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# ConCap: Designing to Empower Individual Reflection on Chronic Conditions using Mobile Apps

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## ABSTRACT
The world is faced with a growing number of people who live with chronic medical conditions. There have been numerous digital interventions into personal management of these diseases in recent years, yet gaps remain in the HCI literature. In particular, we lack a systematic understanding of user requirements in tools that support independent management while away from external influences. This paper presents a first investigation into low-intervention support for self-management. A mobile application enabled individuals to capture contextual information related to their health in the form of photographs. Through a month-long user study, we identify four management trends amongst our participants and describe their influence on mobile application adoption.

### Author Keywords
Health care; chronic disease management; ubiquitous computing; deployment studies; diabetes

### ACM Classification Keywords
H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous

## INTRODUCTION
The HCI community is increasingly engaged with investigating requirements and designs for digital healthcare. This field can directly impact people's lives, with tangible benefits for individuals. The existing research in this domain has emerged into three broad strands, which demark different approaches to the role of digital systems in an individual's health.

The first, and perhaps predominant approach is the use of 'persuasive' or 'nudge' interactions that encourage patients to adhere to specific behaviours that contribute to good health (e.g., [2, 21]). This theme benefits from a wider contemporary interest in persuasive interaction and 'nudge' in HCI generally. There is also a clear potential benefit in helping individuals take specific actions that are likely to improve their wellbeing. However, there can be concerns that this technique necessarily imposes normalised models that may be a poor clinical match to an individual patient, and that in the long-term, maintenance of new behaviours can fail. This style of research relies on encoding guidance or advice from medical experts into tools, games or other interactive experiences that encourage adoption of the expert opinion.

A sharply different, but complementary, technique is remote monitoring. These place the clinical expert in a central role. Records of the patient's clinical readings, or their behaviour, are first gathered via sensors and telecommunication (e.g., [16]). Expert(s) then review the data, diagnose problems, respond to critical events, or provide tailored guidance. This approach brings the patient closer to clinical expertise, and enhances treatment by improved information gathering and targetted advice. There are countervailing concerns that the high level of monitoring can appear intrusive, or increase conflict between a patient and clinician, if the level of advice is found to be overly prescriptive. The scalability of the costs inherent in this approach, particularly of the availability of sufficient volumes of expertise, is also a key practical issue.

Our own research follows a third tradition, which seeks to enable individual management of a patient's condition. This potentially avoids the costly routine involvement of clinicians, but can also enable a more detailed discussion between patient and clinician when required. The sense of intrusion or compulsion in the other two routes can also be avoided. However, the technique does not directly address the issue of conformance that typically underpin the research in either persuasion or remote monitoring. This setting of health-management has been labelled as *'unanchored'* [13], as it is detached from the influences of external actors.

The smartphone has transformed the research landscape across all these approaches, reducing the need for traditional PCs. While some substantial research has been undertaken in the both persuasive and remote monitoring techniques, the third, self-management, field lags behind in terms of both research and practice in the current technological environment.

Diabetes is a chronic condition that affects millions of people worldwide. It has been estimated that in 2000, 2.8% of the world's populace were sufferers [29]. The prevalence of diabetes is expected to rise to 4.4% by 2030, due to the increasing number of older and obese individuals. This equates to the worldwide population with diabetes rising from 171 to 366 million. The increasing impact of chronic conditions such as diabetes, makes it timely to further investigate the potential for mobile devices to support their management.

This paper presents an investigation into effective design within the domain of chronic condition management in *unanchored* settings. The longitudinal deployment of *ConCap*, a mobile app, uncovers the contexts where taking photographs proved an effective tool for reflection for those with diabetes. Participants highlighted the challenges of using mobile interventions in everyday social situations, and demonstrated how mobile apps fit into existing management strategies.

## BACKGROUND

Chronic conditions are a matter rising concern for many health organisations. The World Health Organisation estimated that in 2008 these conditions accounted for 36 million deaths globally [24]. The management of chronic conditions is a major societal challenge, and HCI can make a substantial contribution. Though the field is young, there are already a number of diverging approaches to HCI in the domain.

The *'Patient Empowerment'* [8] movement has seen practitioners attempt to move patients from being 'passive recipients of services' to 'being active and self-determining parts of their healthcare' [23]. The aim is to ensure that patients are more prominently involved in their own treatment, from decision-making to an increased role in daily maintenance.

Patients with chronic conditions are no longer simply given regimes they must follow to manage their condition. Instead, clinicians aim to provide individuals with problem-solving skills that relate specifically to their circumstances [3]. By enabling patients to solve problems that they encounter, they can take more complete control of their condition and become a key decision-maker in their treatment. Patient input into their own medical records is also being explored [28].

Patients who have been managing chronic conditions are likely to have formed their own routines and habits as part of their management [20]. These habits then provide individuals with reassurance and predictability, while also potentially allowing for tight control over their condition. However disrupting good routines by introducing technology may cause a lack of uptake in their usage due to a break in routine. Adding in a large scale tertiary device seems inappropriate and perhaps, interventions must be made on a smaller scale.

### Chronic Condition Management

Researchers in mobile interaction have already investigated the specific needs of patients with diabetes. The key research is from Mamykina et al. [17]. Their initial research focussed on enabling those with diabetes reflect on their condition,. In later work, they [16] used a mobile intervention to allow for people with diabetes to gather data about their condition for the purpose of feedback from peers and clinicians.

Their system, MAHI, captured data on mobile phones, leading to, separate management tasks using desktop PCs. It was well received in use, and the recorded information was in keeping with the participants' existing monitoring. The underlying interest in patients' management of their conditions presents the closest existing research to our own. However, we aim to understand how modern mobile technology can support self-reflection in the management of diabetes, independently of the desktop. MAHI predated the smartphone, and used a limited range of mobile interaction. There is a vast scope for more sophisticated and usable interventions.

One specific approach that has been attempted to capture rich information in a lightweight form was to use photo imagery alongside glucose reading results. Mamykina et al introduced the use of photographs, which they only reported in summary form (e.g. the number of pictures taken). Smith and Frost [26] took a more specific approach, associating images of food with glucose levels. They visualised a timeline of images and glucose results, which had been colour-coded based on their likely contribution to health. However, Smith et al used desktop PCs, and we [20] have demonstrated that this can lead to low levels of capture and reflection. The use of photographs for reflection is thus ripe for further investigation, to identify if 'casual' photography can genuinely help those with a chronic condition understand and manage their disease.

It has been noted that clinical success should not be the only measure of an appropriate personal healthcare intervention [1]. The considerations of how technology may impact on a persons everyday life are also critical. Previous HCI work has adopted this stance, to allow individuals to share experiences that are richer than bare health data. Personal reflections have been added to medical data capture [10, 18]. Wagner et al. [27] suggest that the management of chronic conditions is multi faceted: made up of a variety of stakeholders who assist in an individuals' own personal management. By providing the capability to capture wider forms of information, a more complete picture of an individuals' current state of management can be determined by the stakeholders.

Previous work has sought to enhance the ability of individuals to collate health information for dissemination to various external stakeholders. We believe there is currently an opportunity to provide further support when individuals are away from external sources, or perhaps do not wish to share particular parts of their recorded data. It is in this space where we position our research, while additionally considering how to provide a platform for sustained engagement from users.

### Personal Health Informatics

The gathering and reflection on information to control a chronic condition can also be understood as a form of personal informatics. When studying those gathering "quantified self" data, Choe et al report that 35% of their respondents gathered data about their health [6]. While we do not know how many of their respondents had a chronic condition, that work clearly demonstrates the frequency of the gathering of health data generally. Li et al [14] introduce a model that divides this process into different stages, from preparation to reflection. One issue with this model from the perspective of chronic management is that, in contrast to Mamykina's [17] and our [20] models, it focuses on data gathering, and plays less attention to reflection: which is addressed in one, rather than several steps, of the process.

The use of photographs as a specific form of capturing data about food is also established. Beside's Mamykina's work, Cordiero et al [7] have recently focussed on the topic of photo-journaling food as a general phenomenon, often tied to attempts to measure healthy eating or general wellbeing. However, as we noted previously [20]. and indeed Cordeiro reiterates, this is an unreliable method for gathering diagnostic and specific data such as calorie intake. Those focussing on diabetes research have progressed to analysing not only energy intake, but also energy consumption (e.g. exercise), personal context (e.g. stress, illness) and environmental issues (e.g. weather, stress at work).

## MOTIVATION

People with diabetes need to carefully control the level of glucose in their blood. Patients use one or more glucose-meters to identify their current glucose level. Based on this information, adjustments to diet or exercise can ensure that the reading remains in, or returns to, the ideal range. Effective management includes the prediction of future changes, in light of anticipated eating and exercise. Patients must therefore analyse multiple, conflicting factors, to predict the response of their glucose levels in different contexts.

Our research builds on earlier studies of the monitoring needs of people with diabetes. Previous work has been based on pre-conceived regimens of ideal monitoriing practices. In contrast, we wanted to undertake the first study that elicits what self-directed behaviours emerge when users work "unanchored", independent of clinical or peer oversight. As we shall see, there are a number of different strategies, from strict regimens to more flexible, responsive plans.

To represent how a mobile application for diabetes may be used in daily life, we developed a potential usage scenario based on prior research [17, 16, 20]. The usage scenario was used to guide the design of the ConCap application.

> Lucy has had type 1 diabetes for 15 years and typically checks her glucose value four times a day. She has recently decided to start attending the gym, in an effort to improve her fitness. Unsure of how the increased level of exercise will impact on her need for insulin, she begins to keep a record of her glucose scores and location on her mobile phone. Using this data, she can correlate the occasions that she was at the gym and how much it affects her glucose scores. She can then make more accurate future decisions about how much insulin is required on days she attends the gym.

While the scenario suggests how applications may be used in a real world setting, the expected outcomes are not comprehensive. There are likely to be many individual approaches to personal condition management. Therefore, accurately predicting how the application may be used is perhaps unfeasible. Yet, the scenarios provide a crucial link back to the research conducted previously. The design of the application relied heavily on both the previous literature in the area and the data gathered from the previous research [17, 20].

We undertook a longitudinal study to obtain concrete data on the use of ConCap in real-world settings. Data on long-term use of management tools is still sparse, and it is unclear how an tool such as ConCap will be accepted into the daily habits of people with diabetes. The study will reveal if apps like ConCap can assist people with diabetes manage their condition. Furthermore, unanchored strategies are undocumented: how tools for independent management are accepted and used is not known. Finally, a mobile, unanchored system may reveal previously unknown behaviours.

Previous work on supporting individual well-being has largely focused on systems that require external interventions from clinicians or family members. In contrast, we know little of how mobile applications can support self-management of personal health information. It is clear that people with diabetes often have to deal with challenging situations outside of clinical appointments. In these cases, termed "unanchored" settings, individuals have to calculate their own treatment decisions based on current, and past information.

The motivation behind our research therefore, is twofold. Firstly, the primary aim of the research is to approach an understanding of how mobile interventions can support management of health information. Secondly, the study sets out to contribute additional knowledge to the domain of mobile well-being support without external intervention.

## SYSTEM DESIGN

ConCap is a mobile app that allows a user to enter glucose scores and insulin units, and present the information as a graph. ConCap also allows photographs to be taken using a phone's built-in camera, and gather location information which is presented as a map snapshot. Rich media such as images and location have been shown to be help users in previous self-reflection systems [9, 22]. However, most systems were not focused on chronic disease management.

Within the domain of managing chronic conditions, systems that support images have required desktop PCs [26, 15]. Images were therefore captured on cameras and phones before being collated on a central device. ConCap allows users to take photos using their mobile phone's camera. Even so, including images in diabetes management tools has been been positively received by users [26]. ConCap allows the images captured by users to be automatically stored and displayed alongside the health data entered on one mobile device.

As well as including imagery data, ConCap can also capture a user's location at regular intervals during the day. Location data has been seen as a useful tool in pervasive health applications [12]. In principle, users can trackl thir location across a period of time, which in turn may allow them to recall what activities were performed: e.g. if an application indicates that a user had been close to a gym address, the user may then be able to recall that they had performed an hour of exercise.

The ConCap application was not designed to replace participants' existing management patterns, or to provide clinical assistance. Instead, ConCap acts as a platform to capture daily activities and to display information relevant to diabetes management. The aim of ConCap was to assist in trend-spotting, and understanding of causes of glucose scores by capturing daily activities through imagery data, and act as a supplementary glucose reading logging tool.

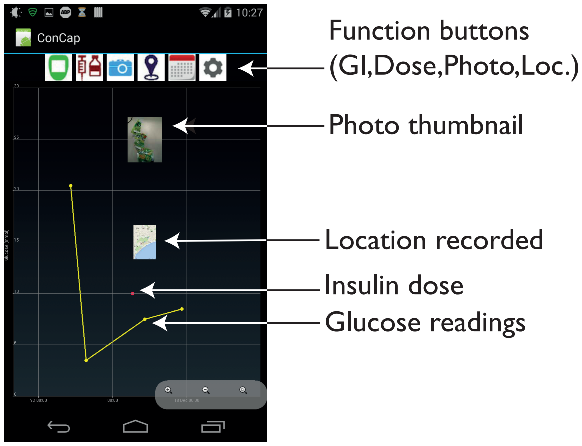



**Figure 1. Screenshot ConCap app. The home screen of the app displays input information on a timeline. Icons at the top provide navigation to functions such as input of information and settings.**

The main screen of the application is shown in Figure 1: the displayed graph makes use of the achartengine [1] open source graphing library for Android. The thumbnail images can be made full screen by pressing on thumbnail itself.

## DEPLOYMENT STUDY

The aim of our research is to discover the user behaviours and needs with mobile self-management tools. While studies of persuasive and remote monitoring systems have increasingly captured user behaviour over several weeks, there is a lack of comparable data for self-management tools.

As we were primarily concerned with longer-term use, we followed the diary study approach reported by Carter and Mankoff [5] to achieve extended, indirect, observation of natural behaviour. The lack of existing software in common use led us to provide a platform for participants to capture their own experiences in managing their condition. We used three sources of data – interviews, application logs and images – to allow for contextualisation of data in our analysis [25].

### Study Methodology

To understand the impact of ConCap on how users managed their diabetes, a four-week user study was conducted.

#### *Procedure*

Participants were recruited through an email call to local Diabetes Support groups and sessions were organised either through similar correspondence, or through telephone conversations. As incentive for taking part in the study, participants were offered a sum of £114 for completion of the whole 4 weeks. This was broken down into two £7 payments for completing the interview sessions, and four payments of £25 for each week of using the ConCap application.

Participants were asked to use the application to both enter data (such as glucose scores and taking pictures) and reflect on the data presented back to them (e.g. location and images). Data collection across the in-situ study was obtained from a database that stored values throughout the application. This database, along with images captured, was retrieved at the end of the study. This data makes it possible to assess what factors participants considered to be important to the management of their condition. Participant consent was sought before accessing images taken using the application. To protect anonymity, the names that appear below have been changed.

Smartphones, while common, are not used by everyone. To avoid learning effects and general unfamiliarity with devices, only experienced users of mobile phones were recruited. Although these technologies afford individuals an opportunity to increase their health literacy, a minimum level of proficiency is necessary before users can effectively use the system resources to manage their illness [11].

To ensure participants remained engaged across the study, regular contact 'checkpoints' were used. In addition to entry (start of week 1) and exit interviews (end of week 4), contact was made with participants at the end of weeks 1 to 3. The weekly contact involved short telephone conversations, arranged at a time convenient to the participant and in all except one case, exactly seven days after the previous contact.

Throughout the course of the study, participants were informed that any subject they are not comfortable with discussing would be omitted from the study, and that they was no expectation to discuss embarrassing topics. We explained that the study was not an evaluation on their ability or knowledge, instead it was an evaluation of the impact the application may have on the management of their condition.

At the exit interview, we elicited the participants' general usage of ConCap and the photos they took during the study. Throughout the interviews, note-taking and audio recording were used to capture data. Permission was requested for audio recording for the purpose of later analysis.

#### *Participants*

A total of 12 participants were recruited for the study, all of whom had had type 1 diabetes for a period of 2 years or longer. Type 1 diabetes is a condition where a person's pancreas does not produce insulin, meaning there is no means to break down the glucose in the body.

There were 7 female and 5 male participants, whose ages ranged from 21 - 56 (average age of 32.25). They had lived with diabetes for a total of 201 years (mean=18.27, sd = 10.4). All of the participants were regular users of glucose monitoring devices, and had regularly used Android for at least one year, with current access to an Android phone. A summary of the participants, is presented in Table 1.

#### *Analysis*

The interview sessions formed the primary area of analysis, with each serving different purposes. The entry session elicited each individual's existing attitudes and management practices of diabetes. The exit interview sessions were used to query participants regarding their usage of the ConCap application during the four-week long study period.

Notes were taken throughout each interview, capturing important pieces of information, and recording key moments to

[1] achartengine available at `http://www.achartengine.org/`

| | Sex | Age | Time with Diabetes | Insulin Pump | Records |
|---|---|---|---|---|---|
| ***Joe*** | M | 37 | 20 yrs | Yes | No |
| ***Naira*** | F | 28 | 27 yrs | No | No |
| ***Sarah*** | F | 44 | 18 yrs | No | No |
| ***Paul*** | M | 37 | 7 yrs | No | Yes |
| ***John*** | M | 34 | 21 yrs | Yes | Yes |
| ***Hayley*** | F | 27 | 12 yrs | No | No |
| ***Matt*** | M | 56 | 44 yrs | No | Yes |
| ***Ruth*** | F | 25 | 22 yrs | Yes | No |
| ***Julie*** | F | 23 | 13 yrs | No | No |
| ***Holly*** | F | 21 | 7 yrs | No | No |
| ***Lauren*** | F | 28 | 15 yrs | No | No |
| ***Mark*** | M | 27 | 17 yrs | No | No |

**Table 1. Details of participants at the start of the study period.**

| | Glucose | Insulin | Camera | Location |
|---|---|---|---|---|
| ***Joe*** | 57 | 57 | 0 | 6 |
| ***Naira*** | 118 | 48 | 3 | 2 |
| ***Sarah*** | 141 | 134 | 12 | 33 |
| ***Paul*** | 38 | 41 | 20 | 35 |
| ***John*** | 49 | 14 | 9 | 9 |
| ***Hayley*** | 264 | 20 | 1 | 5 |
| ***Matt*** | 116 | 103 | 10 | 4 |
| ***Ruth*** | 41 | 34 | 32 | 28 |
| ***Julie*** | 13 | 11 | 0 | 0 |
| ***Holly*** | 72 | 82 | 8 | 7 |
| ***Lauren*** | 62 | 45 | 10 | 10 |
| ***Mark*** | 40 | 6 | 1 | 5 |

**Table 2. Entries into the ConCap application during the study period.**

return to with the audio recording. Upon completion of the study, the first step in processing the data was to return to the notes to gain a brief understanding of how each participant used the ConCap application. The audio recordings of the interview sessions were reviewed to gain further insights, and double-check of the accuracy of the notes. Exact quotations were also transcribed from the relevant audio recordings.

ConCap also logged a variety of information during the study, allowing verification of participant's reports. The application recorded all of the glucose and insulin information entered, the images taken, and locations noted. From this captured data, participants' daily interactions with the application were determined. The application also logged instances when participants opened the application without entering any data. This provided a database with a set of log data which enabled triangulation with reported incidents and behaviours discussed by participants in the interview sessions.

## RESULTS

Over the four-week study, participants entered a significant amount of data: 1011 glucose and 595 insulin enteries, 106 photos taken and 144 locations tagged. The daily averages were: glucose 36.61, insulin 21.25, images 3.79 and 5.14 locations. Unfortunately, data from Holly was partially lost from their ConCap database: we presented here the remaining information from her device, plus her interview responses.

### Participant Contexts

Based on the information gathered in the entry and exit interviews, the participants were categorised into groups based on the current state of their health information management. Two main alternatives were 'Standard' conditions, where the participant's condition and practices were stable, versus, 'Change' conditions where the overall pattern was in the process of adjustment. This further broke down into standard (rigid), standard (fluctuating), change (voluntary) and change (forced), which we will now describe in further detail:

***Standard - Rigid*** - Participants within this pool were determined to be at a phase of their management in which their condition was largely stable, due to their own strict control of factors. These factors include typically; the choice of food, times of meals and portion sizes. The participants assigned to this category were *Joe* and *Ruth*, who both described extremely tight glucose control through their planning and monitoring of a variety of activities.

***Standard - Fluctuating*** - Individuals in this class are satisfied with their health status, yet experience moments of uncertainty in areas such a special events that disrupt the norm. The participants in this category were *Sarah, Paul, John, Matt, Holly* and *Mark*. Those in this category all expressed being largely happy with their control, but still experienced some areas of concern, such as Paul who had noticed an increase in his glucose levels and was determining what action to take.

***Change - Voluntary*** - Those who are going through a change in either their condition or management through a choice that they have made. The participants in this category were *Naira, Hayley and Lauren*. Hayley, for example, had recently made the decision to try for a baby which required her to increase the level of control she had previously been performing.

***Change - Forced*** - Those who are experiencing change which is out of their control, such as Julie who had to change treatment halfway through study and moved onto an insulin pump. Change was known before entry into study and likely explained low number of interactions early on, before a change in medication was required by their clinicians. The only participant included in this category is *Julie*, due to her change of treatment plan during the study.

These groups had distinct approaches to using ConCap, and they will be referred to throughout the rest of this paper.

### Images Captured

Participants used the camera feature on the application to depict several different situations. Understanding the types of images taken will help reveal the scenarios where images are most helpful in the context of chronic disease management.

All of the images from participants' devices were collected and individually coded for what it depicted (e.g., a plate of food as seen in Figure 4 was labelled as 'food and drink'). Four primary categories of images emerged: food and drink, location, scene and physical artefact.

***Food and Drink*** - Based on previous research [26] participants were informed at the start of the study that images of food may be helpful. All of the participants recruited for the study took at least one picture that fits into this category.

***Location*** - Rather than use the location maps offered on the application, several participants took pictures of their surroundings to represent where they had been during a day. This was the most prominent method of capturing location, potentially due to participants' ability to contextualise a picture in a much more meaningful way than simply a map.

***Scene*** - Scenes were specific events that happened during the study that didn't simply match the location category. Lauren's barbecue picture (Figure 3a), was not just about place, and similarly, Ruth took pictures of her bedsheets in the morning. This was so she knew that her tests had been taken at home, and the photo represented the time the tests were taken (i.e., on waking or before breakfast).

***Physical Artifact*** - Participants also took pictures of objects that they felt were relevant to their condition. For example, Figure 2b displays a match ticket, representing a entire day of activity. Similarly, Paul captured his own monitor screen whilst he was having a hypoglycaemic episode.

### Changes in Management

By using the ConCap application, two participants were able to make notable differences to their management. Matt stated that his average glucose level had dropped half a point during the month. Holly noticed a trend in her daily glucose levels that had previously gone unnoticed. When designing the application, tangible impact on participants' health had not been considered achievable. Yet, our low impact intervention appears to have increased the ability of participants to manage and interpret their information in a meaningful way.

### Frequency of Use

The approach taken to entering information into the application was varied across all of the participants, with the two primary methods of entering information being: at the time of a reading, and bulk inputs at set periods of time.

For eight participants, their use of ConCap was sustained across the four weeks, with no notable or statistically significant changes occurring. In contrast, four participants described how their interactions with the application had decreased over the study period. The reasons given for the decrease appear to correlate with the current behaviours of the participants reported in their entry interview.

The "standard-rigid" group all showed declining use. Ruth was one example, stating in her exit intervew that she rarely recorded her glucose results, and that the novelty of using the application had worn off during the study period. However, this should not be a surprise, as those with highly structured and predictable routines are unlikely to benefit strongly from self-reflection. Even for those with rising use, integration could be a problem were routines were highly developed.

John, in the "standard fluctuating" group, had only 13 uses in the first week, but rose to 42 in the final week. His logging of glucose increased across the study, while his use of location and photographs remained consistent throughout. He reflected that he had used paper records for over 13 years, and altering that habit over 4 weeks was a challenge.

Those in the standard fluctuating or change groups used Concap more. When in intensive stages of monitoring, or engaging in *'unusual'* activities, more data was captured: e.g. Naira and Lauren (Change, voluntary), Matt and Sarah (standard, fluctuating) each showed rising use in these contexts.

### Occasions of Use

There were two recurring patterns that related to the moment of ConCap's use. The first was almost universal, whereas the second occurred most frequently in the change groups.

Almost every participant said that they were more likely to use the photograph and location functions during times that they were engaging in activities that were beyond their usual routine. These events often occurred at weekends. Activities such as eating out, alcohol consumption and increased physical activities triggered greater use of the application.

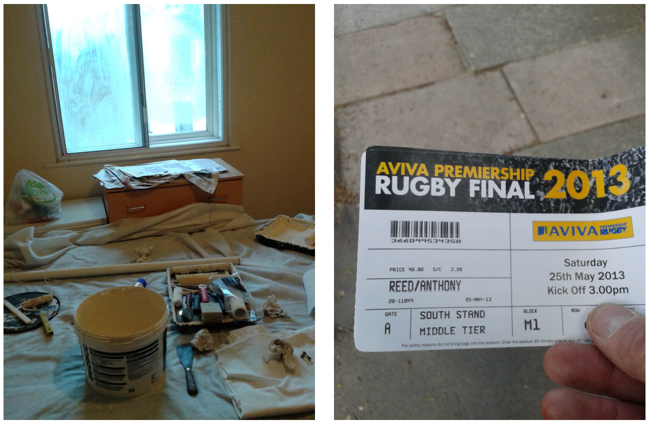
More routine events were also captured, particularly when control was a concern. During the initial interview, Lauren highlighted a recurring problem with minor daily hypoglycaemic episodes at mid-morning. The intermittent nature of the episodes made arriving at a correct insulin dose each day difficult. She speculated that her daily commute into her workplace was a key factor. Her work was in two different sites which she alternated between on different days. One office required her to walk to the workplace, and Lauren felt that might be contributing to her recurrent problems in the mornings. To capture these instances during the study, Lauren took pictures of pavements. These images represented the days on which she walked into work, allowing her to confirm the correlation between days she had walked to work and days in which she had low blood sugars.

## EMERGING THEMES

Through our analysis of the ConCap data and feedback received from our participants, similarities emerged between individuals. This section describes the key themes that arose.

### Exceptions

All but two participants captured events that broke their regular routine. Capturing unusual events was seen as important in pre-empting potential unusual readings later in the day. Lauren photographed a barbecue (Figure 3a). It first appeared that this image had been taken to show that Lauren was eating food that was atypical, and might need to be considered in later reflection. However in interview she explained that the image was taken to show the *irregular* manner in which she had eaten. Food at barbecues typically comes in small, infrequent batches. Lauren was capturing her eating in bursts, with gaps of 15-30 minutes, rather than a larger amount within




(a) (b)

**Figure 2. (a) Matt's image of home decorating equipment, representing increased physical activity (b) Matt took a picture of a Rugby match ticket, capturing a day of increased walking, alcohol and fast food.**

(a) (b)

**Figure 3. (a) Lauren captured an image at a barbecue to represent the small, irregular intakes of food likely to complicate insulin dosing. (b) Lauren usually took public transport to work, but sometimes walked. To illustrate these days, she took pictures of street pavements.**

a condensed period of time. This pattern makes calculating insulin injections challenging, and Lauren had marked this event to help her understand her glucose trend that day.

### Habits and Routines

As seen in previous literature ([17, 20]), those engaging in diabetes self-management are likely to form methods to control their condition, which they implement recurrently. This was seen in the two "standard" groups, for whom a new intervention interrupted their routine, and consequently part of these groups struggled to integrate ConCap into their management.

> Paul: *"I didn't use it that often, but occasionally when something interesting happened I took a photo."*

> John: *"I think it takes a bit more time for something like this to become part of a routine, I have been using paper and an insulin pump since 2001."*

Conversely, Lauren was tring to get into a habit of walking, and so was altering her routine. This increased physical activity was not yet routine, and Lauren was experiencing great variation in her glucose readings. As noted above, to help her analysis, she tagged the occasions she walked to work by taking pictures of the pavement on her route. This allowed her to correlate between her walking and glucose levels, and in turn adjust her insulin dosing. It appears then, that during moments of change ConCap was able to assist in the understanding of the impact new factors were likely to have.

### Reflection

Support for reflection was a common requirement we encountered in our earlier research on diabetes self-management. Two thirds of the participants, none of whom were in the Standard/Stable condition, reported that ConCap was helpful in acquiring some understanding of their condition. The underlying reflection was helped in several different ways:

> Sarah: *"Sometimes when things are going well, you don't really realise it. When you see it on the graph, you are kind of pleased with yourself."*

Sarah was the only participant who stated that the graph provided her with a sense of satisfaction in her diabetes control. But, the graph also highlighted points where her glucose scores were not so well controlled.

In order to distinguish glucose readings taken before and after breakfast, Ruth took several images which represented Scenes. She typically captured images of bedsheets illustrated where she was at the time of taking a reading. Therefore, the bedsheets were designed to show that she was still in bed in the morning and had not yet got out of bed to have breakfast. The image had now added an extra layer of context to the morning glucose results, and allowed to quickly distinguish results for the purpose of later understanding.

Ruth typically used the location and the photographs at the same time, but felt that the location information provided little insight. Ruth attributed this to the fact that that she was usually at her desk or at home, and as such location information didn't offer any additional insight.

> *"I generally took pictures of what I ate, or where I was so I could look back and remind myself where I was when I took a reading."*

Ruth thus appears to have used the application to capture settings where she had taken a glucose reading, rather than capturing daily activities when they happened.

Holly highlighted that she took pictures if she went out for dinner, or a coffee. These events are outside her routine, and typically occurred at weekends, leading to more photography:

> *"If I can see a picture of what I have eaten it gives me a better idea of what my blood sugars are doing and why."*

> *"I had a couple of hypos and I looked back at the photographs and saw that I had a coffee and a muffin and had really overestimated the insulin."*

By using the photographs in this manner, Holly was able to determine that she had incorrectly calculated a dosage of insulin. During the exit interview, Holly highlighted this issue with little prompting, suggesting that by viewing the glucose and insulin values alongside an image of the food, she had a distinct memory of the event. It is possible then, that ConCap can facilitate reflective learning around specific events.

### Environmental Factors in Capture

During entry interviews, the performing medical tasks in a public setting was highlighted as a concern. The process of piercing skin for a glucose reading, or carrying out injections for insulin, were described as socially awkward. Participants expressed similar, if lesser, concerns with mobile phones. Mark described not making use of the photo feature while using the bathroom (which he used for glucose tests to prevent people seeing, as per O'Kane [19]), who dubs this problem *Unexpected Social Situations*. Sarah also commented on the challenge of ensuring data entry during social situations:

> *"I entered results every time, except when it was rude to get my phone out then I would retrospectively add them."*

## DISCUSSION

The entry interviews confirmed that few participants regularly logged their health information (3 of 14). Those who regularly logged were the also most frequent users of ConCap.

Previous research has shown the value of "anchored" management, supported by analysis from experts [16, 26]. Continuous use was associated with superior management, and seen as a positive sign of acceptance. However, our study shows that when the focus is shifted from anchored, monitored, compliance, this pattern of behaviour is displaced.

Nearly half of the participants felt that they would struggle to use ConCap concurrently over a substantial period of time (2 rarely, 4 periodically). They were content in their current management and knowledge, and found a personal balance between rigorous inspection of results and 'getting on with life'. These respondents were in our "standard" groups, with either rigid regimes or limited fluctuation.

In contrast, those facing change or high fluctuation within a standard control, found great benefit in ConCap. Matt, who had an established regime, but higher fluctuations, credited a fall in his weekly averages – by 0.5mmol/L – to new insights found through ConCap. Matt's use of the imagery feature in the application was perhaps also the most interesting with his ability to capture complex events in a single picture.

Our distinction between current health contexts proved critical in understanding the relative utility both of ConCap as a whole, and individual features. Neither MAHI [16], nor Vera [2] report such distinctions. Each user's current health context drove their adoption or disinterest in ConCap, and it appears both plausible and likely that rising concern leads to higher use for monitoring interventions more generally.

### Capture and Access

Participants are engaging in capture, following the criteria laid out by Brown et al. [4]; to archive, to collect and collate, to read and reflect, to re-use and share. Each of these criteria were observable in our participants' interactions with ConCap. While it was intended that the application was purely for self-management, Naira reported using the data gathered with her clinician during subsequent appointments. Naira also highlighted a point where ConCap gave her new insight:

**Figure 4. Naira captured an image of a Thai takeaway. The image assisted in the understanding of the impact the type of food had on blood glucose levels and insulin requirements.**

> *"For instance, one time I had Thai and took too much insulin. The next time I had Thai I knew to take less. I've got it now, I have sussed it out."*

The participants thus used the information ConCap collected for various reasons and in different ways. Our adoption of a lightweight tool for information gathering appears to have facilitated greater capture in those in both Standard/Fluctuating and Change/Voluntary stages. Those who in the other two categories felt that even a low-impact intervention was an unnecessary additional level of management.

### Illustrating Points of Interest

The MAHI study [16] provided only a limited overview of the use of photographs. Vera [2] investigated the social interactions that arose as a result of sharing photographs with others. Neither investigated individual use of photographs, and neither assessed the content of the photographs.

The primary aim of the inclusion of location and camera images in the application was to provide participants with a quick method of capturing a moment they felt was relevant to their condition. Location information illustrated a trace of where people had been throughout the day, and images visually displayed events that a participant had engaged in.

While the camera and location use were similar, The camera received more praise in the exit interviews. Inherent limitations in GPS positioning may have been a factor, but the ability for participants to capture what they felt was relevant, in a fashion they understood, appeared to be a bigger influence. Location data was relatively limited, but pictures could capture both simple and complex situations. Matt highlighted that a day of home improvement is not easily translated into corresponding adjustment to medication. His picture of DIY tools (Fig. 2a) created a record of a day's activities as a point of reference, which could later explain an unusual set of glucose results, or act as a guide for similar instances.

The photo and location data captured two distinct types of setting. Participants like Ruth and Mark only took pictures when they performed a glucose test, contextualising a reading. However, other participants such as Lauren and Matt captured activities as they happened, without measuring their GI. Those who had captured images at a reading were able to infer why they took the reading and then recall their previous activity. However, those actively capturing these activities when they happened had a immediate depiction of the events. This distinction in timing and utility has not been previously reported, and may confuse social commenting (c.f. [2]).

Participants suggested that this "photo-memo"ing is a potential likely scenario over a longer period of time. They speculated that had there been more situations that were out of the ordinary, imagery data may have assisted in diagnosing the cause of unexplained glucose events.

The study of ConCap has thus shown that mobiles can capture images either during an activity or at a later reading, that users can utilise photographs in four powerful, varied ways to capture relevant information, and that these images have the power to provide insights via autonomous reflection.

### Key Design Considerations

The ubiquity of smartphones render them more discreet than traditional 'medical' devices, which as O'Kane notes, socially expose their users. The unremarkable form of a phone and its frequent presence make it a potentially powerful tool. ConCap exploits methods of capture that require limited attention and input from a user at the moment of use. This enabled its users to achieve their key short-term objective of collecting contextual information, with limited disruption to their current primary task (e.g., socialising at a BBQ).

Those with chronic conditions feel that managing their health already consumes too much time. Good tools should be quick and discreet: it is vital to provide lightweight tools that capture of information quickly. Focussing on short-term, app-style functions made ConCap easier to adopt. Given the difficulties in changing routine that even our ten positive users reported, the cost of adopting a new device needs to be extremely low. Lowering such barriers by simple, almost simplistic interaction, makes users more likely to engage in recording of health information.

In longer term use, the current hope of achieving sustained high levels of self-monitoring [17] seems misplaced. Our standard, fixed users had rigid regimes that enabled lower monitoring, and even those experiencing fluctuations reported regular periods of similar behaviour. Change, expected or unexpected, led to heightened monitoring, and increased reflection, to determine underlying causes and processes. This cycle of rising and falling use is, for 10 of our 12 participants, central to their experience and need, and every one described instances where their monitoring had fallen. It would thus be unwise for apps to demand regular and frequent interaction. Systems which intrude and demand attention at periods where management is perceived by the patient as good are likely to be met with hostility. Ideally a system should sense when to provide support, and when not to. Intermittent use, driven by external triggers, is also weakly supported in the context of PIM, which emphasises linear processes [14]. This is therefore a key issue for future research.

## CONCLUSION

Through our low-impact intervention, it became clear that there are several contextual factors that affect the management of chronic conditions. For those facing voluntary change, or strong fluctuations, there was a higher level of reflection, and a raised frequency of monitoring. Conversely, when health was stable and variation low, particularly when supported by a fixed regime of diet and exercise, monitoring continued at a regular rate and reflection was infrequent.

Adopting an unfamiliar technology was most difficult when routines were highly structured, and long-established. Nonetheless, the inherent cost of adapting to a new technology proved valuable to ten of our twelve participants. While location sensing provided some utility, it proved subjectively less useful than mobile photography, despite an almost identical level of use. Even Ruth, one of the four more skeptical users, found value in individual images. Photographs were used in four different ways, and capture was seldom literal. Images that resulted in insights and understanding often had meanings that were clear to the participant, but opaque to the outside observer. The connection between established tools – insulin doses and glucose readings – and the lightweight capture proved particularly valuable to those with a heightened concern in their condition, be it recent fluctuations or chosen life-changes such as raised exercise or pregnancy.

Mobile technology has great potential in managing of chronic conditions. The immediate availability of everyday devices such as mobile phones makes them a suitable platform for logging of personal health information. We have demonstrated that mobile lightweight tools can assist individual reflection, without close monitoring by health experts. With the rising tide of chronic disease, and increasing costs of specialist medical advice, unanchored mobile tools could make a powerful contribution to world health.

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