

# Concealing or Revealing Mobile Medical Devices? Designing for Onstage and Offstage Presentation

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## ABSTRACT

Adults with Type 1 Diabetes have choices regarding the technology they use to self-manage their chronic condition. They can use glucose meters, insulin pumps, smartphone apps, and other technologies to support their everyday care. However, little is known about how their social lives might influence what they adopt or how they use technologies. A multi-method study was conducted to examine contextual factors that influence their technology use. While individual differences play a large role in everyday use, social factors were also found to influence use. For example, people can hide their devices in uncertain social situations or show them off to achieve a purpose. We frame these social behaviours using Goffman’s theatre metaphor of onstage and offstage behaviour, and discuss how this kind of analysis can inform the design of future mobile medical devices for self-management of chronic conditions.

## INTRODUCTION

Type 1 Diabetes (T1D) is a serious chronic condition that can involve the use of various mobile medical devices to support everyday self-care, and people’s adoption and use of diabetes technologies can differ significantly as devices become individually appropriated [36]. The range of T1D technologies includes glucose meters, continuous glucose meters, insulin pumps, and mobile phone applications. As T1D devices are mobile and need to be used in various contexts, it is important to understand how user experience might influence how devices are used in practice.

T1D is an auto-immune chronic condition that is often associated with childhood onset [27], but people of all ages can be diagnosed with it. It involves the pancreas producing insufficient quantities of insulin, a hormone required for the regulation of blood glucose (BG), but the condition can be managed [21]. For T1D, careful self-management practices

are encouraged by medical practitioners: low BG levels (hypoglycemia, or ‘hypos’) can lead to immediate health concerns, including feeling physically ill or even falling unconscious, while excess levels of BG (hyperglycemia or ‘hypers’) can eventually culminate in complications, such as eye, foot, kidney, and heart disease. Personal management practices include calculating medication doses to inject based on factors such as personal situation (e.g. digested sugars and carbohydrates, exercise, sickness, and stress), temperature/weather, their current BG level, and past experience. Balancing BG levels with ingested glucose and injected insulin can control the condition, significantly reducing the impact on a person’s life.

Most diabetes care involves some form of self-management. This means people with diabetes are “*more than passive recipients of medical expertise*” [10]. Lutfey and Wishner [22] suggest that the term ‘compliance’ should not be used in efforts to improve self-management practices. Instead, they propose using ‘adherence’, which suggests appropriate autonomy in defining and following self-management plans for diabetes. However, people’s plans are not necessarily the same as the actions they take: actions are contingent on the unfolding context [39], which is relational, dynamic, occasioned, and arising from the on-going activity [9]. This is of particular relevance when looking at the self-management plans of people with T1D, where self-management occurs on a “*daily basis within the context of the other goals, priorities, health issues, family demands, and other personal concerns that make up their lives*” [10]. Self-management practices vary [37] but there is little research on how mobile T1D technologies are chosen to be used for everyday self-management and how everyday social life might influence practice.

To address this gap, we conducted three user studies that examined how T1D devices are adopted, carried, and used. We used contextual interviews, a diary study, and observation of a T1D group meet-up. In the data analysis reported here, we used Goffman’s theatre metaphor of how people present themselves to others. This conceptual framing provides insight into the nuanced ways adults with T1D conceal or reveal the use of mobile self-management devices in social situations, which could benefit the design of future mobile self-management devices for chronic conditions.

## SOCIAL FACTORS AND SELF-MANAGEMENT

A person's sociocultural context has an impact on how they cope and prioritize care when self-managing a chronic condition [18, 19, 24, 31, 38]. It has been found that chronic conditions can lead to disruptions in relationships, and that how people adapt self-care is influenced by social factors [5]. Healthcare is personal, so privacy can be important to people with diabetes (e.g. [29]). They can perceive stigma from their communities and their workplaces [26]. Perceived stigma can also cause self-consciousness around glucose meter testing and insulin pump use [30, 33], and people often go to great lengths to hide their condition [18]. Beyond stigma, concerns about discretion around family and friends can interfere in diabetes self-care practices [26], and strangers can ask awkward questions [30].

On the other hand, showing off medical devices has become a popular trend in social media. For example, recently, a model posted bikini pictures showing the colostomy bag that she requires for self-managing Crohn's disease. These pictures were intended to spread awareness of the condition. They went viral, with over nine million people viewing them [41]. Similarly, Miss Idaho 2014 showed off her insulin pump during the bikini competition, causing #showmeyourpump to trend on Twitter leading to more people posting photos of their devices [7].

The social act of broadcasting versus hiding devices presents a dilemma for designers. Should they design future ones to be hidden from view or make them more visible, even fashionable? To help address this question we propose using Goffman's theoretical framing of the ways that people present themselves in their daily lives [13]. Goffman uses the metaphor of theatre to explain face-to-face interactions where people attempt to control the impression they give: "*Sometimes the individual will act in a thoroughly calculating manner, expressing himself in a given way solely in order to give the kind of impression to others that is likely to evoke from them a specific response he is concerned to obtain*" [13]. People perform in front of others as if they were actors, choosing the props, and costume they present *onstage* to their audience. In their *offstage* life, while still in a social context, they can set aside the performance and interact with others without performing, yet still managing the impression they give. *Backstage* is when people can put down their 'front' and be themselves, for example when they are alone. In social settings, people present themselves to others either offstage or onstage, which is the focus of this paper.

Goffman's concept of performance has been used previously in HCI to discuss 'stages' in social media [42] or collaborative tablet use [14]. In the healthcare domain, Benjamin and colleagues found that seniors with chronic pain went to great lengths to manage the impressions they gave others [2]. It was found that people participated in revealing as well as concealing their chronic pain to different audiences, depending on factors such as how

supportive the social context was. For the presentation aspect of Goffman's metaphor, the setting and the appearance of the act are influenced by the props the player is using or, in the case of diabetes, the technologies used. Although there have been attempts to mitigate the influences of social factors on self-care through educating people with T1D about potential social challenges [11], less is known about how the design of mobile medical devices might impact the presentation of self for people with T1D in the context of their everyday social lives.

## CONTEXT AND MEDICAL DEVICES

Stressing the importance of understanding context, the usability engineering standard for medical devices, including T1D technologies, provides methods, processes, and considerations that suggest observation of real world use. As "*context of use can have a significant impact on usability of the medical device user interface*" [1], practitioners are urged to understand spatial, social, technological, hygienic, physical, and activity contextual factors. Given a defined clinical workplace such as a hospital, this is difficult with regards to ethics, access, privacy, etc. [12], but for pervasive healthcare technology used beyond the walls of an institution, observation becomes notably more complex.

Studying technology use 'in the wild' is inherently difficult and there is uncertainty in the outcomes [15]. It can be challenging as "*the researcher has to make sense of data in the wild, where there are many factors and inter-dependencies at play that might be causing the observed effect*" [34]. These inter-dependencies have led to a broadening of concerns, and the incorporation of perspectives such as Technology as Experience [25], which according to Rogers [33] promotes expanding the realm of focus to not only include usability or utility, but also the felt experience of technology use as these "*interlinked facets and concerns are what most of us engage with in our everyday actions and interactions with others*" [34].

## DIABETES TECHNOLOGIES IN EVERYDAY LIFE

Isomursu, Kuutti, and Väinäm point out that "*mobile applications are designed to be used in a mobile context, so they should also be evaluated in a mobile context*" [16]. However, this can be hard to achieve with T1D technologies, so retrospective measures of experience have typically been used such as self-report and clinical outcomes, as well as contextual probes [24]. In building a mobile phone application, Owen and colleagues [30] interviewed people about their use of glucose meters focusing on their need for contextual information to interpret results, particularly during non-routine times. Also for the purpose of building technology to aid reflection on how lifestyle might impact self-care practices [23], Mamykina et al. [24] conducted interviews, attended support groups, and used cultural probes to investigate self-

management practices, highlighting how participants generate hypotheses during self-care.

Storni used an ethnomethodological approach and also attended support groups, shadowed participants, and conducted in-depth interviews to understand technology use [36, 37]. His work focused on the different ways technology is appropriated individually and how people's lay expertise informs management, ultimately arguing for an approach to design that is less technologically deterministic and focused on non-compliance, as there are large individual differences between users.

User studies conducted in the healthcare technology domain have adopted a variety of methods to understand the context of use (e.g. [35]), but there is very little research on how people use a range of mobile T1D technologies during their everyday self-management in social settings. Here we use a pragmatic multi-method situated approach in conjunction with Goffman's analytic framing to reveal the nuanced contextual factors that influence mobile device use, with a focus on how they are used in social settings during people's everyday lives.

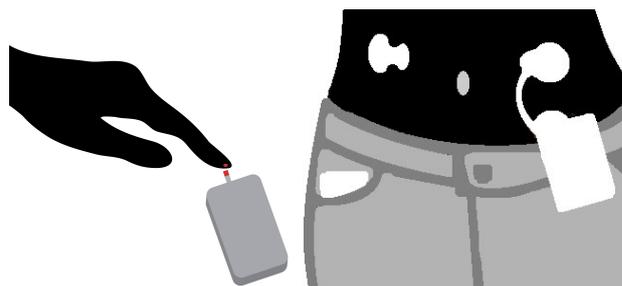
## METHODOLOGY

### Technologies Investigated

As noted above, a range of devices can be used in T1D self management care, and it is necessary to understand their use and functions, at least superficially, to 'make sense' of the studies reported here. Glucose meters (Figure 1, left) are most frequently used to measure BG levels for the everyday calculation of medication doses as well as for identifying hypos and hypers [8]. The meter is used in conjunction with a finger-pricking device so that a small droplet of blood is put on a testing strip, and the meter reports BG levels via an interface. Continuous glucose monitors (CGM) are not as commonly used, but still part of some people's everyday T1D care routines (Figure 2, right). They give a BG reading every few minutes [17]. A sensor is attached to a person's torso or arm with a small needle to test the level. This is communicated through a small wearable transmitter or cord to a receiving device with an interface showing the levels.

A self-administered shot (e.g. in the arm, abdomen, or thigh) or an insulin pump is used to inject the required amount of insulin. Insulin pumps come in various form factors, including being attached to the back of a user's arm or in a pager-sized device attached by a tube to a removable patch with a needle on the abdomen (Figure 1, right). The user adds insulin to the device and they can use an interface to control the injection.

People with diabetes can track their own health data and get suggestions for insulin doses using apps that they have downloaded on their mobile phones or other devices. There are many diabetes apps currently available (over 900 in Apple App store and 1500 in Google Play at the time of writing).



**Figure 1: A glucose meter on the left and a continuous glucose monitor with remote and an insulin pump on the right**

Although adults with Type 1 Diabetes can choose to use a variety of these mobile technologies, the majority have typically used at least one, a glucose meter, for many years. We were interested in how people carry their technologies throughout the day and the ways they use them in a variety of everyday contexts.

### Methods

A multi-method approach was used to explore the use and adoption of T1D technologies, including contextual interviews, a diary study, and observation of a T1D tech meet-up, all conducted by the first author.

Contextual Interviews (CI)	7 (5 female) in Los Angeles aged 23-53 6 (2 female) in London aged 26-65 7 (5 female) in Toronto aged 23-31
Diary Study (DS)	9 (9 female) in London aged 24-39
Tech Meet-Up (TM)	12 (10 female) in London aged 20-60
<b>TOTAL</b>	<b>41 participants aged 23-65</b>

**Table 1. Participants' location, ages, and gender**

All participants (Table 1) were over the age of 18, had been diagnosed with T1D at least six months prior to the study, were responsible for their own self-management, and used at least a glucose meter in their daily self-care. Because of difficulties with recruitment [28], a variety of recruitment methods were used: posters at grocery stores, flyers given out in pharmacies, online recruitment notices on public forums such as Reddit and Craigslist, diabetes email lists, T1D charity social media, and through snowball sampling. All participants were compensated for their time and gave informed consent as stipulated by UCL ethics clearance and human protection policies for international fieldwork research.

### Contextual Interview Study

Interviews in the context of use can give a richer account than other types of interviews [3]. We conducted our interviews with participants in a public social situation. The first author met participants (n=20) in cafes or restaurants of their choosing and discussed their use and adoption of

T1D technologies. Three different styles of interview questions were asked to probe a range of use situations (e.g., “*Are you comfortable using your glucose meter in public?*”), to challenge the participants to think creatively about their T1D technologies (e.g., “*If my glucose meter had a personality, it would be...*”), and to discuss past issues that they have had with their devices (e.g., “*Think about the last time you did not use your glucose meter even though it might have been useful. What were the general circumstances leading up to this?*”). The interviews were semi-structured and the interviewer probed any issues with adoption or use of the devices. Each interview concluded when the interviewer felt a clear picture of the participant’s everyday use of the devices had been gained. They were then asked to demonstrate their use of the glucose meter and were free to add any further thoughts in an open conversation format. All interviews lasted at least one hour and were audio recorded for transcription.

#### *Diary Study*

Diary studies are a non-invasive way of gaining information from users’ natural settings [32]. We asked participants (n=9) to capture the moment after they had used their glucose meter and a diabetes application used to track blood glucose levels [6]. An entry interview using the same interview questions as above was conducted at UCL, where the diabetes app was set up on their iPhone and an observation took place with their first use of it. The participants then made diary entries (a range of photos, wide angle lens photos, and text entries) for four weeks when they used their glucose meter. An exit interview was then held using an open conversation format where the entries were reviewed. The entry interviews were at least one hour long, there were 5-minute weekly phone check-in conversations, and the exit interviews were at least 90 minutes long; all were audio or video recorded for transcription.

#### *Observation of a Group Meet-Up*

Participant observation can capture the situated use of technologies [3]. The first author attended a diabetes tech meet-up that happens every four months in London, where people gather at a hotel restaurant to casually drink, eat, and chat about T1D technologies, which also allowed for insights from friendly group discussions. She was introduced to the group through their email list and then attended the meet-up where she introduced herself to people (n=12) arriving at different times. She wore her university ID and did not attempt to participate in the conversations, other than to answer questions about her research interests. Audio recording was determined to be inappropriate for the setting, so she took detailed handwritten notes for the duration of the meeting. These were based on the conversations between attendees and observations of their diabetes tech use as they ate and drank over the course of the evening. The meet-up lasted five hours.

#### **Data Analysis**

Thematic analysis was used to analyse what the participants said, did, and revealed in the three different studies [4] and AtlasTi was employed together with discussions among the authors about the themes. The first set of themes focused on the misuse, inappropriate use, appropriate use, and unintended use of the technology discussed by the participants. Issues included not bringing the technology with them, not adopting the technology at all, not using the technology when they should, or using it in a way that it was not designed for; instances of appropriate use were compared against those of misuse. The second phase examined what circumstances led to these instances, including looking at contradictions within an individual’s data set or inconsistencies between participants. The third phase of analysis involved identifying commonalities and contradictions across the data set. The emergent themes were each considered in relation to Goffman’s conceptual metaphor for presentation of self.

#### **FINDINGS**

As it is a condition that requires management throughout a person’s day (and particularly around mealtimes), the use of T1D devices sometimes happens in situations that involve other people. A number of specific issues with adoption of devices, carrying devices, and use of devices were identified, and these often occurred in social situations. They included encounters with family, friends, colleagues, romantic partners, people in different countries while travelling, and strangers. Everyday normal routine involved a broad range of self-care practices in front of familiar people and social situations (offstage), but non-routine times led to uncharacteristic hiding in uncertain social situations and showing off in social situations where there was something to be gained (onstage).

#### **There is a Wide Variation in “Normal Use”**

Participants showed a wide range of individual differences in how they handled their devices in their everyday offstage routines, which involve familiar public situations, routine work lives, and their personal lives.

#### *Public Use*

Some participants do not care about strangers noticing if they are using their devices or that they have T1D. Many described how they were blind to the general public (“*Honestly, honestly I don’t care. Everybody’s got something.*” – CI6). Others explained that they did not care if strangers were squeamish about blood: “*They’ve got a problem with it, they’ve got to deal with it.*” – DS6.

Many participants described how their normal routine would involve consistent use of their devices on public transport. One participant described herself as “*always late for something*” and said that she would wait until she got on public transport to use the devices as she considered it “*dead time*”, and did not bother to try to hide her glucose meter or insulin pump: “*People usually stare at me on the*

*tube if there's anyone around when I pull that out but, again, I think I'm so used to it sort of, it's like, I don't know no one's... [It doesn't matter someone will see?] Yes."* – DS8.

Other participants tended to be more private with their device use and self-care in public, often trying to conceal their devices. One participant described it as *"secrecy in a way"* and she did not want attention of strangers: *"I won't want to do anything too out in the public that might create, sort of, someone looking at me or something."* – DS2.

Another participant said that although she doesn't care if strangers know she has a medical condition, sometimes she just didn't want to risk having to bother answering any questions about it if someone noticed and was curious: *"Sometimes that's fine and sometimes I'm, like, kind of a bugger to explain, whereas if you're obviously trying to do it discreetly, they're less likely to ask a question."* – DS9.

#### **Work Life Use**

Although a few participants were currently unemployed or were students, most had full-time jobs. As going to work was part of their weekly routine, they developed habits for dealing with self-care in front of colleagues. Some people were quite protective and secretive about their diabetes when with colleagues. One participant discussed how she had to tell her boss when she started for health and safety reasons, but avoided conducting self-care activities when co-workers were around: *"There's no one that walks past me, you know. And maybe I just pick it when it's quiet. Although people over the other side of the desk won't see me."* – DS4.

Others were far more open with their self-care activities and use of their devices. One participant travelled to different construction sites as part of her job, as well as having a desk in an open office. She routinely tested herself at her desk and *"on site"* with no concerns about being seen by her co-workers: *"I would have told most people [...]. And then, because you're doing blood tests and doing injections, people will just figure it out or they'll ask you or whatever."* – DS9.

#### **Use Around Family, Friends and Partners**

Participants' everyday lives involved regular contact with family, friends, and romantic partners. This regular contact allowed for self-care regimes to become routine, but how open people were in front of close family and friends differed quite significantly.

Some people were very comfortable with their romantic partners and did not hide their self-care from their view. One participant (DS5) described an inside joke among insulin pump users that their *"partner knows when they're going to get lucky because, you know, you're snuggling in bed and then you're, like, 'let me just disconnect my pump.'"* She was very comfortable showing her devices in these intimate situations: *"We've got to disconnect the*

*insulin pump because we don't want to get the tubing wrapped up in any awkward places. And sometimes... well, not sometimes, it's, kind of, like, clockwork there will be some buzz or some vibration from the table while we're... you know."* – DS5.

CI7 was also very open with her self-care regime in front of her live-in partner so he was familiar with the devices and how she used them. She was so comfortable with him being involved in her self-care, that if she fell asleep when drunk, he would use her glucose meter to test her BG levels and then would inject her if necessary.

Some participants were very open with their use of the devices around close friends who also had T1D or who worked in diabetes care. For example, DS5 described a glucose meter drinking game they made up called *"blood glucose bingo."* CI6 described borrowing insulin saying *"he owed me one"* and DS1 described testing together as well: *"If she's testing and then I'm like, I may as well and then try and see who gets the best reading"* – DS1.

In other cases, participants concealed their routines from their friends and families, incorporating knowledge from prior experience about how people react to their self-management practices. One participant knew that her sister was quite squeamish about blood, and chose to hide her use of the glucose meter from her: *"It's a weirder, sort of, social thing to do, and then others might be a little bit squeamish, a little bit... because testing of blood in front of someone, some people... my sister, she's just like, 'ooh!'"* – DS7.

CI18 was very private about her self-management in front of her parents, who she lived with. She knew that her diagnosis from three years ago was very upsetting for her mother and that she still got upset when reminded of it, so she tended to go to her bedroom where she could keep her self-care and devices away from her mother's eyes, including before every family meal.

#### **Summary of 'Normal Use'**

The findings highlight individual differences between the participants in how they practice self-care in their day-to-day lives, leading to varied use of the mobile medical technology. People ranged from open use to slightly hidden use to going into different rooms to conceal device use. Routine social situations influenced how people use their devices, dependent on their preferences, past experiences, and the social situations they regularly encounter. Although they were accustomed to the social situations, they were still aware of the way they presented themselves to others when using their T1D devices, despite their familiarity (offstage).

#### **Uncertainty in Social Situations can Lead to Hiding**

Familiarity with a social situation enabled some participants to adopt consistent management strategies, while unfamiliar settings led to a sense of uncertainty among participants,

which influenced their use of the devices. Several participants described situations where they felt uncomfortable using their devices out in the open. For example, DS2 described the link between uncertainty and the personal aspect of the condition: *“When you take it out you feel like you’re exposing something about yourself for people to, sort of, either, sort of, judge that it’s good or bad, in a way, and then I more, sort of, fear someone’s reaction”* – DS2.

Practices of hiding the devices in times of uncertainty, such as in new romantic situations, starting a new job, and meeting unfamiliar people, are examples of Goffman’s *“protective practices”* [13].

#### *Uncertainty in Romance and Attraction*

When asked about times they may have benefited from using their devices, but chose not to, people described instances related to their romantic lives. Even chance encounters in public could lead to hiding devices: *“It sounds really silly, but if you see someone, like, attractive or on the bus or something, you don’t really want to do something potentially, like, weird, and they’d be like, “ugh””* – DS2.

The first author met CI20 in a cafe where he ordered a sandwich and proceeded to test and inject visibly in front of a busy line of people at the counter. He was very relaxed in describing his self-management habits, but looked uncomfortable when asked if there were times when he should have used his glucose meter and didn’t. He went on to describe a time he did not use his glucose meter for an entire day. He was on a first date and they spent the day at the beach. As there were no washrooms or places to hide his use of the glucose meter, he decided not to use it at all, leaving it in his backpack. He did not want his date to see his medical device kit, nor want her to know about his condition that early in their courting.

A first date can be a nerve-racking experience where you might not want to reveal everything about yourself. The beginning of a relationship is a time when people can be quite uncertain, as they do not know where the relationship will lead, and do not want to mess it up. Although one participant did not personally agree, she said many friends concealed their conditions and devices: *“I have lots of friends that go out with guys, and they don’t even tell them they’re diabetic for, like, months. I don’t even know how they hide it”* – DS1. Another participant said that she did not want to make it an issue too early: *“I try to keep it secret but not secret as in I don’t ever want them to know; it’s just whether it comes up or not because I don’t want to make it a big deal.”* – DS2.

Even when relationships are established, there can be uncertainty over time with regards to attraction. Attraction can change with life changes, including the addition of a new mobile medical device. A lot of participants avoided adopting an insulin pump, as they said they did not want to

feel physically attached to something and mentioned it looked unattractive to be physically hooked up to a device. An older married participant (TM1) initially said she was interested in getting an insulin pump, but revealed to the group at the meet-up that she was concerned that *“it is not very sexy”* to use during intimate situations and also that she was concerned about *“what it will be like to use it in the summer with tighter and more revealing clothing.”*

#### *Furthering Jobs and Careers*

Some first dates can feel like job interviews and both involve what Goffman calls *“impression management”* [13]. Uncertainty in jobs or careers was also found to influence participants in hiding their medical devices. DS8 was very open about her glucose meter use and wore an insulin pump quite openly. She was quite adamant that there were no times where she would hide or not use them. However, in one of her diary entries, there was a photo of what looked like a trade show and the first author probed further on how she used her devices at this time. She said she hid them when there were potential clients around. She went on to explain that even when in the office, if she had a face-to-face meeting with a client *“I normally schedule it around a time where I don’t necessarily have to take my blood sugar.”* This was because she felt a certain level of vulnerability with regards to her career, saying that only *“if I were very senior in my position I’d feel comfortable doing it.”*

In the case of changing jobs or trying to get a new one, there was even more uncertainty about the situation. A participant in the diary study had changed jobs recently, so was more private at work. Another participant was unemployed at the time of the study and was going for job interviews. As Goffman describes: *“the interviewee will pay much attention to his appearance and manner, not merely to create a favourable impression but also to be on the safe side and forestall any unfavourable impression that might be unwittingly conveyed”* [13]. In one case, the participant did not want to risk being seen with her medical devices, so she used her glucose meter in the building beside where her interview was to take place: *“Something like that could possibly sway them to take someone else rather than me. Because yes, as much as people say the discrimination doesn’t happen, it does happen.”* – DS2.

In other situations, the reason for participants hiding their devices was not based on conjecture, but on past experiences. A participant who was a substitute teacher described a situation where she was at a new school and went to the staff room to test and inject. The principal at the school saw her and told her that it was a health and safety concern, which she believed led to her losing that job. Even after leaving that place of employment, the experience had a lasting effect preventing her from again openly using her devices or injecting in front of people at work: *“I’m more careful about injecting when I’m in a new school, like, in the staff room and stuff. I don’t really just, like, flash all the*

syringes around. I just do it really quickly, you know.” – DS3.

#### **Unfamiliar People**

Some social situations involved uncertainty with people at arm’s length. For example, DS9 referred to a “*group of people who I know but I don’t really know*” influencing her self-care practices. Many participants discussed how they were either comfortable or uncomfortable using their devices among the public, friends, and family at meals as part of their more regular routines, but sometimes meals involved engaging with new people, such as meeting friends of friends for dinner. This kind of new encounter also influenced participants to hide their devices: “*The under the desk or under the table or whatever scenario. It’s people who I’m just acquainted with rather than friends with or don’t know at all.*” – DS9.

There were also cases where the general public became a lot more uncertain. For example, one participant used a diabetes app to track her BG levels in an area of London where she would not normally show off her iPhone (DS1). There were other unfamiliar situations people found themselves in, such as taking public transport when on holiday. One participant, who had earlier described herself as not caring about strangers, found herself hiding behind her boyfriend as she was uncertain of the social situation: “*Maybe in Morocco, I might be more particular about... I’d maybe get my boyfriend to just stand there and I’ll do this, you know.*” – DS9.

#### **Summary: Hiding Devices**

Most of the participants discussed times where they hide or might not use their medical devices even though it would be useful for them to do so. Many of these situations were linked to the nature of the social situation that they were in. Specifically, that they felt uncomfortable using the devices because of the presence of other people they were not familiar with. Such situations made them feel uncertain, leading them to actively hide their self-care and their mobile medical devices rather than show them off, not knowing what might happen. Being uncertain about their audience means they participate in “*protective practices*” [13] onstage to manage the impression that they give off.

#### **Showing Off to People can Achieve a Purpose**

There were situations described by participants where they actively showed off their devices to other people. These situations were not as common as instances where they felt they needed to hide their devices, but there were numerous instances where participants used their devices to achieve a purpose, performing onstage to a specific audience.

#### **Making it Normal**

There were several instances where participants went out of their way to show off their self-care activities in order to make it seem normal. This included trying to educate

children about T1D: “*There was another kid there, I’d kind of talk them through it. I’d say, “oh, I’m going to do a blood test. This is how I, you know, manage...” you know, to make it so I’m not sick*” – DS9.

In another case, a participant who was normally quite private with her self-care went out of her way to show a newly diagnosed child that it was normal: “*At a friend’s house today. Her 16 month olds just been diagnosed weirdly with type1 so we tested together!*” – DS2 (diary entry).

#### **Getting Perks**

There were also cases where the purpose of showing off the device was not as noble as educating people about T1D self-care practices: where the devices were shown off in order to get personal benefit. For example, during the tech meet-up, participants talked about instances akin to Goffman’s notion of “*misrepresentation*” [13].

One participant described how she used the condition, including her mobile medical devices, to get a disability pass at a large amusement park. She was even able to get her brother a caregiver pass so they could skip lines for popular rollercoasters: [*Sheepishly*] “*I get the Alton Towers Priority line. Me and my brother for years never lined up. Not even a sob story needed: given right away.*” – TM5.

This instance steered the conversation at the table towards times where they used their condition for gaining benefits in other ways. This included a participant proudly telling the table that she had been bumped up twice to first class. TM1 had “*made a fuss about it*”, including showing off her mobile medical devices to the airline staff in order to benefit from a better seat on the plane. When asked by TM6 “*word for word, what did you do?*” TM1 suggested “*lay it on thicker next time!*”

#### **Controlling a Social Situation**

There were times when a participant wanted to have more control over the social situation, and used their devices to achieve this. In these cases, their mobile medical devices became props in these outward displays. This was the case for one participant who perceived that a woman was being disdainful of her and her mother on a train. In order to elicit a reaction from the woman, the participant, who is normally quite private about her condition, actively used her glucose meter when she didn’t need to. She made sure that the woman saw what she was doing in order to ‘wind her up’: “*A snooty woman that was sitting opposite us and she didn’t like the fact that we were sitting opposite her, and so I, like, got it out of my bag, and was, like, “really, why not? Bet she’s not going to like this.”*” – DS2.

There were also situations where participants wanted to make a certain impression on new people, which sometimes involved showing devices off. TM10 was discussing that she had been Internet dating and “*tried to get out of one*”. She wanted to deter the unsuitable suitor, so she made a big

deal about her medical condition. She warned how she got crazy when hypo and tried to make her self-management activities seem overwhelming: *“It didn’t turn him off, but it didn’t turn him on!”* – TM10.

New romantic situations that were going well also meant that some of the participants were showing off their devices, however to achieve a different purpose. DS1 described first dates where she was using the glucose meter more often than usual to test a potential partner: *“I, kind of, almost do it more, [...] like, the first date; just get it out of the way, and if they can’t deal with it then too bad.”* – DS1.

#### *Summary of Showing Off for a Purpose*

There were fewer cases mentioned of onstage showing off than of onstage hiding, but some participants described times when they used their mobile medical devices as props in social situations. The reasons behind this included showing that T1D self-management is normal, getting perks because of the condition, and controlling social situations. In these cases, the medical devices weren’t being used as per adherence plans and the medical aesthetic of the device was important for the social situation. These outward displays with their devices being used as props meant that the participants were performing onstage to an audience to achieve a particular purpose, noble or otherwise.

#### **DISCUSSION**

The three studies have revealed how instrumental the social setting is in influencing how people with T1D use their mobile medical devices: feeling comfortable or uncomfortable to reveal their devices in their normal routines, hiding or retreating to private places in uncertain situations, and showing off for good effect. However, our study has also shown that use of a device is socially situated and a device that might be appropriate for someone in one situation might not be appropriate in others they encounter. A participant who is quite private and would normally hide their devices from friends and family (offstage), wanted to show off their devices in order to make it normal for a child who was just diagnosed (onstage). A person who wears their medical device visibly outside their clothing on their routine train commute (offstage), wanted to actively hide it from a potential external client (onstage). Goffman’s notion of presentation of self shows how these behaviours are not consistent across individuals: there isn’t one practice. People have multiple ‘fronts’ depending on the social situation they encounter.

So what are the implications for designers? The divergent everyday uses of mobile medical devices point to a need for both impressing and concealing designs. For adults who prefer to hide their devices during their everyday routines, a device designed to be inconspicuous would be best. For others who are more open about their everyday device use, a design should be more eye-catching. For instance, an insulin pump that can be worn outside the clothing with different covers might be appropriate for some people with

T1D who consistently use their devices in an outward way. On the other hand, an insulin pump that was designed to look like an inconspicuous mobile phone might suit those who prefer to carry their devices in a pocket and are discreet about their self-care activities. But could they be designed to accommodate both attributes? Some might want a device that looks fashionable but also one that is small and subtle for when they want to try to hide their use.

In other situations, some might want it to look clearly like a medical device so that they are treated preferentially: for example, in situations that were not everyday occurrences, such as trying to get upgraded to first class on a plane. In this case, neither a fashionable nor a subtle device would suit the person who is trying to ‘misrepresent’ their condition to get a perk, as it would benefit them most if it looked ‘medical’. But this raises ethical issues for the designer to contend with. Should they be condoning this kind of behavior, when the person does not really need to be upgraded?

Medical devices can be designed to be smaller and compact. However, this might not suit the social needs of users. Such a move to miniaturization might reduce the participant’s onstage efforts to make the condition normal for a newly diagnosed child and would make it harder to present the condition to control a social situation. Moreover, it might cause self-care to fade into the background where it becomes invisible, increasing the potential for feelings of stigmatization [18]. This might lead people to feel they need to perform self-care privately, such as not using a device all day during a first date.

There is also a push towards making devices that are embedded into existing consumer products or making medical devices look like them, such as mobile phones and smart-watches. This of course brings with it all the onstage issues of adoption, use and carrying associated with consumer devices, such as not wanting to show off expensive looking technology on holiday nor wanting to use a diabetes app on their iPhone in rough areas of London. Furthermore, neither of these trends to make devices smaller or more like mobile phones take into account the times when people are onstage showing off the device to achieve a purpose, such as preferring a medical aesthetic when trying to get a disability pass.

It is clear that a one-size-fits-all solution is not appropriate, but this idea is further complicated by the discovery that even one device does not fit all social situations. Adults with chronic conditions have a variety of values, preferences, and past experiences, as well as different health concerns. Furthermore, they vary their onstage or offstage strategy depending on the social context. The failure of a device to fit into a person’s everyday life and also non-routine occurrences means that devices may not be adopted, carried, or used for self-care in all circumstances when they might be needed. Adults choose to carry and use mobile medical devices as part of everyday self-

management. As such, they are both medical devices and consumer technology, and consumer needs have to be accommodated if they are to be adopted, carried, and used for self-management.

This has implications for the design and evaluation of current and future mobile medical devices used for self-management of chronic conditions. Like using design probes with children [40], using cognitive probes with people with T1D and T2D [24], and conducting participatory design and running a living lab with families [19, 20], *user-driven design* might provide another way forward for self-management tools. This could involve using rapid prototyping and open source hardware and software in creating bespoke mobile medical technology. Empowering people with T1D could help designers understand more how to develop devices that can serve multiple purposes in people's everyday and non-routine social lives.

## CONCLUSION

Our study has revealed how the vagaries of the real world use of T1D technologies can affect how open people feel when using them in different social situations. Using Goffman's conceptual framing, we have explored the motives people have for hiding or showing off their technologies in their everyday social lives, hiding them when they are in uncertain social situations, and how people show off technologies to achieve a purpose. We have discussed this form of adaptation in terms of its implications for designing future technologies. While customisation might seem the obvious route, it needs to be flexible enough to switch from being a prop that is shown off to being small and inconspicuous. Hence, although there are design trends towards making devices smaller or more like other consumer technology, our study has shown how changing social contexts influence the way adults choose to use and adopt mobile medical technology, both onstage and offstage, in their everyday social lives.

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