

Young people's views on digital access to primary care

Results from engagement with a youth panel



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Young people's views on digital access to primary care:

Results from engagement with a youth panel

Executive summary

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. This includes using the practice website or NHS app to contact their practice and conduct their consultation remotely, in addition to existing telephone and in person routes. This growth is broadly welcome, increasing access and efficiency. However, it may also bring challenges that are unique to some groups, including young people. This engagement project set out to ask a diverse range of young people about their experiences and views. Hearing these experiences directly from young people themselves is critical for getting digital access to primary care right.

The Association for Young People's Health (AYPH) recruited a group of ten young people aged between 16 and 22 years to be part of a youth panel to discuss digital access to primary care. They met five times over five months on video calls. Each session focused on a different area of primary care engagement being worked on by NHS England and NHS Improvement. Staff from the Digital First Primary Care team developed the content for each panel with AYPH staff and attended the panel meetings which were facilitated by AYPH participation staff.

There were a number of themes from the panel meetings:

- **Choice:** Young people want the choice to engage with primary care in different ways on their own terms. These choices can differ depending on their needs at the time.
- **Confidentiality:** Young people are concerned with confidentiality and who can access information about them. The clearer this can be explained the more comfortable they will feel.
- **Safeguarding & opportunities:** Safeguarding questions online can feel challenging. Young people do not want to trigger a safeguarding procedure inadvertently. However, they may provide an opportunity for services to signpost to community groups or third sector support.
- **Communication:** Different visual communication tools can help young people (particularly neuro-diverse young people) communicate with staff and healthcare professionals. Young people also wanted more clarity around language and terminology used by clinicians as it can be a barrier to understanding pathways and treatment.

- **Young person friendly:** Some young people have experiences of primary care staff communicating in an unhelpful or disinterested way. Young people want to be taken seriously, have their experiences validated and not feel dismissed because of their age.
- **Seeking health information:** How young people seek information about their health varies. Young people value primary care and want to engage with it. However, it can be challenging for young people when faced with waiting lists. Some young people will use Google, friends or family before engaging with primary care.

Digital primary care works best for young people when they understand the digital pathways, know what to expect and receive clear communication about appointments, care plans and what they can expect moving forward with their treatment.

We defined digital pathways as: Digital pathways offer different routes that allow patients to access NHS services and in this case, primary care. They are intended to make healthcare systems more streamline, accessible and provide patient focused care. Typical examples are GP or primary care service websites as well as NHS Apps. The Youth Panel workshops also took into account remote access, such as phone calls and post.

Introduction

The adoption and implementation of digital delivery in primary care is growing. Although this is broadly welcomed as a way of improving efficiency and increasing access, it may also bring particular challenges for some groups including children and young people. Hearing directly from young people about their experiences is critical to getting this right.

In order to hear from young people, the Association for Young People's Health (AYPH) convened a panel of young people aged 16-22 who took part in a series of engagement events. The panel aimed to work with young people across the UK including young people from groups that have been marginalised and who had less opportunity to contribute to discussions to date, and may be more likely to be disadvantaged if digital access is not accessible.

The panel met five times online via a video call over five months in 2021. Each meeting focused on a different element of digital access to primary care. Participation staff from AYPH led the facilitation of the panel meetings which were planned with and attended by NHS England and NHS Improvement staff from the Digital First Primary Care team.

Methods

Recruitment of participants

We created a short job description for panel members as part of the recruitment process. It explained the purpose of the panel, the commitment expected, methods of engagement and details of payment for taking part to recognise young people’s time and contribution. Payment was based on the recommended INVOLVE rate for young people taking part in engagement exercises. The Involve Foundation is a UK based think tank and charity that works on public participation.

The job description included a link to a digital application form. There was also the option of requesting a Word version or for young people to create and send a video of themselves answering the application questions. These recruitment materials were circulated among AYPH’s networks including the Young People’s Health Partnership and the #iwill youth social action network. AYPH also approached specific organisations to promote diversity on the panel. These organisations were:

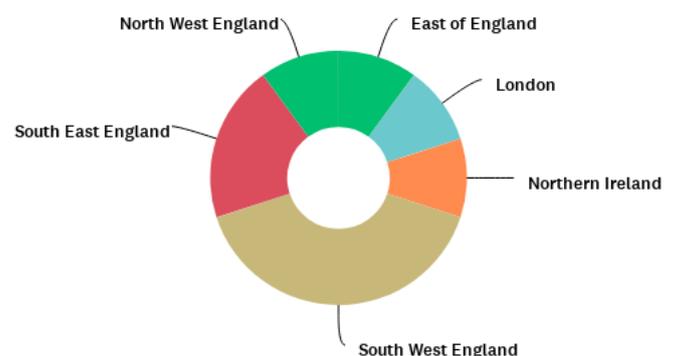
- Young Lives vs Cancer, a cancer charity for children, young people and their families.
- The Race Equality Foundation, a charity that helps promote race equality in public services, including health, housing and social care.
- Friends, Family and Travellers, A national charity that works on behalf of all Gypsies, Travellers and Roma.
- AYPH’s Youth Advisory Panel, a group of young people from across the UK who meet regularly to discuss the governance, projects and engagement of AYPH.

Ten young people applied via the online application. All were suitable, offered and accepted a place on the panel.

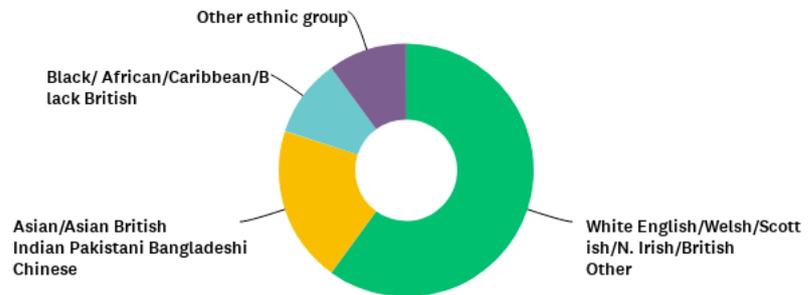
The young people who took part

The young people joining the panel represented a diverse group. They were geographically based in the North West, South East and South West, the East of England, London and one young person was in Northern Ireland.

Five of the young people were women, four were men and one was transgender.



The group's ethnicity was majority White English/Welsh/Scottish or Northern Irish. Four were made up of Black, Asian and Other ethnicities not categorised on the application.



The age range of the panel was between 16 and 22 years.

The engagement sessions

Before the start of the panel meetings AYPH held an introductory meeting to welcome the young people and introduce the facilitators from AYPH and staff from NHS England and NHS Improvement. It also gave the young people a chance to meet each other, create a group agreement around safety and set the tone for the future meetings. The group agreement also included everyone's consent to have the sessions recorded and later transcribed anonymously. Young people were reminded of this at the start of each session to ensure they were informed and consenting to the recording and group agreement.

In between the meetings the young people were invited to look at the materials and resources to be discussed in the upcoming panel meeting. They could briefly scan the materials, or take an in-depth look. It was important for the young people to understand they were welcome to engage with the materials outside of the session in the way that best suited them, so as not to put pressure on them and ensure the engagement met their access needs and time commitments.

AYPH participation staff created a methodology template for each of the five sessions. The purpose of this was to create a familiar online environment for each meeting. This ensured that young people knew what to expect from each session, even if the topics discussed were new or challenging.

We also enabled the public chat function during the video calls. This meant young people who did not want to have their screens on or did not feel comfortable speaking in the large group could input to the discussion. Closed captions were also used to aid young people who were neuro-diverse, displaying what was being said in the group.

Panel workshop topics:

- **Workshop 1 Introductory meeting:** An informal meeting to meet the young people, facilitate them meeting each other and establish a group agreement to keep the panel feeling respectful and safe.
- **Workshop 2 Safety and Safeguarding screening questions:** Focused on the content of screening questions encountered when accessing primary care digital systems to

book an appointment or ask for help. The focus of the session was reframing and rephrasing the questions to ensure they were meaningful and acceptable to young people.

- **Workshop 3 Training needs:** A discussion of skills and attributes primary care staff need to deliver effective digital primary care to young people.
- **Workshop 4 Feeding back on materials to support engagement:** A session to feedback on materials prepared for a pilot of digital access to primary care being undertaken in Humber Integrated Care System. This included reviewing language, layout and messaging of digital adverts, posters, flyers and letters being used by GP practices in the pilot.
- **Workshop 5 Reviewing content, evaluation impact:** This workshop gave us the chance to feedback the key themes and points the young people had made over the course of the project and allow them to ensure we had correctly identified the themes and reflect on any additional points.

Six key themes from young people on improving digital access to primary care

Across the five sessions the young people raised a wide range of issues. We have distilled these into five main themes that recurred in different ways across the whole of the engagement work.

1. The importance of being kept up to date with appointments, follow ups and care plans.

Young people want to know how to engage with primary care, what to expect from services and where to go next if they need additional information. Young people are dissatisfied with digital services when they do not know what to expect or what is going to happen next. This can cover a range of things; not knowing when a GP will call them back, where their data is stored, how to access care plans or further information about their illness or condition.

Young people felt these suggestions would help services communicate with them better:

- Services acknowledging when a young person has made an enquiry is really important
- Knowing when follow ups may take place and how to request one
- GPs, nurses and practice staff explaining how long an appointment is
- Healthcare professionals not assuming young people understand care plans and taking time to find out if they need further support – this can be especially hard for young people to ask for digitally
- Updates about where they are on waiting lists or when they could expect a call back
- GP practices proactively offering follow ups on care plans, medication and treatments

2. Offering digital options and other forms of communication

Young people welcome digital options, however, they still want the choice to engage with a service face to face. This can be due to a dislike of digital engagement. Some young people told us they felt unheard or rushed using digital interactions and would always prefer to visit a service in person. Other young people told us about other digital challenges, particularly around access to technology. Young people may not have tablets, computers or access to phones in order to contact their local health services. In addition, young people may have the technology but economic barriers such as having no credit on their phones, may prevent them from engaging.

When it comes to digital engagement and technology, a blended approach suited the young people best. Some young people will be happy to communicate on the phone or digitally while others will find that challenging.

It can be difficult for young people to communicate why they are seeking medical help and how they feel about doing it. The quality of interactions with a GP practice can cause a lot of anxiety for young people, and poor physical health can come with a range of difficult feelings and emotions. Young people suggested that mood cards and emoji symbols can help them communicate feelings and emotions about their health, particularly for those with spectrum based or neurodevelopmental disorders where communication can be an extra challenge. These kinds of strategies could help at reception and when communicating with a clinician.

"I don't mind you know, going to an appointment face to face, I don't mind that, I just don't like talking on the phone with strangers." Young person from Youth Panel

Young people also suggested that charts which identify what they are seeking help for OR how severe an issue is can really help them. These could be used at reception or with healthcare staff. Examples shared in the panel meetings included a practice that had a list of reasons for attending the GP which anyone could point to rather than explaining their problem verbally. Another example arose when young people considered the question, *you seem anxious, on a scale of one to ten how anxious are you?* This could help with communicating about physical and mental health and it can be a simple way of supporting young people to communicate symptom severity.

NHS information leaflets, letters or posters should make it clear how young people can access primary care as accessing services differs with age. This is both in relation to being above or below 18 years old but also in relation to other age cut offs for access to records e.g. the NHS App is accessible to those 13 and above.

3. Confidentiality and consent

Confidentiality is a big issue for young people when engaging digitally and this starts from the minute they interact with a website or booking system. Knowing where their data is stored and who can access it is important. Young people also want to understand digital

safeguarding processes. Young people value safeguarding and consider it important, particularly for those young people who may be in danger or in urgent need of professional interventions. However, if they don't know what questions come next, answering safeguarding questions via a digital form of engagement can feel risky. For example, they may worry that answering questions in certain ways may trigger a safeguarding process inadvertently.

4. Communication skills and their impact on young people

How healthcare and reception staff communicate with young people can have a big effect on how they are able to engage with services. The young people in the engagement sessions stressed that they wanted to be spoken to with respect, empathy and in a way that validates their experience. Non-judgmental attitudes and allowing time for them to say what's on their mind is important to creating a safe and welcoming space for them.

Young people highlighted the following things that were important to them in relation to reception staff:

- Staff showing empathy and being welcoming, whether this is face to face or over the phone
- Young people wanting to feel staff are competent
- Not rushing young people off the phone
- Proactively using visual communication prompts to aid communication where this is helpful to the young person.
- Patience, reassurance and not giving one word answers

I once had a phone call at 8am when I was booked in for 10.40, I think it's convenient for GPs because they can do it whenever they want, rather than having patients waiting in the waiting room and getting impatient.

But it only lasted one minute 47 seconds if I remember accurately and it was just regarding my asthma, "What's your peak flow? Fine, I'll give you the medication", whereas if it was face to face, they would have taken my peak flow reading there, they probably would have heard my breathing, they probably would have I-I don't know, advised me in a better way or seen my body language? – Young person from Youth Panel

The panel spoke about the challenges communicating via phone. They noted that it is hard for some young people to communicate emotionally and clearly when they are in pain, worried about an illness or phoning for a loved one they are caring for. In some cases phone calls feel like a way for services to rush consultations with young people. There was a concern that if the panel members felt rushed on the phone they would not be able to communicate what was wrong and therefore not get the healthcare support they needed from services.

5. Seeking information when unwell

Like everyone, young people will use the NHS website as well as Google to find out information when unwell. Some young people felt that it was better to Google a health concern as they believe it is a quicker way of getting information, rather than waiting for a GP appointment. Others, felt that the NHS website was good at providing medical information. As a result, having information in a youth friendly format was considered important.

I think people turn to Google because it's so hard to get an appointment with your GP, like roughly you're waiting about two weeks until you can see someone –
Young person from Youth Panel

I personally wouldn't feel comfortable asking my parents –
Young person from Youth Panel

Young people may also speak to a family member or close friend, but this can depend on what the health issue is and their family circumstances. Different health issues can mean a young person feels more or less comfortable talking with a personal friend or loved one.

When it comes to how young people get their health information, no one way fits all experiences.

The panel had mixed feelings about the NHS Symptom Checker. Some compared it to calling 111 saying it is easy to use and helpful, while others felt it was too general and they did not get what they wanted from it – if anything they found it alarming when it recommended serious action be taken, such as going to A&E or calling an ambulance.

Young people also told us that they may seek alternative sources of information about their health as they did not want to access NHS services unnecessarily. They were conscious of news stories and reports that highlighted GP practices (and all NHS services) being overstretched. As a result some young people would use primary care as a last result so as not to misuse services or be burdensome.

6. Young people's reflections on the emerging themes

In the last panel meeting, the young people were asked what points, issues or thoughts had stayed with them over the course of the engagement. Here's what they told us they would take away from the process:

- **Confidence around data protection and personal information:** knowing where and how personal information is stored, used and who gets to see it is important. It's also important to know how to update personal information and how young people can access it themselves.
- **The importance of accessible user interfaces for digital care:** Good user experiences of digital sites (mobile phone friendly websites, accessible information online) make young people feel safer about their information and the security around it.

- **The GP can feel like a last resort:** On reflection the panel noticed a trend among them that making an appointment with the GP felt like a last resort, rather than the first place they would go. This was partly because some felt there would be a long wait or because they were able to find support elsewhere, such as family, friends or internet searches. Others told us young people were concerned about the pressure practices were under as well as how services can be misused. This meant young people did not want to over burden or misuse primary care services.
- **Language is important:** Language used on websites, posters and in digital access can assume young people understand jargon, when in fact unclear language can be a barrier.
- **Young people can feel stigma and bias:** Young people can feel professionals are dismissive of them and their problems purely because they are young. Problems feel like they are written off as hormones or exam stress.
- **Healthcare systems are daunting:** Services should remember that young people are more than likely to have limited experience navigating them. Not all young people will have support from family or friends to help them and this can make both digital and physical access daunting and frightening.

I don't think when I was younger, I had a clue what "triage" meant, it could be quite helpful to have just some sort of consolidated information on the NHS website... if the NHS could actually just define these kind of centrally on their website as in "this is what we mean" and it's something that you can easily then look up to, you know, get layman's understanding of these things – Young person from Youth Panel

Interim actions (What has happened so far?)

Following each panel meeting the staff from AYPH leading this process met with staff from NHS England and NHS Improvement who had been involved in the session to reflect on the implications of the young people's perspectives on their work as well as any themes to follow up. In relation to some work in NHS England and NHS Improvement which was fast moving this led to changes being made to materials directly as a result of young people's views.

For example, materials that were being prepared for the North East Yorkshire and Humber pilot of new approaches were amended where possible to make them more accessible to young people, on the basis of the advice the panel had provided. In follow up meetings the need to specifically mention children and young people in a letter being sent to patients from the practices in the pilot was discussed and following discussion a new configurable part of the letter was added.

"Parents, carers and young people: If you are a parent or carer, you can use our online form for your children or those you care for. Young people aged between [x and y] who want to get in touch directly, can phone us or visit us."

Staff at NHS England and NHS Improvement are hoping to follow this up with more targeted information for children and young people in the future. This includes issues around online safeguarding and how it is communicated.

Conclusions

Young people make up 20% of the general population and a substantial proportion of visitors to primary care. We know from data that they make frequent use of their local doctors to support their health, and are a part of core business. Core information about how to access primary care needs to include them. In our five sessions with the panel ten young people shared a range of issues and themes about the implications of digital access to primary care for young people. Many of these themes reflect what we already know from the literature and previous engagement exercises about how young people want to be viewed by, and engage with, health services of all kinds.

Repeating a familiar message from most engagement with young people, the panel welcomed choice when it comes to engaging with digital primary care. One pathway may be appropriate and accessible for them for one condition but not for another. Different young people may have different preferences. Choice gives them an element of agency in how to get the right help for them. Clear youth friendly information about different access routes into care can support young people's informed choice about how they want to engage with their practice.

Young people shared that they have concerns about engaging with digital services when it comes to their data, confidentiality and safeguarding. The more information and understanding they can access while using these pathways the more comfortable they will feel using them.

It is important that young people know they are still able to see a healthcare professional face to face, as for some, this will be the only way they feel heard or can overcome digital exclusion.

Staff and healthcare professionals need to bear in mind that for young people, engaging with primary care can feel daunting, it can be difficult for them to communicate how they feel both in their physical and mental health. Supporting them to engage can make a huge difference. This could be, for example, by using visual communication cue cards or mood cards as well as interpersonal skills.

Ultimately, young people want to be informed about all the ways they can engage with primary care in order to make a decision that best suits them. Regardless of which pathway they choose, they want to know their confidentiality will be respected and that staff and healthcare professionals will treat them as individuals with respect and empathy.

Recommendations

A series of recommendations can be developed on the basis of the young people's messages. These include:

Clarifying pathways. Explaining the pathways young people can expect to encounter at each entry point to primary care can help young people feel more comfortable. This includes knowing what actions will be taken by using different routes (websites, phones, etc.) and what happens next and in what time frame. Where there is face to face or telephone contact with young people, allowing time to ask them if they understand or have any follow up questions is important to ensure they understand their care plan or future engagement. On digital and other systems follow up and next steps must be clear.

Choice is important. Young people value choice and ensuring they are informed about their options is an important way for them to engage in primary care in a way they feel comfortable with. Keeping up to date with different ways of communication can help young people, particularly if they are not used to describing how they feel, get nervous or have neurodiversity needs. Recording young people's communication preferences so that all practice staff can see them is one way of improving contacts with primary care for young people.

Investing in skills and training for staff. By engaging with staff who are listening, taking an interest and being respectful, young people are more likely to feel satisfied with their healthcare. Looking at training for staff and best practice of youth focused services can help staff and services meet young people's needs better.

Being aware of language. It is important to ensure that online resources, posters, flyers and correspondence are in language that young people understand. By making resources youth friendly and by advertising in places where young people are based, such as educational institutions, social media, youth and sports clubs, young people will be able to stay informed about healthcare information and where to go for help.

Improving participation. Young people want agency over their own health. They are interested and want to be asked and engaged with, where discussions about them and their health are concerned. By looking at the research and working with young people directly, services can make simple changes that have a big impact on how young people use primary care.

Focusing on communication: Practices need to communicate clearly how the various ways to access services work for young people – at what age can they access digital systems? What should they do if they don't want to use them – what are their choices? When visiting primary care, young people are taking the first steps to communicating about their health – removing jargon and communicating respectfully helps – potentially considering the use of charts, emoji's and other ways to help them communicate. Being clear about how information is stored and who sees it is part of what needs to be communicated.

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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