Additional data analysis chapters and further appendices

The role of digital communication in patient-clinician communication for NHS providers of specialist clinical services for young people receiving specialist clinical services (The LYNC study): a mixed methods study

Authors

Frances E Griffiths[1], Xavier Armoiry[1], Helen Atherton[1], Carol Bryce[1], Abigail Buckle[1], Jonathan AK Cave[2], Rachel Court[1], Kathryn Hamilton[3], Thandiwe Rebecca Dliwayo[3], Melina Dritsaki[1], Patrick Elder[1], Vera Forjaz[3], Joe Fraser[4], Richard Goodwin[3], Caroline Huxley[1], Agnieszka Ignatowicz[1], Eleni Karasouli[1], Sung Wook Kim[1], Peter Kimani[1], Jason J Madan[1], Harjit Matharu[5], Mike May[1], Luhanga Musumadi[6], Moli Paul[8], Gyanu Raut[7], Sailesh Sankaranarayanan[9], Anne-Marie Slowther[1], Mark A Sujan[1], Paul A Sutcliffe[1,] Isabelle Svahnstrom[1], Frances Taggart[1], Ayesha Uddin[1], Alice Verran[1], Leigh Walker[1] and Jackie Sturt[3]

[1]Warwick Medical School, University of Warwick, Coventry, UK

[2]Department of Economics, University of Warwick, Coventry, UK

[3]Florence Nightingale Faculty of Nursing and Midwifery, King's College London, London, UK

[4]Patient and Public Involvement (PPI) representative, London, UK

[5]University Hospitals Coventry and Warwickshire NHS Trust, Coventry, UK

[6]Guy's and St Thomas' NHS Foundation Trust, London, UK

[7]King's College Hospital NHS Foundation Trust, London, UK

[8]Coventry and Warwickshire Partnership Trust, Coventry, UK

[9]University Hospitals Coventry and Warwickshire NHS Trust, Coventry, UK

Corresponding author: Frances Griffiths, Warwick Medical School, University of Warwick, CV4 7AL, UK. Email: f.e.griffiths@warwick.ac.uk, Telephone: +44 (0)24765 22534

This document contains three chapters which contain additional data and analysis related to the LYNC study that was not central to the final report. In addition there are appendices containing all the interview schedules, questionnaires and observation checklists used in the study.

Additional Chapter 1: Personal Health Records: their use in six specialist care settings

Introduction

This analysis was undertaken following discussions with NHS England about the LYNC study findings to inform their policy development in relation to Personal Health Records (PHR). The results presented in this chapter formed the results section of our previously unpublished report for NHS England. The LYNC study was not designed to focus on PHRs although a PHR meets our LYNC criteria for digital clinical communication. During the LYNC study, PHR platforms had been mentioned by clinicians and patients in clinics where they existed.

We re-interrogated our data from the 6 study sites currently using a PHR which included interviews from 5 IG managers, 56 clinicians and 55 young people with long term conditions. Of these 116 participants, 17 made reference to the PHR. It is these 17 interviews from which we have drawn the findings in this chapter. Eleven of these interviews were drawn from a Diabetes and an Inflammatory Bowel Disease (IBD) clinic with 1 or 2 interviews each for the remaining clinics. The lack of data on the PHRs may be because we did not specifically prompt interviewees about PHRs during interviews. Interviewees may also not have recognised a PHR as a form of digital clinical communication and so did not think to mention it.

In this chapter we describe how the PHRs are currently being used in the 6 sites, perceptions of the PHR, how they were adopted in the clinical sites and how these systems may impact on the care provided to patients.

The six clinical sites using a PHR consist of the following specialties Liver, Diabetes x 2, Inflammatory Bowel Disease, HIV, and Renal.

Liver clinic

One of the clinicians at the liver clinic had a recently created a website. This system is bespoke, double encrypted, which the clinician has developed themselves. It is an interactive website to which patients and parents can upload and monitor their data from an App on their mobile phone (e.g. their weight, blood pressure, fluid intake, fluid output), as well as ask questions. Apart from this one clinician, no one else in the Trust is using it. The website is only for complex patients or those recently discharged who require greater monitoring. The clinician was not using it with young people eligible for the LYNC study.

The clinician is prompted to review a patient's data if they call, email them with a query, or follow up is required because they have recently come into clinic or they have just been discharged from hospital. They then review the data and send a direct message to patients and/or parents advising them about the results or asking them to come and see them in clinic. The message goes to the APP on the patients' smartphone. The

patient receives notification that a message has arrived. The clinician can tell when patients have opened it and read it (there is a list of messages they have sent down the right hand side of the web page and whether messages have or have not been opened is indicated here). Patients cannot respond to them via the website, they have to email them or call the nurses/specialist registrars. The reason patients cannot reply via the website is that the clinician is not continually monitoring it, so messages may go unanswered for some time.

The webpage is used as an aid in consultations, for example, looking with the patient at how the patient's weight has varied over time.

Reminders are sent to patients to prompt them to enter their data on the App. The clinician either sends these manually (e.g. from the weight screen they will send a reminder that says 'don't forget to record your weight), or they can set this up to be done automatically, four times per day.

The clinician is currently piloting the website with complex patients as such patients are closely monitored. This normally means the specialist nurse has to call them by telephone to see how they are and discuss their results regardless of whether the results are problematic or not.

The clinician considered the website made patient monitoring process quicker so saved time and patients seemed able to use it. The clinician hoped the system will replace some regular check-ups and be used for all clinic patients by the whole clinical team.

Diabetes clinic (1)

The clinic uses a system that allows people to upload the data stored on their blood glucose meters so that their blood glucose data can be viewed in graphs. Patients can upload their data at home, ring the clinic and tell them when the data is on the system. Patients do this before a clinic appointment so it can be discussed in the consultation.

The system is seen to provide a structured way of completing the routine task of blood glucose monitoring.

> It's incredibly useful and it's used pretty much with every consultation that I do, but it can also be used remotely. As I say, people can log on from home, download their data and then be in contact with me to say…can you look at this, I'm a bit worried about that, or what do you reckon I should do next? (Clinician)

The clinic has been running system pilots out in the community. They have approximately 12 of their GP surgeries with PHR boxes. They can get the data from the GP surgery and then do a consultation either with the practice nurse or with the patient directly because they've already seen the patients' data without having to bring them to the hospital.

A patient had downloaded their reading on the system and what they wanted to do was just have their consultation without coming here. So you look at the readings; now can you do that over email – of course you can. Do you need to see the person – probably not. (Clinician)

I think one key thing, for our patients, is that we have to have blood glucose data… so if we're having a meaningful consultation with a patient over email communication, then we need that blood glucose data… so if they have uploaded it to… (the system)…then we can access that remotely and work through things with them, but if we don't have that, or have anything written down, then it's very hard to help the majority of people without that information. (Clinician)

One young person described their use of the system:

They phone me, ask me what's up, ask me for my readings on my little blood testing, sugar testing machine, which I can go on and then, I have to press two or three buttons to get them all up, and I go back and tell them what…. (my blood glucose levels)…have been over the past few days, or however long they want it, so that's pretty cool.

Inflammatory Bowel Disease (IBD) clinic

The IBD clinic uses a PHR system where patients can upload symptoms. There is an alarm for nurses depending on the severity of symptoms. This system was established in 2012-2013 using software provided by an external company to which the clinical team added an IBD symptom checklist. The clinical team offers the possibility of using this PHR to all of their 3,016 IBD patients. Staff are widely aware of how to use the PHR but only two clinicians manage it. Other clinicians have withdrawn their contact details.

The clinicians interviewed described the system as a helpful way for patients to upload their symptoms and access their own data and medication. The two clinicians managing the system check the messages in the system anytime, throughout the day. To register patients on the system the IBD clinicians ask patients for their email address. The two IBD clinicians invite patients to register, sending an initial message through the PHR. Through the PHR, the IBD clinicians are able to send out a mass email to all the patients on the system which they do occasionally.

Any new things that come out, we can tell five hundred people at a stroke, rather than waiting to see them in clinic or sending them all a letter and all the cost of stamps and things, you save all that. (Clinician)

When patients log in they can complete an optional symptom checklist which can be submitted to the IBD clinicians managing the PHR for review. Where patients score above a threshold the IBD clinicians receive

an email alert. The clinician then logs in and reviews the alarm. Based on the patient's profile, the clinicians decide on the required intervention, for example, recommending a change in medication or further investigation/tests.

> There's an alert system in there that gives us an alert if someone's doing badly out there in the community; it's a way of connecting with us wherever they are, if they're off at university or off on holiday on a cruise ship. We've been contacted by one guy getting married in Lithuania and they couldn't communicate with a GP but did so through the website. (Clinician)

One of the clinicians explains that patients come onto the system for many reasons, looking for their results, looking for flare-up advice, wanting to change their appointments, requesting blood testing, requesting to see a dietician and asking about holiday insurance.

> The majority tend to be that they are having a flare-up, or it's an ongoing discussion with a flare-up and they have had their bloods done and they want the results and then some step-up advice. But some may be that they have come away from clinic and they're a bit confused and they just want to clarify something from clinic….We get quite a few calls about not being able to get hold of their medication. Diet advice. We get quite a few ladies ring up and say that they have just found out they're pregnant and what should they do, should they stop their medication or continue. (Clinician)

Clinicians thought that IBD patients are getting a better service, having easier access to professional advice.

> Not relying on the internet and googling some weird stuff. Still do, but at least this time they're telling us about it and asking about this, that and the other. (Clinician)

Clinicians also felt it enabled young people to provide them with a truer picture of how they are:

> Sometimes I think we get a slightly truer perspective, particularly from the transitional and young adults, who are just intimidated by face-to-face contact, and some people do feel intimidated in the clinical scenario. (Clinician)

They also talked about maintaining engagement with patients:

> As for the patients, I think they feel more connected. We have comments …from people saying that they felt unwanted and unloved…. And this is a way of keeping patients on an umbilical cord, connected to a specialist at a point at which they need them, rather than just dragging them up and pulling them out of their caring, picking kids up from school, university, work, you know. (Clinician)

One of the nurses explains when it doesn't work so well:

They keep coming back with the same question in a different format, rephrasing it, or they will send it to [nurse] and then just send it to me and wait for a different response from the two of us, not realising we're sat next door to each other and we can see. (Clinician)

Regarding workload, a clinician explained that it has increased dramatically:

It's expanded enormously, so just look at checking alarms, three times a day, only 5 minutes, that's 15 minutes a day, five days a week, 52 weeks of the year… One might just be a quick answer about a blood results, then they usually come back with another question and another one and another one, and all those things add up. (Clinician)

Young people reported uploading their symptoms and trying to get in contact with the clinic when they have a 'flare-up.' One of the young people explains how they would like to have an urgent message system on the PHR, describing the need of having a system where some messages could take priority and staff would be able to see it instantly. One young person explains how they use the PHR:

I log in and then you simply just fill in details of… basically it's a template and you put in the details and it allows anyone to see your general wellbeing …Basically it's a log, it's a diary, that's all it is really. (Young Person)

One of the young people describes the benefits of the PHR:

When you have a session with them (clinician) next, …they refer to your previous entries. So they use the PHR for four weeks and each week you update it. What they do in your session you're telling them the symptoms or something and they will just flick through and they will see how your condition has improved or worsened rather than needing to go through a full depth conversation. So it's pretty handy that it summarises how your condition was. (Young Person)

HIV clinic

The Trust where this clinic is based was evaluating a PHR portal with a number of patients. The system is currently in use in other many specialties across the same Trust. A single clinician is the main lead in the clinical site studied and the PHR allows patients to remotely access their clinical information, including letters and test results. Patients can submit information, and their consultant is able to see the updates and respond to them if needed. Patients can also interact with each other within the portal. Currently the system has 888 patients signed up. Views on the system are only from the healthcare assistant, the person responsible for implementing the system in the Trust. Patients with some conditions are able to talk to other

patients to share experiences. The health care assistant explains that the majority of patients want to know their test results.

The system was set up by the Trust and then the service implemented it. They were told the system was happening but no training was given. The healthcare assistant started to implement it because they had a personal interest in communication.

> I like everything about communication, I love it, so I think this is the way forward... So I was like, okay, let's do it. I took a leaflet, read it myself, went into website to get familiar with everything. I say, okay, how are we going to do it? …I thought, who else is going to do it, let me do it. I took over and I said that's it, let's sign everyone up. (Health Care Assistant)

Patients can see their results, appointments and consultation letters. Patients can see the consultation themselves, so if they have questions or they forgot what the doctor said, they can check. Patients can get blood results over text, over the phone or see it on the system. The majority of patients check their blood results on the system.

The Health Care Assistant running the system reported differences in how people perceived the system. Young people were comfortable with using whereas:

> older patients were concerned… about confidentiality, can everyone else see it, is the first question they ask. (Health Care Assistant)

However, some young people didn't use it:

> They don't want to know, 'why do I want to know my results, I come, it's enough.' (Health Care Assistant)

Diabetes clinic 2

This clinical service has a database system which collates information about patients. This was particularly aimed at patients using insulin pumps. Access by patients to this system was developed, but the Trust encountered problems while testing it so patients don't at present have access to it.

One of the nurses explains the convenience of using the database

> When you've done home visits, at the end of the day you've obviously got to log that, you're not going to come back here because it takes forever to go and park your car. So you might as well go home and hook up to the mainframe here and catch up on your workload. (Clinician)

If a clinician receives a text from a patient they can refer to the database before responding. Patients using insulin pumps download their blood sugar reading onto their computers then email them to staff. This is copied and pasted into the database. Text messages are transcribed onto the database along with records of telephone calls.

Renal clinic

The clinic uses a database that patients can access. Currently 836 patient users are registered and 346 users are active. The information recorded includes pre and post dialysis weight, blood pressures, fistula access, dialysis, blood flows, erythropoietin drugs administered, adverse reactions to dialysis session, transplants, etc. Staff members are able to record on the system what drugs patients are on. Patients can log in from anywhere to access their clinical information. Patients are also able to contact any of the team through the system using a special email system. The nurse gives one example:

> So, for example, this week there was a problem with pathology and we didn't get any results for four days, so Tuesday morning there was a tranche of emails in the inbox saying, where are my blood results. Which is good because … if they're complaining they can't see it, we know they're using it.

Patients were introduced to the PHR at education sessions run by specialist nurses.

Summary of findings

PHRs were used in six of the 20 clinics studied. The use of the PHR to share data between and in consultations was important to both patients and clinicians. Advice could be given/requested when needed between consultations. Whilst use of a PHR could increase clinician workload, clinicians reported more benefits than dis-benefits. In sites were there was evidence that clinicians and patients had been prepared for using the PHR it was then used successfully. Supporting a local champion to lead both patient and clinician engagement with the PHR was effective for one site and establishing a formal care pathway to signpost the PHR for patients was effective in another.

Additional Chapter 2: Perceptions of Information Governance managers regarding SKYPE (or equivalent) for clinician patient communication

Introduction

This chapter presents the results section of a previously unpublished report prepared for NHS Digital (formerly the Health and Social Care Information Service (HSCIC)) in response to their request to understand how Information Governance (IG) managers in NHS Trusts viewed the use of Skype for clinical encounters. It presents analysis of data collected as part of the LYNC study.[1] At the time of undertaking this analysis we had undertaken 12 interviews with IG managers in 12 NHS Trusts on a range of issues related to their role, the use of digital channels for communication with patients about clinical matters within their Trust, policies and procedures and the national context for IG and digitalisation of NHS communication. In these interviews, the IG managers discussed the use of SKYPE in their NHS Trust generally not restricted to, or necessarily including, the young person's clinic that was the focus of our research interest. The main goal of this chapter is to present the IG managers' views and perceptions, and the use of SKYPE or equivalent in their NHS Trust.

Methods of data analysis

All interviews were transcribed, checked for accuracy and anonymized. Each transcript was then key word searched to identify all references to SKYPE or equivalent during the interviews. The key words used were 'SKYPE', 'VOIP', 'VIDEO', 'WebEX' and 'FaceTime.' All relevant data were extracted from the transcripts and themes developed sequentially. Six main themes were identified. All quotes are from IG manager interviews. We identify the source by the clinic recruited to the LYNC study in the Trust in which the IG manager worked. However, the IG manager was interviewed about what was happening in the Trust as a whole, not just the recruited clinic.

Findings

Table 1 NHS Trust use of SKYPE or equivalent

Clinic recruited to the LYC study in the Trust in which IG manager worked	Does the trust use SKYPE or equivalent?
Liver	No
Mental health 4	Lync yes, SKYPE no

Diabetes 2	No- looking at it
Sickle cell	Yes
Inflammatory bowel disease 1	No mention of SKYPE or equivalents
Cancer 1	No mention of SKYPE or equivalents
Cancer 2	Yes, pilots
Cystic fibrosis 1	No- considering it
Mental health 2	No mention of SKYPE or equivalents
Mental health team 3	Yes SKYPE and FaceTime
Arthritis	No
School nurse service	Pilot with a VOIP product, not SKYPE, not progressed beyond pilot yet.

Infrastructure considerations

A number of IG managers had concerns regarding their infrastructure capacity to deliver a reliable SKYPE service, in particular, bandwidth was a concern for 3 IG managers.

> I think the technology here is probably really important with Skype consultations. More so than emails, because you know, it doesn't really matter how many seconds it takes for that email to go from your inbox to somebody else's. But I think if you're having a face to face dialogue with a patient, it's got to be as near to real as it can be. … Now we're using bandwidth every day of the week in terms of the hospital. When you introduce technologies that will use that bandwidth what's the impact to the hospital, what's the impact on patient care, you know, how do we restrict the flow and so on and so forth. So all those things have to be considered. (Cancer 2)

> A picture where you can see the individual, you have the advantage of being able to sort of see the tone of the voice with the look on the face, so there's a bit more of a personal element to the Skype type interaction. Disadvantage of course is the internet itself is not, regardless of how good it is within an area, a stable platform in the sense that you get the good strong continuous signal. (Mental health team 3)

If we go to some of the other sites, the way their network is configured they haven't got the bandwidth and actually one of those is one of our CAMHS sites which is, you know, the sites who would probably want to do it but the way their network is that would suffer more than it would here. And they're the ideal service to say right, do you want Skype or use these technologies? Oh yeah, yeah, yeah. But you've got a rubbish little network down there compared to what you'd have coming out of here. (Mental health 4)

Two IG managers touched on the cost or cost saving of using Skype for clinical encounters.

It would be expensive if… well it doesn't work over normal 3G or 4G, but if you're using our corporate Wi-Fi, I guess Wi-Fi networks that could also swamp it with stuff we don't really want it to be there for, and that's not what it's provisioned for. We haven't got the strength in the network just to handle the bandwidth. (Mental health 4)

So you might be able to see more patients, but your team might actually be smaller, because what you're doing is you're using other types of engagement methods with them. If you were having Skype consultations with a patient, you might be able to see more patients that way, because you're not having to travel. (School nurse service)

The IG manager quoted below could see the potential benefits of using Skype, including improving engagement of young patients and reducing missed appointments but had concerns about data security.

And as I mentioned Skype is something that we're now looking at as another potential avenue for virtual consultations. It certainly won't suit the way of all of our clinicians work, but for some services, for example with the younger population, the rationale behind it is that it might improve or increase engagement. Could avoid issues with missed appointments and so on. So again it's at the pilot stage and we'll see how successful that is before any decisions are made on whether to roll it out more widely. That obviously brings with it other security concerns. There's a bit of a lack of central NHS guidance on the use of Skype. There are a couple of papers out there that suggest the technical security settings are sufficient. We're looking at encryption standards to make sure that the virtual consultation is secure while it's happening. From a more IT centred perspective, Skype was purchased by Microsoft a few years ago and that's brought with it some issues in light of the Edward Snowden revelation about what happens to the monitoring of communications data for American based organisations. So again the issue is around making individuals aware of those risks. (Diabetes 2)

The concern about data security was raised by other interviewees:

I'm not aware of any video conferencing incidents per se. I don't think we've had any… I mean the technology is not so widely used with patients anyway, so… but I don't believe we've had any video conferencing related incidents. We do have incidents with email, usually people email putting the wrong email address and send it to the wrong place. (Sickle cell)

And you know, if we ever do something like Skype it would have to go through data comms. to make sure that it's putting the right DMZ's – please don't ask me what that is - you know, demilitarised zones, and make sure that firewalls and ports are open and blah-blah-blah. Not my world, but my colleague produces massive A1 diagrams for me which I just can't understand but I take as assurance because we haven't been breached, and not for a long time. (Cancer 2)

Because obviously, with the bog standard Skype, the servers aren't in the UK, it can, you know, it can be hacked, so we have to be really very careful. So we're looking at, I suppose, an internal type Skype. So the other thing we're using, not in a clinical environment at the moment, is Lync. (School nurse service)

But there's still no reason why certain, you know, if something was identified as being suitable and everything… all the different factors were considered that, you know, Skype wouldn't be an option so long as confidentiality and everything was protected as well. (Liver)

One IG manager talked about the potential for people posing as other people when using digital channels, and the importance of the clinician knowing their patient before using Skype.

Skype actually is quite an interesting one because you could get an imposter who'd get so far pretending to be a patient; an organisations should never expect that these processes are 100% secure…. One of the benefits from Skype is that the doctor and patient will never have their first meeting via Skype the doctor will always know that individual, so when the screen fires up, if that is not the person you're expecting to see at the other end then you haven't disclosed anything or breached any confidentiality unless you've said, hello Mrs Jones, or something like that, which is not too bad. (Diabetes 2)

One IG manager discussed the legal issues involved

It's difficult because you've got to adhere to the law. And the law is very, very difficult in the sense that data can only reside or can be processed within the European economic area …So when things are being used in terms of say cloud or pinged from one server to the next, we're very, very careful, where the data resides, where it's going to end up, which territories it's going through, and that in itself is quite a challenging task because you don't know sometimes where your information is being held. And as a data controller the Trust has to be very, very careful what it does. So in terms of

where we had the Skype pilot it was very, very limited in terms of maybe one patient and the data was held here and we made safeguards for that. We're then limited because then we have to invest in the equipment to make sure that the data stays where we can see it and use it. (Cancer 2)

Two IG managers discussed clinical record keeping, the rights of patients to access records about them and concern about whether clinicians would keep a record of Skype consultations.

So it was interesting, I just, in anticipation of our meeting today I just rechecked actually the section of the Caldicott Report that looks at emerging technologies, and I thought apart from the sentence about email where she's establishing beyond doubt that it's okay to email with precautions so we've talked about… with things like Skype consultations the assumption is already there that hospitals are doing it, but her concern was that hospitals haven't recognised that the patient would have the right of access to a record of that consultation in the same way as they do for notes that are written on a piece of paper, so that was the challenge for Trusts actually was to make sure that patients' rights weren't being compromised by use of modern technologies. Which I thought was an interesting slant on it because it rather assumes that the consultations were already happening. For us it's still quite new and brave. (Mental health 1)

The disadvantages of telehealth, in terms of things like Skype, is the recording of the correct information. So you've got to either physically write your notes, so you've got to record the video and storage and ... because you've got to make sure ... it's got to be accurate at the end of the day, you know, you can't have the patient saying, well, Dr Blogs said to me that I was fine, and we've got no record of it. So we will have to have a process for the note-taking and make sure that those kind of notes got into the record. (Rheumatology)

One IG manager discussed how they were approaching collection of patient consent and current limitations on this.

One of the issues both for email and for Skype is how do you effectively record someone's consent and particularly for email where it might be used a little bit more widely. We don't have currently an administration system that would allow us to record a patient's consent preference which could then be seen by all other clinicians within the hospital. So at the moment we've said, if you are looking to use email, because email is going to be more widely used at the moment, but I think the same would probably apply for Skype, is that at a local level you're going to be responsible for recording the consent, and that's what they do in diabetes and endocrinology, they will hold the consent forms within… well not within the electronic system, but within the files that they manage locally. (Diabetes 2)

Training to maximise safety

Clinician training in the use of SKYPE to deliver patient care was seen as important and some IG managers have begun to support this activity.

> So the advice we provided was policy and procedure based. We advised them on what procedures they should use when using Skype, communicating with patients. So things like making sure that the instance of Skype they're using is configured in the right way so people can't just contact that account without authorisation. Making sure they confirm who is on the other end securely, making sure that the patient on the other end is aware of using Skype securely as well. We've sent them information about how to do this on public available websites, which gives simple advice on stay safe online and that sort of thing. So we've done it on a case by case basis so far, but obviously, you know, it's useful, people want to use it, but we want do it in a secure way. (Sickle cell)

> Until yesterday I couldn't do something, today I press a button and things go wrong. And it's like wrong in a sense like here I've got Skype, if it is given to one of the nurses and they mistakenly press the button and it has gone to the whole world, so I think the training in all this is another challenge which we need to look at if we are talking about mobile technology. (Liver)

Where it may not work well

There was some agreement that the use of Skype in diagnostic consultations was not appropriate.

> They tried Skype clinics in dermatology but found that actually it was the wrong kind of clinic to run via Skype because dermatologists still need to be able to physically see and examine the conditions. So those sort of were very quickly stopped. So although they could see over Skype, it was not sufficient for dermatologists because they need to actually have the actual condition in front of them for examination. (Liver)

> As for consultations… is an examination legitimate over a video camera? I don't know. But those are …questions that people will have to address once it's established. I think it increasingly is, that it's okay to try it. (Cystic fibrosis 1)

> So this isn't running yet, but it's likely to be up and running within the next three months. So we are currently looking at the issues around how the consultations, the form of the consultations, because the clinicians themselves have got to be really careful not to diagnose, they can consult but not diagnose remotely, and things like that. So it's more the process and the procedure, rather than the technical bits. I think they've already got some patients who have said, yeah, we've got Skype, we're quite happy to give you our details and we'll be the pilot. (Arthritis)

I think the learning we took from that is, you've got to be very careful that you don't compromise patient safety in diagnosis if you do something via Skype. (Liver)

Future positivity

In all the IG manager interviews, Skype or equivalents was talked about in a positive way for future delivery of patient care, notwithstanding concerns about how to deliver it safely and reliably.

I don't have a problem with using technology like that (Skype), I think it's a great fall back… we cover a vast geographic area, so for our clinicians to be able to have a face to face consultation, albeit over a screen, could be a cost saving. Also when we have appalling weather and the roads off the main roads (are impassable), if we can't get out there for a week we can actually have a video conference…. It's not perfect but it's better than doing it over the telephone. So I'm all in favour of going down that route. (Mental health 4)

(Using Skype with patients who live at a distance) is in our corporate strategy for ICT. (Mental health 4)

I think when these kinds of services are more mature then I think it's going to be of benefit to patients. I would hope that at some point in the future that to get access to the dermatologist you don't go on a waiting list for 18 months to get your appointment, but you actually get to the appointment whilst you've got that rash,. You might not get to see the dermatologist in person, but maybe you'll be able to get to meet a specialist nurse in a video clinic who could press the button to record it at the right moment to escalate it through the process. So you're fast tracking the capability for some sort of assessment. (Sickle cell)

We can't keep on with the same policies as we've had because we need to assure that there are these modes of communication for patients. Because why would I want to take time off work to come for a ten minute consultation, if that could be done, you know, by telephone, or by Skype, or even by email. (Cancer 2)

I can see huge advantages in using Skype for remote consultation. Any kind of remote consultation with patients, I think particularly when you're in a big geographical area, I think it's great. (Arthritis)

So that (Lync) is being used for remote meetings, but we are looking at the potential of whether that could be used in a clinical sense as well. (School nurse service)

Marketing the service

Some experience is starting to emerge about how to market Skype services to patients.

So as Skype is being piloted within diabetes and endocrinology they're going to use information materials that are just set out quite objectively, very fact base, this is something that you may find useful and if you do, here's some information about it, here's some information about the risks and so on. So the promotion if you like has to be very neutral; from my perspective has to be very neutral so that we're not trying to coerce or push people to use a particular product or platform for communicating something that's confidential. (Diabetes 2)

One IG manager described how their Trust was not actively promoting the use of digital channels to clinicians

We didn't sort of roll out the change to email communication with a bang, so we hadn't said, now you may do this. The policy has changed and if people ask about it then it's there and it's no longer prohibited. So I'd imagine to some level it probably has always happed a little bit, probably with the best of intentions, but in a slightly insecure way. So I'd imagine it's probably going to be drip change rather than something that's quite explosive. So at the moment we haven't really looked to sort of assess numbers or how widely it's being used. And obviously with Skype it's much too early at the moment. (Diabetes 2)

Clinical use examples

A number of NHS Trusts who were currently using Skype or equivalents to deliver care.

Speech therapy would be able to … to develop an outpatient system, to create video clinics, they'd be able to book video clinics. The patients to join that clinic at a particular time. Hopefully we'll even get to the point where we get paid for doing those kinds of things. (Sickle cell)

We are doing lots of other video stuff at the moment ……be able to put video by every intensive care bed in the Trust, so that's 60-something beds will be remotely supported by intensive care professionals sitting behind a computer. And we're doing some other things in terms of being able to send diagnostic images from one location to an expert somewhere else. (Sickle cell)

It was piloted in orthopaedics for people that couldn't come into clinic. It was a very short pilot. (Cancer 2)

We're about to pilot where we are going to Skype patients from clinic. An orthopaedic group … they want to use ... because we have very specialist services, we have patients who travel over from [area], which is 100 miles. And so they want to try and do consultation by Skype. (Arthritis)

Additional Chapter 3: Consensus conference

Introduction

The aim of the consensus conference was to engage stakeholders (e.g. service users, patient groups, clinicians) with the key findings from our project, the LYNC study, and gain feedback on how they can be best applied within the NHS. As part of the LYNC study, we produced a set of Quick Reference Guides (see http://www2.warwick.ac.uk/fac/med/research/hscience/sssh/research/lyncs/outputs/) in collaboration with patients and clinical staff, and these formed the focus of discussions at our Consensus Conference. The Guides are designed to be in an accessible format for service users and health professionals, and contain a distillation of our results from 'what works', patient safety and ethics. The health economics results were presented as an oral presentation with time for discussion.

The specific objectives of the meeting were:

- To externally validate the Quick Reference Guides with key stakeholder groups.

- To achieve consensus on how the Quick Reference Guides can promote the development and delivery of digital clinical communication in NHS health care settings.

- To achieve consensus on the degree of transferability of the LYNC findings and the Quick Reference Guides to broader populations.

Method

Participant recruitment

We aimed for an audience drawn from:

- Clinicians from primary care, specialists in long-term conditions, acute specialist care, paediatrics, obstetrics and other specialties (clinicians of any role – doctors, nurses, professions allied to medicine).

- Service users.

- Representatives from the charity/patient advocacy sector.

- Information Governance and Information Technology professionals.

The conference was advertised to our study database of interested professionals, to advocacy groups and through social media via our LYNC Study Twitter and Facebook accounts. To identify service users we approached known service user organisations such as UNTRAP ((University/User Teaching and Research Action Partnership, University of Warwick), NIHR INVOLVE (via social media), the King's College

Hospital Rheumatology Patient and Public Involvement (PPI) group, the South London Health Innovation Network Diabetes PPI group and Twitter and Facebook accounts of the following patient advocacy organisations, Anthony Nolan Trust, Arthritis Care, Arthritis UK, Ask My GP, Asthma UK, Association for Young People's Health, British Skin Foundation, Cystic Fibrosis Trust, Cystic Fibrosis UK, Diabetes UK, Eczema Society, Guy Francis Bone Cancer Research Fund, Healthy Skin 4 All, Kidney Research, King's Liver Kids, Shine Cancer Support, Sickle Cell and Young Stroke Survivors, Teenage Cancer, Youth Cancer Trust, Young Epilepsy and Young Minds UK. We asked our Patient and Public Involvement Project Management Group members to circulate in their networks and we also contacted those respondents who had previously participated in a LYNC study Survey Monkey questionnaire.

We approached charity and patient advocacy organisations by contacting clinicians associated with the LYNC study and who work closely with advocacy organisations. Consequently, this method enabled us to invite Diabetes Scotland, Diabetes UK, the Cystic Fibrosis Trust, Young People's Health, British Renal Society and the Sickle Cell Society.

To interest health professionals we contacted King's Health Partners, Health Innovation Network Diabetes Team, Accenture, the Health and Social Care Information Centre's (HSCIC) Clinical Information Officers Network, the Royal College of Physicians' Teenage and Young Adults specialist group, the South London Collaboration for Leadership in Applied Health Research and Care women's health group, the Collaboration for Leadership in Applied Health Research North Thames, the Royal College of General Practitioners, NHS England (via social media), the Chief Clinical Information Officers' Digital Health Network, the NIHR Digital Clinical Research Network programme and all LYNC investigators. We also emailed all potential site PIs from our LYNC case sampling database.

Information Governance specialists were invited through our LYNC study IG co-applicants. We asked these applicants to inform their networks and the HSCIC advertised it through their Chief Clinical Information Officers' Network.

We promoted the Consensus Conference during the LYNC study breakout session at the King's Fund Digital Health and Care Congress on 5 July 2016, at our conference stand and on Twitter throughout the day.

The conference was also promoted by the communications lead for the HS&DR Programme on the NIHR Twitter and LinkedIn accounts.

We sent 54 tweets over a five-week period to continue to raise awareness and encourage registration.

The consensus meeting process

The conference took place on 12 July 2016, in a central venue in London. The main focus for the meeting was gaining feedback from participants on the Quick Reference Guides. Throughout the meeting, the Quick Reference Guides were available to participants as A4 leaflets inside a folder and as large posters displayed on the meeting room walls.

The programme included:

- An introduction to NHSmail2 and digital NHS more generally by representatives from the Health and Social Care Information Centre and Accenture (NHSmail2 provider).

- An outline of LYNC project methods, a summary of 'what works' results and a summary of health economics results.

- A brainstorm session where participants viewed poster size versions of our Quick Reference Guides and added their reactions and reflections on sticky notes.

- 'Quick fire' discussion sessions – we called them quick fire discussion sessions as they were 30 minutes long designed to be a rapid exchange of views and ideas ensuring engagement of all participants in the group (6-7 participants per group) but based on focus group research methodology. For the first quick fire discussion, participants were in groups of either health professionals (with one information governance lead), service users or patient advocacy sector. The Information Technology Professionals were spread between groups as they acted as a resource for the group. For the second, the groups were mixed.

The first quick fire discussion session considered the following questions:

- How might clinicians use the Quick Reference Guides to initiate or expand their digital service and become digital professionals?

- How might service users use the Guides in order to influence the development pathways of care that include digital clinical communication?

- How might advocacy organisations use the Guides in order to support the development of the digital patient?

- How might Information Governance specialists use the Guides in order to support the roll out of NHSmail 2 (and options such as Skype and management of mobile devices) or their Trust's alternative secure digital communication system?

The second quick fire session considered the following questions:

- How relevant are the Quick Reference Guides for patient groups not included in the LYNC study?

    o Adult long-term condition services.

    o Adult acute services e.g. post-surgery clinics.

    o Paediatrics (parents).

    o Primary care.

    o Midwifery/Obstetrics.

    o Other?

- What would your concerns be and how might they need amending?

- What new research/evaluation questions need tackling?

- In your organisation what are the roles of the people who would be most interested to receive the Quick Reference Guides?

The facilitator encouraged the group to identify two key issues from their discussion that were reported back in a plenary with the opportunity for further discussion or comments.

It was agreed during the consensus meeting that we would send the summary of the discussion to all participants. Participants would respond with any additions or changes that they wanted to make to the summary documents and also inform us within a specified deadline if they did not want to be associated with the conference report.

Data management and analysis

A scribe for each group wrote contemporaneous notes of each group discussion and all plenary discussions. The post-it notes from the brainstorming session were typed up.

Immediately following the meeting, on the same day, facilitators discussed the key themes of the day's discussion as a whole. The group discussion notes were then coded for:

- Data validation (or not) of our Quick Reference Guides;

- Themes identified by facilitators as being significant;

- Answers to our specified questions.

The discussion notes were coded to each of the above by one facilitator or scribe. One facilitator interrogated the notes for any additional themes. Facilitators then wrote a comprehensive summary of the discussion responding to a question or a theme.

Following the meeting, the discussion summary was sent to all participants for review.

Results

A total of 49 participants attended the conference. Of these seven were service users, six were representatives of a charity, 30 were health professionals, one was an information governance manger and five were Information Governance specialists. We held eight quick fire discussion groups for each of the two discussion sessions. All participants attended for the whole conference.

Of those attending the conference four sent comments and amendments to the report and none said they did not want to be associated with the report.

We report a summary of the discussion data validating (or not) the Quick Reference Guides, a summary of discussion under the identified key themes, and responses to the questions that we posed to the groups. Quotations are taken from notes taken at the time of the discussions.

External Validity of the Quick Reference Guides

To assess the external validity of the guides, we analysed the plenary and small group event notes in order to observe where the themes had emerged, firstly, within the context of other focused discussions about digital clinical communication use and, secondly, where participants spontaneously volunteered examples, from their own areas of practice and experience, which related closely to the themes contained in the Quick Reference Guides. All of the themes were validated according to the above 2 criteria across the recorded notes of several group discussions.

Themes identified by facilitators as being significant

Immediately after the conference, through discussion with facilitators, the following key themes were identified:

- Workload and boundaries to accessibility and flexibility

- Ethical issues

- Digital literacy

- Supporting the digital patient/carer/clinician

- Negotiating boundaries and managing expectation

Workload and boundaries to accessibility and flexibility

Workload themes were found in 5 of the 8 discussion groups:

> We still live in a 9 to 5 world but people aren't just ill between these hours. People expect you to be accessible at all times.

> A lot of it is the concerns we've been voicing e.g. volume of email, and patients wanting an instant response, hard to manage expectations, but of a challenge.

> Health Care Professionals can manage their time much better, allowing them to have a fluid, flexible, agile workplace [...]

> Perhaps there is a way of shifting the workflow of where these messages come in.

Clinicians could see the potential for digital clinical communication to enable better time management, but this was coupled with a concern over the blurring of boundaries with clinicians finding it difficult to switch off from work and feeling patients had access at any time. Indeed, there is the perception that one response outside of hours could reset patient expectations, blurring the boundaries of access to clinical teams. Leaving mobile phones switched on after hours is easy to do whether purposively or accidentally so clinicians might feel obliged to respond, particularly if they are a lone worker. Some clinicians have been voicing concerns over the volume of emails and that patients expect an instant response to email contact, which makes managing expectations a challenge. Moving with the digital age was also seen as creating pressure on health professionals to work from home, although there are currently no guidelines on how to manage this issue.

Despite these issues, however, our stakeholders identified that there were workload advantages to be explored such as flexible working and some solutions to fielding messages in a way that ensures patient and staff safety.

Ethical issues

Privacy issues were identified in relation to the patient and to the clinician being unaware of who is present with the patient:

> I find that my clients don't want others to know they have his condition for example they don't want to use Facebook.

> There was a lovely example of an endocrinologist (who was using teleconferencing to see) … a patient, (then the doctor realised)… the whole family was there offering cake to the patient. But even on the phone you have that problem to an extent and what about shared email accounts – the same can happen with letters.

In relation to consent, participants identified some solutions around centralising consent in order to communicate digitally and ensure that this is an informed consent process:

> Consent made and kept centrally with individual consent for each service they do or do not wish to use.

> Knowing what is and isn't secure. Education of what is and isn't secure, what they can and can't do!

Themes of 'duty of care' and 'equity of care' for patients were represented strongly in the group discussions with many participants voicing concerns over enabling consistent clinical practice.

> Can I just add – having a mobile phone – what do you do about voicemail – could we have a bounce back for voicemail or text so they are not left hanging…. It's about expectations – people need to know not to use text for urgent things……. because I'd hate to wake up and find a missed message.

> One response outside of hours can reset expectations.

> No guidelines and boundaries (i.e. when do you turn your phone off?). Different staff may have different boundaries and how do you decide on a policy as a team?

The comments illustrate the range of concerns relating to duty of care, all of which can be found in the rest of the LYNC data set.

Participants considered an existing relationship between patient and clinician is important for successful digital communication.

> Whichever group we look at, there needs to be a relationship between the patient and clinician which is key to make it work in whatever setting it goes in to.

The topic of trust existing within therapeutic relationships reinforced the validity of the theme of enhancing patient engagement and improving face to face communications.

> (There) needs to be a relationship between Dr and patient for digital clinical communication to work.

> Any kind of digital clinical communication requires some sort of relationship with the healthcare professional that you are working with as a patient. Implications for thinking about relationships, considering trust etc. If the patients were to be involved they must understand the boundaries.

It was suggested that clinicians might need to protect themselves from patients recording consultations or taking photographs of their medical records.

Digital Literacy

The most appropriate form of digital clinical communication to use for different circumstances generated a lot of discussion.

> Interesting, look at definition of digital clinical communication. When I started we had bleeps and landlines and everything and it was confusing to patients.

> I had some thoughts about the IPad and phone. Clinicians are given a basic phone and I can't even text on it. Clients text me and I'd like to text back but I find it easier to email. Some trusts do give iPad but I refused one but it doesn't link to our desktop apps. It would be useful to have a dicta phone that I can use away from the office. What I found really interesting was the skype.

> They'd like a social media group with others with same condition but not FB, they prefer WhatsApp and have used groups in that and sometimes allow clinicians. It's limited because of number of characters in a text

> WhatsApp? Free! And can get it on desktop so can upload and document. More efficient.

> What platform to use? Do we engage all platforms? Ask patients. – 1 nurse suggested that her patients preferred Facebook for info sharing and peer support, not for digital clinical communication (i.e. blood test results).

Conference participants suggested that the assumption all young people are technologically competent in contrast to older generations must be dispelled as individual differences determine levels of, and preferences towards, digital literacy. Fast-changing technology also means that competence on one platform is not readily transferrable to all other forms. One participant reported that even amongst the young people, not all had engaged with all types of digital technologies on offer; the majority use text messages, WhatsApp and Instagram with less email usage.

It has been argued that individuals can be classified into two distinct groups: 'digital natives' and 'digital immigrants'.[2] Digital natives were born into the digital world (from 1980 onwards) and were the first generation to grow up with the technology. They are accustomed to receiving and processing information fast and have the ability to adapt to new technologies with relative ease. On the contrary, digital immigrants are depicted as people who learn to use digital technology somewhat begrudgingly and with some level of difficulty. Further research has suggested that differences in digital skills are not so much a generational effect but the result of experience in using a range of digital technologies.[3]

Our stakeholders raised concerns about inequalities if care pathways are digitised. Indeed, there is the risk of excluding certain patient groups if all services suddenly become digital-based. Digital literacy can be associated with language skills so non-English speakers could be excluded from engaging with services.

Conference participants also reported that those with mental or cognitive impairments could find it difficult to engage with digital healthcare. Parents who coordinate care for their children could become excluded if their range of digital literacy differs from their child. Inequalities could also result due to some patients not having the right equipment, internet access or phone credit.

There was concern that some older generation healthcare professionals resort to taking early retirement in order to avoid using IT. The digital literacy of clinicians was thought to impose a direct effect on the quality of healthcare provided. While emailing may be commonly used, Skype remains unfamiliar territory for many clinicians. Clinicians that feel comfortable with a technology are likely to engage with these more frequently than those who are not, and this could translate into inconsistencies in the level of clinical input.

Supporting the digital patient/carer/clinician

Patients may need support and training to enable them to engage with digital health services to ensure equitable services. Healthcare providers should consider deploying the least complex technologies that minimise the influence of disparities in levels of digital literacy.

There was the view that considerations need to be made for the older people in the workforce who find IT burdensome. Our stakeholders also warned against making assumptions of competence regarding the digital literacy of clinicians working in services aimed at young patients. Conference participants advocated strongly for training in technology to be provided.

While health care professionals and service users/patient advocates appreciated the potential of digital clinical communication, they also acknowledged that targeted training and support would be required in order to facilitate the effective introduction of digital clinical communication on a large scale. Training could be delivered in formats appropriate to the audience. Of particular importance for both clinicians and patients is recognising what constitutes an acceptable use of digital clinical communication. Everyone involved with its use should receive some form of guidance on how to use it effectively. Consequently, it was suggested that this training could be delivered on an individual basis e.g. a GP showing a patient how to access blood results online, or in a more formal group training session, whether that be for health care professionals or service users. Interestingly, one group thought that a non-clinician might be better at delivering training sessions. Training could also support clinicians in managing their time efficiently with the increased workload of using digital clinical communication. One group thought that the Quick Reference Guides would be useful for clinical teams to begin a discussion on how they might go about implementing digital clinical communication in their work. Some sort of national guidance or training would be required in

order to establish certain standards, such as when clinicians can switch off their phones and not answer e-mails. However, there is concern about funding for training and whether or not it could be delivered.

The groups expressed concern that parents of young people would need to be supported regarding the use of digital clinical communication by their children, particularly in the transition phase between paediatric and adult clinics. The difficult issues around confidentiality and moving from sharing information with parents to respecting a child's right to manage their own condition are common to all care pathways but the use of digital clinical communication makes it easier for parents to be excluded and feel out of the loop. Consequently, information for parents would also need to be developed and tailored to their needs.

Groups stated the importance of service users having information about digital clinical communication in an accessible format, either to know what technologies are available so that they could make an informed choice about using the service, or to choose not to use it and stay with more traditional forms of communication. Information also needs to be tailored to specific groups and specific types of digital clinical communication. Several groups recommended using videos (e.g. YouTube) with service users who could talk about their experience of using digital clinical communication. Other suggestions included making resources available via apps, podcasts and electronic information sheets in order to use digital media to inform digital communication. In addition, personal stories are a powerful way of getting a message across. These could be communicated in the form of videos or in real time at patient support organisation meetings. Indeed, patient organisations can perform a key role in disseminating such information guides through their networks, on their website or at meetings. When developing information for service users it will be important to ask them what they require. Finally, the type of language used must be considered, as any written document would need to be in several languages.

Patients and carers would need to understand the boundaries of use and their responsibilities as users of the service, for example service users need to understand the importance of confidentiality and safety issues.

Negotiating boundaries and managing expectation

It was clear from the feedback provided by patient representatives and health care professionals that there is a need for guidelines surrounding the use of digital clinical communications to be established, ideally when any service is set up and, where services are in existence, for these standards to be reviewed as services evolve.

Patients need clear guidance on what type of digital clinical communication they are going to use, along with an observed time frame within which they will receive the communication that they are expecting. If no timeframe is provided then patients could feel apprehensive. Indeed, one of the patient representatives at the

conference was waiting for a call from her consultant on the results of an MRI scan. She was looking for an email or text to give a time to receive the phone call but there was no time set by which the communication would happen. She was already anxious about the results and without a defined timeframe for the communication her anxiety levels were increasing. For her, the idea of no news could mean that there was bad news, which the consultant was reluctant to convey over the phone. While this illustrated well the feeling of the group that having a defined timeframe for response was really important, it was generally felt that busy health care professionals may not be aware that delays caused anxiety, especially if there was no bad news to convey, therefore the communication was not considered a priority.

One patient representative who ran a charity for young people with chronic illness knew that some patients use social media and forums as a first port of call when in fact they should be seeking immediate care. Although this could be viewed as avoidance behaviour, it highlights the need for services offering forums to be aware of this as potential misuse of these digital modes.

There is a need for clear boundaries on what type of digital modalities are appropriate for different forms of digital clinical communication. This is because digital communication could lead to over-dependence on health care teams with patients taking less responsibility for their own health. To illustrate, a concern was raised that patients may become too dependent on health care professionals if they could send a text regarding anything. Needy patients use text as a way of avoiding attending out-patient clinics. In addition, our stakeholders reported concerns that social media would be used for urgent enquiries and patients may expect faster responses than would be practicable. Consequently, there was an acknowledgement that patients cannot expect digital communications to generate an immediate response.

Conference participants considered how services respond to out of hours contact and whether automated responses were sufficient.

Different teams may offer varying levels of service. Individual members of one team may have differing views on appropriate boundaries. This led to the question of how to decide on policy within a team.

One member of the group stated that a longer timeframe would be preferable to a short timeframe that was not met. Where delays were going to be experienced the patient would prefer some communication regarding the delay rather than silence. Further, the patient who was waiting for the communication stated that she would have preferred some 'rules of the game' prior to agreeing to the communication. A suggestion was made that workflows could be shifted in order to enable better responses to digital communications, perhaps making specific individuals responsible. Although clinical teams should sign up to

timeframes and agree to abide by them, there was uncertainty in how conflicting demands of consultant diaries and patient expectations could be managed.

There was seen to be a need for guidance and policies setting appropriate standards and highlighting liability. This must be done differently for each type of digital clinical communication. There is a need for guidance on setting out the strengths and weaknesses of different types of digital clinical communications and when to use each appropriately, and what is acceptable.

To ameliorate over dependence, boundaries about the appropriate use of digital communications must be set while enabling free flowing communication that helps patients avoid unnecessary appointments and, in doing so, can improve cost effectiveness. There was also a suggestion that managing patient anxiety might be more important than managing patient expectations. This requires setting out clear expectations on when the communication will happen and what will happen if the system breaks down.

Participants recognised the importance of having a system that flags up non-response of a patient to a clinician's attempted digital contact.

While conference participants reported that the health service must catch up in terms of digital communications, in this world of 24-hour digital access for many aspects of life, health care professionals also need training and management support on achieving an appropriate work/life balance.

There was a view that establishing clear working hours and guidance on what to do outside of these hours, including guidance on how to deal with urgent issues, could standardise policy within a team.

How might clinicians, service users, advocacy groups and information governance managers use the Quick Reference Guides?

Stakeholders identified a number of positive and negative aspects of the Quick Reference Guides for service users' and health professionals' practical needs. Concerns often related to how relevant they would be for patients or carers, particularly for the young person population from which the data were collected. Other limitations related to the length and presentation of the information:

> We are already doing a lot of this. The quotes and comments are relevant but there are too many things – just make it 4 key points.

> What are the key messages? There are way too many quotes.

> We'll take it back to our teams and no one will read it. If sent by email we can ask for comments by a date…..the method of communication needs questioning – paper leaflets are old-hat……..there are so many digital platforms.

It's not clear, I'd like to see much clearer labelling: e.g. what are the issues? What am I supposed to take away from these guides? I'm not clear what to do with these ….. it's all too long I want my eye to be drawn straight to e.g. ethics and see the 3 key points…..I like numbers, that's what I look for but nothing here…….I wasn't sure of order to read them in….. at least if numbered I could …….sometimes a checklist would be good.

These are quite some way off being useful in terms of how to get the services up and running – No information on the financial aspect of implementing all this on the leaflets. Not the kinds of tools to have a conversation about initiating these services.

A lot of the results sound like predictions, not results!

However, our stakeholders also reported that the guides could be useful for a range of purposes including, developing policy guidelines, training staff members, and sharing information about good practice:

Very interesting – the flyers show a lot of the issues we've been discussing for years and months now.

Useful for clinical teams and information governance to make guidelines together.

We thought the guides would be useful for clinical teams to train their teams and start a discussion and also for negotiating for kit, smartphones etc.

We also thought about how useful they [the guides] could be for service users – maybe good for confidentiality.

Local policies as to what is and isn't acceptable. The quick reference guides will help.

Quick reference guides can help shape local policies for digital clinical communication.

Need to share good practice – Quick Reference Guides help.

Focus guides on patient stories to motivate clinicians – current balance is reasonable.

The group discussions highlighted that the Quick Reference Guides, in their current format, appear to be written for clinicians rather than service users or carers. Young people are unlikely to read large amounts of text but respond more to visual media. It is also important to cater for the older age group if digital clinical communication is to be used more widely. A range of methods to communicate the information effectively will need to be adopted in order to enable widespread usefulness across the NHS. There was also a less strongly heard voice about the need for both additional content e.g. cost and resource implications and potentially more structure to improve their usefulness when considering the adoption of digital clinical communication across the NHS.

The Quick Reference Guides provide a clear and strong framework for:

- Considering how digital clinical communications could support clinical services, and the topics that could need to be addressed when initiating digital clinical communications within a clinical setting.
- Supporting both champions of digital clinical communications and clinicians and managers who struggle to conceptualise how this may work within their clinical setting.
- Sharing within clinical teams as well as with service managers prior to meetings around service development. Indeed, a number of participants suggested that the guides could support conversations around introducing digital clinical communication services within a clinic.
- Helping information governance officers structure clinicians' thoughts when using technologies for service development or seeking approval for digital communication pathways.

Participants who are developing digital services and had undertaken this process expressed a wish that the guides had been available earlier in order to support the development of such services into planned clinical care pathways.

Despite the usefulness of the guides for supporting discussions on the development of services, participants also reported the following concerns:

- The current content does not provide a persuasive argument on how to use digital clinical communication.
- The guides are too long and technical for patients or their carers to engage with, although the messages contained within them are applicable for patients and would support them in considering whether they wish to receive care via digital means.
- The current content of the guides could be of limited benefit to advocacy groups unless they develop their own digital communication services.

Participants considered possible solutions to improving the guides' accessibility:

- Additional material and a stronger argument (e.g. about cost-effectiveness) might be required in order to convince digital sceptics that digital clinical communications are valuable to service delivery. Clinicians also felt that 'real life stories' could support the argument that digital clinical communication services were beneficial to patients and services alike.
- Distilling the current messages within the guides into short video clips would provide a better platform for patients and carers to engage with the study findings. Clinicians were comfortable in

signposting patients to such content and felt that this could support their consenting process, ensuring patients were informed about digital clinical communication technologies.

- Participants believed that patients would benefit from additional material specific to the technology platforms supported by their clinic. Clinicians within their clinic could signpost patients to short videos describing the benefits and weaknesses of using the technologies employed within the clinic in order to manage their health. For example, a clinic that supports patient care through text messaging, a Facebook page and Skype could signpost patients to videos on the strengths and weaknesses of such technologies. There was a strong sense that patients should have free access to a range of videos surrounding the use of digital clinical communications. However, individual clinics should advertise these modalities using the technology platforms that service users engage with.

- Advocacy groups would benefit from 'real life' examples of clinics using technologies. Patients' narratives could inform advocacy organisations on how such services supported them in managing their condition, along with the benefits they experience. Such content would support advocacy groups in disseminating the findings of the LYNC study to patients, while also acting as a powerful tool to lobby policy makers.

- Clinicians requested that additional guides are technology specific. They felt that exploring the strengths and weaknesses of different technology types, and how these could be used within the clinical setting, would support them in developing digital clinical communication services within their practices.

How relevant are the Quick Reference Guides for patient groups not included in the LYNC study? What would your concerns be and how might they need amending?

There was a view among many participants that the information within the Quick Reference Guides would be relevant for all health care professionals and patient groups, but that it may need adapting for different groups. Some participants said the information would need to be condensed and simplified. Digital methods for disseminating the information were advocated, such as short e-videos and podcasts. The use of vignettes or stories as to how health professionals (in different roles) and diverse patients/service users have used digital clinical communication and the benefits and challenges they faced would be useful for people to relate to. It was also suggested that guidance for using specific technologies would be beneficial (for example, information dedicated to using Facebook in order to communicate with patients).

Definite benefits were seen to the Quick Reference Guides, and the use of digital clinical communication more broadly, within primary care. While there was some concern that this would increase pressure in an already stressed general practice, there was a view that as digital clinical communications could prevent face to face care that was not needed, it could save time. Furthermore, our stakeholders reported that people who have rare conditions could use digital communications in order to educate their GP about their condition by

emailing links to relevant information. Significant benefits were also noted within midwifery, where patients tend to have a strong ongoing relationship with a range of health professionals in different settings (e.g. midwives, GPs, obstetricians, etc.). Remote monitoring was seen as reducing the medicalisation of pregnancy. Digital clinical communication would also be useful postnatally in supporting new mothers and allowing them to communicate whenever they required (i.e. at any time of day). Furthermore, our stakeholders reported that digital clinical communication could be beneficial for caring for all people with long term conditions, particularly illnesses with 'flares'. Other primary care patient groups that could benefit from digital clinical communication include end of life patients, as carers could be communicated with easily and quickly, and rural patients who have to travel long distances in order to attend their appointments. Patient groups who experience communication barriers (non-English speakers, deaf people etc.) were also seen as potentially benefitting from digital communication. Some people suggested that interpreters and signers could be included in Skype consultations. There was some concern that older patients may not benefit from digital clinical communication as many do not use digital technology and are not IT-literate. These patients would need access to standard communication methods.

Conference participants reported that digital communications might not be appropriate in acute healthcare settings as patients with short term conditions tend to have a less ongoing relationship with their clinician.

What new research/evaluation questions need tackling?

The following suggestions for research/evaluation were made:

- Ongoing collection of data on service user experiences with digital clinical communication, via forums where new service users can use to learn how best to use digital clinical communication.

- Cost-effectiveness analysis of providing tablets etc. to staff/patients.

Research to inform National guidelines which are needed on:

- Which method of digital clinical communication to use in any particular context.

- Best practice on when to read and respond to digital clinical communication (to balance patient expectations with burden on staff).

- Appropriate boundaries for digital clinical communication interactions (e.g. on social media).

- Involvement of parents and carers.

- Reducing liability for the professionals/health care organisations.

Service-level evaluation of:

- Available and feasible options for digital clinical communication.

- Structures in place to support digital clinical communication and mitigate risks.

Research to identify when and why patients with chronic conditions access care via A&E, and how digital clinical communication might help redirect this to the relevant clinic.

Research on how to improve integration of digital communication across public services (NHS, social care, education, police).

Research on how to improve integration of digital clinical communication across public services (NHS, social care, education, police).

Benefits and cost-savings associated with reducing Did Not Attend rates.

Impact of digital clinical communication on 'throughput' i.e. whether and when digital clinical communication reduces the time needed per patient.

Evaluation of groups for whom the benefits of digital clinical communication are limited e.g. the elderly, mental health service users, ethnic minority groups. How might it be tailored to increase its benefits in these groups?

Development of digital technology for clinical communication that incorporates effective translation.

Understanding how the appropriate use of digital clinical communication varies according to age, communication styles, rural vs urban location etc.

Evaluation on the need for, and cost-effectiveness of, improved IT support.

Further research on the value to patients, e.g. reductions in patient costs from face-to-face visits avoided.

RCT of digital clinical communication in establishing effectiveness and cost-effectiveness.

Evaluation of cultural changes required at a service level in order to incorporate routine use of digital clinical communication.

In your organisation what are the roles of the people who would be most interested to receive the Quick Reference Guides?

The following roles of people were identified:

Patients and clinicians

All users of digital clinical communication (could be placed on Trust intranet for staff)

Caldicott guardians

Charity representatives

Clinical Information Officers

Clinical Safety Officers

Clinicians/GPs/Chief nurse/Directors of nursing/Specialist nurses

Communication officers/teams of NHS Trusts and of Charities/Advocacy organisations

Information Governance teams

Information Technology teams

Outpatient services

Patients

Royal college of General Practice, Royal College of Physicians, General Medical Council

Financers and decision makers:

CEO of health service provider organisations

Department of Health

Clinical Commissioning Groups

NHS London and other regional offices of NHS England

NHS Trust management teams

Trustee boards of charity/advocacy organisations.

Summary

We have found the LYNC findings presented in the Quick Reference Guides to be externally validated but some changes would need to be made in order to ensure that they are accessible and contain the relevant information for all audiences. Whilst negotiating boundaries and managing expectations are issues dealt with in the guides, they were a particularly prominent theme in the discussions. The variation in digital literacy among clinicians, patients and carers was a concern both for the uptake of digital clinical communication and the potential for creating inequalities across health services. Training and support for clinicians and patients is needed. The Quick Reference Guides have a place in such training, and in particular helping service providers think through service redesign. While patients reported that the guides needed to be

simplified and available in alternative formats, overall, most participants were aware that the Guides could be applicable across all patient groups and types of healthcare services.

Appendix 1: General Interview Schedules

Appendix 1.1: Interview schedule for young people with long term conditions

Follow up on what is observed (i.e. use this data as cues/see how people feel about it)

GET AS MANY CONCRETE EXAMPLES AS POSSIBLE (& IF THESE AREN'T FORWARDED BEFORE THE INTERVIEW ASK THEM TO FORWARD THEM AFTER IT)

(Interviewee will have received participant information sheet and signed consent form)

Introductions

[*Before consent if taken verbally…..*

My name is X and I am one of the researchers working on the LYNC study

Just to remind you **the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X**.

Today I'm going to ask you some questions about you and your health, your use of digital communication technologies (if you do use these things), and how you feel about using/the idea of using these things.

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

Face to face and telephone interviews will be audio recorded, the recordings are stored securely and will be transcribed with anonymisation so that they can be analysed.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

Tell me about **yourself** (home, education, work). E.g. how old are you? Who do you live with? Whether you work or are in education?

Tell me about **your health**

Probes:

>What sort of things do you do to look after your X?

>How would you describe your expertise on managing your condition yourself?

What sources of support do you have?

What types of issues do you face for which you would get in touch with the clinical team? Is that within or between consultations?

What sort of things do you think digital communication includes (encourage them to name as many as possible)?

Tell me about your **use of digital communication generally** (email, text, social media, Skype etc.)

Probes:

> **What** types do you use?
>
> With **whom**?
>
> For **what purpose**?

Tell me (more) about your **use of digital communication for health**

> Probes:
>
> Do you use it **in relation to health**? If yes, how?
>
> Do you use it to communicate with **health professionals**?
>
> (If yes) Approximately **how often** do you use it?
>
> **What** do you use?
>
> What **sorts of things** might that be about (I.e. **content**/medical purpose) (for each type of DCC used)?
>
> What is the **purpose** of using it (i.e. medical, economic, e.g. saves time and travel, and patient impact) (for each type of DCC used)? **Why** do you use this method of communication? What in particular is **useful** about it?
>
> **When/where** do you use it (for each type of DCC used)?

Can you tell me how you **started using X**? Tell me more about how you started using X?

Can you tell me exactly what the **process** is when you use X with the clinical team from 'start' to 'finish' (for each type of DCC used)? E.g. What 'kit' do you use? How do you send them a message?

If use email:

Do they have individual email addresses or a team email address?

(If team email address) what are your views on having **a generic email address and NOT using clinicians own named accounts** (i.e. does this approach miss the point (reduce the advantage) of patients having DCC email communication (i.e. named person to named person) with the relationship being really important for many clinicians and patients)?

Which members of the team do you use DCC with?

Probes:

> **Which technologies** do you use with each of these people?

> What **sorts of things** is your communication with each person normally about?

> How do you exchange **contact details** (e.g. mobile phone numbers, email addresses, etc.)?

Do you do it **differently any other time** (e.g. when you are at University)?

Can you tell me **what you think happens to your communication** (for each type of DCC used)?

Probes:

> Who can see it your end?

> Can anyone see it in transit?

> Who sees it once it has arrived?

> What happens after you have sent them a message (at yours and the clinical team's end)?

> When do you think these health professionals look at it?

> Are there ever any delays when sending or receiving messages?

> When would you expect to get a response?

What **conversations have the X team had with** you about how and when you can use DCC to contact them?

What do you do if you send an email, text, etc. but **don't get a reply**?

DRAW DIAGRAMS OF THE PROCESS OF USING EACH TYPE OF DCC TO PROMPT THEM & START TO THINK ABOUT ELICITING SPECIFIC EXAMPLES

WHERE SITES USE DCC

We really want to understand more about the process of using DCC with specific examples if possible. Have you brought examples of recent DCC?

Researcher reads examples and uses them to support asking about the following topics.

If no examples provided, researcher asks them to describe a recent example of where it was used.

ALSO – in both instances – the researcher asks them to share their communications going back years (if appropriate).

What did you use?

CONTENT

What was it about?

Probes:

      What correspondence happened beforehand?

      What happened after?

      What did you expect to happen after? (get detail)

What was the result of the communication, e.g. saved appointment, medication change etc..…

PURPOSE

Why do/did you do it that way? **Why do/did you use that?** Why did you use X/digital communication technology?

OBJECTIVES

What were you hoping to achieve by using the DCC (*at each step of the process relevant to them*)?

Probes:

      Were these aims achieved? What was achieved?

What tools did you use when you did that (*at each step of the process of using the DCC*)?

What were you thinking when you did it (*at each step of the process of using the DCC*)?

What knowledge, social norms and rules were you drawing upon when you did it (*at each step of the process of using the DCC*)?

ASK QUESTIONS ABOUT CONCERNS, IMPACT & COST ETC. (SEE LATER)

It would be really helpful if you could now tell me about a situation where DCC did and did not work well for you related to your health

If participant is unable to describe a relevant situation, then researcher explores these issues based on a recent occurrence of DCC in relation to their health care:

Can you tell me a bit more about <u>what we just talked about</u>? How did that work for you?

What about <u>the last time you used X</u> with your clinical team? How did that work for you?

When example identified:

Firstly, what worked well?

What did not work well?

What happened (**unfolding**)?

Why did that happen (**cause**)?

How frequently does something like this happen (**likelihood**)?

What happened after the 'event' (refer to what it was)? What effect did it have? What did you do afterwards (**consequence**)?

What did that mean? What problems did that cause? What bad things could have happened? What are the worst possible things that could have happened (**severity**)?

Now we would like to try and understand how you feel about using DCC in general:

WHAT ARE THE RISKS AND SECURITY ISSUES?

BE SURE TO PICK UP ON ANY UNCERTAINTY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW DOES COMMUNICATION USING X COMPARE TO USING THE POST

Do you **want to use DCC with the clinical team?**

In general, **how comfortable** do you feel using X with the clinical team?

What is your **experience** of using DCC?

Tell me how you use it and what you won't do on it?

Is this any different to what you use at home?

Do you feel there is a **problem** with anything?

Do you have any **concerns** about its use?

Is there anything that would worry you about using this technology to talk about your health?

What do you perceive the risks to be in terms of **patient safety**?

What do you perceive the risks to be in terms of **ethical issues**?

What do you perceive the risks to be in terms of **storing the data**?

What are your thoughts on the nature of **privacy and confidentiality** in the context of DCC?

What are things / outcomes that you definitely **want to avoid** when using this technology?

What are the common **security concerns**?

What **new risks** does DCC introduce?

What do you consider to be **confidential**? Who would you not want to see that? Who would you mind, and not mind, seeing a X containing that information? E.g. parents, friends, etc.

What would you mind, and not mind, the X team communicating with you about <u>via different kinds of digital communication</u>?

What **could go wrong** (*at each of the steps of using each type of DCC that they are involved in (e.g. sending a text message)*)?

E.g. Where do you leave your phone? Do you share your phone with anyone? Who has access to your PC/Laptop and email account?

Probes:

      What are **common failures / failure opportunities** in the process?

How important are these risks/issues to you?

   Probes:

      How concerned are you about these issues?

      Do these issues influence your decision to use DCC with your doctors/nurses?

How would you feel about the things you have said could go wrong happening? Would you care? How much would that matter to you?

E.g. How would you feel if other people (friends, family, colleagues, strangers) read your communication with the clinical team? What sorts of things would you mind people seeing?

RE: IDENTIFIED RISKS: HOW ARE THEY/SHOULD THEY BE DEALT WITH….

Would you/do you do anything to **deal with these risks** (e.g. never include sensitive data in a text message)? Is anything in place to prevent other people accessing these things (e.g. where do you leave your phone and is anything password protected)?

What risks would there be **if you didn't use DCC** with the clinical team?

Probes:

Is there any positive effect of DCC on risk?

OLDER PATIENTS: Is how you feel about these things now different or the same as how you felt when you were younger (i.e.16-18 years of age)?

Has the way you feel about these risks changed at all as you have become more familiar with these technologies? If so, how has this changed?

Does the use of DCC affect the **relationship between you and your doctors/nurses**?

To what extent do you think it would improve your **engagement with your treatment regimens**?

Probes:

Would you anticipate any changes in the responsibility for your care/self-care?

Do you feel more or less confident in managing things to do with your condition yourself as a result of using DCC?

What **benefits** (e.g. patient experience and reduced travel time to clinics) do you think are linked to digital communications?

Probes:

What impact does using DCC have for you?

Does it have any impact on your health?

In what ways has using DCC make your life easier, or more difficult, compared to how you would otherwise communicate with the clinical team?

Has it had any impact on **how you use hospital services**?

Probes:

Has it had any impact on your X clinic attendance?

Is there any impact on things like the number of **adverse events/acute episodes** you have (i.e. preventative or causal)?

Probes:

Are there any examples of things that have been avoided by using DCC?

What would it be like/might happen if you couldn't use DCC with the clinical team?

What **costs** do you think are linked to digital communications?

In the **future**, how would you like to use digital communication for your health care?

Probes:

What do you think will need to change for this to happen?

Would patients need any training for using digital communication with their clinical team? If so, what training would they need?

What risks might there be if the NHS introduced the ability to get in touch with clinicians via [suggest technology not used currently]?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where they would need to pay for digital communication.

Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide you with a basic service, so clinic appointments as usual and contact with your medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). **In addition to this the**

NHS is going to set up a premium service which you would have to pay for. This would include the facility to email/text/Skype (as appropriate) your healthcare team. This service would have to be paid for by patients. What would be the sort of things you would think about in deciding to subscribe to this service?

Probes:

> What would be important/what would you value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).

> If you think you would subscribe to such a service, how much would you be willing to pay? £10 or how much?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

<u>WHERE SITES DON'T USE DCC</u>

How do you **normally communicate** with the clinical team?

Why don't you use DCC at the moment?

What sorts of things would you like to use these technologies for in terms of using them to communicate with your clinical team about your health?

PAY ATTENTION TO INSTANCES OF NON-DATA

We would like to try and understand how you generally feel about the idea of using DCC

WHAT ARE THE RISKS AND SECURITY ISSUES?

BE SURE TO PICK UP ON ANY UNCERTAINTY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW WOULD COMMUNICATION USING X COMPARE TO USING THE POST

How do you feel about the idea of using DCC with the clinical team?

How comfortable would you feel with the idea of using DCC?

Probes:

> What do you think the **problems** are in relation to using DCC?

Do you have any **concerns** about the use of DCC?

Is there anything that would worry you about the idea of using this technology to talk about your health?

What do you perceive the risks to be in terms of **patient safety**?

What do you perceive the risks to be in terms of **ethical issues**?

What do you perceive the risks to be in terms of **storing the data**?

What are your thoughts on the nature of **privacy and confidentiality** in the context of DCC?

What are the **common security concerns**?

What are things / outcomes that you would definitely **want to avoid** when using this technology?

What **new risks** would DCC introduce?

What do you consider to be **confidential**? Who would you not want to see that? Who would you mind, and not mind, seeing a X containing that information? E.g. parents, friends, etc.

What **could go wrong?**

E.g. Where do you leave your phone? Do you share your phone with anyone?

Probes:

What are common **failures / failure opportunities** in the process?

How important are these risks/issues to you?

Probes:

How concerned are you about these issues?

Would these issues influence your decision to use DCC with your doctors and nurses?

How would you feel about the things you have said could go wrong happening? Would you care? How much would that matter to you?

E.g. How would you feel if other people (friends, family, colleagues, strangers) read your communication with the clinical team? What sorts of things would you mind people seeing?

RE: IDENTIFIED RISKS: HOW SHOULD THEY BE DEALT WITH….

Would you do anything to **deal with these risks** (e.g. never include sensitive data in a text message)?

What risks are there in **not using DCC** with the clinical team?

Probes:

What risks are there in **not using DCC** with the clinical team?

Probes:

Is there any positive effect of DCC on risk?

OLDER PATIENTS: Is how you feel about these things now different or the same as how you felt when you were younger (i.e.16-18 years of age)?

Has the way you feel about these risks changed at all as you have become more familiar with these technologies? If so, how has this changed?

Would the use of DCC affect the **relationship between you and your doctors/nurses**?

To what extent do you think it would improve your **engagement with your treatment regimens**?

Would you anticipate any changes in the responsibility for your care/self-care?

Do you feel more or less confident in managing things to do with your condition yourself as a result of using DCC?

What **benefits** (e.g. patient experience and reduced travel time to clinics) do you think are linked to digital communications?

Probes:

What impact do you think using DCC might have for you?

Would there be any impact on your health?

In what ways would using DCC make your life easier, or more difficult, compared to how you communicate with the clinical team now?

Would it have any impact on **how you use hospital services**?

Probes:

Would it have any impact on your X clinic attendance?

Would there be any impact on things like the number of **adverse events/acute episodes** you have (i.e. preventative or causal)?

Probes:

Are there any examples of things that might be/have been avoided by using DCC?

What would it be like/might happen if you could use DCC with the clinical team?

What **costs** do you think are linked to digital communications?

In the **future**, how would you like to use digital communication for your health care?

If email/text, would you want individual email/text rather than team email addresses/mobile phone number?

How would you feel about a number of team members having access to your email rather than one person (when talking about generic email to a service)?

In what time frame you would like a response by text/email?

Probes:

What do you think will need to change for this to happen?

What training needs do you think there are for patients for using digital communication?

What risks might there be if the NHS introduced the ability to get in touch with clinicians via [suggest technology not used currently]?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where they would need to pay for digital communication.

Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide you with a basic service, so clinic appointments as usual and contact with your medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). **In addition to this the NHS is going to set up a premium service which you would have to pay for. This would include the facility to email/text/Skype (as appropriate) your healthcare team. This service would have to be paid for by patients.** What would be the sort of things you would think about in deciding to subscribe to this service?

Probes:

What would be important/what would you value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).

If you think you would subscribe to such a service, how much would you be willing to pay? £10 or how much?

Assessment of generic measures identified in literature review

The interviewee will be shown any identified generic measures and asked to what extent the success or not of their digital service is captured by these outcome measures.

How likely are you to recommend using [*state the digital technology*] with your clinicians to friends and family if they needed similar care or treatment? On a scale of 1 to 5, where 1 is extremely likely, 5 is extremely unlikely and 6 is don't know. TBC.

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

Close of interview

Thanks

Any questions from interviewee

Reminder of study contact details

Can we contact their parent/carer/household member; someone they consider to be their main source of support who would be happy to be interviewed too (this could be a parent or anyone else they feel is someone they rely on a lot)? The purpose of the interview is to find out about their experiences and opinions as someone who knows them well and is an important source of support.

Instruction about how they will receive their £20 voucher

Appendix 1.2: Interview schedule for parents/carers of young people with long term conditions

Follow up on what is observed (i.e. use this data as cues/see how people feel about it)

GET AS MANY CONCRETE EXAMPLES AS POSSIBLE (& IF THESE AREN'T FORWARDED BEFORE THE INTERVIEW ASK THEM TO FORWARD THEM AFTER IT)

(Interviewee will have received participant information sheet and signed consent form)

<u>Introductions</u>

[*Before consent if taken verbally…..*

My name is X and I am one of the researchers working on the LYNC study

*Just to remind you **the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X**.*

Today I'm going to ask you some questions about you and your health, your use of digital communication technologies (if you do use these things), and how you feel about using/the idea of using these things.

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

Face to face and telephone interviews will be audio recorded, the recordings are stored securely and will be transcribed with anonymisation so that they can be analysed.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

Tell me about **yourself** (home, education, work)

Tell me about your **relationship to (name)**

Tell me about **(name)'s health**

Probes:

> What sort of things do they do to look after their X?

How much and what kind of **involvement do you have in (name)'s care**? [If they are or were involved]
What do/did you do for them?

How much and what kind of i**nvolvement do you have in (name)'s communication with the X team**? [If they are or were involved] How do/did you normally communicate with the clinical team? What is/was the nature of this communication? What types of issues do/did you face for which you would get in touch with the clinical team? Is/was that within or between consultations?

What sort of things do you think DCC includes (encourage them to name as many as possible)?

Tell me about your **use of digital communication generally** (email, text, social media, Skype etc.)

Probes:

      What types do you use?

      With **whom**?

      For **what purpose**?

PARENTS/CARERS ETC. THAT ARE OR WERE INVOLVED IN (NAME)'S CARE AND COMMUNICATION WITH THE X TEAM

Tell me (more) about your **use of digital communication in relation to (name)'s health** (now or back when you were involved in their care)

Probes:

      Do/did you use it **in relation to (name)'s health**? If yes, how?

      Do/did you use it to communicate with **health professionals**?

      (If yes) Approximately **how often** do/did you use it?

What do/did you use?

What **sorts of things** might that be/have been about (I.e. **content**/medical purpose) (for each type of DCC used)?

What is/was the **purpose** of using it (i.e. medical, economic, e.g. saves time and travel, and patient impact) (for each type of DCC used)? **Why** do/did you use this method of communication? What in particular is/was **useful** about it?

When/where do/did you use it (for each type of DCC used)?

A1. WHERE PARENT/CARER HAS BEEN INVOLVED IN DCC

Can you tell me how you **started using X**? Tell me more about how you started using X?

Can you tell me exactly what the **process** is/was when you use/used X with the clinical team from 'start' to 'finish' (for each type of DCC used)? E.g. What 'kit' do/did you use? How do/did you send them a message?

Which members of the team do you use DCC with?

Probes:

Which **technologies** do you use with each of these people?

What **sorts of things** is your communication with each person normally about?

How do you exchange **contact details** (e.g. mobile phone numbers, email addresses, etc.)?

Can you tell me what you **think/thought happens to your communication** (for each type of DCC used)?

Probes:

Who can/could see it your end?

Can/could anyone see it in transit?

Who sees/saw it once it has/had arrived?

What happens/happened after you have/had sent them a message (at yours and the clinical team's end)?

When do/did you think these health professionals look/looked at it?

Are/were there ever any delays when sending or receiving messages?

When would/did you expect to get a response?

What **conversations have the X team had/did they have with** you about how and when you can/could use DCC to contact them?

DRAW DIAGRAMS OF THE PROCESS OF USING EACH TYPE OF DCC TO PROMPT THEM & START TO THINK ABOUT ELICITING SPECIFIC EXAMPLES

We really want to understand more about the process of using DCC with specific examples if possible. Have you brought examples of recent DCC?

Researcher reads examples and uses them to support asking about the following topics.

If no examples provided, researcher asks them to describe a recent example of where it was used.

ALSO – in both instances – the researcher asks them to share their communications going back years (if appropriate).

Where parents had used DCC re: the patients' health but were no longer involved, the researcher asks them to share their communications when they were involved in the patient's care going back years (if appropriate).

What did you use?

CONTENT

What was it about?

Probes:

>   What correspondence happened beforehand?
>
>   What happened after?
>
>   What did you expect to happen after? (get detail)
>
>   What was the result of the communication, e.g. saved appointment, medication change etc….

PURPOSE

Why do/did you do it that way? **Why do/did you use that?** Why did you use X/digital communication technology?

OBJECTIVES

What were you hoping to achieve by using the DCC (*at each step of the process relevant to them*)?

Probes:

>   **Were these aims achieved?** What was achieved?

What tools did you use when you did that (*at each step of the process of using the DCC*)?

What were you thinking when you did it (*at each step of the process of using the DCC*)?

What knowledge, social norms and rules were you drawing upon when you did it (*at each step of the process of using the DCC*)?

ASK QUESTIONS ABOUT CONCERNS, IMPACT & COST ETC. (SEE LATER)

It would be really helpful if you could now tell me about a situation where DCC did and did not work well for you in relation to (name)'s health care

If participant is unable to describe a relevant situation, then researcher explores these issues based on a recent occurrence of DCC in relation to their health care:

Can you tell me a bit more about <u>what we just talked about</u>? How did that work for you?

What about <u>the last time you used X</u> with the clinical team? How did that work for you?

When example identified:

When example identified:

Firstly, what worked well?

What did not work well?

What happened (**unfolding**)?

Why did that happen (**cause**)?

How frequently does something like this happen (**likelihood**)?

What happened after the 'event' (refer to what it was)? What effect did it have? What did you do afterwards (**consequence**)?

What did that mean? What problems did that cause? What bad things could have happened? What are the worst possible things that could have happened (**severity**)?

Now we would like to try and understand how you feel/felt about using DCC in general in relation to (name)'s health care

WHAT ARE THE RISKS AND SECURITY ISSUES?

BE SURE TO PICK UP ON ANY UNCERTAINTLY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW DOES/DID COMMUNICATION USING X COMPARE TO USING THE POST

Do/did you **want to use DCC with the clinical team?**

In general, **how comfortable** do/did you feel using X with the clinical team?

Probes:

>What is/was you **experience** of using DCC?

>Tell me how you use/used it and what you won't/wouldn't do on it?

>Is/was this any different to what you use/used at home?

>Do/did you feel there is/was a **problem** with anything?

>Do/did you have any **concerns** about its use?

>Is there anything that would worry you about using this technology to talk about (name)'s health?

>What do you perceive the risks to be in terms of **patient safety**?

>What do you perceive the risks to be in terms of **ethical issues**?

>What do you perceive the risks to be in terms of **storing the data**?

>What are your thoughts on the nature of **privacy and confidentiality** in the context of DCC?

>What are the common **security concerns**?

>What are things / outcomes that you would/would have definitely **want/wanted to avoid** when using this technology?

>What **new risks** does DCC introduce?

What do you consider to be **confidential**? Who would you not want to see that? Who would you mind, and not mind, seeing a X containing that information? E.g. parents, friends, etc.

What would you mind, and not mind, the X team communicating with you about via different kinds of digital communication?

What **could go/could have gone wrong** (*at each of the steps of using each type of DCC that they are involved in (e.g. sending a text message)*?

E.g. Where do you leave your phone? Do you share your phone with anyone?

Probes:

>What are common **failures / failure opportunities** in the process?

How important are/were these risks/issues to you?

Probes:

How concerned are/were you about these issues?

Do/did these issues influence your decision to use DCC in relation to (name)'s health care?

How would you feel/have felt about the things you have said could go wrong happening? Would you care/have cared? How much would that matter/have mattered to you?

E.g. How would you feel if other people (friends, family, colleagues, strangers) read your communication with the clinical team? What sorts of things would you mind people seeing?

RE: IDENTIFIED RISKS: HOW ARE (OR WERE) THEY/SHOULD THEY BE DEALT WITH….

Would you or do/did you do anything to **deal with these risks** (e.g. never include sensitive data in a text message)? Is/was anything in place to prevent other people accessing these things (e.g. where do/did you leave your phone and is/was anything password protected)? GET EXAMPLES

What risks would there be if you **didn't/hadn't used DCC** with the clinical team?

Probes:

> Is/was there any positive effect of DCC on risk?

If the main carer/supporter is a parent/guardian of the participants (even if the participant is now in their 20s)

Do/did you think it alters your **relationship** with your son/daughter concerning their health?

Probes:

> How do/did you feel about the independent DCC relationship your child may now have/had with their clinical team?
>
> How do/did you and your son/daughter communicate about their DCC health care communications?
>
> What impact does/did it have on your role as main carer/supporter?
>
> Does/did it have any impact on the relationship between you and the clinical team and your access to information about their health/healthcare?

To what extent do you think it improves (name)'s **engagement with their treatment regimens**?

Have/did you experienced/experience any changes in the responsibility for (name)'s care/self-care?

Does/did (name) feel more or less confident in managing things to do with their condition yourself as a result of you using DCC?

What **benefits** (e.g. patient experience and reduced travel time to clinics) do you think are linked to digital communications?

Probes:

> What impact does/did using DCC have for (name)?

> Does/did it have any impact on (name)'s health?

> In what ways does/did using DCC make your life easier, or more difficult, compared to how you would otherwise communicate with the clinical team?

Has/did it had any impact on **how they use hospital services**?

Probes:

> Has/did it had any impact on their X clinic attendance?

Is/was there any impact on things like the number of **adverse events/acute episodes** they have/had (i.e. preventative or causal)?

Probes:

> Are there any examples of things that have been/were avoided by using DCC?

> What would it be like/have been like / might happen/might have happened if you couldn't use DCC with the clinical team?

What **costs** do you think are linked to digital communications?

In the **future**, how would you like/have liked to use digital communication for (name)'s health care?

Probes:

> What do you think will need to change for this to happen?

> Would patients/parents need any training for using digital communication with their clinical team? If so, what training would they need?

> What risks might there be if the NHS introduced the ability to get in touch with clinicians via [suggest technology not used currently]?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where they would need to pay for digital communication.

Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide a basic service for (name), so clinic appointments as usual and contact with their medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). **In addition to this the NHS is going to set up a premium service. This would include the facility to email/text/Skype (as appropriate) their healthcare team. This service would have to be paid for by patients or their families.** What would be the sort of things you would think about in deciding whether (name) should subscribe to this service?

Probes:

> What would be important/what would (name) value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).

> If you think (name) should subscribe to such a service, how much should they be willing to pay? £10 or how much?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

A2. WHERE PARENT/CARERS HAVE NEVER BEEN INVOLVED IN DCC

Why don't/didn't you use DCC?

What sorts of things would you like/have liked to use these technologies for in terms of using them to communicate with your clinical team about (name)'s health?

PAY ATTENTION TO INSTANCES OF NON-DATA

We would like to try and understand how you generally feel/would have felt about the idea of using DCC in relation to (name)'s health care

WHAT ARE THE RISKS AND SECURITY ISSUES?

BE SURE TO PICK UP ON ANY UNCERTAINTLY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW WOULD COMMUNICATION USING X COMPARE TO USING THE POST

How do you feel/would you have felt about the idea of using DCC with the clinical team in relation to (name)'s health care?

How comfortable would you feel/have felt with the idea of using DCC with the clinical team in relation to (name)'s health care?

Probes:

> What do you think the **problems** are in relation to using DCC?

> Do you have any **concerns** about the use of DCC?

> Is there anything that would worry you about the idea of using this technology to talk about (name)'s health?

> What do you perceive the risks to be in terms of **patient safety**?

> What do you perceive the risks to be in terms of **ethical issues**?

> What do you perceive the risks to be in terms of **storing the data**?

> What are your thoughts on the nature of **privacy and confidentiality** in the context of DCC?

> What are the common **security concerns**?

> What are things / outcomes that you would/would have definitely **want/wanted to avoid** when using this technology?

> What **new risks** would DCC introduce?

What do you consider to be **confidential**? Who would you not want to see that? Who would you mind, and not mind, seeing a X containing that information? E.g. parents, friends, etc.

What would you mind, and not mind, the X team communicating with you about <u>via different kinds of digital communication</u>?

What **could go/have gone wrong**?

E.g. Where do you leave your phone? Do you share your phone with anyone?

Probes:

What are common **failures / failure opportunities** in the process?

How important are/would these risks/issues (have been) to you?

Probes:

How concerned are you/would you have been about these issues?

Would these issues influence/have influenced your decision to use DCC in relation to (name)'s health care?

How would you feel/have felt about the things you have said could go wrong happening? Would you care/have cared? How much would that matter/have mattered to you?

E.g. How would you feel if other people (friends, family, colleagues, strangers) read your communication with the clinical team? What sorts of things would you mind people seeing?

RE: IDENTIFIED RISKS: HOW SHOULD THEY BE DEALT WITH….

Would you do anything to **deal with these risks** (e.g. never include sensitive data in a text message)? Would anything need to be in place to prevent other people accessing these things (e.g. where do/did you leave your phone and is/was anything password protected)? Why would you do/not do these things? GET EXAMPLES

What risks are there/would there have been in **not using DCC**?

Probes:

Is/was there any positive effect of DCC on risk?

If the main care/supporter is a parent/guardian of the participants (even if the participant is now in their 20s)

Do/did you think it would alter your **relationship** with your son/daughter concerning their health?

Probes:

Would you anticipate/have anticipated any impact on the relationship between you and the clinical team and your access to information about their health/healthcare?

What impact might it have/have had on your role as main carer/supporter?

To what extent do you think it would improve/have improved (name)'s **engagement with their treatment regimens**?

Probes:

Would you anticipate/ have anticipated any changes in the responsibility for (name)'s care/self-care?

Would (name) feel more or less confident in managing things to do with their condition yourself as a result of you using DCC?

What **benefits** (e.g. patient experience and reduced travel time to clinics) do you think are linked to digital communications?

Probes:

What impact might using DCC have/have had for (name)?

Would there be/have been any impact any impact on (name)'s health?

In what ways would using DCC make your life easier, or more difficult, compared to how you communicate with the clinical team now?

Would there be/have been any impact on **how they use hospital services**?

Probes:

Would there be/have been any impact on their X clinic attendance?

Would there be/have been any impact on things like the number of **adverse events/acute episodes** they have/had (i.e. preventative or causal)?

Probes:

Are there any examples of things that might be/might have been / have been avoided by using DCC?

What would it be like/have been like / might happen/might have happened if you could use/have used DCC with the clinical team?

What **costs** do you think are linked to digital communications?

In the **future**, how would you like/have liked to use digital communication in relation to (name)'s health care?

Probes:

What do you think will need to change for this to happen?

What training needs do you think there are for patients/parents for using digital communication?

What risks might there be if the NHS introduced the ability to get in touch with clinicians via [suggest technology not used currently]?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where they would need to pay for digital communication.

Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide a basic service for (name), so clinic appointments as usual and contact with their medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). **In addition to this the NHS is going to set up a premium service. This would include the facility to email/text/Skype (as appropriate) their healthcare team. This service would have to be paid for by patients or their families.** What would be the sort of things you would think about in deciding whether (name) should subscribe to this service?

Probes:

What would be important/what would (name) value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).

If you think (name) should subscribe to such a service, how much should they be willing to pay? £10 or how much?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

<u>PARENTS/CARERS ETC. THAT ARE NOT/HAVE NEVER BEEN INVOLVED IN (name)'s CARE (I.E. INCLUDING PARTNERS)</u>

Don't worry about specific questions, just have a conversation about their experience and views on digital communication for someone in their situation

Would you and (name) like for you to be involved in (name)'s care/have access to communication with the X team? Would you like to be able to ask the X team about (name)'s care/condition directly?

[If yes]

What would you like to be able to do? Why?

How would DCC help with that process? Why do you say that?

*[If they would **not** want to have direct communication with the team themselves focus on their **general views about patients communicating with the team based on their observations/experiences of (name)'s communication with the team**]*

How much do you know about (name)'s care? How do you feel about that? How happy are you with that level of knowledge? Why do you say that? Would you like that to be altered in any way? How? Why?

How much do you know about (name)'s contact with the X team?

Does (name) use DCC with the X team?

B1. [If patient **does use** DCC with the X team:]

How do you and (name) communicate about their DCC health care communications? How much do you know about this? How do you feel about that? How happy are you with that level of knowledge? Why do you say that? Would you like that to be altered in any way? How? Why? What are your views about this? Why do you say that?

Where could it be improved? Why do you say that?

Where is it working well? Why do you say that?

THEN RE: THEIR PERCEPTIONS AROUND THE PATIENT'S USE OF DCC WITH THE X TEAM ASK QUESTIONS ABOUT SECURITY, PATIENT AUTONOMY, BENEFITS, HEALTH CARE USE, ADVERSE EVENTS/ACUTE EPISODES, COSTS & FUTURE USE OF DCC (SEE A1 ABOVE)

B2. [if patient **does not** use DCC with the X team:]

What are your views about this? Why do you say that?

THEN RE: THEIR PERCEPTIONS AROUND THE PATIENT'S USE OF DCC WITH THE X TEAM ASK QUESTIONS ABOUT SECURITY, PATIENT AUTONOMY, BENEFITS, HEALTH CARE USE, ADVERSE EVENTS/ACUTE EPISODES, COSTS & FUTURE USE OF DCC (SEE A2 ABOVE)

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where (name) would need to pay for digital communication.

Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide a basic service for (name), so clinic appointments as usual and contact with their medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). **In addition to this the NHS is going to set up a premium service. This would include the facility to email/text/Skype (as appropriate) their healthcare team. This service would have to be paid for by patients or their families.** What would be the sort of things you would think about in deciding whether (name) should subscribe to this service?

Probes:

> What would be important/what would (name) value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).

> If you think (name) should subscribe to such a service, how much should they be willing to pay? £10 or how much?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

<u>Close of interview</u>

Thanks

Any questions from interviewee

Reminder of study contact details

Appendix 1.3: Interview schedule for clinic staff

Follow up on what is observed (i.e. use this data as cues/see how people feel about it)

GET AS MANY CONCRETE EXAMPLES AS POSSIBLE

(Interviewee will have received participant information sheet and signed consent form)

Introductions

[*Before consent if taken verbally…..*

My name is X and I am one of the researchers working on the LYNC study

Just to remind you **the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X**.

Today I'm going to ask you some questions about you and your role, your use of digital communication technologies (if you do use these things), how you communicate with patients and how you feel about using/the idea of using these things.

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

Face to face and telephone interviews will be audio recorded, the recordings are stored securely and will be transcribed with anonymisation so that they can be analysed.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to emphasise - whatever you tell me will be kept confidential; it will not be possible to identify you or the clinic from our research report.

Some of the ways you use digital communication with patients as part of your clinical practice may not be in line with NHS Information Governance. Our ethics protocol recognises this; we do not report this type of practice to anyone - we are only obliged to report professional conduct which puts patients at serious risk.

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

Tell me about your **work role** (role, tasks, duration)

What sort of things do you think digital communication includes (encourage them to name as many as possible)?

Tell me about your **use of digital communication generally** (email, text, social media, skype etc.)

Probes:

> **What** types do you use (i.e. out of work)?
>
> With **whom**?
>
> For **what purpose**?

How do you normally communicate with patients (& vice versa)?

PAY ATTENTION TO INSTANCES OF NON-DATA

Tell me (more) about your **use of digital communication for health**

Probes:

> Do you use it to communicate with patients?
>
> (If yes) **What** do you use?
>
> What **sorts of things** might that be about (I.e. **content**/medical purpose) (for each type of DCC used)?
>
> What is the **purpose** of using it (i.e. medical, economic, e.g. saves time and travel, and patient impact) (for each type of DCC used)?
>
> **When/where** do you use it (for each type of DCC used)?

What **hardware** (PC, mobile phone, tablet etc.) and **software** (Microsoft Outlook, Skype, etc.) do you specifically use with patients/parents?

Probes:

> Who has ownership of this technology?
>
> Who provides, supports / maintains the technology used? Is there a specific person or helpdesk you go to (if this is the NHS)?
>
> Is this equipment you already have for your day job, or is it provided specifically for digital communication? Has the use of DCC required any new technology to be developed?
>
> Is any technology provided to the patient so that they can participate in DCC?

ARE YOU USING THE AUTOMATED APPOINTMENT REMINDER SMS SYSTEM?

Can you tell me how you **started using X**? Tell me more about how you started using X?

Can you tell me exactly what the **process** is when you use X with your patients from 'start' to 'finish' (for each type of DCC used)?

If use email:

Do you have individual email addresses or a team email address?

(If a team email address) What are your views on having **a generic email address and NOT using clinicians own named accounts** (i.e. does this approach miss the point (reduce the advantage) of patients having DCC email communication (i.e. named person to named person) with the relationship being really important for many clinicians and patients)?

Are any **context dependent judgments** made about who you use DCC with? (If yes) how are these decisions made?

Is there any **difference between paediatric and adults services**? (If yes) Why is that?

What conversations do you have with patients about how and **when they can use DCC to contact you**?

How do you exchange **contact details** (e.g. mobile phone numbers, email addresses, etc.)?

Are these **contact details stored**? If so, how? Who has access to them?

When you use X do you need to **refer to other notes** before responding (i.e. clinical notes)? Is it different for different types of X (e.g. email/text)?

When/how **quickly do you respond**? Do you access/respond to X outside working hours?

What are **patient's expectations about how quickly you will respond**? How do you **manage these expectations** (e.g. email signature and out of office reply)?

What happens to **"emergency" requests** that come in via digital communication?

Probes:

> How soon do you respond?

(If relevant) How is **continuity of responsibility and information** across shifts and departmental boundaries ensured?

How is the DCC activity **logged** (for each type of DCC used)?

Probes:

What is the **purpose** of logging this?

How well **does logging work** in practice (e.g. is it possible that an email isn't logged (maybe because somebody thinks it's irrelevant), or maybe it's logged by one member of staff but another member of staff forgets to check or simply isn't aware that there is an email)?

Who has **access** to this/is able to view and read this information? How do you know only these people can access this information?

Can you tell me **what you think happens to your communication** with patients/parents (for each type of DCC used)?

Probes:

Who can see it your end?

Can anyone see it in transit?

Who sees it once it has arrived?

What happens after you have sent them a message (at yours and the patient/parent's end)?

Are there ever any delays when sending or receiving messages?

What is **useful** about X? **What factors** do you think contribute to its successful/unsuccessful use?

Probes:

What is it about X that makes it useful/not useful (i.e. **the actual system**)?

What is it about the **content of the message** that makes it useful/not useful?

Are there any other things that make it useful/not useful (i.e. **contextual factors**)?

WHERE SITES USE DCC

We really want to understand more about the process of using DCC with specific examples if possible. Have you brought examples of recent DCC?

If we have patient consent to read them, the researcher reads examples.

If no consent then the clinician gives a summary of the issues covered in the communication and this is used to support asking about the following topics.

If no examples then researcher asks them to describe a recent example of where it was used.

ALSO - in both instances:

*The researcher asks them whether they can tell them about the **last patient** they communication with digitally (& encourages them to look it up).*

Once they have answered the questions below about this, the researcher asks them whether, using the clinic records, they can tell them about their digital communication with this patient <u>in the past</u> (& encourages them to work backwards through the clinic notes).

*Once they have answered the questions below about this, the researcher asks them the same about the **one before the last patient** (or if they can't think of one the researcher asks them if they can think of one in the last few days or weeks) – and so on until time runs out.*

What did you use?

CONTENT

What was it about?

Probes:

What correspondence happened beforehand?

What happened after?

What did you expect to happen after? (get detail)

What was the result of the communication, e.g. saved appointment, medication change etc….

PURPOSE

Why do/did you do it that way? **Why do/did you use that?** What was the context? Why did you use X/digital communication?

OBJECTIVE

What were you hoping to achieve by using the DCC (*at each step of the process of using DCC*)?

Probes:

Were these aims achieved? What was achieved?

What tools did you use when you did that (*at each step of the process of using the DCC*)?

What were you thinking when you did it (*at each step of the process of using the DCC*)?

What knowledge, social norms and rules were you drawing upon when you did it (*at each step of the process of using the DCC*)?

ASK QUESTIONS ABOUT CONCERNS, IMPACT & COST ETC. (SEE LATER)

It would be really helpful if you could now tell me about a situation where DCC did and did not work well for you or your patient

If participant is unable to describe a relevant situation, then researcher explores these issues based on a recent occurrence of DCC in relation to their health care:

Can you tell me a bit more about <u>what we just talked about</u>? How did that work for you?

What about <u>the last time you used X</u> with your patients/their parents? How did that work for you?

When example identified:

Firstly, what worked well?

What did not work well?

What happened (**unfolding**)?

Why did it happen (**cause**)?

How frequently does something like this happen (**likelihood**)?

What happened after 'the event' (refer to what it was)? What did you do afterwards? What effect did it have (**consequence**)?

What did it mean? What problems did that cause? What bad things could have happened? What are the worst possible things that could have happened (**severity**)?

Now we would like to try and understand how you feel about using DCC in general:

WHAT ARE THE RISKS AND SECURITY ISSUES?

BE SURE TO PICK UP ON ANY UNCERTAINTY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW DOES COMMUNICATION USING X COMPARE TO USING THE POST

In general, **how comfortable** do you feel using X with your patients?

Probes:

What is you **experience** of using DCC?

Tell me how you use it and what you won't do on it?

Is this any different to what you use at home?

Do you feel there is a **problem** with anything?

Do you have any **concerns** about its use?

What do you perceive the risks to be in terms of **patient safety**?

What do you perceive the risks to be in terms of **ethical issues**?

What do you perceive the risks to be in terms of **storing the data**?

What are your thoughts on the nature of **privacy and confidentiality** in the context of DCC?

What are the common **security concerns**?

What are things / outcomes that you definitely **want to avoid** when using this technology?

What **new risks** does DCC introduce?

What do you consider to be **confidential**? Why do you think that? How do you decide whether something is or is not confidential?

What **could go wrong** (*at each step of the process of using each type of DCC*)?

E.g. Where is your mobile phone left? Who has access to your PC/Laptop, email account and/or phone?

Probes:

What are **common failures / failure opportunities** in the process?

When issue identified:

What might happened (**unfolding**)?

Why might that happen (**cause**)?

How likely is it that that might happen (**likelihood**)?

What might happen after this? What effect would it have (**consequence**)?

What would that mean? What problem would that cause? What bad things could happen? What are the worst possible things that could happen (**severity**)?

E.g. What might happen if you sent a text to a patient about their health and it were stolen?

How important are these risks/issues to you?

How concerned are you about these issues?

Do these issues influence your decision to use DCC?

How would you feel about the things you have said could go wrong happening? Would you care? How much would that matter to you?

RE: IDENTIFIED RISKS: HOW ARE THEY/SHOULD THEY BE DEALT WITH….

Is there/should there be anything in place that would **alter/reduce the risks** you have identified (*at each step in the process of using each type of DCC)?*

Prompt

> Do you do anything to **deal with these risks** (e.g. never include sensitive data in a text message)?

> Is anything in place to prevent other people accessing your phone, PC or laptop etc.? (e.g. where do you leave your phone and is anything password protected)? Why do you do/not do these things?

What risks are there in **not using DCC** with your patients/parents?

Probes:

> Is there any positive effect of DCC on risk?

Does the use of DCC affect the relationship you have with your patients? If so, how?

Probes:

> What do you perceive your responsibilities to be in terms of accessing/using DCC outside working hours and how quickly you respond to X from patients?

> What impact does it have, if any, on your sense of duty of care?

> What are the implications for continuity of care?

To what extent do you think digital communication influences patient **engagement with treatment regimens**?

Probes:

> Have you experienced any changes in responsibility for care/self-care?

What **outcomes/benefits** do you think are linked to digital communications? E.g. patient experience, staff work experience, evaluated health outcomes

Probes:

> Are there any differences between patients who use DCC and those who don't?
>
> Do you think that the use of DCC can have an impact on patients' health? Could you provide some examples of how the use of DCC has directly or indirectly affected the health of your patients?

Why are these outcomes good?

Do you think that the availability of DCC to you and your patients has changed **how often they use hospital services**? (If yes) how/why?

Probes:

> Does it impact on the number of clinic visits that patients attend?
>
> Are any clinic visits saved by the use of digital communication? If so, could you estimate how many per week?

Could you please describe in detail situations where **unintended/unwanted outcomes /side effects** have been prevented (or caused) because patients had the opportunity to communicate digitally with you?

Probes:

> Are there any examples of things that have been avoided by using DCC?
>
> Does it impact on things like adverse events/acute episodes requiring care?
>
> What would it be like/what might happen if you couldn't use DCC with your patients?
>
> Where patients have contacted you with "emergency requests" via DCC, what would have happened if these patients did not contact you digitally (e.g. would they try to contact someone else, visit hospital outpatient services, or go to A&E?)?

Why are these outcomes bad? What is the consequence of any avoided incidents/risks?

What **costs** do you think are linked to digital communications? E.g. impact on other services, financial costs and savings

What are the **future implications** from greater use of digital communications?

Probes:

Looking to the future and the developments that are taking place with communication technology, how would you like to be able to communicate with your patients?

What training needs do you think there are for clinicians, and patients, for using digital communication?

What risks might there be if the NHS introduced the ability to get in touch with patients via [suggest technology not used currently]?

Do any particular safeguards need to be in place for this kind of communication?

Now we would like to know a bit about the time you spend on DCC and the impact on your workload (ASK EVERY MEMBER OF THE CLINICAL TEAM).

It might be helpful if we break it down a bit and plot it on a timeline… USE TIMELINE TECHNIQUE

<u>What is done now?</u>

How does it **fit into work practices**/other activities you undertake?

Probes:

Does it affect the other things you must do? How?

Do you have to trade off efficiency for thoroughness elsewhere? How?

How do you make trade-offs/judgements about how much time to spend on DCC in the context of the other things you have to do?

If you weren't using DCC what else would you be doing in that time?

If you didn't spend time on DCC, would your **workload** be **increased or decreased**?

Probes:

Why?

<u>What was it like before/what was done then?</u>

What was your workload like **before**?

<u>What has changed/what is different now?</u>

Has the use of DCC made a **difference to your workload**?

Probes:

How has your workload changed compared to before you were using DCC?

What ways has DCC made your life easier or more difficult?

Are there any positive implications for workload?

Can you quantify the impact on your workload at all?

Now we would like to ask you a couple of questions about your Trust Information Governance policies

Thank you for explaining all of this to me.

Your dedication to doing the best for your patients is clear.

With digital communication developing so rapidly we are aware that developments on the ground, such as the initiatives you have described, are not always in step with formal policies and procedures.

Again - our ethics protocol acknowledges this too.

We would like to understand from you how you consider your use of digital communication with patients to fit or not fit within your Trust's current information governance policies.

How do you consider your **use of DCC with patients to fit or not fit within your Trust's current information governance policies**? (pause for response)

Probes:

How do you feel about that?

What do you like about the current information governance policy?

What needs to change? (pause for response) (if no response) What needs to change in the information governance policy? *(i.e. what regulatory framework is needed to reassure patients and clinicians regarding the use of DCC)*

What discussions have you had about information governance

With colleagues?

With patients (i.e. re: making them aware of risks etc.)?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

WHERE SITES DON'T USE DCC

Why do you not currently use it?

What sorts of things would you like to use these technologies for in terms of using them to communicate with your patients about their health?

PAY ATTENTION TO INSTANCES OF NON-DATA

We would like to try and understand how you generally feel about the idea of using DCC

WHAT ARE THE RISKS AND SECURITY ISSUES

BE SURE TO PICK UP ON ANY UNCERTAINTY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW WOULD COMMUNICATION USING X COMPARE TO USING THE POST

How do you feel about the idea of using DCC with your patients?

What factors do you think contribute to its successful/unsuccessful use?

How comfortable do you feel with the idea of using DCC?

Probes:

      What do you think the **problems** are in relation to using DCC?

      Do you have any **concerns** about the use of DCC?

      What do you perceive the risks to be in terms of **patient safety**?

      What do you perceive the risks to be in terms of **ethical issues**?

      What do you perceive the risks to be in terms of **storing the data**?

      What are your thoughts on the nature of **privacy and confidentiality** in the context of DCC?

      What are the common **security concerns**?

      What are things / outcomes that you would definitely **want to avoid** when using this technology?

      What **new risks** would DCC introduce?

What do you consider to be **confidential**?

What could go wrong?

E.g. Where is your mobile phone left? What might happen if you sent a text to a patient about their health and it were stolen?

Probes:

What are common **failures / failure opportunities** in the process?

How important are these risks/issues to you?

Probes:

How concerned are you about these issues?

Do these issues influence your decision to use DCC?

How would you feel about the things you have said could go wrong happening? Would you care? How much would that matter to you?

RE: IDENTIFIED RISKS: HOW SHOULD THEY BE DEALT WITH….

Would you do anything to **deal with these risks** (e.g. never include sensitive data in a text message)?

What risks are there in **not using DCC** with your patients/parents?

Probes:

Is there any positive effect of DCC on risk?

Would the use of DCC affect the relationship you have with your patients? If so, how?

Probes:

What would you perceive your responsibilities to be in terms of accessing/using DCC outside working hours and how quickly you respond to X from patients?

What impact do you think it might have, if any, on your sense of duty of care?

What would the implications be for continuity of care?

To what extent do you think it would improve **engagement with treatment regimens**?

Probes:

Would you anticipate any changes in responsibility for care/self-care?

What **outcomes/benefits** do you think are linked to digital communications? E.g. patient experience, evaluated health outcomes.

Probes:

> Would you anticipate any differences between patients who use DCC and those who don't?

> What would it be like/what might happen if you could use DCC with your patients?

> Do you think that the use of DCC would have an impact on patients' health?

> Do you think it would impact on things like self-management or adverse events/acute episodes requiring care?

Do you think that the availability of DCC to you and your patients would change **how often they use hospital services**? (If yes) how/why?

Probes:

> Would it impact on things like patient attendance?

Why are these outcomes good?

Could you please describe in detail situations where **unintended/unwanted outcomes /side effects** could be prevented (or caused) because patients had the opportunity to X you?

Probes:

> Are there things that could be avoided by using DCC?

> Would it impact on things like adverse events/acute episodes requiring care?

Why are these outcomes bad? What is the consequence of any avoided incidents/risks?

What **costs** do you think are linked to digital communications? E.g. impact on other services, financial costs and savings.

What effect do you think it might have, if any, on your **workload**?

What are the **future implications** from greater use of digital communications?

Probes:

> Looking to the future and the developments that are taking place with communication technology, how would you like to be able to communicate with your patients?

> If email/text, would you want individual email/text rather than team email addresses/mobile phone number?

What training needs do you think there are for clinicians and patients for using digital communication?

What risks might there be if the NHS introduced the ability to get in touch with patients via [suggest technology not used currently]?

Do any particular safeguards need to be in place for this kind of communication?

Should there be anything in place that would alter/reduce the risks you have identified?

Now we would like to ask you a couple of questions about your Trust Information Governance policies

What do you like about the current information governance policy?

What needs to change? (pause for response) (if no response) What needs to change in the information governance policy? *(i.e. what regulatory framework is needed to reassure patients and clinicians regarding the use of DCC)*

What discussions have you had about information governance

With colleagues?

With patients?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

Close of interview

Thanks

Any questions from interviewee

Reminder of study contact details

Advise staff we might need a quick follow-up conversation after the field work (i.e. re: ensuring data capture data)

Appendix 1.4 Telephone interview schedule for lead clinician /manager at potential study site

Start of interview

Appreciation for agreeing to take part, reminder about the project (information about the project sent in advance of interview), explanation that researcher is taking written notes only of interview, verbal consent to interview.

Researcher tells interviewee:

- How we identified the clinic as a potential research site
- What we already know about the clinic from public sources and from the contact who suggested the clinic as a potential research site.

Topics to be covered in the interview

Clarification of the nature of the clinic: specialty, disease area, age group served, treatments provided, intensity of routine follow up.

Issues for clinic patients that the clinic team deal with during and between clinics that are additional to the routine outpatient follow up e.g. side effects, medication dose adjustment, social and psychological issues.

Use of digital communication technology between clinicians and patients:

- Number and roles of people using it
- Types of technology used
- Types of content of communication
- Extent to which the development, implementation and maintenance of technology is managed internally, or commissioned from external specialists.

Is the clinical team interested in participation in the study?

Are there any likely barriers to participation (e.g. upcoming move of clinic location)?

End of interview

Thank you.

Information about when the clinic will hear if they have been included in the sample for data collection and what will happen after that.

ASK ALL QUESTIONS ABOUT THE TRUST IN GENERAL (NOT IN RELATION TO ANY SPECIFIC SERVICE)

[*Before consent if taken verbally…..*

My name is X and I am one of the researchers working on the LYNC study

*Just to remind you **the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X**.*

The purpose of interview is to gain an understanding of the context in which the service we're studying has to operate. We are not just interested in the opinions of the clinical team, we would like to know about your opinions too.

I'm going to ask you some questions about your work role, the use of digital communication technologies within the Trust, any policies, and incidents, relating to this and how you feel about the use of these technologies.

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

Face to face and telephone interviews will be audio recorded, the recordings are stored securely and will be transcribed with anonymisation so that they can be analysed.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to emphasise - whatever you tell me will be kept confidential; it will not be possible to identify you or the Trust from our research report.

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

Tell me about your work role (role, tasks, duration)

What digital communication for clinical purposes occurs within your Trust?

Prompt:

> E.g. Is email / text message / social media / videoconference / mobile phone used to communicate with patients about clinical issues?

(If yes) In which services?

What do they use?

How do they use it?

How does it work?

Are mobile technologies or hand-held devices used in your Trust?

(If yes) How are they used?

If digital clinical communication does take place:

What are the advantages of these types of communication?

What are the challenges?

Do you have any concerns about these types of communication?

Policies

What policies are in place within your Trust that affect the use of the digital communication for clinical purposes?

Prompt:

What policies apply to communication with patients via email / text message / social media / videoconference / mobile phone?

What policies are in place about sharing staff contact details with patients? E.g. is there a requirement to share certain information (e.g. email addresses on clinic letters)?

What safeguards are written into these policies (i.e. what things are in place to prevent problems/incidents relating to DCC, e.g. procedures, recommendations, etc….)? What do they recommend about the use of these technologies and sharing such information?

Features/procedures

What safety features/procedures are in place for these communications? How is safety of the technology guaranteed, i.e. firewalls, secure servers, etc….? What protects, e.g. emails?

How pro-active are they/what do they perceive their role to be….?

How would you be/were you involved if/when a clinic started/started using X? What would your role be/was your role?

What policies and procedures did/would you implement to ensure that this didn't/doesn't introduce risk?

How do you know/ensure that people know about these policies and procedures?

How do/would you ensure that your policies and procedures are implemented/adhered to?

Are these communications systems monitored in any way?

Have there been any low-grade or serious incidents relating to digital clinical communication?

Prompt

> E.g. has any information ever been lost in transit (e.g. emails sent to the wrong person) or perhaps a notebook has been left in people's houses or stolen from cars?

(If they struggle to give specific examples), what about the last time something happened? And then the time before that?

TRY TO GET ACTUAL EXAMPLES

WE WANT TO KNOW ABOUT ALL INCIDENTS AT ALL LEVELS INCLUDING NEAR MISSES

Are such incidents logged/reported? (If yes)

How? E.g. Are low grade incidents logged by Trusts and serious incidents reported via the IG toolkit (& published online via the HSCIC website), which determines the severity of the event and justification for notifying the Department of Health & Information Commissioners Officer (IOC)?

If it doesn't take place:

Are there any plans to introduce digital communication for clinical purposes?

What has prevented the introduction of this type of communication?

What are the advantages of these types of communication?

What are the challenges?

What concerns do you have about this type of communication?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

Close of interview

Thanks

Any questions from interviewee

We might need a quick follow-up conversation after the field work (i.e. re: ensuring data capture data). Would that be ok?

Would you be able to provide us with or signpost us to the Trust Information Governance policies and procedures you have just told me about, please?

Who is responsible for the supply, support and maintenance of the DCC used (specific person or helpdesk if NHS)? Who has oversight of this? Is/was the technology managed internally (I.e. and identify the person with oversight, e.g. IT manager/practice manager), or commissioned from external specialists?

Are you aware of any endeavours to evaluate the use of DCC within the Trust?

How can we collate outcome and cost data? Who should we contact?

Might it be possible to interview the Caldicott Guardian? Perhaps by email? If so, would you be able to signpost me to them please?

Appendix 2: Patient Reported Outcome Measures Cognitive Interview Schedules

Appendix 2.1: Cognitive interview schedule for young people with long term conditions

When recruiting patients we don't need to go into too much detail about the specific outcome measure questions. We just offer the usual same information and consent forms that we used before and explain how the cognitive interview will work.

Consent is the same as before, with some additional information (in bold):

(Interviewee will have received participant information sheet and signed consent form)

Introductions
[Before consent if taken verbally…..

My name is X and I am one of the researchers working on the LYNC study

Just to remind you the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X.

Today I'm going to ask you some questions about you and your health, your use of digital communication technologies (if you do use these things), **and what your opinion is about the care that is provided to you. We will ask you some questions and then then ask you to reflect on your answers and tell us your thoughts.**

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

Face to face and telephone interviews will be audio recorded, the recordings are stored securely and will be transcribed with anonymisation so that they can be analysed.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

Questions from the main interview schedule:

Instructions: We will ask questions from the main interview schedule in order to orientate their thinking to the topic. We want to develop an introduction to the questionnaire that enables the participants to see that the questions should be answered in the context of their current access and communications (in face to face and DCC) with their HCP.

Tell me about yourself (home, education, work). E.g. how old are you? Who do you live with? Whether you work or are in education?

Tell me about your health
Probes:
- What sort of things do you do to look after your X?

What sort of things do you think digital communication includes (encourage them to name as many as possible)?

Tell me about your use of digital communication generally (email, text, social media, Skype etc.)
Probes:
- What types do you use?
- With whom?
- For what purpose?

Tell me (more) about your use of digital communication for health
Probes:
- Do you use it in relation to health? If yes, how?
- Do you use it to communicate with health professionals?
- (If yes) Approximately how often do you use it?
- What do you use?
- What sorts of things might that be about (I.e. content/medical purpose) (for each type of DCC used)?

Can you tell me how you started using X? Tell me more about how you started using X?

Can you tell me exactly what the process is when you use X with the clinical team from 'start' to 'finish' (for each type of DCC used)? E.g. What 'kit' do you use? How do you send them a message?

Which members of the team do you use DCC with?
Probes:
- Which technologies do you use with each of these people?
- What sorts of things is your communication with each person normally about?

Outcome measures:

Instructions: We will use the Patient Activation Measure (PAM) and the Physicians' <u>Humanistic</u> Behaviors Questionnaire (PHBQ). We developed 3 different versions which include items from both measures such that patients are not burdened by having to consider all of the items in each scale. Where the original measure comprises domains, we have ensured that each domain is represented in each version. As each patient is 4 [to this sort of interview], we will use the next version in a looped 1, 2, 3 sequence. This will be documented in a separate worksheet within the recruitment spreadsheet.

Be prepared for the patients to find it difficult to separate out DCC from other aspects of clinical

communication – if this is the case it is important we know this – but we need to encourage them to try

to separate it out.

*We will present the appropriate version to the patient and ask them to spend around 10 to 15 minutes with each one (**looking at each item in turn – though note that it is the overall emphasis and relevance of the scale that we are interested in rather than the specific items**).*

- *READ NAME OF THE QUESTIONNAIRE(S) USING ALOUD FOR THE TAPE*

- *READ THE ITEM ALOUD FOR THE TAPE*

- *NOTE RESPONSE TO THE ITEM ON QUESTIONNAIRE(S)*

Introduction

We are going to show you two questionnaires and would like to know about how completely you feel the questions address the sorts of things that are important to you in terms of using digital communication technologies to talk about your health care with your health care team.

We will ask you some questions and ask you to think about them in terms of your current access to and communication with your HCP, face to face and via digital communications such as email, text, social media (e.g. Facebook) or Skype.

As you are trying to answer each question, it would be really helpful if you could think aloud (i.e. **narrate your thought processes**), for example sometimes when I fill out questionnaires I think to myself 'that's not particularly relevant to people like me' or 'I don't fit into these boxes'.

As interviewee answers each question ask (to identify whether DCC use is in their mind at all when they are formulating their answers):

Tell me about the answer to that question?
Probes:
- What led you to answer it in that way?
- What examples/experiences did you have in mind when you answered that question?
- How was your answer influenced by your relationship with your HCP?
- How was your answer influenced by your current access to and communication with your HCP?

After completing each questionnaire ask (to identify whether DCC use is in their mind at all when they are formulating their answers):

What was it like for you when you were answering the questions?

Do you think the questions include everything that matters to you? If not, what is missing?

How did you work out which answers to choose?

What made answering the questions difficult?

What helped you answer the questions?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

Version 1

The Patient Activation Measure (PAM)

Item	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
Believes Active Role Important					
1.When all is said and done, I am the person who is responsible for managing my health condition					
Confidence and knowledge to take action					
4. I am confident I can tell my health provider concerns I have even when he or she does not ask					
7.I am confident that I can follow through on medical treatments I need to do at home					
10.I am confident that I can follow through on recommendations my health provider makes such as changing my diet or taking regular exercise					
Taking action					
13.I have been able to maintain the lifestyle changes for my health that I have made					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
16.I have made the changes in my lifestyle like diet and exercise that are recommended for my health condition					
Staying the course under stress					
19.I am confident that I can maintain lifestyle changes, like diet and exercise even during times of stress					
22. Making the lifestyle changes that are recommended for my health condition are too hard to do on a daily basis					

Physicians Humanistic Behaviour Scale

This doctor (identified by photo or name)…………..NA because not asking about a particular HCP?

Item	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. Follows through on problems					
4. Expresses concern for my feelings and needs, not just my physical status					
7. Keeps his or her promises to me					
10. Answers my questions					

13. Uses terms that I can understand					
16. Has a neat, clean, well-groomed appearance					
19. Doesn't rush or spend too little time with me					
22. Seems knowledgeable and concerned about me and my case					
• Asks me how I feel about my problems					

Version 2

The Patient Activation Measure

Item	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
Believes Active Role Important					
2. Taking an active role in my own health care is the most important factor in determining my health and ability to function					

Confidence and knowledge to take action					
5.I am confident that I can tell when I need to get medical care and when I can handle the health problem myself					
8.I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition					
11. I understand the nature and causes of my health condition/s					
Taking action					
14.I know how to prevent further problems with my health condition					
17.I am confident I can figure out solutions when new situations or problems arise with my health condition					
Staying the course under stress					
20.I am able to handle problems of my health condition on my own at home					

Physicians Humanistic Behaviour Scale

This doctor (identified by photo or name)…………..NA because not asking about a particular HCP?

Item	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
2. Is truthful and honest with me without avoiding the issues					
5. Comforts or reassures me and my family					
8. Pays attention to concerns or requests that I feel are important					
11. Makes uncaring remarks or does things I find offensive					
14. Includes me in decisions and choices about my care					
17. Is short tempered or abrupt with me and my family					
20. Asks if I need anything or what he or she can do for me					
23. Asks questions about my symptoms					

Version 3

The Patient Activation Measure

Item	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
Confidence and knowledge to take action					
3. I know what each of my prescribed medications do					
6.I know the lifestyle changes like diet and exercise that are recommended for my health condition					
9. I am confident that I can find trustworthy sources of information about my health condition and my health choices					
12. I know the different medical treatment options available for my health condition					
Taking action					
15.I now about the self-treatments for my health condition					
18.I am able to handle symptoms of my health condition on my own at home					

Staying the course under stress					
21.I am confident I can keep my health condition from interfering with things I want to do					

Physicians Humanistic Behaviour Scale

This doctor (identified by photo or name)…………NA because not asking about a particular HCP?

Item	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
3. Is in a hurry					
6. Asks how I am doing					
9. Explains and clarifies information for me					
12. Discussed the options for my treatment					
15. Arranges for adequate privacy when examining or talking with me					
18. Makes changes in my treatment without telling me					

21. Asks how I want to be addressed and then greets me in that way					
24. Treats me with too intimate or personal a manner					

Appendix 2.2: Cognitive Interview schedule for clinicians

If the interview is conducted prospectively:

We will start by explaining the interview process and ask for consent. Consent is the same as before, with some additional information (in bold):

(Interviewee will have received information sheet and signed consent form)

Introductions
[Before consent if taken verbally…..

My name is X and I am one of the researchers working on the LYNC study

Just to remind you the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X.

*Today I'm going to ask you some questions about you and your role, your use of digital communication technologies (if you do use these things), **and what you are hoping to achieve through the use of digital communication with your patients. We would also like to know your views on two specific measures as a means of assessing the outcome related to the use of digital clinical communication.***

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

The interview will be audio recorded, the recordings are stored securely and when they are transcribed they are anonymised.

So just to emphasise - whatever you tell me will be kept confidential; it will not be possible to identify you or the clinic from our research report.

We are aware that some of the ways you use digital communication with patients may not be in line with NHS Information Governance. Our ethics protocol recognises this; we do not report this type of practice to anyone - we are only obliged to report professional conduct which puts patients at serious risk.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

THEN FOCUS ON GETTING THE CORE DATA REQUIRED FOR THE NORMAL INTERVIEW BEFORE MOVING ONTO OUTCOME MEASURES

<u>If the interview is conducted retrospectively:</u>

(Interviewee will have received information sheet and signed consent form before the first interview)

We will just describe briefly what is going to happen:

Today I'm going to ask you what you are hoping to achieve through the use of digital communication with your patients. We would also like to know your views on two specific measures as a means of assessing the outcome related to the use of digital clinical communication.

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

The interview will be audio recorded, the recordings are stored securely and when they are transcribed they are anonymised.

So just to emphasise - whatever you tell me will be kept confidential; it will not be possible to identify you or the clinic from our research report.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

<u>Instructions re: asking about the outcome measures:</u>

Instructions: We will use The Patient Activation Measure (PAM) and the Physicians' <u>Humanistic</u> Behaviors Questionnaire (PHBQ).
- *Patient Activation Measure (PAM); the objective is to determine whether the measure is useful in terms of assessing the impact of the use of DCC for patients (i.e. whether the measure is useful, in their opinion, in capturing patient self-care outcomes related to use of DCC/whether patients have achieved their previously specified objectives)?*
- *Physicians' <u>Humanistic</u> Behaviors Questionnaire (PHBQ); the objective is to determine whether the items assess aspects of clinician's consultation performance via DCC (from the*

patient's perspective) (because the data thus far has suggested that <u>connecting to the</u> <u>human side of clinicians is facilitated by DCC</u>).

Be prepared for the clinicians to find it difficult to separate out DCC from other aspects of clinical communication – if this is the case it is important we know this – but we need to encourage them to try to separate it out.

*We will present both scales to the clinicians and ask them to spend around 10 to 15 minutes with each one (**looking at each item in turn – though note that it is the overall emphasis and relevance of the scale that we are interested in rather than the specific items**).*

We will ask them to use the answers in the scale as you are considering each item, I.e. strongly agree – strongly disagree or N/A [MUST ENSURE THAT THEY COMMIT TO A DECISION]. If they only tick the boxes; 'can you me about your answer to that item, please'.

The Patient Activation Measure: E.g., item 3. "I know what each of my prescribed medications do". If they say strongly disagree or N/A, Why? I.e. is this because they do not discuss medication with patients via DCC (& therefore the item is not relevant in terms of assessing the impact of the use of DCC for patients)? Or if they say strongly agree, why? I.e. is this because they do discuss medication with patients via DCC (in which case the item is relevant in terms of assessing the impact of the use of DCC for patients)?

Physicians Humanistic Behaviour Scale: E.g., item 3. "Is in a hurry". If they say strongly disagree or N/A, why? Is this because they would not engage with DCC when they are in a rush (& therefore the item is not a good indicator of aspects of their consultation performance via DCC from the patient's perspective)? Or if they say strongly agree, why? Is this because sometimes they will engage with DCC and respond even when they are in a hurry even if it is just to say to patients that they can't answer properly at the moment but will respond later (in which case the item is a valid indicator of aspects of their consultation performance via DCC from the patient's perspective).

- **READ NAME OF THE QUESTIONNAIRE(S) USING ALOUD FOR THE TAPE**
-
- **READ EACH ITEM ALOUD FOR THE TAPE**

- **NOTE RESPONSE TO EACH ITEM ON QUESTIONNAIRE(S)**

<u>Objectives:</u>

(Taking each form of DCC they use in turn), **what do you hope to achieve through using that form of DCC?**
Prompts:
- Facilitated self-management?

- Better patient/clinician relationship?
- Better health outcomes?

<u>Outcome measures:</u>

We have two candidate measures, one as a possible means of eliciting *the impact of the use of DCC for patients* and the other as a possible means of assessing *aspects of clinician's consultation performance via DCC (from the patient's perspective)*

The Patient Activation Measure

To what extent do you think each of the items are relevant in terms of assessing the impact of the use of DCC for patients (i.e. whether the measure is useful, in their opinion, in capturing patient self-care outcomes related to use of DCC/whether patients have achieved their previously specified objectives)?

Please use the answers in the scale as you are considering each item, I.e. strongly agree – strongly disagree or N/A

We are going to stop you once in a while and ask you to explain your answers in more detail. Probes:

Individual items:
- Why did you answer in that way?
- Could you just explain your answer, please?
- In your opinion, is the question relevant to patients in terms of using DCC?
- Would this question make sense to the patient in terms of using DCC?
- In your opinion, would the patient find this question easy to answer in terms of using DCC? If not, why not?
- In terms of assessing the impact of the use of DCC for patients, would you choose to keep this question in the measure, remove it or replace it with another question? If you were to replace it, what would you replace it with?

Full measure:
- Are there any items specific to assessing the impact of the use of DCC for patients that are missing from this measure?
- Which items were the most relevant?
- Which items were the least relevant?

Item (are these items an impact of DCC… ?)	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
Believes Active Role Important					
1.When all is said and done, I am the person who is responsible for managing my health condition					
2. Taking an active role in my own health care is the most important factor in determining my health and ability to function					
Confidence and knowledge to take action					
3. I know what each of my prescribed medications do					
4. I am confident I can tell my health provider concerns I have even when he or she does not ask					
5.I am confident that I can tell when I need to get medical care and when I can handle the health problem myself					
6.I know the lifestyle changes like diet and exercise that are recommended for my health condition					
7.I am confident that I can follow through on medical treatments I need to do at home					
8.I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition					

Item (are these items an impact of DCC… ?)	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
9. I am confident that I can find trustworthy sources of information about my health condition and my health choices					
10.I am confident that I can follow through on recommendations my health provider makes such as changing my diet or taking regular exercise					
11. I understand the nature and causes of my health condition/s					
12. I know the different medical treatment options available for my health condition					
Taking action					
13.I have been able to maintain the lifestyle changes for my health that I have made					
14.I know how to prevent further problems with my health condition					
15.I know about the self-treatments for my health condition					
16.I have made the changes in my lifestyle like diet and exercise that are recommended for my health condition					
17.I am confident I can figure out solutions when new situations or problems arise with my health condition					

Item (are these items an impact of DCC… ?)	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
18.I am able to handle symptoms of my health condition on my own at home					
Staying the course under stress					
19.I am confident that I can maintain lifestyle changes, like diet and exercise even during times of stress					
20.I am able to handle problems of my health condition on my own at home					
21.I am confident I can keep my health condition from interfering with things I want to do					
22. Making the lifestyle changes that are recommended for my health condition are too hard to do on a daily basis					

Physicians Humanistic Behaviour Scale

To what extent does this questionnaire elicit aspects of your consultation performance via DCC (from the patient's perspective) (because the data thus far has suggested that <u>connecting to the human side of clinicians is facilitated by DCC</u>)?

Again, please use the answers in the scale as you are considering each item, I.e. strongly agree – strongly disagree or N/A

Again, we are going to stop you once in a while and ask you to explain your answers in more detail.
Probes:

Individual items:
- Why did you answer in that way?
- Could you just explain your answer, please?
- In your opinion, is the question relevant to patients in terms of using DCC?
- Would this question make sense to the patient in terms of using DCC?
- In your opinion, would the patient find this question easy to answer in terms of using DCC? If not, why not?
- In terms of assessing aspects of your consultation performance via DCC (from the patient's perspective), would you choose to keep this question in the measure, remove it or replace it with another question? If you were to replace it, what would you replace it with?

Full measure:
- Are there any items specific to aspects of your consultation performance via DCC (from the patient's perspective) that are missing from this measure?
- Which items were the most relevant?
- Which items were the least relevant?

Item (does DCC facilitate the connecting to your 'human side' such that these items reflect aspects of your performance via DCC… ?)	Strongly Disagree	Disagree
2. Follows through on problems		
3. Is truthful and honest with me without avoiding the issues		
4. Is in a hurry		
5. Expresses concern for my feelings and needs, not just my physical status		
6. Comforts or reassures me and my family		
7. Asks how I am doing		
8. Keeps his or her promises to me		
9. Pays attention to concerns or requests that I feel are important		
10. Explains and clarifies information for me		
11. Answers my questions		
12. Makes uncaring remarks or does things I find offensive		
13. Discussed the options for my treatment		
14. Uses terms that I can understand		
15. Includes me in decisions and choices about my care		
16. Arranges for adequate privacy when examining or talking with me		
17. Has a neat, clean, well-groomed appearance		

Item (does DCC facilitate the connecting to your 'human side' such that these items reflect aspects of your performance via DCC… ?)	Strongly Disagree	Disagree
18. Is short tempered or abrupt with me and my family		
19. Makes changes in my treatment without telling me		
20. Doesn't rush or spend too little time with me		
21. Asks if I need anything or what he or she can do for me		
22. Asks how I want to be addressed and then greets me in that way		
23. Seems knowledgeable and concerned about me and my case		
24. Asks questions about my symptoms		
25. Treats me with too intimate or personal a manner		
• Asks me how I feel about my problems		

Appendix 3: Specialist Ethics Interview Schedule

Appendix 3.1: Specialist Ethics Interview Schedule for young people

Follow up on what is observed (i.e. use this data as cues/see how people feel about it)

GET AS MANY CONCRETE EXAMPLES AS POSSIBLE (& IF THESE AREN'T FORWARDED BEFORE THE INTERVIEW ASK THEM TO FORWARD THEM AFTER IT)

(interviewee will have received participant information sheet and signed consent form)

Introductions
[*Before consent if taken verbally.....*

My name is X and I am one of the researchers working on the LYNC study

*Just to remind you **the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X**.*

Today I'm going to ask you some questions about you and your health, your use of digital communication technologies (if you do use these things), and how you feel about using/the idea of using these things.

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

Face to face and telephone interviews will be audio recorded, the recordings are stored securely and will be transcribed with anonymisation so that they can be analysed.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

Tell me about **yourself** (home, education, work). E.g. how old are you? Who do you live with? Whether you work or are in education?

Tell me about **your health**
Probes:
- What sort of things do you do to look after your X?
- How would you describe your expertise on managing your condition yourself?
- What sources of support do you have?

- What types of issues do you face for which you would get in touch with the clinical team? Is that within or between consultations?

What sort of things do you think digital communication includes (encourage them to name as many as possible)?

Tell me about your **use of digital communication generally** (email, text, social media, Skype etc.)
Probes:
- **What** types do you use?
- With **whom**?
- For **what purpose**?

ELICIT STORY OF HOW THEY USE DCC then probe for ethics issues - elicit experience then reflections

- *Suggestions when prompting for reflections (BUILD UNDERSTANDING):*
- *Key questions – can you elaborate/tell me more about that/why do you do that/why do you do it like that/why do you think that is/why do you think that/why does that bother you (i.e. don't let them gloss other things)?*
- *It sounds like you do this for this reason, is that right?*
- *Have you thought about that from this perspective? What do think about that?*
- *Are there any other ways of looking at that? What would they be?*
- *Some people have experienced that in a different way/have said (specify), what do you think of that?*
- *Introduce hypothetical situations and ask them to reflect on this rather than just their own situation*

Tell me (more) about your **use of digital communication for health**
   Probes:
- Do you use it **in relation to health**? If yes, how?
- Do you use it to communicate with **health professionals**?
- (If yes) Approximately **how often** do you use it?
- **What** do you use?
- What sorts of things might that be about (I.e. **content**/medical purpose) (for each type of DCC used)?
- What is the **purpose** of using it (i.e. medical, economic, e.g. saves time and travel, and patient impact) (for each type of DCC used)? **Why** do you use this method of communication? What in particular is **useful** about it?
- **When/where** do you use it (for each type of DCC used)?

Can you tell me how you **started using X**? Tell me more about how you started using X?

Can you tell me exactly what the **process** is when you use X with the clinical team from 'start' to 'finish' (for each type of DCC used)? E.g. What 'kit' do you use? How do you send them a message?

DRAW DIAGRAMS OF THE PROCESS OF USING EACH TYPE OF DCC TO PROMPT THEM & START TO THINK ABOUT ELICITING SPECIFIC EXAMPLES

Which members of the team do you use DCC with? Which technologies do you use with each of these people? What sorts of things is your communication with each person normally about?

We really want to understand more about the process of using DCC with specific examples if possible. Have you brought examples of recent DCC?

Researcher reads examples and uses them to support asking about the following topics.

If no examples provided, researcher asks them to describe a recent example of where it was used.

ALSO – in both instances – the researcher asks them to share their communications going back years (if appropriate).

What did you use?

(CONTENT) What was it about? What correspondence happened beforehand? What happened after? What did you expect to happen after? (get detail)

What was the result of the communication, e.g. saved appointment, medication change etc….

(PURPOSE) Why do/did you do it that way? Why do/did you use that? What was the context? Why did you use X/digital communication?

(OBJECTIVE) What were you hoping to achieve by using the DCC (*at each step of the process of using DCC*)? Were these aims achieved? What was achieved?

ASK QUESTIONS ABOUT ETHICS AS INTERVIEWEE DESCRIBES EXAMPLES (SEE PROMPTS BELOW)

SUGGESTED ETHICS PROMPTS

Equity in access to DCC

Are you aware of other patients with the same team using this type of communication? (If yes) who else is able to do this? Would you recommend it to others? Why?

Do you think the care you receive is any different from the care that people who do not use X with the X team receive? Why do you think that is?

Consent

Who invited you to use DCC with the X team?

How did you exchange contact details (e.g. mobile phone numbers, email addresses, etc.)?

Where are your details stored? Who has access to them? Why do you think that?

Where/how do you store the X team's contact details? Why do you do it like that?

What conversations did you have about whether you would be happy to use DCC? Exactly what did you discuss?

When you had these conversations, how much detail do they go into about the different ways in which DCC might be used?

When did these conversations happen?

Who did you have these conversations with?

How did you let them know that you were happy to use DCC? What did you say?

Did anyone ever document these conversations? If so, how? Why do you think that is?

Privacy and confidentiality – try to let them bring this up

Can you tell me what you think happens to your communication (for each type of DCC used)? Who can see it your end? Who can see it when it has arrived? Why do you think that?

Who has access to your PC/Laptop, email account and/or phone? Is anything in place to prevent other people accessing these things (e.g. where do you leave your phone and is anything password protected)? Why do you do/not do these things?

Is your DCC communication recorded at all (by you and/or the X team)? If so, how/where? Who can access this information? Why do you think that?

In general, how comfortable do you feel using X with the clinical team? What is your experience of using DCC? Do you feel there is a problem with anything? Do you have any concerns about its use? Why do you think that?

What are your thoughts about privacy and confidentiality in the context of DCC? Why do you think that?

Is there anything that would worry you about using this technology to talk about your health? Why do you think that?

Tell me how you use digital communication and what you won't do on it? Why do you do it/not do it that way?

Is this any different to what you use at home? How is it different/not different? Why is that?

What do you consider to be confidential? Why? Who would you not want to see that? Who would you mind, and not mind, seeing a X containing that information? E.g. parents, friends, etc. Why? Have you told anyone in the X team about this? How did you tell them/why have you not told them?

What would you mind, and not mind, the X team communicating with you about via different kinds of digital communication? Why? Have you told anyone in the X team about this? How did you tell them/why have you not told them?

OLDER PATIENTS: Is how you feel about these things now different or the same as how you felt when you were younger (i.e.16-18 years of age)? Why do you think that is?

Has the way you feel about these things changed at all as you have become more familiar with these technologies? If so, how has this changed? Why do you think that is?

Risks/benefits to staff

What conversations have the X team had with you about how and when you can use DCC to contact them?

When do you think these health care professionals look at your X? Why do you think that?

Are there ever any delays when sending or receiving messages? (If yes) Why do you think that is?

When do you expect to get a response? Why do you think that?

Patient-doctor relationship

Does the use of DCC affect the relationship between you and your doctors/nurses?
If so, how? What positive impact has it had? What negative impact has it had? Why do you think that?

Does using DCC make it more or less likely that you can communicate with the same doctor/nurse each time you contact them? Why do you think that is?

How does the communication and relationship you have with the X team via DCC differ compared to talking to them face to face etc.? Why do you think that is?

Do you think you have any particular responsibilities when using DCC to communicate with the X team? Eg when you should or should not contact them? Making sure you respond to their messages? Why do you think that?

Tell me what you think is and is not appropriate via DCC? Why do you think that?

Patient autonomy

Who suggested using DCC, you or the X team? Do you want to use it? Why/why not?

Who decides when DCC is used, you, the team, or both? Why do you think that is?

Do you feel more or less involved in your treatment when you use DCC? In what way? Why do you think this is?

Do you feel more or less confident in managing things to do with your condition yourself as a result of using DCC? Why do you think this is?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where they would need to pay for digital communication.

Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide you with a basic service, so clinic appointments as usual and contact with your medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). **In addition to this the NHS is going to set up a premium service which you would have to pay for. This would include the facility to email/text/Skype (as appropriate) your healthcare team. This service would have to be paid for by patients.**

What would be the sort of things you would think about in deciding to subscribe to this service?

What would be important/what would you value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).

If you think you would subscribe to such a service, how much would you be willing to pay? £10 or how much?

Where sites don't use DCC:

I realise that you aren't really using DCC, but these technologies are being used more and more by young people in relation to their health care so it would be really helpful if we could hear your general views about DCC?

How do you normally communicate with the clinical team?

Why don't you use DCC at the moment?

What sorts of things would you like to use these technologies for in terms of using them to communicate with your clinical team about your health?

Do you think it is a good idea?

Are there any pitfalls? Risks? Downsides?

Would there be any benefits in certain situations?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

<u>Close of interview</u>
Thanks
Any questions from interviewee
Reminder of study contact details
Can we contact their parent/carer/household member; someone they consider to be their main source of support who would be happy to be interviewed too (this could be a parent or anyone else they feel is someone they rely on a lot)? The purpose of the interview is to find out about their experiences and opinions as someone who knows them well and is an important source of support.
Instruction about how they will receive their £20 voucher

Appendix 3.2: Specialist ethics interview schedule for parents/carers of young people with long term conditions

Follow up on what is observed (i.e. use this data as cues/see how people feel about it)

GET AS MANY CONCRETE EXAMPLES AS POSSIBLE (& IF THESE AREN'T FORWARDED BEFORE THE INTERVIEW ASK THEM TO FORWARD THEM AFTER IT)

(Interviewee will have received participant information sheet and signed consent form)

Introductions

[*Before consent if taken verbally…..*

My name is X and I am one of the researchers working on the LYNC study

Just to remind you **the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X**.

Today I'm going to ask you some questions about you and your health, your use of digital communication technologies (if you do use these things), and how you feel about using/the idea of using these things.

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

Face to face and telephone interviews will be audio recorded, the recordings are stored securely and will be transcribed with anonymisation so that they can be analysed.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

Tell me about **yourself** (home, education, work)

Tell me about your **relationship to (name)**

Tell me about **(name)'s health**
    Probes:
-    What sort of things do they do to look after their X?

How much and what kind of **involvement do you have in (name)'s care**? [If they are or were involved] What do/did you do for them?

How much and what kind of i**nvolvement do you have in (name)'s communication with the X team**? [If they are or were involved] How do/did you normally communicate with the clinical team? What is/was the nature of this communication? What types of issues do/did you face for which you would get in touch with the clinical team? Is/was that within or between consultations?

What sort of things do you think DCC includes (encourage them to name as many as possible)?

Tell me about your **use of digital communication generally** (email, text, social media, Skype etc.)
Probes:
- **What** types do you use?
- With **whom**?
- For **what purpose**?

ELICIT STORY OF HOW THEY USE DCC then probe for ethics issues - elicit experience then reflections

- *Suggestions when prompting for reflections (BUILD UNDERSTANDING):*
- *Key questions – can you elaborate/tell me more about that/why do you do that/why do you do it like that/why do you think that is/why do you think that/why does that bother you (i.e. don't let them gloss other things)?*
- *It sounds like you do this for this reason, is that right?*
- *Have you thought about that from this perspective? What do think about that?*
- *Are there any other ways of looking at that? What would they be?*
- *Some people have experienced that in a different way/have said (specify), what do you think of that?*
- *Introduce hypothetical situations and ask them to reflect on this rather than just their own situation*

A. PARENTS/CARERS ETC. THAT ARE OR WERE INVOLVED IN (NAME)'S CARE AND COMMUNICATION WITH THE X TEAM

Tell me (more) about your **use of digital communication in relation to (name)'s health** (now or back when you were involved in their care)
Probes:
- Do/did you use it **in relation to (name)'s health**? If yes, how?
- Do/did you use it to communicate with **health professionals**?
- (If yes) Approximately **how often** do/did you use it?
- **What** do/did you use?

- What **sorts of things** might that be/have been about (I.e. **content**/medical purpose) (for each type of DCC used)?
- What is/was the **purpose** of using it (i.e. medical, economic, e.g. saves time and travel, and patient impact) (for each type of DCC used)? **Why** do/did you use this method of communication? What in particular is/was **useful** about it?
- **When/where** do/did you use it (for each type of DCC used)?

A1. WHERE PARENT/CARER HAS BEEN INVOLVED IN DCC

Can you tell me more about how you **started using X**? Tell me more about how you started using X?

Can you tell me exactly what the **process** is/was when you use/used X with the clinical team from 'start' to 'finish' (for each type of DCC used)? E.g. What 'kit' do/did you use? How do/did you send them a message?

If use email:
- Do they have individual email addresses or a team email address?
- (If team email address) what are your views on having **a generic email address and NOT using clinicians own named accounts** (i.e. does this approach miss the point (reduce the advantage) of patients having DCC email communication (i.e. named person to named person) with the relationship being really important for many clinicians and patients)?

DRAW DIAGRAMS OF THE PROCESS OF USING EACH TYPE OF DCC TO PROMPT THEM & START TO THINK ABOUT ELICITING SPECIFIC EXAMPLES

Which members of the team do you use DCC with? Which technologies do you use with each of these people? What sorts of things is your communication with each person normally about?

We really want to understand more about the process of using DCC with specific examples if possible. Have you brought examples of recent DCC?

Researcher reads examples and uses them to support asking about the following topics.

If no examples provided, researcher asks them to describe a recent example of where it was used.

ALSO – in both instances – the researcher asks them to share their communications going back years (if appropriate).

What did you use?

(CONTENT) What was it about? What correspondence happened beforehand? What happened after? What did you expect to happen after? (get detail)

What was the result of the communication, e.g. saved appointment, medication change etc….

(PURPOSE) Why do/did you do it that way? Why do/did you use that? What was the context? Why did you use X/digital communication?

(OBJECTIVE) What were you hoping to achieve by using the DCC (*at each step of the process of using DCC*)? Were these aims achieved? What was achieved?

ASK QUESTIONS ABOUT ETHICS AS INTERVIEWEE DESCRIBES EXAMPLES (SEE PROMPTS BELOW)

SUGGESTED ETHICS PROMPTS

Equity in access to DCC

Are/were you aware of other patients with the same team using this type of communication? (If yes) who else is/was able to do this? Would you recommend/have recommended it to others? Why?

Do you think that the care (name) receives is/received was different from the care that people who do/did not use X with the X team receive/received because of using DCC? Why do you think that is/was?

Consent

Who invited you or (NAME OF PATIENT) to use DCC with the X team?

How did you exchange contact details (e.g. mobile phone numbers, email addresses, etc.)?

Where are/were your details stored? Who has/had access to them? Why do you think that?

Where/how do/did you store the X team's contact details? Why do/did you do it like that?

What conversations did you have about whether you would be happy to use DCC? Exactly what did you discuss?

When you had these conversations, how much detail do they go into about the different ways in which DCC might be used?

When did these conversations happen?

Who did you have these conversations with?

How did you let them know that you were happy to use DCC? What did you say?

Did anyone ever document these conversations? If so, how? Why do you think that is/was?

Privacy and confidentiality

Can you tell me what you think/thought happens to your communication (for each type of DCC used)? Who can/could see it your end? Who sees/saw it once it has/had arrived? Why do/did you think that?

Who has access to your PC/Laptop, email account and/or phone? Is/was anything in place to prevent other people accessing these things (e.g. where do you leave your phone and is anything password protected)? Why do/did you do/not do these things?

Is/was your DCC communication recorded at all (by you and/or the X team)? If so, how/where? Who can/could access this information? Why do/did you think that?

In general, how comfortable do/did you feel using X with the clinical team? What is/was your experience of using DCC? Do/did you feel there is/was a problem with anything? Do/did you have any concerns about its use? Why do/did you think that?

What are your thoughts about privacy and confidentiality in the context of DCC? Why do/did you think that?

Is there anything that would worry you about using this technology to talk about (name)'s health? Why do/did you think that?

Tell me how you use/used digital communication and what you won't/wouldn't do on it? Why do/did you do it/not do it that way?

Is/was this any different to what you use/used at home? How is/was it different/not different? Why is that?

What do you consider to be confidential? Why? Who would you not want to see that? Who would you mind, and not mind, seeing a X containing that information? E.g. parents, friends, etc. Why? Have you told/did you tell anyone in the X team about this? How did you tell them/why have/did you not told/tell them?

What would you mind/have minded, and not mind/have minded, the X team communicating with you about via different kinds of DCC digital communication? Why? Have you told/did you tell anyone in the X team about this? How did you tell them/why have/did you not told/tell them?

Risks/benefits to staff

What conversations have/did the X team had/have with you about how and when you can/could use DCC to contact them?

When do/did you think these health professionals look/looked at it? Why do/did you think that?

Are/were there ever any delays when sending or receiving messages? (If yes) Why do you think that is/was?

When do/did you expect to get a response? Why do/did you think that?

Patient-doctor relationship

If the main care/supporter is a parent/guardian of the participants (even if the participant is now in their 20s)

Does/did DCC have any impact on the relationship between you and the X team and your access to information about (name)'s health/healthcare? If so, how? What positive impact has it had/did it have? What negative impact has it had/did it have? Why do you think this?

Does/did using DCC effect the continuity of care (name) receives/received? If so, how? Why do you think this is?

How does/did the communication and relationship you have with the X team via DCC differ relative to the communication you might have with them face to face etc.? Why do you think that is/was?

What do/did you perceive yours, and the X teams', responsibilities to be when using DCC? Why do/did you think that?

Tell me what you think is/thought was and is/was not appropriate via DCC? Why do/did you think that?

Patient autonomy

Who suggested using DCC, you or the X team? Do/did you want to use it? Why/why not?

Who controls/controlled the digital communication you have/had with the X team? Why do you think this is/was?

To what extent do you think it improves (name)'s involvement in their treatment? Have you experienced/did you experience any changes in the responsibility they took for management of their condition? In what way? Why do you think this is/was?

Have/did you experienced/experience any changes in the responsibility for (name)'s care/self-care? In what way? Why do you think this is/was?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where they would need to pay for digital communication.

Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide a basic service for (name), so clinic appointments as usual and contact with their medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). **In addition to this the NHS is going to set up a premium service. This would include the facility to email/text/Skype (as appropriate) their healthcare team. This service would have to be paid for by patients or their families.** What would be the sort of things you would think about in deciding whether (name) should subscribe to this service?

Probes:
- What would be important/what would (name) value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).
- If you think (name) should subscribe to such a service, how much should they be willing to pay? £10 or how much?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

A2. WHERE PARENT/CARERS HAVE NEVER BEEN INVOLVED IN DCC

I realise that you aren't/weren't really using DCC, but these technologies are being used more and more by young people in relation to their health care so it would be really helpful if we could hear your general views about DCC?

How do/did you normally communicate with the clinical team?

Why don't/didn't you use DCC (at the moment)?

What sorts of things would you like/have liked to use these technologies for in terms of using them to communicate with your clinical team about (name)'s health?

Do you think it is a good idea?

Are there any pitfalls? Risks? Downsides?

Would there be any benefits in certain situations?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where they would need to pay for digital communication.

Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide a basic service for (name), so clinic appointments as usual and contact with their medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). **In addition to this the NHS is going to set up a premium service. This would include the facility to email/text/Skype (as appropriate) their healthcare team. This service would have to be paid for by patients or their families.** What would be the sort of things you would think about in deciding whether (name) should subscribe to this service?

Probes:
- What would be important/what would (name) value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).
- If you think (name) should subscribe to such a service, how much should they be willing to pay? £10 or how much?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

B. PARENTS/CARERS ETC. THAT ARE NOT/HAVE NEVER BEEN INVOLVED IN (NAME)'s CARE (I.E. INCLUDING PARTNERS)

Don't worry about specific questions, just have a conversation about their experience and views on digital communication for someone in their situation

---

Would you and (name) like for you to be involved in (name)'s care/have access to communication with the X team?   Would you like to be able to ask the X team about (name)'s care/condition directly?

[If yes]

What would you like to be able to do? Why?

How would DCC help with that process? Why do you say that?

*[If they would **not** want to have direct communication with the team themselves focus on their general views about patients communicating with the team based on their observations/experiences of (name)'s communication with the team]*

How much do you know about (name)'s care? How do you feel about that? How happy are you with that level of knowledge? Why do you say that? Would you like that to be altered in any way? How? Why?

How much do you know about (name)'s contact with the X team?

Does (name) use DCC with the X team?

B1. [If patient **does use** DCC with the X team:]

How do you and (name) communicate about their DCC health care communications? How much do you know about this? How do you feel about that? How happy are you with that level of knowledge? Why do you say that? Would you like that to be altered in any way? How? Why? What are your views about this? Why do you say that?

Where could it be improved? Why do you say that?

Where is it working well? Why do you say that?

> ***THEN RE: THEIR PERCEPTIONS AROUND THE PATIENT'S USE OF DCC WITH THE X TEAM ASK THE REMAINING QUESTIONS (SEE ABOVE)***

B2. [if patient **does not** use DCC with the X team:]

What are your views about this? Why do you say that?

> *** THEN RE: THEIR PERCEPTIONS AROUND THE PATIENT'S USE OF DCC WITH THE X TEAM ASK THE REMAINING QUESTIONS:***

Do you think it is a good idea?

Are there any pitfalls? Risks? Downsides?

Would there be any benefits in certain situations?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where (name) would need to pay for digital communication.
Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide a basic service for (name), so clinic appointments as usual and contact with their medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). **In addition to this the NHS is going to set up a premium service. This would include the facility to email/text/Skype (as appropriate) their healthcare team. This service would have to be paid for by patients or their families.** What would be the sort of things you would think about in deciding whether (name) should subscribe to this service?

Probes:
- What would be important/what would (name) value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).

- If you think (name) should subscribe to such a service, how much should they be willing to pay? £10 or how much?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

<u>Close of interview</u>
Thanks
Any questions from interviewee
Reminder of study contact details

Follow up on what is observed (i.e. use this data as cues/see how people feel about it)

GET AS MANY CONCRETE EXAMPLES AS POSSIBLE

(Interviewee will have received participant information sheet and signed consent form)

<u>Introductions</u>
[*Before consent if taken verbally…..*

My name is X and I am one of the researchers working on the LYNC study

Just to remind you **the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X**.

Today I'm going to ask you some questions about you and your role, your use of digital communication technologies (if you do use these things), how you communicate with patients and how you feel about using/the idea of using these things.

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

Face to face and telephone interviews will be audio recorded, the recordings are stored securely and will be transcribed with anonymisation so that they can be analysed.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to emphasise - whatever you tell me will be kept confidential; it will not be possible to identify you or the clinic from our research report.

Some of the ways you use digital communication with patients as part of your clinical practice may not be in line with NHS Information Governance. Our ethics protocol recognises this; we do not report this type of practice to anyone - we are only obliged to report professional conduct which puts patients at serious risk.

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

Tell me about your **work role** (role, tasks, duration)

How do you normally communicate with patients (& vice versa)?

PAY ATTENTION TO INSTANCES OF NON-DATA

ELICIT STORY OF HOW THEY USE DCC then probe for ethics issues - elicit experience then reflections

- *Suggestions when prompting for reflections (BUILD UNDERSTANDING):*
- *Key questions – can you elaborate/tell me more about that/why do you do that/why do you do it like that/why do you think that is/why do you think that/why does that bother you (i.e. don't let them gloss other things)?*
- *It sounds like you do this for this reason, is that right?*
- *Have you thought about that from this perspective? What do think about that?*
- *Are there any other ways of looking at that? What would they be?*
- *Some people have experienced that in a different way/have said (specify), what do you think of that?*
- *Introduce hypothetical situations and ask them to reflect on this rather than just their own situation*

Tell me (more) about your use of digital communication for health
Probes:
- Do you use it to communicate with patients?
- (If yes) **What** do you use?
- What sorts of things might that be about (I.e. **content**/medical purpose) (for each type of DCC used)?
- What is the **purpose** of using it (i.e. medical, economic, e.g. saves time and travel, and patient impact) (for each type of DCC used)?
- **When/where** do you use it (for each type of DCC used)?

ARE YOU USING THE AUTOMATED APPOINTMENT REMINDER SMS SYSTEM?

Can you tell me how you **started using X**? Tell me more about how you started using X?

Can you tell me exactly what the **process** is when you use X with your patients from 'start' to 'finish' (for each type of DCC used)?

When you use X do you need to **refer to other notes** before responding (i.e. clinical notes)? Is it different for different types of X (e.g. email/text)?

How is the DCC activity **logged** (for each type of DCC used)?

We really want to understand more about the process of using DCC with specific examples if possible. Have you brought examples of recent DCC?

If we have patient consent to read them, the researcher reads examples.

If no consent then the clinician gives a summary of the issues covered in the communication and this is used to support asking about the following topics.

If no examples then researcher asks them to describe a recent example of where it was used.

ALSO - in both instances:
- *The researcher asks them whether they can tell them about the **last patient** they communication with digitally (& encourages them to look it up).*
- *Once they have answered the questions below about this, the researcher asks them whether, using the clinic records, they can tell them about their digital communication with this patient <u>in the past</u> (& encourages them to work backwards through the clinic notes).*
- *Once they have answered the questions below about this, the researcher asks them the same about the **one before the last patient** (or if they can't think of one the researcher asks them if they can think of one in the last few days or weeks) – and so on until time runs out.*

What did you use?

(CONTENT) What was it about? What correspondence happened beforehand? What happened after? What did you expect to happen after? (get detail)

What was the result of the communication, e.g. saved appointment, medication change etc….

(PURPOSE) Why do/did you do it that way? Why do/did you use that? What was the

context? Why did you use X/digital communication?

(OBJECTIVE) What were you hoping to achieve by using the DCC (*at each step of the process of using DCC*)? Were these aims achieved? What was achieved?

What tools did you use when you did that (*at each step of the process of using the DCC*)?

What were you thinking when you did it (*at each step of the process of using the DCC*)?

What knowledge, social norms and rules were you drawing upon when you did it (*at each step of the process of using the DCC*)?

ASK QUESTIONS ABOUT ETHICS AS INTERVIEWEE DESCRIBES EXAMPLES (SEE PROMPTS BELOW)

SUGGESTED ETHICS PROMPTS

Equity in access to DCC

Do you use DCC with all or just some of your patients? Are any context dependent judgments made about who you use DCC with? Why do you do that?

(If yes) how are these decisions made? What are the differences between patients you do and do not use DCC with?

(If yes) do you think this leads to differences in care for patients you do and do not use DCC with? Why do you think that?

Consent

How do you invite patients to use DCC? Why do you do it like that?

How do you exchange contact details (e.g. mobile phone numbers, email addresses, etc.)? Why do you do it like that?

Are these contact details stored? If so, how? Why do you do that/do it like that? Who has access to them? Who do you think patients expect will be able to access this information? How do you know they think/expect that?

What conversations do you have with patients about whether they would be happy to use DCC? Exactly what do you discuss with them? Why do you do it like that?

When having these conversations with patients, how much detail do you go into with regards to the different ways in which DCC might be used? Why do you do it like that?

When do these conversations happen? Why do you do it then?

Do you ever document these conversations? If so, how? Why do you do that, do it like that?

Which members of the clinical team have these conversations with patients? Why do they do that?

When do you feel happy that patients have agreed to use DCC? Why?

If DCC is logged, how much do patients know about this process? How do they find out about this? Who do patients' expect will be able to view/read this information? How do you know they think/expect that?

How does patient's age relate to your use of DCC with them/their parents? Why do you do that?

If you use DCC with parents do you discuss this with the patient?

Privacy and confidentiality – try to let them bring this up

In general, how comfortable do you feel using DCC with your patients? What is you experience of using DCC? Do you feel there is a problem with anything? Do you have any concerns about its use? Why do you think that?

What are your thoughts on the nature of privacy and confidentiality in the context of DCC? Why do you think that?

Do patients want to use DCC? (If applicable) Why might they not want to? What are the implications, if any, of using DCC in terms of patients' privacy? Why do you think that?

What do you consider to be confidential? Why do you think that? How do you decide whether something is or is not confidential?

Tell me how you use DCC and what you won't do (in general and on different types of digital communication technologies)? Why do you do it/not so it like that?

Who has access to your PC/Laptop, email account and/or phone? Is anything in place to prevent other people accessing these things (e.g. where do you leave your phone and is anything password protected)? Why do you do/not do these things?

If DCC is logged, who has access to this/is able to view and read this information? How do you know only these people can access this information?

Risks/benefits to staff

What conversations do you have with patients about how and when they can use DCC to contact you? Why do you do this?

When/how quickly do you respond?

Do you access/respond to X outside working hours? Why do you do that?

What are patient's expectations about when you will respond? How do you manage these expectations (e.g. email signature and out of office reply)? Why do you do it that way?

What do you feel you must do differently when using X to communicate with patients relative to using this with colleagues and family and friends? Does this particular use of DCC raise any unique issues for you?

In what ways has DCC made your life easier or more difficult? Has the use of DCC made a difference to your workload at all? How has your workload changed compared to before you were using DCC? Why so you say that?

How do you manage this impact? Why do you do it like that?

How much control do you feel you have over the impact on your workload? Why?

Has DDC had any impact upon the way that you manage your patients? If so, what?

Are there any implications of DCC for your work life balance at all? If so, what? Why do you think that?

Patient-doctor relationship

Does the use of DCC affect the relationship you have with your patients? If so, how? What positive impact has it had? What negative impact has it had? Why do you think that?

What are the implications for continuity of care? Why do you think that?

What impact has DCC had upon your professional boundaries and your ability to manage these?

How does the communication and relationship you have with patients via DCC differ relative to the communication you might have with patients face to face etc.? Why do you think that?

What do you perceive to be the boundaries of your role and responsibilities when using DCC with patients? Why do you think that?

Tell me what you think is and is not appropriate via DCC? Why do you think that?

Duty of care

What do you perceive your responsibilities to be in terms of accessing/using DCC outside working hours and how quickly you respond to X from patients? Why do you think that?

Patient autonomy

Who suggests using DCC, you or your patients? Why is that?

Who controls the digital communication you have with your patients? Why do you think that?

To what extent do you think digital communication influences patient engagement with treatment regimens? Have you experienced any changes in patient's responsibility for their care/self-care? How does DCC influence their ability to care for themselves/manage their own care? Why do you think that?

Do patients want to use DCC? Do patients want the autonomy DCC can bring? How do you know this? Why do you think that is?

Where sites don't use DCC:

I realise that you aren't really using DCC, but these technologies are being used more and more by a range of HCPs in young people with long-term conditions so it would be really helpful if we could hear your general views about DCC?

Why do you not currently use it?

What sorts of things would you like to use these technologies for in terms of communicating with your patients about their health?

Do you think it is a good idea?

Are there any pitfalls? Risks? Downsides?

Would there be any benefits in certain situations?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

<u>Close of interview</u>
Thanks
Any questions from interviewee
Reminder of study contact details
Advise staff we might need a quick follow-up conversation after the field work (i.e. re: ensuring data capture data)

Appendix 4: Specialist Patient Safety Interview Schedules

Appendix 4.1: Specialist patient safety interview schedule for young people

Follow up on what is observed (i.e. use this data as cues/see how people feel about it)

GET AS MANY CONCRETE EXAMPLES AS POSSIBLE (& IF THESE AREN'T FORWARDED BEFORE THE INTERVIEW ASK THEM TO FORWARD THEM AFTER IT)

(Interviewee will have received participant information sheet and signed consent form)

<u>Introductions</u>
[*Before consent if taken verbally.....*

My name is X and I am one of the researchers working on the LYNC study

Just to remind you **the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X.**

Today I'm going to ask you some questions about you and your health, your use of digital communication technologies (if you do use these things), and how you feel about using/the idea of using these things.

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

Face to face and telephone interviews will be audio recorded, the recordings are stored securely and will be transcribed with anonymisation so that they can be analysed.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

Tell me about **yourself** (home, education, work). E.g. how old are you? Who do you live with? Whether you work or are in education?

Tell me about **your health**
Probes:
- What sort of things do you do to look after your X?
- How would you describe your expertise on managing your condition yourself?
- What sources of support do you have?

- What types of issues do you face for which you would get in touch with the clinical team? Is that within or between consultations?

What sort of things do you think digital communication includes (encourage them to name as many as possible)?

Tell me about your **use of digital communication generally** (email, text, social media, Skype etc.)
Probes:
- **What** types do you use?
- With **whom**?
- For **what purpose**?

ELICIT STORY OF HOW THEY USE DCC then probe for ethics issues - elicit experience then reflections

- *Suggestions when prompting for reflections (BUILD UNDERSTANDING):*
- *Key questions – can you elaborate/tell me more about that/why do you do that/why do you do it like that/why do you think that is/why do you think that/why does that bother you (i.e. don't let them gloss other things)?*
- *It sounds like you do this for this reason, is that right?*
- *Have you thought about that from this perspective? What do think about that?*
- *Are there any other ways of looking at that? What would they be?*
- *Some people have experienced that in a different way/have said (specify), what do you think of that?*
- *Introduce hypothetical situations and ask them to reflect on this rather than just their own situation*

Tell me (more) about your **use of digital communication for health**
  Probes:
- Do you use it **in relation to health**? If yes, how?
- Do you use it to communicate with **health professionals**?
- (If yes) Approximately **how often** do you use it?
- **What** do you use?
- What **sorts of things** might that be about (I.e. **content**/medical purpose) (for each type of DCC used)?
- What is the **purpose** of using it (i.e. medical, economic, e.g. saves time and travel, and patient impact) (for each type of DCC used)? **Why** do you use this method of communication? What in particular is **useful** about it?
- **When/where** do you use it (for each type of DCC used)?

Can you tell me how you **started using X**? Tell me more about how you started using X?
Can you tell me exactly what the **process** is when you use X with the clinical team from 'start' to 'finish' (for each type of DCC used)? E.g. What 'kit' do you use? How do you send them a message?

Which members of the team do you use DCC with?
Probes:
- **Which technologies** do you use with each of these people?
- What **sorts of things** is your communication with each person normally about?
- How do you exchange **contact details** (e.g. mobile phone numbers, email addresses, etc.)?

Do you do it **differently any other time** (e.g. when you are at University)?

Can you tell me **what you think happens to your communication** (for each type of DCC used)?
Probes:
- Who can see it your end?
- Can anyone see it in transit?
- Who sees it once it has arrived?
- What happens after you have sent them a message (at yours and the clinical team's end)?
- When do you think these health professionals look at it?
- Are there ever any delays when sending or receiving messages?
- When would you expect to get a response?

What **conversations have the X team had with** you about how and when you can use DCC to contact them?

DRAW DIAGRAMS OF THE PROCESS OF USING EACH TYPE OF DCC TO PROMPT THEM & START TO THINK ABOUT ELICITING SPECIFIC EXAMPLES

WHERE SITES USE DCC

We really want to understand more about the process of using DCC with specific examples if possible. Have you brought examples of recent DCC?

Researcher reads examples and uses them to support asking about the following topics.

If no examples provided, researcher asks them to describe a recent example of where it was used.

ALSO – in both instances – the researcher asks them to share their communications going back years (if appropriate).

What did you use?

CONTENT

What was it about?
Probes:
- What correspondence happened beforehand?
- What happened after?
- What did you expect to happen after? (get detail)

What was the result of the communication, e.g. saved appointment, medication change etc….

PURPOSE
Why do/did you do it that way? **Why do/did you use that?** Why did you use X/digital communication technology?

OBJECTIVES
What were you hoping to achieve by using the DCC (*at each step of the process relevant to them*)?
Probes:
- **Were these aims achieved?** What was achieved?

What tools did you use when you did that (*at each step of the process of using the DCC*)?

What were you thinking when you did it (*at each step of the process of using the DCC*)?

What knowledge, social norms and rules were you drawing upon when you did it (*at each step of the process of using the DCC*)?

<div align="center">

ASK QUESTIONS ABOUT PATIENT SAFETY (SEE LATER)

</div>

It would be really helpful if you could now tell me about a situation where DCC did and did not work well for you related to your health

If participant is unable to describe a relevant situation, then researcher explores these issues based on a recent occurrence of DCC in relation to their health care:
- *Can you tell me a bit more about <u>what we just talked about</u>? How did that work for you?*
- *What about <u>the last time you used X</u> with your clinical team? How did that work for you?*

Re: understanding of their DCC use acquired earlier – E.g. Where do you leave your phone? Do you share your phone with anyone? Who has access to your PC/Laptop and email account?

When example identified:
- Firstly, what worked well?
- What did not work well? What has gone wrong? (elicit actual risks)
- What happened (**unfolding**)?
- Why did that happen (**cause**)?
- How frequently does something like this happen (**likelihood**)?

- What happened after the 'event' (refer to what it was)? What effect did it have? What did you do afterwards (**consequence**)? If there are no consequences for (name), could there be for others?
- What did that mean? What problems did that cause? What bad things could have happened? What are the worst possible things that could have happened (**severity**)?
- Why do you think that (i.e. elicit their subjective risk assessment of the situation)?

Now we would like to try and understand how you feel about using DCC in general:

WHAT ARE THE RISKS AND SECURITY ISSUES……..

BE SURE TO PICK UP ON ANY UNCERTAINTLY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW DOES COMMUNICATION USING X COMPARE TO USING THE POST

Do you **want to use DCC with the clinical team?**

In general, **how comfortable** do you feel using X with the clinical team?
- What is your **experience** of using DCC?
- Tell me how you use it and what you won't do on it?
- Is this any different to what you use at home?
- Do you feel there is a **problem** with anything? Why do you think that (i.e. elicit people's subjective risk assessment)?
- Do you have any **concerns** about its use? Why do you think that?
- Is there anything that would worry you about using this technology to talk about your health? Why do you think that?
- What do you perceive the risks to be in terms of **patient safety**? Why do you think that?
- What do you perceive the risks to be in terms of **storing the data**? Why do you think that?
- What are the common **security concerns**? Why do you think that?
- What are things / outcomes that you definitely **want to avoid** when using this technology? Why do you think that?
- What **new risks** does DCC introduce? Why do you think that?

What do you consider to be **confidential**? Who would you not want to see that? Who would you mind, and not mind, seeing a X containing that information? E.g. parents, friends, etc.

What would you mind, and not mind, the X team communicating with you about <u>via different kinds of digital communication</u>?

What **could go wrong** (*at each of the steps of using each type of DCC that they are involved in (e.g. sending a text message)*)? (Elicit realistic risks and prompt people to think about risks that aren't always apparent)

Re: understanding of their DCC acquired earlier - E.g. Where do you leave your phone? Do you share your phone with anyone? Who has access to your PC/Laptop and email account? Is it conceivable that an email sent to the X team could be misconstrued?

Probes:
- What are **common failures / failure opportunities** in the process?
- When issue identified:
    - What might happen (**unfolding**)?
    - Why might that happen (**cause**)?
    - How likely is it that that might happen (**likelihood**)?
    - What might happen after this? What effect would it have (**consequence**)? If there are/were no consequences for you, could there be for others?
    - What would it mean? What problem would that cause? What bad things could happen? What are the worst possible things that could happen (**severity**)?
    - Why do you think that (i.e. elicit their subjective risk assessment of the situation)?

How important are these risks/issues to you?
    Probes:
- How concerned are you about these issues?
- Do these issues influence your decision to use DCC with your doctors/nurses?
- How would you feel about the things you have said could go wrong happening? Would you care? How much would that matter to you?

    E.g. How would you feel if other people (friends, family, colleagues, strangers) read your communication with the clinical team? What sorts of things would you mind people seeing?

RE: IDENTIFIED RISKS: HOW ARE THEY/SHOULD THEY BE DEALT WITH….

Would you/do you do anything to **deal with these risks** (e.g. never include sensitive data in a text message)? Is anything in place to prevent other people accessing these things (e.g. where do you leave your phone and is anything password protected)? Why would you do/not do these things? GET EXAMPLES

Is there any **positive effect** of DCC on risk? What risks would there be **if you didn't use DCC** with the clinical team?

OLDER PATIENTS: Is how you feel about these things now different or the same as how you felt when you were younger (i.e.16-18 years of age)?

Has the way you feel about these risks changed at all as you have become more familiar with these technologies? If so, how has this changed?

---

*USE EXAMPLES FROM STAFF INTERVIEWS TO ELICIT PATIENTS PERCEPTIONS OF RISKS AND THREATS, e.g. if a member of the clinical team says that patient's sometimes email them expressing suicidal ideation etc. out of working

hours and that they are upset when they do not receive a response, ask patients what the ACTUAL consequence of this would be*

THEN ASK 'POP UP QUESTIONS FROM ITERATIVE ANALYSIS, e.g. if patient's say that they would not want certain information to be communicated via text messages – how is this decided?

ASK THE REMINING QUESTIONS FROM A PATIENT SAFETY PERSPECTIVE, e.g. does using DCC mean patients are able to get a more rapid response to medical queries better hence mitigating risk?

Does the use of DCC affect the **relationship between you and your doctors/nurses**?

To what extent do you think it would improve your **engagement with your treatment regimens**?
Probes:
- Would you anticipate any changes in the responsibility for your care/self-care?
- Do you feel more or less confident in managing things to do with your condition yourself as a result of using DCC?

What **benefits** (e.g. patient experience and reduced travel time to clinics) do you think are linked to digital communications?
Probes:
- What impact does using DCC have for you?
- Does it have any impact on your health?
- In what ways has using DCC make your life easier, or more difficult, compared to how you would otherwise communicate with the clinical team?

Has it had any impact on **how you use hospital services**?
Probes:
- Has it had any impact on your X clinic attendance?

Is there any impact on things like the number of **adverse events/acute episodes** you have (i.e. preventative or causal)?
Probes:
- Are there any examples of things that have been avoided by using DCC?
- What would it be like/might happen if you couldn't use DCC with the clinical team?

What **costs** do you think are linked to digital communications?

In the **future**, how would you like to use digital communication for your health care?

Probes:
- What do you think will need to change for this to happen?
- Would patients need any training for using digital communication with their clinical team? If so, what training would they need?
- What risks might there be if the NHS introduced the ability to get in touch with clinicians via [suggest technology not used currently]?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where they would need to pay for digital communication.
Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide you with a basic service, so clinic appointments as usual and contact with your medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). **In addition to this the NHS is going to set up a premium service which you would have to pay for. This would include the facility to email/text/Skype (as appropriate) your healthcare team. This service would have to be paid for by patients.** What would be the sort of things you would think about in deciding to subscribe to this service?

Probes:
- What would be important/what would you value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).
- If you think you would subscribe to such a service, how much would you be willing to pay? £10 or how much?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

WHERE SITES DON'T USE DCC

How do you **normally communicate** with the clinical team?

Why don't you use DCC at the moment?

What sorts of things would you like to use these technologies for in terms of using them to communicate with your clinical team about your health?

PAY ATTENTION TO INSTANCES OF NON-DATA

We would like to try and understand how you generally feel about the idea of using DCC

WHAT ARE THE RISKS AND SECURITY ISSUES?

BE SURE TO PICK UP ON ANY UNCERTAINTLY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW WOULD COMMUNICATION USING X COMPARE TO USING THE POST

How do you feel about the idea of using DCC with the clinical team?

How comfortable would you feel with the idea of using DCC?
Probes:
- What do you think the **problems** are in relation to using DCC? Why do you think that (I.e. elicit people's subjective risk assessment)?
- Do you have any **concerns** about the use of DCC? Why do you think that?
- Is there anything that would worry you about the idea of using this technology to talk about your health? Why do you think that?
- What do you perceive the risks to be in terms of **patient safety**? Why do you think that?
- What do you perceive the risks to be in terms of **storing the data**? Why do you think that?
- What are things / outcomes that you would definitely **want to avoid** when using this technology? Why do you think that?
- What are the **common security concerns**? Why do you think that?
- What **new risks** would DCC introduce? Why do you think that?

What do you consider to be **confidential**? Who would you not want to see that? Who would you mind, and not mind, seeing a X containing that information? E.g. parents, friends, etc.

What would you mind, and not mind, the X team communicating with you about via different kinds of digital communication?

What **could go wrong?** (Elicit realistic risks and prompt people to think about risks that aren't always apparent)

E.g. Where do you leave your phone? Do you share your phone with anyone? Who has access to your PC/Laptop and email account? Is it conceivable that an email sent to the X team could be misconstrued?

Probes:
- What are **common failures / failure opportunities** in the process?
- When issue identified:
  - What might happen (**unfolding**)?
  - Why might that happen (**cause**)?
  - How likely is it that that might happen (**likelihood**)?
  - What might happen after this? What effect would it have (**consequence**)? If there are no consequences for you, could there be for others?

- o What would it mean? What problem would that cause? What bad things could happen? What are the worst possible things that could happen (**severity**)?
- o Why do you think that (i.e. elicit their subjective risk assessment of the situation)?

How important are these risks/issues to you?
Probes:
- How concerned are you about these issues?
- Would these issues influence your decision to use DCC with your doctors and nurses?
- How would you feel about the things you have said could go wrong happening? Would you care? How much would that matter to you?

  E.g. How would you feel if other people (friends, family, colleagues, strangers) read your communication with the clinical team? What sorts of things would you mind people seeing?

RE: IDENTIFIED RISKS: HOW SHOULD THEY BE DEALT WITH….

Would you do anything to **deal with these risks** (e.g. never include sensitive data in a text message)? Would anything need to be in place to prevent other people accessing these things (e.g. where do you leave your phone and is anything password protected)? Why would you do/not do these things? GET EXAMPLES

Would there be any **positive effect** of DCC on risk? What risks are there **when you don't use DCC** with the clinical team?

OLDER PATIENTS: Is how you feel about these things now different or the same as how you felt when you were younger (i.e.16-18 years of age)?

Has the way you feel about these risks changed at all as you have become more familiar with these technologies? If so, how has this changed?

USE EXAMPLES FROM STAFF INTERVIEWS TO ELICIT PATIENTS PERCEPTIONS OF RISKS AND THREATS, e.g. if a member of the clinical team says that patient's sometimes email them expressing suicidal ideation etc. out of working hours and that they are upset when they do not receive a response, ask patients what the ACTUAL consequence of this would be

THEN ASK 'POP UP QUESTIONS FROM ITERATIVE ANALYSIS

ASK THE REMINING QUESTIONS FROM A PATIENT SAFETY PERSPECTIVE, e.g. does using DCC mean patients are able to get a more rapid response to medical queries better hence mitigating risk?

Would the use of DCC affect the **relationship between you and your doctors/nurses**?

To what extent do you think it would improve your **engagement with your treatment regimens**?
Probes:
- Would you anticipate any changes in the responsibility for your care/self-care?
- Do you feel more or less confident in managing things to do with your condition yourself as a result of using DCC?

What **benefits** (e.g. patient experience and reduced travel time to clinics) do you think are linked to digital communications?
Probes:
- What impact do you think using DCC might have for you?
- Would there be any impact on your health?
- In what ways would using DCC make your life easier, or more difficult, compared to how you communicate with the clinical team now?

Would it have any impact on **how you use hospital services**?
Probes:
- Would it have any impact on your X clinic attendance?

Would there be any impact on things like the number of **adverse events/acute episodes** you have (i.e. preventative or causal)?
Probes:
- Are there any examples of things that might be/have been avoided by using DCC?
- What would it be like/might happen if you could use DCC with the clinical team?

What **costs** do you think are linked to digital communications?

In the **future**, how would you like to use digital communication for your health care?
Probes:
- What do you think will need to change for this to happen?
- What training needs do you think there are for patients for using digital communication?
- What risks might there be if the NHS introduced the ability to get in touch with clinicians via [suggest technology not used currently]?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where they would need to pay for digital communication.
Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide you with a basic service, so clinic appointments as usual and contact with your medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). **In addition to this the NHS is going to set up a premium service which you would have to pay for. This would include the facility to email/text/Skype (as appropriate) your healthcare team. This service would have to be paid for by patients.** What would be the sort of things you would think about in deciding to subscribe to this service?

Probes:
- What would be important/what would you value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).
- If you think you would subscribe to such a service, how much would you be willing to pay? £10 or how much?

Assessment of generic measures identified in literature review
The interviewee will be shown any identified generic measures and asked to what extent the success or not of their digital service is captured by these outcome measures.
How likely are you to recommend using [*state the digital technology*] with your clinicians to friends and family if they needed similar care or treatment? On a scale of 1 to 5, where 1 is extremely likely, 5 is extremely unlikely and 6 is don't know. TBC.

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

Close of interview
Thanks
Any questions from interviewee
Reminder of study contact details
Can we contact their parent/carer/household member; someone they consider to be their main source of support who would be happy to be interviewed too (this could be a parent or anyone else they feel is someone they rely on a lot)? The purpose of the interview is to find out about their experiences and opinions as someone who knows them well and is an important source of support.
Instruction about how they will receive their £20 voucher

Appendix 4.2: Specialist patient safety interview schedule for parents/carers of young people with long term conditions

Follow up on what is observed (i.e. use this data as cues/see how people feel about it)

GET AS MANY CONCRETE EXAMPLES AS POSSIBLE (& IF THESE AREN'T FORWARDED BEFORE THE INTERVIEW ASK THEM TO FORWARD THEM AFTER IT)

(Interviewee will have received participant information sheet and signed consent form)

Introductions

[*Before consent if taken verbally…..*

My name is X and I am one of the researchers working on the LYNC study

Just to remind you the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X.

Today I'm going to ask you some questions about you and your health, your use of digital communication technologies (if you do use these things), and how you feel about using/the idea of using these things.

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

Face to face and telephone interviews will be audio recorded, the recordings are stored securely and will be transcribed with anonymisation so that they can be analysed.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

Tell me about yourself (home, education, work)

Tell me about your relationship to (name)

Tell me about (name)'s health

Probes:

What sort of things do they do to look after their X?

How much and what kind of involvement do you have in (name)'s care? [If they are or were involved] What do/did you do for them?

How much and what kind of involvement do you have in (name)'s communication with the X team? [If they are or were involved] How do/did you normally communicate with the clinical team? What is/was the nature of this communication? What types of issues do/did you face for which you would get in touch with the clinical team? Is/was that within or between consultations?

What sort of things do you think DCC includes (encourage them to name as many as possible)?

Tell me about your use of digital communication generally (email, text, social media, Skype etc.)

Probes:

What types do you use?

With whom?

For what purpose?

ELICIT STORY OF HOW THEY USE DCC then probe for ethics issues - elicit experience then reflections

Suggestions when prompting for reflections (BUILD UNDERSTANDING):

Key questions – can you elaborate/tell me more about that/why do you do that/why do you do it like that/why do you think that is/why do you think that/why does that bother you (i.e. don't let them gloss other things)?

It sounds like you do this for this reason, is that right?

Have you thought about that from this perspective? What do think about that?

Are there any other ways of looking at that? What would they be?

Some people have experienced that in a different way/have said (specify), what do you think of that?

Introduce hypothetical situations and ask them to reflect on this rather than just their own situation

<u>PARENTS/CARERS ETC. THAT ARE OR WERE INVOLVED IN (NAME)'S CARE AND COMMUNICATION WITH THE X TEAM</u>

Tell me (more) about your use of digital communication in relation to (name)'s health (now or back when you were involved in their care)

Probes:

Do/did you use it in relation to (name)'s health? If yes, how?

Do/did you use it to communicate with health professionals?

(If yes) Approximately how often do/did you use it?

What do/did you use?

What sorts of things might that be/have been about (I.e. content/medical purpose) (for each type of DCC used)?

What is/was the purpose of using it (i.e. medical, economic, e.g. saves time and travel, and patient impact) (for each type of DCC used)? Why do/did you use this method of communication? What in particular is/was useful about it?

When/where do/did you use it (for each type of DCC used)?

A1. WHERE PARENT/CARER HAS BEEN INVOLVED IN DCC

Can you tell me how you started using X? Tell me more about how you started using X?

Can you tell me exactly what the process is/was when you use/used X with the clinical team from 'start' to 'finish' (for each type of DCC used)? E.g. What 'kit' do/did you use? How do/did you send them a message?

If use email:

Do they have individual email addresses or a team email address?

(If team email address) what are your views on having a generic email address and NOT using clinicians own named accounts (i.e. does this approach miss the point (reduce the advantage) of patients having DCC email communication (i.e. named person to named person) with the relationship being really important for many clinicians and patients)?

Which members of the team do you use DCC with?

Probes:

> Which technologies do you use with each of these people?

> What sorts of things is your communication with each person normally about?

> How do you exchange contact details (e.g. mobile phone numbers, email addresses, etc.)?

Can you tell me what you think/thought happens to your communication (for each type of DCC used)?

Probes:

> Who can/could see it your end?

> Can/could anyone see it in transit?

> Who sees/saw it once it has/had arrived?

> What happens/happened after you have/had sent them a message (at yours and the clinical team's end)?

> When do/did you think these health professionals look/looked at it?

> Are/were there ever any delays when sending or receiving messages?

> When would/did you expect to get a response?

What conversations have the X team had/did they have with you about how and when you can/could use DCC to contact them?

What do/did you do if you send/sent an email, text, etc. but don't get a reply?

DRAW DIAGRAMS OF THE PROCESS OF USING EACH TYPE OF DCC TO PROMPT THEM & START TO THINK ABOUT ELICITING SPECIFIC EXAMPLES

We really want to understand more about the process of using DCC with specific examples if possible. Have you brought examples of recent DCC?

Researcher reads examples and uses them to support asking about the following topics.

If no examples provided, researcher asks them to describe a recent example of where it was used.

ALSO – in both instances – the researcher asks them to share their communications going back years (if appropriate).

Where parents had used DCC re: the patients' health but were no longer involved, the researcher asks them to share their communications when they were involved in the patient's care going back years (if appropriate).

What did you use?

CONTENT

What was it about?

Probes:

      What correspondence happened beforehand?

      What happened after?

      What did you expect to happen after? (get detail)

What was the result of the communication, e.g. saved appointment, medication change etc….

PURPOSE

Why do/did you do it that way? Why do/did you use that? Why did you use X/digital communication technology?

OBJECTIVES

What were you hoping to achieve by using the DCC (*at each step of the process relevant to them*)?

Probes:

Were these aims achieved? What was achieved?

What tools did you use when you did that (*at each step of the process of using the DCC*)?

What were you thinking when you did it (*at each step of the process of using the DCC*)?

What knowledge, social norms and rules were you drawing upon when you did it (*at each step of the process of using the DCC*)?

ASK QUESTIONS ABOUT PATIENT SAFETY (SEE LATER)

It would be really helpful if you could now tell me about a situation where DCC did and did not work well for you in relation to (name)'s health care

If participant is unable to describe a relevant situation, then researcher explores these issues based on a recent occurrence of DCC in relation to their health care:

Can you tell me a bit more about <u>what we just talked about</u>? How did that work for you?

What about <u>the last time you used X</u> with the clinical team? How did that work for you?

Re: understanding of their DCC use acquired earlier – E.g. Where do you leave your phone? Do you share your phone with anyone? Who has access to your PC/Laptop and email account?

When example identified:

Firstly, what worked well?

What did not work well? What has gone/went wrong? (Elicit actual risks)

What happened (unfolding)?

Why did that happen (cause)?

How frequently does something like this happen (likelihood)?

What happened after the 'event' (refer to what it was)? What effect did it have? What did you do afterwards (consequence)? If there are no consequences for you, could there be for others?

What did that mean? What problems did that cause? What bad things could have happened? What are the worst possible things that could have happened (severity)?

Why do you think that (i.e. elicit their subjective risk assessment of the situation)?

Now we would like to try and understand how you feel/felt about using DCC in general in relation to (name)'s health care

WHAT ARE THE RISKS AND SECURITY ISSUES?

BE SURE TO PICK UP ON ANY UNCERTAINTY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW DOES COMMUNICATION USING X COMPARE TO USING THE POST

Do/did you want to use DCC with the clinical team?

In general, how comfortable do/did you feel using X with the clinical team?

Probes:

What is/was you experience of using DCC?

Tell me how you use/used it and what you won't/wouldn't do on it?

Is/was this any different to what you use/used at home?

Do/did you feel there is/was a problem with anything? Why do you think that (i.e. elicit people's subjective risk assessment)?

Do/did you have any concerns about its use? Why do you think that?

Is there anything that would worry you about using this technology to talk about (name)'s health? Why do you think that?

What do you perceive the risks to be in terms of patient safety? Why do you think that?

What do you perceive the risks to be in terms of storing the data? Why do you think that?

What are the common security concerns? Why do you think that?

What are/were things / outcomes that you definitely want/wanted to avoid when using this technology? Why do you think that?

What new risks does DCC introduce? Why do you think that?

What do you consider to be confidential? Who would you not want to see that? Who would you mind, and not mind, seeing a X containing that information? E.g. parents, friends, etc.

What would you mind, and not mind, the X team communicating with you about via different kinds of digital communication?

What could go/have gone wrong (*at each of the steps of using each type of DCC that they are involved in (e.g. sending a text message)*? (Elicit realistic risks and prompt people to think about risks that aren't always apparent)

Re: understanding of their DCC acquired earlier - E.g. Where do you leave your phone? Do you share your phone with anyone? Who has access to your PC/Laptop and email account? Is it conceivable that an email sent to the X team could be misconstrued?

Probes:

What are common failures / failure opportunities in the process?

When issue identified:

What might happen/have happened (unfolding)?

Why might that happen/have happened (cause)?

How likely is/was it that that might happen/have happened (likelihood)?

What might happen/have happened after this? What effect would it have/have had (consequence)? If there are/were no consequences for (name), could there be for others?

What would it mean? What problem would that cause/have caused? What bad things could happen/have happened? What are the worst possible things that could happen/have happened (severity)?

Why do you think that (i.e. elicit their subjective risk assessment of the situation)?

How important are/were these risks/issues to you?

Probes:

How concerned are/were you about these issues?

Do/did these issues influence your decision to use DCC in relation to (name)'s health care?

How would you feel/have felt about the things you have said could go wrong happening? Would you care/have cared? How much would that matter/have mattered to you?

E.g. How would you feel if other people (friends, family, colleagues, strangers) read your communication with the clinical team? What sorts of things would you mind people seeing?

RE: IDENTIFIED RISKS: HOW ARE (OR WERE) THEY/SHOULD THEY BE DEALT WITH….

Would you or do/did you do anything to deal with these risks (e.g. never include sensitive data in a text message)? Is/was anything in place to prevent other people accessing these things (e.g. where do/did you leave your phone and is/was anything password protected)? Why would you do/not do these things? GET EXAMPLES

Is/was there any positive effect of DCC on risk? What risks would there be if you didn't/hadn't used DCC with the clinical team?

USE EXAMPLES FROM STAFF INTERVIEWS TO ELICIT PARENT ETC.'S PERCEPTIONS OF RISKS AND THREATS

THEN ASK 'POP UP QUESTIONS FROM ITERATIVE ANALYSIS, e.g. if parent's etc. say that they would not want certain information to be communicated via text messages – how is this decided?

ASK THE REMINING QUESTIONS FROM A PATIENT SAFETY PERSPECTIVE, e.g. does using DCC mean parent's etc. are able to get a more rapid response to medical queries better hence mitigating risk?

If the main care/supporter is a parent/guardian of the participants (even if the participant is now in their 20s)

Do/did you think it alters your relationship with your son/daughter concerning their health?

Probes:

> How do/did you feel about the independent DCC relationship your child now may have/had with their clinical team?

> How do/did you and your son/daughter communicate about their DCC health care communications?

> What impact does/did it have on your role as main carer/supporter?

> Does/did it have any impact on the relationship between you and the clinical team and your access to information about their health/healthcare?

To what extent do you think it improves (name)'s engagement with their treatment regimens?

Probes:

> Have/did you experienced/experience any changes in the responsibility for (name)'s care/self-care?

> Does/did (name) feel more or less confident in managing things to do with their condition yourself as a result of you using DCC?

What benefits (e.g. patient experience and reduced travel time to clinics) do you think are linked to digital communications?

Probes:

What impact does/did using DCC have for (name)?

Does/did it have any impact on (name)'s health?

In what ways does/did using DCC make your life easier, or more difficult, compared to how you would otherwise communicate with the clinical team?

Has/did it had any impact on how they use hospital services?

Probes:

Has/did it had any impact on their X clinic attendance?

Is/was there any impact on things like the number of adverse events/acute episodes they have/had (i.e. preventative or causal)?

Probes:

Are there any examples of things that have been/were avoided by using DCC?

What would it be like/have been like / might happen/might have happened if you couldn't use DCC with the clinical team?

What costs do you think are linked to digital communications?

In the future, how would you like/have liked to use digital communication for (name)'s health care?

Probes:

What do you think will need to change for this to happen?

Would patients/parents need any training for using digital communication with their clinical team? If so, what training would they need?

What risks might there be if the NHS introduced the ability to get in touch with clinicians via [suggest technology not used currently]?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where they would need to pay for digital communication.

Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide a basic service for (name), so clinic appointments as usual and contact with their medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). In addition to this the NHS is going to set up a premium service. This would include the facility to email/text/Skype (as appropriate) their healthcare team. This service would have to be paid for by patients or their families. What would be the sort of things you would think about in deciding whether (name) should subscribe to this service?

Probes:

> What would be important/what would (name) value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).

> If you think (name) should subscribe to such a service, how much should they be willing to pay? £10 or how much?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

A2. WHERE PARENT/CARERS HAVE NEVER BEEN INVOLVED IN DCC

How do/did you normally communicate with the clinical team?

Why don't/didn't you use DCC (at the moment)?

What sorts of things would you like/have liked to use these technologies for in terms of using them to communicate with your clinical team about (name)'s health?

PAY ATTENTION TO INSTANCES OF NON-DATA

We would like to try and understand how you generally feel/would have felt about the idea of using DCC in relation to (name)'s health care

WHAT ARE THE RISKS AND SECURITY ISSUES?

BE SURE TO PICK UP ON ANY UNCERTAINTY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW DOES COMMUNICATION USING X COMPARE TO USING THE POST

How do you feel/would you have felt about the idea of using DCC with the clinical team in relation to (name)'s health care?

How comfortable would you feel/have felt with the idea of using DCC with the clinical team in relation to (name)'s health care?

Probes:

> Do/did you feel there is/was a problem with anything? Why do you think that (i.e. elicit people's subjective risk assessment)?
>
> Do/did you have any concerns about its use? Why do you think that?
>
> Is there anything that would worry you about using this technology to talk about (name)'s health? Why do you think that?
>
> What do you perceive the risks to be in terms of patient safety? Why do you think that?
>
> What do you perceive the risks to be in terms of storing the data? Why do you think that?
>
> What are the common security concerns? Why do you think that?
>
> What are/were things / outcomes that you definitely want/wanted to avoid when using this technology? Why do you think that?
>
> What new risks would DCC introduce? Why do you think that?

What do you consider to be confidential? Who would you not want to see that? Who would you mind, and not mind, seeing a X containing that information? E.g. parents, friends, etc.

What would you mind, and not mind, the X team communicating with you about <u>via different kinds of digital communication</u>?

What could go/have gone wrong (*at each of the steps of using each type of DCC that they are involved in (e.g. sending a text message)*)? (Elicit realistic risks and prompt people to think about risks that aren't always apparent)

Probes:

What are common failures / failure opportunities in the process?

When issue identified:

What might happen/have happened (unfolding)?

Why might that happen/have happened (cause)?

How likely is/was it that that might happen/have happened (likelihood)?

What might happen/have happened after this? What effect would it have/have had (consequence)? If there are/were no consequences for (name), could there be for others?

What would it mean? What problem would that cause/have caused? What bad things could happen/have happened? What are the worst possible things that could happen/have happened (severity)?

Why do you think that (i.e. elicit their subjective risk assessment of the situation)?

How important are/would these risks/issues (have been) to you?

Probes:

How concerned are you/would you have been about these issues?

Would these issues influence/have influenced your decision to use DCC in relation to (name)'s health care?

How would you feel/have felt about the things you have said could go wrong happening? Would you care/have cared? How much would that matter/have mattered to you?

E.g. How would you feel if other people (friends, family, colleagues, strangers) read your communication with the clinical team? What sorts of things would you mind people seeing?

RE: IDENTIFIED RISKS: HOW SHOULD THEY BE DEALT WITH….

Would you do anything to deal with these risks (e.g. never include sensitive data in a text message)? Would anything need to be in place to prevent other people accessing these things (e.g. where do/did you leave your phone and is/was anything password protected)? Why would you do/not do these things? GET EXAMPLES

Is/was there any positive effect of DCC on risk? What risks are there when you don't DCC with the clinical team?

USE EXAMPLES FROM STAFF INTERVIEWS TO ELICIT PARENT ETC.'S PERCEPTIONS OF RISKS AND THREATS

THEN ASK 'POP UP QUESTIONS FROM ITERATIVE ANALYSIS, e.g. if parent's etc. say that they would not want certain information to be communicated via text messages – how is this decided?

ASK THE REMINING QUESTIONS FROM A PATIENT SAFETY PERSPECTIVE, e.g. does using DCC mean parent's etc. are able to get a more rapid response to medical queries better hence mitigating risk?

If the main care/supporter is a parent/guardian of the participants (even if the participant is now in their 20s)

Do/did you think it would alter your relationship with your son/daughter concerning their health?

Probes:

> Would you anticipate/have anticipated any impact on the relationship between you and the clinical team and your access to information about their health/healthcare?

> What impact might it have/have had on your role as main carer/supporter?

To what extent do you think it would improve/have improved (name)'s engagement with their treatment regimens?

Probes:

> Would you anticipate/ have anticipated any changes in the responsibility for (name)'s care/self-care?

> Would (name) feel more or less confident in managing things to do with their condition yourself as a result of you using DCC?

What benefits (e.g. patient experience and reduced travel time to clinics) do you think are linked to digital communications?

Probes:

> What impact might using DCC have/have had for (name)?

> Would there be/have been any impact any impact on (name)'s health?

> In what ways would using DCC make your life easier, or more difficult, compared to how you communicate with the clinical team now?

Would there be/have been any impact on how they use hospital services?

Probes:

> Would there be/have been any impact on their X clinic attendance?

Would there be/have been any impact on things like the number of adverse events/acute episodes they have/had (i.e. preventative or causal)?

Probes:

> Are there any examples of things that might be/might have been / have been avoided by using DCC?

> What would it be like/have been like / might happen/might have happened if you could use/have used DCC with the clinical team?

What costs do you think are linked to digital communications?

In the future, how would you like/have liked to use digital communication in relation to (name)'s health care?

If email/text, would you want/have wanted individual email/text rather than team email addresses/mobile phone number?

How would you feel/have felt about a number of team members having access to your email rather than one person (when talking about generic email to a service)?

In what time frame you would like/have liked a response by text/email?

Probes:

What do you think will need to change for this to happen?

What training needs do you think there are for patients/parents for using digital communication?

What risks might there be if the NHS introduced the ability to get in touch with clinicians via [suggest technology not used currently]?

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where they would need to pay for digital communication.

Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide a basic service for (name), so clinic appointments as usual and contact with their medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). In addition to this the NHS is going to set up a premium service. This would include the facility to email/text/Skype (as appropriate) their healthcare team. This service would have to be paid for by patients or their families. What would be the sort of things you would think about in deciding whether (name) should subscribe to this service?

Probes:

What would be important/what would (name) value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).

If you think (name) should subscribe to such a service, how much should they be willing to pay? £10 or how much?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

<u>PARENTS/CARERS ETC. THAT ARE NOT/HAVE NEVER BEEN INVOLVED IN (NAME)'s CARE (I.E. INCLUDING PARTNERS)</u>

Don't worry about specific questions, just have a conversation about their experience and views on digital communication for someone in their situation

Would you and (name) like for you to be involved in (name)'s care/have access to communication with the X team?   Would you like to be able to ask the X team about (name)'s care/condition directly?

[If yes]

What would you like to be able to do? Why?

How would DCC help with that process? Why do you say that?

[If they would not want to have direct communication with the team themselves focus on their general views about patients communicating with the team based on their observations/experiences of (name)'s communication with the team]

How much do you know about (name)'s care? How do you feel about that? How happy are you with that level of knowledge? Why do you say that? Would you like that to be altered in any way? How? Why?

How much do you know about (name)'s contact with the X team?

Does (name) use DCC with the X team?

B1. [If patient does use DCC with the X team:]

How do you and (name) communicate about their DCC health care communications? How much do you know about this? How do you feel about that? How happy are you with that

level of knowledge? Why do you say that? Would you like that to be altered in any way? How? Why? What are your views about this? Why do you say that?

Where could it be improved? Why do you say that?

Where is it working well? Why do you say that?

*THEN RE: THEIR PERCEPTIONS AROUND THE PATIENT'S USE OF DCC WITH THE X TEAM ASK QUESTIONS ABOUT *PATIENT SAFETY*, POP UP QUESTIONS FROM THE ITERATIVE ANALYSIS & THEN THE REMAINING QUESTIONS FROM A PATIENT SAFETY PERSPECTIVE (SEE A1 ABOVE)*

B2. [if patient does not use DCC with the X team:]

What are your views about this? Why do you say that?

*THEN RE: THEIR PERCEPTIONS AROUND THE PATIENT'S USE OF DCC WITH THE X TEAM ASK QUESTIONS ABOUT *PATIENT SAFETY*, POP UP QUESTIONS FROM THE ITERATIVE ANALYSIS & THEN THE REMAINING QUESTIONS FROM A PATIENT SAFETY PERSPECTIVE (SEE A2 ABOVE)*

We are also interested in how much value people place on using digital communications with the clinical team, and so we now have a specific question we would appreciate your help with

The interviewee will be asked to consider the hypothetical situation where (name) would need to pay for digital communication.

Link to digital clinical communication from earlier in interview.

Imagine a situation (emphasising that this is hypothetical) where the NHS was going to provide a basic service for (name), so clinic appointments as usual and contact with their medical team through letters and telephone calls to the clinic (or whatever is appropriate for the condition/service). In addition to this the NHS is going to set up a premium service. This would include the facility to email/text/Skype (as appropriate) their healthcare team. This service would have to be paid for by patients or their families. What would be the sort of things you would think about in deciding whether (name) should subscribe to this service?

Probes:

What would be important/what would (name) value about this (e.g. practical issues – speed of response or convenience, health benefits, etc.).

If you think (name) should subscribe to such a service, how much should they be willing to pay? £10 or how much?

Close of interview

Thanks

Any questions from interviewee

Reminder of study contact details

Appendix 4.3: Specialist patient safety interview schedule for clinic staff

Follow up on what is observed (i.e. use this data as cues/see how people feel about it)

GET AS MANY CONCRETE EXAMPLES AS POSSIBLE

(Interviewee will have received participant information sheet and signed consent form)

Introductions

[*Before consent if taken verbally.....*

My name is X and I am one of the researchers working on the LYNC study

Just to remind you the LYNC study is looking at the use of digital clinical communication for young people with a long-term condition like X.

Today I'm going to ask you some questions about you and your role, your use of digital communication technologies (if you do use these things), how you communicate with patients and how you feel about using/the idea of using these things.

There are no right or wrong answers, we are just interested to hear about your experiences and opinions.

Face to face and telephone interviews will be audio recorded, the recordings are stored securely and will be transcribed with anonymisation so that they can be analysed.

You can stop the interview at any time, just let me know.

Do you have any questions?]

So just to emphasise - whatever you tell me will be kept confidential; it will not be possible to identify you or the clinic from our research report.

Some of the ways you use digital communication with patients as part of your clinical practice may not be in line with NHS Information Governance. Our ethics protocol recognises this; we do not report this type of practice to anyone - we are only obliged to report professional conduct which puts patients at serious risk.

So just to confirm, are you happy to proceed?

And are you happy for this to be audio-recorded?

Tell me about your work role (role, tasks, duration)

What sort of things do you think digital communication includes (encourage them to name as many as possible)?

Tell me about your use of digital communication generally (email, text, social media, skype etc.)

Probes:

What types do you use (i.e. out of work)?

With whom?

For what purpose?

How do you normally communicate with patients (& vice versa)?

PAY ATTENTION TO INSTANCES OF NON-DATA

ELICIT STORY OF HOW THEY USE DCC then probe for ethics issues - elicit experience then reflections

Suggestions when prompting for reflections (BUILD UNDERSTANDING):

Key questions – can you elaborate/tell me more about that/why do you do that/why do you do it like that/why do you think that is/why do you think that/why does that bother you (i.e. don't let them gloss other things)?

It sounds like you do this for this reason, is that right?

Have you thought about that from this perspective? What do think about that?

Are there any other ways of looking at that? What would they be?

Some people have experienced that in a different way/have said (specify), what do you think of that?

Introduce hypothetical situations and ask them to reflect on this rather than just their own situation

Tell me (more) about your use of digital communication for health

Probes:

> Do you use it to communicate with patients?
>
> (If yes) What do you use?
>
> What sorts of things might that be about (I.e. content/medical purpose) (for each type of DCC used)?
>
> What is the purpose of using it (i.e. medical, economic, e.g. saves time and travel, and patient impact) (for each type of DCC used)?
>
> When/where do you use it (for each type of DCC used)?

ARE YOU USING THE AUTOMATED APPOINTMENT REMINDER SMS SYSTEM?

What hardware (PC, mobile phone, tablet etc.) and software (Microsoft Outlook, Skype, etc.) do you specifically use with patients/parents?

Probes:

> Who has ownership of this technology?
>
> Who provides, supports / maintains the technology used? Is there a specific person or helpdesk you go to (if this is the NHS)?
>
> Is this equipment you already have for your day job, or is it provided specifically for digital communication? Has the use of DCC required any new technology to be developed?
>
> Is any technology provided to the patient so that they can participate in DCC?

Can you tell me how you started using X? Tell me more about how you started using X?

Can you tell me exactly what the process is when you use X with your patients from 'start' to 'finish' (for each type of DCC used)?

If use email:

Do you have individual email addresses or a team email address?

(If a team email address) What are your views on having a generic email address and NOT using clinicians own named accounts (i.e. does this approach miss the point (reduce the advantage) of patients having DCC email communication (i.e. named person to named person) with the relationship being really important for many clinicians and patients)?

Are any context dependent judgments made about who you use DCC with? (If yes) how are these decisions made?

Is there any difference between paediatric and adults services? (If yes) Why is that?

What conversations do you have with patients about how and when they can use DCC to contact you?

How do you exchange contact details (e.g. mobile phone numbers, email addresses, etc.)?

Are these contact details stored? If so, how? Who has access to them?

When you use X do you need to refer to other notes before responding (i.e. clinical notes)? Is it different for different types of X (e.g. email/text)?

When/how quickly do you respond? Do you access/respond to X outside working hours?

What are patient's expectations about how quickly you will respond? How do you manage these expectations (e.g. email signature and out of office reply)?

What happens to "emergency" requests that come in via digital communication?

Probes:

How soon do you respond?

(If relevant) How is continuity of responsibility and information across shifts and departmental boundaries ensured?

How is the DCC activity logged (for each type of DCC used)?

Probes:

What is the purpose of logging this?

How well does logging work in practice (e.g. is it possible that an email isn't logged (maybe because somebody thinks it's irrelevant), or maybe it's logged by one member

of staff but another member of staff forgets to check or simply isn't aware that there is an email)?

Who has access to this/is able to view and read this information? How do you know only these people can access this information?

Can you tell me what you think happens to your communication with patients/parents (for each type of DCC used)?

Probes:

Who can see it your end?

Can anyone see it in transit?

Who sees it once it has arrived?

What happens after you have sent them a message (at yours and the patient/parent's end)?

Are there ever any delays when sending or receiving messages?

What is useful about X?

Probes:

What is it about X that makes it useful/not useful (i.e. the actual system)?

What is it about the content of the message that makes it useful/not useful?

Are there any other things that make it useful/not useful (i.e. contextual factors)?

WHERE SITES USE DCC

We really want to understand more about the process of using DCC with specific examples if possible. Have you brought examples of recent DCC?

If we have patient consent to read them, the researcher reads examples.

If no consent then the clinician gives a summary of the issues covered in the communication and this is used to support asking about the following topics.

If no examples then researcher asks them to describe a recent example of where it was used.

ALSO - in both instances:

The researcher asks them whether they can tell them about the last patient they communication with digitally (& encourages them to look it up).

Once they have answered the questions below about this, the researcher asks them whether, using the clinic records, they can tell them about their digital communication with this patient <u>in the past</u> (& encourages them to work backwards through the clinic notes).

Once they have answered the questions below about this, the researcher asks them the same about the one before the last patient (or if they can't think of one the researcher asks them if they can think of one in the last few days or weeks) – and so on until time runs out.

What did you use?

CONTENT

What was it about?

Probes:

> What correspondence happened beforehand?
>
> What happened after?
>
> What did you expect to happen after? (get detail)
>
> What was the result of the communication, e.g. saved appointment, medication change etc....

PURPOSE

Why do/did you do it that way? Why do/did you use that? What was the context? Why did you use X/digital communication?

OBJECTIVE

What were you hoping to achieve by using the DCC (*at each step of the process of using DCC*)?

Probes:

Were these aims achieved? What was achieved?

What tools did you use when you did that (*at each step of the process of using the DCC*)?

What were you thinking when you did it (*at each step of the process of using the DCC*)?

What knowledge, social norms and rules were you drawing upon when you did it (*at each step of the process of using the DCC*)?

ASK QUESTIONS ABOUT PATIENT SAFETY (SEE LATER)

It would be really helpful if you could now tell me about a situation where DCC did and did not work well for you or your patient

If participant is unable to describe a relevant situation, then researcher explores these issues based on a recent occurrence of DCC in relation to their health care:

Can you tell me a bit more about <u>what we just talked about</u>? How did that work for you?

What about <u>the last time you used X</u> with your patients/their parents? How did that work for you?

Re: understanding of their DCC use acquired earlier - E.g. Where is your mobile phone left? Who has access to your PC/Laptop, email account and/or phone? Is it conceivable that an email sent to a patient could be misconstrued?

When example identified:

Firstly, what worked well?

What did not work well? What has gone wrong (*at each step of the process of using each type of DCC*)? (Elicit actual risks)What happened (unfolding)?

Why did it happen (cause)?

How frequently does something like this happen (likelihood)?

What happened after 'the event' (refer to what it was)? What did you do afterwards? What effect did it have (consequence)? If there are no consequences for some patients, could there be for others?

What did it mean? What problems did that cause? What bad things could have happened? What are the worst possible things that could have happened (severity)?

Why do you think that (i.e. elicit their subjective risk assessment of the situation)?

Now we would like to try and understand how you feel about using DCC in general:

WHAT ARE THE RISKS AND SECURITY ISSUES………

BE SURE TO PICK UP ON ANY UNCERTAINTY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW DOES COMMUNICATION USING X COMPARE TO USING THE POST

In general, how comfortable do you feel using X with your patients?

Probes:

> What is you experience of using DCC?
>
> Tell me how you use it and what you won't do on it?
>
> Is this any different to what you use at home?
>
> Do you feel there is a problem with anything? Why do you think that (i.e. elicit people subjective risk assessment)?
>
> Do you have any concerns about its use? Why do you think that?
>
> What do you perceive the risks to be in terms of patient safety?
>
> What do you perceive the risks to be in terms of storing the data? Why do you think that?
>
> What are the common security concerns? Why do you think that?
>
> What are things / outcomes that you definitely want to avoid when using this technology? Why do you think that?
>
> What new risks does DCC introduce? Why do you think that?

What do you consider to be confidential? Why do you think that? How do you decide whether something is or is not confidential?

What could go wrong (*at each step of the process of using each type of DCC*)? (Elicit realistic risks and prompt people to think about risks that aren't always apparent)

Re: understanding of their DCC use acquired earlier - E.g. Where is your mobile phone left? Who has access to your PC/Laptop, email account and/or phone? Is it conceivable that an email sent to a patient could be misconstrued?

Probes:

What are common failures / failure opportunities in the process?

When issue identified:

What might happened (unfolding)?

Why might that happen (cause)?

How likely is it that that might happen (likelihood)?

What might happen after this? What effect would it have (consequence)? If there are no consequences for some patients, could there be for others?

What would that mean? What problem would that cause? What bad things could happen? What are the worst possible things that could happen (severity)?

E.g. What might happen if you sent a text to a patient about their health and it were stolen?

Why do you think that (i.e. elicit their subjective risk assessment of the situation)?

How important are these risks/issues to you?

How concerned are you about these issues?

Do these issues influence your decision to use DCC?

How would you feel about the things you have said could go wrong happening? Would you care? How much would that matter to you?

RE: IDENTIFIED RISKS: HOW ARE THEY/SHOULD THEY BE DEALT WITH….

Is there/should there be anything in place that would alter/reduce the risks you have identified (*at each step in the process of using each type of DCC)?* GET EXAMPLES

Prompt

Do you do anything to deal with these risks (e.g. never include sensitive data in a text message)?

Is anything in place to prevent other people accessing your phone, PC or laptop etc.? (e.g. where do you leave your phone and is anything password protected)?

Why do you do/not do these things?

Is there any positive effect of DCC on risk? What risks would there be if you didn't use DCC with patients?

THEN ASK 'POP-UP' QUESTIONS FROM ITERATIVE ANALYSIS, e.g. if clinicians say that they don't put sensitive information in text messages – how is this decided?

ASK THE REMINING QUESTIONS FROM A PATIENT SAFETY PERSPECTIVE, e.g. does using DCC mean clinicians are more responsive to patients needs such that they are then able to respond to medical queries better hence mitigating risk?

Does the use of DCC affect the relationship you have with your patients? If so, how?

Probes:

> What do you perceive your responsibilities to be in terms of accessing/using DCC outside working hours and how quickly you respond to X from patients?

> What impact does it have, if any, on your sense of duty of care?

> What are the implications for continuity of care?

To what extent do you think digital communication influences patient engagement with treatment regimens?

Probes:

Have you experienced any changes in responsibility for care/self-care?

What outcomes/benefits do you think are linked to digital communications? E.g. patient experience, staff work experience, evaluated health outcomes

Probes:

Are there any differences between patients who use DCC and those who don't?

Do you think that the use of DCC can have an impact on patients' health? Could you provide some examples of how the use of DCC has directly or indirectly affected the health of your patients?

Why are these outcomes good?

Do you think that the availability of DCC to you and your patients has changed how often they use hospital services? (If yes) how/why?

Probes:

Does it impact on the number of clinic visits that patients attend?

Are any clinic visits saved by the use of digital communication? If so, could you estimate how many per week?

Could you please describe in detail situations where unintended/unwanted outcomes /side effects have been prevented (or caused) because patients had the opportunity to communicate digitally with you?

Probes:

Are there any examples of things that have been avoided by using DCC?

Does it impact on things like adverse events/acute episodes requiring care?

What would it be like/what might happen if you couldn't use DCC with your patients?

Where patients have contacted you with "emergency requests" via DCC, what would have happened if these patients did not contact you digitally (e.g. would they try to contact someone else, visit hospital outpatient services, or go to A&E?)?

Why are these outcomes bad? What is the consequence of any avoided incidents/risks?

What costs do you think are linked to digital communications? E.g. impact on other services, financial costs and savings

What are the future implications from greater use of digital communications?

Probes:

> Looking to the future and the developments that are taking place with communication technology, how would you like to be able to communicate with your patients?

> What training needs do you think there are for clinicians, and patients, for using digital communication?

> What risks might there be if the NHS introduced the ability to get in touch with patients via [suggest technology not used currently]?

> Do any particular safeguards need to be in place for this kind of communication?

Now we would like to know a bit about the time you spend on DCC and the impact on your workload (ASK EVERY MEMBER OF THE CLINICAL TEAM).

It might be helpful if we break it down a bit and plot it on a timeline… USE TIMELINE TECHNIQUE

<u>What is done now?</u>

How does it fit into work practices/other activities you undertake?

Probes:

> Does it affect the other things you must do? How?

> Do you have to trade off efficiency for thoroughness elsewhere? How?

> How do you make trade-offs/judgements about how much time to spend on DCC in the context of the other things you have to do?

If you weren't using DCC what else would you be doing in that time?

If you didn't spend time on DCC, would your workload be increased or decreased?

Probes:

Why?

What was it like before/what was done then?

What was your workload like before?

What has changed/what is different now?

Has the use of DCC made a difference to your workload?

Probes:

How has your workload changed compared to before you were using DCC?

What ways has DCC made your life easier or more difficult?

Are there any positive implications for workload?

Can you quantify the impact on your workload at all?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

WHERE SITES DON'T USE DCC

Why do you not currently use it?

What sorts of things would you like to use these technologies for in terms of using them to communicate with your patients about their health?

PAY ATTENTION TO INSTANCES OF NON-DATA

We would like to try and understand how you generally feel about the idea of using DCC

WHAT ARE THE RISKS AND SECURITY ISSUES?

BE SURE TO PICK UP ON ANY UNCERTAINTY OR LACK OF AWARENESS ABOUT RISKS

PUT RISKS IN THE CONTEXT OF OTHER MEANS OF COMMUNICATING WITH PATIENTS, E.G. IS X MORE OR LESS SECURE THAN THE POST & HOW WOULD COMMUNICATION USING X COMPARE TO USING THE POST

How do you feel about the idea of using DCC with your patients?

What factors do you think contribute to its successful/unsuccessful use?

In general, how comfortable do you feel using X with your patients?

Probes:

> What do you think the problems are in using DCC? Why do you think that (i.e. elicit people subjective risk assessment)?
>
> Do you have any concerns about its use? Why do you think that?
>
> What do you perceive the risks to be in terms of patient safety?
>
> What do you perceive the risks to be in terms of storing the data? Why do you think that?
>
> What are the common security concerns? Why do you think that?
>
> What are things / outcomes that you definitely want to avoid when using this technology? Why do you think that?
>
> What new risks would DCC introduce? Why do you think that?

What could go wrong? (Elicit realistic risks and prompt people to think about risks that aren't always apparent)

E.g. Where is your mobile phone left? Who has access to your PC/Laptop, email account and/or phone? Is it conceivable that an email sent to a patient could be misconstrued?

Probes:

> What are common failures / failure opportunities in the process?
>
> When issue identified:
>
> What might happened (unfolding)?

Why might that happen (cause)?

How likely is it that that might happen (likelihood)?

What might happen after this? What effect would it have (consequence)? If there are no consequences for some patients, could there be for others?

What would that mean? What problem would that cause? What bad things could happen? What are the worst possible things that could happen (severity)?

E.g. What might happen if you sent a text to a patient about their health and it were stolen?

Why do you think that (i.e. elicit their subjective risk assessment of the situation)?

How important are these risks/issues to you?

How concerned are you about these issues?

Would these issues influence your decision to use DCC?

How would you feel about the things you have said could go wrong happening? Would you care? How much would that matter to you?

RE: IDENTIFIED RISKS: HOW SHOULD THEY BE DEALT WITH….

Should there be anything in place that would alter/reduce the risks you have identified (*at each step in the process of using each type of DCC)?* GET EXAMPLES

Prompts

Would you do anything to deal with these risks (e.g. never include sensitive data in a text message)?

Would anything need to be in place to prevent other people accessing your phone, PC or laptop etc.? (E.g. where do you leave your phone and is anything password protected)?

Why would you do/not do these things?

Would there be any positive effect of DCC on risk? What risks are there when you don't use DCC with patients?

THEN ASK 'POP-UP' QUESTIONS FROM ITERATIVE ANALYSIS

ASK THE REMINING QUESTIONS FROM A PATIENT SAFETY PERSPECTIVE, e.g. does using DCC mean clinicians are more responsive to patients needs such that they are then able to respond to medical queries better hence mitigating risk?

Would the use of DCC affect the relationship you have with your patients? If so, how?

Probes:

> What do you perceive your responsibilities to be in terms of accessing/using DCC outside working hours and how quickly you respond to X from patients?

> What impact do you think it might have, if any, on your sense of duty of care?

> What would the implications be for continuity of care?

To what extent do you think it would improve engagement with treatment regimens?

Probes:

> Would you anticipate any changes in responsibility for care/self-care?

What outcomes/benefits do you think are linked to digital communications? E.g. patient experience, evaluated health outcomes.

Probes:

> Would you anticipate any differences between patients who use DCC and those who don't?

> What would it be like/what might happen if you could use DCC with your patients?

> Do you think that the use of DCC would have an impact on patients' health?

> Do you think it would impact on things like self-management or adverse events/acute episodes requiring care?

Do you think that the availability of DCC to you and your patients would change how often they use hospital services? (If yes) how/why?

Probes:

Would it impact on things like patient attendance?

Why are these outcomes good?

Could you please describe in detail situations where unintended/unwanted outcomes /side effects could be prevented (or caused) because patients had the opportunity to X you?

Probes:

Are there things that could be avoided by using DCC?

Would it impact on things like adverse events/acute episodes requiring care?

Why are these outcomes bad? What is the consequence of any avoided incidents/risks?

What costs do you think are linked to digital communications? E.g. impact on other services, financial costs and savings.

What effect do you think it might have, if any, on your workload?

What are the future implications from greater use of digital communications?

Probes:

Looking to the future and the developments that are taking place with communication technology, how would you like to be able to communicate with your patients?

If email/text, would you want individual email/text rather than team email addresses/mobile phone number?

What training needs do you think there are for clinicians and patients for using digital communication?

What risks might there be if the NHS introduced the ability to get in touch with patients via [suggest technology not used currently]?

Do any particular safeguards need to be in place for this kind of communication?

Should there be anything in place that would alter/reduce the risks you have identified?

Now we would like to ask you a couple of questions about your Trust Information Governance policies

What do you like about the current information governance policy?

What needs to change? (pause for response) (if no response) What needs to change in the information governance policy? *(i.e. what regulatory framework is needed to reassure patients and clinicians regarding the use of DCC)*

What discussions have you had about information governance

With colleagues?

With patients?

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD THAT I HAVEN'T ASKED YOU OR WE HAVEN'T TALKED ABOUT?

Close of interview

Thanks

Any questions from interviewee

Reminder of study contact details

Advise staff we might need a quick follow-up conversation after the field work (i.e. re: ensuring data capture data)

Appendix 5: Health Economics Questionnaire

1. How much time do you spend per day, on average, using each of the methods of digital clinical communication listed below directly with patients (excluding communication about patients with colleagues)? For each method, please place a tick in the box corresponding to your best estimate. If this is >60 minutes, please provide an approximate duration.

	rarely/never	15min	30min	45min	60min	more than 60 min (please provide time)
Email						(_ _ _ min)
Text						(_ _ _ min)
Social Media (e.g. Facebook, Twitter						(_ _ _ min)
Mobile phone						(_ _ _ min)
Other (please specify						(_ _ _ min)

2. Please could you indicate what equipment you use for digital clinical communication directly with patients (excluding communication about patients with colleagues), and who provides it:

(please tick boxes below)

	Don't use	Provided by employer	Purchased myself
Mobile phone			
Tablet			
Laptop			

Other (please specify):			

3. a) Could you please tell me your grade?   ……………….

b) How many hours do you work a day?   (_ _ hour)

c) How many days do you work a week? (_ _ day)

Appendix 6: Clinic Observation Schedule

Framework for Collection of Observation Data in Clinics

The following framework will be used by the study researcher to guide observation. For each observation period (2 hours) a new copy of the framework will be used.

General observation of clinic function

Observation will be in the waiting area, administration areas, meeting rooms and offices.

*Collect demographic data from patients observed & confirm their age (but do not record identifiable patient data without consent and especially if <16)

Observation will be enhanced by asking clinic staff and clinic attendees clarifying questions about what is observed.

Study ID of clinic	
Date of observation	
Location of observation	
Start time of observation	
End time of observation	
Name of person making observations	
Reason this time period was chosen for observation (e.g. one of the two outpatient clinic sessions that take place each week)	

Clinic appointments (on that day)

Number of appointments

Number of patients seen

Number of missed appointments (i.e. DNAs)

HOW THE CLINIC FUNCTIONS

Numbers of staff and roles

Clinic lead/NHS PI only:

Patient's journey within the service: How clinic functions (i.e. 'process walk' to identify the process steps) – define a 'start' and 'end' point and delineate exactly what happens in the clinic (& beyond) from start to finish in terms of the patient's journey (start with one hypothetical patient and then explore how this varies across patients).

How they communicate with patient/patients: The communication process steps and the information generated/communicated at each process step. Try to underpin with actual examples. Include all communication activity (even if not DCC, e.g. landline telephone use); capture how clinicians communicate with patients normally and via DCC (i.e. map ALL interactions clinician to patient and vice versa).

Draw/check map of DCC use (i.e. the services' DCC use or just theirs if this is unrepresentative).

Clinic lead/NHS PI only:

Do you know anything about how long this technology has been used in the service?

Why was it introduced?

Who drove it/was keen to use it?

What were the motivations for using it?

What were the pitfalls (i.e. barriers)?

What were the opportunities (i.e. facilitators)?

How does it fits into the work process?

ASK FOR A SHORT SUMMARY OF THE CLINICAL MANAGEMENT OF THE CONDITION BEING TREATED AT THEIR CLINIC, E.G. ASK WHAT IS THE CLINIC AIM?

ELICIT WHETHER THEY ARE USING AUTOMATED APPOINTMENT REMINDERS

WHERE DCC IS USED

Use of DCC/DCC pathways clinicians to patients and vice versa (in the context of the process steps)

Staff

What digital communication technology is available for clinic staff (computer, clinic mobile phone)?

What hardware (i.e. equipment/technology) and software (i.e. systems) is used?

What new equipment/technology has had to be obtained re: DCC?

Is any equipment provided to patients so that they can use DCC?

Who uses it?

For specific members of staff using DCC

Seek as many CONCRETE EXAMPLES OF RECENT DCC ACTIVITY/CRITICAL INCIDENTS as possible

What do they use?

How do use it?

When do they use it?

Where do they use it?

How many X do they send per day/week?

How long do they spend on each X (minutes)?

How long do they spend on each type of DCC used (minutes per day/week)?

[Look for instances of non-data, I.e. opportunities for DCC that are missed (perhaps which you have seem other clinic use); elicit why this is not being done, what the barriers might be and what impact it might have (e.g. might DCC help make something more efficient at all)].

Identify differences/similarities in DCC used between members of the clinical team

(If relevant) How is continuity of responsibility and information across shifts and departmental boundaries ensured?

Are any context dependent judgments made about who they use DCC with? If so, how are these decisions made?

Patient safety at each process step

Probe each member of staff re: any relevant incidents of risk or opportunities for risk observed re: DCC use for each type of DCC used (i.e. ask them what could go wrong <u>at each step in the process related to DCC</u>; failure (re: intended use of systems and system failure/unintended use of systems), cause, consequences (what could happen?), likelihood (how likely is this to happen?), severity (what would the consequences mean and what is the personal salience of these implications?) & mitigation (is there/should there be anything in place that would reduce the risk in terms of likelihood and severity) (consider one's own thoughts and concerns re: opportunities for risk <u>at each step in the process related to DCC for each type of DCC used</u> based on observations).

Ethical issues

Observe anything that raises an issue in terms of:

Confidentiality and privacy

Responsibility (i.e. how use of DCC relates to the patient/clinician relationship and clinicians' duty of care)

Acting against Trust policy/Information Governance (i.e. whether clinicians are in working within these policies or breaching them)

Patients

Usage of DCC within clinic premises (e.g. waiting room by patients) (estimate from general observation to estimate familiarity with the technologies)?

Information about the clinic for patients (posters, leaflets, verbal communications) – does it include digital communication contact details?

Brief conversations about use of DCC in general, and with clinical team, with patients (& parents) (i.e. elicit exactly what happens when using each type of DCC from the patient perspective).

[Probe patients re: opportunities for risk re: the process steps they are involved in for each type of DCC used (e.g. receiving texts)].

Monitoring of use of digital communication technology

How, where, when and by whom is the use of DCC recorded/logged?

Is use of DCC regulated at all?

Is there evidence of the evaluation of the impact of the use of DCC? If so what is the evidence (I.e. what did the evaluation comprise)? SEEK ACCESS TO THIS DATA

Maintenance of the use of DCC

For each type of DCC used

Who has ownership of the technology/ies?

Who is responsible for the supply, support and maintenance of the DCC used (specific person or helpdesk if NHS)? Who would people go to about a fault?

Who has oversight of this?

What evidence is there of the extent to which the development, implementation and maintenance of technology is managed internally (I.e. and identify the person with oversight, e.g. IT manager/practice manager), or commissioned from external specialists?

Where does DCC seemed to be used/by whom is it used (to guide approach to shadowing)?

What is the degree of DCC use for that site?

How similar are paediatric and adult services in their communication with patients?

WHERE DCC IS NOT USED

Obtain the same data but for other communication activity

What do they use?

How do use it?

When do they use it?

Where do they use it?

Pay attention to instances of non-data, I.e. opportunities for DCC that are missed (perhaps which you have seem other clinic use) (& also observe this even if DCC is used).

Why is this not being done?

What are the barriers?

What impact it might have (e.g. might DCC help make something more efficient at all)?

Shadowing of clinicians

This observation will involve shadowing up to 6 clinic clinicians who use DCC (if a site which engages in this) for up to two hours at any one time and shadow during times where DCC is likely (if DCC isn't used shadow a representative sample of clinic staff and try to capture a 'typical day'). This will include, for example, **sitting with the clinician while laboratory results are reviewed and emails read and answered**, **clinic sessions when the clinician sees patients**, **clinic meetings**, **going to hospital wards** and **potentially home visits**.

* **Collect demographic data from patients observed & confirm their age (but do not record identifiable patient data without consent and especially if <16)**

Observe all potentially relevant communication activity (even if not DCC, e.g. landline telephone use); capture how clinicians communicate with patients normally and via DCC (i.e. map ALL interactions clinician to patient and vice versa).

Observation will be enhanced by asking clarifying questions about what is observed.

Study ID of clinic	
Date of observation	

Study ID and role of clinician being shadowed	
Location of observation	
Start time of observation	
End time of observation	
Name of person making observations	
Reason this time period was chosen for observation (e.g. clinician reviews lab results at this time)	

WHERE DCC IS USED

Use of DCC/DCC pathways clinicians to patients and vice versa (in the context of the process steps). Seek as many CONCRETE EXAMPLES OF RECENT DCC ACTIVITY/CRITICAL INCIDENTS as possible

Staff (elicit exactly what happens when using each type of DCC from the patient and clinicians perspective).

What type of digital communication technology was used?

When did they use it?

Where did they use it?

What was it about? What correspondence happened beforehand? What happened after? (get detail)

Who was involved in the communication, I.e. roles (e.g. clinician/carer/patient - include grade of clinician for economic costing purposes)?

Timing of initiation and responses (synchronous, asynchronous, duration of gaps for asynchronous, any failed attempts to make contact)?

Who initiated each episode of communication?

Who ended each episode of communication?

Time spent on the communication

Number of times clinician(s) used digital clinical communication

What was the result of the communication, e.g. saved appointment, medication change etc….

Psychological, cognitive and behavioural context for each process step

Probe re: the following at each step in the process related to DCC interactions (for each use of DCC observed)

What were they **hoping to achieve** by using the DCC (at each step of the process of using DCC)? Is there any evidence of multiple/alternative aims (e.g. from comments made by clinician)? Were these aims achieved (& is there any evidence of this)? What was achieved?

What tools did they use when they did that (at each step of the process of using the DCC)?

What were they thinking when they did it (at each step of the process of using the DCC)?

What knowledge, social norms and rules were they drawing upon when they did it (at each step of the process of using the DCC)?

Patient safety at each process step

Probe each member of staff re: any relevant incidents of risk or opportunities for risk observed re: DCC use for each type of DCC used (i.e. ask them what could go wrong at each step in the process related to DCC; failure (re: intended use of systems and system failure/unintended use of systems), cause, consequences (what could happen?), likelihood (how likely is this to happen?), severity (what would the consequences mean and what is the personal salience of these implications?) & mitigation (is there/should there be anything in

place that would reduce the risk in terms of likelihood and severity) (consider one's own thoughts and concerns re: opportunities for risk <u>at each step in the process related to DCC for each type of DCC used</u> based on observations).

Ethical issues

Observe anything that raises an issue in terms of:

Confidentiality and privacy

Responsibility (i.e. how use of DCC relates to the patient/clinician relationship and clinicians' duty of care)

Acting against Trust policy/Information Governance (i.e. whether clinicians are in working within these policies or breaching them)

WHERE DCC IS NOT USED

Obtain the same data but for other communication activity

What do they use?

How do use it?

When do they use it?

Where do they use it?

Pay attention to instances of non-data, I.e. opportunities for DCC that are missed (perhaps which you have seem other clinic use) (& also observe this even if DCC is used).

Why is this not being done?

What are the barriers?

What impact it might have (e.g. might DCC help make something more efficient at all)?

References

1. Griffiths FE, Atherton H, Barker JR, et al. Improving health outcomes for young people with long term conditions: The role of digital communication in current and future patient–clinician communication for NHS providers of specialist clinical services for young people–LYNC study protocol. Digital Health 2015;**1**(1-13):2055207615593698

2. Prensky M. Digital natives, digital immigrants part 1. On the horizon 2001;**9**(5):1-6

3. Helsper EJ, Eynon R. Digital natives: where is the evidence? British educational research journal 2010;**36**(3):503-20