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Down the line: Patient stories of digital primary care in a pandemic, and building better access for all

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This work was commissioned by the Transformation Team – Public Health and Primary Care, NHS England and Improvement, East of England.

The overall aim was to hear directly from patients about their experience of using primary care, with a particular emphasis on using digital primary care, between October 2020 and February 2021.

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Introduction

Background

There have been gradual changes to the ways in which primary care has been delivered in the last five years, with some online and video and phone consultations being introduced. During the 2020/21 Covid-19 pandemic, the pace of these changes has significantly accelerated in order to minimise direct contact between staff and patients.

A number of reviews have explored the impact of these changes, but few have focussed on the perspectives of patients and carers.

This work sought to hear about primary care experiences in patients' and carers' own words. The focus was not only on the practical aspects of seeking and receiving care but on understanding how these changes were felt within the context of the pandemic. The work was designed to seek the views from a diverse group of people to understand how people's backgrounds, context and specific needs or barriers might have impacted their experiences.

We have produced a summary of the themes from these conversations with some recommendations for those involved in designing future digital primary care services. These themes and stories also informed the development of an animated film to support training for primary care staff and others.

This work was developed in close collaboration with a multi-disciplinary team consisting of GPs, digital specialists; as well as patient engagement, transformation, commissioning and communications managers, referred to in this report as the patient voice steering group.

Objectives

- To work in partnership with the patient voice steering group - a multi-disciplinary team consisting of GPs, digital specialists; as well as patient engagement, transformation, commissioning and communications managers. The team was drawn from CCGs and various regional teams (NHS England and Public Health England) with the express purpose of shaping and supporting the delivery of this commission.

- To speak with at least thirty people from a variety of backgrounds, with different needs from a range of geographical locations across the East of England;
- To produce a summary of the themes from discussions, including anonymised quotes from participants to illustrate these;
- To produce a set of recommendations and a report;
- To work with a specialist digital and film media company, and with the patient voice steering group to develop a set of personas, based on the outcome from the interviews, to be used within an animated training film.

Approach

Working in partnership with the patient voice steering group, we identified the **characteristics** of people we wanted to involve in interviews.

A **screening survey** was developed and the link to this was sent out to potential participants via three local Healthwatch organisations in the East Region. To ensure we also engaged those individuals who were not able or confident to complete the survey online, Healthwatch also **directly recruited** people based on a set of agreed criteria. In addition, we worked with a range of other organisations to recruit from groups for whom access to digital services is difficult or impossible.

Using a **semi-structured interview discussion guide** designed to capture authentic stories from patients we carried out 30 interviews, via video conference, phone or in some cases a supported phone call. These were (with permission) recorded, analysed, anonymised and coded to themes. All original notes and recordings were then deleted.

The report and recommendations were developed in partnership with the patient voice steering group.

Who we talked to

We spoke with 30 people – a diverse group of patients and carers, in terms of age, health conditions, socioeconomic circumstances, caring responsibilities, and digital life. Whilst we made specific effort to reach a diverse and range of people, future work should prioritise engaging with men and with people from BAME communities.

1 in 6 participants were **men**

We spoke to 2 people from **BAME communities**

Over a quarter of participants had **caring responsibilities**

The age of participants ranged from **20 years-old to 95 years-old**

Nearly two thirds of participants identified as having some kind of **disability**

We spoke with 5 **digitally excluded** people

Who we talked to

We spoke to patients and carers from across the East of England, with representation from both urban and rural communities.

This map shows the approximate location of the participants' GP surgeries.

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What we heard from patients and carers

Changing expectations

- **Appreciating the context, and the hard work of practice staff:** Almost everyone we spoke to said they had sympathy with practice staff. There was a perception that staff were working incredibly hard, going above and beyond, and those we spoke to understood why things might be taking longer than normal.

- **Lack of visibility:** However, some felt that GPs were less accessible, and it wasn't clear how they were spending their time. Some of those we spoke to wanted clearer communication on how the pandemic was affecting their surgery and staff, so they knew what to expect, and why.

- **What counts as urgent?** Interviewees talked about the feeling that they should refrain from contacting the GP unless it was urgent. Participants talked about how their own perception of the kinds of issues and questions which required an appointment with the GP had shifted, and people talked about putting off making appointments or going for screenings they felt were not urgent.

> "They are all working hard. My own GP periodically gives me a call to check I am OK – I really value this, though it must be hard to fit in because I know they are busy."

Getting an appointment

- **Varied systems and response times:** Participants made appointments through online systems, over the phone, or through email. Some interviewees talked about how they had received much quicker responses by submitting an online form, whilst response times over the phone were felt to have been much slower in recent months.

- **Barriers to booking appointments over the phone:** For those who were calling their surgeries, almost all participants mentioned challenges and barriers to booking appointments. These included extremely long queues on the phone, reduced availability of appointments, and not being able to book anything but same day appointments. Having to call at 8am to get an appointment was a common experience, and some said they found this impossible due to disability or working patterns.

> ”I was really worried about my husband who I care for, and I rang the practice at 8am when the lines open… I listened to the hold music for over forty minutes before I got through, only to be told all the appointments for the day had been taken and I would have to phone the next day.”

Inclusion and access

- **Being “digitally savvy” is not the only thing that people need to feel confident and comfortable using online forms to contact their GP** – it’s also about the kind of questions they have, the nature of their relationship with their doctor and surgery, and how easy it is to use specific systems. For example, we spoke to several young people who use digital technology for work, in their studies, and to stay in touch with friends and family, but said they would still much prefer to talk to a GP on the phone or in person if given the choice.

- **The psychological impact of being digitally excluded:** One person who had both neurological and physical access barriers described a feeling of ‘fading out of society’ as the world was moving more online. Research published by the Good Things Foundation supports the link between digital exclusion and Health Inequality.

> “I went onto the practice website but it was difficult to follow the process to get an appointment. There were a series of rooms but it wasn't clear which room you should go to for what. I was very confused.”

Inclusion and access (continued)

- **Services are less visible at this time:** For patients who are less able to access information and care online it can feel that services have disappeared.

- **The shift to remote care increases dependence on children and carers:** In addition to hearing from carers about their growing burden of responsibility, one visually impaired participant talked about how the changes in the way care was being delivered had left him feeling much less independent, relying more heavily on friends to support him to access care.

> "There is no one-size-fits-all. It takes away people's independence if they have to rely on a friend or family member... and some people don't have those support networks."

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Accessibility of online systems

- In almost every interview, participants raised concerns around **the accessibility of online systems**, whether for themselves, or for other people. Multiple interviewees talked about how **older patients had become re dependent on their children**, having to rely on them to use these systems on their behalf. This comes with the added issue of compromising these patients' **privacy and dignity**, as described in the quote below.

- Participants who had experience **seeking mental health support** in the last few months faced particular challenges using online systems. They felt that the forms did not enable them to explain their issues. Some said they found the process **stressful and frustrating** when they felt they just needed a person to talk to, with one participant reporting she 'gave up' seeking help in the end.

- **Visually impaired** participants felt that these systems are difficult to navigate for them, and that all practices' online systems should meet accessibility standards.

"The only way to get an appointment with our practice without spending hours on the phone is to fill in a form on the website. I don't have a computer so I asked my grandson to help me. I felt really embarrassed, because it was him who had to type the answers in about what was wrong with me."

Remote GP appointments

- **Benefits of phone appointments:** Many participants talked about how relieved they were not to have to go to the surgery, due to the time they saved and the reduced risk. One person said she found it easier to speak to the GP on the phone than in person, because she felt less self-conscious.

- **Barriers and challenges:** A few people felt uncomfortable talking about their problem with the GP when they couldn't secure a confidential space at home. One participant talked about having to lock herself in the bedroom for four hours to ensure she was away from other family members when she got the call back.

> "Phone consultations with my GP are a godsend. I have a physical disability and getting to the surgery is a real mission. This way… I get what I need quicker than waiting for an appointment."

Remote GP appointments continued

- **Quality of communication:** Some interviewees felt their interactions with their GP were more regimented and less personal over the phone. Participants talked about how it can feel harder to ask difficult questions or mention other things that bothered them, and that they don't feel fully seen or heard in the way they do when they are in the same room as the doctor.

- **It depends on the issue:** There was a feeling that some things are better (more efficiently and effectively) dealt with over the phone, but that some things really require in person interaction.

"I'm conscious that if the doctor isn't seeing you, they're not picking up on something that you might not mention on the phone… On the phone, it feels more regimented."

Follow up

- **Referral to secondary care and mental health support:** Most people were happy with the follow up they received, including referral on to other clinicians or secondary care. However, those who talked about seeking support for mental health problems were less satisfied with the follow up and support they received.

- **Sharing results**: Some interviewees said that the way the GP practice shared information wasn't always appropriate – for example, receiving test results over text at 7:45am, so there was no way of asking questions. Another person talked about receiving a call from the GP an hour after they were supposed to ring, so they were no longer in a private, quiet space.

"I received a text with my results at 7:45am while I was walking the dog… "A phone call would have been better… then I could ask the questions. The text gave me no idea if the results were normal or abnormal.

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Opportunity spaces

Opportunity spaces for local service design and delivery

Through this research, four opportunity spaces for increasing the accessibility and inclusivity of digital and remote primary care delivery emerged. Below we explore prompts and considerations around each of these opportunity spaces in turn.

1. How can we **ensure patients and carers have choice** over the ways in which they can engage with their GP surgery?

2. How can we **support practice staff** to continue to deliver high quality care over phone and video consultations?

3. How can we **involve patients and carers** in the design of new systems, processes and services?

4. How can we **embed access and inclusion** into the design of our communications, systems and services?

1

How can we **ensure patients and carers have choice** over the ways in which they can engage with their GP surgery?

Prompts and considerations

- What choice do patients and carers currently have at different points in the patient journey? I.e. from how they can contact or share information with their surgery to how they can book an appointment, the type of appointment they can have, and how they receive information.

- Is there potential for patients and carers to have greater choice at any point along this journey?

- Do patients and carers understand the choices they have available to them, and why this is the case?

2

How can we **support practice staff** to continue to deliver high quality care via phone and video consultations?

Prompts and considerations

- Many GPs have been able to access training to deliver phone and video consultations, including the RCGP 'Top 10 Tips for successful GP Video and Phone Consultations'.
- Could training be developed specifically around supporting people with mental health concerns via phone and video call?
- Could training be made available to other primary care staff including nurses, allied health professionals and reception staff?
- Where this doesn't happen already, could phone and video consulting be included in GP training?

3

How can we **involve patients and carers** in the design of new systems, processes and services?

Prompts and considerations

- Are existing routes for patient and community engagement being fully utilised? Do we offer engagement opportunities across all types of communities, and Is there any scope to further or deepen the level of engagement or involvement?
- Are patients and carers currently involved in co-developing or testing digital platforms before rolling them out? What feedback mechanisms exist?
- Can patient experience data/feedback be used in assessing the impact of delivering care in different ways? Is there potential for this data to be linked into data on clinical and patient safety outcomes?
- Could local volunteer digital champions play a role in supporting those patients and carers who are keen to access digital services but lack the skills or confidence to get online?

4

How can we **embed access and inclusion** into the design of our communications, systems and services?

Prompts and considerations

- Are current public facing communications, including pre-recorded messages, written and online content, accessible to everyone? What changes might help to ensure all patients and carers have access to the same level and quality of information?
- Are people with a range of technical abilities, disabilities and ages involved in testing or providing feedback on communications, systems and services?
- Do any systems disadvantage certain groups? For example, do call waiting systems disproportionately affect those with pay as you go phone and data services?

> "It would be great if before a practice website goes live it is accessible, for example all content can be used in 'read aloud' software. There are visually impaired people who would be willing to work with practices to help this to happen."

Opportunities spaces for regional and national programmes

There have been a significant number of studies commissioned and carried out before and during the pandemic which have focussed on the impact of remote primary care consultations, but very few of these have been developed with input from patients and carers. Further work to develop a deeper, broader understanding of remote healthcare from the perspective of patients and carers will help to address this gap.

Research to understand the impact of virtual appointments on patients and carers would help decision makers to gather useful insight to feed into primary care service delivery. This could include systematic collection of patient experience data to underpin priorities within digital service development work.

Outputs from this work, including this report and the accompanying animation, can be used to illustrate relevant areas of digital primary care development and transformation work, as well as stimulate interest in the relationship between the way people access and experience healthcare, and their clinical outcomes.

There is an opportunity to reflect on current and planned digital primary care programmes of work and explore approaches such as co-production to enhance the opportunities for patient involvement, in order to optimise patient experience and maximise positive clinical outcomes, and patient safety. This could involve developing a reference group of patients and carers recruited from amongst participants in this study.

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We are grateful to the 30 patients and carers who shared their stories with us.

You can see the animation that was developed to accompany this report here.