



The LYNC study

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



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Patient

“ Someone emailing us at 8 o'clock at night because they had got severe abdominal pain - we would want them to be seen straight away not the next day. That's what worried us about the safety of email. But we've never, ever had that problem and patients actually use it very safely and effectively. **”**

Physiotherapist

“ They probably wouldn't call or turn up but they might email and say, *'I can't come or I haven't come', or 'I've run out of medicine', or 'can you organise this for me?'* So it's that first rung on the ladder of self-management. We can then help them think about what they would like to do next. **”**

Psychologist

“ It's more personal. Because I have more contact now outside of clinic they know me a bit better and I know them a little better. It doesn't feel like I'm just 'another patient'. **”**

Patient

“ If you're trying to assess their mental health it's quite hard to gauge through text, whereas if you can hear them over the phone you can hear how they sound and whether they sound flat or not. **”**

Specialist Nurse

Clinical care for people living with long term conditions – the role of digital communication between NHS clinical teams and their patients

Evidence based practice



These points for you to think about when using digital communication with patients come from a research study funded by the National Institute of Health Research.

We observed and interviewed nearly 200 members of specialist clinical teams from across the UK working with young people living with long term conditions.

We interviewed over 150 young people living with a range of conditions including diabetes, cancer, mental illness, liver disease, kidney disease, blood disorders, cystic fibrosis, inflammatory bowel disease and arthritis.

Young people and their clinical teams used text, mobile phone calls and emails to communicate about clinical issues. A few clinical teams engaged on social media sites with their patients.

The clinical teams were using digital communication to improve the engagement of the young people with their services. There is good evidence that improved engagement leads to improved health outcomes.

These young people and their clinical teams have worked out where and when it works well to communicate digitally about clinical matters such as symptoms, drug regimes and emotional distress. From their experience, they know what needs to be discussed and planned before using digital communication about clinical matters.

Their experience can be applied to working with other people with long term conditions who are accustomed to using digital communication (mobile phone, text, email), particularly if they have a smartphone, so access to this communication is straightforward.

If you are planning to communicate digitally with patients, talk about the points we raise with your team and with your organisation's Information, Governance, IT and Patient Safety Leads.

The study name is:

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; the LYNC study

The study was led by:

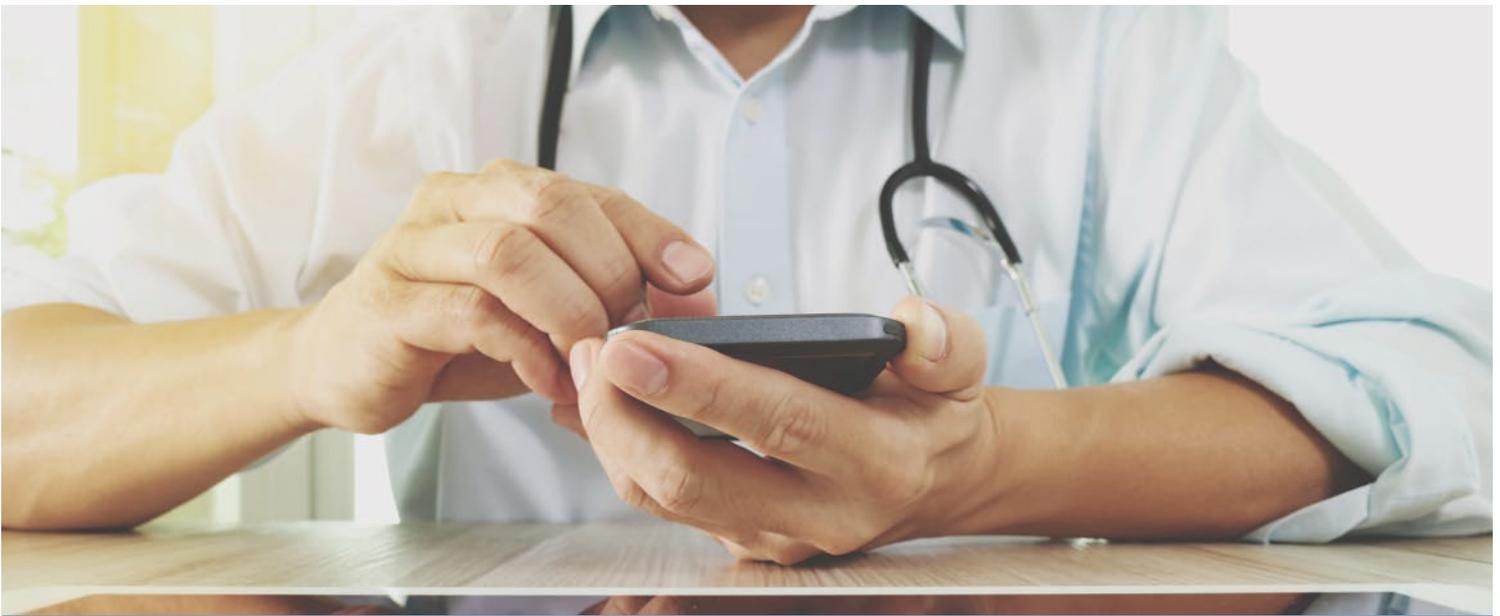
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Further details about the study are available at:
www.nets.nihr.ac.uk/projects/hsdr/1220951

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Funding Acknowledgement: This project was funded by the National Institute for Health Research Health Services and Delivery Research (HS&DR) Programme (Project Number 12/209/51)
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When is sending text messages and email useful? – and what about Skype?

Text is good for:

Appointment management – if patients receive a personal text from their clinical team about attending an appointment, they feel cared for as an individual.

Patients like to use text to change appointments. This can reduce wasted appointments BUT patients can more easily disengage as they don't need to explain to someone why they are cancelling.

“ It makes it easier for them to not turn up, to cancel or act avoidantly. ”

Senior Mental Health Practitioner

Keeping in touch – sending a quick text message to check in with patients was valued by clinicians and patients. Text is a non-intrusive way of gauging whether a patient needs more contact.

“ It's reassuring for her that I'm on the end of a text and sort of supporting her in any way I can. ”

Paediatric Social Worker

Delivering some forms of therapy – in-between face to face appointments, text messages remind patients of steps to take or skills to use.

Making direct contact with young people where parents are involved in a young person's treatment – this allows issues to be raised that would not be raised in front of parents.

Email is good for:

Sending complex information

“ Patients can take things in, in their own time, and re-read things. ”

Physiotherapist

Sending a summary of discussion at an appointment along with links to other resources

“ We'd gone over some treatments at clinic. I said to the patient, 'would you like me to email you this so that you've got it, rather than trying to remember it?' So I emailed her afterwards. ”

Physiotherapist

Sending test results – this is useful where the results are routine or as expected and the individual is well known to the service.

“ They come and have their blood test and then they email me, and I tell them the results and what to do next. It is generally young, fairly sensible people who are working and can't afford the time to attend hospital. ”

Consultant

Illustrating what is happening – patient can send a photograph, for example of a rash, to help health professionals decide whether or not they need to see the patient.

“ Emails can be good, as they can avoid the patient coming into an unnecessary consultation. Email is better than telephone as patients can send photos, and they can feel empowered and happy that they are doing the right thing, so it is better for compliance. ”

Consultant

Ordering equipment and supplies – for some conditions these are collected during appointments. Emails in advance make the process smoother.

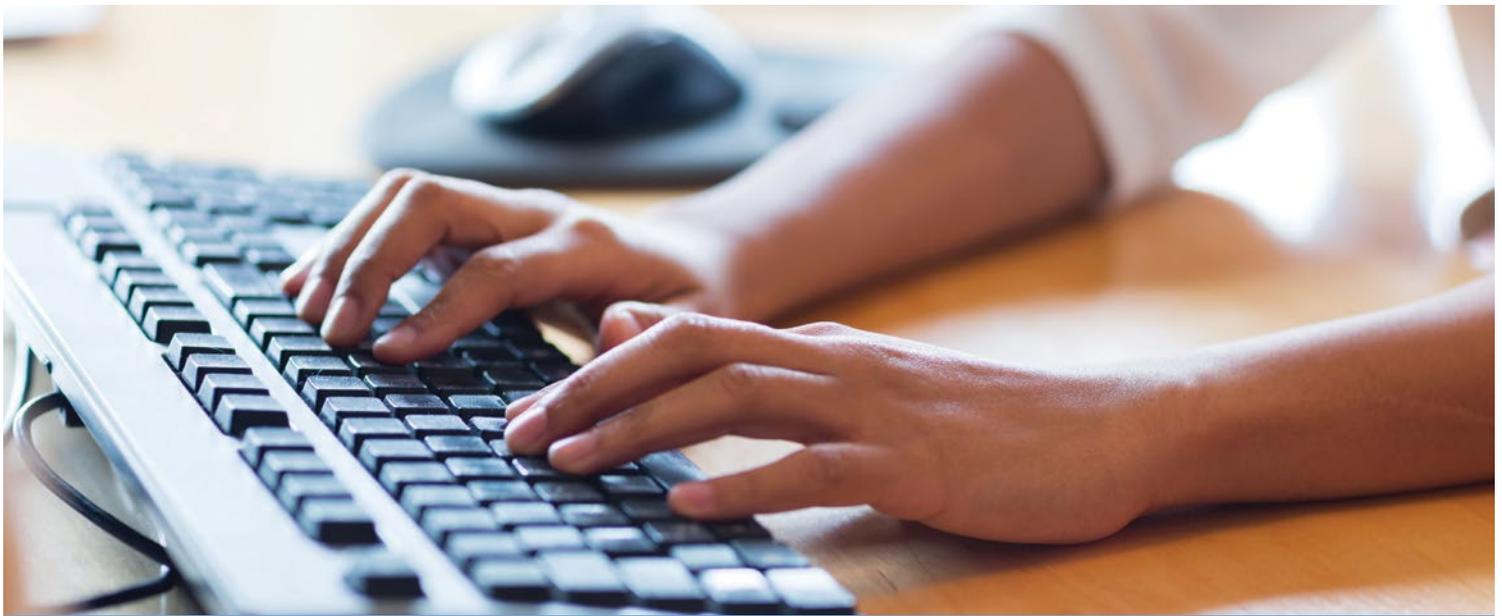
Skype or equivalent is being used in a few clinics

Delivering virtual classes – e.g. exercise classes to patients who cannot easily attend the class.

Talking therapy – because you can see the person and pick up on visual clues BUT patients could find it intrusive.

“ I think it's quite intrusive. I think that's how they perceive it, and I find it quite intrusive as well. ”

Senior Mental Health Practitioner



Common concerns and suggestions to help resolve them

Missing urgent calls from patients

Concern among clinicians varies depending on whether the health condition can become serious quickly. In all services studied, healthcare professionals reported very few missed contacts and knew of no adverse outcomes:

- ▶ Give clear instructions to patients about hours of service and what to do out of hours (via leaflet as well as digital)
- ▶ Remind service users frequently about parameters of the service
- ▶ Set up answerphone messages and email bounce back messages, which automatically kick in when the service is not operational
- ▶ Access training on how to set up automatic messages on all clinic communication systems

“Someone emailing us at 8 o'clock at night because they had got severe abdominal pain - we would want them to be seen straight away, not the next day. That's what worried us about the safety of email. But we've never, ever had that problem and patients actually use it very safely and effectively.”

Physiotherapist

Emails and text messages could be misinterpreted by clinician or patient

There is no immediate feedback and no cues such as tone of voice.

“If you're trying to assess their mental health it's quite hard to gauge through text, whereas if you can hear them over the phone, you can hear how they sound and whether they sound flat or not.”

Specialist Nurse

Building good relationships with patients enhances text based communications.

Who is receiving the digital communication - is it the patient?

- ▶ Clinical services must pay attention to their contact record keeping
- ▶ Ensure patients have agreed to be contacted by digital means
- ▶ Some uncertainty will remain so consider the nature of the information being shared

Will the communication technology work?

- ▶ Seek training as needed
- ▶ Ask advice about network coverage, particularly in rural areas and within NHS premises
- ▶ Many patients like to receive a text first so they know you will be calling
- ▶ If a patient phones, offer to ring them back to conserve their credit

“I always offer to ring them back... I'm always mindful that their money is their money and it's already quite expensive.”

Advanced Nurse Practitioner

Management may see use of digital communication with patients as a means of cost saving

Clinicians who use digital communication with patients are convinced of its value as an adjunct to seeing patients face to face, not a replacement.

“I worry that it could be part of a streamlining process that would see less clinicians on the ground.”

Senior Mental Health Practitioner

“It's time saving for me because I can impart information really rapidly in an accessible format. I can point people towards resources and so on in a helpful way so I find it actually acts as an addition to any therapy I might be doing.”

Psychologist



Ethical considerations when communicating digitally: Confidentiality, privacy and consent

Confidentiality and Privacy

The patient has a right to privacy, and healthcare professionals have a legal and professional requirement to maintain confidentiality of all patient information. There are risks to confidentiality when using all forms of communication – digital and non-digital, mobile and non-mobile. All need careful consideration.

Patients and health professionals may have different concerns about confidentiality.

“ I don’t ever think about the fact that someone else could read my emails. Doctors’ notes are exactly the same. They’ve got a pile of papers so anyone could read them in the same way that they could read an email. In fact, an email is probably more secure as it goes to her direct inbox rather than just lying on the side somewhere. ”

Patient

“ When patients email me they are emailing me from non-secure email accounts, so that’s the reason why I hesitate to respond to them at that email address. ”

Consultant

For patients at work or college, receiving a phone call can be problematic as they may not be in a private space at the time, whereas text or email can be viewed when in private. Health professionals may prefer to phone.

“ They’ve made the choice to send us the data by text and we would respond, but I wouldn’t give any data out by text, I would only give it over the phone, which I feel is more secure. ”

Consultant

Patients vary in their understanding of, and concern about, confidentiality and privacy of digital communication as illustrated by these two young people.

“ I wouldn’t mind my friends seeing the messages to my nurses and the replies. ”

Patient

“ You know, even just my brother and sister could be playing on the iPad or on the phone. If you put lock codes on people work them out or if somebody stole your phone – these kinds of things are quite easy to access. Or if you forget to log out of the computer at university somebody could see and I don’t publicise the fact that I have an illness. I wouldn’t want somebody to find out accidentally, and I think that can definitely happen with email, and even worse, texts. I mean texts flash up on people’s phones and people press the lock screen to see the time or whatever and there’s a text from the hospital. ”

Patient

Consent

Health professionals gain patient consent to use digital communication with patients in a number of ways. Some have a paper based consent procedure. Others gain consent with the first digital communication.

“ I say to the patient, you need to email me first and say in your email, I give you permission to email me confidential information, and then I would reply to that email. ”

Clinical psychologist

A clinical team running a private forum for their patients on social media, gain consent for each posting they make where patients are identifiable.

“ I always get permission. For Facebook, if I go out on a trip with them, say we’re going for a pizza evening and we take photographs, I always say to each one of them, are you happy if the pictures go up on Facebook? ”

Advanced Nurse Practitioner

Check you are following your organisation’s guidance on consent and confidentiality.



Ethical considerations when communicating digitally: Duty of care and equity

A key element of a health professional's duty of care is to respect patients' wishes and values, and facilitate and enhance their autonomy in the management of their care.

Care can be more patient centred using digital communication. Patients may be able to access quickly and easily, advice and support when they want it or need it. This can enable them to more confidently manage their long term condition in a way that fits with their life.

" Being in contact with someone about something like that instantaneously eases your anxiety. Just the fact that you know someone is going to read the email and provide some sort of response about what they think is going on without having to wait to see the doctor, that's the main thing. **"**

Patient

" Time and ease of communication, closer working relationships, and a breakdown of the paternalistic model of healthcare into a much more patient-empowered model of healthcare - working in partnership is the benefit. **"**

Consultant

Health professional/patient boundaries and the limits of the duty of care

This boundary can become blurred with digital communication, leading to some health care professionals experiencing uncertainty over the limits of their responsibilities.

" It's your decision to look at emails out of hours, it's your decision whether you're going to reply. The problem is when you reply, you acknowledge that you've responded to something. So then you are... responsible. **"**

Consultant

Health professionals have no control over the content and timing of digital communication from patients and this can be a cause for concern. They need to set clear boundaries.

" They will put a kiss on the end and I feel it starts to get a bit more friendly rather than professional, it's hard to keep those boundaries in place with text messages. **"**

Psychologist

" We've put a note on the bottom of our emails explaining that we will pick up our emails during working hours Monday to Friday, and that if there is anything urgent, they need to go to their local health provider. **"**

Consultant

Equity

Although most patients will own a mobile phone, not all will have credit, particularly for accessing voicemail and making phone calls.

" A lot of our patients don't ever have money to check their voicemail, so leaving them a voicemail is irrelevant. Sending a text is quite effective. **"**

Psychologist

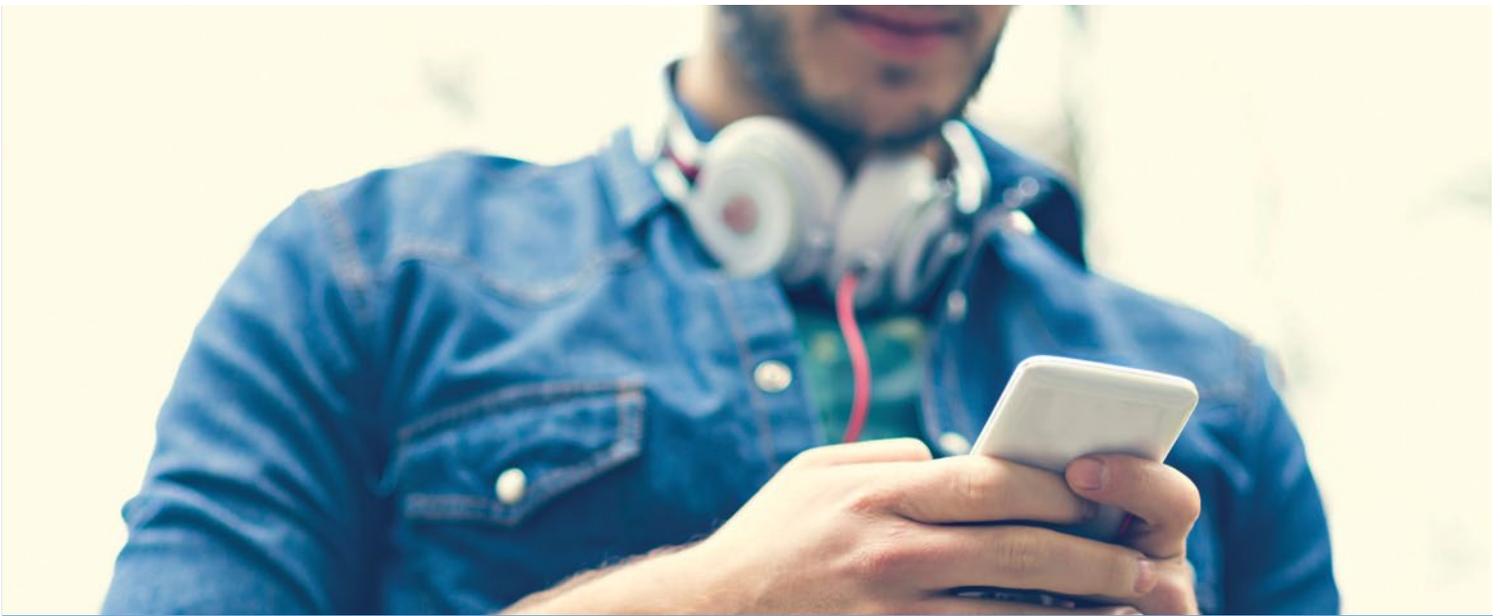
" I always offer to ring them back as well, especially when I know the conversation is going to take a bit of time. **"**

Advanced Nurse Practitioner

" FaceTime is something that our Trust is trying to work with. There's the difficulty - when young people don't have Apple products, you can't use it. **"**

Senior Mental Health Practitioner

When planning new forms of communication consider who will be excluded.



Engaging with the right person at the right time to enable effective condition management

Using a smart phone or tablet makes it easy to email or text at any time

Patients value the ease of using digital communication and want a timely response. They see digital communication as reducing the burden for health professionals.

"I wouldn't feel that I had such a direct access if I had to phone them really. I know that I can just email and ask a question, and I'll get an answer back. I wouldn't feel like I'm taking up too much of her time."

Patient

Health professionals need to respond to digital communication from patients in a timely manner - not always easy in the face of numerous clinical demands.

"I do try and do it but if I'm not around, if I'm busy, then I often forget or just don't do it and they email again and I have to do it."

Consultant

Health professionals have developed strategies such as:

- ▶ make a quick decision on when and how to respond to text or email
- ▶ use telephone when immediate communication needed
- ▶ use mobile technology so communication is more easily integrated with other work

"It means I can do it anywhere, so quite often I might be in the middle of doing something and I'll think, oh I just need to text this young person about their benefits."

Social Worker

Asynchronous communication (email/text) has advantages over telephone calls

Health professionals value being able to construct a measured message for their patient in an uninterrupted moment. Email and text are NOT used for conveying bad news, which is always given face to face.

"Email gives you thinking space so that you can formulate a really strong response."

Specialist Physiotherapist

Patients value the non-intrusive nature of text and email. They can look at the message and reply at a time convenient to them. Phone calls, particularly for those who are at work or college, require the patient to find a space where there is privacy.

"I don't have time to find my own private space. What I am talking about to the nurse is private, I don't want people around me to hear. Being able to send him a quick text is so helpful."

Patient

Text and email can reach the right person at the right time

Patients value being able to text or email a question as it occurs to them rather than tracking down a member of the clinical team on the telephone or waiting until they have an appointment.

"It's really good for us to be able to have contact and catch up at intervals throughout the six months (between appointments) rather than having to make long journeys."

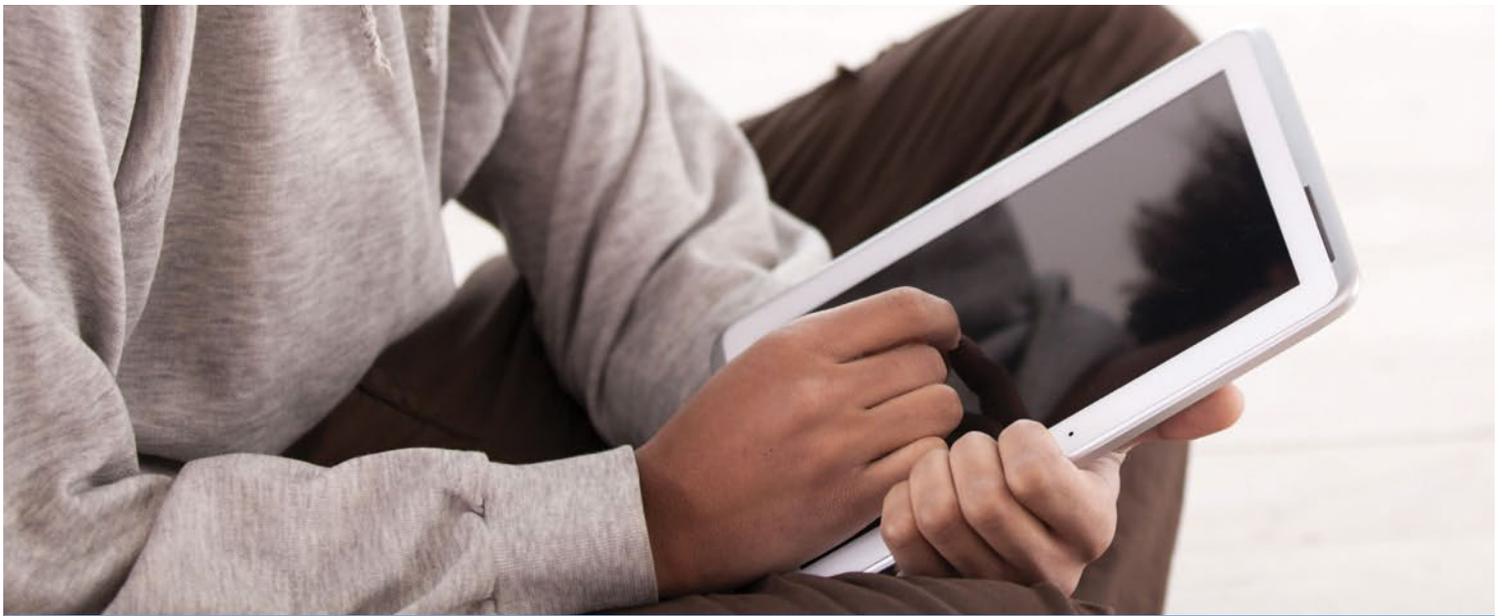
Patient

Email is good for sending information to patients quickly. Embedded links can be used to signpost patients to resources.

Providing a range of methods of communication is the best way to engage patients

"They'll say, 'oh it's easier to text me', or 'I never check my emails, don't email me'. I go by whatever they say."

Social Worker



Enhancing patient engagement and improving face to face consultations

Enhancing patient engagement

Digital communication can be used to reach out in a non-threatening way to patients who have disengaged from a service.

"We had someone recently who hadn't responded to any automatic DNA letters from clinic, so we just dropped her an email saying, 'not heard from you for a bit, is everything okay, can we do anything, do you need anything?' And she emailed us back so it was quite successful."

Physiotherapist

Many patients are more likely to email or text to get in touch rather than telephone, particularly those considered hard to reach patients and those with communication difficulties.

"Unless patients know me very well, they don't ever call. So I think it does definitely help the relationship overall."

Psychologist

The use of less formal and non-clinical language can help engagement.

Patients' feelings of control and empowerment can be enhanced so they actively manage their condition.

"It gives me more individuality because I'm able to know myself what to do and what not to do... if I call I can tell them that I don't feel well, this is what I'm doing, is this okay? And they will advise me on what to do."

Patient

"There were a few emails where he described what his symptoms were and we asked him a few more questions. He responded to those. We gave him some advice about his medication, we told him we'd contact the GP to prescribe the medication and could he pick it up from the surgery. And then he said, 'oh I've done this, I'm feeling better.'"

Nurse Specialist

"They probably wouldn't call or turn up but they might email and say, 'I can't come or I haven't come', or 'I've run out of medicine', or 'can you organise this for me?' So it's that first rung on the ladder of self-management. We can then help them think about what they would like to do next."

Psychologist

Patient activation can be enhanced through having confidence in their health professionals.

"It's knowing that I can contact her easily and that she's so nice about it all the time, she'll always send a really friendly reply. I think I have a lot more trust in her, I feel quite confident in her care."

Patient

Improving face to face consultations

Patients with difficult issues to discuss value being able to do so by text before a face to face meeting.

"They can bring it up instead of you bringing it up."

Patient

"If I have got something important that I need to try and talk about but I can't talk about it, I can just text it over to them. If they bring it up, I can just say that I don't want to talk about it but that is what happened."

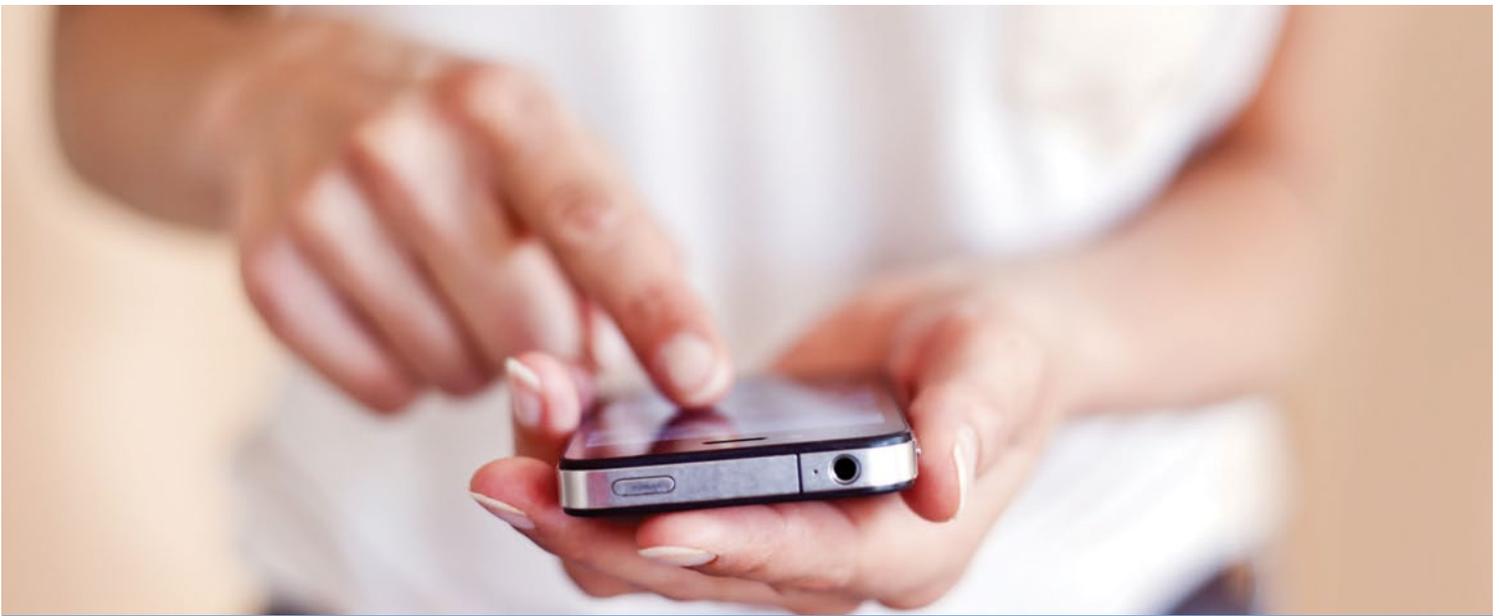
Patient

Building relationships with patients digitally can improve face to face appointments.

"If we can engage via text then they're more willing to engage with us in sessions."

Mental Health Support Worker

If minor issues (such as ordering supplies) are dealt with between clinic appointments, then the health professional and patient can concentrate on the really important issues during the appointment.



Improving your patients' access to advice and information – when they need it

Use a wide range of digital communication

Text: best for making quick contact and for arranging a phone call or meeting.

Email: considered more formal and useful for giving written information and sending test results – when the result is routine or as expected. Also seen as useful for ordering supplies and prescriptions.

Social media: good for support forums where patients share experiences and information.

“ I ring and they're not there, it doesn't mean that they don't want to talk, it just means that they're that generation where it's hard to access them. They're much more likely to reply to a text and say, 'no I don't need a chat today' or they can arrange a time. ”

Clinical Psychologist

Not everyone will talk on the phone – but they might email or text

The asynchronous nature of email and texts gives patients and health professionals time to think and compose a question or response.

Patients may write but not talk about:

- ▶ their emotions
- ▶ what embarrasses them
- ▶ things they find difficult to face

Written communication can be re-read. This is important for those:

- ▶ who feel overwhelmed by information
- ▶ whose first language is not English
- ▶ who have a communication disability

Texts can be good for hard-to-reach patients

“ I've got one person that I've been working with. He's more likely to respond to a text than a phone call. If I text, he normally comes back within a couple of hours, but if I try and phone and leave a message, sometimes I don't get a reply at all. ”

Senior Mental Health Practitioner

Using text or email means the patient has a record of the information they need from you

Patients value having a written record of care plans they have discussed, test results and answers to their questions. Email works well and texts have a role too.

“ Gives them written documentation that they can hang on to rather than a phone call, which they will often not have written down and then they will lose it. ”

Haematologist

Using familiar communication technology improves access

Communicating by text or email with a smartphone is an everyday activity for many. For young people a conversation over the phone is less familiar than text or email.

“ I'm not really comfortable with calling people, that's why I prefer any other option. I find it a lot easier, less hassle. You can plan it and get all the information you need, if I was talking on the phone I would probably forget a point. ”

Patient

Knowing who to contact and how, speeds up access

Patients who need advice between appointments value quick access so they can quickly resolve their problem. If a patient is familiar with the clinical team, contact details for the team are as welcome as individual contact details. Avoid asking patients to call the hospital switchboard. Each additional step the patient has to take to make contact reduces access and they may give up.

Use a phone that allows the patient to know who is calling

Many people do not answer if the caller ID is withheld.

“ I think it is far better when they know your number and they can see that it's you calling or the text is from you, and they tend to respond better. ”

Community Nurse



Patient safety and the use of digital communication

Patients mostly focus on benefits and regard risk as acceptable or negligible. They are often unaware of potential safety risks.

" I'm happy to use the technology, I don't really see a huge downside to it. "

Patient

Health professionals will often use their common sense to reduce risks to patient safety - and so do patients.

" I wasn't feeling very well, so I'd emailed... we'd emailed each other. When I hadn't emailed back, he was worried, so he text me and said I'm available now if you want to call. "

Patient

" If I've had a hypo for like three days at the same time each day, I will text them and say... and then if they haven't responded during that day, I will usually ring them the next day. "

Patient

" There are four nurses, so say I text one of them and they've responded, then I have to ring again, and another nurse might answer. Lately I've got into the habit of texting all four and seeing who gets back to me. "

Patient

BUT occasionally patient safety is put at risk when communication fails, as in this example:

" I just altered my insulin dose myself to how I thought it would be, which actually turned about to be wrong, so it did leave an impact because it took a good week to sort itself out. "

Patient

Check the processes your organisation has in place to identify and manage potential patient safety and security risks proactively - before patients are harmed. Here are just some examples of the precautions taken by clinical teams.

" When I put the number in my phone, I always check on EPR with the screen that the number I'm entering is correct before I actually press send. "

Nurse

" So the email comes to me. I'm the only person that gets to see it. Anything that's clinically relevant, I will cut and paste the conversation and put it in our electronic notes so that the rest of team are aware of what I've done. "

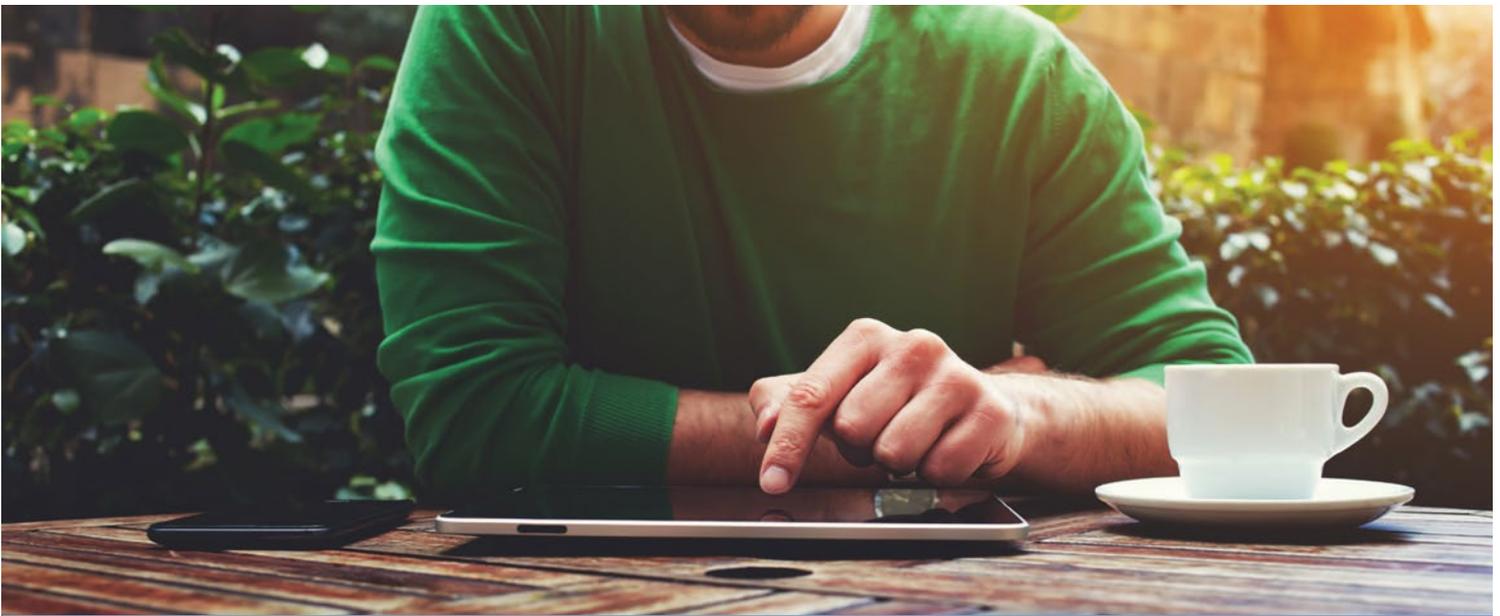
Specialist Nurse

" Email has its place but there are limits. So there are often times when an email will come through and I will make the decision to actually ring the person back or email them back and say, can't do this on email, when is a good time to call you, or for you to call me. "

Specialist Nurse

" I put a message on my out of office that says, 'I'm not back in the office until such and such a date', so that people know that they're not going to get a response from me. I don't put any more detail than that. I know a number of people will say, 'if you've got this problem ring this person, and if you've got this problem ring that person', but I don't hold their diaries so I don't know whether all of those people are around. So I always tell people if you've got a problem, ring the centre because there's always somebody here during office hours. "

Dietitian



Between appointments, digital communication enhances patient experience of care

Patients feel that the clinical team know them better.

"It's more personal. Because I have more contact now outside of clinic they know me a bit better and I know them a little better. It doesn't feel like I'm just 'another patient'."

Patient

Clinical teams gather more knowledge about the patient's condition.

"They asked me to email them my current blood pressure in order to monitor how healthy I am. So I take my blood pressure every two weeks and send it to them then."

Patient

Where there is an established relationship between a patient and health professional, test results can be given and medication adjusted through digital communication rather than the patient attending clinic. This saves the patient time and can be enabling.

"They used to say 'come in a week's time and we'll tell you the result'. Now with the text messages it's 'your blood levels are fine, you don't need to come in'."

Patient

"If there's anything wrong in-between I'll let her know and then she'll adjust this medication. It helps me to look after myself more because I know exactly what I'm doing... I'm constantly clued in."

Patient

Knowing someone is there and will answer a query is reassuring for patients.

"They say they like getting text messages because it reminds them that there's someone there for them and that someone is caring about them, even if they're not visibly being seen."

Nurse Practitioner

Knowing there will be a reply is the key to reassurance. Contact is equally valued if it is with an individual or a whole team or if the reply comes from a different member of the team than the one initially approached.

"If my usual nurse can't reply to me, someone else from the team will call back and try and give me the information that I want... it's been excellent."

Patient

Health professionals can use digital communication to maintain their relationship with a patient:

"If he messages and says, 'hi, how are you, blah, blah, blah', that will then remind me I was meant to text him a week ago and completely forgot."

Patient

Digital communication with patients can help catch problems early and act as encouraging reminders for patients to stick to treatment regimens.

"I'm absolutely convinced it's helped keep some people out of hospital, and in some cases I think it's actually stopped people dying. A couple of really poorly people - we've been able to communicate quickly and sort things really, really quickly."

Nurse Specialist

Some clinical teams enable patients to self-refer to therapists within the wider team via email.

"I get a lot of patients self-referring to me through email. I used to be uncomfortable with this. Now I just go with it because it feels so helpful."

Psychologist



Going digital with patients will increase my workload – concerns, real world experiences and solutions

More work for an already stretched service

The volume of communication goes up, which means more work BUT clinical teams see the benefits:

- ▶ better communication with often hard to reach patients
- ▶ more efficient working
- ▶ reduction in duplication of work

“ It has massively improved the contact that we have with some of our patients. ”

Physiotherapist

The number of emails and texts was not overwhelming or inappropriate BUT clinical teams need to:

- ▶ establish a system for dealing with any misuse that does occur
- ▶ work out as a team how to deal with emails and texts
- ▶ strike a balance between enhancing care and workload

“ Having direct access to the consultant is great for the patient but it's not so great for the consultant. ”

Consultant

Patient expectations will be high so need managing

- ▶ set reasonable expectations from the start
- ▶ be clear about times when the service is available and expected response times
- ▶ put bounce back and answer messages in place for communication received out of hours and when staff are away

“ There's a schedule for the month that goes out to the young people who are receiving that treatment to say who the named contact is for that day, during what hours they are contactable and their mobile number. ”

Team Leader

Patients may overburden the service with unnecessary communication

Clinical teams have found this rarely happens. The one or two cases cited were dealt with at clinic level:

- ▶ be aware of potential misuse by patients and have a strategy for dealing with individuals
- ▶ keep service users aware of the scope and purpose of available digital communications

Plan how to keep clinical records updated

“ We started printing off every email and it would go in the back of the patient notes. That just hasn't been feasible to continue. ”

Physiotherapist

Using your own mobile to make timely contact with patients during your busy day

Although done with the best of intentions, this can be problematic for ensuring patient/clinician boundaries are retained, and for patient safety and confidentiality.

“ There have been a couple of incidents when I've done a home visit and I have forgotten to take our shared Trust mobile with me. I've used my own mobile to send a message to the person. That person then has my number... and that has been a bit of an issue. ”

Medical Lead Nurse

The study name is:

**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; the LYNC study**

The study was led by:

▶ Professor Frances Griffiths

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Further details about the study are available at:

🌐 www.nets.nihr.ac.uk/projects/hsdr/1220951

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Funding Acknowledgement: This project was funded by the National Institute for Health Research Health Services and Delivery Research (HS&DR) Programme (Project Number 12/209/51)

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