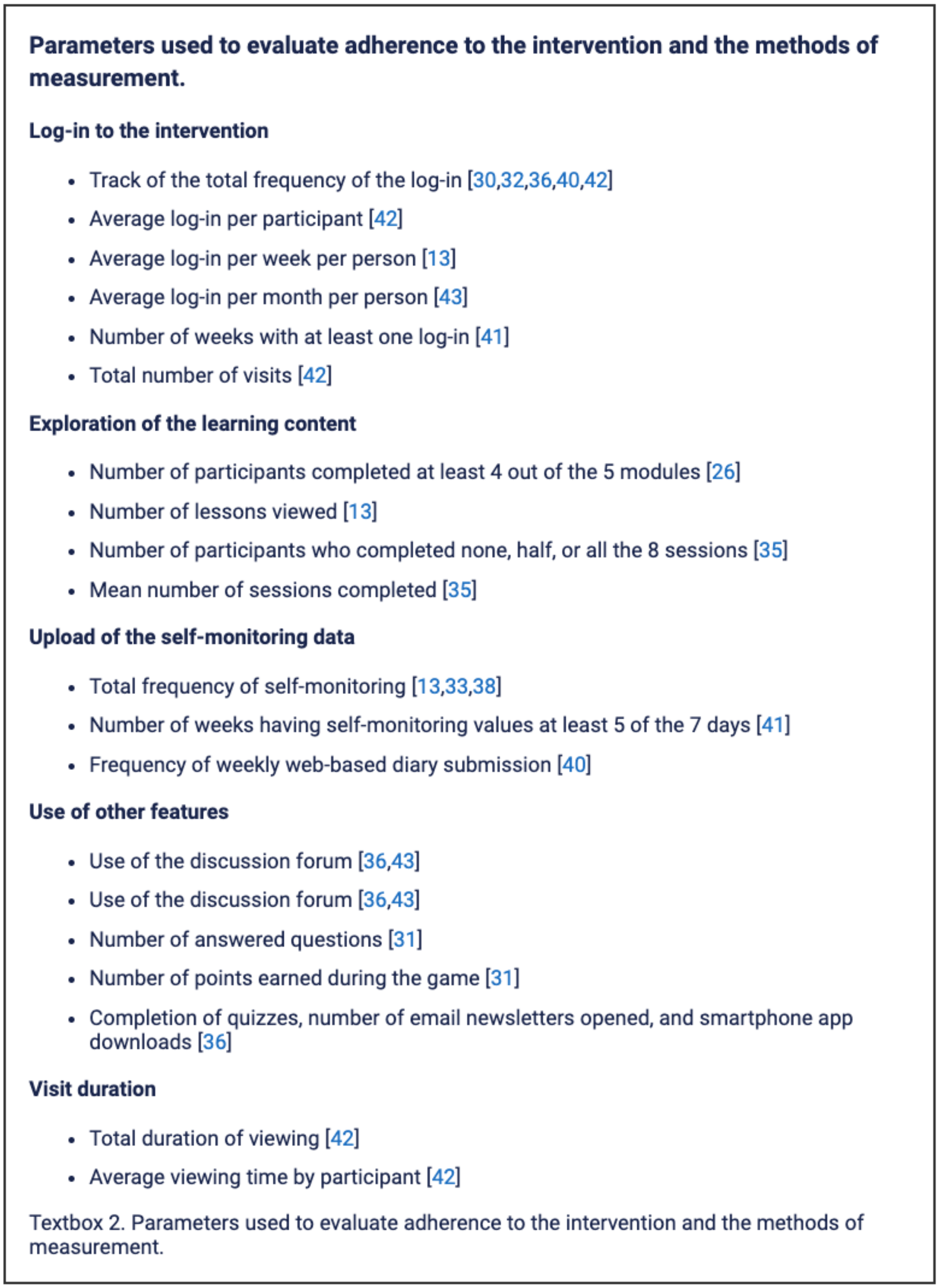
The presence of technical support was mentioned in 3 studies. Participants could ask their questions by posting on a designated section of a discussion forum [43] via a link through the web-based program [28] or through hotline support [30]. In all instances, direct communication with a research team was restricted to technical support purposes.

Adherence to the Intervention

Adherence to the intervention was mentioned in 15 studies (75% of the eligible studies, 15/20) using different terms (eg, engagement, use of intervention, retention rate). The rate was reported in 4 studies. The parameters used to measure adherence to the intervention are summarized in Textbox 3.2.

A decrease in the use of the intervention throughout the study was observed in 6 studies [26,30,36,40,41,43]. For the length of a 16-week intervention, the percentage of log-ins in the study by Hansel et al [30] decreased by one-third in the final month. Moy et al [43] reported a similar decrease in the number of log-ins with time (from 6.8 per month in the first month to 3.0 per month at 12 months). A decrease in the use of the features was also observed, such as the number of opened newsletters [36], answered quizzes [36], and the use of the discussion forum [43]. A similar decrease in the frequency of monthly log-ins was observed in the study by Tate et al [40]. Although this decrease seemed to be progressive with time, Thomas et al [41] reported that it mainly occurred midintervention, 3 months from the beginning. Hutchesson et al [36] also observed that some features (eg, discussion forum and goal settings) had poor usage throughout the intervention and Morgan et al [38] reported that <50% of their participants complied with self-monitoring instructions. However, based on the general use of the intervention (eg, 7 weeks of submission of self-reporting data and weekly log-ins during the 3 months of the intervention), Morgan et al [38] qualified a retention rate of 41% as high. The term retention rate was also used by Sainsbury et al [26] and was measured with the use of the intervention. It was shown that 49.5% of the participants completed 4 of the 5 learning modules, but the authors considered this as a poor retention rate. Kessel et al [35] related the high dropout level (9/20, only 45% of the participants completed the intervention) to the absence of individual support, lack of feedback, and technical challenges. Bosak et al [27] explained that participants with better adherence had increased self-efficacy, but no additional information was provided.

Textbox 3.2 Parameters used to evaluate adherence to the intervention and the methods of measurement



Parameters used to evaluate adherence to the intervention and the methods of measurement.

Log-in to the intervention

- Track of the total frequency of the log-in [30,32,36,40,42]
- Average log-in per participant [42]
- Average log-in per week per person [13]
- Average log-in per month per person [43]
- Number of weeks with at least one log-in [41]
- Total number of visits [42]

Exploration of the learning content

- Number of participants completed at least 4 out of the 5 modules [26]
- Number of lessons viewed [13]
- Number of participants who completed none, half, or all the 8 sessions [35]
- Mean number of sessions completed [35]

Upload of the self-monitoring data

- Total frequency of self-monitoring [13,33,38]
- Number of weeks having self-monitoring values at least 5 of the 7 days [41]
- Frequency of weekly web-based diary submission [40]

Use of other features

- Use of the discussion forum [36,43]
- Use of the discussion forum [36,43]
- Number of answered questions [31]
- Number of points earned during the game [31]
- Completion of quizzes, number of email newsletters opened, and smartphone app downloads [36]

Visit duration

- Total duration of viewing [42]
- Average viewing time by participant [42]

Textbox 2. Parameters used to evaluate adherence to the intervention and the methods of measurement.

3.5 Discussion

Principal Findings

This systematic review highlights the use of specific features in the design of web-based self-guided interventions for people with chronic health conditions and reports on the evaluation of their acceptability. Previous researchers have investigated the importance of features included in guided web-based interventions for people with chronic diseases on their success rate (eg, adherence to the intervention and transfer of health-related information) [11,12]. However, limited data were found on the functionalities of self-guided web-based educational interventions. In-person and one-on-one interactions with an HCP might increase the adherence and use of a web-based intervention [47] but that can also increase the cost of the intervention [13]. Therefore, it is important to investigate the characteristics of web-based interventions. This review demonstrated that goal setting, self-monitoring, and feedback were the most common features. The acceptability of the different features was measured based on the comments collected from users, their influence on clinical outcomes, or device (eg, pedometer) adherence. The use of personalized features with feedback (eg, quizzes) was positively reported. The negative acceptability of the features was mainly related to technical issues and the choice of discussion topics for the intervention. This review also showed that the evaluation of adherence to the intervention was inconsistent among the studies, which limited comparison. A clear definition and measurement of adherence to web-based interventions is lacking.

Categorization of Features

Our review identified 7 features that were most commonly included in the selected studies (Table 3.2). Other features such as the use of a pedometer, rewards, adaptation of the website intervention for smartphones, and technical support were also observed but less frequently used.

On the basis of the results of this paper, we categorized the included features under the following 3 categories: personalization, interaction, and support. Personalization refers to a function tailored to the individual needs of each participant and can be changed throughout the intervention based on the user's experience and progress [12]. Goal setting and self-monitoring have this characteristic by adjusting to the needs and progress of the user. The interactive features facilitated the engagement of the participants, increased learning retention [36], and provided a sense of community [31]. These characteristics were found in features such as quizzes, feedback, reminders, and online communities. They allowed an interaction between the intervention and participants and encouraged the users to return to the intervention [27,34,36]. Feedback and reward features correspond to both categories by personalizing the feedback report and varying the amount of rewards or type of written encouragement given to the participants based on the individual's progress [31,36]. Other features not included in these 2 categories were providing support and reducing the technical barriers of the intervention.

Importance of Evaluating the Features

Web-based educational interventions have been shown to be cost-effective compared with traditional face-to-face formats [48-51] and can reduce the production of physical materials (eg, printed documents) [52]. However, the cost related to the development of web-based educational interventions is still significant [52]. Creation of web-based educational modules can be classified into 3 levels: (1) basic content with text, graphics, simple audio, video, and test questions, (2) level 1 content with 25% interactive content (exercise, audio, video, and animations), and (3) level 2 content with highly interactive features (eg, adding game, avatars, custom interactions, and competitions) [53]. According to a study published in 2010, the average number of working hours to produce 1 hour of finished training associated with each of these levels is at least 79, 184, and 490 hours, respectively [53], and the average cost in US dollars is $10,054, $18,583, and $50,371, respectively [53]. Other factors such as the addition of new content and interactive features will further increase the cost [53]. Therefore, it is important to consider the choice of the features and their evaluation to minimize the cost and distribute the financial resources effectively. Our systematic review highlights that features are not frequently evaluated, with only 8 studies (8/20, 40%) reporting on the evaluation of some of the features used. In addition, the negative acceptability of a feature on the user's experience, clinical outcomes, or device adherence was shown to be related to a lack of responding to the population's needs, low human contact, and technical difficulties.

Factors Impacting the Acceptability of a Feature

Lack of Responding to the Population's Needs

A previous systematic review investigating features to be included in a commercial smartphone app for people with type 1 diabetes highlights the importance of integrating features related to personalization and patient empowerment for optimal disease self-management [54]. Similar to this study, our review showed the benefits of these groups of features [36,38]. For instance, the self-monitoring feature showed positive acceptability for the user's experience, clinical outcomes, or device adherence. Participants in a weight loss intervention conducted by Morgan et al [38] expressed that the self-monitoring features helped to increase mindfulness of their dietary choices. The participants also liked the *save favorite meals* option, which was associated with their eating habits and facilitated their diet entries [38]. Another feature that can increase patient empowerment is feedback, but it was found to lack personalization. Being able to effectively provide information [36] and improve behaviors [38] are some of the benefits of providing feedback through self-monitoring and quizzes. However, the use of a generic message was criticized by some participants, and they expressed a preference for having more personalized communication [38]. This evidence shows the potential benefits of these features and highlights the necessity of adapting them to patients' needs.

Indeed, the effectiveness of a feature can only be maximized when there is a deep understanding of the targeted population's needs [15,38]. For example, peer support is often identified as an essential component in web-based interventions across different areas of health care [55-58], but its use should be based on the specific population's preferences. Kerfoot et al [31] and Moy et al [43] found a positive correlation between participants' engagement, learning, and use of an online community. However, men in a weight loss study also expressed their resistance in using the discussion forum mainly because of the personal nature of the topic and they preferred to have face-to-face contact with their instructor [38]. Similar feedback was also reported in a weight loss study in women [36]. As the interest and needs of patients vary with different types of chronic diseases, the topics involved in these discussion forums should also be based on the interests of the population group being targeted. For instance, Lanoye et al [59] found the importance of discussing the stigma and peer pressure related to obesity within a young adult population, whereas Cook et al [60] found that emotional support and use of medication are priorities in an older population with obesity. Therefore, the demographic background [11,61,62] and type of chronic diseases [7] are all factors potentially influencing the acceptability of a feature and should be considered when designing and evaluating web-based interventions.

Low Human Contact

In addition to the lack of responding to the population's needs, the frequency of human contact was another element mentioned in the selected studies that could interfere with the acceptability of a feature [36]. Hutchesson et al [36] suggested that the low level of human contact in their weight loss intervention could have been a reason for the low usage of the discussion forum. Leahey et al [13] verified this hypothesis in their study on weight loss by adding a face-to-face component to their web-based intervention; however, it was shown that improved clinical outcomes also resulted in a higher monetary cost. Kessel et al [35] also mentioned that having human contact (eg, telephone support) might lead to a higher engagement with the intervention. Therefore, a greater in-person or one-on-one consultation with an HCP in the intervention has the potential to increase its efficacy, but the cost should also be considered. As the goal of this systematic review is to investigate the features presented in self-guided web-based interventions, with the primary inclusion criteria of the studies being the absence of face-to-face contact, it would be contradictory to suggest the addition of a face-to-face component for an intervention. However, having patient moderators implicated in the intervention can be a potential solution for this barrier [63].

Moderators have the role of being the *housekeeper* of the discussion forum. They adopt an objective point of view by balancing the opinions of different sources in a respective environment. It also acts as a conversation stimulator, conflict resolver, feedback provider, and discussion supporter [63,64]. Previous studies highlighted the importance of their role by showing that participants can develop an attachment with community moderators and that their departure can lead to cessation in the use of the forum among some participants [65]. Having HCPs and peer moderators will combine the expertise for the delivery of web-based interventions [12]. As the use of the intervention is also associated with its impact (eg, on clinical outcomes or behavioral change) [12], it is important to be able to define and measure the level of adherence [12]. Adherence can be associated with factors such as chronic health conditions

[26,42], study design, and inclusion of a variety of features [12,66]. In our review, the eligible studies reported different ways of measuring adherence to the interventions (eg, log-ins to the intervention [42], exploration of the learning content [13], and uploading of the self-monitoring data [41]) using different terms (eg, engagement [36], retention rate [38]), and none of them defined the effective engagement or intended usage of the intervention.

Technical Difficulties

Technical barriers were a third reason for the lower acceptability of a feature. Users in the weight loss trial conducted by Morgan et al [38] expressed that despite an improvement in behavioral changes related to the use of self-monitoring, the difficulty in tracking their food decreased their use of the intervention. Hutchesson et al [36] also suggested that the lack of usage of the goal-setting feature might be related to the difficulty in finding this feature in the intervention. This low usage was attributed to technical issues and was previously reported in the literature [14]. The action planning feature usage was reported as relatively low in a study of people with type 2 diabetes conducted by Glasgow et al [14], and this could be related to navigational difficulties. These observations highlight the importance of simplifying the intervention navigation and including technical support features (eg, introductory session), providing contact information of the research team, and technology usage learning to help decrease these barriers [67].

Adherence and Future Direction

Intended usage is estimated by the developers and refers to the usage level needed to have the maximum benefit from the intervention (eg, clinical outcomes), and defining the intended usage would allow for standardization in the calculation of adherence [12]. Although Kelders et al [12] used the term intended usage, others adopted the term effective engagement [68,69], defined as "sufficient engagement with the intervention to achieve intended outcomes" [69]. As both terminologies focused on the identification of the parameters and the related minimum threshold that can have an impact on the intended behavior [12,68,69], these terms were used interchangeably.

Effective engagement should reflect the multidimension of the intervention in relation to the primary outcome, and both objective and subjective measurements should be evaluated [70]. The back-ended intervention usage data are considered an objective measurement [70] and can be assessed by using the Analyzing and Measuring Usage and Engagement Data framework [68]. This framework is designed for web-based interventions and can be used during the intervention development phase or after data collection. It contains 3 stages, and each stage is guided by a checklist of generic questions. In stage 1, the usage of data is classified into 3 categories: intervention characteristics (eg, architecture and content), accrued data (eg, data collected during the use of the intervention), and contextual data (eg, factors influencing the use of the intervention). Stage 2 consists of the selection of meaningful measures of usage and generation of research questions related to the primary outcome, usage data collected, and characteristics of the target population (eg, a web-based intervention focusing on the reduction of hospital visits can have “Will the number of content views be associated with hospital visits?” as a research question [68]). The final stage focuses on the selection of analytical tools and data preparation. A plan of analyses can then be conceived if the intervention is in the developmental phase or the analyses can be performed if data have already been collected [68]. In addition to the usage data, qualitative analysis (eg, with a semistructured interview or focus group) should be performed and combined with the quantitative methods [70] to reflect participants’ experiences. The threshold of effective engagement found with the combination of these 2 methods can then be compared with the actual intervention usage of each participant. Those who failed to reach this threshold will then be categorized as nonadherent to the intervention. Therefore, adherence to the intervention and its cutoff should only be defined after data collection is completed and a proof-of-concept or pilot study is recommended for testing [71].

Limitations

Our systematic review had some limitations. The search terms were selected based on MeSH terms; however, other important keywords could have been included. Exclusion of these important keywords might decrease the level of comprehensiveness of the search results. All the qualitative analyses were based on the content of the articles; the omission of information within the published articles might have led to a different interpretation of the results. For example, authors might only have listed the major features in their intervention instead of providing a complete list of all the available features. Only 8 studies (8/20, 40%) reported the acceptability of the features on the clinical outcome, users’ experience, or device adherence, which is a limitation for extrapolating the conclusions of the interventions. The articles included in this review were only selected from 3 databases, limited to published or in-press articles in English and French. In addition, to ensure a higher level of effectiveness in the results, this review also excluded self-guided interventions having individual contact between participants and research professionals during the study for reasons other than technical support or introductory sessions. Therefore, the results of this review might have limited external validity and cannot be applied to all web-based self-guided interventions or specific to any of the selected disease categories.

3.6 Conclusions

In conclusion, this systematic review investigated features included in 20 self-guided web-based educational interventions focusing on the self-management of chronic health conditions. It demonstrated the positive implication of specific features related to personalization and interactivity in the interventions on clinical outcomes, users' experience, or device adherence. However, only a few studies reported the acceptability of the included features; therefore, future research is needed to gain a greater understanding of the roles that each feature plays on the use of web-based interventions. The results of this systematic review provide evidence on the choice and implementation of specific features for future web-based health education interventions, highlighting the importance of understanding the needs of the target population and the need to incorporate more human contact and reducing technical barriers for the effectiveness of self-guided web-based interventions. Moreover, this study also found poor consensus related to the definitions and measurements of adherence in self-guided interventions used to target chronic health conditions. A method for evaluating the level of adherence is proposed in this review but requires future studies for its validation.

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Conflicts of Interest

None declared.

Abbreviations

COPD: chronic obstructive pulmonary disease
e-counseling: electronic counseling
EMBASE: Excerpta Medica dataBASE
GDM: gestational diabetes mellitus
HCP: health care professional
MeSH: Medical Subject Headings

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Bridge statement 1

The systematic review (chapter 3) provided an overview of the development of self-guided web apps for the self-management of people living with chronic health conditions. It indicated the most frequently used features (e.g., goal setting, self-monitoring, and feedback), discussed how their acceptability was measured and highlighted potential gaps in the evaluation of adherence of users to these platforms. My review also showed that despite the presence of self-guided web apps for gestational diabetes and T2D, none of the English literature was related to a self-guided web app with published clinical outcomes in the area of T1D.

Considering the gaps in the literature and health care, this literature review guided the development of a web app for the self-management of adults living with T1D. More specifically, this review provided insights into 1) which features should be included within the web app; 2) why they should be included; 3) the importance of defining the choice of measurement for adherence to the web app.

I will explain in chapter 4 the development process of the *Support* self-guided web app for adults living with T1D in the province of Quebec, Canada. The chapter will elaborate on how the stakeholders were involved in the development, how different topics for the content were chosen, and what was the format composed of. This chapter will also discuss how the developed web app differs from existing DSM programs and discuss strengths in its development process.

Chapter 4: Manuscript 2- Development of *Support*

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Development of the *Support* self-guided web application for adults living with type 1 diabetes in Canada by a multi-disciplinary team using a people-oriented approach based on the Behaviour Change Wheel

Li Feng Xie, RD, MSc[1], Amélie Roy-Fleming, RD, MSc[1], Sarah Haag, RN, BSc[2],
Deborah Da Costa, PhD[3,4], Anne-Sophie Brazeau, RD, PhD[1,5]

Authors' Affiliation:

[1]McGill University, School of Human Nutrition

[2]Montreal Clinical Research Institute

[3] Research Institute of the McGill University Health Centre

[4]McGill University, Department of Medicine

[5]Montreal Diabetes Research Center

4.1 Abstract

Background: Diabetes self-management education and support (DSME/S) are central in type 1 diabetes (T1D) where individuals are responsible for 95% of care. In-person DSME/S programs have been proven clinically effective (e.g., optimizing glycemic management, improving diabetes-related behaviors) but are limited by a lack of accessibility and long-term follow-up. Self-guided digital tools such as web applications (web apps) can be an alternative for delivering DSME/S.

Objective: This article describes the development of *Support*, a behavioral theory-based, self-guided, web app for adults living with T1D in the province of Quebec, Canada.

Methods: A multi-disciplinary team developed *Support*. Patient partners first proposed its focus, learning topics, and expressed barriers to using digital tools for DSME/S. These barriers were analyzed based on the Behaviour Change Wheel. A group of healthcare providers (HCPs) drafted the evidence-based learning content which was reviewed by external HCPs and by patient partners.

Results: *Support* is a bilingual (English and French) web app accessible at any time via the Internet. It has four learning paths focusing on hypoglycemia and based on the user's method of diabetes treatment. Learning modules are divided into six categories with a maximum of three learning levels. It contains features such as a discussion forum, videos, and quizzes to ensure interactivity, provide social support, and maintain the motivation and long-term engagement of users.

Conclusions: To the best of the authors' knowledge, *Support* is the first self-guided evidence-based web app for adults living with T1D. It is currently under study to evaluate its feasibility and clinical impacts.

Keywords: e-health; diabetes self-management; type 1 diabetes; web app

4.2 Introduction

Type 1 diabetes (T1D) is a chronic autoimmune health condition characterized by an insulin deficiency due to the destruction of beta-cells in the islets of Langerhans, leading to hyperglycemia[1]. Based on a modelling study published in 2022, from the sum of mid-year prevalence estimates, for people born in 1922 up to 2021, in Canada, the prevalence of people living with T1D (PWT1D) was 276 284 in 2021[2]. Daily insulin administration and blood glucose monitoring are required starting at diagnosis. A sub-optimal blood glucose management can lead to short-term (e.g., hypoglycemia and coma) and long-term (e.g., retinopathy and stroke) health complications[3], and a reduced life expectancy[4]. Diabetes self-management (DSM) is complex and further challenged by life stage changes, daily factors (e.g., stress, medication, food intake, social stigma), and the development of diabetes-related complications and comorbidities[5].

Diabetes self-management education and support (DSME/S) are central for PWT1D who are responsible for 95% of their own care[6]. DSME/S programs contain people-centred learning components (e.g., case management) aiming for behavioral changes and are traditionally delivered in group settings[7, 8]. Positive outcomes include lowering of hemoglobin A1c, a key indicator of blood glucose management[9-11]. For instance, the *Programme for diabetes education and treatment for a self-determined living with type 1 diabetes* (PRIMAS) contains 12 lessons (twice a week for 6 weeks) of 90 minutes each with materials (e.g., worksheet for carbohydrate estimation) to be completed between lessons[9]. It aims to help PWT1D adjust their insulin dosage, detect, and treat acute complications such as hypoglycemia. The *Dose Adjustment for Normal Eating* (DAFNE) is another program and is delivered over five consecutive days or one day per week for five weeks[12]. DAFNE aims to teach PWT1D skills for adjusting insulin to increase their dietary freedom and has been extensively supported by research evidence with positive clinical outcomes[10, 12, 13]. However, despite the positive impact of these in-person DSME/S programs, their fixed schedule, required on-site presence of care receivers and health care providers (HCPs), and group delivery format can decrease their accessibility, increase delivery cost, and limit personalization of the learning content[7, 14]. In addition, the lack of sustained follow-up can be an obstacle for PWT1D to maintain long-term behavioral changes[15].

Digital tools, such as mobile applications (apps) and responsive websites (web apps), are feasible and accessible alternatives for delivering DSME/S. The idea of using digital tools for DSME/S emerged around 2013[16] and was accelerated by the COVID-19 pandemic where in-person consultations were limited[17]. The number of mobile apps related to DSM increased rapidly in recent years. However, there is still a lack of evidence regarding their clinical effectiveness[18-21] and their use over time[17]. For example, in a meta-analysis published by Wu et al. in 2019 there is inconclusive evidence on the efficacy of mobile apps for lifestyle modification in T1D[22]. Similarly, in the “Mobile Applications for Self-Management of Diabetes” report published by the Agency for Healthcare Research and Quality in 2018, hundreds of commercial mobile apps for DSM were identified but only 11 apps were evaluated for impact on health outcomes, and 5 (2 in T1D and 3 in type 2 diabetes) showed a clinically significant reduction of hemoglobin A1c of 0.5%[23]. Furthermore, compared to web apps, mobile apps require more resources for development and maintenance due to the multiple and rapidly evolving operating systems[24]. Therefore, it could be beneficial, both clinically and financially, to have a self-guided (i.e., absence of live and individual contact between the user and HCPs) web app for DSME/S that is based on behavior change theories and scientific evidence[25]. For instance, the Behaviour Change

Wheel (BCW) is a framework based on 19 behavior change theories, it proposes a 3-layer behavior system with the capability, opportunity, and motivation (COM-B) model at its core, followed by nine interventions, and seven policies[26]. This model has previously been identified as a key factor for digital health tools in diabetes to facilitate behavior changes and increase adherence to the intervention[27]. Therefore, considering these gaps, our research team developed *Support*, a DSME/S self-guided web app guided by the BCW for adults living with T1D. This article describes its development process.

4.3 Methods

The *Support* web app was designed by a multi-disciplinary team, based on a people-oriented participatory approach, and the BCW to meet the needs of its intended users (adults with T1D living in Quebec, Canada). Description of its development is reported based on Template for Intervention Description and Replication checklist[28] (Appendix II: Supplementary 4.1).

People-oriented development process

Patient partners, a multi-disciplinary team of HCPs, an e-health intervention specialist, and external information technology and design agencies were involved in the development of *Support*.

In 2017, an initial group of patient partners was recruited through T1D clinics and networking to discuss their needs and research priorities, and to draft the outline of a research proposal to submit for funding. Our patient partners were formed by a mixed group of Anglophones and Francophones from various age ranges. The number of patient partners varied during the development of *Support* from 9 to 11 with a similar number of men and women. During an initial in-person meeting with researchers and HCPs, they expressed their interest to have access to more educational resources, mainly related to the use of new medical technologies (e.g., insulin pumps). They also felt that access to education and training varied across regions and therefore alternative means of delivering DSME/S should be explored. The patient partners have been involved in every step of the web app development (e.g., brainstorming of the digital tool design, content creation, tool testing). In 2019, two in-person meetings were organized as well as phone/videoconference discussions with patient partners and researchers every six weeks to gather their impressions and suggestions throughout the process. E-mail communication was used for content revision in between the meetings. Patient partners each decided their degree of involvement which could vary throughout time. Financial compensation was given for their involvement, as recommended by the Canadian Institutes of Health Research[29].

Content creation

Content refers to the learning information within *Support*. The focus of the content was first identified after a brainstorming session between the researchers, HCPs, and patient partners. A list of topics to be included was then drafted and categorized based on patient partners' suggestions. The initial list of content topics was completed following a review of clinical guidelines for diabetes[30-32] and an assessment of educational programs[33-35]. It was circulated for external review by seven dietitians, three nurses, and one endocrinologist. Additional topics were added based on their suggestions.

Clinical literature review and writing of educational content were performed by T1D specialists including two dietitians/certified diabetes educators, one kinesiologist, one psychologist, and one nurse and overviewed by one dietitian and one endocrinologist. To develop the learning content, the team used guidelines published by the diabetes organizations[30-32], provincial diabetes association website (e.g., Diabète Québec), reference books[36, 37], consensus guidelines[38-40], health centers' publications[33, 34], and user manuals (e.g. for insulin pumps). When scientific evidence was not available (e.g., what to do in case of insulin dose errors, dose of insulin needed for alcoholic beverages containing carbohydrates), a discussion between the core team took place until consensus was obtained. The content was reviewed by patient partners and a team of external HCPs specialized in T1D including two dietitians, two nurses, three endocrinologists, and one psychiatrist.

The words' choice was inspired by The Use of Language in Diabetes Care and Education [41] to ensure a neutral, nonjudgmental message transfer. Content underwent a linguistic revision and was professionally translated from French to English.

Web app format development

Format refers to the skeleton of the web app, including the visual design, method of presenting the content, and features. In this context, a feature is defined as functionality that facilitates the user's learning and navigating experiences such as the discussion forum and videos[25].

The initial web app format emerged from discussions with patient partners, HCPs, and researchers. It was suggested that the app regroup an education component, including at least videos, texts, a discussion forum to facilitate peer support, and a blog section for scientific news. The team requested a visual design adapted to an adult population, showing cultural diversity, having an appealing color scheme, and being coherent to facilitate the learning process. The web agency also suggested relevant features based on their expertise. In parallel, a literature review on features used in digital interventions for chronic health conditions was conducted[25]. To ensure long-term engagement in the intervention, a brainstorming session with patient partners was performed to have a better understanding of barriers related to the use of a self-guided digital tools for DSME/S compared to in-person sessions. The identified list of barriers was returned to patient partners by e-mail and they were invited to return their comments after the meeting throughout the development process. These barriers were analyzed based on the COM-B model and associated with interventions from the BCW[42], translated into behavioral change techniques (BCTs) version 1 using the BCTs taxonomy[43], to be finally translated to various features. Once determined by the researchers, the feature list was reviewed again by the patient partners to confirm that these features were related to barriers previously identified.

Confidentiality and data safety

For confidentiality and navigation safety, the web app was built on WordPress.ca and hosted on a Canadian server (HostPapa.ca). Usage data is tracked through Google Analytics with an anonymous identifier attributed to every user.

4.4 Results

This project resulted in the development of the *Support* bilingual (English and French) web app[44]. The initial brainstorming session was held in September 2017, research funding was awarded in March 2018 and the web app was launched in January 2020 as part of a proof-of-concept study.

Content

The educational content is divided into six main categories (medication, blood glucose monitoring, diet, physical activity, hypo- and hyperglycemia, health and other situations). Each category is subdivided into courses, each taking 5 to 20 minutes to complete (length labelled on each course). Topics are divided into a maximum of three levels: basic, intermediate, and advanced. The basic level introduces participants to some key concepts of DSM (e.g., understanding insulin action, understanding continuous glucose monitors, identifying foods with carbohydrates). The intermediate level is an extension of the previous level and involves specific situations (e.g., counting carbohydrates, downloading continuous glucose monitors). The advanced level requires more mathematical calculation (e.g., how to calculate an insulin-carb ratio, how to adjust insulin) or deeper analysis (e.g., understanding the ambulatory glucose profile). Content is updated or new material is added according to the publication of new clinical guidelines, expert consensus, or access to new medical therapies and technologies for T1D.

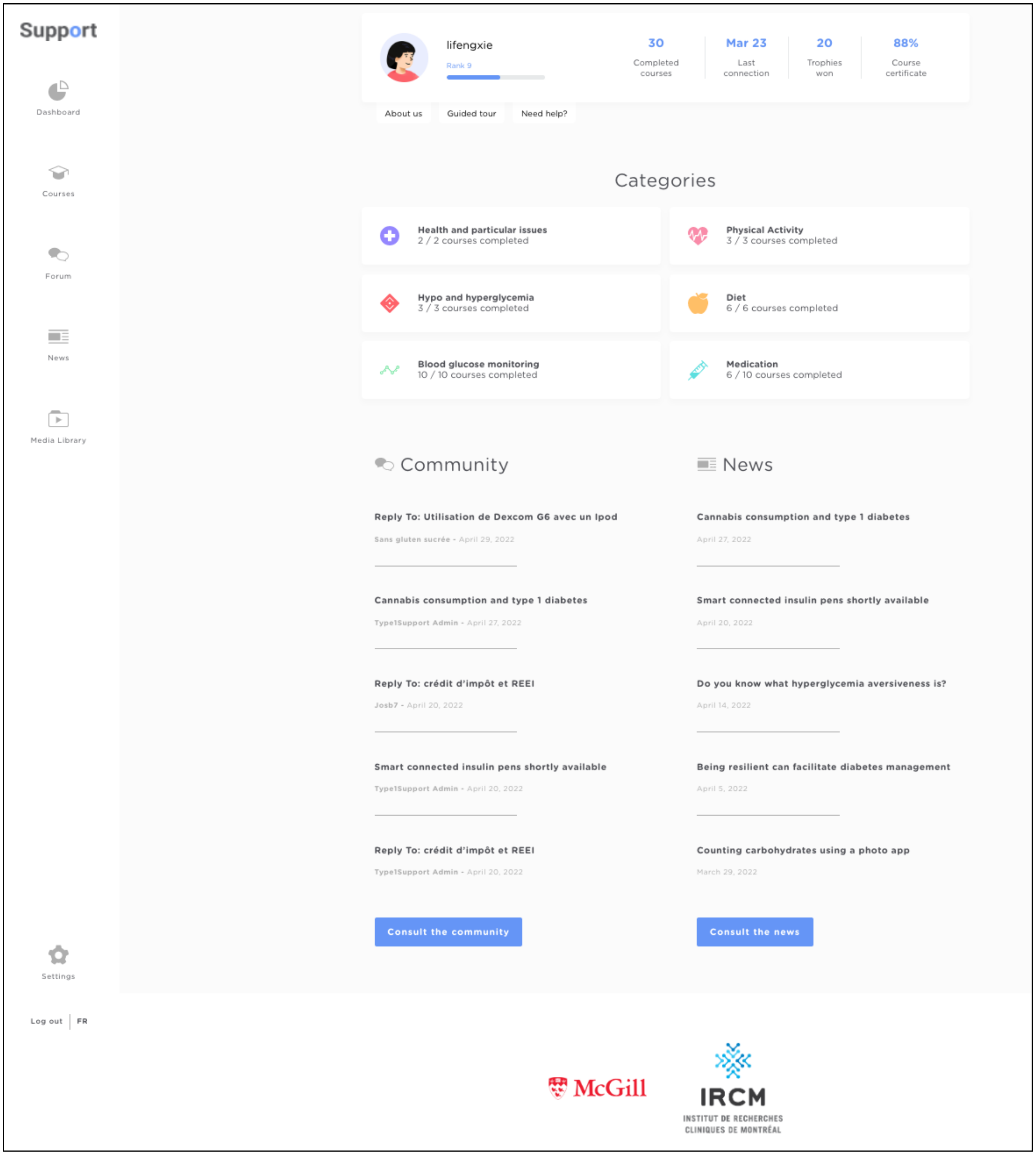
To personalize the learning experience, four learning paths were developed based on the individual's diabetes treatment and each path has its specific learning content: 1) multiple daily insulin injections (MDI) with capillary blood glucose (CBG) monitoring; 2) MDI with continuous glucose monitoring (CGM); 3) continuous subcutaneous insulin infusion (CSII) with CBG monitoring; 4) CSII with CGM.

Users are prompted to do a mandatory course on hypoglycemia at their first log-in to the app. This initial focus on hypoglycemia is related to the important daily burden and was voiced by patient partners as a limiting factor for health behavior change. After completing this basic mandatory course on hypoglycemia, users have access to the basic level of all categories. If multiple levels are available within a topic, completing the basic course is required to unlock the course of the following level. A summary of courses offered in learning path four is provided in Appendix II: Supplementary 4.2.

Web app format

The web app was built using a desktop-first responsive design. The web agency proposed a cartooned visual design with six pastel colors (blue, green, orange, red, pink, and purple), one for each learning category. Human characters with different ethnic backgrounds were incorporated. A visual presentation of the home page is available in Figure 4.1.

Figure 4.1 Screenshot of the Support web app (Home page)



lifengxie
Rank 9

30 Completed courses
Mar 23 Last connection
20 Trophies won
88% Course certificate

Categories

Health and particular issues
2 / 2 courses completed

Physical Activity
3 / 3 courses completed

Hypo and hyperglycemia
3 / 3 courses completed

Diet
6 / 6 courses completed

Blood glucose monitoring
10 / 10 courses completed

Medication
6 / 10 courses completed

Community

Reply To: Utilisation de Dexcom G6 avec un Ipod
Sans gluten sucrée - April 29, 2022

Cannabis consumption and type 1 diabetes
Type1Support Admin - April 27, 2022

Reply To: crédit d'impôt et REEI
Josb7 - April 20, 2022

Smart connected insulin pens shortly available
Type1Support Admin - April 20, 2022

Reply To: crédit d'impôt et REEI
Type1Support Admin - April 20, 2022

News

Cannabis consumption and type 1 diabetes
April 27, 2022

Smart connected insulin pens shortly available
April 20, 2022

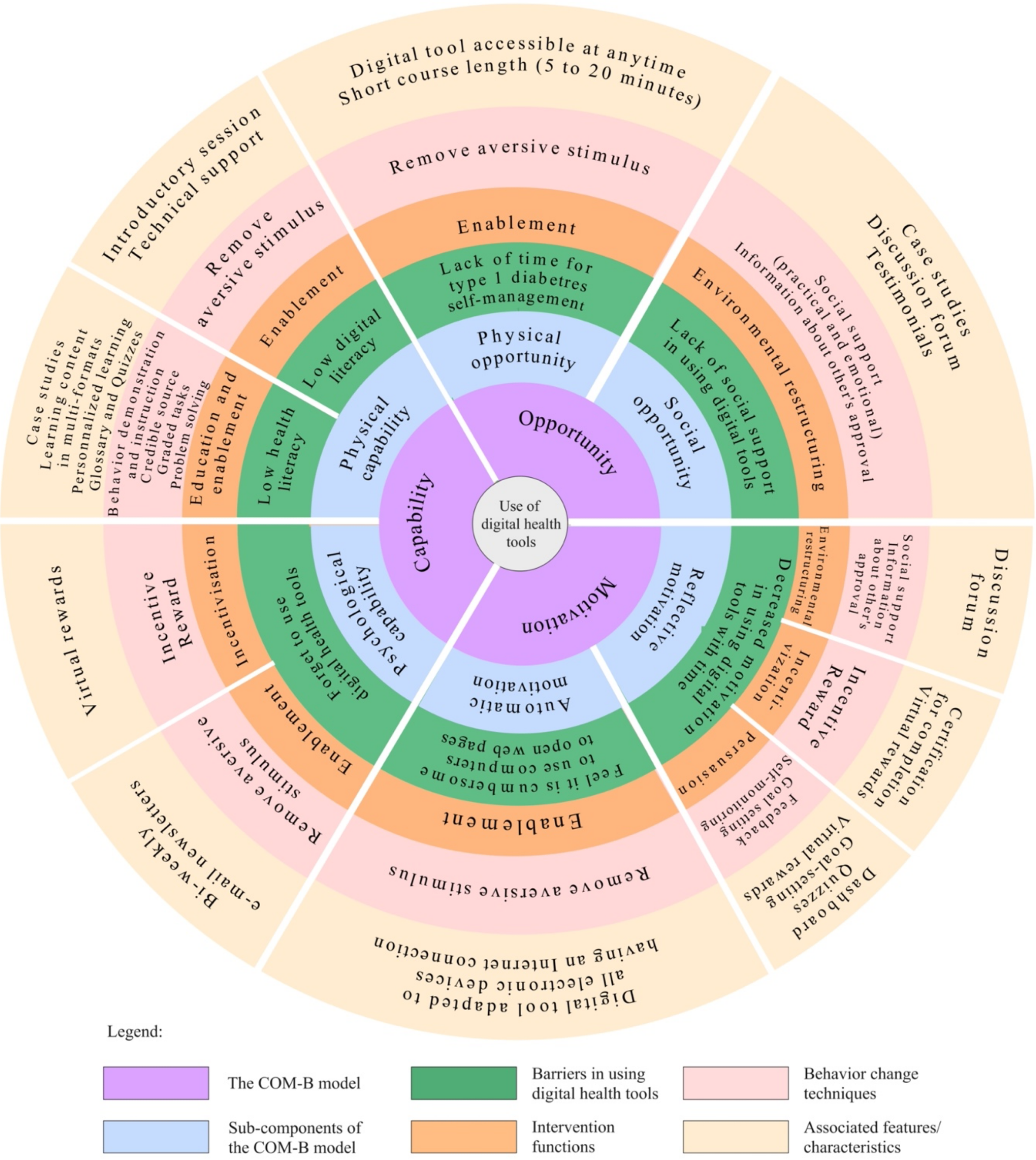
Do you know what hyperglycemia aversiveness is?
April 14, 2022

Being resilient can facilitate diabetes management
April 5, 2022

Counting carbohydrates using a photo app
March 29, 2022

Throughout the content development, the team varied the format of educational material and used features such as quizzes, videos, downloadable PDF documents, news blogs, case studies, and glossary definitions to enhance user experience and overcome the potential barriers of using self-guided digital tools for DSME/S compared to in-person sessions. These features also aim to facilitate comprehension, adapt to different learning types, and increase interactivity between users and the digital tool. In addition, a list of potential barriers was established by researchers and patient partners and was categorized based on the COM-B model (Figure 4.2). Each of the barriers was associated with interventions from the BCW[42], to BCTs, and then translated into characteristics or features included in the web app.

Figure 4.2 Barriers to use self-guided digital tools for DSME/S compared to in-person sessions: analysis and categorization from the COM-B model to web app building



Based on these methods of selection, a total of 17 main features were included *Support*. They are described below.

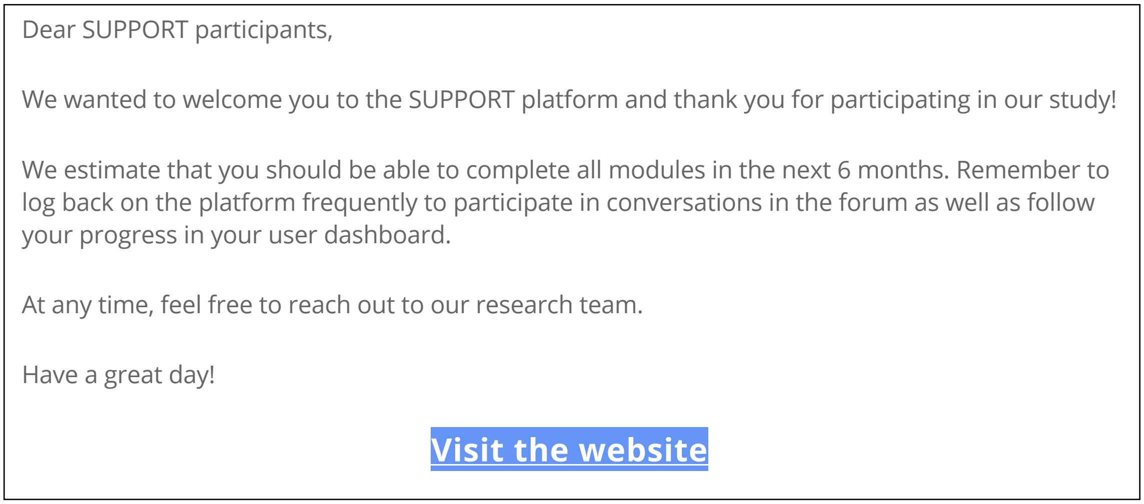
Personal username and password

At the moment of this article publication, only people invited to the *Support* research study were allowed to create an account. To ensure user's confidentiality, users log-in with their e-mail address and personal password. They can choose their pseudonym showed in the discussion forum and change it at any time.

Welcome e-mail

Once the user creates a *Support* account, a welcome e-mail is sent with the template below (Textbox 4.1):

Textbox 4.1 Welcome e-mail sent to users



Dear SUPPORT participants,

We wanted to welcome you to the SUPPORT platform and thank you for participating in our study!

We estimate that you should be able to complete all modules in the next 6 months. Remember to log back on the platform frequently to participate in conversations in the forum as well as follow your progress in your user dashboard.

At any time, feel free to reach out to our research team.

Have a great day!

Introductory session

When users first log-in to the *Support* web app, they are directed to an introductory slideshow (6 slides, takes 2 minutes to view) explaining how to use the app. After viewing these slides for the first time, users are directed to the mandatory course on hypoglycemia. They can come back to these slides at any time under "Guided tour" displayed on top of the home page.

Avatar/Profile picture

Users can choose their own avatars from an avatar database. The more the user completes courses, the more avatars are unblocked.

Personal dashboard

The user's personal dashboard displays a summary of their recent activities (e.g., the last date of connection, goals, completed courses, number of trophies and certificates) and the latest updates on the app (e.g., post on the discussion forum and news blogs).

Goal setting

A textbox is available in the user's personal dashboard for them to set personal goals. They are introduced to set a specific, measurable, attainable, relevant, and time-bound goal[45] in the physical activity learning category.

Videos

Videos are embedded within courses and available in the media library once users have finished the course. Three types of videos can be found: narrated animations (Figure 4.3), technical manipulations (e.g., insulin injection technique) by HCPs, and PWT1D testimonials. Narrated animations repeat the main written information and aim to increase the accessibility for people with a lower literacy[46] level and for those who prefer watching over reading. Technical manipulations and testimonials were filmed to facilitate self-identification. The content coordinator prepared the video scripts for the first two video types and led the testimonial interviews. Narrated animations and technical manipulations are available in English and French.

The testimonials are in the individual's mother tongue, and subtitles in the other language were added (e.g., if the video was in English, a subtitle in French would be added).

Figure 4.3 Example of a narrated animation video

Quizzes

At the end of each course, users are prompted to answer two to three multiple choices or True/False questions to validate their understanding. Correct answers are given once the quiz is submitted. Virtual points are attributed to completed quizzes, regardless of the answers given. These questions aimed to help users integrate the learned knowledge and increase interactivity with the app.

Downloadable PDF documents

Downloadable PDF documents are available to summarize information and facilitate future reference. They are at the end of each course and can be found in the media library once the related course is completed.

Glossary definitions

Medical jargon and technical words are underlined in their first appearance in each course. When the user places their cursor on the word, a definition bubble appears. These definitions can also be found in the "Glossary" section at all times.

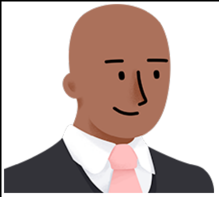
Calculators

A series of automated calculators are available in courses when relevant, and at all times in the media library. They aim to simplify calculations such as calculating the number of carbohydrates in food using a carbohydrate factor, assessing the accuracy of a capillary blood glucose meter when compared to a laboratory value, and establishing a sensitivity factor.

Case studies with different PWT1D profiles

To facilitate the integration of knowledge and self-identification, six fictional characters with different profiles (e.g., age, gender, ethnicity, diabetes treatment) were created (Figure 4.4). They are found as case studies throughout the courses and provide practical application of DSME/S.

Figure 4.4 Case study characters

 **Alex** 20 year-old man Omnipod® pump Freesyle Libre® Does weight training 4 times per week, inactive during weekends.	 **Anne** 18 year-old woman Tandem® pump Dexcom® CGM[1] Very active and has a hemoglobin A1c of 7.4%.
 **Patrick** 42 year-old man Omnipod® pump CBG[2] Walks daily at lunch.	 **Christine** 30 years old woman Medtronic® pump Enlite® CGM Restaurant chef.
 **Paul** 60 years old man MDI (Lantus® and NovoRapid®) CBG[3] Has a hemoglobin A1c of 7.6% (a lot of hypo and hyperglycemia). 1-hour stationary bike workout per week.	 **Mary** 40 year-old woman MDI (Tresiba® and Fiasp®) Dexcom® CGM Businesswoman, eats a lot at the restaurant. Bike as daily transportation and hiking during weekends.

[1]CGM: Continuous glucose monitoring [2] Capillary blood glucose [3]MDI: Multiple daily injection

Virtual rewards and trophies

Users receive virtual points for different aspects of their use of the web app (e.g., completing a quiz, completing a course, participating in the discussion forum) and virtual trophies are unblocked at the accumulation of virtual points.

Certificates

A completion certificate is available in the user's dashboard after completing mandatory courses in each category. Mandatory courses are defined as information applicable to most PWT1D and need to be completed to advance to a further level. Optional courses are related to specific needs (e.g., driving with diabetes). A final certificate is also given when completing all the mandatory courses in *Support*.

Discussion forum

Users from the four learning paths in the English and the French version of *Support* share the same discussion forum and can post in the language of their choice. Posts on the discussion forum are classified as the following: in addition to the six main learning categories, there are sections for weekly news blogs, general discussion, frequently asked questions, and technical support. The *Support* coordinator (who is a bilingual registered dietitian and certified diabetes educator) is in charge of moderating the forum daily. Patient partners are invited to post on the forum to encourage a flow of conversation and the research team also created four user accounts to promote discussions. All the users can participate in the online forum (make a new post, respond or "like" other posts). At all times, the moderator can modify or delete a post (e.g., if it contains confidential information).

News blog

The *Support* coordinator posts bilingual news blogs once to twice weekly. The topic of the news blogs is based on current events (e.g., how winter cold affects blood sugar), recent scientific publications (e.g., Diabetes Canada's Position on Ketogenic Diets), updates from the research team (e.g., upcoming webinar), and T1D topics that are not currently covered in any courses (e.g., hormonal therapy and T1D). Users from the four learning paths have access to the same news blogs.

E-mail newsletters

Biweekly newsletters are sent to users by e-mail. They contain a preview of the latest news blogs with a link to read more and two suggested basic courses (common to the four learning paths). These newsletters are also used as reminders for users to log-in on *Support*.

Other

Once the user ends a learning course, related courses are proposed at the end of the page. Users can also find the contact information (including for technical support) and condition of use page at the bottom of every page of the *Support* web app.

4.5 Discussion

To reduce the risk of developing diabetes-related complications, PWT1D need to adequately manage their blood glucose which is affected by multiple factors (e.g., nutrition, physical activity, insulin adjustments, stress). Regrouping these aspects in a cohesive manner within one digital tool can facilitate DSME[47]. This article describes the development process of the *Support* web app for adults living with T1D. It was created by a multi-disciplinary team using a people-oriented approach. Unlike existing in-person DSME/S programs for PWT1D, the *Support* web app is self-guided, combines up-to-date evidence-based information (Appendix II: Supplementary 4.2), enables interactive learning based on the BCW with learning paths specific to the user’s treatment modalities, includes opportunities for peer support, and is accessible at any time on any device with an Internet connection.

The educational content offered through *Support* and its accessibility has the potential to bridge the gap between current DSME/S programs and the needs of PWT1D. Indeed, despite the presence of multiple DSME/S programs, a number of them only focus on specific aspects (e.g., physical activity[48] or nutrition[49]) or cover multiple aspects only in a basic manner[9, 10, 50]. For instance, HypoAware is a group-based diabetes education program focusing on hypoglycemia management combining in-person and online components. Although it has a broad spectrum of learning curriculum (recognition of hypoglycemia symptoms, nutrition, medication, physical activity, and stress management), it lacks real-life applicability and is offered in the same way to individuals living with type 1 and insulin-treated type 2 diabetes[50]. Despite commonalities in the hypoglycemia symptoms and health complications, these two populations encounter different daily challenges and should receive tailored information respective to their health condition[51]. Different from HypoAware, PRIMAS and DAFNE are two programs designed specifically for PWT1D. They elaborated on many topics of DSM (e.g., impact of diabetes on partnership, on quality of life)[9] but information is only offered at a specific moment (e.g., at diagnosis). When people transit from the program to everyday life, they tend to encounter new barriers and decrease the recall of information, which can increase difficulty in applying DSM behaviors[52, 53]. *Support* is different from these in-person programs in the way that it is exclusively online and self-guided, thus accessible over time and at the user’s own pace. The ease of access to *Support* makes it a potentially effective method of providing ongoing DSME/S with continuous up-to-date learning content and the opportunity to exchange their concerns at all times with peers via the discussion forum.

Indeed, social interaction is one of the most apparent differences between an in-person and a self-guided digital program. The in-person group programs have the advantages of providing timely dialogue between people and direct support from HCPs. This human interaction has been reported by studies as important to increase engagement and acceptability of the intervention[25], and to improve people's motivation in DSM[54]. However, it can further increase the program's cost[25]. To compensate for this lack of social support and human contact inherent to the digital world, interactive features, such as a discussion forum and quizzes, have been added to *Support*, since these have shown to be effective methods of providing feedback and social communication[55]. As demonstrated by previous literature[52], virtual points, trophies, and certificates were also included to increase motivation and confidence in DSM. In addition, compared to in-person programs, digital tools might also increase the engagement of people who have confidentiality or stigma concerns as users can choose to stay anonymous during their learning process[53].

The inclusion of different stakeholders is one of the main strengths of the development process of *Support*. Patient partners were involved in each step and contributed their perspectives. Including the end-users within the development process generates valuable ideas and helps to produce an intervention that is practical rather than only theoretical[47, 54]. The identification of a target focus (i.e., hypoglycemia) based on their reality can also increase the long-term engagement of end-users with the digital tool[54]. Participation of HCPs from different areas ensured that the learning content was evidence-based and clinically relevant. Outsourcing information technology teams optimized the design quality of the digital tool.

The development of *Support* was further strengthened with the use of the BCW, COM-B model, and BCTs. They served as frameworks for intervention development by facilitating the understanding of target behaviors (e.g., use of the digital tool) and providing an explanation for why a BCT can be effective or ineffective[21]. In addition to promoting an increased engagement to the web app, our BCTs can also potentially foster the sustainment of DSM behaviors. Hamilton et al.[47] used the BCW and COM-B model to investigate barriers and enablers to sustained self-management among PWT1D based on the DAFNE program and found barriers such as “difficulty incorporating DAFNE principles [learning content] into everyday life and challenges”, “feelings of failure and hopelessness”, and “didactic culture of healthcare inhibiting independent decision”. These barriers could be reduced by incorporating the BCTs such as “demonstration of the behavior” (e.g., case studies), “social support” (e.g., discussion forum), and “problem solving” (e.g., able to solve their DSM problems by independently learnt information) which can all be found on *Support*. Hamilton et al.[47] also reported on enablers namely “having clear targets and guidelines” and “feeling empowered by new knowledge and skills”. *Support* incorporates these enablers with its learning content available under diverse format (e.g., video, PDF documents, quizzes) translated from BCTs such as “credible source”, “information about health and social consequences”, and “demonstration of the behavior”.

Furthermore, when the same in-person program is given by multiple facilitators, any update of the literature implies extra hours of training and increases the possibility of inconsistent content delivery. Providing the learning content through digital tools facilitates content update and ensures consistency in its delivery[56].

To the best of the authors' knowledge, *Support* is the first self-guided web app for DSME/S in PWT1D. Because of the proof-of-concept phase of its development, the research team had to prioritize the selection of features and some potential features impacting on DSM behaviors were not integrated. For instance, a feature enabling self-monitoring might increase positive clinical impact and self-awareness[25], but it is excluded in the current version due to the development cost and goal setting was used as a proxy. E-mail and text message reminders were first integrated into *Support* and were then replaced with a newsletter due to technical difficulties. Our patient partners proposed the idea of expanding this tool to family and friends of PWT1D through shareable links on social media channels or subscriptions to newsletters. As *Support* is currently only accessible through a research study targeting PWT1D themselves, this feature was not integrated. However, the format of web apps provides the developers with the possibility of making modifications and easy updates[24]. Despite the current lack of certain features and content, the research team can make adaptations continuously depending on the needs of the population. Another improvement that can be made would be the composition of our patient partners group, as they were composed of Whites in the majority, efforts to include people from other ethnic groups would be needed in the future.

4.6 Conclusions

In conclusion, this article describes the development of the self-guided web app *Support* for DSME/S in PWT1D. This web app was developed by a multi-disciplinary team with patient partners and is based on the BCW. *Support* provides evidence-based and periodically updated content with a variety of features to facilitate DSM. It is now under research study to evaluate its clinical impacts, usability, and feasibility among PWT1D in the province of Quebec, Canada. These results will guide the improvement of this web app and suggest methods for integrating it as part of routine diabetes care.

Declarations

Conflicting interests

None to declare

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Ethical approval

As this is the development of a platform, ethical approval does not apply.

Guarantor

ASB

Contributorship

Li Feng Xie co-designed the web app, drafted the manuscript, and revised the final version.

Amélie Roy-Fleming co-designed the web app, coordinated the development of the web app and its content and revised the manuscript.

Sarah Haag participated in the development of the content and revised the manuscript.

Deborah Da Costa advised the development of the web app and revised the manuscript.

Anne-Sophie Brazeau co-designed the web app and developed this project. She contributed to the manuscript preparation and revision.

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Abbreviations

Apps: Applications

BCW: Behaviour Change Wheel

BCTs: Behavior change techniques

CBG: Capillary blood glucose

COM-B: Capability, Opportunity, Motivation-Behavior

CSII: Continuous subcutaneous insulin infusion

DAFNE: Dose Adjustment for Normal Eating

DSM: Diabetes self-management

DSME/S: Diabetes self-management education and support

HCPs: Healthcare providers

MDI: Multiple daily injection

PRIMAS: Programme for diabetes education and treatment for a self-determined living with type 1 diabetes

PWT1D: People living with type 1 diabetes

SMBG: Self-monitored blood glucose

T1D: Type 1 diabetes

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Bridge statement 2

Chapter 4 gave a detailed description of how *the Support* self-guided web app for adults living with T1D was developed, including the choice of content and selection of features.

In addition to being the first self-guided web app for PWT1D developed based on a theoretical framework (based on the systematic review of chapter 3), *Support* also has the following strengths in its development process:
1) involvement of multiple stakeholders, especially the inclusion of its end-users (PWT1D); and
2) incorporation of evidence-based content.

The strengths ensure that different needs of stakeholders can be meet and increase potentially the engagement of the users.

Furthermore, despite the strengths in its development, a healthcare tool can only be used as part of clinical care if it is positively accepted by its end-users (i.e., adults living with T1D in the province of Quebec, Canada). Chapter 5 contains the results of a proof-of-concept mixed methods study regarding *Support* user satisfaction, impact on frequency and fear of hypoglycemia, and self-efficacy in DSM (i.e., in preventing hypoglycemia episodes and glycemic management). Data was primarily collected after 6 months of web app usage with a follow-up at 12 months from the baseline. Potential optimization of *Support* will also be elaborated.

Chapter 5: Manuscript 3- *Support* evaluation

Prepared for submission to *Diabetes Care*

Evaluation of *Support*, a self-guided online type 1 diabetes self-management education and support web application- A mixed-methods study

Li Feng Xie[1], MSc., Asmaa Housni[1], BSc., Amélie Roy-Fleming[1], MSc., Aude Bandini[2], PhD., Treena Delormier[1], Ph.D., Deborah Da Costa[3,4], PhD, Anne-Sophie Brazeau[1,5], Ph.D.

[1]McGill University, School of Human Nutrition, Montreal, Canada

[2]Université de Montréal, Department of Philosophy, Montreal, Canada

[3]McGill University, Department of Medicine, Montreal, Canada

[4]Research Institute of the McGill University Health Centre, Montreal, Canada

[5]Montreal Diabetes Research Center, Montreal, Canada

Short running title: Evaluation of a web app for type 1 diabetes management

Corresponding author: Anne-Sophie Brazeau. anne-sophie.brazeau@mcgill.ca

Number of words: 4000 Number of figures: 1 Number of tables: 3

Keywords: type 1 diabetes; self-management; e-health; user's experience; intervention evaluation; hypoglycemia

5.1 Abstract

Background: Type 1 diabetes (T1D) requires making numerous daily decisions to maintain normoglycemia and avoid complications. *Support* is an evidence-based self-guided web application providing training for T1D diabetes self-management (DSM).

Objective: Evaluate users' satisfaction with *Support* and investigate changes in self-reported frequency of-, fear of-, and self-efficacy to prevent hypoglycemic episodes, and for glycemic management.

Methods: Adult participants from a Quebec T1D registry were invited to create an account on *Support*. Data was collected through online surveys or extracted from the registry at 0, 6 and 12 months (number of episodes of hypoglycemia and fear of hypoglycemia). At 6 months, participants reported satisfaction with *Support* and on self-efficacy for preventing hypoglycemia and for glycemic management. A sub-group of 16 users was interviewed to describe their experience. Transcripts were analyzed using inductive and deductive approaches.

Results: 207 accounts were created (35% men, 96% White, mean age and diabetes duration were 49.3 ± 13.8 and 25.2 ± 14.7 years). At 6 months, the median [Q1; Q3] satisfaction score was 40/49 [35; 45] with a mean decrease in hypoglycemia frequency of 0.43 episodes per 3 days (95% CI: -0.86; 0.00, p=0.051) and of -1.98 score for fear of hypoglycemia (95% CI: -3.76; -0.20, p=0.030). Half (51%) of participants reported increased self-efficacy for preventing hypoglycemia and for glycemic management. Participants appreciated features facilitating access to the web app and personalization.

Conclusion: Participants reported a high level of satisfaction with *Support*. Its use has the potential to facilitate hypoglycemia management and increase self-efficacy for DSM.

Trial Registration: This study is registered on ClinicalTrials.gov NCT04233138.

5.2 Introduction

Digital health tools for health care communication and delivery can be a more accessible and flexible alternative than in-person approaches (1). Compared to other digital health solutions, web applications (apps) have lower development costs, can be faster to develop and require fewer updates and technical support over the long-term (2). This makes them suitable to deliver chronic disease self-management education and support to a larger population, especially when regular content updates are needed (3).

People living with type 1 diabetes (PWT1D) need to make numerous daily decisions to maintain an adequate glycemic level and avoid complications (4). Factors such as food intake, physical activity, stress, and change of routine (3; 5; 6) need to be considered to maintain normoglycemia. Hypoglycemia is considered one of the main barriers to optimal glycemic management (7). Frequent episodes can lead to fear of hypoglycemia which can consequently lead to adaptative behaviors (e.g., increasing food intake, avoiding physical activity) which potentially increase the risk of hyperglycemia and long-term complications (7). Therefore, for PWT1D, diabetes self-management education and support (DSME/S) are essential.

DSME/S aims to facilitate long-term diabetes self-care by providing key concepts of diabetes management (e.g., factors influencing glycemic control) and by training individuals to engage in self-management behaviors (e.g., carbohydrate counting, insulin dose adjustments) (8). Compared to in-person DSME/S, online DSME/S allows people to learn at their own pace (9), and can potentially lead to higher satisfaction (10). Self-guided tools (i.e., absence of live involvement from healthcare professionals [HCPs]) can further decrease the DSME/S program maintenance cost and adds flexibility to the learning process (11). Continuous evaluation is essential to understand how people are using those tools and for ongoing improvement (12). In addition, as behavior change theories facilitate the understanding of behavior mechanisms and increase the precision of interventions, their incorporation in DSME/S web apps can potentially lead to better clinical outcomes and intervention engagement (13; 14). However, there are limited self-guided DSME/S web apps for T1D that are informed by behavior theories or frameworks, in particular for adults (11) and a lack of evidence on web apps' development to ensure satisfaction among end-users (11; 12).

Support is a self-guided web app developed for adults with T1D with a focus on hypoglycemia. Through a proof-of-concept study, we investigated 1) *Support* user satisfaction and 2) changes in the self-reported frequency of hypoglycemia, in the fear of hypoglycemia, and in self-efficacy in preventing hypoglycemia and in managing glycemia). Potential optimization of the web app to facilitate its use and training in hypoglycemia management will also be discussed. We expected that *Support* would be appreciated by users since previous digital interventions on chronic health conditions received a high satisfaction score (15) and that its use would be associated with reduced fear and frequency of hypoglycemia and with increased self-efficacy in DSM.

5.3 Methods

This mixed-method concurrent triangulation study combined a registry-based quasi-experimental design and a phenomenological design (ClinicalTrials.gov. registration number: NCT04233138). The study was approved by the Montreal Clinical Research Institute's Research Ethics Committee and participants provided online informed consent. The results are reported based on Mobile Health Evidence Reporting and Assessment Checklist (16).

Intervention

Participants had access to the web app *Support* (French or English) for 12 months with bi-weekly e-mail newsletters during the first 6 months. Briefly, *Support* was developed by a team of patient partners, HCPs and researchers specialized in T1D (e.g., certified diabetes educator, dietitian, nurse, psychologist, endocrinologist). All content is based on the most recent literature, and peer-reviewed by patient partners and HCPs. The learning modules are divided into six categories with several courses in each. Categories have three learning levels (basic, intermediate, and advanced) and course lengths vary from 5-20 minutes. Completing the basic level unlocks the intermediate level and so forth. Four learning paths are available based on the diabetes treatment profile (Appendix III: Supplementary 5.1). Several features are included (such as videos, testimonials, downloadable PDF) to enhance user experience (Appendix III: Supplementary 5.2). The choice of features was guided by the Behaviour Change Wheel (17), its related behavior change techniques (18), and evidence from previous literature (11) to encourage the use of this web app. At onboarding, every participant needs to complete a mandatory module on hypoglycemia.

Recruitment

Recruitment was done using a registry of PWT1D in Quebec (BETTER: BEhaviors, Therapies, TEchnologies and hypoglycemic Risk in T1D (19)) on an enrolling basis. Adults (≥ 18 years old) with a self-reported diagnosis of T1D ≥ 1 year, and daily use of ≥ 4 insulin injections or insulin pumps were invited by email. Other inclusion criteria were having access to the Internet, an active e-mail address, and understand English or French. People with ongoing pregnancy or illnesses limiting diabetes care or limiting access to educational tools (e.g., dementia and blindness) were excluded.

Data collection

At baseline, socio-demographic information and diabetes history data were extracted from the BETTER registry. Participants completed an online survey asking about their readiness for change to improve glycemic management, their level of health literacy (20) and the number of hypoglycemia episodes (blood glucose <4.0 mmol/L) in the last 3 days. Participants also completed the 33-item Hypoglycemia Fear Survey-II (HFS-II) (21). Questions related to hypoglycemia were repeated at 6 and 12 months. The presence of elevated fear of hypoglycemia (i.e., a score of ≥ 3 on any of the items in the HFS-II (22)) was calculated. At 6 months, participants were asked to report on changes in their confidence level in self-efficacy (in preventing hypoglycemia and in managing blood glucose).

At 6 months, the level of satisfaction with *Support* was measured using a 7-question face-validated satisfaction questionnaire (Likert scale from 1- *strongly disagree* to 7- *strongly agree)* (23; 24). Two questions were purposively asked in a negative form (the score was reversed before analysis for a maximum total score of 49) to ensure participants read questions properly. Thus, data from respondents who answered all “1” or all “7” would be removed from the analysis. A single question rating overall appreciation from 1 to 10 was also asked. Participants chose a maximum of three most preferred features from a list of 14 and answered two mandatory open-ended questions on what they liked most about *Support* and what should be improved. The study-specific questionnaires were administered online through Research Electronic Data

Capture 11.1.0.

Web app usage and engagement

Google Analytics was used to track the usage of the web app (number of page views, number of sessions, and average session duration) and of specific embedded features (calculator use, downloaded PDF documents, and submitted quizzes). The number of page views included only pages with specific uniformed resource locator (URL; i.e. learning content, dashboard, media library, frequently asked questions, discussion forum, and news blogs) and included pages seen multiple times. They were reported per period of 6 months and used to describe engagement with the web app. When a user logged in to *Support* and remained active, a session was tracked (25). Usage of the calculator was defined as the number of times a calculation's result was displayed, PDF documents referred to the number of downloaded documents after being opened, and a quiz was counted when the user clicked on "submit". The number of posts on the discussion forum was analyzed from the front end of *Support*. Mailchimp tracked the number of opened and clicked newsletters (out of 13 sent) (26).

Natural evolution of hypoglycemia within the BETTER registry participants

Using the BETTER registry, we contrasted the change in the frequency and fear of hypoglycemia observed among the *Support* participants from baseline to 6 months to the natural evolution observed in the registry over a similar 6-month period. The data included in this description are from participants in the registry not part of the actual study but who met the inclusion and exclusion criteria.

Quantitative data analysis

Descriptive analyses are presented (median and interquartile range or mean and standard deviation). Cronbach's alpha was used to measure the reliability of the satisfaction questionnaire. Pearson correlation, paired t-tests and independent t-tests were performed. Analyses were conducted using SPSS Statistics version 28.

Semi-structured interviews

At 6 months, semi-structured individual interviews based on a phenomenological design were conducted to deepen the understanding of the participants' experience using *Support* (content and format). Of those who completed the satisfaction questionnaire, 16 users were included. To decrease recall bias, four participants were randomly selected, using R Studio, for every 25 participants who completed their first 6 months. To ensure an equal number of men or women, purposive sampling was employed with the last group of 25 participants. Participants were excluded if they explicitly expressed never using *Support*.

The interviews lasted about 60 minutes and were conducted in French on Microsoft Teams. A doctoral student (LFX), trained in qualitative data collection and unknown to the participants, conducted all interviews. The interview guide was developed following work from Arnold et al. (27) with guidance from HCPs (dietitians, nurses, and an endocrinologist) and patient partners. It consisted of five sections with a total of 24 questions, including three open- and 21 closed-ended questions. Participants were invited to share their general experience using the healthcare system and then to focus on their experience with Support. Factors influencing their use of Support, feedback on the contents and the features, and the consolidation of knowledge learned from

Support into their DSM were explored. Following the interview, participants received a summary of their interview's key points by email and were asked to comment within 2 weeks. Each participant was sent an electronic gift card (40 CAD) for their participation.

Open-ended questions from satisfaction questionnaires were qualitatively analyzed along with the semi-structured interview transcripts using NVivo (QSR International, Melbourne, Australia). Two researchers (LFX and AH) performed the initial inductive coding independently on two transcripts randomly selected. Then, all the interviews were analyzed with the created coding book in an iterative approach. Codes were refined as needed (e.g., through rewording). After independently coding all transcripts, 100% agreement was achieved through discussion. Codes were grouped into themes using a combination of inductive (i.e., using concept mapping) and deductive methods (i.e., guided by the interview questions) (28). Analyses were performed in French and were translated into English using a forward-backward translation process for publication.

5.4 Results

Satisfaction and change in hypoglycemia

From October 28th, 2019, to September 30th, 2021, 259 participants consented, and 207 created a *Support* account and were included in the analysis (Appendix III: Supplementary 5.3). The baseline characteristics of the 207 users are summarized in Table 5.1.

At 6 months, 169 participants answered the satisfaction questionnaire (Cronbach's alpha of 0.88). The median [quartile 1; quartile 3] score was 40/49 [35; 45], which is similar to the overall rating of *Support* on a 10-point scale (8 [8;9]) (n=166) (Appendix III: Supplementary 5.4). During the first 6 months, the self-reported frequency of hypoglycemia over 3 days decreased by -0.43 episodes (95% confidence interval [95% CI]: -0.86, 0.001; n=166) from 2.47 episodes to 2.04 episodes. Self-reported hypoglycemia from 6 to 12 months showed an average additional decrease of -0.51 (95% CI: -1.13 to 0.12; n=89) (Table 5.2). In contrast, in the BETTER registry, a sub-group of 244 participants, reported on average no change in the number of hypoglycemic episodes (0.01 episodes per 3 days, 95% CI: -0.22, 0.25) during the same 6-month period.

A decrease in HFS-II total score (out of 132) was observed during the first 6 months (-1.98; 95% CI: -3.76 to -0.20; n=170) and by -10.20 (95% CI: -13.84, -6.56; n=100) during the following 6 months (Table 5.2). The percentage of users having elevated fear of hypoglycemia at baseline, 6-month, and 12-month were 82% (n=166/203), 53% (n=78/146), and 48% (n=53/111) respectively. In the BETTER registry, there was no change in their fear of hypoglycemia during the same period (mean 0.94 95% CI: -0.64; 2.52; n=248). The changes in the frequency of hypoglycemia and in fear of hypoglycemia were not associated with satisfaction scores with the web app (respectively r=-0.064; p=0.442 and r=0.021; p=0.786) during the first 6 months. At 6 months, about half of the users reported an increase in their confidence in managing blood glucose levels (47%, n=79) and in their confidence in preventing hypoglycemia (51%, n=85) (Appendix III: Supplementary 5.5).

Support usage

The use of *Support* is described in Table 5.3. No web app usage was tracked by Google Analytics for 25 users due to their privacy parameters and four users did not receive newsletters due to a human error (their email address was not added to the newsletter list).

The median number of page views during the first 6 months was 54 [24;147] and decreased to 0 [0;10] in the following 6 months. Based on a stratification analysis with the median split of the number of page views in the first 6 months (n=90 for lower engagement vs n=92 for higher engagement), all baseline characteristics were similar except that people with a higher engagement reported a slightly higher readiness for glycemic management's change at baseline (9.0 ± 1.0 vs 8.8 ± 1.1; p = 0.047). The number of page views was not associated with changes in hypoglycemia frequency (r=-0.008; p=0.917) or fear (r=0.004; p=0.961) during the first 6 months

Among the 14 listed features, downloadable PDF documents, blog news, newsletters, and videos were selected as the most three preferred features followed by the quizzes. Discussion forums, certificates for course completion, virtual rewards, and glossary definitions were the least frequently selected features.

User's experience with *Support*

The interviews were held between February 2nd to June 30th, 2021. Thirty-one invitations were sent. Three participants declined, 11 didn't respond, and 17 accepted. One participant admitted not using *Support* despite creating an account and was therefore not interviewed. The mean age of the 16 participants (50% women, 100% White) was 53.8 ± 16.1 years (ranging from 27 to 79) with a mean diabetes duration of 26.5 ± 14.7 years. Among those participants, the median number of page views on *Support* was 130 [30; 323]. Based on descriptive analyses, the change in the self-reported frequency of hypoglycemia during the last 3 days was -0.4 ± 2.8 episodes and total fear of hypoglycemia was -1.98 ± 11.75 during the first 6 months. Only one participant provided comments after receiving the interviewee's summary (i.e., by highly suggesting the use of a mobile app instead a web-based one).

Interview code saturation was reached after 14 transcripts. Feedback and suggested modifications are summarized in Appendix III: Supplementary 5.6. Participants reported on the factors that could impact their experience with *Support* and these factors were further divided in relation to the content and the format (Figure 5.1). Examples of quotes can be found in Appendix III: Supplementary 5.7.

Experience with the content

Participants expressed the importance of having content that is accessible, personalized, and credible. Users suggested unblocking all modules to increase accessibility and flexibility in navigating the content. Having information that was concise and easy to understand (e.g., using PDF documents to summarize the information or delivering information with videos) was reported among the main strengths of *Support*. Participants stated that the content's length was a factor impacting content accessibility. They appreciated that a written module could be completed within 10 to 15 minutes and a video to be viewed between 2 to 4 minutes.

Participants elaborated on the need of having personalized information, that should be level- and need-adapted, and to be able to integrate the new skills into their daily life. A participant suggested having "*a knowledge validation questionnaire*" *(woman, 37 y.o.)* at the beginning to then guide users to the appropriate level of content. As suggested by our users, diabetes duration can be a potential factor influencing their level of understanding. The feature "Case studies with the six characters" was positively viewed by some participants as it can potentially help users save time by identifying the scenario corresponding to their needs, going beyond the basics, and making direct applications.

The credibility of the information was associated with scientifically up-to-date information and the involvement of HCPs in designing the web app and monitoring the forum (e.g., have HCPs involved and supervised the discussion forum).

Experience with the format

Participants explained that they would need active exposure to the information on the web app, such as through email newsletters, social media, or reminders from HCPs. Although categorization of the information was mentioned to facilitate information searching, some participants shared difficulties in navigating *Support*, especially not understanding how each section or feature was connected. To increase accessibility, some participants suggested transferring to a mobile application because "*it's easier to log on the phone than on a computer*." *(woman, 37 y.o.)*

The web app format should be personalized through flexibility in the learning process and the ability to track self-progress. Participants appreciated that *Support* is completely online and self-guided allowing them to *"stop at any moment and resume where [they] were" (woman, 27 y.o.).* Compared to in-person classes where participants might only *"retain 25% of what they heard in 4 days" (woman, 67 y.o.)*, being able to repeat the modules on *Support* allowed them to revisit information. The dashboard was mentioned as a feature that facilitated self-tracking and personalized the learning progress based on user needs.

Some interactive features received mixed feedback. On one hand, participants found that the interaction between peers in the discussion forum allowed them to *"know that [they are] not alone in [their] situation" (woman, 60 y.o.).* On the other hand, some participants expressed that questions asked in the forum by others were not relevant to them and do not feel the need of referring to the forum. Similarly, concerning gamification, some mentioned it might facilitate the learning process (e.g., with the quizzes) and maintain motivation (e.g., through the trophies), though others expressed it had no impact on their use of the web app. Participants reported that the interactive features should align with their expectation or objective of using *Support*, as some people were expecting to "*have a good hemoglobin A1c*" *(woman, 51 y.o.)* or to "*confirm whether [they] understood the content*". *(man, 75 y.o.)*

Only a few participants mentioned aesthetics during the discussion. One participant reported that *"I like the visuals because it's attractive and simple. It's nothing too childish nor adultlike or serious." (woman, 32 y.o.)* Another comment received on the visual was regarding the color and the characters' font. It was suggested to have a greater contrast to facilitate the reading. In addition, a participant suggested the integration of an in-person component to the intervention, as *"[an online intervention] is a computer and can't be compared with a human. It is cold and has no [human] contact". (man, 42 y.o.)* As a future direction, a participant also proposed to expand the web app for family and friends of people with T1D to increase their "*medical literacy*". *(man, 79 y.o.)*

5.5 Discussion

Users reported an overall high satisfaction after 6 months of use and the potential of *Support* in decreasing the self-reported frequency and fear of hypoglycemia. Similarly, users reported increased self-efficacy for preventing hypoglycemia and for managing blood glucose levels after having accessed *Support*. Engagement in *Support* was greater during the first 6 months than in the subsequent one. Features supporting the information viewing, such as case studies and news blogs, were the most appreciated. When users expected to receive peer-to-peer interaction, they tend to appreciate social support-related features such as testimonial videos and the discussion forum.

The high level of user satisfaction can be related to the development and delivery method of *Support* compared to other in-person DSME/S interventions. To our knowledge, *Support* is the first self-guided web app for PWT1D built using a behavior change framework. The material is evidence-based and peer-reviewed. These characteristics bridge gaps in the development of digital healthcare tools, namely the user's distrust in the information (29) and the lack of an evidence-based design (30). Its development also involved a multidisciplinary team including its end-users, PWT1D. Their participation in every step of the development can contribute to increased acceptability by the end-users given their shared experiences and needs (12; 31).

The decreased self-reported frequency and fear of hypoglycemia reported after 6 and 12 months of accessing *Support* are comparable to results reported from other DSM programs for PWT1D. In a 6-week in-person intervention, 23 participants were taught about hypoglycemia symptoms, causes and consequences of impaired awareness of hypoglycemia. The intervention was delivered over three weekly full-day group sessions, homework using home glucose monitoring for two weeks, and one final full-day group session in week 6. Participants reported significant improvement in hypoglycemia awareness at 12 months and a decreased median range rate of severe hypoglycemia (32). In another in-person program, 81 PWT1D were gathered in 12 group lessons of 90 minutes each. The program focused on intensive insulin therapy, detection and treatment of acute complications, and prevention and early identification of late complications. An improvement in hypoglycemia awareness and decreased incidence of severe hypoglycemia were reported after 6 months of the program. The self-guided online delivery format of *Support* is an alternative to in-person programs (32; 33) providing the opportunity to reach a greater population that may not have physical access to those programs and also providing the opportunity to learn at one own pace (34).

Similar to previous studies (35), our results also showed a decrease in engagement with time and low usage of downloadable PDF documents, calculators, and newsletters in general. This low feature usage can be explained by the method used for measuring web app usage. For example, downloadable PDF documents can be viewed in a browser without being downloaded, whereas only actual downloaded documents were tracked by Google Analytics. Because the recruitment was on an enrolling basis, the small number of participants at the beginning of the study can also contribute to a low activity level on the discussion forum. The absence of newsletters in the second 6 months may partially explain the lower engagement. However, results show that the newsletters were mainly used to obtain information rather than promote engagement with *Support*. Some participants explained that when receiving sufficient information from the newsletters, they do not perceive the necessity to log in online or click the links; while others only connect to the web app when they receive a reminder as an external stimulus. The decreased engagement can also be related to the idea that users perceived *Support* as a source of information and once they finished viewing the content relevant to them, they might only refer to it based on their needs. Therefore, a decreased engagement (measured by the number of page views) would be expected, especially because there was only one new module that was added during the study period.

Limitations

Our study has some limitations including the absence of Anglophone users for the interview and the lack of ethnic diversity. Our interviewed participants also had a higher engagement than the general users, indicating a greater preference for using digital tools for DSM or higher digital literacy. These participants were also included in the second 6 months' engagement analysis, their interview invitation might have encouraged them to use the web app during this period. Recruitment through cultural communities could improve the sample's diversity and enhance the findings' generalisability. When responding to the satisfaction survey, some participants might not have explored all the components of *Support*. This reflects one of the challenges in delivering digital interventions, as it is often difficult to evaluate if the users received the intervention content in the intended way (36). During the delivery of the intervention, we learned that some participants were not receiving the newsletters due to human errors. This lack of fidelity in the intervention delivery highlights the need of having utility and feasibility studies before larger pivotal studies to advocate adjustments needed in future intervention deliveries. We also encountered challenges in tracking the usage data, as 25 (12%) of the users had no usage data from Google Analytics due to privacy parameters.

5.6 Conclusions

In conclusion, our study showed that *Support* is highly appreciated by PWT1D. This online education and support web app has the potential to decrease the self-reported frequency and fear of hypoglycemia and increase self-efficacy in DSM among adults living with diabetes. Such a web app could be used as an adjuvant tool to DSME/S in clinical settings. Future steps include adjusting the web app based on the suggestions provided by the participants and investigating its clinical implementation and effectiveness for scalability.

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Authorship contribution statement

All authors read and accepted the manuscript.

Li Feng Xie designed the study, interviewed the participants, recruitment, data collection, performed the statistical analysis, performed the qualitative coding, drafted, reviewed, and corrected the manuscript.

Asmaa Housni involved in the coding process, translated the quotes, participated in the draft and revision of the manuscript.

Amélie Roy-Fleming coordinated the development of *Support*, study recruitment, intervention and data collection, helped in the data analysis and interpretation, and reviewed the manuscript.

Aude Bandini participated in the study design, development of *Support,* data interpretation, and reviewed the manuscript.

Treena Delormier participated in the study design, data analysis and interpretation, and reviewed the manuscript.

Deborah Da Costa participated in the study design, data analysis and interpretation, and reviewed the manuscript.

Anne-Sophie Brazeau is the principal investigator of the project. She co-designed the study, guided the development of the *Support* web app, participated in data analysis and interpretation, and reviewed the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

App: Application

BETTER registry: Behaviors, therapies, technologies and hypoglycemic risk in type 1 diabetes

CBG: Capillary blood glucose

CI: Confidence interval

CGM: Continuous glucose monitoring

CSII: Continuous subcutaneous insulin infusion

HbA1c: Hemoglobin A1c

HCP: Healthcare professionals

HFS-II: Hypoglycemia Fear Survey-II

MDI: Multiple daily insulin injections

PWT1D: People living with type 1 diabetes

Q1:Q3: Quartile 1 : quartile 3

SD: Standard deviation

T1D: Type 1 diabetes

y.o.: Years old

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Table 5.1 Baseline characteristics of Support users

Variables, n (%) unless specified	n=207
Gender (self-identified)	
Men	73 (35%)
Women	135 (65%)
Age in years, mean ± SD	49.3 ± 13.8
Duration of type 1 diabetes in years, mean ± SD	25.2 ± 14.7
Ethnicity	
White	196 (96%)
Others	9 (4%)
Level of education	
College or lower	87 (43%)
Bachelor's degree or higher	117 (57%)
Employment status	
Full-time	105 (51%)
Retired	58 (28%)
Others	43 (21%)
HbA1c in the last 3 months	
7% or less	81 (41%)
7.1-8%	82 (42%)
8.1 or more	34 (17%)
Number of hypoglycemia in the last 3 days, mean ± SD	2.38 ± 2.37
Fear of hypoglycemia total score, mean ± SD	33.8 ± 16.5
Readiness of making changes to improve glycemic management (/10), median [quartile 1; quartile 3]	9 [8;10]
Level of health literacy (/5), [quartile 1; quartile 3]	5 [4;5]

Table 5.2 Changes in hypoglycemia frequency and fear

	Paired t-test		
Number of hypoglycemia/3 days	Mean ± SD	Mean difference (95% CI)	p-value
6-month to baseline (n=166)		-0.43 (-0.86; 0.001)	0.051
Baseline	2.47 ± 2.38		
6-month	2.04 ± 2.10		
12-month to 6-month (n=89)		-0.51(-1.13; 0.12)	0.109
6-month	2.38 ± 2.47		
12-month	1.88 ± 1.83		
Fear of hypoglycemia total score (/132)			
6-month to baseline (n=170)		-1.98 (-3.76;-0.20)	0.030
Baseline	33.8 ± 16.1		
6-month	31.8 ± 15.5		
12-month to 6-month (n=100)		-10.20 (-13.84;-6.56)	<0.001
6-month	33.8 ± 16.4		
12-month	23.6 ± 11.3		

Table 5.3 Web app usage during the first 6 months of intervention

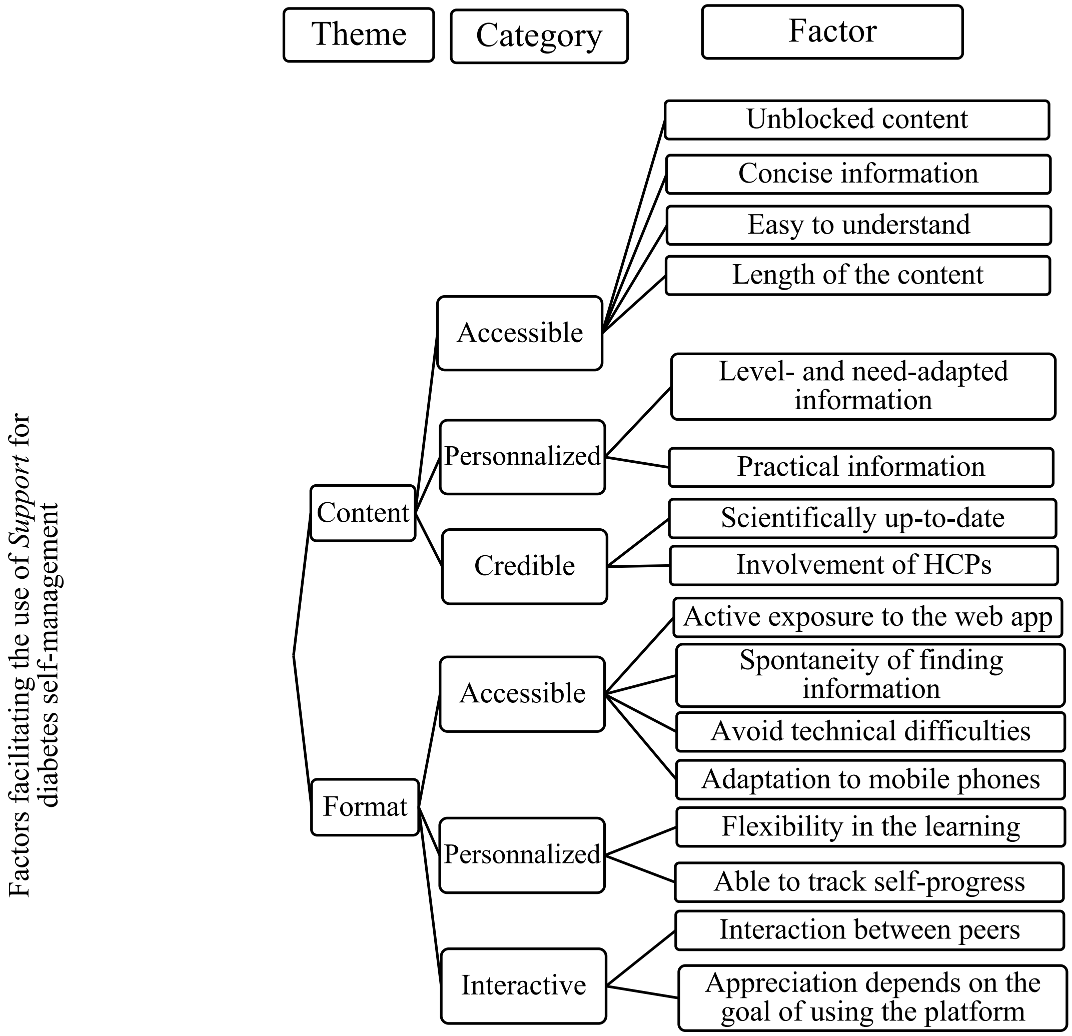
Web app usage*	**Median [quartile 1, quartile 3]**
Number of page views[†]	54 [24;147]
Number of sessions	7 [3;12]
Average session's duration, in minutes	12 [7;23]
Calculator	
Number of people who used at least once, n (%)	30 (16%)
Discussion forum	
Number of users who posted at least once, n (%)	33 (16%)
Total number of posts[‡], n	89
Newsletters	
Number of people who opened at least once, n (%)	198 (98%)
Number of opened newsletters (out of the 13)	11 [7;13]
Number of people who clicked the link from newsletters at least once, n (%)	170 (84%)
Number of newsletters with the embedded link clicked at least once (out of 13)	3 [1;6]
PDF documents	
Number of people who downloaded at least once, n (%)	101 (54%)
Number of downloaded PDF documents	1 [0;6]
Quizzes	
Number of people who submitted at least once, n (%)	126 (67%)
Number of submitted quizzes	3 [0;14]

[*] n=202 for newsletters, n=207 for the discussion forum, and n=182 for others

[†] A same page, PDF documents, and quiz view/usage can be tracked more than once. Pages related to administrative purposes were excluded.

[‡] Total number of posts based on the respective 6-month of each participant.

Figure 5.1 Factors facilitating the use of Support *for diabetes self-management*



Bridge statement 3

Previous chapters detailed the development of a web app for DSM among adults living with T1D (chapter 4) and have shown a high level of satisfaction and potentiality of decreasing the burden of hypoglycemia (chapter 5). However, whether this web app can be used on another population, such as in youth, still needs investigation.

It is estimated that the prevalence of T1D in Canada is 31 601 people in the population of 19 years and lower [49]. According to the Diabetes Atlas published by International Diabetes Federation in 2021, based on research conducted between 2005 and 2020, Canada is ranked the 5th of the top countries or territories for an incidence rate of T1D in children of 0-14 years with 37.9 per 100,000 population per year [130]. Youth and young adults have different needs than older adults living with T1D, especially regarding the gain of autonomy from their parents and transition from the pediatric to adult care [131]. Therefore, a digital tool for T1D self-management adapted to a younger population would be needed.

The World Health Organization suggested that young people should be involved at every step of the development of digital health for an effective design [7]. The following chapter will present the qualitative process used to understand how *Support* can be adapted to the needs of a younger population.

Chapter 6: Manuscript 4- Adaptation of *Support* to youth

Submitted: *Journal of Medical Internet Research September 2022*

Adaptation of an adult web application for type 1 diabetes self-management to youth: use of the Behaviour Change Wheel to tailor the needs of healthcare transition- A qualitative study

Li Feng Xie[1], Asmaa Housni[1], Meranda M Nakhla[2,3], Rosemarie Cianci[1],
Catherine Leroux[1], Deborah Da Costa[2,4], Anne-Sophie Brazeau[1,5]

Author's Affiliation:

[1]McGill University, School of Human Nutrition, Montréal, Canada

[2]The research institute of the McGill University Health Centre, Montréal, Canada

[3]Division of Endocrinology, Montreal Children's Hospital, Montréal, Canada

[4]McGill University, Department of Medicine

[5]Montreal Diabetes Research Center, Montréal, Canada

Corresponding author: Anne-Sophie Brazeau

T: (514) 398-7848

E: anne-sophie.brazeau@mcgill.ca

A : 21111 Lakeshore, Ste-Anne-de-Bellevue, Sainte-Anne-de-Bellevue, Quebec H9X 3V9 ;

Contribution: All authors have read and approved the final manuscript

L.F.X.: Participated in the design of the study; transcribed the interviews; analyzed the data; wrote, reviewed, and corrected the manuscript.

A.H. Transcribed the interviews; analyzed the data; wrote, reviewed, and corrected the manuscript.

R.C.: Translated all the quotes from French to English; contributed to the initial draft of the manuscript; reviewed the manuscript.

C.L.: Participated in the design of the study; performed the interviews; reviewed the manuscript.

M.M.N.: Co-investigator of the study; participated in the design of the study; provided feedback on the analysis of the data; reviewed the manuscript.

D.D.C.: Provided feedback on the analysis of the data; reviewed the manuscript.

AS.B.: Principal investigator of the study; participated in the design of the study; supervised the process; provided feedback on the analysis of the data; reviewed the manuscript.

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6.1 Abstract

Background: Youth (14 to 24 y.o.) living with type 1 diabetes (T1D) encounter increased challenges in their diabetes self-management (DSM), especially during the transition to adult care. While DSM education and support are imperative, there is insufficient information on how online digital tools tailored to their demands can be developed.

Aims: Based on the Behaviour Change Wheel, 1) to identify, among youth living with T1D, needs and factors influencing their DSM in the context of healthcare transition and 2) to inform the adaptation (content and features) of an adult self-guided web application (*Support*).

Methods: Virtual semi-structured individual interviews based on a phenomenological study design were conducted with 21 youths and transcripts were analyzed using an inductive approach with concept mapping.

Results: Factors influencing T1D self-management were categorized into barriers and facilitators and then as external or internal. Features influencing the accessibility to information, increasing a sense of support, and engagement with the tool were positively accepted. Features unrelated to their expectation of the digital tool use or difficulty navigating were negatively viewed. Participants expressed interest in reliable, practical, and novel educational content. Although youth considered information provided by medical professionals to be important, peer exchange was deemed necessary to obtain a practical perspective and real-life examples.

Conclusions: Compared to the adult population, in addition to tailored content and a simplified information search process, when building a DSM education and support digital tool for youth, features should be selected to encourage supervised peer exchange.

Keywords: Type 1 diabetes, youth, e-health, self-management

6.2 Introduction

In Canada, based on the sum of mid-year prevalence estimates of people born in 1922 up to 2021, the prevalence of people living with type 1 diabetes (PWT1D) was 276 284 in 2021, including 31 601 people 19 years and lower [1]. Type 1 diabetes (T1D) is an autoimmune disease requiring external insulin injection and sustainable diabetes self-management (DSM) behaviors from diagnosis for optimal glucose levels [2]. Based on an American survey of certified diabetes educators published in 2018, a child diagnosed with T1D needs 78 to 305 minutes daily to complete all the recommended components of DSM [3]. Given this intensity and lifelong efforts, adherence to medical treatment is difficult to reach, especially for adolescents and young adults with T1D (14-24 y.o.) [4]. The adolescent period is characterized by physiologic changes (e.g., an increase in insulin resistance), navigating social constructs, peer influence, a shift in family dynamics, and the transfer of responsibilities from parent to child [5]. For instance, in the province of Quebec, Canada, adolescents aged ≥14 years old (y.o.) can consent to care alone if there is no serious risk to health [6], and make their own decisions in their diabetes management. Despite the varied T1D management priorities across earlier adolescence (e.g., 14 years old [y.o.]) to young adulthood (e.g., 24 y.o.) [7], both groups are challenged with the transition to healthcare. Indeed that some parents might still play a central role and participate in the transition process [8] but with age, youth are searching for more diabetes autonomy and emancipation from their family [9, 10]. This healthcare transition period can thus be viewed as an opportunity to equip the youth with the necessary education. Furthermore, pairing them with peers who recently experienced the transition (e.g., ≥18 y.o.) can support them in acquiring DSM behaviors and address these additional responsibilities [11].

One approach to increase the acquisition of DSM behaviors among youth living with T1D is the use of self-guided (i.e., absence of individual contact with healthcare providers [HCPs]) digital tools. Especially with web-based approaches where the development cost can be lower compared to a mobile-based tool [12]. Studies have shown that youth are active users of digital health technologies, and they appreciate using online information as an opportunity to improve their health and use social media as an emotional support [13]. However, there is a gap in resources specially developed for this population [13] and limited information on how their needs can be linked to behavior change theories and be translated DSM education and support (DSME/S) interventions. For instance, the Diabetes Youth Empowerment and Support is a 12-week self-guided web-based program developed for youth adults (18-35 y.o.) in Australia [14]. Regardless of its acceptability among the target population and inclusion of topics related to transition, the intervention only addressed people who were at their end of healthcare transition (e.g., 18 y.o. and over) and did not prepare adolescents for the transition. In addition, the development of this intervention was not guided by behavior change theories. Another study focused on a younger population of 12 to 16 y.o. living with T1D, but the designed mobile application (app) was related mainly to the tracking of blood glucose value and the challenges of healthcare transition were not addressed [15] .

The integration of behavior change theories such as the BCW guides the understanding of behavior mechanisms and can increase the applicability of an intervention in the real-world setting [16, 17]. The BCW starts with the Capability, Opportunity, Motivation-Behavior model at its core to understand a behavior; then encircled by nine intervention functions needed to change behaviors; such interventions are supported by seven policy categories [18]. The BCW also links these interventions to behavioral change techniques (BCTs), which are the backbone of each behavioral change intervention [19]. The integration of BCTs within interventions can potentially increase their replicability and increase positive outcomes of behavioural changes. To convey these behavioural changes from a technological perspective, BCTs can guide the choice of characteristics and features [19, 20]. An example of the application of BCTs for T1D is *Support* [21], the first self-guided web app for PWT1D that has an evidence-based design [22]. It offers multidimensional education and support to adults living with T1D to improve their DSM. Developed by HCPs in the field, in collaboration with patient partners, it is personalized based on the user's treatment regimen to offer tailored content. This web app also includes a discussion forum mediated by HCPs, and interactive features (e.g., quizzes, calculators) [21]. However, as youth living with T1D encounter specific challenges of healthcare transition, DSME/S for this population should address this specific issue.

Considering the lack of accessible self-guided web apps based on youths' interests and needs [23, 24], as an early exploratory developmental study, based on the Behaviour Change Wheel (BCW), our study aimed 1) to identify, among youth living with T1D, needs and factors influencing their DSM in the context of healthcare transition and 2) to inform the adaptation (content and features) of an adult self-guided web app (*Support)* to their needs.

6.3 Methods

Study design and recruitment

We conducted a phenomenological qualitative study (i.e., a study focusing on the experience of the participants related to their DSM in the context of healthcare transition, and their interest in using digital health tools for DSM) using semi-structured individual interviews. The study was approved by the McGill University Research Ethics Board. This method section follows the Consolidated criteria for Reporting Qualitative Research Checklist [25].

We recruited participants from two age categories (14-18 y.o. to understand the needs of people who are preparing for healthcare transition and 19-24 y.o. to understand the experience of people who recently transitioned to adult care from pediatric care). Inclusion criteria were age between 14-24 y.o.; living in the province of Quebec, Canada; diagnosed with T1D; and able to communicate in English or French. The recruitment followed three main convenience and purposive sampling methods: 1) word of mouth; 2) email invitation via the BEhaviors, Therapies, TEchnologies and hypoglycemic Risk in T1D (BETTER) registry (a registry of people living with T1D in Quebec, ClinicalTrials.gov Identifier: NCT03720197 [26]); 3) advertisement on social media (e.g., private T1D Facebook groups) and on the study website. Potential participants were screened for eligibility by phone by the research assistant. Written informed consent was sent by email before the interview which was conducted on Microsoft Teams.

Semi-structured interview

The interviews were planned to be 60 minutes, in French or English. The participants had the option to turn on their cameras or proceed with voice only. All the interviews were recorded and then transcribed. The interviews followed a guide developed by a multidisciplinary team (dietitians, nurses, endocrinologists, and pediatricians), reviewed, and tested by patient partners (Appendix III: Supplementary 5.1). The interview guide was adapted (e.g., modify the wording;

convert a few closed-ended questions to open-ended questions) after four interviews. All the interviews were led by a female research assistant (CL, registered dietitian with experience in clinical diabetes care). The participants did not know their interviewer before the study.

The interviews were based on an existing self-guided web app designed for adults with T1D (i.e., *Support* [21]) as an example of an online DSME/S resource. The information on *Support* is divided into six learning categories with three levels of complexity. The web app integrates various features to facilitate the learning and navigation experience (e.g., a discussion forum facilitated by a healthcare professional, quizzes, and videos). This web app is completely self-guided (i.e., no personal contact between HCPs and users except for technical support), and users can learn at their own pace. Before each interview, participants received a PowerPoint presentation of the adult *Support* and a 3-minute explanatory video of the web app (Appendix III: Supplementary 5.2). At the beginning of each interview, the research assistant confirmed that the participants had the opportunity to review this material and asked if they have any related questions. If the participant did not review the material, the interviewer presented them before the interview.

The interview consisted of four sections with a total of 20 questions (including open- and closed-ended questions). Interviews started with a self-introduction of the participants, followed by participants' current diabetes management practices (e.g., their treatment plan [e.g., type of insulin use, method of blood glucose monitoring], where they find information related to health and diabetes, their confidence in managing diabetes), and their general use of online education tools. The interviewer then probed for feedback regarding *Support* (e.g., most preferred features, adaptations that should be made for youth), the potential for creating new content (e.g., by providing examples of barriers in their daily life and other topics that they would like to discuss), and concluded the interview. Some of these questions included probes that facilitated the discussion if participants initially had no answers.

Each participant received an electronic Amazon gift card (40$ Canadian dollars) to compensate for their time upon completion of the interview. Each participant was interviewed once and was also invited to send their comments or suggestions by email following their interview if applicable. However, no comment was received after the interviews.

Transcript and Analysis

The interviews were first transcribed by one of the researchers (LFX or AH) and then reviewed by the other researcher to confirm the accuracy of the information. Two researchers (LFX and AH) performed the coding independently, using NVivo software (QSR International, Melbourne, Australia), and discussed the agreement on the coding attributed to each transcript section. Researchers reached a mutual agreement for all the codes included. The percentage of agreement was calculated based on the total included codes divided by the largest number of codes independently found by the two researchers. Interviews were analyzed with an iterative inductive approach. Initial codes were determined based on two randomly selected interviews and then adapted throughout the analyses. Inductively, codes having similar topics related to their DSM or feedback regarding *Support* were then merged into categories and further into themes, using concept mapping. All the analyses were performed in French. Codes and quotes were translated into English using a forward-backward translation process by three bilingual researchers (LFX, AH, and RC) for the purpose of the publication. Results were discussed with research patient partners but were not returned to the participants.

6.4 Results

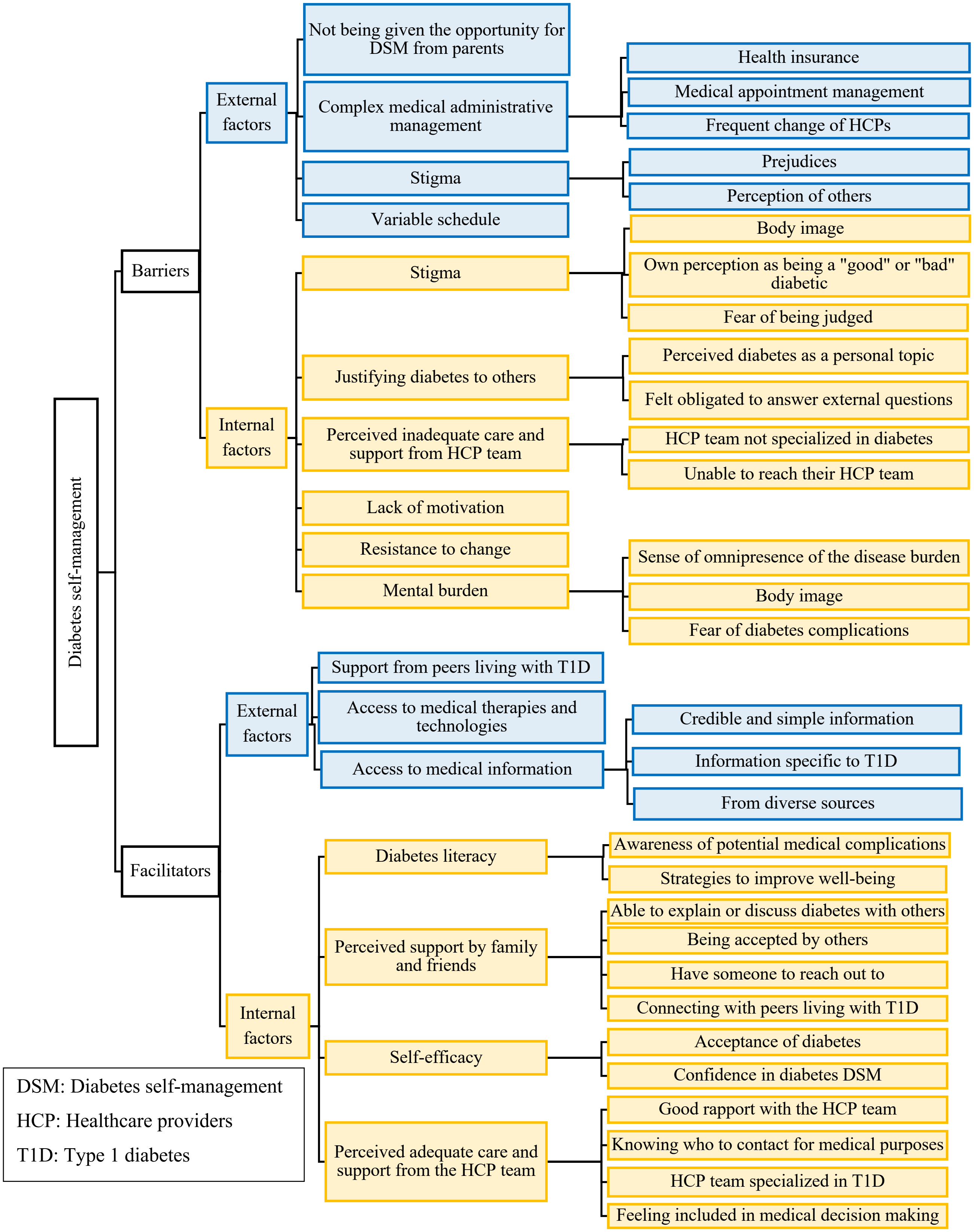
Among the 32 invitation emails sent, 27 potential participants contacted the research assistant and were screened for eligibility. Among the eligible participants, 22 participants agreed to participate, but one participant was excluded during the interview because of her difficulty understanding the questions and responding to them. The final sample size included 21 participants: eight participants in the 14-18 years of age category (five women and three men) and 13 participants in the 19-24 years of age category (seven women and six men). The mean diabetes duration ± standard deviation was 9.4 ± 4.5 years, the median was 10 years, the mode was six years, and the range was 1 to 16 years; 86% (n=18) were White. Most of the participants were using an insulin pump (n=16, 76%) and continuous or flash glucose monitoring systems (n=15, 71%). One participant *(participant 5, man, 23 y.o., 17 years of diagnosis [y.d.])* used *Support* for 6 months prior to the interview. The interviews took place between October 2020 and January 2021. The mean length of the interviews was 44 minutes (ranging from 27 to 62 minutes).

Data saturation (i.e., no new codes were determined during the analysis) was reached after analyzing 17 transcripts and the average agreement score was 72% among the two interviewers for all the interviews. Codes related to DSM were categorized into themes using a concept-mapping approach (Figure 6.1) and feedback regarding the features was analyzed (Table 6.1).

Understanding the needs for diabetes self-management

Participants expressed their experience and needs with DSM in the context of healthcare transition. The information was grouped into barriers and facilitators to DSM and further categorized into external (i.e., factors that participants cannot alter on their own) and internal factors (i.e., factors that participants can alter on their own) (Figure 6.1). Examples of quotes considered for each code are presented in Appendix IV: Supplementary 6.3.

Figure 6.1 Barriers and facilitators of diabetes self-management



External barriers

Four external barriers were identified (Figure 6.1). With adolescents gradually acquiring more autonomy, one external barrier they faced was not being given the opportunity to self-manage their diabetes from their parents. It was described by one youth as feeling *“handicapped” (Participant 10, woman, 19 y.o., 3 y.d.)*. This prevented them from managing their diabetes autonomously given the involvement of their parents in their diabetes care. Autonomy also brings more responsibility, such that youth slowly take over the administrative aspects of their diabetes like making medical appointments and dealing with health insurance. Participants also cited the transition process as a barrier including the transfer to a new healthcare team and healthcare setting. The administrative factors were described as complex and as barriers to adequately managing T1D. A variable schedule was also stated as adding difficulty to DSM at this age. This affected their sleep, exercise, and meal patterns, which has a magnified impact on diabetes management. As one participant said *“Basically everything can affect your blood sugar is how I see it. Like stress, eating, sleep [...] anything can, which is really hard.” (Participant 19, boy, 16 y.o., 9 y.d.)*

Stigma was also a barrier and was expressed to be both external and internal. Prejudices and perceptions of others were external stigmas experienced by participants. It ranged from the misconception that sugar intake was alone responsible for diabetes development, wrongful associations between insulin injection and drug use, discrimination in their capability to perform actions, to stereotyping the body weight of “*a diabetic*”. One participant shared *“I have often been told: «I do not understand why you are diabetic, you seem to eat well and you don’t seem to* *be very overweight.» No, but it's not that." (Participant 18, girl, 16 y.o., 15 y.d.)*

Internal barriers

Stigma can also be an internal barrier. In fact, participants expressed concerns about their body image and internalized behavior labelling such as considering themselves as a "*good*" or "*bad diabetic*". *(Participant 21, man, 24 y.o., 10 y.d.)* Additionally, youth's fear of being judged by others prevents them from properly managing their diabetes if they perceive it to be a "*burden*" for others. For example, one of the participants said*: "I will wait until the end of the class to eat something. Otherwise, people will look at me as if I were sick [...]. So, it happened to me to wait for class to end to treat hypos." (Participant 3, man, 22 y.o., 6 y.d.)* In addition, the difficulty of navigating the high expectations from their healthcare team was expressed by a participant and can prevent suitable healthcare support: *"To understand that [...] we are not perfect patients, who take their blood sugar on time, and then they eat a certain number of grams of carbohydrates." (Participant 21, man, 24 y.o., 10 y.d.)* Participants also expressed their observations related to the lack of specialization in T1D care transition from pediatric to adulthood and their apprehensions of being left alone. One youth shared *"It was like a shock to me, because [my new healthcare team] was supposed to be medical specialists; but they had no expertise in diabetes technology at all. Then he didn't even look at my blood sugar." (Participant 3, man, 22 y.o., 6 y.d.)*

Another internal barrier was feeling the need to justify diabetes to others and to answer continuous inquiries from others. In fact, some participants perceived diabetes as a personal topic and preferred to not spend more time discussing it. In contrast, it was important for them to feel heard and supported by people around them.

The lack of motivation was expressed by some participants as a lack of interest and lower priority placed on their DSM. It was mainly related to the difficulty of dealing with and accepting their diabetes. A participant said, *"I wanted to hear […] the stuff that might help people with diabetes acceptance and take responsibility [...]. Talk about it a little more when I was young, to have cues to deal with diabetes […] to be able to explain it without living in too much discomfort." (Participant 17, woman, 23 y.o., 10 y.d.)* This becomes an even greater challenge when coupled with the mental burden. Concerns were expressed regarding body image and difficulty with weight, a sense of omnipresence of the diabetes burden, and the fear of consequences related to T1D that adds to the toll of this condition.

A final mentioned internal barrier was the resistance to change. The difficulty breaking behavior and acquiring a new way of managing their diabetes encompassed the struggles of keeping a habit. In fact, more than understanding and knowing how to deal with certain aspects of diabetes, consistency in performing these actions is an issue. One participant said: *"I know how to calculate my carbohydrates, I know everything to do, but sometimes it's to take the initiative, calculate […] it's more doing it than knowing it." (Participant 18, girl, 16 y.o., 15 y.d.)*

External facilitators

Several facilitators were voiced by our participants as opportunities to strengthen their DSM, such as connecting with peers living with T1D to share their daily lives and routine. Their peers are also a source of practical information, a participant shared “*[The doctor] doesn’t live the same reality as me, [and I would be more interested] to see how people can apply it, sometimes it helps me when I meet a diabetic person.” (Participant 17, woman, 23 y.o., 10 y.d.)*

Other external facilitators included the use of medical technologies and therapies and access to medical information. A participant shared that consulting a resource like *Support* was interesting because it was *“a way to acquire information more easily, more quickly, because an appointment with an endocrinologist is long.” (Participant 12, boy, 14 y.o., 6 y.o.)*

Internal facilitators

Participants’ knowledge of technology use contributed to their diabetes literacy and facilitated DSM. A participant expressed her enthusiasm saying *“I am very excited! I can know how long it has been since I injected my last dose [using an insulin pump therapy].” (Participant 4, woman, 24 y.o., 10 y.d.)* While acquiring strategies to improve wellbeing was deemed important for youth’s DSM, being aware and understanding complications and their breadth of impact on their health and lives were central to facilitating DSM, as a youth inquired: *“If I didn't inject, what would it do? At 10 months of diabetes, I still don't even know what it [the consequences of not injecting diabetes] does [...].*” *(Participant 11, girl, 16 y.o., 1 y.d.)*

According to the participants, adequate DSM is closely linked to perceived support (from their families, friends, and healthcare team), as this can facilitate their communication with others about diabetes, being accepted by others beyond their health condition and having someone to reach out to if they ever feel the need to.

Factors impacting the acceptability of a web app's features

Participants individually proposed a list of potential features or characteristics included in self-guided DSM digital tools based on pre-existing features in *Support* (Table 6.1). According to participants, a feature or a characteristic tends to be positively accepted if it 1) provides access to the information, 2) increases a sense of support, and 3) increases engagement with the web app. They were viewed negatively mainly due to 1) personal preferences, 2) difficulty using the feature, and 3) perceived irrelevance to DSM. A feature can be associated with one or more of these factors.

Accessibility to the information

A feature increases the accessibility to the information when it facilitates autonomous web app navigation by the participants, organizes the content in a logical and simple way, or adds flexibility to their learning process. Features such as an internal search engine, downloadable PDF documents, and specific module categories were all considered as methods to organize information in a simplistic way and facilitate navigation on the web app. The participant who used *Support* for 6 months found it difficult to navigate without an internal search engine. He stated that "*there was one [module] I wanted to go see and then I was like oh my God where is it. I had to scroll, look a bit through the pages [...] I think [a search engine] can be handy." (Participant 5, man, 23 y.o., 17 y.d.)* Therefore, implementing features to help users save time should be considered as one of the main priorities during the design of the digital tool.

To add flexibility to the learning experience, participants suggested features such as smartphone compatibility should be considered, as viewing the platform on a phone (webpage or app-based) can be more convenient than opening a browser on a computer.

Sense of support

Sense of support refers to the need for youth to not feel alone in their diabetes management. This idea includes being able to communicate diabetes-related information with people who do not and who have this condition. This can be realized through a discussion forum, chatrooms, or the incorporation of testimonials. As one participant mentioned, *"For young adults, we are more and more focused on the connection with others, the discussion, the socializing on networks." (Participant 2, woman, 23 y.o. 14 y.d.)* Communication with others helps them understand that others are in the same situation and that there is not only one solution to issues. *"[Having] people giving their experiences, then showing or demonstrating to people that we are all different, that each body reacts differently […],'it's really just learning to know how the body reacts with regards to it." (Participant 14, girl, 16 y.o., 4 y.d.)*

Engagement with the web app

Participants discussed how the choice of features can impact their use of the web app. For instance, a platform that is visually appealing can increase their motivation and curiosity to learn and encourage them to return. Displaying the progress of the module completion was also seen to make users feel accomplished and setting personal objectives may increase their desire for knowledge application, further reinforcing their learnings. The use of notifications can increase the digital tool's use by reminding people of its existence and informing users about new content.

Other features having a potential impact on engagement include the virtual rewards, but the opinions were divided. The integrated gamification (e.g., trophies, certificates, quiz) may benefit some participants by keeping them engaged with the tool: *"I think that can be a motivator and make me feel proud. Like I got my new trophy […], basically, it can be a personal pride" (Participant 12, boy, 14 y.o., 6 y.d.)* while for others, it would have no impact on their use: *"I think that [trophies] don't matter to me, [...] I would like it for the younger people." (Participant 5, man, 23 y.o., 17 y.d.)*

Characteristics leading to negative acceptability

In addition to not perceiving a feature as being useful for its intended goal, the difficulty of using a feature can also be a barrier. For instance, the discussion forum received mixed feedback due to its current format (i.e., under a specific tab and participants needed to click on each topic to investigate the posts):*"Well maybe a different format, […] because I have the impression that a forum is good for asking your own questions, but you lose some of the information because you don't tend to look at [the answer of other posts]." (Participant 10, woman, 19 y.o., 3 y.d.)* Therefore, it was suggested to display all the posts in chronological order and have them automatically shown on their dashboard. The discussion forum could also be directly integrated into a social media platform (e.g., Facebook) as many youths are already using it.

Personal preferences were a third explanation given by the participants regarding the negative acceptability of the features. This can be reflected via the comments on the design of the web app (e.g., considering cartoon illustrations as childish) or related to their experience (e.g., associating quizzes with academic performance). Participants specifically highlighted that they do not feel *"like reading huge paragraphs and then answering quizzes again [...] after a day of school." (Participant 16, woman, 19 y.o., 9 y.d.)* One of the proposed solutions is to increase the use of videos as they *"are lighter, as it is more like listening to a show." (Participant 22, man, 22 y.o., 13 y.d.)*

Table 6.1 Discussed features and examples of quotes

Characteristics or features	**Related behavioral change techniques**	**Description**	**Feedback**[a]	**Example of quotes**
Anonymity	• Avoid aversive stimulus[b]	Ability to use the tool without being known by others	(+) • Access to information • Sense of support	"They [youth with T1D] are afraid to confess to others [peers or healthcare professionals]. It might be important for them to use these platforms. Like knowing the information without others knowing about it." *(Participant 12, boy, 14 y.o., 6 y.d.)*
Carbohydrate calculator	• Avoid aversive stimulus • Problem solving	Calculator to estimate the food's carbohydrate content	(+) • Access to information	"I was wondering if it would be possible if you have an app that when taking a photo, it would be able to estimate your carbs." *(Participant 15, man, 21 y.o., 6 y.d.)*
Cartoon illustrations	• Avoid aversive stimulus	General visual design of *Support* (e.g., pictures, colors, front of the texts)	(+) • Access to information • Sense of support (-) • Dislike due to personal preference • Not perceived relevant for DSM	"Then the site is also visually beautiful, I have the impression that since I find that it is interesting, it can motivate me to go on it." *(Participant 10, woman, 19 y.o., 3 y.d.)* "[…] I found that it [the profile avatars] was a little bit childish. Maybe I would have put it a little more suited because it is a clientele over 18 years old." *(Participant 15, man, 21 y.o., 6 y.d.)*
Categories	• Avoid aversive stimulus	Learning modules classified in categories	(+) • Access to information	"The ease of finding information, with it clearly divided into sections. If the first time I had difficulty finding the answer to my question, for example, in relation to food, I would be less inclined to go to this site." *(Participant 16, woman, 19 y.o., 9 y.d.)*
Chatroom	• Social support	One-on-one message with a healthcare professional or another participant	(+) • Access to information • Sense of support	"I would say drugs and alcohol are not the most comfortable topic. […] I think it's more comfortable to talk about it anonymously, or in a chatroom, than it is face-to-face with your doctor, especially as a 15, 16, 17-year-old. […]."*(Participant 19, boy, 16 y.o., 9 y.d.)* "I don't know if that would be possible, but sometimes, on sites, there are little chats, something where if you have a

				question […] you sometimes contact someone who is there directly.” *(Participant 5, man, 23 y.o., 17 y.d.)*
Discussion forum	• Social support	A healthcare professional-moderated forum where users can ask questions or post comments.	(+) • Access to information • Engagement with the tool • Sense of support (-) • Difficulty using the feature • Dislike due to personal preference • Not perceived relevant for DSM	“Also, the exchange blog, because sometimes yes there are professionals, but they can't really feel 100% what it is like as a diabetic. So sometimes having support from other people who aim for the same things as you, […] it's more reassuring I would say.” *(Participant 18, girl, 16 y.o., 15 y.d.)* “[I liked] the discussion forums, […] I could find them everywhere else; the only difference is that they are not like moderated by a health professional, but you know a lot of social networks have people sharing their experience, there is even a social network that was created just for diabetics.” *(Participant 13, girl, 16 y.o., 5 y.d.)*
Downloadable summary documents	• Credible source • Avoid aversive stimulus	Summary documents that are ready to be downloaded and printed	(+) • Access to information	“I also like when there are, let's say, cheat-sheets, or whatever, that you can print out and keep with you, not necessarily to have to look for them on the site, that also helps a lot.” *(Participant 18, girl, 16 y.o., 15 y.d.)*
Gamification	• Non-specific reward	Accumulation of virtual points, trophies, and certificates. Provide possibilities of having competitions among participants.	(+) • Access to information • Engagement with the tool • Sense of support (-) • Dislike due to personal preference	“We accumulate them [points] on the different categories. It’s fun. […] I find it must be like a kind of self-fulfillment feeling, you say to yourself, I'm a good person.” *(Participant 14, girl, 16 y.o., 5 y.d.)* “Maybe if I had been younger, that I just got diagnosed with diabetes, that would motivate me more, but now it's been 10 years that I have it, so I learned to manage well. So, whether I have a trophy or not, it won't influence me to change my control.” *(Participant 17, woman, 23 y.o., 10 y.d.)*

			- Not perceived relevant for DSM	
Internal search engine	- Avoid aversive stimulus	Search engine by keywords	(+) - Access to information	"You forget something, you want to remember, you are going to look for the specific information, but this is found in lesson 3, you have to do all the lessons before." *(Participant 3, man, 22 y.o., 6 y.d.)*
Links to external resources	- Social support	External resources provided (e.g., from governmental and health institutions) within the digital tool	(+) - Access to information	"[It would be useful to have information] which is not necessarily on the platform, but links to other external links or phone numbers." *(Participant 18, girl, 16 y.o., 15 y.d.)*
Module duration display	- Avoid aversive stimulus	Estimated time needed for completion	(+) - Access to information - Engagement with the tool	"When you see that it's 10 minutes, it motivates you a little to finish the class." *(Participant 21, man, 24 y.o., 10 y.d.)*
Notifications	- Avoid aversive stimulus	Update notifications of the app, news, or diabetes self-management	(+) - Access to information - Engagement with the tool	"Maybe there should be a notification to say that there is some news that came out. But I'm not sure people have, let's say, the habit to log in once a week just to go and see if there is any news." *(Participant 15, man, 21 y.o., 6 y.d.)*
Personal objectives	- Commitment - Goal setting - Review behavior goal	Self-given or provided personal objectives for DSM	(+) - Engagement with the tool	"Maybe weekly goals to achieve. Like maybe "Have you managed to measure your blood sugar a certain number of times?", goals to achieve which really makes you want to do it." *(Participant 21, man, 24 y.o., 10 y.d.)*
Placement quiz	- Graded tasks	Diabetes-related questions to adjust the learning at beginning of the program	(+) - Access to information	"Maybe it could be [helpful] to take a little test to establish the level and know […] at what course we should be placed at." *(Participant 13, girl, 16 y.o., 5 y.d.)*
Progress visualization	- Self-monitoring of behavior	Timeline within the platform to see the learning progress	(+) - Access to information	"There are little points that show our progress in the program, I find that relevant because […] it's a visual cue. It tells us we're about halfway." *(Participant 16, woman, 19 y.o., 9 y.d.)*

		and option to exit the learning modules at any time with the progress saved	• Engagement with the tool	"I also found it fun that you could see your progress so that you don't have to do [the course] all at once. You can do part of it, and come back, you know where you've been, […] it's visual." *(Participant 20, man, 19 y.o., 11 y.d.)*
Quiz	• Feedback on outcomes of behavior	Questions for participants throughout the learning modules. Correct answers are provided right after their answer	(+) • Access to information • Engagement with the tool (-) • Dislike due to personal preference	"I think the quizzes are good, I think they're important just to make sure you know what you're doing so that you don't get in trouble when you're actually dealing with stuff. Like, just basic stuff in the quizzes." *(Participant 19, boy, 16 y.o., 9 y.d.)* "Personally, the quizzes appeal to me a little less, but at the same time, I tell myself that there may be people for whom it is easier to know that they have understood the material." *(Participant 18, girl, 16 y.o., 15 y.d.)*
Sharable link	• Credible source • Social support	Automated generated sharable link	(+) • Sense of support	"Maybe articles they can be shared on social media […]., Like if there is a way to share an article that discusses a particular topic on Facebook […] with everyone and say: Take 2 seconds of your day to read this." *(Participant 5, man, 23 y.o., 17 y.d.)*
Smartphone compatibility	• Avoid aversive stimulus	Ability to navigate using a smartphone	(+) • Access to information	"In the format of an application, […] it appeals to me a lot more in my cellphone, since I already have my sensor, everything is in there." *(Participant 17, woman, 23 y.o., 10 y.d.)*
Tangible rewards	• Material incentive	Rewards (e.g., pen, booklets) given based on the virtual points	(+) • Engagement with the tool	"Maybe a way to attract teenagers more, […], but also like having small prizes, but physical ones, then it could be a Dex4 package […] or pencils. [...] I think that it might motivate." *(Participant 13, girl, 16 y.o., 5 y.d.)*
Testimonials	• Credible source • Identification of self as role model • Social support	Stories from people living with type 1 diabetes	(+) • Engagement with the tool • Sense of support	"People giving their experiences, and showing, demonstrating to people that we are all different, and that each body reacts differently, […] it's really just learning to know how the body reacts in relation to it all." *(Participant 14, girl, 16 y.o., 5 y.d.)*

Unrestricted access to all the modules	• Avoid aversive stimulus	All the learning modules are unblocked initially and free of access	(+) • Access to information	“Another suggestion would be keeping the order of the modules but leave them unblocked, […] if you don't have a lot of knowledge in diabetes, it can be useful to start with the basics.” *(Participant 3, man, 22 y.o., 6 y.d.)*
Videos	• Credible source • Avoid aversive stimulus	Information given in a video format	(+) • Access to information	“I think videos are more relevant for learning purposes away from an academic context”. I think it's easier for people to learn by video than by written stuff, the concentration is different I find.” *(Participant 1, woman, 22 y.o., 19 y.d.)*

[a] (+) sign refers to positive feedback regarding to the presence of features or characteristic on the platform for the diabetes self-management (DSM) of the participants and (-) sign refers to negative feedback. A feature or characteristic can have a mix of positive and negative feedback

[b] “Avoid aversive stimulus” is adapted from the “remove aversive stimulus” of the behavior change techniques taxonomy

Suggestions of diabetes education content

Based on the existing educational content provided to the participants, a list of other potential topics was discussed and is shown in Appendix IV: Supplementary 6.4. The results highlighted characteristics of learning content that will be the most appreciated by the participants: 1) reliable, 2) practical, and 3) novel.

Reliability of the educational information provided

The source of reliability of information differs for medical (e.g., understanding the impact of alcohol on glycemic control) and experience-related topics (e.g., how to limit alcohol consumption at a party). For medical information, a high level of reliability would be the ones sourced from governmental or organizational websites/magazines/journals:*"I'm really looking for [...] something reliable. Either by the government or anything, such as a project or a foundation that is relatively reliable." (Participant 7, girl, 17 y.o., 14 y.d.)* A few participants questioned the reliability of the information from discussion forums and social media group pages. Their reliability, or potential lack thereof, is a barrier for participants seeking information within these tools. However, this issue of credibility could be resolved with the supervision of an HCP who would address invalid recommendations: *"It's true that having a forum with specialized [healthcare professionals] would be a real bonus because on the Internet we really get advice that we think we can follow [but they are] not given by professionals." (Participant 21, man, 24 y.o., 10 y.d.)*

While the role of HCPs and information coming from credited references were essential for medical advice, this appeared to be lessened when referring to personal experience-related information. One of the participants mentioned that *“Testimonials [...] [are] still pleasant, [...] we see that we are not all alone. In the same boat, there are also others who have the same problem.” (Participant 4, woman, 24 y.o., 10 y.d.)* To increase this sense of belonging, the information should also be from people who are in the same age group and living the same reality as them: *“Me versus someone who is 18 years old, who tells me that it has happened to them before [...], versus someone who tells me that as a 45-year-old, they did that. [...] Maybe it's not the same reality, maybe it's not the same management [...]. So I'm gonna trust more people of my age.” (Participant 7, girl, 17 y.o., 14 y.d.)*

Practicality of the information

Information is considered practical when it is directly related to a real-life situation that participants can identify with and goes beyond theoretical knowledge. Participants are looking for a resource that will *“help [them] more with the practical aspect of everything than with the theory”* and *“that would [...] support them in a follow-up, because of course the lessons are very good, but in the end, [...] the practical aspect [...] is most important [...].” (Participant 21, man, 24 y.o., 10 y.d.)*

Information related to blood glucose management and the choice of medical technologies, devices, and suppliers were of high interest. Participants expressed that they should live with a situation to find a use of the information. The use of an insulin pump was given as an example by one participant: *“I don't have a pump. Anything that is linked to the pump? No. [...] I'll just tell you [that] what didn't happen to me, it looks like I'm not interested [in].” (Participant 17, woman, 23 y.o., 10 y.d.).*

Novelty of the information

The novelty of the information refers to the idea that the educational content should provide information that was not known to the participants previously or that the information cannot be found in other places (e.g., HCPs, family and friends, pharmaceutical companies). According to many participants, the amount of unknown information seems to be related to the duration of T1D. For the same reason, participants inquired about having the function of finding specific information in a convenient way to not lose interest in the digital tool. In addition, it was suggested that the tool does not only include *"basic topics that can be found on the internet, but that pushes the questions a little further." (Participant 7, girl, 17 y.o., 14 y.d.)*

6.5 Discussion

Our study explored barriers and facilitators encountered in DSM in the context of healthcare transition by youth living with T1D; and adaptation (feature and content) to an adult self-guided DSME/S web app by connecting needs expressed by youth in their DSM with the BCW [18] and its related BCTs [19]. The user-oriented approach used in this study aligned with recommendations from the Lancet and Financial Times Commission on governing health futures 2030: growing up in a digital world, where youth should voice their needs and be placed at the center of the digital health tool development [27]. Having the end-user as the primary expert can also increase its usability [28]. In our study, participants highlighted that features and characteristics included in the self-guided digital tool should facilitate access to the information, increase social support, and engagement with the tool. The content provided should be reliable, practical (adapted to their reality), and novel.

Simplicity in finding information

Barriers encountered by youth in their physical and social environment can often be perceived as uncontrollable and decrease their physical and mental opportunity for performing DSM behaviors. For instance, the ‘enablement’ intervention function of the BCT should be a primary consideration while designing an online DSME/S tool, as participants in our study needed easy access to information due to their variable schedule. Information categorization, short videos, progress saving, and smartphone compatibility are all potential features and characteristics to decrease this barrier and make both the tool and its content available at the convenience of the participants.

Importance of receiving support

The social environment also includes interaction with others, which can imply barriers such as stigma and a perceived lack of social support. Due to these factors, participants reported that they might experience a decrease in their level of confidence in managing their diabetes, make decisions based on the attitude of others, or have less opportunity to access DSM-related information. To address these concerns, the BCT ‘social support’ can be employed and translated into features such as discussion forums, chatrooms, and shareable links of information from the digital tool. These exchanges provide opportunities of bridging the gap of understanding between youth living with T1D and their family and friends who do not, raising awareness of the realities of living with T1D, and decreasing stigma and the fear of being judged by others.

In addition, the BCT ‘feedbacks’ could be another integration to decrease external stigma and increase social support while increasing access to information. This technique can be combined with features relating to ‘social support’ (e.g., providing feedback for a discussion forum post”) or be used alone (e.g., answers given after quiz completion); it can be given in a text format (e.g. “Congratulation for your good answers!”), virtual rewards (e.g., unblocked profile pictures with the number of quiz completion), communication with the healthcare team (e.g., providing a medical certificate for program completion), or individualized communication (e.g., follow-up phone calls). However, although this method may be effective in reaching self-management outcomes, it may not be as feasible due to financial constraints to produce the feedback algorithm in all circumstances [21]. In addition, feedback must be given by a qualified person, which further increases the cost of human resources. When comparing feedback via phone calls versus a discussion forum, scheduled calls may not provide the spontaneity that a discussion forum can allow, increasing the risk of forgetting the inquiry or losing interest in the matter. The acceptability of this technique also varies based on its context. For instance, providing results after a quiz can be psychologically associated with academic performance and becomes a barrier to the use of the related feature. Therefore, it would be important to further investigate using feedback as a BCT in different groups and its most suitable format.

Enabling self-identification

The presence of a role model (intervention function: ‘modeling’) can increase self-regulation in early adolescence [29] and impact motivation [30]. Associated techniques include ‘identification of self as a role model’ and ‘social support’ and can be brought by the feature ‘testimonials’. Participants could have the opportunity to become a mentor for others or be able to identify themselves in the stories of others. Other formats of providing social support in this population demonstrated by the literature include creating virtual teams using a participant messaging system and the option to share content on social media [31]. However, despite the spontaneity provided by these social groups [23], it would be essential to consider the confidentiality of users, especially for the discussion of stigmatizing topics [24]. Therefore, an option of posting information in an anonymous manner should be provided.

Adapted content from credible sources

While some of the DSM factors can be modified by the general design of the digital tool, others such as self-efficacy, diabetes literacy, and access to medical information are directly related to the learning content [32] and the intervention function ‘education’. The BCT ‘credible sources’ should be integrated to increase the quality of the information. In the current study, participants distinguished ‘credible medical source’ vs ‘credible practical source’. The first one often refers to information from HCPs, and governmental and diabetes-related organizations whereas the second refers to information related to daily issues coming from their peers living in a similar situation. Therefore, the digital tool should be adapted with the help of different stakeholders to ensure the diversity and credibility of the information. In addition, the BCT ‘instruction on how to perform a behavior’ can be referred to when the information is related to a behaviour change; the format of the demonstration (e.g., with a real person, in cartoon, in video) can vary depending on the topic.

Consider tangible rewards

Learning content targeting the needs of the population alone might not be sufficient to ensure adherence to the digital tool and maintain user motivation. As reported by our participants, the lack of motivation for DSM and in using digital tools can be addressed with the use of BCT ‘goal setting’ [11] associated with the intervention function ‘persuasion’. This can be translated into a ‘goal setting’ feature within the tool development. The goal can come from the participants or be provided by their healthcare team while establishing realistic and attainable objectives would be key for its use. Similarly, a few studies investigated the use of feature ‘rewards’ and ‘gamification’ (as healthy-living challenges [33, 34] team competitions, a points system with monetary rewards [31], and trivia questions [34]) on the lack of motivation for disease management and digital tool use but controversial results were found [35, 36]. These differences might be related to the type of reward given and the age of the population. For instance, our participants expressed that the rewards might be a motivator for children but not for teenagers and suggested a preference for tangible rather than virtual rewards. As incorporating features related to gamification (e.g., virtual rewards) and a greater level of interactivity is associated with a higher financial cost at the design phase of the digital tool [21] and tangible rewards imply long-term financial investment, it would be suggested to investigate the preferences of the users on these features during its planification.

Limitations

A few limitations are present in the interpretation of the results. Not all the questions were open-ended during the interviews. Closed-ended questions were used to validate some concepts and might bias the participant’s answer. To reduce the risk of bias by the researcher when conducting the interviews, the same interviewer was present for all interviews and was asked to follow an interview guide. Translation of the interviews can increase bias in the reporting of the information; therefore, three bilingual researchers (LFX, AH, RC) reviewed the translation independently to ensure translation accuracy. Most participants were White which can limit the generalizability of the results. The geographical location of participants was not asked during the interviews. However, based on the interview exchanges, there was evidence that people from the Northern area of Quebec, where Internet coverage is limited [37], were not included. Therefore, people with lower access or unfamiliarity with digital health services might have limited access to digital tools discussed in this study and this can lead to issues of health equity. Due to the early exploratory nature of this study, participants provided an overview of their opinion on the included features within the limited time of the interview. Further investigation about how youth would access and use the features would be suggested.

6.6 Conclusions

In conclusion, our study barriers and facilitators considered by youth regarding the transition in their healthcare. Our analysis demonstrated that youth have an interest in a self-guided digital resource for their DSM where they can encounter peers living in similar situations and who can share their experiences. To increase a sense of support from their family, participants also suggested including sharable links for the information contained in such tools. Given the interest in youth for a self-guided digital tool for DSM, as a future direction, a prototype will be developed and exploration of youth opinion via think-aloud and focus group will be conducted.

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List of abbreviations

BCT: Behavior change techniques

BCW: Behaviour Change Wheel

BETTER: BEhaviors, Therapies, TEchnologies and hypoglycemic Risk in type 1 diabetes

DSM: Diabetes self-management

DSME/S: Diabetes self-management education and support

HCP: Healthcare professionals

T1D: Type 1 diabetes

y.o.: Years old

y.d.: Years of diabetes diagnosis

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Chapter 7: General discussion

7.1 Summary of findings

This Ph.D. project investigated the development of self-guided web apps for chronic health condition management using T1D as an area of application.

My first objective was to explore the current status of self-guided web app development for chronic health conditions regarding the most common features and the evaluation of adherence. My scientific proposition was that features related to personalization and feedback would be most appreciated by the users [5]. The results of this systematic review (chapter 3) showed that, effectively, the most preferred features (e.g., goal setting) have these characteristics, but interactive features (e.g., quizzes) also tend to receive positive appreciation. In addition, this study highlighted three gaps in the literature that inspired the following projects: 1) the absence of self-guided web apps for PWT1D built on behavior change theories; 2) the limited information regarding acceptability of their features; and 3) inconsistency in the definition of the term "engagement" and "adherence" to digital health technologies.

Indeed, the term "engagement" and "adherence" to digital technologies are often used interchangeably and confused with "digital tool usage". Defining these terms is important to increase comparability between different digital tools. For this discussion, digital tool usage is defined as a description of the general usage of the tool (e.g., frequency of log-in, number of page views, viewing duration, use of the features). Engagement is defined as the degree of interaction between the user and the tool. Engagement is dynamic and can vary with time. Engagement measures can be identical to parameters used to describe the tool usage but they should reflect the research question or the goal of using the digital tool [38]. Adherence implies the presence of intended usage, or a digital tool usage level pre-determinate by the researchers/developer team, and people who reach this level would be considered as adherent [39].

To bridge the gaps identified from this systemic review, a self-guided DSME/S web app for PWT1D was realized based on the BCW with a multidisciplinary team: the *Support* web app. Consistency with my second objective, I described the procedure used for this web app development (chapter 4), covering the choice of topics, and selection of features (which originated from the needs of PWT1D, the BCW, and BCTs), and detailed contribution of patient partners and other stakeholders.

To optimize this web app (objective 3), a mixed methods proof-of-concept study was conducted to evaluate user satisfaction, impact on hypoglycemia and changes in diabetes self-efficacy. Data was primarily collected at 6 months with a follow-up at 12 months. Similar to my hypothesis of the possibility of reaching a minimum satisfaction score of 75% [6], this web app had a high level of satisfaction (82% as the median) among adults living with T1D in Quebec (n=166). Based on paired t-tests, there was a decrease in the frequency of hypoglycemia after six months (mean difference [95% CI] of -0.43 [-0.86; 0.001], p-value 0.051) and from six to 12 months (-0.51[-1.13; 0.12], p-value 0.109). Similar observation was seen for the total score of fear of hypoglycemia, a decrease of -1.98 [-3.76;-0.20], p-value 0.030 and -10.20 [-13.84;-6.56], p-value <0.001 during the first and second six months respectively. After six months, 51% of users reported also increased self-efficacy for preventing hypoglycemia and for managing blood glucose value.

During the semi-structured interviews, users expressed that they perceive *Support* as a source of information to be referred to as needed. They suggested adding an internal search engine and simplifying the navigation structure (e.g., unblocking all the learning modules initially) to facilitate information searching. *Support* users also emphasized the importance of having learning content relevant to their situation (e.g., personalized content) and content adapted to a different level of diabetes literacy (e.g., messages communicated through different formats). Nevertheless, some users also expressed that they used *Support* to feel less isolated and aimed to increase their sense of community, in these situations, interactivity (e.g., between the app and user, or between users) became an important aspect impacting their web app usage. Therefore, investigating user expectations shortly after their first use and exploring factors impacting the implementation would be key to increasing the usability of the digital tool.

Engagement in the web app was defined as the number of page views. Engagement numbers included URLs related to the learning content, media library, discussion forum, and news, but excluded administrative-related matters. The engagement (median of 54 pages during the first six months) was similar across different age groups and gender. This might be related to the process used for the web app development, where patient partners with diverse socio-demographic backgrounds contributed to its design and various needs were considered. Despite the general appreciation and unanimous engagement within our sample, it was observed that there was a decrease in engagement during the second six months compared to the first six months. In addition, it was also observed that there was low usage of the features during the first six months, especially regarding the discussion forum. One of the suggestions provided by some *Support* users to optimize the web app engagement and general usage was incorporating a live human component (e.g., live group classes) or one-on-one contact with a member of the development team within the intervention. Indeed, previous studies identified the use of e-coaching as an engagement strategy for digital tools [132]. However, its impact on user engagement remains the subject of investigation and can potentially be related to factors such as the format of the human component (e.g., in-person or digital face-to-face [133]), previous training of this person (e.g., HCP or a lay person [134]), and moment of delivery [135]. For instance, a German study conducted by Stassen et al. investigated the engagement with a health promotion website among vocational school students (18-25 y.o.) [135]. The engagement was defined as the frequency of ‘log-ins’ to the website. Students were randomized to the website-only group (n=149) or to the website with an in-person contact group (i.e., a mandatory school health day conducted during a regular school day before the intervention; no information was given on who was delivering the school health day, n=187), or the control group with the website only (e.g., no intervention, n=159). They found that having in-person contact, being female, and having a higher self-reported ability to deal with health information were factors positively influencing the likelihood of initially logging in. However, the login frequency during the eight months of intervention was similar between the group who had access to the website only compared to the group with an in-person component [135]. Similar findings were seen in a study published by Mohr et al. on a mobile platform (i.e., IntelliCare) containing 13 apps related to psychological strategies [136]. Researchers randomized adults recruited from social media across the United States (n=301) using a 2x2 factorial design (coached vs self-guided treatment; weekly app recommendations vs no recommendations) for eight weeks. Compared to the self-guided group with only a 10-15 min initial phone call, those who received the coaching session had an initial phone call of 30-45 min followed by two to three weekly text messages provided by a coach trained for the program. The coaching aimed to encourage users to try various apps, promote skill applications, and answer their questions. The recommendation arm consisted of automated weekly notifications recommending new apps to download. The no-recommendation group was simply encouraged to explore new apps. The engagement was assessed based on the time to last use of any app, the number of app sessions, and the number of downloaded apps. Results showed that coaching significantly increased the number of app downloads but had no significant effects on other engagement measurements. The engagement was overall strong across the four groups [136].

The presence of a human component in the engagement of other types of digital tools was also explored. Nelson et al. provided a 12-month text message-delivered intervention supporting self-care in adults living with T2D in Tennessee, United States [137]. In this RCT, participants received daily text messages for 6 months and half of them also had monthly phone coaching provided by counsellors or health coaches. A personal goal was set during the coaching sessions and coaches aimed to support participants in their goals [138]. The engagement was measured as any response to the interactive text message, and it was not impacted by receiving coaching [137]. Therefore, the incorporation of a human component within the digital tool might lead to better clinical outcomes [139] and user satisfaction [140] but evidence is still needed to support its impact on the tool engagement or general usage. In addition, in the case of *Support*, the presence of a human component might attenuate the flexibility in its access, which was reported as one of the main strengths by its users. Considering these factors, instead of incorporating a human component within the digital tool, collaboration can be made with various HCPs and add this resource to the routine care of PWT1D (e.g., suggest the HCPs from user's routine care recommending *Support* to increase engagement to *Support*). This can therefore reduce the human resource cost for the digital tool developers and allow HCPs to concentrate on the key elements of healthcare during the limited time of consultation sessions.

Objective 4 of this Ph.D. project was to explore the needs of youth (14-24 y.o.) in their DSM in the context of healthcare transition using *Support* as a web app of reference and investigate potential adaptations to be made on *Support*. My scientific proposition was that the format of *Support* would be positively accepted by youth, they would have similar feature preferences to adults, but the features might be presented in different ways [7], and that their interest in the learning content would differ from adults. Youth expressed similar ideas regarding feature modification and format to adults (e.g., having a search engine, increased activity in the discussion forum, unblocked modules) and features related to gamification also received both negative and positive feedback depending on their personal preference for the learning process.

Nevertheless, one difference in the needs of DSM digital tools was the importance provided for features related to social support. This difference might be associated with DSM barriers and enablers among youth. When analyzing interviews with youth, factors associated with their DSM were divided into barriers and facilitators, internal and external. We then grouped these factors into the COM-B model based on BCW, analyzed how a digital tool can target these factors, and which BCTs should be integrated. It was highlighted that many of these factors can be targeted through the BCT "social support". For instance, stigma can be categorized as an internal and external barrier. By sharing their own story and witnessing stories of others (e.g., through testimonials or discussion forums), youth expressed that they could feel less isolated in their situation and feel more capable of controlling their status. The sense of community was also mentioned in our adult cohort but to a lower degree. While some adults were seeking social support, most of the adult participants interviewed expressed that they would like to focus on information directly related to DSM rather than the stories of others.

These results are consistent with previous literature where the perceived social support, especially from peers, had a greater impact on DSM in adolescents and young adults compared to older adults [141-145]. This thus suggests the use of a peer-orientated approach in designing an intervention for the younger population, where the emphasis would be put on peer mentoring and understanding of peer context. The need for social support among youth can also be extended to the ability to self-identify through someone else's story. The younger population raised the habit of referring to social media influencers living with T1D as role modelling. This observation was similar to a qualitative study conducted by Sawyer et al. where they interviewed emerging adults (18-30 y.o.) living with T1D regarding their barriers and strategies for DSM [146]. Access to social support via social media was among the strategies to improve coping and living with diabetes. Participants discussed that they consider certain social media influencers living with T1D as role models for their DSM motivation. The use of social media was also perceived as quick access to the T1D community which can provide social accountability by identifying a person living with the same disease to discuss T1D [146]. Therefore, when recruiting a younger population for diabetes-related interventions, recruitment through social media channels, and especially collaborating with influencers in the field, should be considered.

In addition, after considering the use of social media for recruitment, researchers could encourage youth to share the recruitment information within their community to include youth who are less active on social media.

7.2 General strengths and limitations

Strengths and limitations specific to each study are included in the correspondent chapter. This section will provide an overview of the strengths and limitations of this Ph.D. project.

Providing scientific evidence at pace with the fast digital evolution is one of the main challenges when developing health-related digital tools, which can further increase the issue of lack of evidence in the field of digital health [35, 36]. The main strength of this project was being able to demonstrate a balance between these two components. For this purpose, the evaluation and optimization of digital health tools should be iterative with an agile study design specific to the ongoing need of the developers and involve the end-users in the decision process. The use of a pragmatic approach in realizing this Ph.D. project further highlights its strength. Starting from the project conceptualization (e.g., involvement of multiple disciplinary teams including patient partners), to the intervention delivery (e.g., users have access to the web app at any time with their own devices), and data collection stages (e.g., using Google Analytics), the studies were performed in situations similar to what digital technology developers would encounter in their usual setting. Therefore, the procedure used in this research project can be similarly translated to a real-life scenario.

Furthermore, the use of mixed methods in evaluating this web app provided a global overview of feedback from users and these different research approaches (i.e., qualitative and quantitative) were able to complement the weakness (e.g., lack of generality in the qualitative design and lack of deepness to understand an issue in the quantitative design) of each other. The data collection extended to 12 months of intervention, the maximum study length found in the previous literature [1] with self-guided web apps for self-management of chronic health conditions. In addition, an explanation of engagement measurement choice was provided and evaluated at two different moments, which distinguish from most of the studies, that had engagement measured at one moment only or no measurement given [1]

Among the limitations of this research work, we can find a lack of generalizability of the results to other ethnic groups. Despite the recruitment efforts of the research team, most of the patient partners and users were White. Future recruitment from diverse ethnic communities (e.g., from ethnic-targeted social media platforms such as WeChat for Asian population or from local community activities) would be suggested. Adults who participated in the semi-structured interview of *Support* were all users of the French version of the web app. The obtained perspectives thus have limited application in the English version of *Support*. In addition, despite the vast Internet coverage in Quebec [147], people from the Northern area might not have access to any devices with a stable Internet connection. This barrier can decrease their access to *Support* and raise health equity issues. Therefore, future studies on whether other groups of the population, especially those living in rural areas, can benefit from digital health interventions would be needed. This project occurred during the period of the coronavirus pandemic. Limited in-person healthcare accelerated the use of digital health tools and highlighted the importance of developing a self-guided digital tool for chronic health conditions self-management such as *Support*. However, because of the unusual living situation of the pandemic period, the results obtained in this project have limited applicability in circumstances outside of the pandemic, especially regarding the social-demographic characteristics of people using the web app. During the pandemic, some middle-aged adults had to take care of their children who were staying at home, whereas adults from the older age group had greater availability for DSM (e.g., with *Support*) and were less confronted with the shared work and parenting responsibilities [148, 149]. For that reason, it would be relevant to investigate users' profiles during a non-pandemic situation. According to feedback from its users, people used *Support* to mainly obtain information. However, no adapted knowledge questionnaire to *Support* was given and changes in diabetes knowledge were not recorded. Finally, this web app was developed based on behavior change theoretical framework, but participants did not report any behavior changes during the interviews related to this web app and none of the behavior changes were investigated in the quantitative component. Therefore, despite an indication of a positive impact on self-efficacy in DSM, this study could not provide an explanation of the related mechanisms and whether this web app impacts behavior change.

7.3 Public health relevance

The contribution of this Ph.D. project can be categorized as a contribution to the field of digital health and T1D.

Contribution to the field of digital health

First, this project contributed to the advancement of the field of digital health by systematically describing the current status of developed self-guided web apps for self-management of chronic health conditions and highlighting the existing gaps. Secondly, my project suggested a process of developing a scientific-based self-guided digital tool while being updated with the fast digital technological evolution. This model of early-phase digital tool development can be translated to the development of other digital health tools for self-management in chronic health conditions or behavior change-related areas (e.g., to stop smoking). During this process, the project also provided insight into how to select the relevant features from the needs of the population based on a behavior change framework (i.e., the BCW). Thirdly, this work proposed an alternative method of describing engagement to the web app by using the number of page views related to specific sections of the platform. This method requires a low level of technical training for the data collection process, can obtain data directly from daily web app usage (i.e., Google Analytics), and allows researchers/developers to focus on the components of their interest. This method can also be combined with qualitative studies to understand the reason for web app usage and the most viewed learning topics and explore future optimization.

Contribution to type 1 diabetes

My project had a direct contribution to PWT1D by 1) identifying their needs in DSM with the use of digital tools; 2) using a self-guided web app combining multiple aspects of DSM (e.g., diet and physical activity) facilitating behavior changes (to the best of my knowledge, this is the first evidence-based self-guided web app for PWT1D); 3) validating satisfaction and changes in hypoglycemia burden related to this resource to support the feasibility of using *Support* as an adjuvant in routine diabetes care; 4) exploring how a digital DSM tool can be adapted to youth and younger adults compared to adults in general. Furthermore, the use of this self-guided web app can potentially increase PWT1D's empowerment and better prepare them for healthcare appointments.

7.4 Future direction

In line with these ideas, in the future, after optimizing *Support* based on suggestions provided by the users, it would be advised to investigate:

1) health equity concerns: to explore whether *Support* can be accessed equally among people from various ethnic groups and those living in rural areas;
2) moving forward with the ORBIT model: this doctoral project focused on the early developmental phases of the ORBIT model [22], namely phase I and IIa. Given the positive acceptability and usability of the web app, it would be relevant to move forward in the model (phase III and IV) to validate its clinical efficacy through an RCT and explore its impact on DSM behaviors. In addition, implementation studies in real clinical settings (e.g., diabetes healthcare team) would be suggested to evaluate the possibility of integrating *Support* as part of routine care through HCPs;
3) engagement according to the goal of the user: as the engagement can vary in time and change based on the expectation of the user [38], it would be suggested to inquire about user expectations before using the web app and regularly throughout the intervention. Comparing engagement based on different user expectations or goals can be a more personalized measurement of web app interactivity.

Chapter 8: Overall conclusions

In conclusion, this Ph.D. first investigated the current status of web apps for chronic health condition self-management with a systematic review and highlighted the existing gaps.

Considering these gaps in the web app development, the very first evidence-based self-guided web app for DSME/S among PWT1D, *Support*, was designed based on behavior change theoretical framework with a multidisciplinary team using people-oriented approach. Mixed methods combined with a quasi-experimental design study and semi-structured interviews were then used for the web app evaluation. *Support* was demonstrated to be highly acceptable among adults living with T1D in the province of Quebec, Canada and the possibility of decreasing hypoglycemia burden after 6 months of use. With semi-structured interviews, the same web app was presented to adolescents and young adults living with T1D as a reference to explore their needs of DSM in the context of healthcare transition and how can they be tackled with a web app. Youth expressed features related to social support (e.g., discussion forum) and information access (e.g., internal searching engine) should be emphasized on the web app.

This project presented the early developmental phase of a web app and demonstrated the potential of using *Support* as an adjunct of routine diabetes care to increase the empowerment of PWT1D and their self-efficacy in DSM. The methodology used for web app design, evaluation, and optimization can also be applied to the development of digital health intervention in other chronic diseases. Future investigation on its implementation in clinical settings, generalizability in other groups of ethnicities, impact on health equity, clinical effectiveness, and personalization in the measurement of engagement is suggested.

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Appendix I: Chapter 3

Keywords used for the article searches

The searches were performed on June 15 2020 on PubMed, Cochrane Library and Embase.

A) Search on PubMed

The search was applied to *Title/Abstract*, limited to Full text, English and French, years 2005 to 2020.

The following site was used:
https://pubmed.ncbi.nlm.nih.gov/

Each of the following paragraphs represents one search entry:

(“social media” OR Internet OR “ web based” OR web OR online) AND (“distance education” OR education OR “patient education” OR teaching) AND (learning OR intervention OR treatment OR program OR “Program development” OR platform) AND (“pediatric obesity” OR “abdominal obesity” OR “morbid obesity” OR “obesity management” OR “Abdominal obesity” OR “metabolic syndrome” OR “overweight” OR “metabolic syndrome” OR “weight reduction program”)

(“social media” OR Internet OR “ web based” OR web OR online) AND (“distance education” OR education OR “patient education” OR teaching) AND (learning OR intervention OR treatment OR program OR “Program development” OR platform) AND (CVD OR hypertension OR diabetes OR “diabetes mellitus” OR “diabetes insipidus” OR “gestational diabetes” OR “type 2 diabetes mellitus” OR “type 1 diabetes mellitus” OR “Juvenile diabetes” OR “heart failure” OR atherosclerosis OR dyslipidemia OR “Cardiovascular disease”)

(“social media” OR Internet OR “ web based” OR web OR online) AND (“distance education” OR education OR “patient education” OR teaching) AND (learning OR intervention OR treatment OR program OR “Program development” OR platform) AND (IBD OR “inflammatory bowel disease” or “crohn disease” or “ulcerative colitis”)

(“social media” OR Internet OR “ web based” OR web OR online) AND (“distance education” OR education OR “patient education” OR teaching) AND (learning OR intervention OR treatment OR program OR “Program development” OR platform) AND (“respiratory disease” or “respiratory tract disease” or “respiratory disorder” or “asthma” or “chronic respiratory disease” or “copd” or “chronic obstructive pulmonary disease”)

(“social media” OR Internet OR “ web based” OR web OR online) AND (“distance education” OR education OR “patient education” OR teaching) AND (learning OR intervention OR treatment OR program OR “Program development” OR platform) AND (celiac) (“social media” OR Internet OR “ web based” OR web OR online) AND (“distance education” OR education OR “patient education” OR teaching) AND (learning OR intervention OR treatment OR program OR “Program development” OR platform) AND (epilepsy)

(“social media” OR Internet OR “ web based” OR web OR online) AND (“distance education” OR education OR “patient education” OR teaching) AND (learning OR intervention OR treatment OR program OR “Program development” OR platform) AND (“chronic kidney disease” or “chronic renal insufficiency” or “kidney disease” or “chronic kidney failure” or “diabetic nephropathies” or “esrd” or “end stage renal disease” or “nephritis”)

(“social media” OR Internet OR “ web based” OR web OR online) AND (“distance education” OR education OR “patient education” OR teaching) AND (learning OR intervention OR treatment OR program OR “Program development” OR platform) AND (arthritis)

(“social media” OR Internet OR “ web based” OR web OR online) AND (“distance education” OR education OR “patient education” OR teaching) AND (learning OR intervention OR treatment OR program OR “Program development” OR platform) AND (“multiple sclerosis”)

B) Search on Cochrane Library

The searches on Cochrane Library used the same keywords as in PubMed.
The keywords were searched for *Title Abstract Keyword*, years 2015 to 2020, Trials, English. (No French language was available because no French abstract was found on Cochrane Library.)

It was done on the following website: https://www.cochranelibrary.com/search

C) Search on Embase

The search was applied to *Title* or *Abstract*, limited to Full text, English and French, year 2005 to current, exclude Medline Journals, human, article and article in-press.

Each of the following paragraphs represents one search entry:

(social media OR Internet OR web based OR web OR online) AND (distance education OR education OR patient education OR teaching) AND (learning OR intervention OR treatment OR program OR Program development OR platform) AND (pediatric obesity OR abdominal obesity OR morbid obesity OR obesity management OR Abdominal obesity OR metabolic syndrome OR overweight OR metabolic syndrome OR weight reduction program)

(social media OR Internet OR web based OR web OR online) AND (distance education OR education OR patient education OR teaching) AND (learning OR intervention OR treatment OR program OR Program development OR platform) AND (CVD OR hypertension OR diabetes OR diabetes mellitus OR diabetes insipidus OR gestational diabetes OR type 2 diabetes mellitus OR type 1 diabetes mellitus OR Juvenile diabetes OR heart failure OR atherosclerosis OR dyslipidemia OR Cardiovascular disease) (social media OR Internet OR web based OR web OR online) AND (distance education OR education OR patient education OR teaching) AND (learning OR intervention OR treatment OR program OR Program development OR platform) AND (IBD OR inflammatory bowel disease or crohn disease or ulcerative colitis)

(social media OR Internet OR web based OR web OR online) AND (distance education OR education OR patient education OR teaching) AND (learning OR intervention OR treatment OR program OR Program development OR platform) AND (respiratory disease or respiratory tract disease or respiratory disorder or asthma or chronic respiratory disease or copd or chronic obstructive pulmonary disease)

(social media OR Internet OR web based OR web OR online) AND (distance education OR education OR patient education OR teaching) AND (learning OR intervention OR treatment OR program OR Program development OR platform) AND (celiac)

(social media OR Internet OR web based OR web OR online) AND (distance education OR education OR patient education OR teaching) AND (learning OR intervention OR treatment OR program OR Program development OR platform) AND (epilepsy)

(social media OR Internet OR web based OR web OR online) AND (distance education OR education OR patient education OR teaching) AND (learning OR intervention OR treatment OR program OR Program development OR platform) AND (chronic kidney disease or chronic renal insufficiency or kidney disease or chronic kidney failure or diabetic nephropathies or esrd or end stage renal disease or nephritis)

(social media OR Internet OR web based OR web OR online) AND (distance education OR education OR patient education OR teaching) AND (learning OR intervention OR treatment OR program OR Program development OR platform) AND (multiple sclerosis)

(social media OR Internet OR web based OR web OR online) AND (distance education OR education OR patient education OR teaching) AND (learning OR intervention OR treatment OR program OR Program development OR platform) AND (arthritis)

D) The reference list of the selected articles was also searched for potential articles

Appendix II: Chapter 4

Supplementary 4.1

The TIDieR checklist for the *Support* self-guided web app

The TIDieR (Template for Intervention Description and Replication) Checklist*:

Information to include when describing an intervention and the location of the information

Item number		Where located **	
		Primary paper (page or appendix number)	Other † (details)
	BRIEF NAME		
1.	Provide the name or a phrase that describes the intervention.	Methods: 1st paragraph	
	WHY		
2.	Describe any rationale, theory, or goal of the elements essential to the intervention.	Introduction: last paragraph	
	WHAT		
3.	Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL).	Result section	

4.	Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.	Result section	
	WHO PROVIDED		
5.	For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.	NA (self-guided platform)	
	HOW		
6.	Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.	Result section	
	WHERE		
7.	Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.	Result section	
	WHEN and HOW MUCH		
8.	Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.	Result section	
	TAILORING		
9.	If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.	Result section	
	MODIFICATIONS		
10.[‡]	If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).	NA	
	HOW WELL		

11.	Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.	NA (will be from the upcoming articles regarding the proof-of-concept study)	
12.[‡]	Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	NA	

** **Authors -** use N/A if an item is not applicable for the intervention being described. **Reviewers** – use '?' if information about the element is not reported/not sufficiently reported.

† If the information is not provided in the primary paper, give details of where this information is available. This may include locations such as a published protocol or other published papers (provide citation details) or a website (provide the URL).

‡ If completing the TIDieR checklist for a protocol, these items are not relevant to the protocol and cannot be described until the study is complete.

* We strongly recommend using this checklist in conjunction with the TIDieR guide (see *BMJ* 2014;348:g1687) which contains an explanation and elaboration for each item.

* The focus of TIDieR is on reporting details of the intervention elements (and where relevant, comparison elements) of a study. Other elements and methodological features of studies are covered by other reporting statements and checklists and have not been duplicated as part of the TIDieR checklist. When a **randomised trial** is being reported, the TIDieR checklist should be used in conjunction with the CONSORT statement (see www.consort-statement.org) as an extension of **Item 5 of the CONSORT 2010 Statement.**
When a **clinical trial protocol** is being reported, the TIDieR checklist should be used in conjunction with the SPIRIT statement as an extension of **Item 11 of the SPIRIT 2013 Statement** (see www.spirit-statement.org). For alternate study designs, TIDieR can be used in conjunction with the appropriate checklist for that study design (see www.equator-network.org)

Supplementary 4.2

Educational content for learning path 4

(Continuous glucose monitoring and continuous subcutaneous insulin infusion)

Level 1	Level 2	Level 3
Medication		
Understanding how an insulin pump works **PDF:** - Emergency Kit - Hybrid closed-loop systems characteristics **Video:** - Insulin modes of action	Uploading your pump data **PDF:** - Uploading your pump data	Adjusting your insulin doses **PDF:** - How to adjust insulin-t-carb ratios - How to adjust the basal rate? - What affects blood sugar level? **Video:** - Adjusting insulin
Understanding and avoiding lipodystrophies **PDF:** - Measuring your blood sugar - Understanding severe hypoglycemia and taking action when it occurs - What to do in the event of hyperglycemia **Video:** - Lipodystrophies	How to use an infusion set **PDF:** - Pump Catheter Characteristics	Solving pump-related or sensor-related problems **PDF:** - List of products for skin conditions **Video:** - Adhesive products
Understanding the bolus calculator	None	None
Using the sensitivity factor and the correction bolus	Adjusting your correction bolus **PDF:** - How to adjust correction bolus	None
Understanding insulin's duration of action and active insulin	How to handle a missed bolus or an insulin administration error (optional) **PDF:** - Procedure to follow in the event of a missed injection or an insulin administration error	None

What to do in the event of insulin pump failure (optional) **PDF:** - Emergency kit (insulin pump) - Pump backup plan in the event of insulin pump failure	None	None
Blood glucose monitoring		
Understanding target blood sugar levels **Video:** - Target blood sugar levels and HbA1c	Understanding glycated hemoglobin (HbA1c) **Video:** - Target blood sugar levels and HbA1c	None
Measuring your blood sugar	None	None
Understanding and using a continuous glucose monitoring (CGM) system **PDF:** - CGM system comparison table **Video:** - CGM screens	Uploading your CGM data **PDF:** - CGM system comparison table	Understanding reports from your continuous glucose monitoring device **PDF:** - How to analyze the ambulatory glucose profile (AGP) - How to calibrate a CGM device - How to measure capillary blood sugar
Taking the accuracy of the continuous glucose monitoring system into account **PDF:** - How to calibrate a CGM device **Video:** - Accuracy of continuous glucose monitors	Understanding and using a capillary blood sugar meter **PDF:** - Capillary meters: Diabetes Quebec 2021 product guide (French only) - How to measure capillary blood sugar	None
Using trend arrows **PDF:** - What do the trend arrows mean?	Using CGM alerts **PDF:** - Alert features by CGM	None
Diet		
How to identify foods that contain carbs	Counting carbohydrates accurately **PDF:** - Carb factors of some foods - Food journal - Meal planning for people with diabetes	Understanding insulin-to-carb ratios **Video:** - Insulin-to-carb ratio

	- Nutrient value of some common foods **Video:** - Calculating carbs	
How the contents of your plate affect your health and blood sugar **PDF:** - Canada Food Guide 2019	Understanding the impact of certain types of meals on your blood sugar levels **PDF:** - Insulin modes of action **Video:** - Carbs 101	None
The impact of alcohol on blood sugar **PDF:** - Carb content of various alcoholic beverages - Emergency kit (insulin pump) - Emergency kit (pen or syringe) - Examples of snacks in various situations **Video:** - Alcohol stories	None	None
The importance of eating patterns and the role of snacks **PDF:** - Examples of snacks in various situations **Video:** - Sleeping late	None	None
Hypo and hyperglycemia		
What to do in the event of hypoglycemia **PDF:** - Emergency kit (insulin pump) - Emergency kit (pen or syringe) - How to administer injectable glucagon - How to administer nasal glucagon - How to treat hypoglycemia **Video:** - Causes of hypoglycemia	Understanding severe hypoglycemia and taking action when it occurs **PDF:** - Emergency kit (insulin pump) - Emergency kit (pen or syringe) - How to administer injectable glucagon **Video:**	None

- How to administer nasal glucagon - How to use injectable glucagon - Symptoms of hypoglycemia - Treating hypoglycemia	- How to administer nasal glucagon - How to use injectable glucagon	
What to do in the event of hyperglycemia **PDF:** - Emergency kit (insulin pump) - How to manage ketone bodies with the insulin pump - Insulin pump-related causes of hyperglycemia - Products to measure ketones - What affects blood sugar levels? **Video:** - Causes and treatments of hyperglycemia - Ketone bodies - Symptoms of hyperglycemia	None	None
Physical activity		
Partaking in physical activity **PDF:** - Setting a S.M.A.R.T. goal **Video:** - Tips to start physical activity	How to prevent hypoglycemia DURING physical activity **PDF:** - Examples of snacks in various situations - Insulin modes of action - Types of exercise and their effect on blood sugar levels **Video:** - Intimate moments when using a pump - Preventing hypoglycemia during physical activity	How to prevent hypoglycemia AFTER physical activity? **PDF:** - Examples of snacks in various situations **Video:** - Preventing hypoglycemia after physical activity
Health and particular issues		
Understanding fear of hypoglycemia **PDF:** - Abdominal respiration	None	None
Managing sick days **PDF:** - Examples of snacks in various situations	None	None
Driving with type 1 diabetes	None	None

(optional) **PDF:** - Emergency kit (insulin pump) - Emergency kit (pen or syringe) - Precautions for driving		
Planning for a trip (optional) PDF: - Blood sugar unit conversion table - Insulin modes of action - List of supplies-insulin pump - List of supplies-multiple injections - Pump backup plan in the event of insulin pump failure - Travel letter-English - Travel letter-French - Travel letter-Italian - Travel letter-Mandarin - Travel letter-Spanish	None	None
Understanding and dealing with celiac disease when living with type 1 diabetes (optional) **PDF:** - Gluten-free eating	None	None

Appendix III: Chapter 5

Supplementary 5.1

Educational content for each learning path with the respective view during the first 6 months

Diabetes treatment profiles (learning paths):
A) Multiple daily insulin injections (MDI) with capillary blood glucose (CBG) (n=16, 3%);
B) MDI with continuous glucose monitoring (CGM) (n=104, 21%);
C) Continuous subcutaneous insulin infusion (CSII) with CBG (n=5, 1%);
D) CSII with CGM (n=82, 16%)

Category	Title	Learning path	Level	View frequency[a]
Medication	Discovering the insulin pump	AB	1	4
	How the different types of insulins act	AB	1	95
	Understanding active insulin	AB	1	44
	Understanding and avoiding lipodystrophies	ABCD	1	112
	Understanding how an insulin pump works	CD	1	47
	Understanding insulin's duration of action and active insulin	CD	1	29
	Understanding the bolus calculator	CD	1	15
	Using the sensitivity factor and the correction bolus	ABCD	1	64
	What to do in the event of insulin pump failure	CD	1	15
	Adjusting your correction bolus	ABCD	2	56
	Adjusting your insulin doses	ABCD	2[b]	102
	How to handle a missed bolus or an insulin administration error	ABCD	2	45
	How to inject insulin properly	AB	2	40
	How to use an infusion set	CD	2	19
	Uploading your pump data	CD	2	34
	Solving infusion set or sensor-related problems	CDB	3	54
	Blood glucose monitoring			
	Measuring your blood sugar	ABCD	1	96
	Taking the accuracy of the continuous glucose monitoring system into account	BD	1	35
	Understanding and using a capillary blood sugar meter	ABCD	1[b]	33
	Understanding and using a continuous glucose monitoring (CGM) system	ABCD	1[d]	62
	Understanding target blood sugar levels	ABCD	1	83

	Using trend arrows	BD	1	32
	Understanding glycated hemoglobin (A1c)	ABCD	2	67
	Using CGM alerts	BD	2	38
	Utiliser les alertes du lecteur de la glycémie en continu	BD	2	30
	Understanding reports from your continuous glucose monitoring device	BD	3	29
Diet	How the contents of your plate affect your health and blood sugar	ABCD	1	55
	How to identify foods that contain carbs	ABCD	1	73
	The impact of alcohol on blood sugar	ABCD	1	49
	The importance of eating patterns and the role of snacks	ABCD	1	51
	Counting carbohydrates accurately	ABCD	2	107
	Understanding the impact of certain types of meals on your blood sugar levels	ABCD	2	54
	How to calculate and use insulin-to-carb ratios	ABCD	3	62
Hypo and hyperglycemia	What to do in the event of hypoglycemia	ABCD	1	400
	What to do in the event of hyperglycemia	ABCD	1	85
	Understanding severe hypoglycemia and taking action when it occurs	ABCD	2	96
	Managing ketone bodies and preventing ketoacidosis	AB	2	50
Physical activity	Partaking in physical activity	ABCD	1	81
	How to prevent hypoglycemia during physical activity?	ABCD	2	53
	How to prevent hypoglycemia after physical activity?	ABCD	3	58
Health and others situations	Driving with type 1 diabetes	ABCD	1	35
	Managing sick days	ABCD	1	45
	Planning for a trip	ABCD	1	3
	Understanding and dealing with celiac disease when living with type 1 diabetes	ABCD	1	0
	Understanding fear of hypoglycemia	ABCD	1	51

[a] The view frequency of each learning module is defined by the frequency of viewing its first page.

[b] Level 2 for AD and 3 for CD

[c] Level 1 for AC and 2 for BD

[d] Level 1 for BD and 2 for AC

Number of courses in learning paths A, B, C, D are 31, 37, 33, and 38 respectively.

Supplementary 5.2

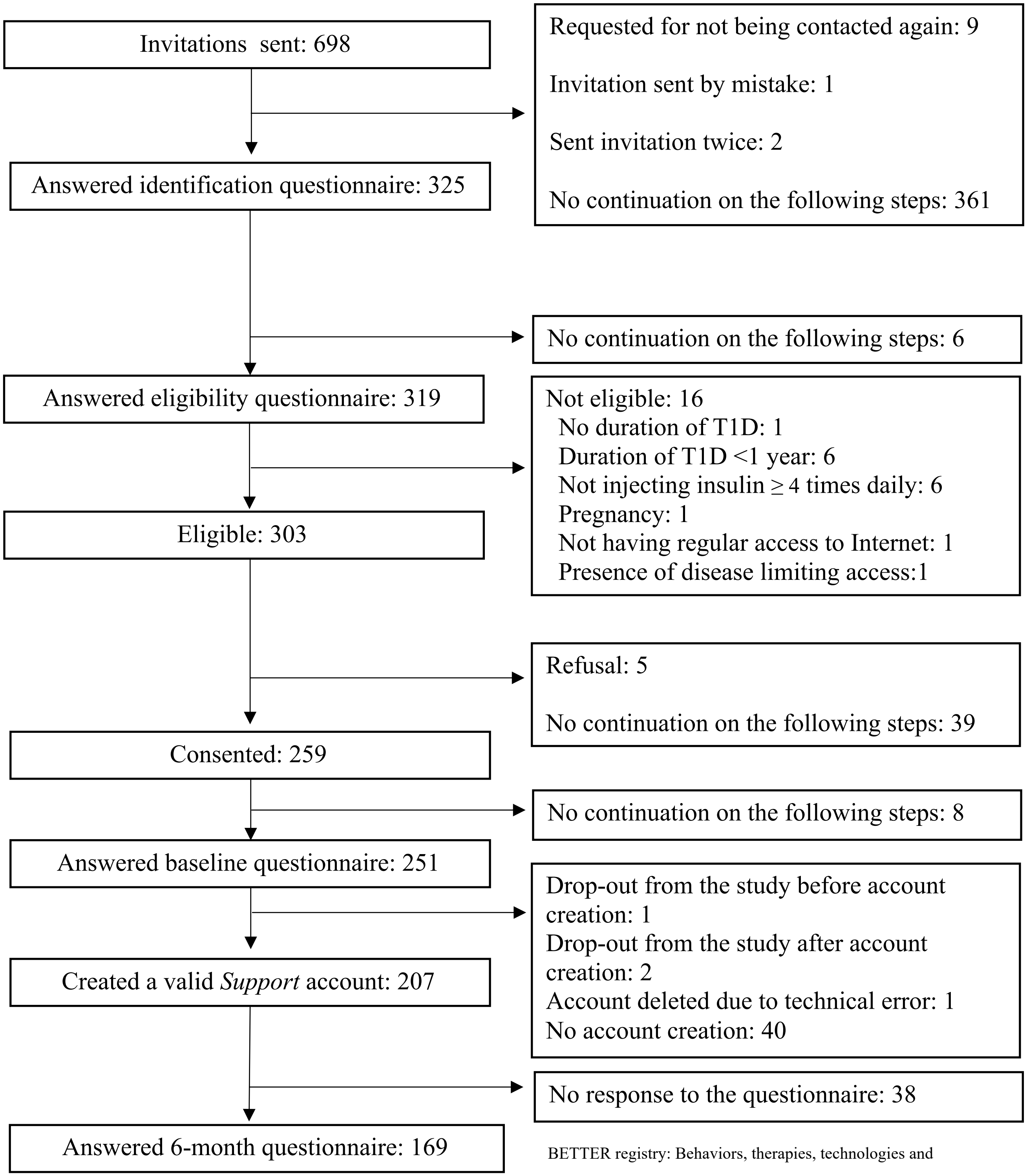
Features of the *Support* web app

Features	**Description**
Automated calculator	Series of automated calculators (e.g., carbohydrate counting, sensitivity factor) embedded within the courses when relevant, and accessible from the media library.
Case studies with 6 characters	Case studies with six fictional characters of different profiles (e.g., age, gender, ethnicity, diabetes treatment) to facilitate integration of knowledge and self-identification.
Certificate	Certificate provided after completing all the courses in one category. A final certificate is given when completing all the mandatory courses in *Support*.
Discussion forum	All users share the same discussion forum moderated daily by the *Support* coordinator (a bilingual registered dietitian and certified diabetes educator). Topics were sub-categorized. Users can post in the language of their choice and “like” or respond to other posts.
Downloadable PDF documents	They contain summarized key information. They are at the end of each course and can be found in the media library once the related course is completed. The same documents are found on the study website available for the general public as well.
Glossary	Medical jargon and technical words are underlined at their first appearance within each course. When the user places their cursor on the word, a definition bubble appears. These definitions can also be found in the “Glossary” section at all times.
Introductory slides to *Support*	At the first log-in, users are directed to an introductory slideshow (six slides, 2 minutes to view) explaining how to use *Support* . These slides are also available under “Guided tour” on top of the home page.
News	News is posted in a blog format (100-1000 words) twice weekly by the *Support* coordinator. It is found within the discussion forum and participants and post under the news blogs.
Newsletters	Biweekly newsletters are sent to users by e-mail and are used as reminders to log-in on *Support*. They contain a preview of the latest news blogs with a link to read more and two suggested basic courses (common to the four learning paths).
Personal dashboard	The user’s personal dashboard displays a summary of their recent activities (e.g., last date of connection, goals, completed courses, number of trophies and certificates) and the latest updates on *Support* (e.g., post on the discussion forum and news blogs).
Personal goal settings	A textbox is available in the user’s personal dashboard for them to set personal goals.
Quiz	At the end of each course, users are prompt to answer two to three multiple choices or True/False questions to validate their understanding. Correct answers are given once the quiz in submitted. Virtual points are attributed to completed quizzes, regardless of the answers given.
Video	Videos are embedded within courses and available in the media library. Three types of videos can be found: narrated animations, technical manipulations (e.g., injection technique) by HCPs, and patient testimonials.
Virtual points and trophies	Virtual points are given for the use of *Support* (e.g., completing a quiz, completing a course, participating in the discussion forum) leading to virtual trophies.

HCPs: Healthcare professionals
PWT1D: People living with type 1 diabetes
T1D: Type 1 diabetes

Supplementary 5.3

Support recruitment flow chart



BETTER registry: Behaviors, therapies, technologies and hypoglycemic risk in type 1 diabetes

T1D: Type 1 diabetes

Supplementary 5.4

Results of the satisfaction questionnaire

Statements	Median [quartile 1; quartile 3][a] 1= strongly disagree 7= strongly agree
1. I enjoyed using *Support*.	6 [5;7]
2. It was easy to navigate on *Support*[b].	5 [5;7]
3. The appearance of *Support* (text size, color, illustrations, animations, etc.) is pleasant.	6 [5;7]
4. Information provided by *Support* is easy to understand.	6 [4;7]
5. The information provided by *Support* met my needs[a].	6 [4;7]
6. I can practice the knowledge gained from *Support* in my daily life.	6 [5;7]
7. I will continue to use *Support* after this study.	6 [5;7]
Total evaluation score (/49)[c]	40 [35;45]

[a] n=166 for item 4 and total evaluation score; n=167 for item 5; n=168 for item 3,6, and 7; n=169 for item 1

[b] These two questions were initially asked in a negative format. Scores were reversed into the positive format during the analysis stage.

[c] This refers to the total of the previous seven items

Supplementary 5.5

BETTER subsample and changes in the burden of hypoglycemia

Table Supplementary 5.5.1 Baseline characteristics of the natural progression of a BETTER subsample

Baseline characteristics, n (%) unless specified	n=251
Gender (self-identified)	
Men	95 (38%)
Women	156 (62%)
Age in years, mean ± SD	47.3 ± 15.0
Duration of type 1 diabetes in years, mean ± SD	26.4 ± 15.6
Ethnicity	
White	242 (97%)
Others	8 (3%)
Level of education	
College or lower	118 (48%)
Bachelor's degree or higher	127 (52%)
Employment status	
Full-time	132 (53%)
Retired	54 (22%)
Others	61 (25%)
HbA1c in the last 3 months	
7% or less	92 (39%)
7.1-8%	105 (45%)
8.1 or more	38 (16%)
Number of hypoglycemia in the last 3 days, mean ± SD	1.91 ± 1.63
Fear of hypoglycemia total score, mean ± SD	31.2 ± 17.2

Table Supplementary 5.5.2 Natural progression of a BETTER subsample for change in self-reported hypoglycemia frequency during the last 3 days and total score of fear of hypoglycemia

Paired t-test			
Frequency of hypoglycemia/3 days	Mean ± SD	Mean difference (95% CI)	p-value
6-month to baseline (n=244)		0.01 (-0.22;0.25)	0.918
Baseline	1.89 ± 1.62		
6-month	1.91 ± 1.77		
Fear of hypoglycemia total score (/132)			
6-month to baseline (n=248)		0.94 (-0.64;2.52)	0.240
Baseline	31.2 ± 17.2		
6-month	32.1 ± 15.7		

Table Supplementary 5.5.3 Change in reported self-efficacy of the *Support* participants at 6 months

Self-efficacy variables, n (%)	n=168
Change in confidence in **managing** blood glucose level	
Decreased a bit or a lot	6 (4%)
Stayed the same	83 (49%)
Increased a bit or a lot	79 (47%)
Change in confidence in **preventing** hypoglycemia	
Decreased a bit or a lot	9 (5%)
Stayed the same	74 (44%)
Increased a bit or a lot	85 (51%)

Supplementary 5.6

Most preferred and suggested modifications on *Support*

	Elements preferred from *Support*	Elements to be improved on *Support*
Content	Able to revise previous learning Accessible, practical, credible, concise, up-to-date, easy to understand, and supportive information Diversity of the content Information topics: - Diabetes related calculations (e.g., insulin to carbohydrate ratio) - Mental health - Particular situations (e.g., what to do in case of insulin pump damage) - Physical activity	Information was long and superficial More elaboration on: - Artificial pancreas - Carbohydrate counting - Hyperglycemia - Latest scientific news - Mental health - Particular situations (e.g., pregnancy and breastfeeding),
Format	General: - Appreciation for the aesthetic - Categorization of the learning modules - Information provided in French - One-stop for T1D self-management education - Presence of a facilitator on discussion forum - Self-paced learning Features: - Case studies - Discussion forum - Downloadable PDF documents - News blogs - Newsletters as a reminder - Quizzes - Videos	General: - Give option of receiving e-mails or not - Have a mobile application - Have access more than one year - Have access since diagnostic - Have videos in English rather than only in French - Need a human component - No interest in gamification (e.g., virtual point, trophies, and certificate) - Receive information on other *Support* users to feel more as a community - Viewing information via social media Discussion forum: - Lack of user participation - Too many categorizations of topics Features to be added: - Able to access to other learning paths - Have a "favorite" option to save the relevant courses or documents - Have more videos - Self-evaluation questionnaires Technical difficulties: - Difficult to find the website link - Difficulty to find information within *Support* - Log-in issues - Low speed of page loading - Navigation path between courses - Too many sent e-mail newsletters

Supplementary 5.7

Example of quotes on factors impacting user's experience to *Support*

Category	Factor	Example of quote
Accessible content	Concise information	"PDF documents I find very useful because we don't have to create them, we can just research them. I look at tables that we use to test or adjust our basal." *(participant 15, man, 75 y.o.)*
	Easy to understand	"The strengths are that [*Support*] gives good explanations and is easy to understand" *(participant 3, woman, 60 y.o.)* "There is text but also videos. Sometimes people talk and repeat the same information in another way or close to it, so it allows to understand even better" *(participant 9, woman, 67 y.o.)*
	Unblocked content	"It's more to adapt the information based on what the person knows or maybe to give free access to all that is possible at the beginning." *(participant 7, woman, 37 y.o.)*
	Length of the content	"What I like is to look at a title and it says *it's 10 min or 15 min* so I know that it's not an hour-long. It's easier to focus for small blocs of information rather than if it was 1 hour" *(participant 9, woman, 67 y.o.)* "For sure the way it's currently made at 2.5 min, it's ok. It could be a bit longer. Not shorter but a bit longer. If it's too long, then you divide the topic and you make another video based on what you wrote" *(participant 13, man, 61 y.o.)*
Personalized content	Level- and need-adapted Information	"I have the impression that the quiz questions are too easy to actually demonstrate if the person understood or not the subject." *(participant 6, woman, 32 y.o.)* "I was wondering if you do validation questionnaires, could it be

		an option to immediately advance to a level that is more appropriate ?" *(participant 7, woman, 37 y.o.)*
	Practical information	"Having 6 different avatar profiles is interesting because I will surely be in one of the avatars, and from there I would lose less time I would know exactly what it is that I would need." *(participant 1, man, 57 y.o.)* "I understand better in context situations that I can analyse or study. I understand better than if someone said that this happened," *(participant 6, woman, 32 y.o.)*
Credible content	Scientifically up-to-date	"I was trying to find news information, on what is happening today, on new things" *(participant 11, woman, 51 y.o.)*
	Involvement of HCPs	"The strength is the confidence that I have in the platform. I think that the information that is there, I could tell everyone that I read it and it's good you know. Whereas my other trainings were ok. I have the impression that there are multiple specialists on the platform, there is a nutritionist and so on, it's not like there was just a medical doctor. I have the impression that there is diversity in the specialists present on the platform " *(participant 11, woman, 51 y.o.)*
Accessible format	Active exposure to the platform	"Logging on my own happened less. I would say that 80% it was the emails that I was receiving and 20%, it was me going on my own." *(participant 10, man, 58 y.o.)* "I would say that everything new on Support, whether it is a study or a video or whatever it is, I would put a reminder to say that new content is released on Support. A study or whatever. I mean we are not on the get go. It's good to have the information but the problem is that we don't take the time to go. If we can have a reminder to let us know, it would be good." (*participant 13, man, 61 y.o.)*

	Spontaneity of finding information	"As much as I liked the modules' categorization, of you know all the subject of trainings. I find the forum too divided, and it was less user-friendly " *(participant 2, woman, 27 y.o.)* "I would usually search by keyword […] but if there is no keyword, I would have to look a long time […]. There was a lot of subjects. A lot of things so I would like a search by keyword." *(participant 11, woman, 51 y.o.)*
	Avoid technical difficulties	"I click on the video, and I follow the process. I was at step 7 and it was horizontal on the page *click on the button to play the video* but there was nothing happening. I don't know if it was because I skipped a step or at the top it was example 6 out 7. I remember that I was here but I was not able to do 7 " *(participant 5, man, 63 y.o.)* "All complementary content it's like I don't know where to go find them." *(participant 6, woman, 32 y.o.)*
	Adaptation to mobile phones	"I think it's better to have an application because it's really designed for a phone or a tablet. So it's always more user-friendly than a website." *(participant 6, woman, 32 y.o.)*
Personalized format	Flexibility in the learning	"The strength, for sure, is that the information written or by video is here as long as I have access to *Support*. It's really the information that remains." *(participant 6, woman, 32 y.o.)* "It's that we have it immediately, I don't have to contact anyone, it's available readily and it's great." *(participant 15, man, 75 y.o.)*
	Able to track self-progress	"The table. Yes it's a tool of where we are because […] it gives us where we are and earlier it confirmed to me that I have numer 6 that I did not complete yet.." *(participant 9, woman, 67 y.o.)*

Interactive format	Interaction between peers	"The use of *Support* is to know that I am not alone in this [situation]" *(participant 3, woman, 60 y.o.)* "The discussion forum I have to say that I never go, I find it too, I tried to go but I never accessed. […] Why? often times it's because problems are too personal." *(participant 14, man, 48 y.o.)*
	Reflect the goal of using the platform	"I don't deal with my diabetes to have a certificate or a trophy. I try to understand how everything functions" *(participant 1, man, 57 y.o.)* "I was answering the quiz. I think it gives a motivation. When you miss your shot, it allows you to study the question" *(participant 4, man, 63 y.o.)* "The least liked [features], points, virtual trophies. It's funny to see but to me it's not important. The essential is that during the quiz, I ensure that I understood correctly. I missed sometimes and I think it's funny. I would go back immediately to what I did not understand, and this is interesting." *(participant 15, man, 75 y.o.)*

Appendix IV: Chapter 6

Supplementary 6.1

Interview guide

Hi, my name is ________, I am a research assistant working on adapting an online education platform, named *Support*, for youth with type 1 diabetes transitioning into adulthood. This interview should not take longer than an hour. Is that okay with you? (*Confirming consent).*

PART A: Background information/ Use of online programs

1. Tell me a little about yourself, how old are you? What grade are you in? How old were you when you were diagnosed with type 1 diabetes?
2. What is your current insulin regimen?
    a. Do you feel comfortable managing your diabetes on your own?
3. Do you ever have questions about your diabetes management?
   If yes, where do you go for information?
    a. *Probe for preferences using online platforms.* Do you use any online programs, websites, or apps for support?
    b. *(If yes)* Which one? What do you like about it? *Probe for details.* How does it help you with managing your diabetes?
4. What do you look for in a website or online platform? *(can be unrelated to diabetes)*
    a. What features do you like on online platform motivate you to continue exploring a platform?
5. What do you think would be most useful in an online support platform that aims to help young people manage their diabetes?

PART B: Feedback on the *Support* platform

In the email you received from our team, there was a PowerPoint presentation and a short video about the functionalities of the adult *Support* platform. Did you have a chance to go through that? (*Verifying that they viewed the PPT and or Video. If not, review them with the participant).*

1. Do you have any questions about the adult *Support* platform?
    a. (If yes) Answer as best as possible, noting down the question.
2. What did you like the most?
3. In terms of the content of the modules *(a list of topics will be provided with/in the PPT)*, what topics are most relevant to you?
    a. What topics are less relevant to you?
    b. Were there any topics missing that you think is important to include?
4. How do you think the adult platform could be modified for adolescents/young adults?
    a. Probes:
        i. Was the language easy for you to understand?
        ii. Did you like the look of the platform?
        iii. Did you like the features (ex: trophy, certificates…)?
5. Do you have any other comments or feedback to help us adapt the adult platform for young people with diabetes transitioning into adulthood?

PART C: New content

To help us get a sense of new content we should create for adolescents/young adults, I will now ask you a few personal questions about how you manage your diabetes.

1. As a young person living with type 1 diabetes, what are you currently struggling with?
    a. *Possible probes:*
        i. Medication regimen? Adjusting insulin?
        ii. How to use continuous glucose monitors/insulin pump/technology?
        iii. Physical activity/sports?
        iv. Disclosing diabetes status to peers/significant other?
        v. Alcohol, drugs, parties?
        vi. Stress management, exams?
        vii. Managing your diabetes at school/work?
            1. *Probe for details.* Tell me more about this. How do you deal with these challenges?
2. What topics related to diabetes management do you think need to be discussed more openly?
3. Are there any topics that you feel uncomfortable discussing with your doctor, but would like to receive information online, anonymously?
4. What are (or were) your expectations/concerns about transitioning to the adult healthcare system?
    a. *Possible probes:*
        i. Meeting a new doctor?
        ii. Dealing with insurance?
        iii. Changing pharmacies?
5. What parts of navigating the adult healthcare system do you feel that you would (or would have) benefit from some extra support?
6. What procedures/processes do (or did) you know nothing about and would like (or would have like) explained clearly?

PART D: Close

1. Is there anything else you'd like to share? Anything that we missed?

Thank you for your time and your willingness to discuss these issues. Your feedback is valuable and will definitely help us develop a support platform for others like you!

Supplementary 6.2

Video explaining *Support*

Video link: https://www.youtube.com/watch?v=hld8l44NTvE

Supplementary 6.3

Example of quotes for diabetes self-management

	Codes	Example of quotes
External barriers	Not being given opportunity for diabetes self-management from parents	“What you want is to be independent. With some parents who can be a bit more overprotective or who are used to being very involved in their children's lives because since they were young, they took care of their diabetes, it can be tough. You can feel a little handicapped if I can say that.” *(Participant 10, woman, 19 y.o., 3 y.d.)*
	Complex medical administrative management	“I would say that my concerns are a bit of the unknown. It's because I've been in the pediatric environment since I was 3 years old, I know it by heart. […] I'm going to move forward with someone I don't know […] Who is taking care of me? who is responsible? You will find a doctor; will it be me or my doctor who transfers my file?” *(Participant 7, girl, 17 y.o., 14 y.d.)* “I would say, mostly, about procedures like meeting your doctor. […] Will we have the same frequency and same level of support that we have now? Are we going to have the same resources? […] Is it going to be as accessible as it is right now?” *(Participant 14, girl, 16 y.o., 5 y.d.)* “For me, it would be more about the administrative aspect. What are the programs that we would have access to, then the criteria, what is important to have your doctor fill out when you meet him? […]” *(Participant 3, man, 22 y.o., 6 y.d.)*
	Stigma	“If sometimes you show up with your insulin, I can't even imagine people who have a pump. You show up with insulin then there are people who look at you like ah is that person drugged, what is it? You know they called me junkie sometimes and I laughed. But sometimes it's tiring." *(Participant 4, woman, 24 y.o., 10 y.d.)* “It's when, people don't seem to necessarily know what diabetes is […] They only know that ah you take too much sugar or you can't eat sugar. That's what their idea |is of you], but they also don't realize that it affects everything, your whole life. Literally everything, everything, everything, everything, everything affects it too.” *(Participant 5, man, 23 y.o., 17 y.d.)* “I have often been told Ah yeah, I do not understand why you are diabetic, you seem to eat well then you don’t seem to be very overweight. No, but it's not that.” *(Participant 18, girl, 16 y.o., 15 y.d.)*
	Variable schedule	“But sometimes it can be hard, like my routine, it can change. One day I’ll have practice, the next day I won’t, and the next day I’ll have a game. Sometimes it’s hard, like I don’t have a daily routine right now. […] Basically, everything can affect your blood sugar is how I see it. Like stress, eating, sleep, I think anything can, which is really hard.” *(Participant 19, boy, 16 y.o., 9 y.d.)*
	Stigma	“Everybody's like oh you got diabetes you can't do this, you can't do that, but no [they] don't know [that]. It's more that." *(Participant 7, girl, 17 y.o., 14 y.d.)*

		"All the time, [it is] so difficult for me to raise my hand and then tell the teacher I'm not feeling well, and that I need to take some sugar. I feel bad all the time because I don't want to interrupt their class and like I always find it frustrating. Then I tell myself like there is like no choice to say it, as I feel worse all the time, I see it, I feel it since in my head I'm no longer [aware]." *(Participant 14, girl, 16 y.o., 5 y.d.)* "I might be afraid of what the person will think if I say I don't want to talk about [diabetes]." *(Participant 2, woman, 23 y.o. 14 y.d.)* "To understand that we are not always good patients […]. That we are not perfect patients, who take their blood sugar on time, and then they eat a certain number of grams of carbohydrates and that we are patients after all and maybe include this aspect of having to respect things." *(Participant 21, man, 24 y.o., 10 y.d.)* "When you are younger, you have less confidence in you and sometimes I was like I will wait to the end of the class to eat something. Otherwise, people will look at me as if you were sick. When you are younger you want to be as other people. So, it happened to me to wait for class to end to treat hypos." *(Participant 3, man, 22 y.o., 6 y.d.)*
	Felt obligated to answer external questions	"You know what makes me uncomfortable, it's when I must explain it to someone." *(Participant 17, woman, 23 y.o., 10 y.d.)* "[Diabetes] is still a part of you. It's a bit like your privacy. Then having to go tell someone else about it, having to explain it to them again when you have been living with diabetes for years." *(Participant 18, girl, 16 y.o.)* "With diabetes, well, we already live with it every day. We do not want to talk more about it to a person for example, who we are just getting to know." *(Participant 2, woman, 23 y.o. 14 y.d.)*
	Perceived inadequate care and support from the healthcare team	"It was like a shock to me because they [my new healthcare team] were supposed to be a medical specialist. Then he had no expertise of technology in diabetes at all. Then he didn't even look at my blood sugar." *(Participant 3, man, 22 y.o., 6 y.d.)* "When I was diagnosed, I was 16, weighed 100 pounds. [the doctor] thought I was type 2. Then he said to me, well you're going to the hospital tomorrow, you know? And all while I was totally in ketoacidosis. […] That's the case for many doctors." *(Participant 10, woman, 19 y.o., 3 y.d.)* "There's a doctor at school but he doesn't really know anything about diabetes, like I'm sure he knows vaguely but not really, so just not having that support and kind of having to deal with it yourself. That's the hardest thing." *(Participant 19, boy, 16 y.o., 9 y.d.)* "But I imagine that we will certainly be more to ourselves because, I mean, we are adults, we still must know how to manage our diabetes well. But of course, I would be afraid. In addition, like having less resources [in adult care]. That quite stresses me." *(Participant 14, girl, 16 y.o., 5 y.d.)*

	Perceived inadequate support from family and friends	“It's like the world isn't really going to pay attention to “are you okay? Were you in depression? Are you too much in isolation?” […] Sometimes I have heard like yes, but it's a disease like any other disease, yeah well there is a worse disease in the world, stuff like that. […] People around can just pay more attention directly when someone has been diagnosed, just pay a little more attention to that person, because for sure for some, it is easier than for others, and for other it’s more difficult.” *(Participant 8, woman, 20 y.o., 6 y.d.)*
	Lack of motivation	“Then it took a little while [after the diagnosis] before I wanted to hear some stuff about diabetes, [...], then maybe a little bit of the stuff that might help these people with diabetes acceptance and take responsibility. I think it would have been fun to talk about it a little more when I was young, to have cues to deal with diabetes […] to be able to explain it without living in too much discomfort, so to speak.” *(Participant 17, woman, 23 y.o., 10 y.d.)* “Since I know how to calculate my carbohydrates, I know everything to do, but sometimes it's to take the initiative, calculate […] it’s more doing it than knowing it.” *(Participant 18, girl, 16 y.o., 15 y.d.)*
	Resistance to cooperate with his/her own behaviour	“They’re habits that we have so it becomes more and more difficult afterwards, to break this habit.” *(Participant 4, woman, 24 y.o., 10 y.d.)* “What is most difficult for me is to be consistent [in my diabetes management]. […] to stay consistent over a few months is a bit difficult.” *(Participant 21, man, 24 y.o., 10 y.d.)*
	Mental burden	“Especially on social media, we want to have a beautiful appearance. When we hear that someone is diabetic, it is very difficult because firstly, you know, when we have hypo, at a certain moment you must eat. Of course, it’s more difficult, especially the weight, and especially at our age, to have a stable weight then in addition being diabetic, I find it even more difficult.” *(Participant 14, girl, 16 y.o., 5 y.d.)* “It is something that we need to show publicly because we don’t have any choice. In the sense that if I feel that I am in a hyper, I have no choice than to sting myself. ” *(Participant 17, woman, 23 y.o., 10 y.d.)* “Above all, I would say that the discipline is most difficult. It is a 24/7 disease [diabetes], 356 days a year.” *(Participant 15, man, 21 y.o., 6 y.d.)* “For sure sometimes it’s more difficult because I mean, it’s like decisions that you constantly make, [...] every moment of the day.” *(Participant 14, girl, 16 y.o., 5 y.d.)*
	Support from peers living with T1D	“Talk [to youth living with T1D] about the little things in our daily life that we can’t talk to anyone else about. Well, we could, but who wouldn’t understands as much.” *(Participant 10, woman, 19 y.o., 3 y.d.)* “The doctor, he’ll give me advice. […] But It’s still easier for him to say it as he doesn’t live the same reality as me, but you know to see a little more how people can apply it, sometimes it helps me when I meet a diabetic person.” *(Participant 17, woman, 23 y.o., 10 y.d.)*

		"A big part that helped me too with diabetes in general is that I went to the Carowanis Camp, where I met very good diabetic friends too. We are a group of 4 girls together. When I have small questions, for example the sensibility factor, to increase or decrease it. When I ask the question, I will get an answer. So, exchange on these small things, advice like this, and it helps me a lot." *(Participant 18, girl, 16 y.o., 15 y.d.)*
External facilitators	Access to medical therapies and technologies	"With new technologies, for me that […] just between the time I was diagnosed and today there has already been a good difference there." *(Participant 22, man, 22 y.o.13 y.d.)*
	Access to medical information	"I think that if there is a way to acquire information more easily, more quickly, because an appointment with an endocrinologist is still long. So? I found it would be interesting to consult an application like this [*Support*]." *(Participant 12, boy, 14 y.o., 6 y.d.)* "Knowing that there are professionals who verify the articles. Then all that, it reassures me." *(Participant 3, man, 22 y.o., 6 y.d.)*
Internal facilitators	Diabetes literacy	"It has only been 6 months that I know we can look at the injected insulin dose on it [the insulin pen] and I am very excited. I can know how long it was since I injected my last dose [from the insulin pen]? I didn't know we could do this." *(Participant 4, woman, 24 y.o., 10 y.d.)* "I don't calculate my carbs down to the nearest carb, let's say. I go more by estimate, it is a method that I have had for several years. Then sometimes I question myself and repeat to myself all the time that I should go back to the good old, well, the good method. […] Am I doing this right? Is it enough to avoid having complications later to have a good life, let's say, without it being too burdensome?" *(Participant 7, girl, 17 y.o., 14 y.d.)* "If I didn't inject, what would it do? At 10 months of diabetes, I still don't even know what it does. It's something to know what the consequences are. […] We talk a lot, do that that that that, but you know, if we do not do that, then what will it do?" *(Participant 11, girl, 16 y.o., 1 y.d.)*
	Perceived support by family and friends	"I tend to talk less about it [my diabetes] because I don't want people to associate me with that only." *(Participant 13, girl, 16 y.o., 5 y.d.)* "My coaches also had to understand that OK, we have to give her more breaks, she really has to have some time to adapt before we can go at the same pace we did before"." *(Participant 8, woman, 20 y.o., 6 y.d.)* "I think making everybody know it [you have diabetes] was the first step. After that, there is no more danger. You will not be judged. Everybody will be okay, he is diabetic, and it is all". *(Participant 3, man, 22 y.o., 6 y.d.)* "When you are young, you really need to not feel judged, then, to know that well okay, it's okay you did your best even if you have a hyper because you ate, I don't know, a cake, because it was the birthday of someone"." *(Participant 4, woman, 24 y.o., 10 y.d.)*

		“For me, it wasn’t a surprise initially because since very young I was watching my father making self-injections. And my sister, who is older than me, was diagnosed with diabetes when she was in elementary school.” *(Participant 15, man, 21 y.o., 6 y.d.)* “You have to prick yourself […]. It might bother the world, but you don’t care. That’s what you need, and you know you’re doing nothing wrong.” *(Participant 22, man, 22 y.o.13 y.d.)*
	Self-efficacy	“[The blood glucose variation] is hard sometimes, it’s just so unpredictable. […] So sometimes just being on it all the time is the best thing and there’s no one way to deal with it.” *(Participant 19, boy, 16 y.o., 9 y.d.)* “I think I accepted my disease because I never really realized that it’s a disease, because for me, it’s normal.” *(Participant 18, girl, 16 y.o., 15 y.d.)* “Having difficulties to manage your diabetes should not be something that you feel embarrassed about. It is not just a lack of motivation, there are other things. It is a chronic disease that you need to manage every day.” *(Participant 18, girl, 16 y.o., 15 y.d.)* “For sure the mental health aspect is an aspect that is very important for a lot of diabetics.” *(Participant 16, woman, 19 y.o., 9 y.d.)*
	Awareness of potential medical complications	“All related to the understanding of why there are complications. Why there is this, why be careful? It is to understand: the why and the how.” *(Participant 18, girl, 16 y.o., 15 y.d.)* “There were like really all the aspects that, that I wondered about, like for me personally like ketoacidosis, that I never really necessarily understood, really detail by detail, what is it.” *(Participant 14, girl, 16 y.o., 5 y.d.)* “Am I going to be able to do the same job [as people who don’t have diabetes] do? They tell me yes, but you know […] they ’on't need to watch blood sugar every half hour.” *(Participant 11, girl, 16 y.o., 1 y.d)*
	Perceived adequate care and support from the healthcare team	“When I was contacted for my first appointment at the adult hospital, [..] I was really told right away where to go, how to proceed. I felt very comfortable to change [healthcare team].” *(Participant 2, woman, 23 y.o., 14 y.d.)* “I have the impression that my doctor knows type 1 diabetes well. […] I was really happy because I have had experiences with less kind doctors about diabetes.” *(Participant 10, woman, 19 y.o., 3 y.d.)* “I found my healthcare team formidable. Honestly, I cannot ask for better. So personally, I have no discomfort in bringing up any subject with them.” *(Participant 14, girl, 16 y.o., 5 y.d.)*

Supplementary 6.4

Topics to be included proposed by participants

Topic	**Sub-topic**	**Example of titles**
Diabetes-related management	- Medical technology management - Medication management - Relationship with healthcare team - Transition to adult care (pre, during, and post)	- How can I correct hypo/hyperglycemia? - How can I keep my blood glucose sensor from falling? - How can I prepare for my transition to adult care? - How to establish a good relationship with my new healthcare team? - How to manage and select my pump parameters? - How to organise my file transfer? - How to select my insulin pump? - List of medical exam recall (e.g., when to do the eye exam) - List of questions to ask to the doctor during my first meeting at adult care - What are my responsibilities to ensure a fluid transition? - What are the different types of insulin and their active period? - What should I do if I want to change doctor? - What to do if I give myself too much insulin? What to do if I miss an insulin dose? - What to do if I have ketone bodies and I am not at home? - What will my adult healthcare team look like?
Medical coverage	- Insurance - Special support program	- How should I transfer from my parent's insurance to mine? - Insurance and bursary programs - What is covered by the provincial health care system?
Latest news	- Latest research results - Social events organized by the diabetes organization	- Advancements in the field of diabetes - New technologies and proposed therapies - Postings on current research participant recruitments
Lifestyle	- Alcohol - Drugs - Mental health - Nutrition - Physical activity - Sexuality - Sleep - Social event - Travel	- Carbohydrate counting with and without pumps - Diabetes and mood swings - How should I prepare for pregnancy? - How to prepare for Halloween? - How to travel with diabetes? - Recipes and their nutritional content - What is the impact of physical activity on glycemia? - Which food should I eat before doing physical activity?

Pathophysiology of diabetes	- Difference between different types of diabetes - Etiology of diabetes (especially of type 1 diabetes) - Medical complications	- Are hyperglycemia less serious than hypoglycemia? - How to deal with nocturnal hypoglycemia? - What are the factors that can induce type 1 diabetes? - What are the potential complications if I don't manage my diabetes properly? - Why can uncontrolled diabetes lead to complications?
Peer experience	- Feedback/review on diabetes-related products - Management of diabetes - Personal story	- How do others live transition in their life (e.g., when changing school, when going to adult care) - How do others travel with diabetes? - How to live with diabetes and coeliac disease? - Opinion on different types of insulin pumps
Social relationships and interactions	- Explaining diabetes to others - Perception of others - Stigmatization related to type 1 diabetes	- How to explain diabetes to my family and friends? - What should I say when I don't want to talk about diabetes with others? - What should we do when we are stigmatized by others?