

Healthcare in the Digital Era

An exploration of young people's health needs and aspirations in
Hammersmith & Fulham

Healthwatch Central West London
January 2020



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Most importantly, we would like to thank all of the young people that trusted us with their views.

1. Introduction

i. Healthwatch Central West London

Healthwatch Central West London (HWCWL) is an independent organisation for people who use health and social care services. We deliver the statutory Healthwatch projects in Hammersmith & Fulham, Kensington & Chelsea and Westminster. Through our research and local engagement, we make sure that local people's views are always at the centre of decision making about health and social care.

We make this happen by:

- Listening to what people like about services and what could be improved
- Monitoring how changes in the healthcare system affect local people
- Helping to improve the quality of services by letting those commissioning, running, and making decisions about services know what people want from care

ii. The Young People and Digital Health project

Healthwatch Hammersmith & Fulham made working with young people (16-24 years old) a priority for 2018-20. Local engagement with this group had been limited in the past, and we set out to better understand their health and wellbeing needs with this project.

The last few years have seen an increased digitalisation of the NHS: more patients are being given the option to access health services and information online, and the number of these services is expected to increase.¹

Discussions of how and where more online services could be used often follow the assumption that young people prefer to access health information and local services online.² We spoke directly to young people, to find out whether or not this assumption is the reality for 16-24 year olds.

The aim of this report is to provide independent, local insight into the healthcare needs and aspirations of young people in Hammersmith & Fulham. It explores how young people would like these needs and aspirations to be met using digital technology.

¹ NHS England (2019) Chapter 5: Digitally-enabled care will go mainstream across the NHS (Long Term Plan, Chapter 5) <https://www.longtermplan.nhs.uk/online-version/chapter-5-digitally-enabled-care-will-go-mainstream-across-the-nhs/>

² NHS England (2016) Healthy Children: Transforming Child Health Information (National Information Board) <https://www.england.nhs.uk/wp-content/uploads/2016/11/healthy-children-transforming-child-health-info.pdf>

We chose to focus on this area in response to the following issues:

- The current lack of information about how young people access healthcare
- Common assumptions that young people want to access healthcare online
- Limited engagement between HWCWL and young people
- Increased digitalisation of the NHS (digital transformation), both in terms of online engagement and the use of digital technology for healthcare service delivery
- The introduction of the Babylon GP at Hand service* in Hammersmith & Fulham, and its popularity suggesting increased demand for online consultations

Overview of the project's methods

To explore the new territory of digital health, and how this links to the needs of young people, we used three different research methods.

1. A survey with 16-21 year olds, mainly from outreach at West London College
2. Four focus groups at Hammersmith & Fulham Youth Council, Youth Action on Disability, Sobus and St Andrews Church (32 participants aged 11-21 years)
3. Four youth leaders sessions with people in their 20s³

The quotes and comments attributed to young people in this report are taken from the focus groups we held for this project. A more detailed breakdown of the methods we used, and how we applied them to reach this report's findings, is available in the Methodology section (page 26).

Overview of the project's goals

This report sets out what young people told us about:

- How they access their healthcare
- What they think about digital healthcare
- Which of their healthcare needs (if any) could be covered by digital technology
- How they would like a digital healthcare system for young people to look

***Babylon GP at Hand**

A practice in Hammersmith & Fulham that offers:

1) general medical services to patients registered with them


2) a digital first service using a mobile app which is provided by Babylon Health.

<https://www.gpathand.nhs.uk/>

³ The project group would be led by older "Project Leads", with a view to having students in their 20s co-produce some of the project's areas of focus and conduct some of the research.

iii. Summary of the key findings

Young people told us:

- 
1. The use of digital technology is not necessarily linked with health
 2. Self-care and patient empowerment through knowledge and information can provide opportunities for digital interventions
 3. A combination of face to face and digital approaches is needed to address wider healthcare needs
 4. They have concerns about receiving incorrect or unreliable information when searching online

Their ideas for how specific needs can be supported using digital technology through applications have been identified and are worth exploring further.

Applying these findings to future research

Engaging with young people has helped us to identify the types of questions about digital technology and healthcare that can be addressed to residents of all ages. Speaking to young people about digital technology and healthcare has shown us that there are some interesting possibilities for healthcare development. However, it will be important for other age groups to be included in the conversations about this. To help with this, we developed an engagement toolkit, which has been included in the appendix.

We hope that this piece of work can contribute to discussions about the digitalisation of health and social care at both the local and national level, particularly following the publication of the NHS Long Term Plan*, which laid out plans for increased investment in digital services over the next decade.

We hope these findings will put the patient's voice at the centre of discussions about current digital interventions, and possible future strategies.

We presented our key findings at the Digital Health and Care Congress at Kings' Fund's "Listening to patients and citizens" panel session in May 2019.

***NHS Long Term Plan**

The NHS Long Term Plan, published in January 2019, is a report that explains the priorities for healthcare over the next ten years. It shows how NHS funding will be used.

<https://www.england.nhs.uk/long-term-plan/>

2. Health needs and the online world

Overview

We explored two main areas:

1. How we could identify what the health needs of young people are
2. Which of these needs could be addressed using digital technology

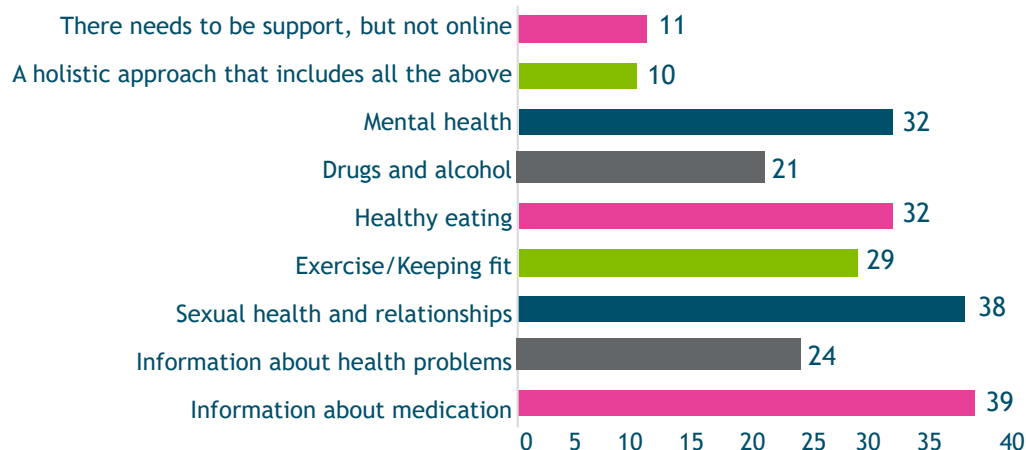
The participants provided their responses to these two areas by completing surveys, the findings of which are displayed as graphs throughout this part of the report. Some young people also participated in our focus groups, in which they selected priority health issues during an interactive exercise, choosing pictures that represented different aspects of health and discussing them.

All of the quotes and comments in the following sections are taken from the focus groups we held with young people for this project. The issues that this report focuses on were those identified as key areas of interest for young people.



We asked young people (11-21) to talk to us about their health needs, and how these needs could be addressed by digital interventions, such as online tools and apps.

For which of the following do you think there should be online/digital health support for young people?



The figures in this graph represent the number of responses for each question. Survey respondents could select multiple options within the survey.

Some of our findings from this part of the study included:

- Young people told us that there are opportunities for online interventions to be developed to address most of the key public health issues (see table above).¹
- More than half of the young people we surveyed believed that it is important for information about medication to be available online.
- Although **38 (52%)** survey respondents identified “sexual health and relationships” as a key issue, it was not widely discussed in the focus groups. This perhaps indicates that engagement about sexual health and relationships should be carried out in a more confidential way.
- Almost **45%** of the survey sample cited the need for digital health interventions regarding mental health (**32 people**) and nutrition (**32**).
- Drugs and alcohol received the lowest number of survey responses as a key issue. Young people demonstrated a general understanding of the negative effects of drinking and smoking during the focus group discussions.

¹ 72 young people completed the survey. Therefore, these findings do not indicate which health need is the most important. However, what is evident is that there are opportunities for all issues to be addressed through online interventions.

The following section provides more detail on how young people responded to questions about the health issues that affect them, and how online tools could support their access to the relevant information and services.

The section focuses on:

- 1) Mental health
- 2) Nutrition and wellbeing
- 3) Drugs and smoking

Mental Health

Raising awareness

“Just because you can’t see it doesn’t mean it’s not there.”

The young people we spoke to in the focus groups, and during the sessions we had with the Project Leads, identified mental health as a key issue.

They said people needed to be more aware of what mental health means, and what can be done to support it, in order to ensure people are given support to speak out and to access services. One young person expressed concern that mental health still carries a stigma that is difficult to change.

Participants suggested that apps and websites could be used to show that mental health issues are normal, and to share resources and spaces that can help. They commented that although mental health is not a “positive” issue, there is the potential to turn discussions of the issue into something positive.

One participant voiced the need for a distinction between mental health illness and “not feeling well”:

“When someone says “mental health” it becomes something - [there is] no need to label it mental health.”



“Feeling low doesn’t necessarily mean a mental health issue. If you say mental health, you feel so crazy; it doesn’t unravel what people are going through.”

Prevention and Self Care

“Somewhere you are free to speak in a non-judgemental way”

The young people we listened to said that there should be a combination of both conventional and online spaces. They expressed the need to be able to freely discuss health concerns in a non-judgmental way, either within a support network or with a trusted friend.

They identified a series of digital interventions that could support these needs:

Mindfulness apps

“I use an app for mindfulness, called Aura; it’s very good. I would suggest someone stick to [meditation]. If it’s not working for you, look for other solutions and alternatives.”

Practical tips and stories blogs

“There are not many blogs out there that are practical.”

“People who have gone through the same thing [could share], how they got through it, positive stories in a blog style.”

Online self-care information

“Simple information on what to do; go for a walk, have a bath.”

Chatrooms

“There could be chatrooms with people who have the same mental health issues.”



Schools online

“Schools should focus on positive messages - [it] would help if there was advice you could receive online to help with exam stress.”

A key theme in the mental health focused discussion was identifying the need for professional intervention, and responding in a timely way, before reaching the point of crisis or engaging with health services. Young people said that digital interventions, along with support networks and individual confidential conversations, could provide young people with the space to understand whether they could address their issue themselves, or if it required them to contact the health services.

Interacting with the health system

“I was speaking with a friend [who] wanted to speak to someone - she didn't know which number to call.”

Participants identified a lack of knowledge around how to identify the most appropriate first contact within the health system. Many of them did not necessarily consider the need to speak with someone to mean they were at a “crisis” point.

They suggested that GPs should provide better access to mental health professionals and that there should be more easily accessible options than medicines and antidepressants. They added that pharmacists should have mental health training, estimating that they are often the first point of contact.

Healthy eating

In focus groups and in the online questionnaire, young people indicated that they lacked knowledge of what is meant by healthy eating and nutrition.

Body Image

During discussions about healthy body image, young people in the focus groups mentioned social media as a cause of unhealthy body image, citing the obsession with appearance and the need to attain a ‘perfect’ body to keep up with those presented to them online. They described seeing models and bloggers advertise meal replacements and weight loss products. Young people reported drastically changing their diet by eating significantly less in response to these trends, explaining that this had a negative impact on their health.

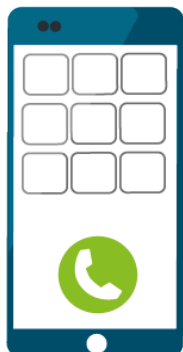
What is healthy?

In addition to social media, the group participants also identified a general lack of awareness of which food is and is not healthy. They were uncertain as to how they could discern between food that is marketed as healthy versus what really is healthy, despite there being extensive available healthy eating advice.⁴ In the focus groups, young people suggested that schools should provide healthy meals, and that GP practices should provide nutrition information to help change this.

⁴ The following online resources provide accessible information about healthy eating:

- NHS England website: <https://www.nhs.uk/live-well/eat-well/>
- Hammersmith & Fulham CCG website: <https://www.hammersmithfulhamccg.nhs.uk/your-services/healthy-living.aspx>
- London Borough of Hammersmith & Fulham Council website: <https://www.lbhf.gov.uk/health-and-care/public-health>

A nutrition app



The young participants in the study identified a need for a digital health intervention. They suggested a mobile health app with scientific information, based on national guidelines, as a way of creating healthy meal plans, designed or adapted to each individual body. Some also expressed a need to know what the nutritional contents in food mean, to know which types of food to purchase for their individual needs and as a reference point for a balanced diet. Language used in any digital intervention should be simple, with any extra scientific knowledge added as a reference.

As one young person put it: “I can eat so many vegetables, I can eat vegetables with no limitation, but they can still have deficiencies. You can eat spinach, but it might not help. The important thing is understanding the combination of what to eat and what is good for your individual body.”

Drugs, alcohol and smoking

In the focus groups, young people expressed concerns about peer pressure through digital platforms and social media that promotes a “cool culture.” This might include drugs, alcohol and smoking. They suggested that it would be good to have more information presented in different ways, including apps to persuade people not to smoke.

However, young people also felt that there is already enough information about the negative health effects of smoking and alcohol, but that people will still do it because it is addictive. Most of the young people who raised the issue of drugs, alcohol and smoking agreed that there should not be imposed controls and that everyone should be free to make their own informed choices.

“Saying don’t smoke, [or] do drugs, makes people do it. You should focus more on treatment because people will still do it.”

“Cigarette packets warn that is bad for you, but if they want to do it and know [the] risks; it’s their choice.”

“Anti-smoking [is] not effective, not changing views. The government is not doing enough because selling cigs is good for the economy.”

3. Health journeys and digital interventions

To complement the survey responses to questions about digital interventions, HWCWL invited the young participants to describe a “health journey,” using pictures to show the different steps they would take to access care if they were unwell.

i. Access

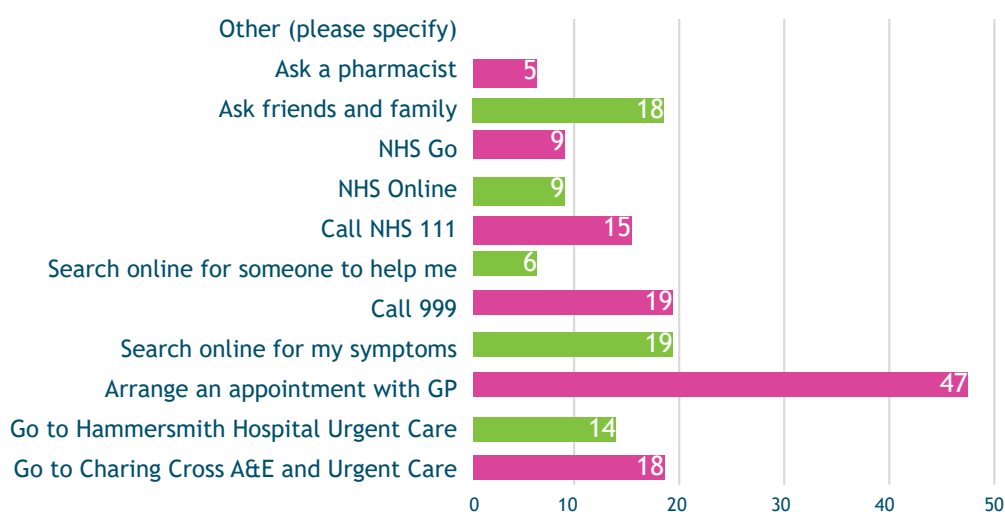
First point of contact

As we explored in the previous chapter, there are opportunities for digital interventions to be applied alongside the current health system, with an emphasis on prevention and self-care. We asked young people which type of digital interventions they thought would be suitable for those using the healthcare system.

To answer this, we asked young people to select the places they would visit first if they had a health concern. In the survey, participants could choose as many different options as applicable.

- The most popular answer, with 47 responses (25%), was to arrange a GP appointment.
- The number of those using NHS Go or accessing 111 online was low compared to the other options.
- 32 responses (18%) selected going to an urgent care centre (Hammersmith Hospital and Charing Cross).

In general, what are you most likely to do when you have a health problem or concern?



The figures in this graph represent the number of responses for each question. Survey respondents could select multiple options within the survey.

Respondents could select multiple options, as this more accurately reflects the different routes that many people make take. From this, we can see that the most popular response was to arrange a GP appointment. Combining the responses for the two urgent care centres shows that they were the second most likely route to take to access health support. It is therefore useful to not only consider the options selected on an individual basis, but to also group responses according to theme, where applicable.

We realised through our conversations with young people that the number of options available could make it difficult for them to know where to go for help. It is particularly important to examine the beginning of the health journey, as the young people we spoke to considered this stage to have most potential for a digital intervention, with digital tools being used to signpost users to the right service.

It is worth mentioning that for a lot of young people - especially the younger ones - their parents or carers were their first point of contact.

Symptoms

The young people we spoke with seemed to be aware of the danger of false diagnosis online. They told us they do not tend to use the internet to check their symptoms because they believe that they might not receive the right information.

“Feel sick - google symptoms and something worse than what it is, can’t always trust the internet.”

“I used to do it all the time but stopped. I thought I had cancer!”

They told us that one way to address this would be to provide appropriate information through the NHS website. However, they said the website is not currently very user friendly and is difficult to navigate.

Having an initial understanding of the symptoms that young people are experiencing is important. This helps the person to decide which is the most effective way to address the issue. A common opinion was that a minor issue could probably be addressed through an online intervention, but that more worrying issues require face to face GP appointments.

“When it’s urgent the internet doesn’t help”

This view demonstrates the need for people to be able to make informed choices about their health.

Lack of suitable information

Use of the NHS 111 number was limited. Some of the youngest focus group participants were not aware of it, and some thought it was the equivalent of 999.

“More info (online) that we can understand, not long words [that leave you wondering] what does that mean? Everything gets a long word when [it] actually is quite simple.”

It is important to make sure that existing services are well advertised, before creating more digital services that people cannot keep up with. As the table on the next page shows, young people we surveyed knew more about Babylon GP at Hand, which was widely advertised through a successful campaign, than NHS 111 Online. There seems to be good knowledge of the NHS Go app*, but this could be improved.

“What is NHS Go? Never heard of it. Is it useful? I don’t know about it, it could be a good service. Could be helpful. We need to have more information.”

We asked young people whether the NHS website could

*NHS Go

A confidential health advice and information service for 16-25 year olds.

It provides free, confidential advice, local services, guides to key health issues, and information about young people’s rights.

<https://nhs.go.uk/>

*NHS HealthHelpNow

An app, which aims to help people find the right service for their health needs, lists common symptoms and offers suggestions for treatment.

<https://www.nhs.uk/apps-library/health-help-now/>

be the most appropriate first point of contact. Although they didn’t find it attractive enough, the group participants were aware of it, and felt it could be used because it is trustworthy.

They suggested that the NHS website should signpost to other health resources and information. They said that they could not find what they need when they used the website, and that it is not very user friendly, or easy to access.

*NHS App

The NHS App enables people to check their symptoms, use NHS 111 online, register as an organ donor, and other services.

If their GP practice is connected to the app, they can register and use the app to book appointments, order repeat prescriptions, and securely view their medical records.

<https://digital.nhs.uk/services/nhs-app>

They suggested that it could work better as an app. There was no mention of the NHS digital app* that had been recently launched or North West London HealthHelpNow*, which was about to be introduced to the public.

“NHS website doesn’t feel aimed at the individual, [it] feels generic, impersonal.”

Other suggestions included for the Council

and the local NHS to provide accessible information and maps of where all the health services are located.

Young people said that this information is useful for someone new in the area or for whom English is not their first language.

ii. Treatment

Preferences

The majority of young people we surveyed were of the opinion that they would prefer to see a GP face to face. They placed greater value on seeing the same health professional for follow up appointments than on being able to access health services quickly.

In the focus groups, these preferences seemed to be particularly strong among the younger participants, aged 11-16, and with young people who have learning disabilities.

They said that they would turn to their parents and carers for advice and stressed that everyone needs to “trust the doctor.”

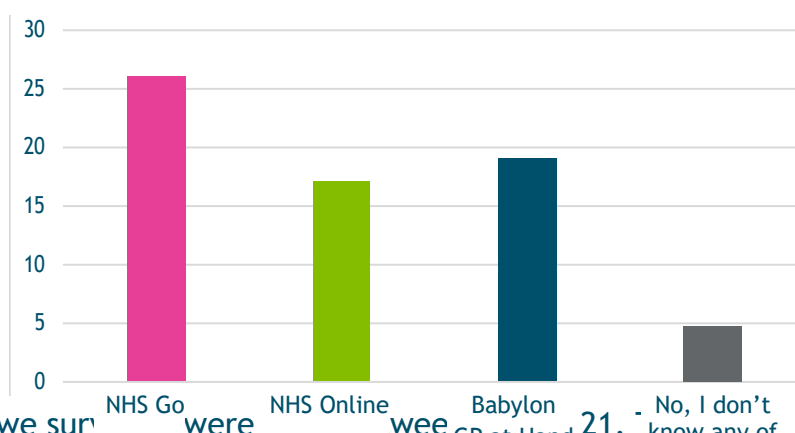
“Go to the doctors straight away. Family might go online to have a look.”

“Family and friends who know [how to] help or healthcare professional. They might go online.”

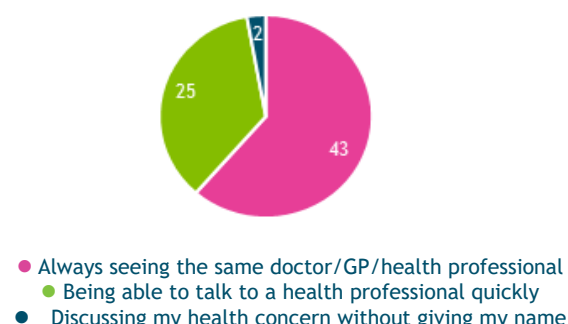
“Always go to the doctor and take what they give you. Trust the doctors. More important to see a doctor. Especially when it's urgent.”

This suggests that relationships with health professionals are important to young people. This has been reflected in the NHS Long Term Plan. A further study looking at how these priorities change as people get older would be interesting: feedback on the Babylon GP at Hand Independent Evaluation⁵ has demonstrated that young professionals are more likely to want to access care services digitally.

Do you know any of these existing digital services?



Which of the following is the most important to you?



⁵ Evaluation of Babylon GP at hand (2019) Ipsos MORI, York Health Economics Consortium, Prof. Chris Salisbury for NHS Hammersmith and Fulham CCG and NHS England <https://www.hammersmithfulhamccg.nhs.uk/media/156123/Evaluation-of-Babylon-GP-at-Hand-Final-Report.pdf>

This suggests that for some groups, access is prioritised over continuity of care. We are also seeing distinctions made between what is and is not considered urgent, which would be interesting to compare between different age groups.

Another concern that was shared in this part of the focus groups was that people had witnessed the health professional searching their symptoms online to provide advice.

Follow ups

One potential intervention identified during this project is the use of digital technology as an alternative to follow up visits to the GP. This could be carried out via video consultations, text messages and phone calls to ensure that the patient is getting better following treatment without having to arrange a revisit, unless necessary.

In most of the experiences that young people shared with us, there was always a follow up visit to the GP because the health issue persisted. They felt that a visit could have been avoided if there were a way to check the progress of the treatment using digital technology. This is another area in which further research may be useful.

Self-care

Participants in the focus groups also said they would like to be able to address health issues themselves, without visiting the doctor at all, if they could find suitable and reliable information.

For example, one young person described an experience where they had gone to the GP for ankle pain. The GP gave them a list of exercises that the person thought that they could have found on their own if there was a website showing them what to do when experiencing ankle pain.



Exercises to address health issues seemed to be a popular choice amongst the

young people we spoke to, as they also suggested an exercise app could provide positive reinforcement and reminders to those undergoing physiotherapy.

Medication

As young people told us, trust in the healthcare system is not limited to where to check the symptoms online or what happens to the patient data; it is also important for finding information regarding medication.

An interesting idea discussed during one of the focus groups, which was popular with the young people in the survey, was the development of a “medication” app that could provide information on each medicine to enable the patient to double check side effects.

They said that this could be used to address concerns that a medicine might cause headaches, skin reactions, or other side effects, especially since most people do not keep the paper version of the information from their medication box. This would help people to “take healthcare into your hands” as one participant said.

“Information about medication” was the most popular choice amongst the survey responses (see table on page 20), which indicates that there might also be some potential for the development of a medication app that innovators could explore further.

“By the time that the medication has a side effect I would have to go back to GP and find a new one. Then I will have another medication. And I am thinking, what are they not telling me?”

“Doctors just want to give you medicine to get rid of you.”

There were also concerns about medication in general, with suggestions for the NHS to explore and accept alternative methods of treatment such as holistic treatment and herbal medicines, as there isn’t always a need for drugs.

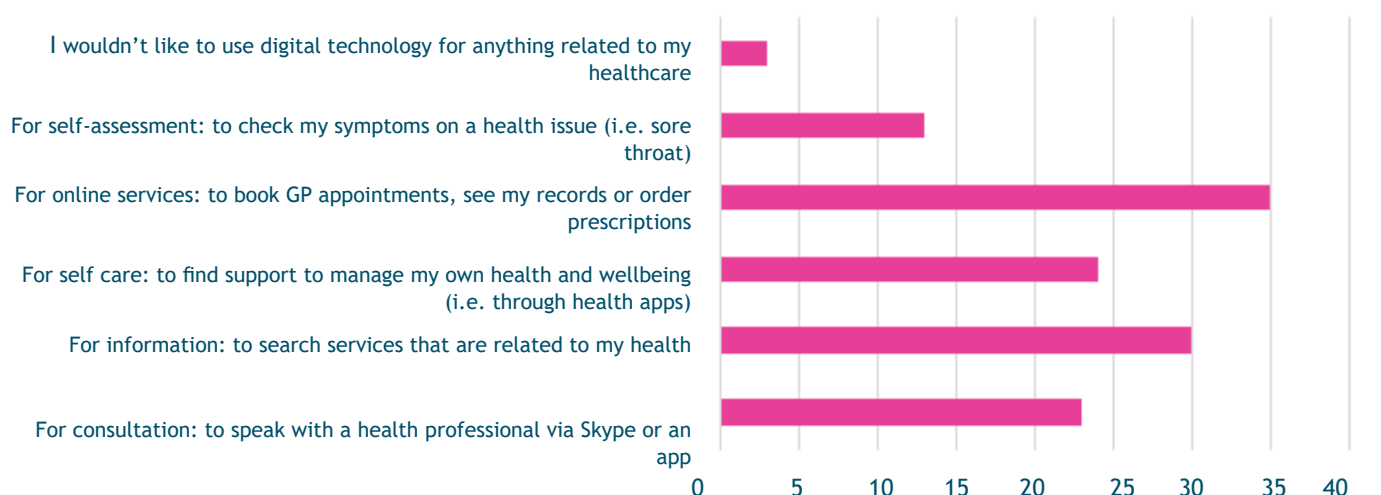


4. Opportunities and Concerns

We asked young people why they preferred to use digital technology for their healthcare and finding health information. We identified key aspects of intervention to ask them about, which included:

- Self-assessment
- Online health services
- Self-care
- Information and video consultation

Why would you prefer to use digital technology to access your care?



Most of the young people selected some healthcare services for which they would use digital technology, with many of them receiving a high number of responses (with the exception of symptoms checking, which we discussed in the previous chapter). These responses suggest that there is scope for digital innovation in healthcare.

However, the young people found it challenging to navigate potential digital interventions in the healthcare system. Although young people use smart phones in their everyday life, they have not necessarily associated digital technology with their health, and find it difficult to imagine a digital healthcare system. This observation applies to the young people we reached through each different research method (focus groups, Project Leads and survey).

Many stated that although digital health would make access to healthcare much easier and seeking advice more efficient, there was still a need for a holistic approach involving healthcare professionals and face to face appointments.

The young people said that websites or applications can be impersonal and they made suggestions to incorporate healthcare professionals within a digital setting or seeking professional advice alongside digital health interventions.

“Real life interactions make things personal. Digital technology can’t offer personal connections.”

At the same time, it was recognised that digital technology can help empower people to be responsible for their own health.

“We all have a phone; it is like a tool to have more information and understanding. You are more autonomous.”

“(Phone) gives you independence and you can take healthcare in your hands.”

There were also concerns about patient data and sharing data online, with some young people saying that they would use fake names and access websites through different devices so that they can’t get tracked.

Concern about patient data is part of a wider issue that has been raised with us by adults as well. This needs to be part of further thinking when digital resources are being designed.

Exploring possibilities for digital technology to help people become more responsible for their healthcare, combined with the reassurance that the existing ways of receiving care will not be lost, is crucial to ensuring that a future digital health system is patient centred and effective.

5. Conclusion and Recommendations

Conclusion

Throughout the delivery of this project, we wanted to explore with young people what a digital healthcare system for young people would look like to them.

We explored this by:

1. Identifying how they could access health digitally
2. Which of their needs could be covered by digital interventions.

Our initial findings show that there are opportunities for digital innovation in healthcare that could be explored more.

This report's findings suggest that digital technology could be used to avoid follow up visits to health professionals and to empower patients with the necessary knowledge and tools to address their healthcare needs. Examples of this, which we have discussed in this report, include interventions for websites that have self-care suggestions and exercises to address issues, as well as phone and tablet apps for nutrition and medication.

Although there is scope for developing digital interventions, there is also a need to maintain the existing face to face approaches that feel more personal and can offer that level of reassurance when needed. A holistic approach was identified as key for mental health and wellbeing in particular, with different choices and options for young people being a priority.

Young people found the idea of being able to take charge of your own health using your phone attractive. Still, with limited knowledge of what digital technology can mean for healthcare, young people found it challenging to explore what this could look like in any depth.

The stage at which service users access healthcare and information online seems to be the best point at which to incorporate digital interventions. However, there are concerns about receiving incorrect or unreliable information when searching online (i.e. symptoms checking) and providing personal information. Young people also have


a lack of knowledge regarding existing NHS digital interventions that focus on access and symptoms checking; those who were aware of them did not consider them user friendly.

Below are our recommendations based on this study. We feel that more work needs to be done in the digital healthcare landscape, for all age groups.

Recommendations

We expect the following recommendations to be implemented in advance of the new GP Contracts in April 2020, which are expected to have a digital priority.

1. Digital Healthcare: Information and communications



Recommendation 1: North West London Collaboration of Clinical Commissioning Groups (NWL CCGs) should develop a communications plan focused on digital healthcare, which should be implemented in advance of the new Primary Care Contracts of April 2020 to support the development of the Primary Care Networks.

This should be co-produced with Hammersmith and Fulham Clinical Commissioning Group (H&F CCG), and future and prospective patients to ensure that digital interventions are based on needs of the local population.

The following should be included and addressed in the engagement plan:

- Provide information about possibilities of using digital healthcare to help people envision a health system where digital can take place.
- Increase awareness about existing online applications such as NHS 111 online, NHS Go, HealthHelpNow app, the NHS App, and advertise a list of approved NHS applications.
- Clarify the different functions of the applications above and when it would be useful for a patient to use them.
- Work with GP Practices to produce videos with self-care tips for common problems to be advertised on GP websites.

How can HWCWL help?

HWCWL will support this by sharing information and promoting opportunities for engagement to its members through its offline and online communications channels.

2. Prevention: Focus on Mental Health

Recommendation 2: Hammersmith & Fulham Health and Wellbeing Board and the Integrated Care Partnership should commit to develop a patient pathway that addresses mental health concerns before reaching the point of crisis. They should set out how they develop this by April 2020.

How can HWCWL help?

HWCWL can support implementation of this pathway bringing together LBHF Public Health, West London Health Trust, H&F CCG, the voluntary sector, current and potential mental health service users and other interested parties into a stakeholder group. o its members through its offline and online communications channels.

3. Checklist: Digital interventions provision

Recommendation 3: H&F GP Federation, H&F CCG and the Primary Care Networks Clinical Leads should co-produce a checklist to ensure that they are delivering digital healthcare that reflects local needs with current and prospective users. The process for this should begin by April 2020.

How can HWCWL help?

HWCWL can work with H&F GP Federation, H&F CCG and the Primary Care Networks Clinical Leads to develop a checklist that could act as a guidance to streamline the digital healthcare offer locally on an ongoing basis.

The following points should be included:

- Ensure that websites and online applications are updated on a regular basis with the latest information.
- Use language that is accessible and easy to understand in line with the NHS Accessible Information Standard (DCB1605) in all existing digital interventions.
- Embrace innovation and be open to explore new technologies and initiatives.
- Ensure that new products/interventions are addressing people's needs and involve people in every stage.
- Ensure that each digital intervention is linked to the NHS logo that people know and trust.
- Ensure that the promotion of digital interventions is accompanied by a reassurance that non-digital methods of healthcare and face-to-face appointments will continue.

Areas for further work

As part of our project, the young people we spoke to identified two areas for further work relating to the development of specific apps that interested parties could explore further to see if there is appetite for these interventions:

Nutrition App

A mobile health application with scientific information based on national guidelines as a way of creating healthy meal plans, designed specifically for each individual body. This should include guidance on nutritional content of foods, what to purchase for their individual needs, and as a reference point for a balanced diet. The app should be scientifically based, but it should be easy for the user to interact with in simple language.

Medication App

An app that could provide information on each medicine to enable the patient to double check side effects. This could be used to address concerns that a medicine might affect you by causing side effects such as headaches and skin care etc. It could also support patients make informed decisions about their healthcare when they need to combine different types of medication to address one specific health matter, especially if they are on a long-term treatment.

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Methodology and Appendix

The strategy and supporting documents used for our reporting in
Hammersmith & Fulham

Research conducted

6. Methodology

Initial desktop research, which we completed in Summer 2018, showed that despite the growing influence of digital technology, there were limited resources exploring what patients want from the digital world more widely.

Initial documents that helped us gain a better understanding of young people and digital healthcare were:

- The Joint Strategic Needs Assessment Report: “The Wellbeing Needs of Young Adults” age 18-25.
- The minutes from the presentation of the above report at the Hammersmith & Fulham Health and Wellbeing Board Meeting (8 February 2017), which acknowledged the difficulty of reaching out to young adults and that there is a need for the digital aspect to be further explored.
- Documents related to the new Babylon GP at Hand service, based in Hammersmith & Fulham, which showed that young adults across London were eager to use the service for online consultation.

Having more information on young adults, we initially decided to focus our research on the 16-24-year-old age group. However, during the delivery of the project, we learnt that we needed to be more flexible, and incorporated the views of younger people as well.

We produced a participation information sheet for those wishing to be involved in the project. To maintain confidentiality, we used consent forms for both comments and pictures. To deal with risk, we engaged with local organisations that work specifically with young people and we followed their procedures.

Since we wanted to make it as easy as possible for young people to participate, while getting a broad understanding of young people’s healthcare needs, we decided not to collect demographic information at this point.



7. Appendix

Appendix i.

What do young people want from healthcare in a digital environment?

Aged 16-24? Do you live in H&F? Answer our questions to enter a prize draw!

Following recent local and national developments in digital healthcare, Healthwatch Central West London is focusing on identifying the healthcare needs and aspirations of young people aged 16-24 living in Hammersmith and Fulham.

1. How would you prefer to contact a doctor or other health professional to talk about your health?

Online (via Skype/video chat)	<input type="text"/>	Face to face	<input type="text"/>
By Phone	<input type="text"/>	Messaging	<input type="text"/>
Other: please specify	<input type="text"/>		

2. Which of the following is the most important to you?

- Always seeing the same doctor/GP/health professional
- Being able to talk to a health professional quickly
- Discuss my health concerns without giving my name

3. In general, what are you most likely to do first when you have a health problem or concern?

- Go to Charing Cross A&E and Urgent Care Centre
- Go to Hammersmith Hospital Urgent Care Centre
- Arrange an appointment with my (doctor) GP
- Search online for my symptoms
- Call 999
- Search online for someone (professional/service) to help me
- 111 Online
- NHS Go
- Call 111
- Ask friends and family
- Ask a pharmacist
- Other: please specify

4. For which of the following do you think that there should be online/digital health support for young people? Select all that apply.

- | | | | |
|---|----------------------|---|----------------------|
| • Information about medication | <input type="text"/> | • Health problems information | <input type="text"/> |
| • Sexual health/relationships | <input type="text"/> | • Exercise/keeping fit | <input type="text"/> |
| • Healthy eating | <input type="text"/> | • Drugs and alcohol | <input type="text"/> |
| • Mental Health | <input type="text"/> | | |
| • There needs to be support, but not online | | • A holistic digital approach that includes all the above | <input type="text"/> |
| • Other (please specify): | <input type="text"/> | | |

5. For which of the following reasons would you like to use digital technology?

- For consultation: to speak with a health professional via Skype or an app ☐
- For information: to search services that are available related to my health ☐
- For online services: to book GP appointments, see my records or order prescriptions ☐
- For self care: to find support to manage my own health and wellbeing (i.e. through health apps) ☐
- For self assessment: to check my systems on a health issue (i.e. sore throat) ☐
- I wouldn't like to use digital technology for anything related to my health. ☐

6. Do you know any of these existing digital services?

NHS Go ☐ 111 Online ☐ GP at Hand ☐ No ☐

☐
☐

7. What is your connection to Hammersmith and Fulham?

Working ☐ Living ☐
My family lives in H&F ☐ Studying ☐
Other: please specify ☐

8. What is your age?

15 or less ☐ 16-17 ☐ 18-21 ☐
22-25 ☐ 26-30 ☐ 31 or over ☐

9. Do you consider yourself to have a disability?

Yes ☐ No ☐ Prefer not to say ☐
Other: please specify

10. To which gender do you identify most?

Male ☐ Female ☐ Transgender ☐
Prefer not to say ☐ Other: please specify

11. Any other comments?

Thank you! Please return the completed form to Healthwatch Central West London, 5.22 Grand Union Studios, 332 Ladbroke Grove, W10 5AD, or contact eva.psychrani@healthwatchcentralwestlondon.org and 020 8968 7049.

You can also fill it in online at www.healthwatchcwl.co.uk

Hammersmith & Fulham

In you wish to enter a prize draw, receives updates from Healthwatch or participate in a focus group, please leave us your contact details.

Your contact details will be kept separate from your answers.

I give my consent to be added to the HWCWL mailing list

I would to enter the prize draw to win a gift card

I would like to participate in a focus group to say more about health and digital care

Name

Email

Phone

Your Data

By filling out this sign-up sheet, you give your consent to have your data processed by Healthwatch Central West London. If you have only consented to be entered in our prize draw, we will not contact you unless you have won a voucher. After the draw we will destroy your personal details.

If you have given your consent to be contacted by us about our project in Hammersmith & Fulham, we will not use your data to contact you about anything else, unless you have also agreed to be added to our mailing list.

To find our more about how we store your data, you can read our privacy policy on our website, or ask a member of Healthwatch staff to send it to you.

www.healthwatchcwl.co.uk
info@healthwatchcentralwestlondon.org
Charity number: 1154777

Appendix ii.

Focus Group Participation Information Sheet

Project title: Young People and Digital Health
What is this project about?

Following recent local and national developments in digital healthcare, Healthwatch Central West London is focusing on identifying the healthcare needs and aspirations of young people in Hammersmith & Fulham.

The project aims to create opportunities for young people in H&F to have a say on:

- a) how and if they want to access healthcare digitally,
- b) which of their healthcare needs (if any) could be covered by digital healthcare, and
- c) what a digital healthcare system for young people would look like.

Do I have to take part?

It is entirely up to you to decide. If you choose to participate in this focus group, we will ask you to complete a consent form to confirm that you have agreed to take part. You will only be able to take part if you have completed this consent form.

What will happen to me if I take part?

If you are happy to take part after reading this information sheet, please fill in the consent form.

Your contact details will be held for the purposes of communication before and during the focus group, but this will not be passed on to any third parties and will be held securely on our database.

The focus group should last for around x minutes and will be audio recorded with additional notes being taken by paper.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this focus group?

There are no anticipated disadvantages, side effects, risks, and/or discomforts of taking part in this focus group as we will only ask you about your own experiences and assessments.

We will ask you and others in the group not to talk to people outside the group about what was said during the discussion. However, we need you to be aware that we cannot stop or prevent participants who were in the group from sharing information that should be confidential.

What are the possible benefits of taking part in this focus group?

This is a chance to make your voice heard and to influence future commissioning of digital offers in healthcare in Hammersmith & Fulham and across North West

London. Your views and aspirations will be added to the information gathered through other engagement activities to conduct a report that will be shared with key decision makers, including Hammersmith & Fulham Council and the Hammersmith & Fulham Clinical Commissioning Group.

Expenses and payments

Healthwatch Central West London will be covering any expenses related to the focus groups such as room booking, travel expenses of participants and refreshments.

Will my taking part be kept confidential?

We will not report your name or anything that would make you personally identifiable in any outputs from this project and we will ensure that data in this report is anonymised.

Contact details will be stored securely in our database and will not be stored in the same place as your data from the focus group. Healthwatch Central West London and its data storage procedures are fully compliant with GDPR. Please see the

privacy notice below for more details about the personal data we will collect from you and how it will be used.

What will happen when the project ends?

The collected anonymised data will be available in a published report. You anonymised data will be stored securely and then destroyed. You will not be contacted again about this or other projects, unless you sign up to be a Healthwatch Central West London member.

What will happen to the results of the project?

A report will be published on Healthwatch Central West London's website. The anonymous data will be stored securely at Healthwatch Central West London for up to two years after the project finishes. After two years this data will be reviewed and may be kept for a further three years. Your contract details will be destroyed securely after the end of the project. You will not be contacted again about this or other projects, unless you sign up to be Healthwatch Central West London member.

What will happen if I don't want to carry on being part of the focus group?

Participation in this focus group is entirely voluntary. Refusal to participate will not affect you in any way. If you agree to participate, you may nevertheless withdraw from the focus group at any time without affected you in any way. You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw. However, if the focus group has already commenced, we may be unable to remove your anonymised responses.

Who is organising this focus group?

Healthwatch Central West London is organising this focus group, with help from Sobus. For the purposes of data protection legislation, HWCWL is the data controller for this project.

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed.

Please address your complaint to:

Healthwatch Central West London
5.22 Grand Union Studios
332 Ladbroke Grove
London, W10 5AD

Email: info@healthwatchcentralwestlondon.org

Phone: 020 8968 7049

What if I want more information on this study?

If you have any questions about any aspect of the study, or your participation in it, not answered by this participation information sheet, please contact: Eva Psychrani at eva.psychrani@healthwatchcentralwestlondon.org

Focus Group Participation Consent Form

Focus Group Consent Form Focus Group Participation Consent Form

You have been asked to participate in a focus group set up by Healthwatch Central West London.

1. I confirm that I have read and understood the participant information sheet dated October 2018 for the above study and the privacy notice at the end of the participant information sheet. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary, and I am free to withdraw at any time without giving any reason. However, if the focus group has started, I understand that it may not be possible to remove my data from the transcript.
3. I understand that all the answers in this focus group are captured and stored by audio recording equipment and any notes taken during this session.
4. The procedures regarding confidentiality and GDPR compliance (e.g. the anonymisation of data, etc.) have been clearly explained to me in the privacy

notice.

5. I agree to anonymised responses to be used in the final report by Healthwatch Central West London.
6. I agree to anonymised responses to be used in any other reports or communications arising from this focus group.
7. The archiving of data has been explained to me, e.g. I understand that my data will be securely stored for 5 years, in line with Healthwatch Central West London's Data Protection Policy.
8. I am aware that I need to be considerate of others and not repeat what other focus group members have said outside of this focus group. I am also aware that Healthwatch Central West London cannot stop or prevent participants who were in the group from sharing information that should be confidential.
9. I agree to take part in the above focus group. If you are under 18 years old this should be completed on your behalf by a parent or guardian.

Name:

Signed:

Date:

10. During the focus group, Healthwatch Central West London will be taking photographs to be used for promotional purposes and not to identify you. For full details please refer to the "consent form for the use of your image" available from HWCWL. Please tick the following boxes to indicate that you give consent for your photograph to be taken and used. If you are under 18 years old this should be completed on your behalf by a parent or guardian.

I consent for my image to be used to represent a fictional person.

I consent for my image to be used for the following purpose(s): In Healthwatch Central West London and Healthwatch England publications, on our website, in advertising and within the media

I consent for my image to be used by Healthwatch Central West London
I consent for my image to be kept by Healthwatch Central West London for five years.

Name:

Signed:

Date:

Focus Group Privacy Notice

Focus Group Privacy Notice Focus Group Participation Privacy Notice

Who we are

Healthwatch Central West London is looking at young people and digital healthcare. For the purpose of data protection legislation, Healthwatch Central West London is the data controller for any personal data processed as part of this project.

How we will use your personal data

If you agree to participate, we will ask you to sign up to the focus group after reading the information sheet and signing the consent form. We will use your data to understand the health and care issues affecting you and monitor who we are hearing from in the local community.

The nature of your personal data that we will be using covers:

- Name
- Contact details
- Gender
- Age
- Ethnicity
- Religion
- Health information
- Sexual orientation

Why our use of your personal data is lawful

Under the GDPR, we are required to have a lawful basis for processing your personal data. For the purpose of this project, the lawful basis is 'consent' and 'public task'.

Who will have access to your personal data

Access to your personal data will be restricted to the Healthwatch Central West London staff and volunteers who are working on this project. We will not report your name or anything that would make you personally identifiable in any outputs from this project and will ensure that data in the report is anonymised.

We will ask you and others in the group not to talk to people outside the group about what was said during the discussion. However, we need you to be aware that we cannot stop or prevent participants who were in the group from sharing things that should be confidential.

The collated researching findings will be published in a research report but none of your personal data will be included in the report.

Your right to withdraw

Participation in this project is entirely voluntary. Refusal to participate will not affect you in any way. If you do agree to participate, you may withdraw from the study at any time: there will not be any consequences of this. You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw. However, if the focus group has already commenced, we may be unable to remove your anonymised responses.

How long we will keep your personal data

We will retain your anonymised data for two years after the project has ended, in accordance with Healthwatch Central West London's retention requirements for project data. This data will then be reviewed and potentially kept for a further three years. Your contact data will be destroyed after the end of the project.

Your data protection rights

Under certain circumstances, you have the right:

- To ask for access to information about you that we told
- To have your personal rectified, if it is inaccurate or incomplete
- To request the deletion or removal of personal data where there is no compelling reason for its continued processing
- To restrict our processing of your personal data (i.e. permitting its storage but no further processing)
- To object to direct marketing (including profiling) and processing for the purposes of scientific/historical research and statistics
- Not to be subject to decisions based purely on automated decision-making

If you need to contact us regarding any of the above, please email Healthwatch Central West London's Data Protection Officer at info@healthwatchcentralwestlondon.org.

For further information please see: <https://healthwatchcwl.co.uk/privacy-statement/>

Your right to complain

If you are unhappy with our use of your personal data, please let us know by contacting us at

Healthwatch Central West London

5.22 Grand Union Studios

332 Ladbroke Grove

London, W10 5AD

Email: info@healthwatchcentralwestlondon.org

Alternatively, you have the right to raise any concerns with the Information Commissioner's Officer (ICO) via their website at <http://ico.org.uk/concerns/>

Engagement Tool for Digital Healthcare

Introduction

During 2018/2019 Healthwatch Central West London did a project to identify health needs and aspirations of young people in Hammersmith and Fulham and to explore how these can be addressed by using digital technology.

For the purposes of the project we produced a baseline survey that aimed to understand the following:

- Which healthcare needs are important for young people and can be addressed by using digital technology
- Where can there be digital interventions
- Where do people go if they have a health problem
- What is their knowledge of existing digital services linked to health

We explored more the issues highlighted in the survey through a series of four focus groups that we conducted at Hammersmith and Fulham Youth Council, Youth Action on Disability, Sobus and St Andrews Church with a total of 32 participants aged 11-21 years during January - March 2019.

What is this toolkit?

This engagement toolkit gives details of the two exercises we created to run the focus group discussions. It acts as a guidance only, and facilitators should tailor it according to the issues they wish to explore and the needs of the group they are engaging with. The questions provided here can be applied to either exercise, in order to adapt to each discussion.

What is this toolkit not?

It is not the aim of this toolkit to provide information about engagement principles on how to run a focus group.

Who should use it?

We hope that this toolkit could be useful to anyone who is interested in actively engaging with people of any age around digital healthcare.

Exercise 1 - Discussing Health Issues

Aim: To inspire conversations about potential uses of digital healthcare based on wider health needs.

Materials: 30-40 pictures depicting key public health issues such as nutrition, mental health, sexual health, smoking etc. This needs to be tailored

according to the specific audience.

Note: During Autumn 2018 we provided work experiences for one week to two students, aged 15-16 years old from Kensington Academy and we asked them to select pictures depicting health issues important for young people that we then use for the first exercise.

Estimated running time: 40 min (5 min picture selection, 5 min. discussion in pairs and 30 min open discussion).

Method: There are three main steps: Select picture; discuss in pairs; and then discuss in an open group.

- Lay all pictures on a big table
- Participants to spend a few minutes looking at all pictures and select one that inspires them
- Participants to discuss their selected pictures in pairs.
- Pairs could be formulated according to two different ways: Sitting arrangements (i.e. two people sitting next to each other) or - Theme selected (i.e. two people who hold a picture relating to the same issue; for example, mental health).

Questions for pairs to discuss:

1. Why did you choose that picture: what is interesting about it? What does it tell you?
 2. What is the main issue/theme that is linked with that picture?
 3. How can this issue/theme be addressed by using digital technology?
- Participants to come back into a group setting and have an open group discussion based on the conversations they had.

Open discussion: The facilitator should encourage a discussion with open questions based on the pictures selected. They could also ask some specific questions:

- Do you look for information online for these issues? Where would you look for it?
- What websites are you looking for?
- What type of information would be useful to find (prevention, self-care, what to do, where to go)?
- What format you would like it to be?
- Do you think it's important to have information only online or in other ways as well?

- Other ways that you can think of linking digital to your health?
- What are the elements that you wouldn't want to lose from "traditional" healthcare?

Learnings:

The young people we engaged with found using pictures to discuss health issues a fun and engaging way to collect their views.

- Having involved young people in the process of selecting pictures themselves helped better engage with the focus group participants that were of the same age group.
- Participants might not select pictures depicting issues that they are reluctant to discuss in a group setting. This does not mean that the depicted health issue is not important to them.

Exercise 2 - Health Journeys

Aim: To explore potential pathways for digital interventions by inspiring a visual representation of personal health journeys.

Materials: Pictures depicting key health places (i.e. hospitals), logos of digital applications (i.e. NHS 111 online) and professionals (i.e. GPs), as well as stickers of different faces (sad, happy, upset etc). Post it notes and coloured pens.

Estimated running time: 40 min. (10min to draw health journeys and 30 min for discussion).

Method: Ask participants to draw their own health journey and then discuss in an open group setting.

- Give clear instructions to participants of what you are asking them to do, inform them that the materials are there to be used should they wish to and they are not obliged to do so and most importantly state that they can choose if they want to share their drawing during the open discussion or not.
- Questions for the individual to explore to help them with their drawing:

Think about a time that you had a health concern or a problem and draw your own journey to address it.

- a) What was the issue?
- b) What were the steps you took?
- c) Who did you contact first? Where did you go next?
- d) What were your feeling in each place?

e) What would make things better?

- Participants to come back into a group setting and have an open discussion narrating their journey to the group.

Open discussion: The facilitator should encourage participants to share their experiences. Following narration, they should concentrate on a discussion with open questions based on what was shared. They could also ask the following questions:

- How did you find this exercise? What was easy/difficult about it?
- Is it important to you to see the same professional all the time? For which health issues?
- Is it important to be able to see someone quickly?
- Let's go around and see who everyone put as their first choice to contact. Why? Tell us more about it.
- What type of information you would like to see online to use that option first?
- Where in the journey could you have a digital intervention? Where you shouldn't have one?
- Are you checking your symptoms online?

Learnings:

- Asking to draw health journeys was very good for engaging with young people with learning disabilities and people of a younger age group (11-14 years old).
- We adapted this exercise by focusing on discussions instead of drawings around the different health places based on personal experiences. This has worked better for this age group.

Overall Learnings:

- Exploring health needs and how these can be addressed by digital technology allows space for innovation and meaningful suggestions. Starting with digital healthcare and asking people to fit it to their health needs, leaves no space for imagination and risks a superficial take on needs.
- The facilitator needs to be aware of the current digital healthcare climate to both inform participants and most importantly to direct discussions in a meaningful way.
- There is a need to reassure people that any engagement taken place around digital healthcare does not mean that face to face healthcare will be lost.
- People might not be familiar linking digital technology with their healthcare

despite having a smart phone or using digital in other aspects of their life. An overview of potential uses, and examples can help participants to envision a system of digital healthcare.

Healthwatch Central West London (HWCWL) is an independent organisation for people who use health and social care services. We deliver the statutory Healthwatch projects in Hammersmith & Fulham, Kensington & Chelsea and Westminster. Through our research and local engagement, we make sure that local people's views are always at the centre of decision making about health and social care.

Contact us to help improve health and social care!

Tel: 020 8968 7049

Email: info@healthwatchcentralwestlondon.org

www.healthwatchcwl.co.uk

Twitter: [@healthwatchcwl](https://twitter.com/healthwatchcwl)

Facebook: [HWCWL](https://www.facebook.com/HWCWL)

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