

# Adolescents' participation in their healthcare: A sociomaterial investigation of a diabetes app

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## Abstract

**Objective:** This article explores how a diabetes app called Diapplo affected adolescents' participation in their healthcare by investigating adolescents' meaning-making in relation to their use of the app.

**Methods:** Using a qualitative single case-study design, we adopted a multimethod responsive approach to data generation that included written data from the app development process, individual and group interviews and observations of the adolescents in the clinical situation. This article presents the results from a qualitative content analysis of group and individual semi-structured interviews conducted with five adolescents diagnosed with type 1 diabetes during and after the four-week test phase of a prototype of the app.

**Results:** The adolescents appreciated the diabetes app's design and interface and having an overview of their blood glucose values. However, they stated that the app's content only partly met their needs and they considered several of its features unnecessary. They would have liked the app to have a social platform and emphasized that the app should be compatible with their blood glucose monitors and pumps for them to continue using it.

**Conclusions:** The participants in our study highlighted the value of social platforms integrated in health apps for patient participation, as well as their preference for health app features that reduced the effort of managing their chronic condition and facilitate greater knowledge. Theories of sociomateriality and material participation helped to account for the challenges of integrating users' perspectives, suggesting the value of early, comprehensive identification and prioritization of users' values when developing mobile health technologies.

## Keywords

Medical apps, mHealth, adolescents, diabetes, participatory design, sociomateriality, material participation

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## Introduction

Patient participation is a complex concept, often used in relation to patients being involved in decision-making regarding health issues and the management of chronic disease.<sup>1</sup> Participation is increasingly used as a byword for *quality* in healthcare and has been promoted as a politically desirable goal in recent years.<sup>2</sup> It is seen as a way of including patients as stakeholders in their healthcare,<sup>3–6</sup> among other things to promote patient empowerment,<sup>5,7</sup> and address concerns about paternalism in biomedical practice.<sup>8</sup> As a concept and a practice, patient participation is associated with mutual respect between patient and

healthcare practitioner,<sup>9,10</sup> collaboration,<sup>11,12</sup> and a patient-centred approach.<sup>5,13</sup> Despite broad endorsement and promotion of patient participation as a model of healthcare praxis and interaction,<sup>14</sup> not all patients want to, or are able to, participate, however.<sup>2,15</sup> Moreover, with patient participation, there is

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the expectation that ‘engaged patients’ will, like ‘good citizens’ or ‘good patients’, be ever-vigilant in relation to their health and adopt health behaviours that benefit population-related risk minimization.<sup>16</sup> This has led to criticism of patient participation for its potential to generate forms of governmentality where individuals are expected to govern themselves in line with biopolitical agendas.<sup>17</sup> A recent Cochrane systematic review also indicated the rather ambivalent health value of decision aids whose purpose was to support patients’ participation, concluding that although patients may have more options and feel better informed, their health outcomes and anxiety levels were not affected.<sup>18</sup>

Despite the lack of incontrovertible evidence of the health-promoting effects of decision aids, the thrust of policy and practice is to endorse and promote them.<sup>19,20</sup> This tendency is a particularly prominent aspect of our increasingly digitized societies: according to Marres,<sup>21</sup> ‘[p]articipation has been one of the principal key-words, slogan or tropes, perhaps *the* principal trope that is invoked to distinguish digital societies’ (p. 144). Indeed, the digital ‘plays a critical role in transforming the opportunities for everyday engagement’<sup>21</sup> (p. 154). With mobile health (mHealth) technologies, then, two lines of thought on participation overlap: the current normative valuation of participation in healthcare provision, and the (assumed) transition from passive audience to active participation associated with current digital societies<sup>21</sup> (p. 146).

mHealth technologies are considered instrumental in promoting patient participation,<sup>22,23</sup> not least of all in Denmark which has one of the most digitized healthcare systems in the world.<sup>24</sup> Due to their popularity and increasing pervasiveness, mHealth technologies – which include medical apps, wearables and the internet of things (interconnected devices) – influence the practice of healthcare in the clinical setting,<sup>25</sup> and are now considered part of the architecture of healthcare provision.<sup>26</sup> Healthcare organizations are increasingly using medical apps operated on smartphones and tablets in their service delivery.<sup>26</sup> There is, at the same time, growing awareness of the challenges involved in integrating mHealth as a complementary form of healthcare into existing healthcare practices, also as mHealth is still in its relative infancy and its potential is not fully understood or exploited.<sup>23,27–29</sup> Moreover, although it is broadly agreed that all relevant players should be involved throughout the development of a new mHealth technology to maximize its quality and usability, the practical, epistemic and power-related challenges of multidisciplinary and multiperspectival collaboration are recognized.<sup>27,30</sup>

Medical apps have increasingly been introduced in healthcare settings to patients with chronic diseases such as type 1 diabetes mellitus (T1DM) to help them

control their disease by improving their blood glucose management.<sup>31,32</sup> Most T1DM cases first arise among children and adolescents,<sup>33</sup> so it is of particular interest to investigate how this population group’s participation in managing their healthcare is influenced by diabetes apps. Most of the literature on diabetes apps in the treatment of adolescents with T1DM has been concerned with possible medical benefits. Some studies have observed improvements in levels of glycated haemoglobin (HbA1c) and diabetes self-efficacy,<sup>34</sup> self-management<sup>35</sup> and self-treatment,<sup>36</sup> while others have found that diabetes apps had no effect on HbA1c levels,<sup>37</sup> glycemic control and self-management<sup>38</sup> or quality of life.<sup>39</sup> In these studies, diabetes apps are mainly conceptualized as a means of motivating young people with diabetes to produce behaviours that result in improved blood glucose management; participation serves primarily biomedical ends.

Digital technologies such as health apps are often represented as tools whose purpose is to fix an existing problem and address specific users’ needs, reflecting the broadly uncritical discourse of technological solutionism.<sup>40,41</sup> However, it is increasingly recognized that apps can usefully be considered material actors that interact with human actors,<sup>25</sup> and that they directly affect the meanings and forms of participation in healthcare. As such, it is not so much about how or to what extent patients use apps to participate in their health, but rather how apps and the contexts in which apps are produced and used make certain forms of participation possible. In drawing on sociomaterial theories to explore this aspect,<sup>25,42,43</sup> this article diverges from the majority of research in health apps for patients with diabetes which has primarily focused on their medical effects, as mentioned earlier. We chose sociomaterial theories to address this issue as apps are sociocultural products just as much as they are tools for achieving medical outcomes. The value of employing sociocultural approaches to mHealth technologies has also been demonstrated in other articles published in this journal.<sup>27,44,45</sup>

In this article, the theories we have chosen provide critical purchase on participation in digitally-mediated healthcare and on the impact of mHealth technologies on subjectivity. First, theories of sociomateriality offer very relevant critical perspectives to the field of digital health, according to Lupton,<sup>25,43</sup> because they focus on the ‘entanglements between humans and non-human actors’<sup>25</sup> (p. 12) such as apps, emphasizing ‘the role played by material artefacts in social relations and the construction and negotiation of meaning’<sup>25</sup> (p. 12). The sociomaterial perspective rests on the idea that digital technologies are not neutral, as mobile technologies ascribe capacities and attributes to, and demand certain activities of, their users.<sup>46</sup>

Sociomaterial theories are particularly relevant to studies of patient participation such as the present, as they recognize ‘the dynamic nature of people’s interactions with technologies in a world in which the digital is increasingly part of everyday lives, social relationships and concepts of subjectivity and embodiment’<sup>25</sup> (p. 13). For Lupton, theories that provide the field of digital health with critical perspectives (such as sociomateriality) hold that apps are sociocultural products located ‘within pre-established circuits of discourse and meaning’<sup>48</sup> (p. 1349). As such, mHealth technologies draw on existing discourses that generate identities and practices for app users, at the same time as they also represent a technical rupture and challenge existing forms of care and knowledge.<sup>25</sup>

Second, we make use of Marres’ theory of material participation. Like Lupton, Marres problematizes the notion that technologies are impartial and neutral. Drawing on Dewey,<sup>42</sup> who situated political and moral problems such as clashes in ‘values, desires and interests’ (p. 15) within objects, giving them force and valuation as well as a reason to be produced in the first place,<sup>48</sup> Marres adopts a ‘device-centred approach’,<sup>42</sup> (p. 133) and focuses on who and what in different participatory arrangements are to be assigned responsibility for problems of participation. Adopting a device-centred rather than a user-centred approach helps to lay bare the social dynamics of valuation. Material participation also makes it possible to open up the ‘division of labour between citizens, government and industry’<sup>42</sup> (p. 135). Participation, in this conceptualization, becomes not just the responsibility of the individual app user, as is often assumed: it is the responsibility of all the social actors involved and their environments, and responsibility for participation needs to be apportioned accordingly<sup>42</sup> (p. 137). To explore material participation, Marres<sup>42</sup> argues that it is necessary to focus on the contexts of development and use – or, in her words, one needs to ‘adopt a performative perspective on these instruments: only by considering their deployment in specific settings, can we determine what is the normative range of different devices of engagement’ (p. 154). In this way, material participation challenges a core principle of patient participation outlined in the opening of the Introduction – the idea that patient participation can be fostered through respectful communication. From a material performance perspective, this would be considered a rather simplistic assumption, given the embeddedness of all the participants in valuating systems.

The present article focuses on the user-app nexus – the connections or entanglements between the adolescents and the diabetes app – situated in the broader context of its development and use, reflecting Marres’ concern with the various settings of deployment.

The aim of our article is to explore how a diabetes app called Diapplo mediated adolescents’ participation in their healthcare, and we investigate adolescents’ meaning-making in relation to their use of the diabetes app with respect to its form, content and use. The theories of material participation and sociomateriality were used to provide perspectives on the analysis. This is because the interviews, which facilitated a ‘user-centred’ approach, allowed us to gain users’ perspectives on how the app affected their participation, while more ‘device-centred’ theories of material participation and sociomateriality provided a complementary focus, sensitizing us with the perspectives that the diabetes app is material in form and the app as an instrument affected the adolescents’ participation in their healthcare in distinct ways, making certain forms of participation possible.

## Methods

### Design

We used a qualitative single case-study design, inspired by Stake’s responsive approach,<sup>49,50</sup> to explore how a diabetes app mediated adolescents’ participation in their healthcare in their everyday lives in real-life settings (outpatient clinics and workshops). A responsive approach involves a focus on participants’ values, ideas and experiences, and as these issues emerge from the participants’ own narratives, it corresponds with the emic perspective.<sup>51</sup> The local orientation of the case-study design also makes it particularly valuable for exploring local arguments and activities influenced by contextual factors. As we were especially interested in the phenomenon ‘material participation’, we (researchers) brought ideas and concepts drawn from theoretical literature to develop new understandings of the empirical material, which corresponds with the etic perspective.<sup>51</sup> As such, our approach is in line with the rationale of an instrumental case-study design;<sup>49</sup> it has its point of departure in adolescents’ views (emic perspective) while simultaneously being inspired by the theoretical perspectives of sociomateriality and material participation emerging from the researchers’ (etic) perspective.<sup>51</sup>

### The case

The diabetes app Diapplo was developed as a decision aid tool in the Danish project entitled ‘Development and test of a decision aid tool’. Mårtensen and Fägerskiöld<sup>19</sup> define decision-making competence as the capacity to make a decision. An app can assimilate data into recommendations for specific actions based on clinical guidelines, and app technology can thereby

provide adolescents with actionable information which is accessible at any time of day. Diapplo was conceived as a digital decision aid tool during the start-up phase of the project based on knowledge of diabetes self-management and the physicians' and nurses' clinical experiences. Adolescents with a chronic disease are considered to be in particular need of developing health decision-making competences.

Diapplo was developed as a prototype at the outpatient clinic for adolescents with diabetes at Aarhus University Hospital and tested at that hospital and at the outpatient clinic for adolescents with diabetes at Viborg Regional Hospital. The prototype of the diabetes app Diapplo provided a critical case for investigating the content, form and uses of a diabetes app from the (emic) perspective of the adolescents (users). It was to be used by adolescents with T1DM aged between 11–18 years to help them manage the disease in their lives and facilitate contact with health professionals, a feature that is not readily available in diabetes apps offered by patient organizations, for example. Diapplo was meant for use both in social settings (adolescents' homes, during leisure activities and at school) as well as clinical situations, such as consultations between the adolescents (and their parents) and health professionals (nurses and physicians).

The developmental phase took 12 months in total (September 2016–September 2017). 37 parents, 35 adolescents, nine health professionals (nurses and physicians), six IT designers and two anthropologists collaborated on developing the app, and were invited to participate in different ways and on different occasions. During the developmental process, IT designers and two anthropologists conducted observations and interviews at the outpatient clinic whose purpose was to identify the adolescents' and health professionals' needs, wishes and preferences. Fifteen workshops were established and during these workshops, health communication issues and medical information on diabetes were discussed and joint decisions about the diabetes app were made. Health professionals and some of the adolescents worked together to produce a number of information videos on using a pump and on being young and receiving treatment. The workshops relied on co-creative processes,<sup>52–54</sup> bringing the different participants (IT designers, anthropologists, physicians, nurses and adolescents) together to generate new ideas and solutions based on the parties' various forms of knowledge and skills. The workshops centred on the treatment and regulation of diabetes, and on how young patients with diabetes could have a social life despite their chronic illness. The adolescents in the developmental phase participated in three different workshops, the first one approximately eight months into the developmental process. Consequently, by the

time the adolescents joined, many aspects had already been determined by the participants at the previous workshops.

A test phase was conducted at two outpatient clinics from October to November 2017. The test involved nine health professionals, who had been involved in the development phase of the app and five adolescents, who had not been involved in the development of the app. Originally, six adolescents (three boys and three girls) from Aarhus University Hospital and five adolescents (five boys) from Viborg Regional Hospital were invited to test Diapplo. During the test period, one girl and one boy from Aarhus University Hospital and four boys from Viborg Regional Hospital withdrew from participating in the project. They explained that they withdrew because they found it too time-consuming and demanding to use the diabetes app during the day. Altogether, five adolescents (three boys and two girls) aged 14–16 years old tested the app over the full test period of four weeks. The adolescents involved in the test phase were not the same as those who had participated in the earlier developmental phase.

The prototype of the diabetes app Diapplo developed for the test comprised six features (Figure 1(a)): *my page* for typing in personal information, rules for calculating insulin intake and a GPS-feature that could be turned on or off; *my blood glucose* that had information on using a pump or pen and insulin adjustment; a *daily schedule* which made it possible to type in blood glucose values and included a bolus calculator; a *calendar* that visualized blood glucose values (Figure 1 (b)), insulin regulation and GPS-tracking; a feature named *consultation* that showed the date of the adolescents' next consultation and included a space for note-taking in relation to future consultations; and *information*, which included information and advice about the illness and its effect on insulin regulation, travelling, as well as guidelines for insulin regulation with respect to physical activity.

## Data

Data from the case study (the whole project as opposed to the interview data set for this article) were collected from September 2016 to November 2017 and were generated from a variety of sources.<sup>49</sup> First, the original project protocol that was used to apply for funding provided an understanding of the background to the project including the disease and its complications, and treatment. Second, written data also comprised minutes from meetings, notes from IT designers, two anthropologists' observations at the outpatient clinics and transcripts from the 15 workshops undertaken during the 12-month developmental phase. During the developmental phase of Diapplo, adolescents



**Figure 1.** Screenshots of (a) the main page and (b) the calendar with an overview of blood glucose values of the diabetes app Diapplo, developed at the Alexandra Institute, Aarhus.

diagnosed with T1DM were included in three workshops on 25 April, 26 June and 4 July 2017. Third, observations were undertaken by AM and LL to gain insights into clinical practices, including how the adolescents communicated with health professionals when they used the diabetes app during consultations.<sup>56</sup> Observations provided insights into how the diabetes app was used in the consultations and how it affected the contact and relations between the adolescents and health professionals. Insights gained from the observations informed the interviews that followed, the findings of which are presented in this article, making it possible to ask questions that were relevant to the adolescents and their situations.<sup>56</sup>

In this article, we present our findings from the interviews conducted during the test phase. With respect to the generation of this data set, AM and LL conducted

two group interviews and one individual interview with the five adolescents who tested the prototype of the diabetes app halfway through the test period; each interview lasted approximately 50 minutes. Then, individual semi-structured interviews were conducted with the same five adolescents after the test period that ended with a consultation at the two outpatient clinics: this time, each interview lasted approximately 30 minutes. The main topics of the interview guides were the adolescents' expectations of Diapplo; their experiences of having a decision aid tool on their smartphone; how they interacted with the diabetes app when monitoring blood glucose and insulin levels; their use of the app in various settings and contexts such as at home, in school and with respect to leisure activities; how Diapplo may have influenced relationships with their friends and family; and how

they experienced the app during consultations. Examples of interview questions from the interview guide include: How did you use the diabetes app with your doctor/nurse in the consultation?; What did you mostly use the diabetes app for?; and Do you think the diabetes app can help you manage your diabetes at school?

### Data analysis

The analysis takes a responsive approach to case study, following Stake.<sup>50</sup> This approach attaches importance to participants' own views, interests and accounts, which helps to elucidate participants' actions. We subsequently used the etic perspective to confront and interpret the data in relation to theory and discuss the results.

During the first phase of analysis of the interviews, we familiarized ourselves with the interview data by reading the transcripts repeatedly. In the second phase, the transcripts were initially coded using NVivo 11.4 software,<sup>57</sup> followed by further organization of the coded material in NVivo into 12 main codes and 11 sub-codes. The codes were generated inductively and iteratively, as they were created in the course of the data-generating process, and the participants' statements were understood in relation to the contexts in which they were uttered. An example of a main code from our NVivo analysis is: 'Features of the diabetes app'; and examples of the related subcodes are: 'Adolescents' expectations of the app', 'Adolescents' use of the app', 'Name and design of the app comprising the adolescents' opinion on colour and organization of information', and 'Adjustments to the diabetes app including their ideas to further develop the app'. A number of codes were altered as the analysis progressed and more data became available. In the third phase, we performed a manifest content analysis, following Graneheim and Lundman,<sup>58</sup> as this allowed us to identify the main meaning (semantic) 'categories' (p. 107) in the text. During this phase, we referred back to the original transcripts to ensure that we stayed as close as possible to the original meanings of the adolescents' experiences of the app and the contexts in which they were uttered. Manifest content analysis involves moving from codes and sub-codes, the identification of which was facilitated by the NVivo analysis, to identify more general categories in the coded interview data. More specifically, it involves identifying the main meaning categories in a data set by comparing and sorting through the codes (p. 109), as we were primarily interested in performing a data squeeze that allowed us to orientate ourselves to 'what' the data were about (p. 107). The identified categories act as structuring

elements in the results section where they are used as subheadings.

### Ethical considerations

The project was accepted by the Danish Data Protection Agency (ref. AU-2016-051-000001) and complies with their rules. The parents, adolescents and health professionals all gave oral and written consent prior to the collection and use of the data. All data were anonymized and kept inaccessible to anyone but the research team. The participants were informed that all participation was voluntary and that they could withdraw from the project at any time and without needing to provide an explanation. According to Danish legislation, the project did not need any approval from the Danish Biomedical Research Ethics Committee System.

### Results

The analysis that follows presents aspects from the data that relate to the form, content and use of the prototype of the diabetes app Diapplo to show how participation was accomplished in the interplay between human actors and a digital technology. The quotations from the interviews that were most illustrative of the points in our analysis were selected from the original Danish data for inclusion and were translated into idiomatic English; these stem from the group and individual interviews undertaken with the adolescents during and after the test phase.

#### Form of the diabetes app

The adolescents were generally positive about the Diapplo's design and appearance. They noted that the six icons on the main page made it easy for them to navigate between the different parts of the app:

It [the diabetes app] is really simple. There are six main topics where you find everything. It's nice that it's not cluttered when you open it, which I think many apps can be where you have everything thrown at you at one time. With this app, you find things yourself. (User 1)

The adolescents also appreciated that the Diapplo enabled them to get an overview of their blood glucose values (Figure 1(b)) which meant that their own impressions of their blood glucose values as either being too high or too low could be confirmed or refuted:

You can get feedback about whether you did something wrong – if your blood glucose value is too high or too low – in that way, you can learn what to change to make sure it is more stable next time. (User 3)

The adolescents stated that the name of the diabetes app was important, as it should be easy to find and install on a mobile device. One of them considered the name ‘Diapplo’ not to be optimal as it did not make them think about diabetes and the majority of the adolescents agreed:

It’s a strange name. At first, I didn’t think that it had anything to do with diabetes. (User 2)

The colours of the app’s interface created interest and appealed to the target group. The app’s design had a modern, colourful look that was valued by male and female participants alike.

### *Content of the diabetes app*

Despite Diapplo being considered visually attractive by the adolescents, some of its features did not seem to meet their needs and expectations. The adolescents said that Diapplo could be helpful for those who had recently been diagnosed with diabetes:

I think it [the diabetes app] could be very relevant for those who have recently been diagnosed with type 1 diabetes. It’s not as relevant for us who have had it for some time. (User 3)

The adolescents perceived several features of the app as being unnecessary, but they valued its calendar. It gave an overview of blood glucose levels, for example in the morning or evening, or one could choose to have a monthly overview. The adolescents also had a blood glucose monitor to help them keep an eye on their insulin intake. These blood glucose devices had programs the adolescents could use on their computer, but they said that none of them provided a good overview or easy accessibility:

[In the past], it wasn’t as easy. Now, you can see the different days at the same time [in the calendar]. . . It’s easier now. Previously, I didn’t go in to my blood glucose monitor to take a look at it. (User 3)

None of the adolescents had used the consultation function whose purpose was to support communication with their healthcare practitioners, as they stated they did not need help remembering questions or noting the date of forthcoming consultations. According to the adolescents, consultations could provide health professionals with the opportunity to tell them off, and the consultation function of the diabetes app did not change the young people’s procedures related to the consultation:

I start by asking my parents. And then, as a possibility, we can search the internet. Otherwise, we

can ask when we come out here [to the hospital]. (User 3)

The adolescents did not use Diapplo to seek medical information about diabetes to support their decision-making and could only imagine themselves using this feature if an urgent need or question came up. They said that they already knew most of the information available in the information function which made it redundant:

A lot of it isn’t relevant to me but [would be to] newer – to people who were just diagnosed with diabetes. . . I’ve had it [diabetes] for a long time. Since I started school. So I’ve already learned most of what it says in there. (User 1)

Diapplo had a GPS function incorporated to give adolescents the opportunity to track themselves geographically. This was to promote their understanding of their blood glucose values by allowing them to relate them to particular locations and associated activities. The objective of this self-tracking function was to help adolescents feel and become more in control of their health and bodies and experience health benefits. However, most of the adolescents saw no advantage in using the diabetes app to track their blood glucose levels, and one mentioned that it created a negative feeling of being under surveillance:

I feel like I’m being monitored when I use it [the GPS-tracking]. It is way too much. I don’t mind it [his blood glucose value] being high before I start [exercising], because it’s usually fine when I’m done. (User 1)

Thus, it seemed that some of the adolescents experienced self-tracking as a burden rather than as a source of self-knowledge and input to their decision-making.

Some of the adolescents thought that Diapplo lacked a private space where they could chat with other young people with diabetes – particularly, if they had had diabetes for a longer period of time and were more experienced:

It would be nice to get to know others who had it [diabetes] and hear how they felt about it. (User 5)

### *Use of the diabetes app*

It varied how frequently the adolescents used the diabetes app during the test period. Some used it daily while others used it a couple of times a week and mainly in the evening. Generally, they used it less frequently over time. On the whole, the adolescents stated

that they did not feel inclined to use the app and its features. Some of its features (the bolus calculator and GPS-tracker) were not fully developed at the time they tested them, which may explain some of their frustrations with the app.

The adolescents were of the opinion that various aspects of the app did not match their needs regarding their everyday lives with diabetes. The format of the app demanded specific forms of interaction. In order to maximize the benefit of the app's features (e.g. get an overview of their blood glucose values for a longer period), the adolescents needed to type in their blood glucose value every time they measured it. They said that this was not compatible with the way in which they wanted to live their lives:

It's too much to do [type in blood glucose values] for every blood glucose measurement. And sometimes I need to do it fast – for example, in the middle of a school period. (User 2)

Many adolescents have different social spaces on their smartphones in the form of apps that they use for social interaction, such as Facebook, Instagram and Snapchat. However, the Diapplo prototype did not provide adolescents with the opportunity to create or maintain social relations. As such, the time spent by the adolescents on typing blood glucose values into the app competed with the time they could have spent on their social networks, online or offline. The adolescents did not want to spend time typing blood glucose values into the diabetes app at school, at after-school activities or while they were with their friends:

When we have a break at school, I'd much rather be outside with my friends than sitting alone typing [blood glucose values] into the pump. (User 3)

None of the adolescents showed Diapplo to their friends or told them about it. They explained that this would not be possible as they mainly used Diapplo in the evening:

they haven't seen the app. I don't need them to. (User 4)

They said that they were not trying to conceal the app or their diabetes from their friends; they just did not want their disease to be a topic of conversation with their friends:

I don't need it [diabetes] to be the object of attention more than it already is. (User 5)

The adolescents also stated that they did not use the diabetes app with their parents. Two of the adolescents would have liked their parents to have had a version of the app so they could see their blood glucose values, without the need for verbal updates:

I actually wondered whether another version of the app could be made where you were able to share your blood glucose levels with your parents because it can be annoying having them ask what your blood glucose levels are. With a different version, they could see it for themselves. I think that could be useful. (User 2)

However, others said that this would make them feel monitored by their parents:

I think you would feel monitored. I definitely think I would feel a bit bad if they saw I had high blood glucose levels a lot. Not that I think it is a bad thing they see it, but you would still feel a bit like – they are monitoring me. (User 5)

The adolescents all agreed that it would be advantageous if their parents had access to the Information feature in Diapplo so that their questions could be answered:

I think it would be great if they [the parents] had one too. Maybe not all the features, maybe just information and the calendar. Nothing else, so they couldn't keep an eye on everything. In that way, they could still be a part of it – but not 100%. (User 1)

At the end of the test period, the adolescents and their parents attended a routine consultation at their hospital. During the consultation, the adolescents were to use the app's interface and features with the doctor and nurse. The adolescents were of the opinion that using Diapplo during consultations had generally been a positive experience. They all found that Diapplo's interface had a simpler, more user-friendly design than the software they had previously used that had graphs that were difficult to understand and made them feel excluded from conversations with the doctor and nurse:

They [the doctor and nurse] included me in the conversation, unlike previous times where it felt like it was just them talking together. It was nice, because that way you are included – you have a better idea of what is actually going on, instead of having something thrown at you or them saying: 'We are just going to change this.' (User 5)



The adolescents were happy to find themselves more included in the dialogue at the consultation, and they attributed this to the app's interface. They thought that they could better understand the doctor's and nurse's explanations regarding changes in their insulin dosage.

The adolescents all stated, however, that they would not continue using Diapplo unless their blood glucose values were transferred automatically to it. They regarded it as doing 'double work' having to type blood glucose values both in their blood glucose monitors or pumps and the diabetes app:

If I have to type [blood glucose values] in, I won't use it [the diabetes app]. It would be more in the way than of benefit. (User 1)

On the other hand, they said they would use Diapplo if their blood glucose values could be transferred automatically to it:

I think I would benefit from it if it happened automatically. I like the thought of having the overview and the fact that it is so handy. (User 2)

## Discussion

T1DM is a chronic condition that necessitates ongoing monitoring and sets of actions, and we investigated in this article how young people with T1DM interacted with a prototype of the diabetes app called Diapplo that was meant to facilitate their health-related decision-making and increase their participation in managing their disease. Despite the best professional intentions and a development pathway intended to facilitate the sharing and co-construction of ideas and values, including the adolescents', our findings showed that the adolescents' needs and preferences were not fully reflected in the diabetes app, with consequences for their inclination and ability to use it. Although the adolescents appreciated the app's design and interface, as well as having an overview of their blood glucose values over time, they considered a number of the app's features to be irrelevant and time-consuming. Using the diabetes app interfered with activities they considered more important. The adolescents prioritized interacting with their peers about everyday life decisions and events, and did not want to give their disease that much attention. They considered it inconvenient that the app was incompatible with their blood glucose monitors or pumps which meant they needed to type their blood glucose levels into the app. The lack of this function, however, may be due to the short

development process of Diapplo and the difficulties in testing a not fully developed app, and the adolescents saw considerable potential for the app's further development and improvement. It must also be kept in mind that all of the participants had been diagnosed with diabetes for at least one year and were young. Thus, the adolescents already knew most of the information that was integrated in Diapplo, and their lives centred more around school, friends and leisure activities than on their diabetes management. This is also likely to have affected the amount of time they wanted to spend on their diabetes treatment. The fact that they did not like having to use another device alongside Diapplo is hardly unexpected, but it does underline the importance of keeping devices and the broader contexts of their use in focus to avoid users' lackluster enthusiasm or disinclination to participate when mHealth technologies are integrated into healthcare.

Our findings are in line with those of previous studies, suggesting a number of more general implications. Although some of these existing studies investigate medical apps for chronic conditions other than diabetes, they are relevant to include for comparative purposes as they also have to do with providing medical information and affecting health behaviours to produce more healthy choices. Similar to our findings about the perceived value of a social support function, Wu et al.,<sup>59</sup> in their qualitative interview-based study of an app for smoking cessation, found that users particularly appreciated the 'social support component of the app' (p. 7), and the authors concluded by suggesting that future apps should 'elevate the types of social support available in apps (e.g. provide a platform for users to share real-time advice and experiences with each other)' (p. 7). The participants of this interview study of the test phase of Diapplo also highlighted the impracticality of having to type in their blood glucose measures and their clear preference for these values being automatically recorded. Similar findings are also evident in the qualitative interview study by Schneider et al.<sup>60</sup> who found that young users of an asthma management app would have preferred a peak expiratory flow meter to be built into the app or if a separate peak flow meter's results could be automatically shared with the app; Peng et al.<sup>61</sup> also concluded in their focus group study of an app for type 2 diabetes that there should be 'smooth integration of health app data with other existing tools, such as glucometers' (p. 736). Thus, in terms of how Diapplo could be developed in the future, greater attention could be paid to integrating social platforms and technical functions to meet the needs and expectations of its users, also to ensure that the app did not end up falling into

disuse in the longer term.<sup>61</sup> Given that our findings are consistent with those of other studies, these points may also be relevant for medical apps for other chronic conditions.

With respect to participation, it is clear that the project on which this article was based entailed a particular framing of the diabetes app users' participation. The project's initiatives and the resultant diabetes app focused on action and impact – on what the adolescents could and should do to manage their diabetes – such as typing in blood glucose values and calories, tracking these values and having questions concerning their disease answered – rather than meeting their specific needs, as highlighted in theories of patient participation described in the Introduction. By expecting adolescents to engage in activities which they may or may not have been prepared to do, the adolescents' commitment to their healthcare was conceived in terms of modifications they were willing to undertake in their daily routines.

From a sociomaterial perspective, Diapplo did not fit well with the adolescents' lives, as it presupposed ways of interacting with the app that were not well-aligned with their needs and preferred practices. Moreover, as noted earlier, digital technologies play an increasing role in our everyday lives, including our social relationships.<sup>25</sup> When adolescents use their smartphones, it is often to communicate with friends by sharing pictures, chatting and commenting on each other's posts, pictures and videos.<sup>62</sup> Diapplo, however, needed to be used on a daily basis by adolescents individually, requiring involvement that was different from the ways in which adolescents tend to use their smartphone apps, as suggested by their request that Diapplo include a social dimension in the future. Moreover, as noted by one of the interviewees, the participation made possible by technology was problematized by the surveillance that the app facilitated. Thus, despite the best intentions on the part of the producers of Diapplo, integration of adolescents' perspectives in the development process did not result in a product that reflected their needs and wishes optimally.

As mentioned in the Introduction, Marres emphasizes the situated, contextual realities of technologies and the responsibility of all the involved actors. In terms of participating in developing the diabetes app, adolescents' perspectives were sought from the start of the development process by observing and interviewing adolescents diagnosed with diabetes, but the workshops where adolescents became fully integrated into the team first took place at approximately 8 months into the 12-month process, when all of the social actors (including the diabetes app) were already implicated in existing institutional concerns. Focusing on practices of participation is in line with Marres,<sup>42</sup>

who moves the discussion away from defining problems of participation (or lack of compliance) as stemming from individuals' 'illiteracy, indifference, short-sightedness' (p. 27). This is because, in her optic, all of those involved in the process are implicated and have a responsibility. Indeed, adolescents' perspectives were likely to have been squeezed out by the power relations that characterized the interdisciplinary environment in which the diabetes app was developed, where adolescents had the least formalized knowledge and authority, and thereby, in Lury and Marres' terminology, a lower 'valuation'.<sup>48</sup> Also, the application for funding was put together by health professionals, IT designers and researchers who invested considerable time and knowledge in the development process, giving them greater ownership of the project. We argue that the process of developing and testing the prototype of the diabetes app involved both social and material aspects and shaped the forms of participation possible.

Our article thus exemplifies a double-participatory challenge and the interrelatedness of that challenge: the difficulties of managing *participatory* processes in developing a material actor – a diabetes app – intended to promote adolescents' *participation*. Marres' deflection of users' participation to contexts and their stakeholders raises the following important question: as all social actors are implicated in facilitating participation (or not), how can *users'* perspectives be integrated so that technologies such as apps reflect *their* needs and preferences, and at the same time support vital treatment of chronic diseases? In the spirit of Lury and Marres,<sup>48</sup> we suggest that a good starting place would be an explicit re-hierarchization of valuations, so that patients' valuations are explicitly and centrally prioritized, with other perspectives and knowledge serving patients' needs. Future studies could help to indicate whether an explicit, timely and profound re-hierarchization of valuations in the development of material artefacts designed to promote participation results in these objects meeting users' needs in ways that better facilitate their participation. Thus, although Albrecht et al.,<sup>28</sup> for example, hail the potential of mHealth for transforming healthcare and underline the importance of patients demanding 'changes to processes' (p. 15) and health professionals leveraging the potential of mHealth technologies by 'adapting organizational processes' (p. 15), a sociomaterial perspective would more cautiously note that the complex ecology around the material objects in question may need reconfiguration. Marres<sup>42</sup> proposes that we could extend an affirmative approach by focusing on the 'social and political capacities of objects' (p. 10), pointing to the importance of being alert to the 'wider participatory arrangements in which a spectrum of

organizations, technologies, subjects, knowledge and things are involved and have a stake' (p. 135).

### Limitations

Potential limitations of this article are that only five adolescents participated in the interviews and the interviews did not explore how the adolescents had engaged in the developmental phase. However, they had been interviewed both during and after the test phase of the diabetes app about their experiences of using the app, so this iterative approach is likely to have improved the quality of the interview data. A different limitation may be the representativity of the participants, as the participants in this project were recruited by health professionals because they were considered to have well-regulated diabetes and to be resourceful. However, as noted earlier, indications from other studies suggest that the present findings may have more general traction. It would also have been optimal if the adolescents who took part in the evaluation of Diapplo and were between 14 and 16 years old reflected a wider age range, as Diapplo was intended for adolescents aged between 11 and 18 years old; as such, the interview data are likely to reflect the concerns of mid-teen adolescents. Another limitation of our article relates to the stage of development of the diabetes app: the diabetes app was a prototype, and as such had not undergone CE marking accreditation procedures. CE marking is a European safety marking that signifies that a product has been assessed and meets high safety, health and environmental protection requirements before it is introduced to the market.<sup>63</sup> Some of the functions were difficult to test optimally, resulting in difficult testing conditions: for example, the bolus calculation function had a pop-up warning whenever the adolescents used it. Such technical difficulties were not compatible with the time the adolescents had for testing or their patience, and the interviewees' accounts of particular weaknesses need to be seen in that light. Having said that, most apps are revised over time as a matter of course, and the focus of this article is not on the diabetes app *per se*, but on whether and how it facilitated participation from the perspective of the adolescents.

### Conclusions

In this article, we explored adolescents' views of a prototype of a diabetes app called Diapplo whose purpose was to promote their participation in managing the disease. Although all of those involved in the developmental process had the best of intentions, the diabetes app only partly met the adolescents' needs and expectations, although the adolescents saw considerable

potential for the app's further development and improvement. In this article, theories of sociomateriality and material participation served to highlight the role played by a diabetes app in affecting adolescents' participation in their healthcare, where the diabetes app also needs to be seen as a 'player', implicated in and reflecting existing professional practices, discourses and contexts of production. Besides acting as a valuable lens on the data, the theories of sociomateriality and material participation also showed their explanatory power as they could account for a number of the problems described by the adolescents with respect to their use and adoption of the diabetes app as well as indicate ways in which some problems of participation could be mitigated. More specifically, it is likely that early integration and prioritization of users' perspectives in app development processes and greater focus on the sociomaterial context of production and usage could help to generate apps that are better aligned with users' needs. Our findings underline the value of sociomaterial theories to the practical business of developing mHealth technologies, as well as the usefulness of ongoing dialogue across the disciplines in mHealth research and development.

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