

# Perspective on digital communication with health professions from close supporters of young people with long-term health conditions (The LYNC Study)

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## Abstract

**Objective:** To understand the impact of digital communication using email and text between young people and their health care team on those in close supporting roles.

**Methods:** Twelve people (nine parents and three partners) of young people with long-term health conditions were interviewed between November 2014 and March 2016. Thematic analysis was performed followed Braun and Clarke's (2006) 6-phase method.

**Results:** Four main themes were identified. Close supporters felt that digital clinical communication was useful for young persons' self-management. As well as young patients, close supporters would also like to have direct access to the clinicians, but it was necessary to build up a trusting relationship between close supporters and clinicians initially. Video appointments were suggested for future digital communication technology.

**Conclusions:** Close supporters were encouraging digital communication for their young person with diabetes. Clinicians should put an emphasis on establishing trusting relationships with both young people and close supporters which would be beneficial for their digital clinical communications.

## Keywords

Chronic disease, family, qualitative research, digital health, digital communication, young people

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## Background

In recent years, there has been increasing focus on the digitalisation of the National Health Service (NHS).<sup>1</sup> The introduction of NHSmail was a part of this demand. Clinicians can access highly secure email and text messages to communicate with patients and use them to share patients' identifiable and sensitive information.<sup>2</sup>

There are many reports that young people (aged 16–24 years) with long-term health conditions can disengage from health services, resulting in poor health outcomes.<sup>3,4</sup> Digital communication such as emails, text messages and

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mobile phone calls has been increasingly used in clinical settings worldwide but the evidence of the effectiveness of digital clinical communication is equivocal.<sup>5–7</sup> In order to understand the impact of digital communication for young people and their health care team, the Long-term conditions Young people Networked Communication Study (The LYNC Study) was formed. In this study, we interviewed young patients, clinical team members and information governance specialists from National Health Service (NHS) trusts in England and Wales in order to investigate whether and how their engagement can be improved through the use of digital clinical communication. LYNC found that timely digital communication between young patients and their clinical team helped young people manage their condition.<sup>8</sup> Also a LYNC rapid review showed the use of digital clinical communication to improve families' and caregivers' involvement in the health management of children or young people.<sup>9</sup>

Parental/family involvement is important for young patients' treatment journey. Young people with long-term health conditions were often diagnosed at a young age at a time when parents are the main point of contact with the clinical team. Current guidelines also emphasise the importance of family involvement during the transition period from paediatric care to adult clinics.<sup>10,11</sup> This transition normally occurs between 16 and 18 years old and young children will transfer to adult clinic from the age of 18. The LYNC study interviewed parents and partners (spouses, and those in an intimate relationship) who supported them with their long-term health condition management. We aimed to understand that parents' and carers' views on the impact of digital communication on the young person's management of their condition and how the use of such technologies affected them in their role as carers of an individual with long-term conditions, where they may be excluded from the discussions, on those in close supporting roles. Here we present the findings from those interviews.

## Methods

### Data collection

We collected data between November 2014 and March 2016.

The inclusion criteria were the parents/carers/friends of young people (age 16–24 years) with long-term conditions (e.g. Sick cell, diabetes, liver disease, cystic fibrosis, cancer or mental health issues) within the 20 study sites across England and Wales which were identified under the following criteria: (1) the clinical team was providing specialist care for young people with long-term conditions; (2) the team was interested in the use of two-way digital communication with the young people; and (3) the long-term conditions had considerable cost implication for the

NHS. Within those sites, young people were recruited for their interviews for the main study. Where young people gave their consent, we invited parents or those identified by the young person as offering close support in relation to their condition for interview. Like the young people in the main LYNC study, these close supporters were each offered a £20 store voucher as a thank-you token. Further details of the recruitment process are described in our previous research by Griffiths et al.<sup>8</sup> Ethical approval (14/WM/0066) was obtained from National Research Ethics Service Committee West Midlands – The Black Country.

The participants could choose from three interview methods: a face-to-face interview; a phone call interview; or an email interview. This was to capture the diverse backgrounds of close supporters such as differences in age and their relationships. At the interview, we asked the close supporter of the young person about: their use of digital communication related to the person's health care; a situation where the digital clinical communication did/did not work well; and ethical and safety issues. These questions were closely aligned to those asked of the young people participants who lived with a long-term condition.

**Data management and analysis.** Interviews were audio-recorded and transcribed, and email interviews were used as they were. All identifiers were removed.

Thematic analysis was used to code all qualitative data. NVivo12 was used to store and analyse the data which followed Braun and Clarke's (2006) 6-phase method.<sup>12</sup> Firstly, the author AT read the interviews many times to familiarise herself with the data set. Then the author AT coded all the qualitative data with the deductive coding methods based on the semi-structured interviews stated above.<sup>13</sup> Within those coded data, thematic analysis was performed where all the quotations are reviewed. Similar codes were merged and some sub-themes were created. As this continued, the main features were categorised as themes. For quality control and consistency of the coding process, the author JS supervised the process. For some cases, AT and JS had discussions of merging codes. The author AT was an independent analyst who was not involved in the interviews.

## Results

Thirteen close supporters were recruited. One person withdrew before the interview process. Therefore, a total of 12 close supporters (nine parents and three partners) were interviewed and included in the analysis. The young people were living with 1 or more of 10 long-term conditions. Interviews were undertaken face-to-face ( $n=7$ ), by email ( $n=3$ ) or by phone ( $n=2$ ). Informed consent was obtained before the interview which was either audio recorded (face-face and phone interviews) or written

**Table 1.** Demographics.

Study number	Age	Relationship	Participants' occupation	Use of digital communication with clinical team	Young person's current age	Type of interview
Liver Parent 01	Not recorded	Parent	Teaching assistant	Email with consultant phone with diabetes nurse	19	Face-to-face
Liver Parent 02	56	Parent	Physiotherapist	Direct phone number given	24	Face-to-face
Cancer 1 Partner 01	19	Intimate relationship	Student	No direct contact details given	Not recorded	Email
Cancer 1 Partner 03	21	Intimate relationship	Student	No contact as the young person does everything	24	Email
Cancer 1 Parent 05	56	Parent	Healthcare assistant	Phone number given (called nurse)	Not recorded	Face-to-face
HIV Partner 01	29	Spouse	Part time student/work at school	Phone, email, texts	24	Face-to-face
Dermatology Parent 01	46	Parent	Babysitter	No direct contact details given	Not recorded	Email
Mental health 2 (CAMHS) Parent 01	49	Parent	Teaching assistant	Phone call to secretary	17	Face-to-face
Arthritis Parent 01	Not recorded	Parent	Carer for her husband	Direct phone call (secretary and nurse), not yet email	23	Face-to-face
Arthritis Parent 02	Not recorded	Parent	Full time worker	No direct contact details given	17	Phone
Cystic fibrosis parent 01	Not recorded	Parent	Teaching assistant	Direct phone call to nurses	Not recorded	Face-to-face
Kidney Parent 01	Not recorded	Parent	Part-time worker	Know phone number, but has not used	17	Phone

(email interview). The demographics of the participants are shown in Table 1.

Four themes are identified: digital communication with clinical team; close supporters' role; issues and concerns of digital communication; and digital communication technology they would like to use. Figure 1 shows the coding framework developed and the resulting themes.

*Theme 1: Digital communication with the clinical team*

Sub-theme 1-1: Young person's digital communication experience

Parents recognised that digital communication is part of their children's lives and children are more comfortable

using digital communication than they are. All close supporters were aware that their young people with long-term health conditions used digital clinical communication with their clinicians.

Whether or not close supporters know about the content, they are happy and comfortable that young people contact the clinicians directly and get responses in a timely manner. Close supporters said that young people used digital clinical communication when their condition changes (e.g. blood glucose monitoring), asking questions about their disease, asking for new medication/equipment, and requesting extra appointments.

Close supporters feel that quickly accessible digital communication with clinicians works well for the young patients for self-management.

I know she was very pleased once she started on the pump and she was testing it over a weekend, and the Diabetes Nurse Specialist was on text all weekend if she had a problem, so when she had a problem, she just text and said 'what about this, I've got this reading, what's that?' and she was getting texts straight back (Liver Parent 01, daughter 19 yrs)

#### Sub-theme 1-2: Preferred methods of communication tool

Most of the close supporters valued their use of email. An email was described as quick, easy and a better way to communicate with clinicians compared to phone calls.

Close supporters used emails to ask questions which are relatively long, complex, formal and non-urgent, while text messages were used for short and quick questions. Text messages were also received for appointment reminders. Some participants worried about the misinterpretation of text messages compared to phone calls. Emails and text messages are both used for timely medical advice where the issue is not urgent enough to need face-to-face appointments, yet the condition is not stable so that they need constant medical advice.

If you think, oh I've got another month and a half to wait before the appointment, so if I can just ask a general question. Whereas you can just ask a general question and get a reply back, and say look, my daughter's knee is sore, so is there any way, can she up the Paracetamol to two a day or something, and things like that. (Arthritis Parent 01, young person 23 yrs)

Close supporters report that contacting clinicians between appointments is very attractive, however, they also report that digital communication can be impersonal as it is not face-to-face.

I think digital communication technologies makes everything easier because for example you don't have to call to make an appointment. You can just email to get one, and that way you save time because you do not have to stay in line on the phone, or have to wait to call at a certain hour when the lines are not busy. You can also go straight to the problem if there is one and that way you reach a solution faster. (Cancer 1 Partner 03, young person 24 yrs)

On the other hand, the telephone was a preferred method of communication for some parents. They preferred the telephone as they get an answer straight away, rather than needing a few emails, meaning that overall the communication took less time. Some close supporters were given direct phone numbers with their clinical team where they could

call anytime. Those who used this service felt that the service worked well for them. One parent was comfortable leaving messages on an answering machine and getting a call back within one day.

You just get advice straight away. (Cystic fibrosis parent 01, young person's age unknown)

One parent suggested that face-to-face consulting was the preferred way to communicate with the clinical team. The reasons were: they preferred nonverbal communication, such as seeing facial expressions; they felt able to explain the situation better; and it is more personal.

Overall, close supporters are comfortable using text messages, email, and the telephone to talk about health issues.

It was mentioned that it is important to build up personal relationships prior to any digital communication.

you're there as the parent, you build up a kind of personal relationship with the team anyway because you are going to the appointments and I think that's why the technology would have worked. I don't think I would have done it with a clinician I hadn't met. (Liver Parent 01, young person 19yrs)

### *Theme 2: Close supporters' role*

#### Sub-theme 2-1: Parental support

Nine interviewees were parents of young people. Most of the young people had been diagnosed at a young age (6 months to 11 years old) where parents had the main responsibility for the patients' condition management. Parents arranged the appointments, took them to the hospital, and attended the appointments together. However, most of the parents expressed that as their children got older (to around 16 years old and over), they tried to give their children an opportunity to manage their conditions by themselves. This is also the time when young people are transferred from paediatric to adult services. Parents reported their children arranged and attended appointments alone and had private conversations with their clinicians.

Although parents are happy to leave their children to self-manage their long-term conditions, some would still like to be informed about treatment updates. Parents were concerned with the balance between their children's independence and their privacy, but they stated that these feelings should reduce as they get older.

I think as a parent, to be able to have an avenue to access support and help around it would also be really constructive. (Kidney Parent 01, young person 17 yrs)

Parents also took a role in gathering information about their child's conditions through the internet, especially at the time of diagnosis. The choice of the website included condition-specific websites such as the Arthritis

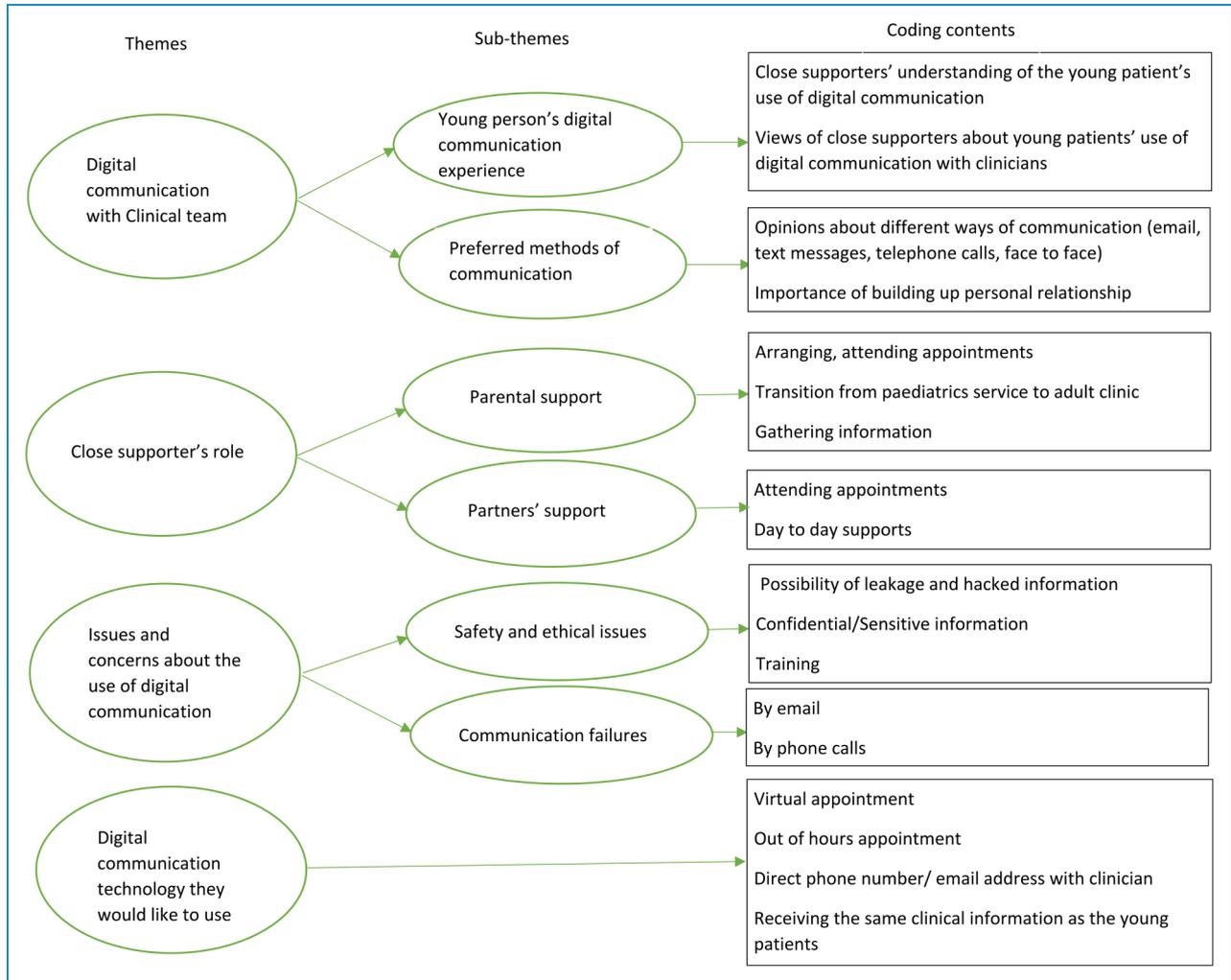


Figure 1. The coding framework developed and the resulting themes.

Association, health pages and forums, and the NHS website. Some parents never carried out online research because they preferred asking clinicians directly or wanted to avoid reading alarming things about the disease which might not apply to their children.

Sub-theme 1-2: Partners' support

Three interviewees were partners (one spouse and two others were in an intimate relationship) of young people. Unlike parents, partners were more recently involved in young people's lives, as a result, their relationship with clinicians is different from parents.

One person was a spouse of someone with mental health issues and HIV where he supported most of her daily activities. In consultation with her doctor, he managed her medications, arranged and attended the appointments with the young person. He also checked her email, text messages, and video calls for her.

Two interviewees were in a relationship with a young person they supported. Although both of them attended appointments, they did not have direct contact with

clinicians. However, they were aware that young people with long-term conditions used digital communication with the clinical team. One partner stated that the current situation in terms of digital communication between the young person and clinician is satisfactory as the young person shared any medical updates. However, they reported that direct contact with clinicians would be useful where their partner was unable to contact clinicians by themselves. The other mentioned that privacy should be respected, but would be very happy to be involved in their care with their consent.

Everyone has the right to privacy and it is very important and therefore his right to privacy means quite a lot to me as if he wanted to express his feelings and tell something to me that he hasn't told anyone or believes that I should know he will. (Cancer 1 Partner 01, young person's age unknown)

Overall, partners had quite different views as to how they wanted to be involved in the young person's treatment, compared with parents, though both of the groups stated that direct contact with clinicians would be useful.

*Theme 3: Issues and concerns about the use of digital communication*

Sub-theme 3-1: Safety and ethical issues

All of the close supporters ( $n = 12$ ) held perspectives about safety and ethical issues and varied in their levels of concern.

Most of the close supporters were aware of safety and security issues about digital communication generally. They especially thought that special care needs to be taken when dealing with personal information on social media such as Facebook. When it comes to using technology with clinical teams, they feared that information might be hacked by a third person or leaked such as an email going to the wrong person. In order to prevent this, removing patient identifiable information and good record keeping within the NHS trust was suggested by some close supporters.

if you've got patient's notes, you wouldn't leave them sitting in the waiting room where everyone can see them, you'd have them in a room, it would be locked when someone left, probably in a drawer that was locked, you know, it's the same ... looking after that information should be the same as confidential notes of any type and if they're printed off, they shouldn't be left lying around. On a computer, I guess you would need a password to get in to any of these files, they should be secure. (Liver Parent 02, young person 24 yrs)

However, some close supporters did not have any concerns as they thought that security is up to date, and the information will be seen by limited people who are supposed to have access. They trusted their clinicians would not send confidential and sensitive information via email/text message.

Close supporters considered confidential and sensitive information to be the names of certain conditions (e.g. mental health, life-threatening diseases such as AIDS, and Sexually Transmitted Diseases) and personal identifiable information such as names, dates of birth and addresses.

Although close supporters have some concerns about the use of technology, they did not consider that training for clinicians and patients was necessary. The reasons were: clinicians know about using the technology safely; and young people know how to use technology already and it would be sufficient to receive a leaflet.

Sub-theme 3-2: Communication failures

There were a few reports where close supporters experienced communication failures.

By email, a communication failure occurred when an email was not picked up by a clinician (or their colleagues)

when they were away and not until the clinician came back to work. The close supporter (HIV Partner 01) who reported this understood that this would have happened because most of the time emails can only be accessed by the addressed person within the hospital trust network. Therefore, extra time to get a response was anticipated.

So like I work in a school so I can access my emails at my school, I can only access them there. (HIV Partner 01, young person 24 yrs)

More generally, close supporters expected to get a reply either immediately or during the following week, depending on the question. While by phone calls, close supporters reported that communication failure included messages that did not get passed on, where they could not get hold of the person, or where the call was not picked up by the clinical team. Parents reported that they had often failed to contact their clinicians via the hospital telephone number.

*Theme 4: Digital communication technology they would like to use*

There are a few suggestions about the future of digital communication in delivering clinical care.

Virtual (skype) appointments were mentioned by four close supporters. It was thought to be useful for people generally who have difficulty going out from the house, such as those who have difficulty walking or who have mental health issues. Also, virtual appointments would be easier than attending in person and saving travel time. It would also be better to see the problem rather than describing the issues over the phone, which would be useful for minor issues, and would have very positive implications for the hospital environment itself with fewer people coming on site.

That would be brill because when you are well we wouldn't have to come down, we could do like a virtual clinic, that would be great. (Cystic fibrosis parent 01, young person's age unknown)

A partner (HIV Partner 01) said that out-of-hours contact (after 5 p.m.) would be useful for mental health conditions.

Close supporters who did not use digital clinical communication because they have not been given telephone numbers or email addresses for their clinician stated that they would like to have direct contact with the clinician. Parents felt this was especially important at the time when their child was diagnosed.

Close supporters would particularly like to be able to access the patient's clinical team, where the patient was unable to make contact themselves. Parents would also like to know what is going on with their children even after their children have moved to adult clinics. It would be valuable for the parents to receive the same information

as the young patients receive, such as appointment reminders and clinical updates, to support them.

Other suggestions included an automated message to say that the relevant clinician had received an email, and a patient-led patient's forum to exchange ideas about their treatment experience.

## Discussion

### Main findings

Digital communication is valued by close supporters of young people, but it is necessary first to build up relationships with the clinicians. Parents are happy that their children, who have reached around 16 years old and over, use digital communication with their clinicians and start to manage their conditions independently. Although close supporters respect the young people's privacy, a system to access the clinicians directly or clinical updates would be useful. Some close supporters were aware of security issues and had concerns about the inclusion of confidential information within digital communication, but most of them agreed that special training was not necessary. Parents reported digital communication would have been useful when the young people were diagnosed when the patients' condition was unstable, and during the transition period from paediatric to adult clinics. In the future, many reported that virtual appointments would be useful.

### Strengths and limitations

To our knowledge, this is the first study of its type that has qualitatively explored the experiences of parents'/partners of young patients aged 16 to 24 in using digital communication with clinical teams.

Age, parents' ethnicity, socio-economic status and levels of education affect the level of information required by parents and young people.<sup>14</sup> In our study, we have recruited a diverse population in terms of their age and relationship to the young people. However, the participants' educational levels were not representative of the general population. The educational level of our sample population was skewed as six people out of 12 worked in the educational or health industry, meaning they might be more willing to discuss their experience and be more aware of security and ethical issues.

We were not able to independently recruit close supporters of our young people LYNC participants and only invited them to participate where the young person gave consent. This likely reflected the nature of the relationships between the young person and their carer and in most cases their parent, which might not be representative of the majority of such relationships.

The coding analysis was carried out by one independent researcher who was not involved in the interview procedure

(AT), although the coding analysis was reviewed by another researcher (JS).

**Comparison with prior work.** Many studies report a positive experience of using digital interventions such as eHealth, telehealth, mobile apps and digital communication.<sup>15–19</sup> We found that close supporters of young people also appreciated direct access to the clinical team especially when the young people were newly diagnosed, the patients' condition was unstable, and during the transition period from paediatric to adult clinics. These results replicate the views of young patients previously reported.<sup>6,8</sup> In addition, a study by Armoiry<sup>9</sup> reports that the use of digital communication improves families' involvement in the health management of children or young people. Our sample population involved carers who were already significantly involved in the young patients' health.

In our sample, all of the close supporters interviewed stated that they would like to know about the patients' condition and receive medical updates irrespective of their relationship to the patients (parents, spouse and in a relationship).

In England and Wales, parents have access to their children's medical records until the age of 18.<sup>20</sup> Guidelines for doctors state 'You should let parents access their child's medical records if the child or young person consents, or lacks capacity, and it does not go against the child's best interests'.<sup>21</sup> There is not right for anyone to access medical information without consent once a young person reaches 18. However, the results from our study suggest that clinicians could consider sharing information with parents/carers if they have the young person's consent. It has also been reported from the educational sector that about 80% of university students support their university contacting their guardians in respect of mental health issues.<sup>22</sup>

The digitalisation of the NHS service is an urgent topic. The Information Governance team at NHS England published guidance for the use of email and text messages with patients and service users.<sup>23</sup> This guidance states that clinicians should agree with patients about the use of email/text messages including what information may be sent, who it can be shared with, and possible security issues. Written informed consent was recommended, but most of the clinicians in the main LYNC study were not aware of policies about digital communication.<sup>8</sup>

The guidance suggests using a generic team email address and not to give clinicians individual email addresses. However, in the LYNC study, some of the young people and close supporters were given clinicians' staff email addresses and numbers. Young people and close supporters emphasised the importance of building up trusting relationships in order to use digital clinical communication. It has been suggested that people feel anxious when sending an email to a generic team address because

they are not sure who will receive it and who will answer their questions.<sup>24</sup> This suggests that for the successful use of digital communication, the person sending the email should know who is likely to respond and, ideally, to have some initial face-to-face interaction with that person prior to the introduction of digital communication.<sup>25</sup>

These interviews took place before the COVID-19 pandemic. The situation has changed since the NHS has started to offer video consultations in primary and secondary care.<sup>26,27</sup> In these papers, the patients' satisfaction was high and they reported that they would like more virtual consultations in the future. However, the current view of virtual consultations is that they are not a replacement for face-to-face consultations and video consultations are not suited for all patients.<sup>27</sup> For example, people with severe conditions or comorbidities need to have an in-person full examination.<sup>28</sup> Although people are more used to digital communication in many settings, all users should be more aware of the safety and ethical issues.<sup>29</sup> Further research is needed, in particular in relation to the timing of digital consulting, safety and ethics, and sharing information. Also, it would be interesting to know if virtual consultations alone can build rapport between clinicians and service users. A study in a research setting has shown that rapport over video platforms is possible, but is assisted by initial contact in person or by email.<sup>30</sup>

## Conclusion

Circumstances and challenges differed from patient to patient. Digital communication can provide tailored advice when the young people/close supporters most need it. Clinicians should support young people's treatment journeys throughout and especially at key stages, that is, at the time of diagnosis, when their conditions are unstable, and when transitioning from paediatrics to adult services. A smooth transition to the adult clinic is a key step for patients to engage with their treatment by themselves. But first, clinicians should put an emphasis on establishing trusting relationships with both young people and close supporters which would be beneficial for their digital clinical communications.

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