

Analysis of LYNC data to look at ethical implications

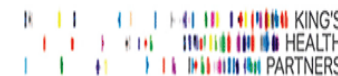
Agnieszka Ignatowicz, Patrick Elder and Anne Slowther

The Team

Frances Griffiths, Xavier Armoiry, Helen Atherton, Jack Barker, Carol Bryce, Abigail Buckle, Jonathan Cave, Kathryn Dennick, Melina Dritsaki, Joe Fraser, Caroline Huxley, Agnieszka Ignatowicz, Sung Wook Kim, Peter Kimani, Jason Madan, Harjit Matharu, Mike May, Luhanga Musumadi, Moli Paul, Gyanu Raut, Sailesh Sankaranarayanan, Anne-Marie Slowther, Mark Sujan, Paul Sutcliffe, Frances Taggart, Alice Verran, Leigh Walker and Jackie Sturt

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)



Ethical analysis: overall findings

➤ **Autonomy and control**

Digital clinical communication can increase patient empowerment and facilitate autonomy, but also create dependence rather than promote patient autonomy.

There can be uncertainty regarding the level of consent required.

➤ **Communication and trust**

Digital clinical communication can improve trust between patient and healthcare professional.

➤ **Defining the limits of a duty of care**

The limits of a clinician's duty of care can become blurred when unlimited access is possible.

➤ **Confidentiality**

There can be difficulty defining and maintaining boundaries of confidentiality.

Patients can have different levels of understanding of, and concern about, confidentiality and privacy.

Ethical analysis: autonomy and control

➤ Patient empowerment

'They've got someone to ask about it so they can feel empowered to ask those questions and control their own health rather than don't know who to ask or whether to come forward with things.'

Consultant, cystic fibrosis

'I think... personally I do think it is too...I think it makes patients a little too dependent on you and you only, which we don't like to happen.'

Nurse Specialist, diabetes

Ethical analysis: autonomy and control

➤ Person-centred care

'It's made [my relationship with the clinical team] stronger because I have more contact with them and more personal contact (...) So it doesn't feel like I'm just "another patient".'

Young person, liver

'If you had to rely on them ringing in the landline here and talk to you sort of through reception, nine times out of ten it wouldn't happen because, you know, for a 14 year old lad or whatever, it's too much like hard work (...) I suppose it's bringing, not bringing yourself down but levelling, getting on the same level.'

Senior Mental Health Practitioner,
CAMHS Outreach Service

Ethical analysis: autonomy and control

➤ Consent

'I think there probably needs to be some sort of formal conversation or information about the use of email (...) Because that doesn't happen really, there isn't any kind of terms of the use of...well, there is information governance policies in the hospital but it doesn't really translate to the clinic.'

Consultant, renal

'For me times have moved on but as long as my responsibilities are professional, as long as I explain those risks to them before I use it, if they are well aware of the risks, well, the ball's in their court.'

Nurse Specialist, liver

Ethical analysis: autonomy and control

➤ Clinician autonomy

'I've had text messages before where they just get a bit more friendly and they will sort of like put a kiss on the end, and I just feel like it starts to get a bit more sort of friendly rather than professional.'

Assistant Psychologist, CAMHS

'A few months ago (...) one young person decided to put texts that I'd been sending to her out on social media, which is inappropriate. She knew it was inappropriate...And although she'd removed my name on all of the texts it was my...you know, the girls [other patients] knew it was what I'd said.'

Nurse Specialist, IBD

Ethical analysis: communication and trust

'I think 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.'

Young person, liver

'I'm trusting these people with my life (...) so I just don't think you can replace that personal one-on-one...from a patient perspective, I quite like to know who is treating me, who is calling the shots, and yes to be able to just discuss with them properly why they're doing the things that they're doing.'

Young person, cancer

Ethical analysis: defining the limits of a duty of care

'I got an email from in the middle of the night (...) telling me she [the patient] was going to kill herself (...) that really raises questions of where does that put me responsibility-wise, because that email was sitting there not accessed, and she'd actually given me that information, which if that was her calling in saying that to me or whatever obviously I'd be professionally obliged to do something significant with that.'

Clinical Psychologist, liver

Ethical analysis: confidentiality

'If someone gets their hands on that email, just a random person reads it, I mean they're not going to care, it's not going to affect their life so, you know (...) So I see that as really the only risk to be honest with email intercepted by someone, really.'

Young person, liver

'If it's your data and you've made the choice to send it, then that's your lookout (...) I suppose 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, HIV

Ethical analysis: overall findings

- The ethical implications of digital clinical communication are complex
- Digital clinical communication raises new challenges for health care professionals in relation to setting professional boundaries and understanding the implications for the professional duty of care
- Our findings highlight the importance of dialogue between health care professionals and young people

Collaborating Organisations:

University of Warwick, King's College London, University of Oxford, University Hospitals Coventry and Warwickshire NHS Trust, King's College London NHS Trust, Guy's and St Thomas' NHS Trust.

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).

Department of Health Disclaimer:

The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR Programme, NIHR, NHS or the Department of Health.

For further information contact:

Professor Frances Griffiths
Warwick Medical School
Warwick University
f.e.griffiths@warwick.ac.uk

Professor Jackie Sturt
Florence Nightingale Faculty of Nursing & Midwifery
King's College London
jackie.sturt@kcl.ac.uk



@LYNCStudy



facebook.com/LYNCS2014

We would like to give a special thanks to all the patients, clinicians and NHS Trusts who have contributed to the Study.

