Research report for DREAMS study

Research questions

The DREAMS study ran from January 2012 to December 2014. The main focus was the organisational feasibility of remote ('Skype') consultations and the acceptability of this service model to clinicians and patients in the Diabetes service at Newham.

The research component aimed to answer the following questions:

1. How does the introduction of remote consultations alter patterns of service use?
2. What is the experience of remote consultations from the perspective of patients, clinicians and administrative staff?
3. What advantages and disadvantages do people perceive in this new service model – and why do some people *not* want to consult remotely?
4. What are the cultural and logistical challenges of introducing remote consultations in a busy hospital diabetes clinic?

Methods

Management and governance of research component

The study was given full ethical approval by the NHS Research Ethics Committee East Midlands, Nottingham 2, on 24th September 2013 (REC reference 13/EM/0370; IRAS project ID 127984). The research component was led by TG (principal investigator) with input from all team members. A research team meeting was held approximately once a month and the research aspects of the study were a rolling agenda item on the wider DREAMS steering group. Data storage and management followed the data protection policies of both QMUL and Barts Health. For example, identifying details (full name, hospital number) were kept separately from anonymised data files.

Study design

The study was designed as a mixed-method organisational case study with three main components: [a] quantitative study of attendance and use of services; [b] clinical case studies of a sample of patients ('index cases'); and [c] qualitative process evaluation of the service. The main data sources are shown in Table 1. The different components are described in detail below.

Quantitative study of attendance and use of services

For users and non-users of Skype, we collected data on number of appointments, do not attend (DNA) rates, and use of the Skype option. These data were collected using the local diabetes database called DIAMOND and a project database, which were populated by the nurse and the consultant after each Skype appointment. The DIAMOND database included outpatient department appointments from Jan

2010 (year before starting the project) to the present (Dec 2014). This includes number of all outpatient department appointments (face-to-face and Skype), and number of Skype appointments that were 'patient initiated'. The project database included the date of the appointment, patient details, if they attended or not, if it was a 'patient initiated' appointment or not, the patient location, duration of the appointments and free text comments.

Key metrics for unplanned use of services were acute diabetes-related admissions and diabetes-related A&E attendance (even when not admitted). These data were obtained from the Trust's electronic patient record (EPR). For each A&E attendance the research nurse looked up the discharge summaries manually to identify those episodes that were Diabetes related. Each discharge summary is also reviewed by the consultant to confirm interpretation. Most patients were known to the consultant and nurse specialist personally hence any A&E episodes which seemed surprising could be confirmed, if necessary looking back into the patient notes. The A&E analysis included both users and non-users of Skype (patients within the same clinic who have not taken up webcam appointments) in the analysis. Historical data for each patient that dates back to their first contact with the Diabetes Department in Newham or Nov 2004 (when the database at Newham was changed), whichever is later, and follow up data to the end of the project or when the patient moved out of the area.

The patients' HbA1c measures were used to investigate clinical outcome of the Skype option. HbA1c measures are routinely recorded on the hospital EPR system for each patient. Patients have HbA1c measured at different times for various reasons, for many it would be annually, depending on their situation. For all Skype patients we were recording the nearest HbA1c measure on a 12 monthly basis.

Clinical case studies

With a view to building a rich picture of how remote consulting either fitted with, or failed to fit with, a person's wider life and their experience of illness, we constructed 16 detailed clinical case studies from three sources: a narrative interview with the patient, extracts from medical case notes (computer and paper) and a semi-structured interview with the doctor and nurse caring for that patient.

The narrative interviews, undertaken by EB, RS or DC-R, used a conversational style to let the interviewee (patient) set the agenda and convey their experiences using the expressions, metaphors and storylines of their choice, hence conveying who or what they believed had led to events unfolding as they did [1]. Patients, who gave written consent, were interviewed in the hospital setting when attending for a blood test or face-to-face appointment (or, on one case, opportunistically during an A&E visit). They were asked to give a brief account of their background and tell the story of their diabetes and how it was managed (by themselves and by the health professionals supporting them). Prompts were conversational in format (e.g. "tell me more about that" or "why do you think that happened?").

Case note extraction went back to the origin of the hospital record (in some cases, birth or very early childhood). A medically qualified researcher (TG) extracted biometric data (e.g. changes in HbA1c over time) as well as narrative data (e.g. on the initial admission when the diagnosis of diabetes was made). Verbatim extracts were taken from outpatient letters and inpatient entries to convey the perspective of the clinicians looking after the patient.

The clinicians responsible for the patients (SV and TO'S) were interviewed together in a single session by TG and JW. Taking each of the 16 patents in turn, we asked the clinicians to give (from memory) their assessment of the patient, their perception of any problems the person had with attendance, and the challenges they perceived in their clinical care. Again, a conversational format was used to allow the clinicians to identify the key issues for each of their patients.

Process evaluation

The aim of the process evaluation was to provide a rich picture of tasks, processes and organisational challenges involved in setting up and running the 'Skype' service, covering clinical, logistical and technical aspects. Informants for this phase included patients (n = 23), clinicians (n = 6), administrative staff (n = 3), technical staff (n = 1) and a senior manager (n = 1). The dataset consisted of three patient focus groups, nine patient interviews, one staff focus group, 12 hours of ethnographic observation in clinic, a single Skype consultation videotaped from both clinician and patient end, three individual interviews with clinical and technical personnel, and documentary analysis of technical guides.

Patients were interviewed in three focus groups conducted by AC, EB and DC-R. These consisted of diabetes patients (aged 18-69) who actively used the Skype option. The focus groups were conducted on clinic premises. The facilitators explained the purpose of the group (to gain experiential data to inform improvements to the service and generate insights about the value and challenges of remote consulting) and gained consent from all participants before giving a series of prompt questions to aid discussion. Prompt questions included: How have you found using Skype? What aspects of the service could be improved? How would you feel if we stop providing the Skype option?

The staff focus group was led by TG and EB. It involved six staff members (diabetes specialist nurse, clinic support nurse, consultant, receptionist, research nurse, healthcare assistant). Staff were asked their perspective on how the Skype service was going, and invited to tell positive and negative stories about their experience using it. The group process was used to invite discussion (e.g. if someone raised an issue, facilitators asked questions like "Has anyone else experienced this?" and "Does anyone have a contrasting story about that?").

A total of 12 hours of ethnographic observation of clinicians was undertaken in clinic by EB and TG. These covered everything the clinician did from arrival to the end of the session, including administrative work, attempting to set up and use Skype, actual Skype consultations and face to face consultations. In all cases the patient was asked for consent by the clinician for EB to be present beforehand and again afterwards for permission to use the data as research data.

Interviews with clinical consultants (x2) and technical support (x1) focused on the process of setting up the Skype technology within the clinic and the various procedures and information flow that takes place to utilise Skype day-to-day. The interview with clinical consultants included topics related to introducing the Skype option to patients, scheduling appointment via Skype and documenting contact/consultations. The interview with IT support (x1) focused on the technical requirements for setting-up and managing Skype and factors related to call quality and reliability.

A single 20-minute Skype consultation was recorded at 'both ends' by two researchers (JM and EB), one of whom travelled to the patient's home and one of whom stayed in clinic. Using two different video cameras trained on the computer screen, simultaneous recording of the clinician and patient view was achieved. This recording also provided the opportunity to capture ethnographic data in the patient's home, their expectations prior to the remote consultation and their reflections after this.

The process evaluation analysis was support by the review of published guidance (e.g. QUIPP guidance on using Skype), correspondence with the Trust's IT support officers (e.g. email correspondents, meeting minutes) and internal notes created by clinic staff to help them use Skype (e.g. a record of key incidents, written prompts on what to cover when introducing Skype).

Data management and analysis

Frequency data were used to provide a summary of the Skype use and clinical outcome measures across the sample of patients. First the analysis included all patients who opted to try the Skype option and used it on at least one occasion, from the inception of Skype (March 2011) to the present (Dec 2014). A separate analysis was then conducted on the sample of 'active' users, which included only those who had subsequent appointments following their first appointment during this period. This included patients (from the DAWN project) who continued using Skype when the DREAMS project began (2013) and all subsequent patients who actively used Skype.

The relationship between A&E attendance and use of Skype was analysed using a Normal-Poisson mixture model. This model assumes that for each patient the risk of an adverse event is a function of an inherent (unknown) susceptibility that is itself affected by the treatment (web-based management or not). The analysis was based on the sample of patients who were provided the Skype option, as well as those not provided the Skype as a comparison group.

All interviews and focus groups, and the video Skype consultation, were audiotaped with consent, transcribed and anonymised with a pseudonym before storage and further analysis. Research and clinic staff names have been anonymised in this report with pseudonyms.

Qualitative data were first read repeatedly to gain familiarity, then analysed thematically to identify key issues and events raised by participants. This initial

thematic analysis is the focus of the present report. A more theoretical analytic lens is also in progress on the same dataset using theories of self-management of illness (e.g. chronic illness as work [2-4]; self-management as phenomenological knowing [5, 6]); theories of interpersonal interaction including ethnomethodology [7], symbolic interactionism [8] and narrative as dialogue [9]; theories of technology use as social practice [10-13]; ethical perspectives on remote consulting and monitoring [14-16]; theories of materiality (how the material properties of things affect their social use [17, 18]) and of 'place and space' including the emotional geography of healthcare spaces [19-21]; and organisational-level theorisations, especially experience-based service redesign [22] and technology as an occasion for organisational sensemaking [23]. These theoretical analyses will be reported separately as academic papers.

The focus of the analysis reported here was to inform a service-focused case study of the main enablers and constraints to successful remote consulting in the context of a diabetes outpatient clinic. To that end, narrative summary was used to juxtapose quantitative findings (e.g. on 'DNA rates' in remote versus face to face consultations) with qualitative ones (e.g. findings from the patient focus groups on why people miss their appointments) [1].

The data sources, description of dataset, first-order interpretations and higher-order theoretical categories are summarised in Table 1.

TABLE 1: Overview of data structure and analysis for DREAMS study

Data source	Description of dataset	First-order interpretations (reported in this paper)	Higher-order theoretical categories (to be reported in detail elsewhere)
DATA ON SERVICE USE			
Demographic and clinical data	Age, gender, ethnicity, country of origin, home postcode, year diagnosed, years in UK, HbA1c.	➢ Descriptive statistics on the clinic population	Access Acceptance of Skype medium
Contact statistics	Out-patient face-to-face appointments Skype consultations (scheduled and patient initiated) 'Do not attend' (DNA) rates (scheduled face-to-face and skype appointments) A&E attendance	➢ Demographics of who attends and who doesn't	
DATA ON INDEX CASES (maximum variety sample of patients who use Skype, n = xx, or who have chosen not to use Skype, n = xx, total = 16)			
Semi-structured interviews with 16 patients ('index cases')	16 in-depth interviews with maximum variety sample	➢ Many and varied in-depth, narrative accounts of people with diabetes, focusing on how their diabetes has affected them over the years, how it affects them now, and other important things in their lives ➢ The experience of healthcare from the patient's perspective ➢ The patient's experience of the clinician-patient relationship and vice versa ➢ Both parties' experience of the technology (if using Skype), contextualised in the wider narrative of the person's diabetes	Illness as biographical work and as phenomenological knowing Patient engagement The therapeutic relationship etc
Extracts from clinical case notes (paper and computer records of index cases)	Key milestones in the illness journey including diagnosis, progress, exacerbations, complications, hospital admissions Biomarkers across the illness journey, especially fluctuations in HbA1c Comments made by clinicians on both clinical and social aspects of the illness		
Clinically-focused interviews with clinicians (on the 16 index cases)	One joint interview with diabetes consultant and specialist nurse, to gain their clinical perspective on the clinical and social aspects of the index cases		
DATA ON THE EXPERIENCE OF 'SKYPE' and 'TRADITIONAL' CONSULTATIONS			

Focus groups with patients (3 groups with total of 15 patients)	Diabetes patients (aged 18-69) who actively used the Skype option	➢ What patients thought of Skype consultations ➢ More generally, what patients thought of the clinic	Theorisation of the patient experience (e.g. experienced-based design Robert [22])
Patient interviews (N=8)	Diabetes patients (aged 18-60) who did not use the Skype option.		
Multi-modal data capture of live consultation (n = 1)	Audio and video of both patient's and clinician's 'end' of a remote consultation, transcribed in detail to capture conversation flow.	➢ Topics covered, style of consultation ➢ Both parties' confidence with using the technology and how this affects interaction ➢ Ethnomethodological issues (turn-taking, 'repairs' etc)	Theorisation of the clinician-patient interaction (e.g. Bakhitin [9])
Ethnographic observation of clinics	Clinical consultations, both Skype and face to face and clinician desk work (12 hours)	➢ Granular data on the nature of work and logistics of running the clinic and doing consultations	Health care, and technology use, as social practice Theorisation of organisational work e.g. socio-materiality (Orlikowski [17]), 'technology as equivoque' (Weick [23])
Focus group with staff	6 staff members (doctors, nurses, administrative staff)	➢ Staff experience setting up and using Skype in the context of a busy diabetes clinic ➢ Staff perspectives on what they think the patients think	
Individual staff interviews	One interview with diabetes nurse and one with diabetes consultant in the context of their clinic.		
Technical data	Standard operating procedures, staff notes/records of technical issues	➢ Inscribed assumptions about staff roles and how the technology will be used at the clinical front line	

Main findings

Description of dataset

The study generated large amounts of data, including quantitative data (e.g. attendance at outpatient and A&E, DNA rates, Skype contact), plus around 300 pages of text comprising interviews with staff and patients, focus group transcripts, and ethnographic field notes. The data was used to explore patients' use of Skype and how this related to adverse events and clinical indicators, their experience managing diabetes with the support of Skype consultations, and the technical and logistical issues to providing the service. Below, we present the key findings from the dataset related to these components. Further analysis is ongoing with a view to producing theorised academic papers.

Use of the service

Firstly, we looked at service use of patients who opted to try the Skype option and used it at least on one occasion. Overall there were 104 patients who used Skype at least once from its inception (March 2011) to the present (Dec 2014). The total number of outpatient appointments for this sample during this time was 1644 with an average DNA rate of 28%. The total number of Skype appointments within this sample for the same period was 480 with an average DNA rate of 13%.

Secondly, we looked at the attendance data for only the active users (those who had subsequent appointments following their first appointment during the time period.). The total number of active Skype users from 2011 – present is 60. A summary of the service use for the 60 active Skype users between March 2011 and the present (Dec 2014) is as follows.

Total number of outpatient appointments was 941 with an average DNA rate of 24%. Total number of Skype appointments was 376 with an average DNA rate of 7% (scheduled appointments only).

For the majority of Skype consultations, the patient used Skype at home (86%). The second most frequent location was work or university (10%), followed by outdoors (3%). One Skype consultation was carried out during the patient's trip abroad.

There has been a consistent increase in patient initiated (unscheduled) Skype appointments over time. Approximately 50% of all Skype appointments in 2013 & 2014 were patient initiated. There has been a reduction in the uptake of new patients for Skype however the year on year retention rate once Skype is being utilised has consistently increased from 39% in 2011 to 100% this year.

Figure 1 shows the DNA rates for face-to-face outpatient appointments (OPD) and scheduled Skype appointments for all users (historic and current). Figure 2 shows the DNA rates for face-to-face outpatient appointments (OPD) and scheduled Skype appointments for the active users. Frequency data for webcam appointment

and usage trends from March 2011 to the present (Dec 2014) are presented in Appendix A. The graph for Appendix figure A.5 shows that use of Skype option was variable across the different users.

Figure 1: DNA Rates for scheduled outpatient and Skype appointments for all users (N=104) during 2011-2014

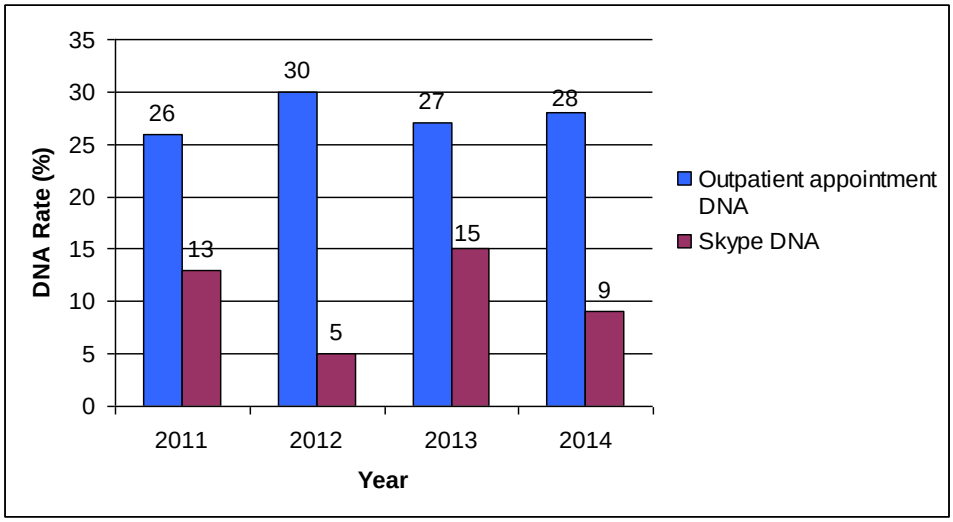
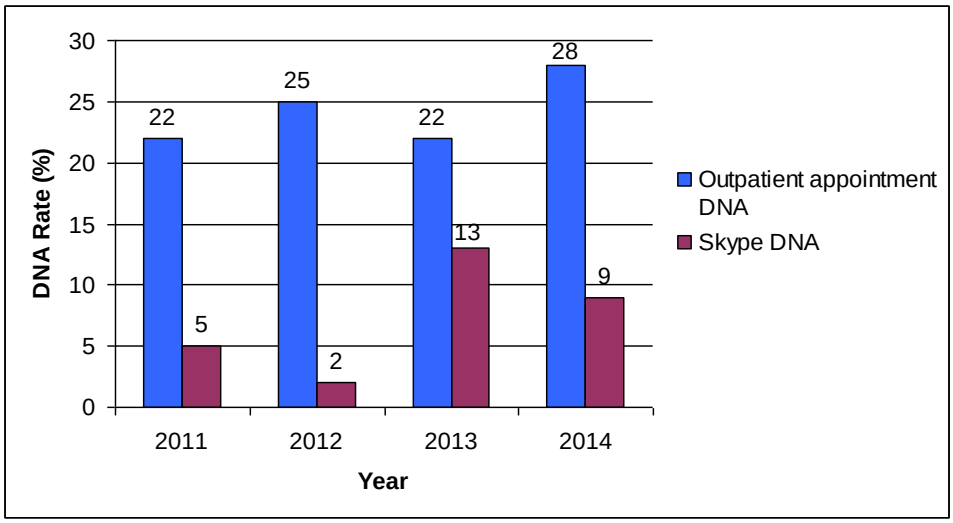


Figure 2: DNA Rates for scheduled outpatient and Skype appointments for active users (N=60) during 2011-2014



Adverse event and clinical outcome measures

The A&E analysis is described in detail in Appendix B. The Normal-Poisson mixture model did not show a significant difference in A&E attendance under the Skype service compared to the provision on outpatient appointments only. However, a significant difference was observed when controlling for age, in which A&E attendance under the Skype service was 21% than otherwise would be without the Skype option ($p = 0.003$). However, the findings should be treated with extreme caution. As can be seen from the analysis, the results are rather different as different patients and different factors are included. There is a suggestion that the event rate is lower under the web system but there are many

possible explanations of this. The sample size is small, as befits a pilot study, and the study is an observational one and not a controlled experiment. Thus the results here should be taken as an illustration of the sort of analysis that might be performed in future studies and not as a valid estimate of the causal effect of offering patients a web-based system.

The HbA1c for current Skype users is shown in Appendix C. The figures show an average HbA1c reduction, which pre-Skype averaged 70mmol/mol, and end of 2013 averaged 65mmol/mol.

Clinical case studies

The in-depth patient case studies (built from analysis of the paper record, electronic record and interviews with clinicians about particular patients) illustrate a number of features of this patient group that are expanded on in the patients' own stories (described in detail below). First, the diagnosis of diabetes is life-changing and emotionally traumatic, perhaps especially when it occurs in the teenage years. Second, the experience of diabetes as a long term condition is burdensome, disruptive, time-consuming and stigmatising.

Third, patients live very varied lives and cope to different extents and in very different ways with the challenges of diabetes. Fourth, patients experience life events – leaving home, starting college or changing jobs, getting married or divorced, having a child, being bereaved, visiting relatives abroad and supporting family or friends in such life events. The care of the diabetes cannot be separated from these wider aspects of the person's life – which can make clinic attendance difficult for a temporary period.

Fifth, some but not all patients establish a positive pattern of proactively managing their condition, attending appointments, engaging with their progress and interacting with health professionals in a way that fits in with their home and work/college life and accommodates the ups and downs of life events. The Skype option helped considerably in some patients but to only a limited extent in others.

Our case studies also revealed that rarely, patients with type 1 diabetes exhibit profound lack of engagement with their care and even self-destructive behaviour such as wilful omission of insulin – perhaps as a result of wider personal, family or social difficulties. In such individuals, the offer of remote consultations was sometimes but not always accepted but when it was, the patient appeared to value the option of unscheduled Skype appointments as it allowed them to make contact on the rare occasions when they felt ready. See Appendix D for example clinical case summaries.

Key themes from patient focus groups

The analysis revealed five main themes and 13 constituent sub-themes related to patients' experience with using Skype consultations. This included: *Convenience* (fitting consultations around everyday lives, saving time and money, traveling and on the move); *Managing diabetes* (guidance, immediate problems, reassurance); *Interaction through video* (engagement, non-verbal cues, physical presence);

Technical functionality (availability, sharing information); and R*elationship with service* (familiarity, trust). Below we present these themes in turn.

Convenience

Participants talked about the benefits of using Skype to fit their appointments around their lives in three respects (fitting consultations around everyday lives, saving time and money, traveling and on the move). These highlight issues that have a bearing on their decision to attend, or not attend clinic appointments, and how Skype can help bypass some of these barriers.

A major perceived benefit of Skype was fitting consultations around every day routines and commitments (e.g. work, university, looking after children). These roles restricted the degree to which they could physically attend the clinic, and often required them to take time off or miss or re-schedule their commitments. However, the Skype option greatly enhanced their flexibility to fit the consultations around their everyday lives (e.g. in-between lectures, lunch or coffee breaks):

> *"For the Diabetes it's great for me personally cause I'm at Uni and I work as well, so fitting it in, I have to have full day off work to come in, can't just do half, it works cause when I'm on my break I can just use my phone and Skype, it's much better, I don't need to take any time off."*

Another aspect of convenience was 'saving time and money'. They talked about the effort and financial cost of visiting a clinic involved in attending the clinic (travel, parking and waiting).

> *"For me it's much better to use skype than to come here because it saves time. The main thing is saving time and this time you can do something else"*

Participants felt that Skype enabled them to consult the clinicians whilst traveling or on the go (e.g. going on holiday, work travel, visiting family/friends). This is supported by the fact that Skype can operate on mobile devices, and can also be used abroad at with no international charges (as long as they have an internet connection).

> *"I'm either out of London or out of the country so Skype is on any device with internet and it's very easy to get to so I'm able to get in touch wherever I am."*

Managing diabetes

Participants felt that Skype had supported and influenced their self-management and ability to cope with diabetes. They felt more connected to the service, and were encouraged to seek guidance or clarify issues following an appointment, rather than wait until the next upcoming appointment:

> *"The other advantage of Skype is when I have an issue I might have a tendency to put it off a bit but if I see her, it's easy to send her a quick message."*

Skype consultations provided a channel to address 'immediate problems'. This included issues or incidents that the patient did not consider as an emergency (that would warrant a 999 call), but still wished for immediate input from the clinician (e.g. abnormal blood sugar reading, uncertainty of insulin intake):

> *"I think with diabetes particularly immediacy is important, generally when you want to know something you want to know it now, or in a couple of hours, in a couple of weeks you might be dead"*

The option to contact the service via Skype provided a strong sense of reassurance and peace of mind. Even when participants were not actively using Skype, it offered a 'safety net', reducing their anxieties about managing their condition effectively:

> *"There's a big safety net because you know if I've got a problem I can just look online and see oh she's on and quickly either give a call or Skype in. There's that little more of a backup isn't it? "*

Interaction through video

A third theme relates to patients' experience with using video webcam to interact with the clinician. They talked about an improvement in the level of engagement from the consultant. In particular, they felt that the consultant spent a greater proportion of the consultation looking at them and focusing on what they were saying. Patients compared this to a face-to-face encounter, in which the clinician would need to look down or away from them to view relevant medical records.

> *"I don't think the consultant or the nurses actually realise, their whole attitude changes when they are in the consultation clinic, they have got the papers in front of them, they are fiddling with that, they are reading through it, but when they are on Skype they just look straight at you and they talk at you, I have not seen them going like that, fiddling with papers or anything, I don't know if they have noticed it but they really look at you"*

They also highlighted how video can support dialogue about their condition through visual and non-verbal cues, both explicit (e.g. showing them physical marks/symptoms on the body), as well as more implicit indicators of their wellbeing (e.g. mood, tiredness, skin complexion):

> *"If you are not well and you are Skyping they can see you are not well, if you are looking a bit rough or whatever…"*

Another issue raise in this theme was the limitations of using video. Participants emphasised a need to use Skype in conjunction with face-to-face appointments.

They felt that some aspects of the patient-clinician interaction can be lost when mediated through the technology. Physical presence was considered important for meaningful emotional support, hands-on practical assistance (e.g. how to operate an insulin pump), and effective collaboration and problem solving that required the sharing of numerical or visual information (e.g. log record or trend in their blood sugar readings).

> *"If I was to come to show her my pump she'll get some readings and put it up on a graph on the computer so with Skype I don't think I'll feel more comfortable talking about anything because it's slightly more impersonal… It's not that I don't want to or have a problem with it but it makes it so much easier if I'm there in person. If there's a technical issue it makes it slightly easier"*

Technical functionality

Some participants had used additional technical features within Skype, which supported their use of the application in a flexible and adaptive way. Firstly, they check the clinician's availability by viewing their 'online' status (which can be set by all Skype users) and sending short messages asking if they are free for a call. The patients acknowledge that the clinician has other patients to see throughout the day, and so use these features to minimise disruption to their clinical schedule:

> *"If you have a slight problem, then you message and the next thing you know, you have a phone call back which is great. You know, you're not invading them but at the same time, you're letting them know that there's something there."*

Secondly, patients have used the messaging feature to bypass administrative processes to request information or reschedule upcoming appointment:

> *"I wasn't sure when the appointment was and I had problems with the reception before and I wasn't sure if it was at X [name of clinic] or Y [name of another clinic] and I knew she [the clinician] would have that information somewhere and it saved me time calling up [the clinics], finding out from all these different sources to try and find out where the appointment was so I sent her a message on skype to say could you perhaps send me a letter or just let me know when my next appointment is and I think a couple days later she sent me a letter through with all the information on and it made me feel.. I was really sure that I could ask her instead of any other source"*

Relationship with clinician

Participants emphasised that it was the 'person behind the technology' that made the Skype option work. They talked about the importance of familiarity with the clinician and other service staff members. They attributed the quality of the conversation via Skype to their existing relationship with that particular clinician, and anticipated a need for the relationship to develop before using Skype with another clinician:

> *"There is still quite a lot of chattiness about it and a lot of times through the chattiness you get more to the underlying reasoning, so there are still aspects of it, even with the Skype, but that's because 9 times out of 10 it's with [name of clinician] who you know, who you have known for a while.".*

Participants' confidence in using Skype as a reliable communication tool was based largely on their trust in the clinician to act in their interests. For example, their perception of the Skype option as a source of reassurance was rooted in their confidence that the clinician would check and respond to their messages quickly. Similarly, they trusted that the clinician would maintain the same level of privacy during a Skype consultation as they would in a face-to-face consultation, and hence considered it to be suitable for clinical appointments:

> *"She always lets you know and when someone does come in she kind of stops and says I'm in a consultation right now and they usually go away"*

Key themes from patient interviews

"Face to face is more real"

Several of the interviewees stressed that there was an element of "reality" to the face to face consultations that was missing – or at least heavily compromised – by the use of Skype. Of the respondents who felt this way, some were regular Skype users and others were not.

For example, Fatima spoke about the annual review appointments as "essential" – these being the only appointments where she came to the clinic. As a working mother of school-age children she appreciated the convenience of Skype for what she calls the "catch-up" sessions she talked about the importance of maintaining "personal contact" with Tanya (consultant) and Ruth (nurse). It is worth noting that Fatima did not class Skype as personal contact.

Misbah was a busy professional who said that he appreciated the convenience of Skype for short, practical discussions but who was adamant that he would not want to entirely replace his clinic visits with videoconferencing. Skype is, he said, "not always useful. Sometimes you need that direct interaction and Skype can't replace that direct interaction. You need a meeting every now and again."

He began with the example of coming to the clinic to get pump supplies and blood sugar testing kits but it soon became clear that there is a less tangible reason for meeting at the clinic. "Sometimes it's simply much easier to talk (face to face). Virtual space doesn't replace completely actual space."

He talked about video consultations as being "fake" – a term he later changed to "unreal." He said that the relationship between the health care practitioner and the patient is an "interaction that requires sympathy and empathy and this wouldn't be strong enough if you used Skype alone. If it was the only way of communication you'd strip the whole process of the human aspect."

He also talked about the "direct interaction" of looking at his records on screen with Ruth. "I like to know that I have a profile here." This bears out previous observations [24] that have shown how important it is to be able to jointly refer to real objects in order to improve dialogue and understanding.

Misbah is not a naïve Skype user by any means. He uses it in his work for carrying out research interviews and to have meetings with colleagues overseas. But he identified a key difference in that his professional use of Skype "is related to something practical rather than personal. Here (at the clinic) we have a private space ready. I'm privileging it because it is a very personal thing – it's not research where you are working together on something for somebody else. It's more working for myself with someone who knows a lot about my personal condition."

"Speaking to someone in person is a lot more assuring"

Face to face consultations have an additional emotional component that Skype calls are perceived to lack, both by patients and by Ruth (see "Key themes from staff interviews and focus groups" on page 17.)

Clayton talked about his feelings and the way that clinic appointments offer him reassurance and emotional support.

"I find when I come to the clinic [pause] speaking to someone in person is a lot more assuring [pause] having a face to face discussion seems to help… When I leave the clinic I would feel – I do feel a lot, lot better than {when speaking} through social media. And for that reason I cannot recall since 1983 that I missed two appointments – and I deem that a very long time."

Gazala is a young woman who found her initial diagnosis to be very emotionally charged. She talked about how unfair it seemed, to be told she was diabetic in her late teens: "because that's your days to enjoy." Her mum and sister provided some emotional support but she spoke at length about her time in the clinic with Ruth, and the importance of the hugs Ruth gave her in those first few, difficult months.

Sophia talked about the consultant's body language: she talked extensively about how much anxiety she has about her diabetes and how anxious she is at appointments but she said that she feels reassured by the face to face contact she has with Tanya. She commented positively on the way Tanya sits in the consulting room, with "open body language, always facing me and she doesn't type on her keyboard." This helps Sophia open up about her condition despite her anxiety.

"It's not my top hobby…" Skype as a non-routine technology.

Several of the interviewees did not use Skype at all because they found the process of using Skype to be intimidating, or simply found it too far removed from their usual patterns of technology use to be able to incorporate it into their routines.

At the time of this consultation, Clayton was still suffering from a leg injury that had been caused by someone hitting him with their car. This made it difficult for Clayton to get around, both physically and emotionally: he talked about losing his

confidence when crossing the road and the bad dreams that he has about the accident.

Clayton also talked about his isolation levels since while recovering from being hit by the car, yet he still would not consider Skype as a way of increasing his social contact. For example, Clayton occasionally uses Skype to talk with friends and family in the Caribbean but he does so *"very very rarely – it's not one of my…um.. what I would call…top hobby."*

Despite the pain he was experiencing when walking, and the stress of coping with traffic, Clayton was adamant that he would attend his appointment rather than use Skype.

When he wants to talk to people, he would rather do it by what he calls *"natural dialing"* – which suggests that phone calls are such a normal part of Clayton's routine that he doesn't frame them as "technology use." What is more, he sees the clinic as the "proper" place for his consultations.

Sophia is an educated, middle-class patient but is very nervous around technology. She has chosen not to use Skype consultations because she fears that her inexperience with the technology would mean that she would miss her appointment. For example, she said that she can't sign in herself and has to get her husband to log her in whenever she uses Skype. As he isn't at home during the day she is worried that, even if he did log her in, she might become disconnected and not be able to attend her Skype appointment.

George is a young man who uses a smartphone and would, on the face of it, seem like a likely candidate for Skype appointments. However, he uses a different application on his phone – Viber – which makes voice calls only. This is a deliberate choice on his part and he said that he doesn't want to use Skype at all, either for personal calls or for consultations because he finds signing in a "hassle."

Clinic is the "appropriate place" for encounters about health

Several of the interviewees talked about the clinic as a place that was somehow special ("privileged" in the words of Misbah) and there is an expectation that the consultation can only take place "properly" in the clinic. Some patients said that they found the clinic atmosphere conducive to focusing on the practicalities of managing their condition. For example, Dabir said that he comes in for "a very practical discussion about [his] condition."

Other participants were reassured by the availability of medical equipment even if they have the ability to take their own readings at home. For example, Clayton said: *"health-wise I would like to come to take my tests to know what is wrong with me."* Fatima talked about the annual review appointment as one appointment that it is "essential" to attend in person. In these appointments, she told me, she is weighed, has her blood pressure checked, her feet examined and so on. I suggested that there might be technology available to allow her to make those

measurements at home but Fatima said that the annual appointment is still important in order to keep the level of personal rapport and trust with Ruth and Tanya going.

Patients have complex relationships with their diabetic status

One patient, Ben, is a member of a small group of patients who do not attend face-to-face or Skype appointments. During his interview, Ben talked about other appointments he needs to keep – for example with the job centre. He said that he attends these regularly - timekeeping and attending appointments are not (universally) issues for him but he avoids the diabetes clinic for a number of complex and interlinked reasons.

He was interviewed during one of his frequent admissions from A&E. This was Ben's second DKA in two weeks and, when he notices that he is becoming ill, his first course of action is always to call an ambulance. Ben received his diagnosis three years ago at the age of 19. In the interview he talks a lot about the unfairness of his diagnosis. He also says that his initial discussions were with a doctor who made him angry because he brought a tape recorder to the meeting which made Ben suspicious and afraid.

Ben's life is burdened with chaos. At the time of the interview he was homeless and sleeping on a friend's sofa. He had recently been evicted from another friend's place in Ilford. He is unemployed and seems troubled: he talks about his anger a lot during the interview. Discussions with Tanya and Ruth reveal some of the background to Ben's case. He has a difficult relationship with his mother.

From his comments about his management of his diabetes (he doesn't take his blood glucose measurements because doing so makes him angry; he forgets to take his insulin dose and is worried that moving from three doses a day to one will mean that he misses out entirely) Ben is either in a state of active denial of the realty of his illness or is fatalistic about it to the point of hastening his own decline.

It is clear from the interview that Ben has complex issues and is currently unwilling to attend appointments either in clinic or via Skype.

Key themes from staff interviews and focus groups

We interviewed clinicians individually and also brought clinic staff together for a focus group. The focus group data revealed a range of perspectives on the effectiveness of Skype as a means of patient engagement. Several of the staff, including the receptionist and the clinic nurse stressed that the service had become part of business as usual. They were happy to offer patients the added convenience of Skype appointments. However, other members of the staff – in particular the diabetes nurse specialist and a research nurse – had developed a more nuanced view of the technology, where benefits and drawbacks were both acknowledged, and a rich picture of appropriate use had begun to emerge.

Engagement is a zillion times more complex

Ruth is a passionate and committed nurse who has been caring for some of her patients continually from early childhood to early adulthood. In an interview she talks about the importance of trust and engagement with the patient: "if you don't have that, you don't have anything."

In the focus group she expressed a vague dissatisfaction with the levels of engagement that the clinic had achieved via Skype:

> *"Ok what do I need to say about it? I think everything that is happening and everything we are doing is fantastic...and somehow I'm marginally disappointed … and I'm not quite sure what that disappointment is, and I think it's an unrealistic expectation I've probably had*
>
> *"Because, for me, I feel passionate about how we engage and what that means [and] I think, I suppose, what I am beginning to realise is that engagement is a zillion times more complex than I may have thought it to be... and I hold a question: are we missing something? And if we are missing something, which we might not be, what is it? Is there some aspect that we haven't uncovered that is a critical component to what determines engagement because I think it's important to say that what we do might suit one person and not the next person,*"

Through her experience of clinic work, Ruth has discovered that patients are not always willing to engage via Skype, even if it would be reasonable to expect that Skype would significantly lower the barriers to engagement for those patients. She summarised her concerns by saying: "*How do you take a horse to water is my question?*"

Patients may say one thing and behave quite differently

Emilie, one of the research nurses, spoke of the patients who "sang the praises" of the Skype service but who then failed to show up to appointments and who did not use the drop-in service.

> *"People who have been using the webcam - to get their feedback - quite a lot of them [say] it's fantastic and you know, all about accessibility and everything else and it's integrated into their normal day so it doesn't feel like it's something extra, but when we actually sit and go through Ruth's list of people who regularly utilising webcam, those same people who have sang its praises are not using it or have had one appointment… when we actually looked at this SKYPE activity it wasn't reflecting what they were saying to us and when we looked at their outpatient activity they were also still missing their outpatient appointments, so I think if we probably revisited those same people and found out from them, ok, well what is really taking place."*

Emilie and Ruth represent a point in their adoption of technology that we might describe as sophisticated uncertainty: they have discovered that the technology is

useful in some circumstances but not others, and they are still developing a mental model of the factors that determine its usefulness. If we map this to the Gartner Hype Cycle, Ruth and Emilie are navigating the transition from their personal "Trough of Disillusionment" to the "Slope of Enlightenment" [25] as they discover the limitations of the tool as a means of "creating" engagement.

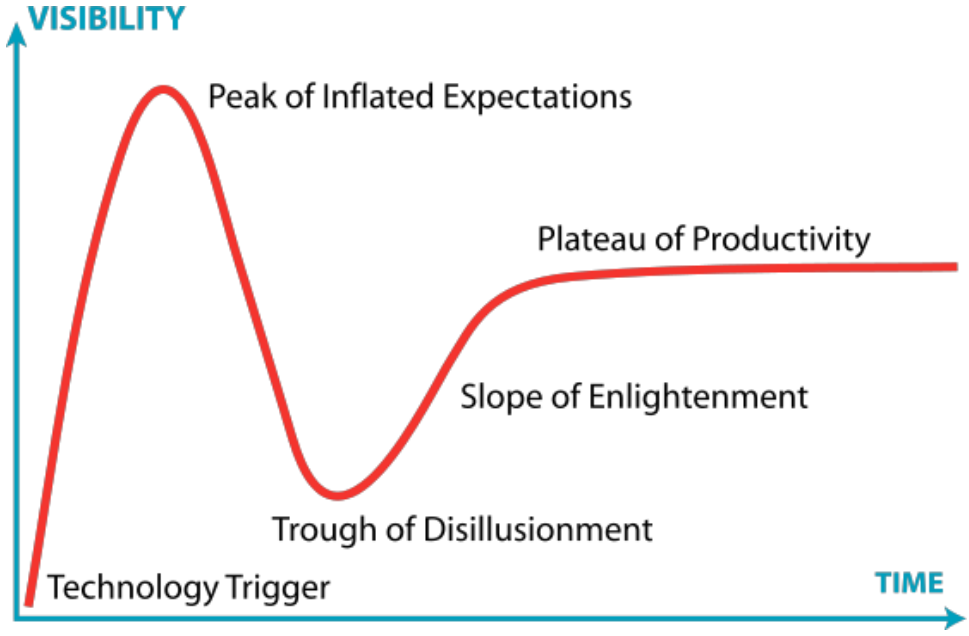


Figure 3: The Gartner Hype Cycle from Elwyn et al [25]

Skype has become "business as usual"

While the clinicians still have questions about how best to encourage user engagement with Skype, it has become "business as usual" in the clinic. Tanya remarked that:

> *"What I've been really impressed by is how clinic staff, Jennifer and Besim have just got into the swing of things and now it's very routine so, you know for example, this morning … this lady had an online appointment that she didn't keep and at the end of the clinic it was a very natural comment that Jennifer just said did she keep her webcam appointment, what do you want me to do? Do you want me to book her another webcam or would she like to come face to face?*
>
> *"Not only is it part of business as usual, Jennifer is quite aware that [the patient] may want to come face to face that's why maybe she didn't keep the online appointment or maybe she wants another online appointment."*

When asked how Jennifer knew that the patient had not attended, Tanya and Jennifer explained their workflow:

> Tanya: *I give her a form, which basically I tick whether she attended or she didn't.*

> Trisha: *So you use paper form to go back and then you then follow that up for...erm.*
>
> Jennifer: *another appointment, yeah, or not.*

Likewise, Tanya relies on her nurse, Besim, for the same sort of logistical support that she needs in her face-to-face clinic appointments. This includes reminding Tanya when it is time to have a webcam appointment, but also ensuring that the patient's paper notes are available for each appointment.

> Tanya: *Haha, yes but he does the same thing, telling me on Friday, erm, remind me if I'm chatting away when there's an online appointment, erm, you know, get all the webcams and the speaker, microphones and the speakers all set up, like you would set up a normal clinic, you know, take the notes Besim would take the notes out for people who have...*
>
> Besim*: So if there are two or three patients that are webcam I put all the webcam patients in her room so at least when she comes she's got the notes ready in her room, she doesn't need to come out and say she needs these notes because she's got a webcam patient as the notes are in her room.*

Besim's role has embraced the Skype appointments without any great upheaval – his work to support Tanya in delivering the clinics has incorporated Skype sessions without the need for new procedures. Instead existing procedures have been applied in a flexible fashion to incorporate the Skype appointments. Likewise, Jennifer's role in setting up appointments has not changed dramatically – the appointments-booking system includes the Skype sessions as a natural extension of the face-to-face sessions.

Problems with admin rights mean that Skype upgrades cause missed appointments

Occasionally, Skype will release an updated version of their software that requires that the users reinstall the client. Because of the controls on the Trust's IT infrastructure, Tanya and Ruth have to as IT support to complete the installation of the update. For Ruth, who runs an on-demand service – this isn't too much of an interruption to business. However for Tanya this can lead to a missed block of appointments, as was the case with a recent update:

> *You've got 15 appointments or 16 appointments back to back so you can't then let them all ring at 8:45-9 O'clock, helpdesk doesn't get there till 9 and my appointments start at 8:45so then you can't ring at 9 and wait on the end of the phone for 20mins while they are installing it for you, so what Besim did was called every one of those patients that were booked for that morning, isn't it, and then said SKYPE wasn't working and rebooked them another appointment and then I, the thing is you*

> *then have to install it on every computer so if I am using 3 computers , I make 3 phone calls and got the administrator to install it on 3 machines that I use separately.*

While interruptions of this scale happen rarely, they are disruptive to the scheduled clinic.

On-demand appointments lead to expectations of 24-hour access.

A small proportion of patients who had been offered the on-demand Skype service developed expectations that the service would be available "round the clock." This is of course incompatible with the way the service was set up and delivered: through the clinic hours of one single nurse. Nevertheless, there were several patients whose anxieties lead them to expect support beyond the bounds of what Ruth was able to provide.

For example, in the staff focus group, Ruth spoke about one 18 year old patient who grew up in a household where both parents suffer from learning disabilities. The patient himself doesn't suffer from learning disabilities but dd develop behavioural problems in his early teens as a result.

This patient has found the on-demand consultations to be extremely helpful – Ruth describes him as having taken to them "like a duck to water." However, when Ruth went on holiday, the patient became quite demanding, requesting that Ruth sign in to Skype while she was on leave, or at the very least that she give him her email address so he could contact her.

Ruth acknowledged that the patient's anxiety was likely to be the driving force behind his request: "We've talked about the safety net… So for him, having that safety net is really, really important." However, she successfully maintained appropriate professional boundaries and reminded the patient that he could telephone the clinic to speak to a nurse during clinic hours.

Key themes from the multi-modal recording of remote interaction

A single interaction, involving a patient (at home) and two clinicians (doctor and nurse, both in clinic) was recorded early in the study. The encounter lasted 23 minutes and covered a routine interim follow-up for type 1 diabetes.. Close analysis of video data and the conversation transcript revealed the following themes:

- The webcam seemed to disrupt and complicate what has been called 'front stage' / 'back stage' demarcations in clinical care (for example, there is no waiting room and once connected, the encounter is 'live'). In traditional consultations there may be cross-talk between doctor and nurse (or students) when the patient is not in the room, but in webcam consultations interpersonal boundaries are different and not physically demarcated by walls and doors.
- Some of the interpersonal interaction appeared somewhat artificial (e.g. participants appeared to be shouting, as if on a long-distance phone call, and conversation was conducted in "question and answer" format). There was a suggestion of awkwardness in turn-taking (e.g. one party interrupting before

the other had completed their turn) but only between remote participants, whereas talk between the co-located participants (doctor and nurse) did not exhibit this phenomenon. This finding resonates with that of previous researchers and merits further exploration.

- Technical quality of the multimodal dataset collected was sub-optimal, but ways to improve quality were readily identified (e.g. repositioning video camera, increasing number of frames captured per second, need for clinicians to sit closer together in joint consultation).
- The paper record was referred to extensively throughout the consultation, emphasising the need to explore both paper and electronic artefacts in the definitive research study.
- In this "routine" encounter, the patient raised an unanticipated clinical problem (a foot injury). The clinicians tried to persuade the patient to show the foot on the webcam but the patient was unwilling and all parties found this idea amusing. This raised the question of how far visual clinical examination will be seen as inappropriate or even absurd even when it is technically achievable. The patient was told to consult their GP, raising questions about knock-on work for primary care.
- Researcher field notes suggested that whilst this consultation had been unproblematic from the perspective of the family, there was a need to "synchronise with the rhythms of the home" since participating in webcam consultations requires privacy and (often) access to the family computer.
- Researcher field notes also revealed that the patient and their relatives had high expectations of the webcam service (such as "24/7" availability, the facility to consult at any time convenient to the patient). Patient users' understanding of the technological and human infrastructure needed to produce the clinician at the end of the webcam may be unrealistic and a potential stumbling block.

Many of the issues noted above were ironed out in further use of the technology but several themes suggest additional research on the detailed interpersonal interaction is needed.

Technical and logistical issues

The technical and logistical processes can be summarised under four main areas: i) *Set-up and maintenance* (installation and upgrades, Skype accounts, contact invitation); ii) *Communication* (scheduled and patient initiated calls, messaging); iii) *Managing access* (logging on/off, availability, privacy, admin); iv) *Procedures in the clinic* (privacy and security, admin)

Setting up and maintaining Skype

- *Installation and upgrades*

Skype is a free service that can be downloaded directly from the Skype website. However, service staff members do not have administrative rights to install new software onto clinic computers. Therefore, installation of Skype software needs to be done by the Trust's ICT support. This can be done remotely from the IT helpdesk.

Skype regularly releases updates (e.g. new features, interface designs). These updates are automatic but require all users to download the updated software when opening the application. The Skype service cannot be used until these updates have been done. As with all other downloads and installations, only the Trust's ICT support staff can run these downloads. Therefore, forced Skype updates can potentially cause disruption and delay to scheduled Skype appointments. The updates can be done remotely, and can be completed within 5 minutes. However, it is important to remain aware of when the updates are due to take place in order to minimise disruption to upcoming appointments.

- *Skype accounts*

Each clinician (that runs Skype consultations) has their own Skype account, specifically set-up to be used within the clinical (i.e. a 'work' account). For DREAMS, two Skype accounts were set up for the two clinicians (nurse and consultant). Both accounts included an **account name**, e.g. 'diabetesclinic1' and 'diabetesclinic2' (pseudonyms) and a **user profile name,** e.g. 'Joanna Bloggs' and 'John Smith'. Both accounts can be 'searched' by other Skype users either by the account name or the user profile name. Note that although the account name cannot be replicated within the Skype database, the user names can be replicated. Therefore, patients should be provided with both the account and user name details before joining as a 'contact'.

Whereas the Skype user profile name can be changed (in account profile settings), the account name cannot. Therefore, it important to use the clinician's name for the user profile name so that it can be updated (e.g. change in staff), and a constant/uniform account name that would not need to be changed at any stage (e.g. service department name).

- *Contact invitations*

It is important to note that patients tend to use their own personal Skype accounts. In many cases, the patients' user profile and/or account names do not reflect their actual name (e.g. 'Batman2000', 'Ladybird86'). This raises potential problems keeping track of patient IDs and risk of contacting the wrong person. It is important to keep an accurate record that links patient IDs with their Skype account and user profile names. Additionally, it is important to only send or accept contact invitations once the patient's Skype account and user profile name has been confirmed.

Communication via Skype

- *Scheduled and patient initiated*

There are two types of Skype consultations: **scheduled** and **patient initiated.** The scheduled consultations are conducted at a date and time previously agreed between the patient and the clinician. They take place within clinic opening hours (as with standard face-to-face consultations). The call will be initiated by the patient or the clinician. The patient initiated consultations can take place at any time during the clinic opening hours and when the clinician is in the clinic.

The Skype application will indicate with an icon if an incoming call has been missed, as well as who made the call and when. If the clinician sees that they missed a scheduled or patient initiated call (e.g. not at desk when call came through), they will call the user back using Skype. If the patient does not answer a Skype call from the clinician, then they will send a Skype message to check patient availability.

- *Messages*

Patients and clinicians can send messages to each other via the Skype messaging feature at any time. However, the recipient needs to online with the Skype application open in order to receive the message. Patients send messages in order to check availability of the clinician to talk over Skype, reschedule appointments, as well as request information (e.g. date of next appointment) and documents (e.g. to post a medical letter).

Managing availability and access

- *Logging in/out of Skype*

The Skype user logs into Skype with the account name and password. Calls cannot be initiated to the contact if they are logged out. However, messages can be sent, but will not be received until the recipient has logged into their account. Once logged into Skype, the default is to remain open, even when the application is closed. It will only log-out if manually selected to do so via the application dropdown menu.

- Checking recent activity

Patients may message the clinician when the clinician is offline. When opening the Skype application, the clinician should check to see if any messages have come through. Similarly, patients may send messages or initiate calls whilst the Skype application is open, but whilst the clinician is away from the desk. Therefore, the clinician must routinely check for messages and missed calls throughout the day (e.g. returning after being away from the desk for a short period). This can be done using the 'recent activity' window on the Skype application, which displays the recent history of messages and received/missed calls.

- *Clinician availability*

Skype users can indicate their 'availability' to receive a Skype call in the profile settings (e.g. 'online', 'away'). The clinician can change this status at any time, e.g. to block calls coming through but still receive messages. However, the clinician should remember to return their availability status to 'online' if they changed the status at any point, as this does not revert to an online status by default.

The status feature is rarely used, as patients have generally understood that the clinician has other appointments and duties throughout the day, and so they would message the clinician before initiating calls.

However, it is necessary to manage patients' expectation as to when the clinician will respond or the types of requests that can meet. For example, some patients would bypass the administrative process of booking or rescheduling and appointment by contacting the clinician directly via Skype. This raises potential

challenges with regard to manageability (e.g. keeping record of upcoming appointments, allocating fixed appointments slots and waiting times) and risk of unequal access (i.e. people with Skype can arrange an relatively quick and immediate appointment face-to-face, whilst those without are restricted to the existing administrative process of fitting into available appointment slots).

Procedures in the clinic

- *Privacy and security*

As with a face-to-face consultation, steps are taken to maintain patient confidentiality and privacy. This includes: i) conducting Skype calls within the clinic offices, 2) closing the office door and informing other staff members that consultation is taking place (door sign), 3) Informing the patient if another person is in the office, and asking them if they are happy to proceed with the consultation.

All other staff members should be aware of the use of Skype within the clinic so that they can respond accordingly (e.g. knock whenever the door is closed, leave the room when a Skype call comes through).

For security all video consultations are securely encrypted, however, it is the patients' responsibility to ensure they have adequate anti-spyware and anti-virus protection on their hardware to prevent unauthorized eavesdropping. Some information is stored on the Skype application (e.g. messages), hence staff and patients need to be aware of this, particularly if they're using a public or shared computer.

- *Admin*

It is important to ensure that Skype does not disrupt or fragment the administrative processes in place. All Skype consultations, scheduled and patient initiated are documented following the same administrative procedures as any other out-patient appointment. This includes input into the Diamond database and letter to their GP. Similarly, appointment bookings or cancelation agreed via Skype need to be reported to the administrative team, and as with standard out-patient appointments, letters confirming the new appointment is sent by letter to the patient.

Conclusions

Summary of main findings

Flexibility and 'Open Access'

The mixed-methods approach to studying patients; experiences and use of the Skype option has provided detailed insight into the ways in which the technology can support management of diabetes and engagement with the service staff. Crucially the data highlight their adaptive use of Skype in order to fit consultations around their daily lives. Each participant used the technology as and when they needed it, fitting consultations around other commitments and in response to changes in personal circumstances or

fluctuations in their condition and/or confidence. This adaptive use was made possible through the technical functionality of Skype (messaging, 'online status') and their existing relationship with the clinician. It is likely that the flexibility afforded through these qualities contributed to the lower rate of DNAs for scheduled Skype appointments than face-to-face outpatient consultations.

It is important to note that staff flexibility, rather than Skype itself, may have been the secret ingredient that made the project so successful. The introduction of any new technology is an "occasion for structuring" [26]. The introduction of Skype didn't mandate that the clinic staff adopt such an open and flexible approach to patient contact. Rather, the flexibility was introduced and popularised because Tanya and Ruth are very patient-centred and were actively looking for ways to provide an accessible service. With another team, the use of Skype may never have evolved this way.

With this in mind, it is important to ensure that standard operating procedures (SOPs) for Skype offer enough guidance for effective and dependable use, but sufficient flexibility to afford the convenience and on-hand support required.

Combined role of face-to-face and virtual consultations

Participants emphasised distinct, but complimentary, differences between online and face-to-face consultations. Skype facilitates brief, but important, encounters, and provides reassurance or peace of mind to the patient. The face-to-face encounters on the other hand are important for emotional support and hands-on practical guidance in which shared physical space and artefacts or displays were necessary.

Shared physical artefacts are a useful driver of collaborative working, particularly when the people collaborating come from different interdisciplinary backgrounds. Paay et al [27] talk about artefacts as "bridging objects" – prompts that allow individuals to challenge their own understanding of their collaborators' mental models, and to update and refine their own understanding of the problem space. As yet there is little if any research into the importance of shared artefacts in the collaboration between patients and healthcare practitioners, but evidence from other disciplines suggests that shared attention to physical objects (insulin pumps, weighing scales, patient information leaflets) helps to build understanding. As yet, no virtual environment affords a high-fidelity virtual replication of the physical manipulation of real world objects and – while this holds true – face to face consultation is the only opportunity for such direct, object-mediated discussion.

Relationship between patient and service

We have found that the personal relationship between patient and the clinician plays an important role in the use and experience of Skype consultations. Participants' confidence in using Skype as a reliable and private communication tool was based largely on their trust in the clinician to act in their interests.

Additionally, establishing and conducting remote communication via Skype relied on shared-understanding or 'common ground' between the patient and clinician (e.g. knowing patient's working hours/routines, patient's confidence or anxieties in managing their condition).

Therefore, it is important to for clinicians to develop and maintain these relationships. We have found that different patients live very varied lives; some but not all patients get into a good pattern of managing their diabetes and interact well with health professionals. Use of Skype needs to be aligned with the wider social and contextual factors in the patient's lives, as well as their clinical and technical knowledge and capabilities. The practitioner is required to draw on their knowledge of the patients' lives and ability to manage their diabetes to support effective and appropriate delivery and use of the Skype for each patient.

Strengths and limitations of this study

It is important to note that the quantitative data were used to support the overarching goal of exploring the acceptability and feasibility of Skype, and not to provide evidence for the efficacy or cost-effectiveness of the intervention. Therefore, the study is not formally controlled. Patients were not randomised to receive either web-based consultation or not and this means that quantitative measures are be subject to many biases. Therefore, caution should be taken in interpreting the findings. Nevertheless analysis of the data has the advantage of showing what in principle is possible and may help inform choices for future studies.

The study was in a single department in a single organisation. The use of Skype in this clinic was shaped and enabled by particular individuals in a particular team (including existing and sometimes longstanding clinician-patient relationships). The personal commitment of these clinicians to increasing patient access (for example) may have shaped the evolution of the Skype service to include a lot of 'on-demand' contacts. In a different service with different clinicians and support staff, the service may have been more or less successful and become customised in different ways.

In sum, whilst this case study illustrates that Skype consultations *can* be integrated successfully and cost-effectively into the business as usual of a busy diabetes service, it does not show that success will be guaranteed in a different service.

Provisional recommendations for practice

Leadership and vision: Leadership is important to ensure that the team functions collaboratively and effectively towards a shared goal. The embedding of the technology within existing work practice requires high-level commitment across the team and the collective engagement and motivation towards a clear vision.

Small pilot to demonstrate proof of concept: The focus on a single locality allows the necessary richness to gain a detailed understanding of the processes and interactions within the service. This helps better understand the practical problems using Skype and the scope to implement and evaluate resolutions to these challenges.

Introduce change slowly and don't force it on staff: Develop the service incrementally with the direct involvement of the team to ensure compatibility and mutual adaptation between the new technology/service and existing practice.

Allow plenty of discussion among staff (and among patients): Encourage and support discussion among staff and patients about what the technology means and how it affects their work (e.g. team meetings, focus groups, ad-hoc conversations), and feed these insights back into the service design.

Develop SOPs: Provide written guidance on the key steps and processes to complete in order to provide a reliable and useful service via Skype. These should be clear and intuitive to both existing and new staff members. Where possible use existing SOPs and customised these to the team requirements.

Support flexible use: Implementation requires some formalised procedures to align the technology with existing processes and practices, but must provide sufficient flexibility to fit the use of the technology around the needs of the patient, and allow them to take the lead in service engagement. Allow scope for clinicians and patients to adapt the system and its use around their needs and existing practices

Collaboration with IT departments: The installation and use of Skype required ongoing collaboration with technical support (e.g. installing software onto new computers, forced upgrades). It is important to establish roles and processes to ensure rapid and consistent response to technical problems and avoid disruption to the service. In particular, build relationships with IT departments so that helpdesk support is on-hand when issues arise.

Manage patient expectations: The technology can change the dynamic between the service user and service provider. Increasing access to the clinician via Skype can sometimes alter patients' expectations about the clinician's role and availability. Patient may seek support outside office opening hours or request administrative information/action from the clinician (e.g. rescheduling appointments). Service managers and staff need to consider the scope and capacity of utilising Skype beyond the consultation, both in terms of manageability and equal access for patients

Understanding patients: The mixed-method approach has provided insight into the complex and sometimes chaotic lives of patients, and how this relates to their management of diabetes and engagement with services. As a tool to support service delivery, Skype should be used with an understanding of the patients' lives and abilities to manage their condition. We will continue this work (PAMS work)

to understand the role of patients' knowledge, self-efficacy and skill to manage their condition, and the role 'formal' tools and process (e.g. the Patient Activation Measure) and 'informal' encounters (e.g. 'small talk' in the clinic).

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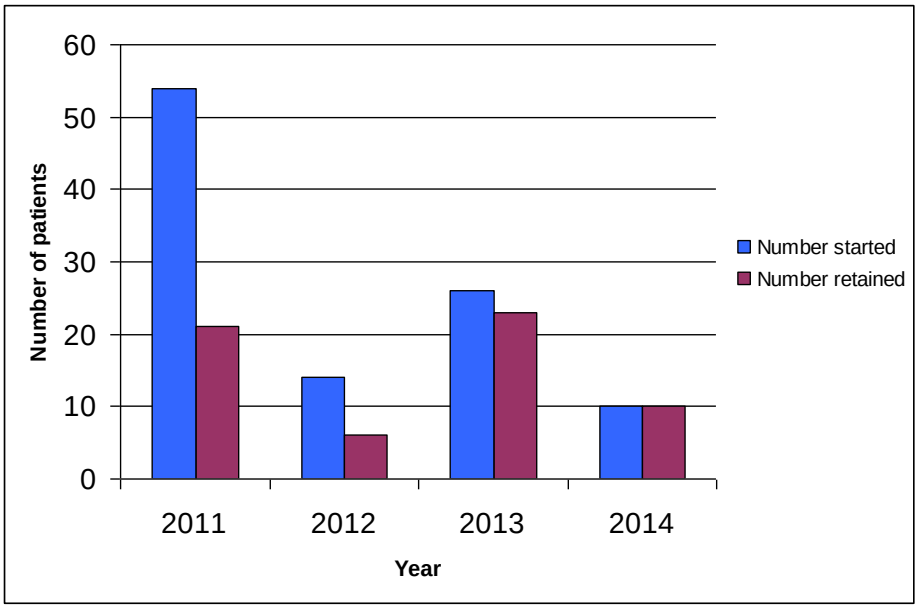
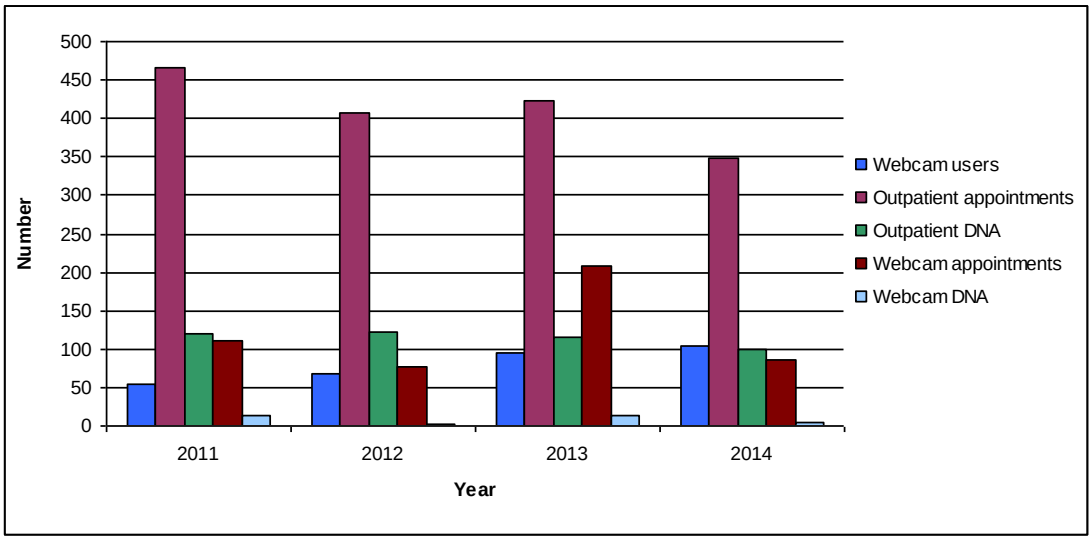
APPENDIX A: Frequency data for Skype usage across active users

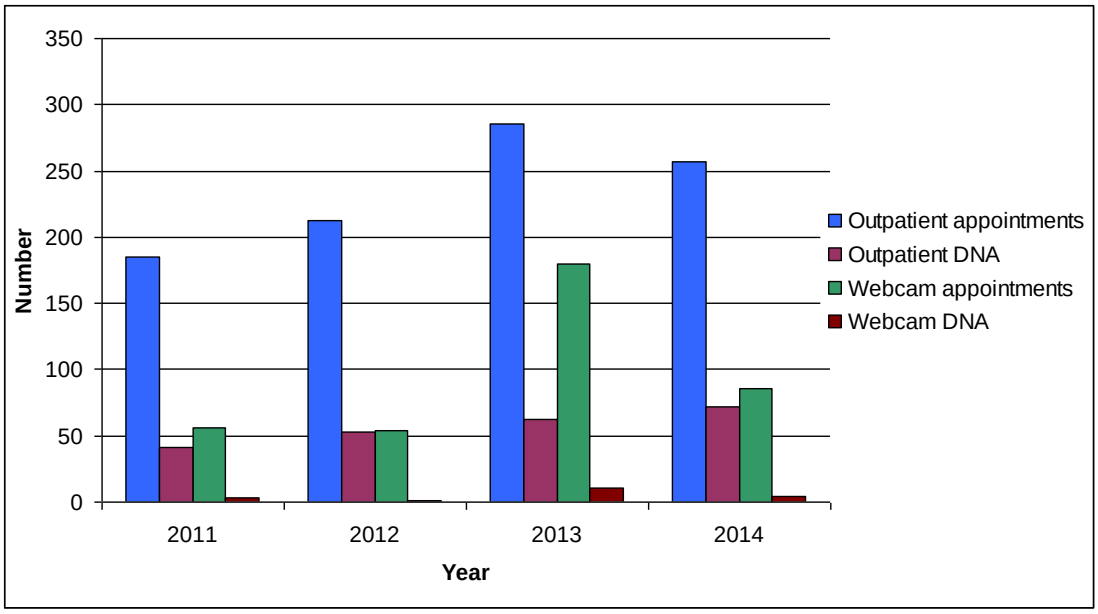
Appendix A.1: Graph shows uptake and retention 2011-2014: There has been a reduction in patient uptake over time but a marked increase in patient retention of users in 3013 and 2014.



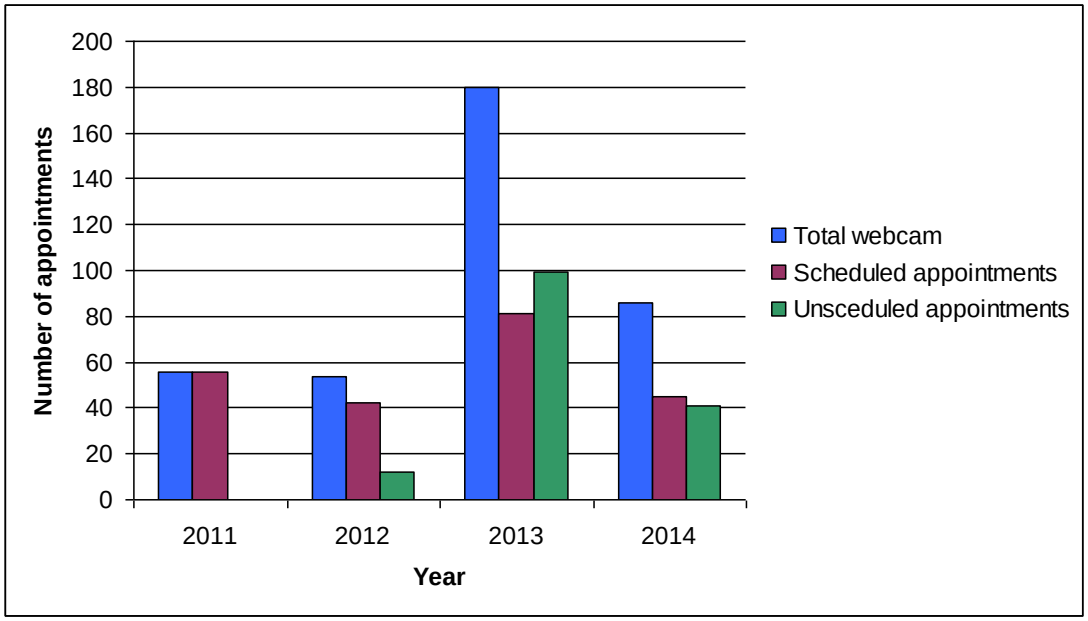
Appendix A.2: Overall webcam activity for all patients (N=104): This chart reflects the activity of all webcam users (historic and current). Users in 2011/2012 are attributed to the initial project (DREAMS).



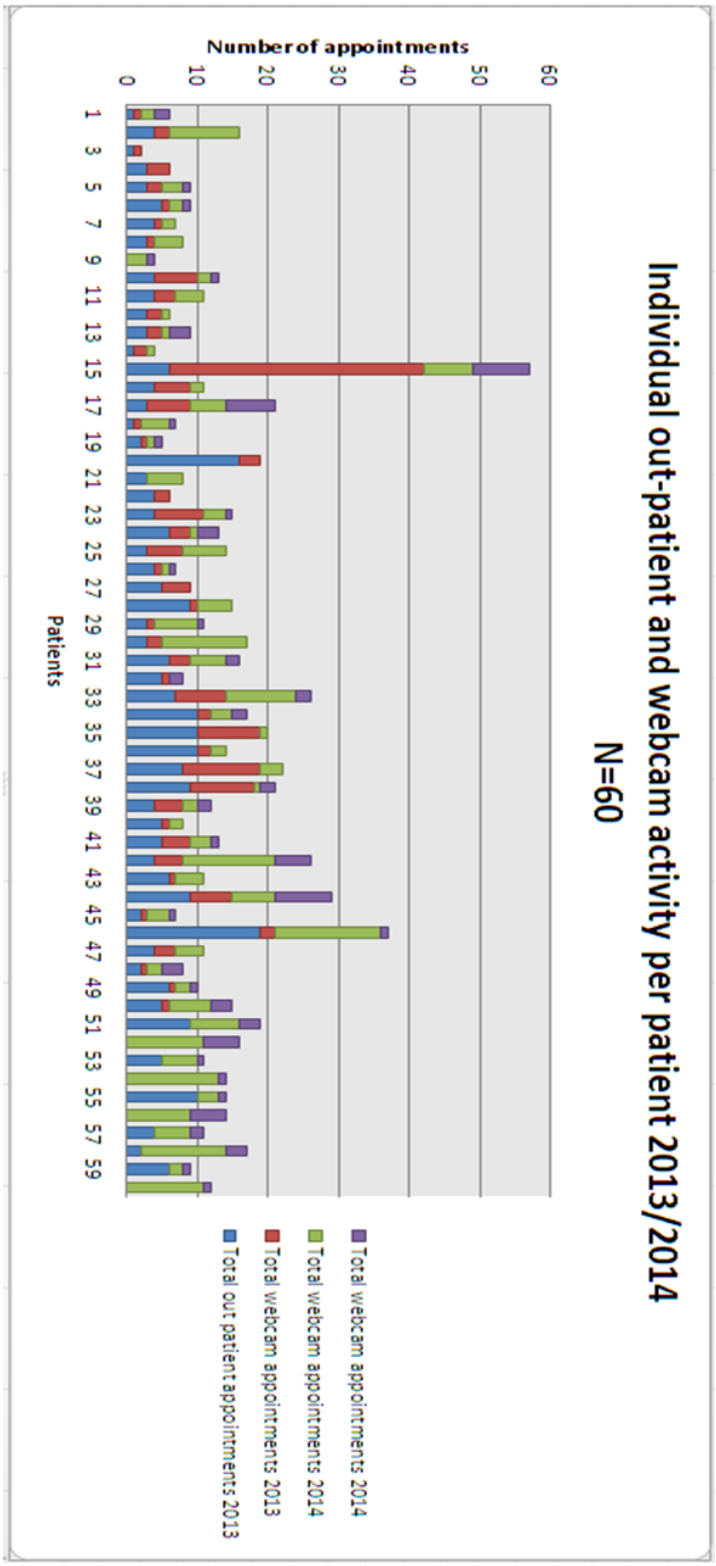
Appendix A.3: Overall webcam activity for active patients (N=60): The average out-patient non-attendance (DNA) rate for 2011-2014 for active webcam users was 24% whereas the webcam DNA rate for the same period was 8.5%. Webcam DNA rate was calculated using scheduled appointments.



Appendix A.4: Trend in scheduled and unscheduled webcam appointments (2011-2014): There has been a consistent increase in patient-initiated (unscheduled) appointments over time. Approximately 50% of all webcam appointments in 2013/2014 were unscheduled.



Appendix A.5: Individualised webcam and out-patient activity: This graph highlights that each persons' use of webcam is determined by their need which may be influenced by diverse factors at any given point in time



APPENDIX B: Statistical analysis of A&E attendance (report from consultant statistician)

Report by Francois Fays and Stephen Senn, Competence Centre for Methodology and Statistics, CRP-Santé, Luxembourg

Possible analysis of the efficacy of the web-based system

The purpose of this section is to present the outlines of a possible analysis of the efficacy of the web-based system. The pilot nature of the study has already been noted and this means that there are two major difficulties in coming to any conclusion about efficacy

1. The study is not formally controlled. Patients were not randomised to receive either web-based consultation or not and this means that the study will be subject to many biases. Some of these (difference in age, ethnicity, time since diagnosis etc) are already noticeable from the summary data. Of course, these could be incorporated in any model or analysis. However, there may be hidden confounders biasing the results.

2. The data-set is relatively small and also not as complete as might have been hoped. The original proposal states, "The cohort of patients will be tracked over time; using before and after measures with each patient acting as their own control". However for many patients the before data are minimal and it was for this reason that some data on patients who were not enrolled on the web system were collected.

Nevertheless a formal analysis of the data has the advantage of showing what in principle is possible and may help inform choices for any new study. Furthermore it will produce estimates of precision that may be an aid in deciding what sort of size a more definitive investigation ought to be.

Analysis of adverse events using a Normal-Poisson mixture model

The idea behind this is to assume that for each patient the risk of an adverse event is a function of an inherent (unknown) susceptibility that is itself affected by the treatment (web-based management or not). Given the susceptibility, the risk of an event would follow the Poisson distribution, however since the susceptibility is unknown it has to be modelled as itself having a Normal distribution. The log-scale is used for such modelling and the observation time is also included as a fixed risk factor using an 'offset'. (This simply dictates that, other things being equal, the expected number of events is twice as great when the observation period is doubled.)

What the approach does is compare the rates (events per time period) under two conditions: web managed and not web-managed. In doing this it has to allow for a rather complex nature of the data set. In some cases a patient was observed under both conditions but in other cases not. This means that some data can be matched by patient but other data cannot. It is also necessary to have some model as to what random variation the data would show. Patients are not clockwork machines

so that even if a given patient had an expected event rate (say) of 2 events per year it would never be possible to guarantee that in any given year the patient would have two events. In some (s)he might have 1 and in others 3 in other 0 and other 4 or even 5 events. Obviously very high numbers of events would be unlikely but not impossible. A simple distribution to describe such events over time is the Poisson distribution. However, it would be naïve to suppose that each patient under identical conditions (e.g web-managed) would have an identical event rate. Therefore a second mixing distribution is used to allow for random variation between patients in the true event rate.

This approach can handle the fact that some patients are observed under two conditions (web managed and not web-managed) and some under one condition only (either web-managed or not web-managed). It has been implemented here using proc nlmixed of SAS® and the results are shown in Table 1.

Table 1 Results of fitting a Normal-Poisson mixture model using proc nlmixed of SAS®. Only patients with a known date of diagnosis are included

Parameter	Estimate	Standard Error	DF	t Value	Pr > |t|	Alpha	Lower	Upper	Gradient
logsig	0.3166	0.2143	156	1.48	0.1417	0.05	-0.1068	0.7400	-0.00011
alpha	-1.0118	0.4682	156	-2.16	0.0322	0.05	-1.9365	-0.08701	-0.00002
mu	-8.8488	0.3325	156	-26.61	<.0001	0.05	-9.5056	-8.1919	-1.28E-7

The important parameter is alpha, which shows that the difference in the adverse event rate between the two modes (web-based or not) is about -1.0 on the natural log scale. This corresponds to a value of 0.37 when anti-logged, which is to say that the event rate under the web-based system is somewhat more than 1/3 of what it is under the other system (not web-based). In other words the data observed are consistent with a reduction of risk under web management. This result has an associated P-value of 0.03, which is to say that given the model assumed and assuming the null hypothesis that there were no true difference between event rates, a difference as big as this would be observed by chance about 3 times in one 100.

The above analysis assigns four patients who were given the possibility of using the web but never did so to the users group but does not include patients who had no date of diagnosis

Table 2: Results of fitting a Normal-Poisson mixture model using proc nlmixed of SAS®. Patients with an unknown date of diagnosis are also included

Parameter	Estimate	Standard Error	DF	t Value	Pr > |t|	Alpha	Lower	Upper	Gradient
logsig	0.6514	0.1845	194	3.53	0.0005	0.05	0.2876	1.0152	-0.00049
alpha	-0.7748	0.5191	194	-1.49	0.1372	0.05	-1.7987	0.2490	-0.00005
mu	-9.7541	0.4239	194	-23.01	<.0001	0.05	-10.5902	-8.9180	-0.00024

When these patients are included, however, as in Table 2, then the result is no longer significant, since the P-value is approximately 0.14, indicating a rather unremarkable probability of finding a result as extreme as this of only 14 in 100 under the assumption of no difference between conditions.

Further analyses are possible by fitting covariates. The purpose of this is to try and explain some of the variation between event rates from patient to patient in terms of possible risk factors. Here, just to illustrate the possibility, age has been included. A simple linear fit with age is given in Table 3. Here the parameter beta gives the relative risk of an AE for an increase in age of 1 year. The parameter suggests about a 5% reduction in risk with each year of life (which is rather surprising but might reflect different types of patient being involved). Table 3 Results of fitting a Normal-Poisson mixture model using proc nlmixed of SAS®. Patients with an unknown date of diagnosis are also included and age is also included as a covariate

Table 3 Results of fitting a Normal-Poisson mixture model using proc nlmixed of SAS®. Patients with an unknown date of diagnosis are also included and age is also included as a covariate

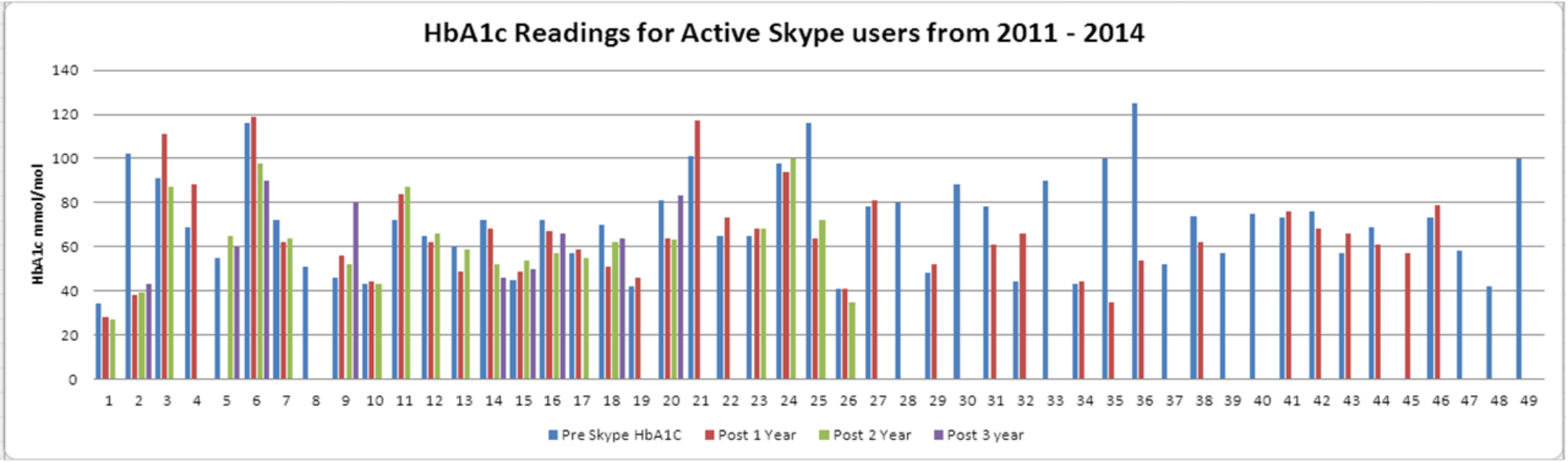
Parameter	Estimate	Standard Error	DF	t Value	Pr > |t|	Alpha	Lower	Upper	Gradient
logsig	0.4473	0.1793	194	2.49	0.0134	0.05	0.09370	0.8008	-7.87E-6
alpha	-1.5367	0.5146	194	-2.99	0.0032	0.05	-2.5516	-0.5219	-1.68E-6
mu	-7.0913	0.5428	194	-13.06	<.0001	0.05	-8.1619	-6.0207	-3.29E-6
beta	-0.05584	0.01297	194	-4.30	<.0001	0.05	-0.08143	-0.03026	-0.00012

When age is included in the model, then the estimate, alpha, associated with use of the web-based system is again significant. The estimated effect is -1.5 on the log scale and this corresponds to a relative risk of 0.21. The associated P-value is approximately 0.003. However, one should not be too impressed by this. The model was not pre-specified and has already been explained the data are subject to many possible baises.

Comment

The analysis here is an illustration of what can be done. *The findings should be treated with extreme caution*. As can be seen the results are rather different as different patients and different factors are included. There is a suggestion that the event rate is lower under the web system but there are many possible explanations of this. The sample size is small, as befits a pilot study, and the study is an observational one and not a controlled experiment. Thus the results here should just be taken as an illustration of the sort of analysis that might be performed in a larger randomised controlled study and not as a valid estimate of the causal effect of offering patients a web-based system.

APPENDIX C: HbA1c data for active Skype users



The above graph displays the HbA1c results for 49 of the 60 patients who are active Skype users. Yearly recordings were obtained where available per patient following their Skype start date. Patients who commenced using Skype in 2014 have not been included either due to no recent HbA1c recording or it being < one year since commencing Skype.

APPENDIX D: Example clinical case summaries

Section 1. Rena's story

Rena was born in India; she lived with her grandparents along with her two younger brothers for much of her childhood but then her mother remarried and the new family came to UK. Soon after arriving here aged 12, Rena was diagnosed with Type 1 diabetes. She had 12 admissions for diabetic ketoacidosis in the subsequent five years.

An early handwritten summary is perfunctory and telling: *"Age 14. DKA [diabetic ketoacidosis]. Problems with compliance. Difficulties in relationship with mother. Known to [Child and Family Consultation Service]."* Another reads: *"SHOs [junior doctors] need session with [psychologist] on management of difficult behaviour in kids with diabetes."*

The outpatient letters in Rena's notes document a story of poor compliance with medication (*"she admits not taking all of her insulin"*), refusal to do home blood glucose monitoring and poor control (HbA1c running at 10-11%). There was cursory allusion to wider family problems (e.g. in the mother-daughter relationship) and social ones (e.g. difficulty making friends at school). Admission to hospital appeared to bring rapid though temporary respite from these difficulties.

Notably, when Rena spent six months in India visiting her grandmother, her diabetes control improved dramatically – an improvement attributed to the consultant to her *"being more active"*, though no comment was made about the removal of the need for secondary gain. Within three months of her returning to UK, Rena's diabetic control had deteriorated again.

At age 18, Rena admitted to a clinician that she *"hates living at home"*, that she had a boyfriend and was a *"social smoker"*.

On transferring to the young adult clinic, Rena developed a good relationship with the diabetes nurse specialist. She moved out of the family home to a rented room in an adjacent borough and after gaining some National Vocational Qualifications got a job in hair and beauty therapy. She told the nurse she felt much more in control of her diabetes now her mother wasn't involved, though she missed her little brothers.

After two years in the adult clinic Rena's control was much improved even though she was formally on a much lower insulin dose (perhaps because she was now actually taking the insulin as directed). Rena and the nurse had conversations about contraception and pre-pregnancy planning, but Rena said she was not planning on a pregnancy yet. She had given up smoking and reduced her alcohol intake considerably.

Rena's job was very demanding, though she was pleased to be promoted to management trainee. But this meant she found it very difficult to miss work for

her diabetes appointments. Her attendance became erratic and her HbA1c rose from 8% to 10.7%. She was offered Skype appointments but initially chose not to take them up. She missed five out of seven appointments, though it is noteworthy that she had no admissions for ketoacidosis since moving out of the family home.

Six months ago, Rena appeared unannounced in clinic and saw the diabetes nurse. She said she had changed her mind about Skype appointments, having learnt to use this technology when her extended family in India started using it to keep in touch. She particularly liked the possibility of contacting the nurse when *she* felt it was necessary, rather than being summoned by the clinic system. Rena has had one Skype appointment and agreed that it was helpful. She feels *"well in control"* of her diabetes right now, but she plans to be in touch with the diabetes nurse when she needs professional advice. She is engaged to be married next year.

Section 2. Summary and comment

This is a child/young woman with complex family and social issues, whose relationship with her mother appears particularly fraught. In her childhood, hospital admission with acute diabetic decompensation was a way of escaping difficult circumstances at home and school. Improvements in her control over the years have been driven not by adjustments in her insulin dose but by her wider social circumstances. As she moved from adolescence to adulthood she became more confident and independent, managing her diabetes competently and giving up smoking. Her non-attendance at diabetes appointments was due not to non-engagement but to her reluctance to miss work. But Skype appointments didn't seem the right solution until recently – perhaps because Rena had only limited exposure to the technology. No pressure was put on her to consult remotely, so she is one of the later adopters of this medium. As Rena looks forward to married life and perhaps starting a family, she now has an 'open door' to make contact with the service.

APPENDIX E: Planned work on PAM pilot study

Summary: The qualitative work done for the DREAMS project has provided rich data related to individual patients, their ability to self-manage and the challenges faced, and the roles of tools like Skype-based contact. We therefore set out to establish their level of activation using PAM, in order to establish the level of engagement required to introduce online care. Early work aimed at co-relating the Patient Activation Scores in some of these patients with their level of engagement and self-management, has however shown discordance between the two. We would like to explore this further in some detail

Aim: This proposed project aims to:

1. Develop a better understanding of the use of the PAM assessment within the diabetes service at NUH and
2. Provide the context in which its use can be maximised to inform the delivery of care.

Work Plan: It is proposed that 35 individuals with different demographic characteristics, diagnosis (T1 or T2 diabetes) and duration of diabetes will be identified to complete the PAM questionnaire. Each patient will be interviewed by an independent social anthropologist who has worked without team on related projects in the past. Bilingual health advocates will be used to assist with completion of the questionnaire and conduct of interviews for patients who are less proficient in English. A social and clinical profile will also be compiled for each individual in order to facilitate a comprehensive evaluation of all the information collected.

We have so far completed questionnaires and interviews for about 15 patients. This will therefore provide information for a total of 50 patients. The project will be carried out between January and March 2015

Project team: Dr S Vijayaraghavan (clinical lead); Anna Collard (Social Anthropologist); Desirée Campbell-Richards (Research Nurse); Raunak Poonawalla (Medical Student Researcher from UCL will help with some of the observation and evaluation as part of his research experience work at UCL. He has a long term illness himself, and speaks a few Asian languages). The estimated cost for undertaking this project is £12,975.

Team member	Time commitment (12 weeks)	Cost	Total (£)
Shanti			£988
Anna	20 days	£250/day	£5000
Desiree	24 days	£244/day	£5856
Bilingual Health Advocate(s)	36 hours	£26/hr	£936
Additional PAM licences	20		£15
Admin	12 hours	£15/hr	£180
TOTAL	-	-	£12,975

APPENDIX F: Questionnaire for leaflet evaluation

Leaflet evaluation (22/04/14 – 13/08/14)

A total of 27 appointments were booked and leaflets were sent out in the post with details of their appointments. A total of seven leaflets were evaluated for patients who attended their appointments.

QUESTIONS	RESPONSES
How easy was it to read the leaflet?	2 – Very easy 4 – Easy 1 - Satisfactory
Do you like the layout of the leaflet?	4 – A lot 3 – A little
How easy was it to understand the information in the leaflet?	3 – very easy 4 - Easy
How useful was the information in the leaflet?	3 – Very useful 2 – Useful 1 – Satisfactory 1 – Not completed
Did the information help you to prepare for your appointment?	3 – A lot 2 – a little 1 – Not at all 1 – N/A
Did the information provided, help you to think about questions to ask at your (doctor or nurse) appointment?	1 – A lot 4 – A little 2 – Not at all
Would you say that the information provided made you feel	6 – Reassured 1 – N/A
How useful was the leaflet in helping you to plan for future appointments?	2 - Very useful 3 – Useful 2 - Satisfactory

APPENDIX G Planned work on SOP development

Summary
We will draw on the DREAMS process evaluation findings and input from informants across the Trust to produce SOPs (Standard Operating Principles) for Skype consultations. This will facilitate the sustained use of Skype (e.g. as clinical, admin, IT staff change), as well as wider uptake across other NHS departments. The work will consist of engagement with clinician and administrative staff (both within the diabetes service and across other departments), as well as input from the Trust's ICT department for technical input, online resource development and approvals.

Aim: To develop standard operating procedures for the implementation and use of Skype consultations in clinical settings

Objectives

- Develop SOP document for the use of Skype within the Diabetes department
- Develop SOP document for the implementation and use of Skype for other clinical departments within the Trust
- Produce an Trust intranet SOP resource
- Develop SOP for other departments in other NHS Trusts across the UK and for use as resource material by our funders, the Health Foundation.

Work plan and timelines

The project will consist of three overlapping phases of work. *Phase 1* will focus on producing the SOP documents specific to the Diabetes department. *Phase 2* will develop SOP documents and intranet resource for other departments within the Trust. *Phase 3* will develop SOP documents for wider dissemination for other NHS Trusts. This work will be conducted during Jan-Feb 2015(8 weeks).

Phase 1 (week 1-4): SOP for the Diabetes
We will produce the SOP specifically for the Diabetes team, drawing on the DREAMS process evaluation findings and direct input from service and IT support staff. This will include protocols for: 1) Setting up and maintaining Skype; 2) Communication via Skype; 3) Managing availability and access; 4) Procedures in clinical settings.

The activity will consist of a review of existing SOPs (internal documents and those available in public domain), weekly meetings with service staff (consultants, nurses, admin) to develop the clinical and administrative component. A final meeting will be held with the service and ICT staff together to finalise and agree the SOP.

Phase 2 (week 3-6): SOP for other departments

We will adapt the SOP document for use across other departments within the Trust. The SOP will be adapted with input from the Trust's ICT support officers and engagement other clinical teams seeking to use Skype consultations. The ICT department will lead on putting the SOP through Trust approval processes and developing an intranet resource for staff.

Phase 3 (week 5-8): SOP for national dissemination
The final phase will focus on adapting the SOP to provide transferable guidelines for other NHS organisations. This will be made publicly available as a pdf document, and can be made available via online resources, including the Health Foundation website.

Resources and support requested

Total cost = £5,000

The costs will cover 5 days of staff consultancy time from Barts ICT department to provide technical input, produce online intranet resource, and lead on gaining Trust approvals for the SOP.

APPENDIX H: List of interested enquiries

Date	Organisation/Contact	Details
05/11/2013	Sandwell and West Birmingham Hospitals NHS Trust, Consultant in Diabetes & Endocrinology	Requested a copy of slides after DREAMS presentation at EHI Live, Nov 13.
11/11/2013	First4Health Federation	They would like to set up webcam consultations
12/12/2013	Barts Health, Cardiology nurse and Lead Nurse for Cardiac Rehabilitation	They would like to use online appointments in Cardiac Rehab
23/01/2014	Clinical Director for Bolton Community Practice,	Received some funding from local CCG to use digital technology within primary care and interested appointments via webcam
12/02/2014	Norfolk and Norwich University Hospital, Diabetes Team	Keen to set up a pilot on the use of Skype as a means of reducing DNAs in their clinics. Wanted advice on some of the issues they felt they should address.
18/03/2014	Barnet, Enfield and Haringey Mental Health Trust, Business Development Manager	looking to reduce DNA in diabetes clinic locally and interested to see how Skype could support this
11/03/2014	Countess of Chichester Hospital NHS Foundation Trust, Diabetes & Endocrinology	Asked for information governance information following DREAMS presentations at Diabetes UK
21/03/2014	James Cook University Hospital, Northern Deanery Diabetes & Endocrinology	Interested in Transitional Diabetes/ Young Persons diabetes and has been by their Diabetes lead to work on improving the service.
08/04/2014	Royal London Hospital, Paediatric Orthopaedics	Advice for web based f/up clinic for pts with club foot needing regular checks. Advice on setting up service and tools you used to collect the qualitative data.
28/04/2014	Portsmouth Hospitals NHS Trust, Endocrinology & Diabetes	They want to do similar work, using Skype to support diabetes patients
09/06/2014	Portsmouth Hospitals Trust, IT department	Wanted to discuss: challenges regarding information governance and IT Security and if there are any SOPs
19/06/2014	Mile End Hospital, Central Community Health Team	Clinical psychologists considering using Skype
31/10/2014	Royal United Hospital, Bath, Diabetes & Endocrinology	Wants to trial Skype within the diabetes clinic and seeking advice on setting up and running service
4/11/2014	Royal London Hospital, Neurology department	They would like to use Skype consultation for MS patients
9/12/2014	Health Innovation Network, Guy's Hospital London	Seeking information on experience and logistical issues around using Skype. They are currently running the diabetes improvement collaborative for diabetes service improvement in South London.