

Young people's views on digital access to primary care

Scoping the evidence



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Young people's views on accessing digital primary care:

Scoping the evidence: March 2022

Executive summary

The adoption and implementation of digital access to, and delivery of, primary care services may bring particular challenges for some groups including children and young people. Hearing directly from young people about their experiences and views is critical to improving these access routes and ensuring they are youth friendly. This brief scoping review of the evidence on young people's views about digital access to primary care accompanied a series of direct engagement workshops.

There was very little directly relevant research literature on youth perspectives on digital access routes. More exists on remote consultation modalities such as telephone and video consultations, and although these studies do not tackle exactly the same thing, some generalisations can be drawn from them about how young people wish to engage and their particular concerns about online communication with healthcare professionals.

Overall, young people want choice in how they communicate with primary care services. They need to be confident about confidentiality, and can feel threatened and insecure communicating with software rather than individuals, worrying in case they 'get it wrong' or miss out something important. They request youth-friendly and easy-to-digest information.

Some groups of young people may need particular support in navigating digital access routes; these may include those with long-term conditions, those from ethnic minority groups or those who are not able to afford the fastest and most efficient digital tools. Mental health problems – common in the age group – may also add to anxiety and difficulties in navigating the system.

The paucity of research on which to draw suggested a need for more evidence specifically on the perspectives of young people specifically within the UK primary care context.

Introduction

The adoption and implementation of digital access to, and delivery of, primary care services is growing. Sometimes referred to as '[digital-first primary care](#)' this usually means a model of general practice where patients have the choice to use an online route (usually via the practice website or NHS app) to contact their practice and/or conduct their consultation remotely. This is in addition to existing telephone and in-person routes. The range of

options and descriptions of patient journeys are provided in a comprehensive NHS England and NHS Improvement implementation toolkit (Bakhai et al, 2020). During the 2020/21 Covid-19 pandemic, the pace of these changes significantly accelerated, partly to minimise direct physical contact between staff and patients.

Although this is broadly welcomed as a way of improving efficiency and flexibility, and of increasing access, it may also bring particular challenges for some groups including children and young people. Hearing directly from young people about their experiences and views is critical to improving these access routes and ensuring they are youth friendly.

In order to inform service development in this area, the Association for Young People's Health (AYPH) was commissioned by NHS England and NHS Improvement to conduct a brief scoping review of the evidence on young people's views about digital access to primary care, to accompany a series of direct engagement workshops.

Review aims and methods

The review addressed the following two key issues:

- Young people's views on what constitutes youth friendly and safe digital access routes into primary care
- Young people's views on exclusion and difficulties faced by particular subgroups of young people in accessing primary care via digital routes

We knew at the outset that there would not be a large number of (if any) directly relevant studies from the UK. We also knew that there was likely to be quite a lot of indirectly relevant material on (a) young people's experiences of digital access to other kinds of services, (b) young people's views about access to non-digital forms of primary care, or (c) the experiences of digital access across a wider age range including but not limited to young people, which all might contain some indirectly relevant perspectives.

As a result a broadly inclusive approach was taken to the review, encompassing all types of studies and grey literature including policy reports. Narrowing down studies to those that were most relevant was undertaken as a second stage. Evidence was identified through online searches and consultations with colleagues working in the field. Searches included Scopus, Healthwatch's searchable database, RCPCH&Us resources, Google and following up leads in existing papers. This was a relatively small scale scoping exercise; the results should be regarded as illustrative of the themes identified, rather than definitive.

The remit for the scoping was young people aged 10-24 years, but the majority of the research focuses on young people up to age 18. After this stage they are generally considered adults by primary care and researchers alike, and the unique perspective of 18-25 year olds (as opposed to older adults) tends to be side-lined.

There were several key sources that informed the review. The first was the recent NICE (2021) guideline on healthcare experience of children and young people. The recommendations in this guideline are relevant to this work because they are based as far as possible on evidence derived from children and young people themselves, rather than parents or healthcare professionals. The systematic reviews on which the guideline was based also only included studies representing the views of children and young people, and were reinforced by focus groups and expert opinions of young people on the guideline Committee. The guideline is not specific to primary care but – in line with AYPH’s general experience – the general principles about youth friendly access to services tend to apply across all different kinds of healthcare services.

A second key source was the 2018 review by Robards et al, on how marginalised young people access, engage with and navigate healthcare systems in the digital age. However this is not UK specific, and again is not focused solely on primary care. Finally it is also worth mentioning Holding and Maxwell (2021), who undertook a study commissioned by the Transformation Team – Public Health and Primary Care, NHS England and NHS Improvement, East of England. The overall aim of this project was to hear directly from patients about their experience of using primary care, with a particular emphasis on using digital primary care, between October 2020 and February 2021, including some 20-25 year olds (but also other patients up to age 95).

Definitional issues

The topic of ‘digital access to primary care’ raises some challenges around concepts and definitions. We have worked around these in the scoping review, pointing out inconsistencies and differences as we come across them, but they are worth noting at the outset. They include:

- ***What do we mean by digital and how broad is the definition?*** At a technical level, ‘digital’ could conceivably involve accessing a website, sending and receiving emails, telephone calls, video calls, and various forms of social media. It can also include the use of apps for self-management of long-term conditions, or of apps to enhance coping skills. It was clear from an early stage that all of these are included in different ways in the literature, and what one study means by digital may vary from what another one covers. As noted, the impetus for this piece of work was the use of software for contacting general practice – which gathers clinically relevant information upfront, supporting practices to deliver care by directing patients to the right person or service (digitally ‘enabled’ services). However there is almost no research on young people’s views of direct relevance to this. On the other hand there’s more research on views about remote consultations – such as telephone and video consultations.

- ***Does ‘access’ mean access to a consultation*** – or can it mean to healthcare information (which may pre-empt the need for direct personalised consultation with a healthcare professional)? We have assumed that access does not mean actual consultation or searching for information, but rather the general process of contacting primary care and being directed to the right ‘next step’. But again, research varies in which part of the journey through primary care it is addressing.
- ***Finally, what do we mean by primary care in this context?*** Although it is often assumed that primary care means NHS general practice, it can also include any healthcare provided in the community for people making an initial approach to a medical practitioner. The formal NHS definition also includes community pharmacy, dental, and optometry (eye health) services, as well as general practice. In addition, it could be argued that for young people this might include sexual health clinics or drop-in mental health services provided by the voluntary sector. It is important to bear this in mind as one of the consequences of any access system that involves care navigation or triage can be that patients are directed to other community services rather than being offered GP care.

Emerging themes

There was very little directly relevant research literature on youth perspectives on digital access routes. More material exists on young people’s thoughts about remote consultation modalities such as telephone and video consultations, and there is some conflation of access and consultations in some of the material. Although the research on remote consultations does not tackle exactly the same thing as digital access routes, some generalisations can be drawn from this about how young people wish to engage and their particular concerns about online communication with healthcare professionals.

Young people’s views on what constitutes youth friendly and safe digital access routes into primary care

There are no studies that we located in the UK research literature that specifically explore young people’s views about digital access to primary care, looking at the systems currently in place (such as e-Consult, Accurx or Patient Access). There are a number of studies of what young people think about remote consultations, although many of these are from the USA and northern Europe, rather than being specific to the UK primary care system, which is unique. In addition, many of the youth perspective studies draw on small samples.

With these provisos in mind, and drawing together the material available, these are the main emerging themes about what constitutes youth friendly and digitally safe access routes into primary care, with some generalisation from views about any kinds of remote communication, not just initial access or triage:

Young people want a choice and to be able to pick a preferred method of communication (NICE, 2021). As a result the NICE guideline suggested that health services should be aware that young people's preferences may vary from those of their parents or carers. The themes of flexibility and choice arise in relation to all sorts of digital resources (eg, Babbage et al (2017) in relation to digital tools for self-management; Healthwatch Central West London, 2020 on all aspects of digital information and support). As Healthwatch Cornwall (2019) reported on the basis of focus groups with young people, *"It was clear from young people in the focus groups that both online and face to face information and support have their place, and that preference for use of online tools depends on the situation."*

Concern around privacy/safe space and time. The NICE guideline recommended that when using digital or virtual methods it was important to young people to ensure they had privacy and could interact freely. For example, young adult participants can vary in their understanding of and concern about confidentiality in the context of digital communication (Ignatowicz et al, 2018), young people can have concerns about online help-seeking and anonymity and over the legal implication of help-seeking (Best et al, 2016), and young people can feel uncomfortable talking about their problem with the GP when they cannot secure a confidential space at home. In one report a participant talked about having to lock herself in the bedroom for four hours to ensure she was away from other family members when she got the call back (Holding and Maxwell 2021). In another example, Raine (2021) undertook a small piece of work looking at young people and GP access, using senior school pupils to investigate this amongst younger ones, and also reported concerns around privacy.

Concern around support. It is important to young people that others are aware that there are times when they would like the involvement of a parent or someone else and times perhaps when they do not. Any digital access needs to ensure both that they can have privacy when they want it, but can also involve others when they want to (NICE, 2021).

Concerns around confidence and knowledge gaps. In her small peer-to-peer research study, Raine (2021) reported that young people felt worried about their own knowledge gaps and also that they would not be taken seriously when getting in touch with primary care, and there are obvious implications if the approach is required to be digital. These might include, for example, a simple reluctance to even ask for help. The concern about getting things wrong may be exacerbated by digital routes where there is no person to ask for advice. Similar themes were reported by Healthwatch Central West London (2020). This is often a finding from broader studies about health information online as a whole; Nightingale et al (2017) for example commented that *"online information could be "scary," as it was either hard to understand or not relevant to the individual's circumstances."* Jamroze et al (2021) noted that young people with diabetes were worried about forgetting to highlight important issues if the consultation was online rather than in-person.

The need for appropriate and age-specific content. Again this is a broad comment emphasised in a number of studies about various aspects of online behaviour around health, over and above simply access to services. This includes Nightingale et al (2017)

again, in relation to a self-care management app and other digital resources for young people with long-term conditions young people reported avoiding things that are ‘dry’, or ‘boring’.

Being ‘digitally savvy’ is not a guarantee that digital methods will be the preferred method for young people. For example, Holding and Maxwell (2021) reported that they spoke to several young people who use digital technology for work, in their studies, and to stay in touch with friends and family, but who said they would still much prefer to talk to a GP on the phone or in person if given the choice. In a study of the consultation preferences of young people with diabetes during the pandemic, Jamroze et al (2021) noted a “technology paradox” in young people with diabetes, where the use of routine technology (internet, social media, smart phones and tablets) is high, but the use of wearable diabetes technology (insulin pumps and continuous glucose monitors) is low. It is important not to conflate the fact that young people are digital natives with a preference for digital communication or interventions. In the Jamroze study, 63% of 60 participants preferred face-to-face consultations, 15% favoured online consultations and 22% preferred telephone consultations. The preference for face-to-face consultations centred on ease of communication and comfort, and the need to build a relationship. Although these were not primary care consultations, and were about treatment and not access, the findings are consistent with other sources.

Young people’s views on exclusion and difficulties faced by particular subgroups of young people

Research has shown that certain population groups are less likely to use digital services or to be potentially disadvantaged, including individuals with disabilities, those with limited access to the internet, people from non-white ethnicities, and those who are economically disadvantaged (Holland and Saloni, 2021). There is clear evidence about the inequalities of access to healthcare for certain groups of people such as those from ethnic minorities (Kapadia et al, 2022). Young people’s understanding of and perspectives on inequalities is of growing interest (McLloyd, 2022). However, that said, the research literature specifically on what young people think about the healthcare access difficulties faced by subgroups of people of their own age is limited. Drawing on a rather varied set of papers, we identified these key themes:

Difficulties faced by young people with long term conditions. A significant proportion of young people live with long term conditions, and there are ways in which digital access may be more difficult for them but also may be easier. Research tends to centre on young people’s views about using health technologies to self-manage long-term conditions, which is rather different from accessing primary care. We did not find any studies about the views of young people with long-term conditions and digital access specifically to GPs.

In one study – again, not specific to primary care – Abrol et al (2017) explored the digital technology preferences of teenagers and young adults with cancer and concluded that digital resources had potential to improve patient experience and engagement. However, this mostly related to receiving clinical information and sharing in online groups, rather than in accessing services. In a study about a customised digital care-management app for young people with long-term conditions (UK based), the authors reported that young people expressed concerns about the understandability and relevance of online information (Nightingale et al, 2017). Again, this was not about access to treatment, but about other kinds of digital resources. A recent review of children and young people’s concerns and needs relating to their use of health technology to self-manage long-term conditions concluded that there was a distinct need for research to involve children and young people more throughout the development of technology, from identifying their unmet needs through to design and evaluation of interventions (Blower et al, 2020).

Ensuring ethnicity does not create access challenges. The recent NHS Race and Health Observatory review has highlighted the importance of ensuring health services access is equitable for people from all ethnic groups (Kapadia et al, 2022). Holding and Maxwell (2021) raise the issue of how to embed access and inclusion into the design of health service communications, systems and services, but this is not specific to young people. More young people fall into ethnic minority groupings than older adults so it could be argued that this is a particular priority. However, despite the clear importance of this topic, we did not find any studies that directly asked young people from different ethnic groups for their experiences of accessing primary care through digital routes. In terms of ethnicity and cultural barriers to accessing mental health services, Chui et al (2021) concluded that factors such as language barriers, social stigma of mental illness, imbalance of power and authority between service users and providers, and insensitivity and discrimination were all important. How these factor in to digital access systems for primary care needs to be assessed.

Challenges of those who are digitally excluded. Although there is an assumption that all young people are permanently immersed in the internet and social media, there is considerable variety of connectivity. The pandemic alerted us to the proportion of young people whose digital access (to education, for example) was limited by not having enough credit (eg, Holmes and Burgess, 2021). Again, we did not come across any research specifically reporting young people’s views on how this might affect their access to healthcare, but the NICE guidance recommendations (NICE, 2021) included the need to ensure that non-digital methods of attending appointments, communicating and providing information were available alongside digital methods. One (non-health) study of young people’s views about digital exclusion confirmed that while access to the Internet in some form is near-universal, the quality of such access, digital skills levels, the availability and expertise of support networks, and, most importantly, outcomes of digital engagement differ radically for disadvantaged young people (Helsper and Smirnova, 2016).

Particular issues for young people with mental health problems. We know that mental health problems are a major issue for young people, with high proportions of diagnoses

happening in the teenage years. This increases the relevance of the Holding and Maxwell (2021) finding that participants (adults and young people) who had experience seeking mental health support in the last few months faced particular challenges using online systems (which systems were not specified). They felt that the online forms they had used did not enable them to explain their issues. Some said they found the process stressful and frustrating when they felt they just needed a person to talk to, with one participant reporting she 'gave up' seeking help in the end. (See also Healthwatch Cornwall, 2019).

The Robards et al (2018) systematic review on how marginalised young people access and navigate health-care systems in a digital age included the views of young people who were homeless, living in rural areas, of refugee backgrounds, of diverse gender and/or sexuality, indigenous, of low income, young offenders or living with a disability. The review emphasised the key factors that young people are looking for when accessing health services generally – friendliness, trustworthiness, consistency, responsiveness, being taken seriously etc. – the question for young people is about the extent to which digital services can offer these. More young person centred research in the UK primary context is clearly needed on this.

Conclusions

Digital routes for accessing primary care in the UK are clearly here to stay, as part of the way in which services help direct patients to the right support. For some young people this may be a distinct advantage, but for others it will come with challenges. Although most young people are digital natives, and sophisticated in their understanding and use of online technology, this is not a guarantee that they will all find digital routes the best route for them in terms of accessing primary care services. Some young people – those more economically deprived, for example – may particularly struggle to get the best out of the system. Any system that young people use on their own needs to be youth friendly.

Overall the review revealed a serious paucity of studies that look specifically at young people's experiences and perspectives on digital access routes to primary care. We had to generalise to some extent from studies that addressed much wider questions about interactions with healthcare across the board, including thoughts about remote consultations and other kinds of online and digital support (such as apps for self-care). The fact that the messages echo those of young people whenever they are asked about *any* kind of interaction with healthcare services (in person or digital) means that we have reasonable confidence that these are indeed the key issues. For example, young people are always concerned about confidentiality, consent, not looking stupid, feeling that they are heard and understood, and wanting materials to be in a youth-friendly format. As with most research on young people and healthcare the young people in the studies we looked at were clear that they wanted choice and agency to choose the best routes for them. In some cases this would not be digital, but in others it might be.

The key thing seems to be to inform and support young people to improve their confidence, health literacy and knowledge around how the 'process' or 'healthcare system' works, to improve their sense of control. As others have concluded, digital access routes must be woven into a holistic model of general practice, considering need and preferences, rather than segmenting out different offers that erode the community-based component of general practice (eg Baird, 2019). We need to know more about what helps to build trust and relationships for young people and how remote modalities can help with the process. Unanswered questions include finding out how young people feel about expressing their concerns or 'hidden agenda' (eg safeguarding issues) online – does digital disinhibition help or not? How can digital access routes make it easier both for patients and for clinicians to identify safeguarding concerns or red flags that might suggest there is a concern?

To answer all these questions we need to seek the perspectives of young people more thoroughly than has been done to date, and to do so specifically within the UK primary care context.

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About AYPH

The Association for Young People's Health works to understand and meet the particular health and wellbeing needs of 10-25 year olds. For more information about our work email info@ayph.org.uk and visit our website ayph.org.uk

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