How does the use of digital consulting change the meaning of being a patient and/or a health professional? Lessons from the Long-term Conditions Young People Networked Communication study

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Abstract

Background: While studies have examined the impact of digital communication technology on healthcare, there is little exploration of how new models of digital care change the roles and identities of the health professional and patient. The purpose of the current study is to generate multidisciplinary reflections and questions around the use of digital consulting and the way it changes the meaning of being a patient and/or a health professional.

Method: We used a large pre-existing qualitative dataset from the Long-term Conditions Young People Networked Communication (LYNC) study which involved interviews with healthcare professionals and a group of 16–24 years patients with long-term physical and mental health conditions. We conducted a three-stage mixed methods analysis. First, using a small sample of interview data from the LYNC study, we identified three key themes to explore in the data and relevant academic literature. Second, in small groups we conducted secondary analysis of samples of patient and health professional LYNC interview data. Third, we ran a series of rapid evidence reviews.

Findings: We identified three key themes: workload/flow, impact of increased access to healthcare and vulnerabilities. Both health professionals and patients were 'on duty' in their role more often. Increased access to healthcare introduced more responsibilities to both patients and health professionals. Traditional concepts in medical ethics, confidentiality, empathy, empowerment/power, efficiency and mutual responsibilities are reframed in the context of digital consulting.

Conclusions: Our collaboration identified conflicts and constraints in the construction of digital patients and digital clinicians. There is evidence that digital technologies change the nature of a medical consultation and with it the identities and the roles of clinicians and patients which, in turn, calls for a redefinition of traditional concepts of medical ethics. Overall, digital consulting has the potential to significantly reduce costs while maintaining or improving patient care and clinical outcomes. Timely study of digital engagement in the National Health Service is a matter of critical importance.

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Background

NHS Digital's publication, *Information and technology strategy for better care 2015–20*,[1] states 'we have the key role in enabling and supporting the whole health and care system to use technology, data and information to transform its services' (p.4). This strategy has five themes, one of which relates directly to patient engagement with their health and healthcare and the responsibilities of clinicians and National Health Service (NHS) organisations to facilitate this. The expectation is to enable citizens to use information tools to manage their health and care, and for healthcare professionals (HCPs) to use data and analytic tools to provide better services at a time when the NHS is facing significant challenges (ever increasing demands in a period of UK and global history when public funding is restricted, and investment constrained). And in the recently published *NHS long term plan*,[2] it was stated that digitally-enabled healthcare 'will go mainstream across the NHS' (p.25). There is, therefore, an evidently strong interest in the role of the digital in enhancing the various aspects and flows of healthcare delivery. In this article, we focus primarily on the communication aspect.

There have been a number of studies exploring the impact of digital communication technology on healthcare, but no systematic research approach. Subsequently, there has been no specified model for using digital technology within clinical teams, and some argue that a paradigm shift would be needed to incorporate digital health advances.[3] This paradigm shift is starting to take shape as a result of the current coronavirus disease 2019 (Covid-19) pandemic, which has forced many healthcare-related processes to move online, almost overnight. It will take some time, though, before one is able to fully comprehend the myriad impacts of recent digital shifts that have been occurring in response to the current pandemic. Here we focus primarily on existing research that preceded Covid-19, given the availability of data.

Traditionally, healthcare interaction is based on synchronous (usually face-to-face) communication between clinician and patient. With no overarching structure in place to incorporate digital communications, digital consulting is currently seen as an adjunct to traditional care. While developing new models of care to incorporate the digital is a priority for the NHS, patients prioritise their relationship with the healthcare providers.[4,5] However, little discussion has been given to the 'human component' (p.4).[3] Introducing digital technologies into clinical interactions raises non-technical questions which concern organisational, professional, ethical and governance questions.[6,7] This means that the challenges we face concern not only the optimisation of the features of the digital consulting tool or the security of the system, but also the way it works in the specific context of clinical practice where patients and clinicians are involved. Healthcare professionals inevitably adapt their practice to the use of digital tools as patients reshape their communication with their healthcare providers and their own role within the health service. These changes in roles, identities and forms/shapes that happen when digital consulting tools are introduced, need to be explored to understand how new models of digital care change the meaning of being a patient and/or a health professional. At stake are not only the technological tools being used but also the social, cultural, economic and political contexts that make up the ecosystem within which patients and healthcare professionals are embedded. Understanding these intertwined elements and their bearing on digital care integration demands a coalition of disciplinary approaches and a multi-level perspective. As Kostkova[8] argues, successful integration of new communication technologies requires a change from a single-disciplinary academic approach to a multidisciplinary one so as to explore these (and other) questions and thereby transform healthcare in a more meaningful and impactful way.

The current study

The National Institute of Health Research (NIHR)-funded Long-term Conditions Young People Networked Communication (LYNC) study[9,10] provided the first comprehensive dataset detailing clinician

and patient digital consulting behaviours. The LYNC participants (clinicians and young people) used email, text, Skype and personal health record systems adjunctive to their usual healthcare provision and receipt. The LYNC dataset consisted of 350 interviews and 80 observations of clinicians and patients using digital consulting with young persons (YPs) across 20 clinical teams and 13 conditions such as mental health and diabetes. A 16–24 years old population was chosen for its 'digital native' status, a term referring to people who grew up in the digital age using digital technologies and media forms. The clinicians, on the other hand, were 'digital migrants', born before the spread of digital technologies and later adopted, and adapted to, digital consulting behaviours driven by the clinical needs of their vulnerable young patient population. The young people had one of 13 physical and mental health long-term conditions and attended NHS specialist services for their healthcare. LYNC found considerable enthusiasm for digital consulting which afforded young people access to healthcare at the point at which it made a difference to how they managed their health. It was valued as a useful addition to traditional face-to-face appointments, increased patient control and resulted in more activated self-management. It also challenged traditional boundaries between clinicians and their patients.

Given the relevance, scale and importance of the LYNC study, we chose to draw on its available dataset to examine how the use of digital consulting changes the shape, nature and identity of being a patient and/or a health professional and the issues that this raises. Informed by our multidisciplinary expertise and backgrounds, we drew on literature from health sciences, history, philosophy, bioethics and humanities to explore the competing meanings of digital health and the values assigned to it. As mentioned earlier, digital consulting is not only a matter of technology or the digital alone but entails various other aspects that are social, cultural, political and so on. Taking these aspects into consideration and approaching them through different lenses can enable a deeper understanding of the interplay between health and the digital as it unfolds within the context of consulting.

Method

Our collaborative project emerged out of an initiative led by one of our institutions, designed to support the development of inter- and multidisciplinary projects and foster collaborative approaches to research. Through this scheme we received seed-funding for developing the project which brought together historians, bioethicists, social scientists, digital philosophers, behavioural scientists, NHS technologists, NHS

clinicians and implementation scientists with a shared interest in the human factors related to health and technology. Non-academic collaborators included artists with expertise in the amplification of evidence to aid public understanding, commercial technologists with contractual obligations to provide and support digital consulting infrastructure to the NHS, and NHS professionals. This eclectic mix of expertise enabled us to approach the research questions from a variety of criss-crossing and interrelated angles while harnessing the strengths of our respective academic disciplines and backgrounds. We conducted a three-stage mixed methods study. First, we identified key themes to explore in the data and literature. Second, in small groups we analysed qualitative data from the LYNC study. Finally, we ran a series of rapid evidence reviews.

Stage 1: identification of key themes

All members of the research group read the same two LYNC study transcripts (one from a health professional, the other from a patient) prior to an initial study meeting. The purpose of this exercise was for everyone from across the different disciplines to read the same, pragmatically small, illustrations of the data, with the aim of reporting on what they saw/understood. Data from the interviews were interpreted from our personal disciplinary backgrounds (informed by literature and theory) and our interpretations shared with the group via PowerPoint presentations and subsequent discussions. The key terms and questions emerging from each presentation and discussion were listed and then grouped together to form three topics of interest transpiring from the studied transcripts, namely 'workload and workflow', 'impacts of increased access to healthcare' and 'vulnerabilities' (see Table 1). Three subgroups were formed from the research team to explore these themes through our subsequent qualitative analysis and literature reviews.

Stage 2: interrogation of LYNC data

Three data analysis groups were established to explore the three topics. The 'workload/workflow' and 'impacts of increased access to healthcare' groups comprised of three members of the research team each, and the 'vulnerabilities' group had four members. Each group was allocated six different LYNC study transcripts purposely selected to represent both healthcare professionals and patients from each clinical setting. Detailed thematic analysis was undertaken by each member of the research group, which involved conducting content analysis of the transcripts and encoding the relevant recurring themes, a method we borrowed from the work of Vaismoradi et al.[14] This initial analysis was

Table 1. Topics of interest and associated research questions.

Theme	Research question
Workload and workflow	What is the impact of the change in patient and health professional workflow and workload brought about by the implementation of digital consulting? Dunbar's social relationships theory[11] states that there is a cognitive limit to the number of people with whom one can maintain stable social relationships. This number increases as the strength of the bond decreases (i.e. we have cognitive capacity for more acquaintances, as the relationship requires little ongoing investment in time and effort, than we do for close friends with whom we invest more time and effort). According to the LYNC study, many clinicians fear being overwhelmed with digital requests from patients; does social relationships theory hold when applied to digital communications? Expectations of more efficient workflow or lower productivity are important for implementation of e-health interventions.[12] We understand e-health as healthcare practices that are supported by electronic processes and communication. Resistance to e-health implementation was found to be related to fear of, dissatisfaction with and uncertainty over new roles and responsibilities that might develop as a result of integrating digital communication in healthcare provision, especially with regard to duty of care and boundaries of care (when one is on duty and when one is off duty).[13]
Impacts of increased access to healthcare	What are the impact (qualitative evidence) and outcomes (quantitative) on patient wellbeing, quality of life, patient activation and therapeutic alliance of interventions designed to improve access to healthcare in long-term conditions? This question is based on the assumption that digital consulting improves access to healthcare. We were therefore interested in what the impact and outcomes are on wellbeing when access is improved.
Vulnerabilities	How does the use of digital consulting contribute to the creation of new vulnerabilities and new forms of (em)power(ment) for all actors (patients, HCPs, etc.) involved in digital consulting? The theme explicitly does not take for granted that power will necessarily flow along the conventional presumed lines between HCP and patient found in paternalistic approaches to healthcare, for instance. Instead, it seeks to explore in, a more open-ended way, how relationships are qualitatively changed by virtue of digital communications.

HCP: healthcare professional; LYNC: Long-term conditions Young people Networked Communication.

discussed and refined within the analysis groups. Each team presented their findings to the wider research group at a subsequent project meeting. In our analysis below, we give edited extracts of direct quotations.

Stage 3: evidence review

Each of the three groups created a search strategy to inform three rapid evidence reviews across disciplinary databases. The selection of electronic databases was tailored according to the disciplinary backgrounds of the group members. Search terms and eligibility criteria (detailed below) were derived through an initial sub-team meeting. Identified evidence was thematically synthesised to produce insights into the questions asked by each group. Searches were conducted in September and October 2017 by one of the authors (CH).

Workload and workflow. The databases PubMed, PsycInfo and Health Management Information Consortium (HMIC) were searched using the following search terms:

1. (healthcare AND access) AND (digital communication OR electronic communication OR computer mediated communication) AND (Workload OR work distribution OR workflow).
2. (healthcare AND access) AND (email OR text message OR SMS OR VOIP OR Skype OR video conference OR patient portal) AND (Workload OR work distribution OR workflow).

Both quantitative and qualitative studies were included, as were both patient and health professional perspectives.

The database search identified 178 citations. There remained 170 citations once duplicates were removed,

14 after abstract screening, and five were included in the review after reading the full article. Two papers reported trials of patient portals which included secure messaging features,[15,16] two surveyed or interviewed healthcare professionals about their use of email communications with patients,[17,18] and one was an observation and interview study of the introduction of a short message service (SMS), a text messaging component of most telephone, internet and mobile devices, between a general practitioner (GP) practice and their patients.[19] All studies were from the USA or UK. Data was extracted from each of the studies included. This was thematically coded to identify prominent or recurrent issues relevant to the research question.[20] These themes could then be related to themes identified in the thematic analysis.

Impact of increased access to healthcare. The PubMed and PsycInfo databases were searched using the terms: healthcare access AND (patient wellbeing OR quality of life OR patient activation OR therapeutic alliance) AND long-term condition OR (diabetes OR depression OR anxiety). We focused on long-term conditions because we were drawing on the LYNC study whose focus was on these types of conditions deemed costly to health services. In our search, we included any intervention that was designed to facilitate better access to healthcare for people with long-term conditions. Our outcomes of interest were (a) patient wellbeing, (b) quality of life, (c) patient activation and (d) therapeutic alliance.

The searches yielded 853 citations. There were 789 remaining once duplicates were removed, and 19 after abstract screening. A total of 11 citations were included after full-text screening. Ten of these articles originated from the USA or UK, with the other from Finland. The studies focused on a range of interventions that increased access to healthcare. Five articles examined the use of digital communications via email,[21] text message,[22] patient portal[23] or (two studies of the same) virtual clinic.[24,25] The other studies focussed on increasing patient access to healthcare via an outreach service,[26] drive to increase uptake of Improving Access to Psychological Therapies (IAPT),[27] increased contact with primary care clinicians,[28,29] through increased contact with a nurse as part of a diabetes education programme[30] and through a supported housing programme.[31]

Vulnerabilities. Following some initial scoping searches of targeted journals, each journal identified was searched using the key terms 'digital consult*', 'digital' or 'telehealth'. Second, a series of searches were made using journal groupings (e.g. ethics, digital health) via PubMed. Searches used different keywords (listed above) likely to retrieve relevant hits in that grouping (e.g. in digital health journals we searched using the term 'empowerment' whereas in the ethics journals we searched for 'digital and health'). This search also included informative articles, literature reviews and commentaries.

The searches produced 3632 potentially relevant citations. One search using the word 'trust' to search the digital culture journals on PubMed was discarded as it yielded too many citations (over 33,000) to feasibly screen. After removing duplicates and screening abstracts this was reduced to 52 citations. We were unable to access one article during the time frame, and after full text screening 11 were included in the review. One article was found in the medical ethics group of journals, one in the ethics of technology, five in digital culture and four in history.

Results and discussion

Below we present our integrated findings and discussion for our thematic analysis and literature reviews, grouped around our three key themes: workload and workflow, impact of increased access to healthcare, and vulnerabilities.

Workload and workflow

The LYNC report[10] identified that many clinical staff were concerned that digital communications with patients would negatively impact their workload. Our thematic analysis identified shifting boundaries, risk taking and decision making as key issues. First, we identified boundaries restricting digital communication between patient and clinician. The literature suggests that some health professionals felt it was a burden to respond to emails out of usual work hours, while at home and other non-clinical locations.[18] However, in our analysis, we found a difference in how health practitioners managed their relationships with different patients. For example, one person described being flexible with some of their digital patient contacts, suggesting that they checked emails and returned calls outside of working hours. They felt obliged to provide a prompt response because 'they wouldn't phone unless there was a real problem' (HCP Rheumatology). Nevertheless, they would impose strict boundaries with other patients based on fear that they would 'abuse the system' (HCP Rheumatology). Changes to working patterns provided for specific patients, could create inequalities in the care provided by health professionals, challenging the nature of their role in providing equal care for all.

As identified by the data derived from the LYNC study, patients themselves were sometimes aware of the

burden on their clinician and imposed their own boundaries on contact. Rather than sending multiple requests, these patients would make the decision to wait for a response 'I just wait and let her sort her stuff out...she usually calls me back' (YP Mental health). Patients were aware of boundaries created by different digital channels. For example, text messages (which can be sent from any mobile phone) were responded to much more promptly than email (which requires a computer or smartphone access). There was discussion as to which communication channel is appropriate to use for what and with whom. Young patients had clear ideas as to their preferences; contacting friends by text message would be appropriate, but for some this method was 'too informal' (YP Rheumatology) for contacting their clinicians. There was also some resistance among young patients to using mobile device for health-related issues, as this would blur the boundaries between their social identity and their 'patient identity': 'my phones my phone and...I wouldn't want to mix like the medical with all my friends' (YP Rheumatology). In this case, patients' preferences and ability to judge communication channels are part and parcel of how they construct and perceive their identities. The introduction of digital communication in healthcare settings has, in a way, changed the patient's identity. Patients are now increasingly responsible for choosing the most appropriate channel for communication, taking into account the healthcare professionals' burden and probable response times. This responsibility also reflects the idea of patient workload identified in some papers. While there is a common idea that digital communication can save both patient time and travel,[19] less discussed is that the patients' mental workload increases, as they decide what communication channels are suitable for the current issue they wish to discuss.[19] HCPs also assume that patients have infinite time to think about their health and 'be' a patient, so this role is not something only adopted in medical settings, but is a more permanent aspect of their identity: 'there is always limited time in the office. With e-mail the patients are unlimited with their time. They can ask me questions that they forgot to ask while they were in the office'.[18]

Patient boundaries also included practical issues, such as losing the relevant telephone numbers or email addresses, and the fact that only a limited number of the clinician's patients will be poorly or need extra contact at any one time, reflecting social relationships theory.[11] The literature we reviewed supported this interpretation; of physicians who directly email with patients, 86% contact 1–10 in a typical week, while 14% contact 11–20 in a typical week.[16] This corresponds with the theory of Dunbar's number for both offline and online interactions. Dunbar identified a four-layered structure; within the first layer, we have around five close relationships, increasing to 15 in the second, 50 in the third and 150 in the fourth. We invest more time and effort maintaining the smaller number of relationships in the first and second layers, and as the number of relationships increase the time invested decreases.[11,32]

In the LYNC study data, we also identified boundaries imposed by institution, health discipline and digital channel. Health professionals were conscious of institutional guidelines, policies and expectations, even if they did not always comply: 'at times you know, I don't feel I follow those guidelines, so contacting people [patients] on my personal mobile phone, things like that would be outside those guidelines' (HCP Rheumatology). We also identified explicit boundaries defined by health discipline. Specifically, we noted that digital contact is routinely established in mental health settings.

Correlatively, we examined how clinicians, who took part in the LYNC study, balance the risks when adopting digital communications in their clinical practice. Adoption of digital communications in clinical practice that is outside of the organisational constructs (policies, standard operating procedures, approved technologies) inherently carries an element of personal and professional risk for the clinician. Clinicians are balancing this risk with the value to patient care added from the adoption of such technologies:

> At the end of the day from my point of view is the patient care is what I'm most interested in, and if not completely following guidelines is required to do that then, you know, yes there are occasions where I would do that. You know, if we had other systems in place which were more robust and mean we follow the guidelines I'd use those. (HCP Rheumatology)

Value to patient care is often a reduction of risk for the patient (such as preventing an escalation of a mental health crisis), or improved the face-to-face relationship:

> Email is so much more efficient, you end up knowing the patients so well by the time they come for follow-up, that you can ask more direct questions about what has been going on with their lives, why their blood pressure is consistently up, etc.[18]

Clinicians who are adopting digital communication technologies against guidelines take on the additional role of intrapreneurs in their organisations.

The above analysis raises questions about the impact of digital communications on the workload and workflow of patients and clinicians. How do we

use our digital identity/identities to manage workload (e.g. slow/rapid responder) or expectations (e.g. young person who never answers his phone when the nurse rings/or reverse patient inundates nurse with calls)? Are we perceived differently by different audiences? Although literature suggests that clinicians feel 'on duty' more of the time,[18] the measurable impact on workload is not clear, and very little evidence has focused on the patients' workload.

Impact of increased access to healthcare

In order to identify what the impact/outcomes are on patient wellbeing when access to healthcare is improved via digital consulting, we focused on finding evidence of patient activation (the patient doing something or positively desiring to do something to manage their health), wellbeing (how it makes them feel), quality of life (wider life impacts determined in some way by access to care) and therapeutic alliance (reciprocal trust, respect and equality at an adult level).

In the identified literature, only one study examined patient activation, and no significant effect was found of access to the patient portal.[23] However, we did identify patient activation in the LYNC data. An example was found in the transcript of the young person under mental health care. This excerpt describes how the patient proactively use the telephone support line to try to protect themselves from harm:

> Well, we have this thing called DBT [dialectical behaviour therapy] phone support and we have to do it before something happens, like if were like self-harming or whatever. Like, if we have urges to do that, we would use phone support and it will...they will tell us skills that we can use and they'll ring us back later in the day to find out. (YP Mental health).

Instances of wellbeing being improved as a result of digital consulting were found in all LYNC transcripts analysed. The immediate response provided by HCPs was particularly useful in protecting wellbeing during mental health crises:

> If you put yourself in a dangerous situation, like overdosing or something, and you rang them about it and you tell them this has happened, they'll ring the ambulance immediately. And it makes you quite annoyed at that moment in time, but then when you've, like, sort of realised after that they've done it because they care, to be honest. (YP Mental health).

In the literature we reviewed, patient wellbeing was examined in terms of clinical outcomes and the reported impact of the interventions on patients.

Using standardised measures, significant improvement was seen in depression[22,26] following increased access to healthcare. However, there were mixed results in terms of anxiety in the same studies. Blood glucose (haemoglobin A1c (HbA1c)) was examined as an outcome in two articles. Again, there was a mixed picture, with no significant difference reported in one[22] and a significant reduction found in another.[30] In terms of intervention impact, it was found that increasing patient access to psychological therapies (IAPT),[27] by allowing them to decide on the venue, dates, times and content session, gave patients a sense of control and empowerment. Patients were subsequently motivated to complete the programme, and engage with 'homework' activities in between the sessions. Access to a virtual clinic was found to be reassuring to people, although it had little impact on diabetes self-management.[24,25] Similarly, after an intervention in which diabetes patients could securely message/email their clinician, most participants felt the intervention increased their health awareness, and helped them to become more focused and accountable to themselves in self-managing their diabetes.[21]

In the literature we examined, there were mixed findings in terms of the impact of increased access to healthcare on patients' quality of life (QoL). One study found a significant improvement,[30] while two found no significant change.[28,29] In the LYNC data, it was not clear how increased access to healthcare was impacting patients' QoL. We also realised that the term itself was amenable to different interpretations. These discrepancies reflect the multifaceted nature of the construct and suggest that further research into the impact of digital consulting on patients' QoL is needed as well as on what is meant by QoL in the first place.

Only one study from the included literature examined therapeutic alliance.[31] No differences were found in therapeutic alliance between 'chronically homeless' clients and their mental health/substance abuse provider when a control group was compared to a group receiving comprehensive housing and healthcare. In contrast, there was most evidence of therapeutic alliance within the sample of LYNC interview transcripts, and it is here that the biggest changes in the nature of being a patient and health professional are potentially apparent. What we deduced from the LYNC data is that frequent communication means that the patient must quickly evaluate the success of advice provided, rather than trialling a therapy over a long time period or waiting for alternative guidance at a face-to-face appointment. For example, one patient discussed how digital communication enables timely contact with their clinician:

> Skills...they tell us to go away and use them, and then, like, they'll either ring me back later or I'll ring them back later, like say half an hour, and then I'll tell them whether the skill has worked or not. And if they didn't they would give me more, and stuff. (YP Mental health).

Digital communication, then, facilitates (or requires) patients to be proactive in rapidly evaluating the state of their own health, a very different role to the one they have traditionally held as passive recipients of care. One mental health HCP discussed the use of text messaging instead of telephone calls and compared using the medium with known patients and those new to them. This health professional must evaluate different digital communication channels and decide what is appropriate for specific patients in their specific circumstances. This evaluation is an added dimension to the nature of their role.

> Respondent: You can't ever be 100% sure what they're trying to communicate, so you're like...it's quite hard to gauge...obviously if you're trying to assess their mental health it's quite hard to sometimes 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. So yeah it can be quite difficult.
>
> Interviewer: And how concerned are you about those sorts of issues?
>
> Respondent: It is quite concerning, again especially with the...at least for my young people, I know them, so it's not too bad, but with the young people that we work with mainly out of hours and at the weekends we don't know these young people, we've never met them before, so it can be quite concerning. And if they just text back saying 'I'm fine' how do we really know that they're fine because we haven't spoken to them? (HCP Mental health)

This analysis raises several questions: is it possible to have therapeutic alliance in a crisis or on-call team? Does therapeutic alliance only work when there is a pre-existing relationship (or trust) between HCP and patient? Is it one-sided? Is the patient the primary beneficiary of the therapeutic alliance, and if so, what about the clinician? Is it possible to have a therapeutic alliance between a patient and the whole team? These are important questions that warrant further research.

Vulnerabilities

This section focuses on the shifting roles and responsibilities among actors involved in digital consulting. In our content and thematic analyses of relevant literature and LYNC transcripts, we identified four themes: the persistence of embodiment; confidentiality and security; connectedness/anonymity/efficiency; and new responsibilities.

Embodiment persists. The identities and roles of 'healthcare professional' and 'patient' are defined by the consultation that occurs between the two. According to Atherton and Ziebland,[33] the clinician's identity is entwined in the face-to-face consultation, and this is where they demonstrate their professional knowledge and clinical skills. This, then, is where care is 'performed'. Engaging in healthcare via different communication channels will inevitably change some aspect of this performance[33,34] and consequently the clinician identity. One study from the literature that we reviewed compared patient and clinician communication styles in face-to-face and telemedicine consultations.[34] The study found that during the telemedicine consultations, clinicians were more likely to dominate the dialogue, and both clinicians and patients were more likely to address biomedical topics, while discussion around psychosocial and lifestyle issues (topics associated with a patient-centred style of communication) was limited. This style of communication was described by some primary care clinicians to be a result of the physical distance from the patient;[35] when conducting video consultations, the clinicians were often exposed to an image of a distressed patient but could not reach out in ways that would normally be considered appropriate. The canonical view among historians of medicine has been that medical technologies have amplified practitioner expertise over the 20th century, by distancing the work of medicine, which technologies render as the analysis of data, from the reports of the patient's embodied experience of symptoms.[36,37] Contemporary HCPs, invested in a notion of healthcare as critically centred on the clinician-patient relationship, have understood this view as more significant for the distancing of clinician from their patient than it is for its suggestion that the disappearance of the embodied patient was the necessary cost of increased expertise.[38] They have thus worried that medicine has become depersonalised as a result.[39] In the LYNC study, clinicians were concerned whether assessments could be made accurately without the added cues of tone of voice or body language. Clinicians need, as such, to develop new skills and adapt the way in which they work in order to successfully utilise digital consulting, which will result in changes to the nature of their role.

Contrary to general intuition that physicality is sidestepped by the digital, embodiment persists in digital communications. Embodiment makes itself evident in at least two ways: first, digital consulting does not

remove physicality of health experiences, and the embodied experience of symptoms; second, digital technologies take place in embodied spaces which are separate from each other (i.e. in the home, etc.). For example, one young patient from the LYNC study who suffers from inflammatory bowel disease (IBD) described the experience of the disease and the pain in its physical expression. The pain takes up her body and determines what movements are (im)possible: 'when it's when I'm in a bad state I physically cannot just . . . any extra movement, even picking up my phone I just avoid that because any extra movement does really incur a lot of pain' (YP IBD). The physicality of mobile devices, their material presence, allows (or prevents) patient's agency in physical spaces. Communication between patient and clinician is permitted in any setting 'I just texted him and I'm in the shopping mall actually right now . . . asking him for information' (YP Sickle cell). Being in another physical space not designed for health could change or normalise the relationship between practitioner and patient. Both of these examples of embodiment point to the way in which digital communication shifts how embodiment is manifested, but it does not erase embodiment altogether, which, in these cases, is not predicated on technology in the first place. This might indicate that there is often a misunderstanding of the impact of technology in a general way when one automatically assumes that technology is in tension with embodiment.

Confidentiality and security. There is a reconsideration of the term 'confidentiality' in the context of digital health communication. Practitioners in particular are considering what value it holds, for whom and whether confidentiality concerns must be different for digital communications such as Skype, email and text message compared with 'traditional' communication such as fax, telephone and letter:

> Email is not very secure at all . . . I will say to the patient up front 'this is not confidential, do you agree for me sending your patient-sensitive data across email, you have to know that it can be looked at by somebody who can do whatever they want with it and I'm not responsible for that. If you want to use this method, it's quick and easy but the cost is that it's not confidential for you'. So that's fine if they agree to that. It's their data, they're the person, it's their illness, their information . . . it's not mine, so if they choose that it can be shared in that way, it's up to them what they take as a risk or a benefit and that their choice . . . if somebody says they are worried I'll just say 'well, you can wait for your letter or you can call in via the secretary'. But again a letter is not confidential, it can go to the

wrong address, a telephone call can be answered by the wrong person . . . so none of the current methods are confidential either . . . we are just old fashioned when we think that. (HCP Sickle cell)

In the above quotation from the LYNC study, the clinician highlights the tension between communication that is 'quick and easy' and that which is confidential. Over the 20th century, confidentiality has evolved to become a fundamental trait to the 'health professional' identity. The introduction of digital communication has prompted a debate about priorities, and this identity may shift again as a result. As digital communications are used more frequently in healthcare we could, for example, imagine a shift away from the value of confidentiality and toward the value of immediacy: a trade-off already implicitly underway in other areas of digital communications. The security of digital communications is a common and predictable concern, but our interest here is less about whether or not something is secure, but whether or not and how that security matters. This possibly redefines what we mean by confidentiality, how it can be ensured, whether it is more important than instantaneous access. This also highlights that digital technology is not different, but rather on a continuum with letters, faxes and more traditional forms of communication.

Highlighting the shifting value of confidentiality is the way in which digital communications can provide a new kind of anonymity. One young person from the LYNC study felt that the anonymity of the Internet is far more desirable than the personal encounter with a practitioner. Confidentiality and security were not mentioned:

> I was 16, an adolescent male, it's really hard to say something like 'yes I want to be a woman' . . . I just feel like it's far more easier to type a message with some level of anonymity to a professional online. (YP Sexual health)

Confidentiality, and the impact that digital communication may have upon it, could then be context-dependent. Health professionals working in different disciplines, and patients with different conditions, might hold different priorities with regards to confidentiality. Therefore, the potential impact of digital communication is not unilateral.

More connection. In the LYNC study, there was discussion among health professionals as to whether digital communications increased the connection with their patients, or the distance:

A better relationship...it's closer and they see me more as a person rather than the doctor up there in the ivory tower...yes, closer and better and more normal and more human. (HCP Sickle cell)

Before the patients would like to...see people, and chat over the telephone, and, you know, we knew details of their personal life that I really wish I didn't know! ...The email stuff is more direct and that's what I mean. It's a little less personal. (HCP IBD)

Connectedness or empathy and distance or anonymity seem stark opposites, yet both sickle cell and IBD practitioners see their different approaches to digital communication as appropriate for the task of making practice more effective and efficient. This raises questions about which form of efficiency/effectiveness will win out, which types of technologies are flexible enough to accommodate multiple circulating visions of more effective/efficient futures, and how these changes will change the nature of being a health professional and patient.

Use patterns (i.e. how people use the technologies) matter, especially insofar as the embodied, culturally embedded selves that use these technologies create their own value.[40] Both practitioners and patients will transform the technology into what they need it to be; for one practitioner, anonymity, for another, connectedness, for some patients, also anonymity, for others convenience. This is facilitated now by the system's lack of fixity: it has not yet been adopted wholesale and policies around it are still unclear. However, within a system like the NHS, this kind of impromptu and organic use is likely to fall away in favour of one, systemic, mandated fix. How do we build a system with flexibility or, instead, how do we choose which uses are more meaningful, effective, efficient and ethical?

New responsibilities. In the LYNC study, patients tend to see emails as a way to obtain 'more appropriate' and 'more useful' responses from HCPs because they believe that HCP emails are monitored. In this sense, the email medium makes HCP more accountable for what they say and for this reason more detailed in their responses. Professional responsibility is based in the model of informed consent, where risks are described before responsibility passes to patient. This model was seen in the discussion of the risks of digital communication between clinician and patient:

I think it's up to them, I put the decision with them...my responsibility as a professional, as long as I explain those risks to them before I use it, if they are well aware of the risk, well, then the balls in their court. (HCP Sickle cell)

According to this HCP, once patients are informed about the risks of sharing their medical information, they have all the tools to decide what they want to keep confidential and what they want to share. They should be able to weigh risks and benefits based on their priorities and values. This choice-model has been critically compared to a care-model by Annemarie Mol.[41] The philosopher/anthropologist explains how the liberal logic of providing patients with information in order to enable them to choose their medical treatment ('empowerment') often raises anxiety and uncertainty for patients who would prefer to feel cared for and guided rather than informed and 'freed'. At the same time, this model reduces the paternalism in traditional doctor-patient relationship and humanises the relationship.

The discussion of 'empowerment' versus 'abandonment' has been addressed in the literature we examined. Telehealthcare is theorised to revolutionise medicine, as it provides patients with opportunities to monitor and manage their own health.[39] Indeed some systematic reviews have highlighted how patients feel 'empowered' as a result of digital communication systems.[42] However, other discussions have criticised this view, since digital consultations and remote healthcare demand patients to participate and take responsibility for their health, in ways in which they are unable or uncomfortable.[43] Hampshire et al.[44] discuss the need for a person to have 'digital capital' (appropriate resources, social networks and skills) in order to access digitally-mediated healthcare. For those who lack digital capital, 'empowerment' may feel much like abandonment.[43] The nature of being a patient can fundamentally change as a result of the introduction of digital communications. However, the shape of this change will vary individually; do patients become empowered or abandoned?

Conclusion

Our collaborative project has produced interesting reflections and questions around the conflicts and constraints in the construction of digital patients and digital clinicians, and the philosophical, social and historical changes associated with this shift towards digital consulting. By drawing on the LYNC study and relevant existing literature, we highlighted some of the competing ways in which issues of workload, confidentiality, empathy, empowerment/power, efficiency and mutual responsibilities are reframed in the context of digital consulting. There is evidence that digital technologies change the nature of a medical consultation[34,35] and with it the identities and the roles of clinicians and patients.[33] Inevitably, digital technologies also redefine traditional concepts of medical

ethics,[45] raising the question as to whether established discourses of bioethics are too limited, especially vis-à-vis doctor-patient relationships. With the changes wrought by digital technologies, are we not seeing something new, but merely a more visible manifestation of how these relationships already function? If this is the case, there is a kind of organicity built into digital communications now in healthcare that could be lost if the controls put on by the NHS are too rigid.

Admittedly, our study is limited in a number of ways. First, our analysis is based on a subset of LYNC interviews and the data was not collected specifically for the research questions underpinning our project. Second, we conducted rapid literature reviews, so some evidence will have been missed. These limitations are due to the nature of our project, timeframe and capacity. Despite these limitations, we were able to generate new findings derived from the data we had available. This helped us raise pertinent questions about how digital consulting reshapes the relationship between patient and health professional, and with it their identities, responsibilities and roles, issues that certainly warrant further research and exploration.

Reflecting on our collaboration, we found that there were both benefits and challenges of integrating multidisciplinary perspectives during our exploration of the role and responsibilities of technology and human agents in digital consulting. Different understandings of concepts and terms created confusion at times. For example, Risling et al.[46] highlighted a lack of conceptual clarity in patient empowerment research, and we certainly experienced this. The term 'empowerment' is used interchangeably, or conflated with 'engagement' or 'activation'. There is criticism of the term altogether with suggestions that, even within a model of patient choice, patients have extremely limited power within the healthcare context and a more complex debate is needed as to the meaning of the term 'power' and the ways in which it is enacted/constructed.[47] Nevertheless, for us, the lack of 'common' understanding, at times, became also a source of new ideas and fruitful discussions, enriched by the different perspectives, theories and concepts brought by people of different disciplines and backgrounds. As such, we believe that the development of digital consulting in healthcare would strongly benefit from further multidisciplinary research. This is becoming all the more urgent during the current Covid-19 pandemic which, as seen in recent months, has forced many healthcare-related processes and operations to quickly move online, including consulting. In this study, we provided some useful signposts for future exploration and engagement.

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References

1. NHS Digital. *Information and technology for better care. Health and social care information strategy 2015–20.* https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/our-strategy (accessed September 2017).
2. NHS England. *The NHS long term plan.* 2019. https://www.longtermplan.nhs.uk/ (accessed 1 July 2019).
3. Meskó B, Drobni Z, Bényei É, et al. Digital health is a cultural transformation of traditional healthcare. *Mhealth* 2017; 3: 38.
4. Coulter A. What do patients and the public want from primary care? *BMJ* 2005; 331: 1199–1201.
5. Wensing M, Jung HP, Mainz J, et al. A systematic review of the literature on patient priorities for general practice care. 1. Description of the research domain. *Soc Sci Med* 1998; 47: 1573–1578.
6. Berg M. *Rationalizing medical work. Decision support techniques and medical practices.* Cambridge; MIT Press, 1997.
7. Berg M. Medical work and the computerbased patient record: A sociological perspective. *Methods Inf Med* 1998; 37: 294–301.
8. Kostkova P. Grand challenges in digital health. *Front Public Health* 2015; 3: 134.
9. Griffiths F, Bryce C, Cave J, et al. Timely digital patient-clinician communication in specialist clinical services for

young people: A mixed-methods study (the LYNC study). *J Med Internet Res* 2017; 19: e102.

10. Griffiths F, Armoiry X, Atherton H, et al. The role of digital communication in patient-clinician communication for NHS providers of specialist clinical services for young people (the LYNC study): A mixed methods study. *Health Serv Deliv Res* 2018; 6.

11. Dunbar RIM. Co-evolution of neocortex size, group size and language in humans. *Behav Brain Sci* 1993; 16: 681–734.

12. Lau R, Stevenson F, Ong BN, et al. Achieving change in primary care – causes of the evidence to practice gap: Systematic reviews of reviews. *Implementation Sci* 2015; 11: 40.

13. Ross J, Stevenson F, Lau R, et al. Factors that influence the implementation of e-health: A systematic review of systematic reviews (an update). *Implementation Sci* 2016; 11: 146.

14. Vaismoradi M, Jones J, Turunen H, et al. Theme development in qualitative content analysis and thematic analysis. *J Nurs Educ Pract* 2016; 6: 100–110.

15. Keplinger LE, Koopman RJ, Mehr DR, et al. Patient portal implementation. *Fam Med* 2013; 45: 335–340.

16. Kittler A, Pizziferri L, Volk L, et al. Primary care physician attitudes towards using a secure web-based portal designed to facilitate electronic communication with patients. *J Innov Health Inform* 2004; 12: 129–138.

17. Neville R, Marsden W, McCowan C, et al. A survey of GP attitudes to and experiences of email consultations. *J Innov Health Inform* 2004; 12: 201–205.

18. Patt MR, Houston TK, Jenckes MW, et al. Doctors who are using e-mail with their patients: A qualitative exploration. *J Med Internet Res* 2003; 5: e(9).

19. Neville R, Reed C, Boswell B, et al. Early experience of the use of short message service (SMS) technology in routine clinical care. *J Innov Health Inform* 2008; 16: 203–211.

20. Dixon-Woods M, Agarwal S, Jones D, et al. Synthesising qualitative and quantitative evidence: A review of possible methods. *J Health Serv Res Policy* 2005; 10: 45–53.

21. Lyles CR, Harris LT, Le T, et al. Qualitative evaluation of a mobile phone and web-based collaborative care intervention for patients with type 2 diabetes. *Diabetes Technol Ther* 2011; 13: 563–569.

22. Pfeiffer PN, Henry J, Ganoczy D, et al. Pilot study of psychotherapeutic text messaging for depression. *J Telemed Telecare* 2017; 23: 665–672.

23. Riippa I, Linna M and Rönkkö I. The effect of a patient portal with electronic messaging on patient activation among chronically ill patients: Controlled before-and-after study. *J Med Internet Res* 2014; 16: e257.

24. Jennings A, Powell J, Armstrong N, et al. A virtual clinic for diabetes self-management: Pilot study. *J Med Internet Res* 2009; 11: e10.

25. Powell J, Jennings A, Armstrong N, et al. Pilot study of a virtual diabetes clinic: Satisfaction and usability. *J Telemed Telecare* 2009; 15: 150–152.

26. Hartley SE. Service users' perceptions of an outreach wellbeing service: A social enterprise for promoting mental health. *Community Ment Health J* 2017; 53: 842–851.

27. Lwembe S, Green SA, Chigwende J, et al. Co-production as an approach to developing stakeholder partnerships to reduce mental health inequalities: An evaluation of a pilot service. *Prim Health Care Res Dev* 2017; 18: 14–23.

28. Weinberger M, Kirkman MS, Samsa GP, et al. A nurse-coordinated intervention for primary care patients with non-insulin-dependent diabetes mellitus. *J Gen Intern Med* 1995; 10: 59–66.

29. Weinberger M, Oddone EZ and Henderson WG. Does increased access to primary care reduce hospital readmissions? *N Engl J Med* 1996; 334: 1441–1447.

30. Kane EP, Collinsworth AW, Schmidt KL, et al. Improving diabetes care and outcomes with community health workers. *Fam Pract* 2016; 33: 523–528.

31. Mares AS and Rosenheck RA. A comparison of treatment outcomes among chronically homelessness adults receiving comprehensive housing and health care services versus usual local care. *Adm Policy Ment Health* 2011; 38: 459–475.

32. Dunbar RI, Arnaboldi V, Conti M, et al. The structure of online social networks mirrors those in the offline world. *Soc Networks* 2015; 43: 39–47.

33. Atherton H and Ziebland S. What do we need to consider when planning, implementing and researching the use of alternatives to face-to-face consultations in primary healthcare? *Digit Health* 2016; 2: 1–13.

34. Agha Z, Roter DL and Schapira RM. An evaluation of patient-physician communication style during telemedicine consultations. *J Med Internet Res* 2009; 11: e(36).

35. May C, Gask L, Atkinson T, et al. Resisting and promoting new technologies in clinical practice: The case of telepsychiatry. *Soc Sci Med* 2001; 52: 1889–1901.

36. Howell J. *Technology in the hospital: Transforming patient care in the early twentieth century*. Baltimore USA: JHU Press, 1995.

37. Jewson ND. The disappearance of the sick-man from medical cosmology, 1770–1870. *Sociology* 1976; 10: 225–244.

38. McKinlay J and Marceau L. When there is no doctor: Reasons for the disappearance of primary care physicians in the US during the early 21st century. *Soc Sci Med* 2008; 67: 1481–1491.

39. Rubeis G, Schochow M and Steger F. Patient autonomy and quality of care in telehealthcare. *Sci Eng Ethics* 2018; 24: 93–107.

40. Cowan RS. The consumption junction: A proposal for research strategies in the sociology of technology. In: Bijker WE, Pinch T and Hughes TP (eds). *The social construction of technological systems: New directions in the sociology and history of technology*. Cambridge: MIT Press 1987, pp.253–272.

41. Mol A. *The logic of care: Health and the problem of patient choice*. London: Routledge 2008.

42. Rouleau G, Gagnon MP, Côté J, et al. Impact of information and communication technologies on nursing care: Results of an overview of systematic reviews. *J Med Internet Res* 2017; 19: e122.

43. Lucas H. New technology and illness self-management: Potential relevance for resource-poor populations in Asia. *Soc Sci Med* 2015; 145: 145–153.

44. Hampshire K, Porter G, Owusu SA, et al. Informal m-health: How are young people using mobile phones to bridge healthcare gaps in Sub-Saharan Africa? *Soc Sci Med* 2015; 142: 90–99.

45. Ignatowicz A, Slowther A-M, Elder P, et al. Ethical implications of digital communication for the patient-clinician relationship: Analysis of interviews with clinicians and young adults with long term conditions (the LYNC study). *BMC Med Ethics* 2018; 19: 11.

46. Risling T, Martinez J, Young J, et al. Evaluating patient empowerment in association with eHealth technology: Scoping review. *J Med Internet Res* 2017; 19: e329.

47. Digeser P. The fourth face of power. *J Polit* 1992; 54: 977–1007.