



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.

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

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

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