

**SHARED DECISION MAKING -
IS PROGRESS THREATENED BY THE MOVE
TOWARDS REMOTE CONSULTATIONS?**

FOREWORD



Alison Dunlop

Senior Director, Patient
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Engine MHP is delighted to have collaborated with the Patients Association, an independent patient charity campaigning for improvements in health and social care for patients, to establish our first Patient Voice Panel. The Panel brings together an ethnically diverse group of patients from a variety of demographics, living with different long-term conditions. Our aim is to understand the unique perspectives of lived patient experiences to help shape the decisions and communications strategies of organisations involved in healthcare.

This report sets out the findings from our first Patient Voice Panel meeting in October 2021, which focused on the hotly-debated topic of remote consultations and their role in enabling effective shared decision making for patients. The discussion explored whether remote consultations are **enabling** or **hindering** the opportunity for patients to

express their values and goals to healthcare professionals in decisions about their treatment options and individual care. With the recent announcement of a £250 million NHS winter access fund for primary care to increase the level of face-to-face appointments, the debate regarding the merits of in person versus remote consultations continues to dominate political and media agendas. While the availability of remote consultations has provided patients with clinical access in unprecedented times, how they are conducted going forward and to what extent, remains a critical focus.

The Panel findings highlighted that remote consultations have the potential to improve some aspects of shared decision making, identifying a clear role for industry to develop targeted digital online tools that provide care and support solutions for patients and clinicians. However, not all patients can engage on equal terms with digital services and there is growing evidence to suggest that remote consultations can act as a barrier to shared decision making if not used correctly.

Industry has a critical role to play in enabling patients to make informed **choices** about their treatment and care. The solution must lie in working in partnership with patient groups to understand the perspective of real life patient voices from different demographics to help meet the diversity of need.

Our collaboration with the Patients Association to create the Patient Voice Panel is an important step in our ongoing commitment to represent the perspective of the **whole** patient population, with the ambition of achieving equitable patient centric and sustainable healthcare systems for the future.

Our commitment to patient partnership at every level makes shared decision making an essential part of an individual's care and treatment decisions. As the NHS strengthens its remote care offer for patients, we hope there will be a thorough evaluation of the benefits and drawbacks for shared decision making. We must work together across government, charities, industry and patient communities to better understand the possible clinical and ethical challenges associated with remote consultations, alongside the impact on existing health inequalities. Together, we need to develop solutions that ensure shared decision making becomes a reality for all patients.”



Rachel Power
CEO Patients Association



I think everyone can understand why, during the height of the pandemic, GPs couldn't provide access in the normal way. But we are way past that now, life is starting to return almost back to completely normal; and as that is happening it should be happening in our GP surgeries too, and more GPs should be offering face-to-face access.

I am determined to ensure patients can see their GP in the way they want, no matter where they live. My only target is choice. I want patients to feel they have a choice.”

+ Savid Javid
Secretary of State for Health and Social Care



In 2022...

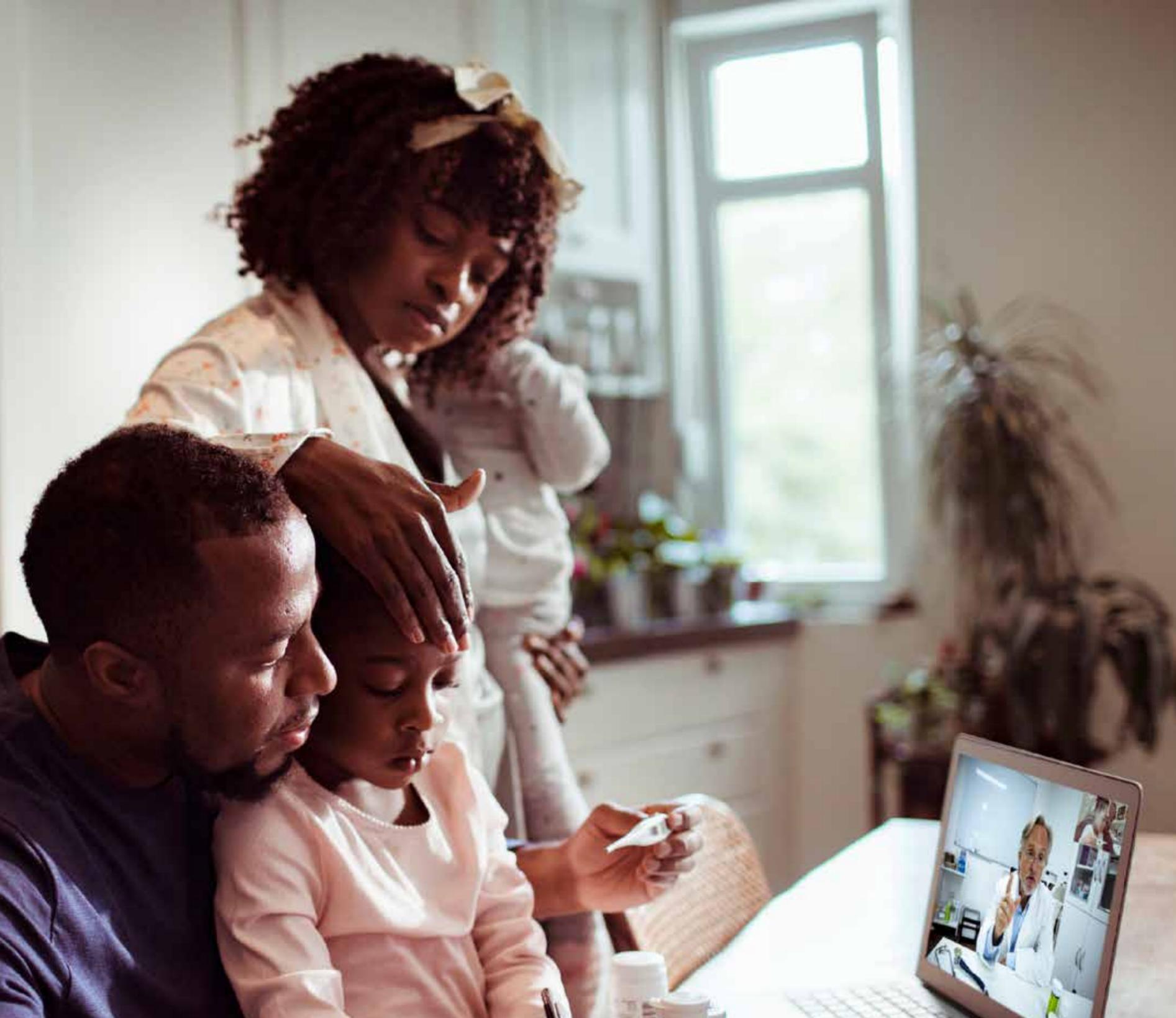
Future Patient Voice Panel workshops are planned to explore patient perspectives across a range of topics that impact health and social care.

The findings in this report are drawn from a small sample of the UK patient population. Responses provide insights into patient views across a diverse group of people from across the UK. Further details regarding the results are available on request from mhpadvocacy@mhpc.com.

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“We need to move forward with digital, as it will benefit us all, but it will need to be done in a proper manner - as it works!”

HEADLINE INSIGHTS

Patients on our Panel valued the flexibility, reduction in travel times and the opportunity to remain in the comfort of their home provided by remote consultations.

They also felt that remote consultations have the potential to improve some aspects of working together with clinicians to agree their treatment goals and gave them the opportunity to speak with and gain the perspectives of more than one clinician. This was seen as a significant benefit that has potential for shared decision making.

However, to enable effective shared decision making, the consultation types offered need to be able to flex to meet the differing needs and preferences of patients. They also need to be in a format that are suitable for the types of issues being discussed. For these reasons, it was felt that there is still some way to go to ensure that all patients are provided with a choice of consultation types that reflects their individual needs.

These are some of the topline findings

- 01** **There is no one-size fits all consultation model and a mix of patient choice and healthcare professional judgement is important.** What may work for one patient, will not work for others. For example, some patients may feel more comfortable and empowered in their home setting, while for others, home is not a comfortable space. Similarly, there are ethical considerations around the use of remote consultations for certain groups, including those for example with dementia and a strong rationale for the benefit of non-verbal cues.
- 02** **Remote consultations can have benefits,** limiting the need to travel, providing flexibility to patients who are also carers, or enabling monitoring of a condition when tests are not required. There is also the potential for health information to be easily disseminated afterwards by email.
- 03** **There are types of appointments for which a face-to-face consultation is more appropriate,** including receiving a diagnosis, needing an examination or receiving test results. It can also be important for these consultations to be immediately followed up with the opportunity to receive support, for example from a nurse specialist.

04

The technology used can make the quality of remote consultations vary widely. As would be expected, the quality of the consultation is only as good as the technology used to facilitate it.

05

Several challenges presented by remote consultations also occur in face-to-face care. Challenges leading to poor-quality consultations, such as a lack of preparation by healthcare professionals and the increased use of locum GPs who do not know the background of the patients need to be addressed across all consultation types.

06

The success of a consultation is linked to the disposition and communication skills of the healthcare professional (and patient).

The diverse perspectives of our patients clearly show some benefits from remote consultations. For example, enabling carers to participate in the discussion can help to ensure that patient perspectives are effectively represented in determining treatment and care. But they also show that it is important to ensure that remote engagement is not at the cost of patient choice. Patients can value face-to-face clinical contact when facing key decision points in their care. This could particularly apply to patients who are socially or digitally disadvantaged. They may feel disenfranchised from shared decision making simply because it involves a channel that they struggle to engage with.



A CLOSER LOOK AT THE PATIENT VOICE PANEL INSIGHTS

In this section, we delve into some of the broader themes highlighted by the patients as part of the Panel discussion. We draw on sector-wide principles from the NHS Comprehensive Model for Personalised Care¹ and recent NICE guidelines, to shine a light on some of the areas of critical importance to understanding and challenging the nuances of shared decision making within remote settings.

¹ NHS Personalised Care Group. Universal Personalised Care: Implementing the Comprehensive Model. January 2019 <https://www.england.nhs.uk/publication/universal-personalised-care-implementing-the-comprehensive-model/>

Empowering patients

The Panel was divided as to whether members felt more comfortable talking about difficult aspects of care with a doctor face-to-face or remotely.

Several patients commented that they are better equipped to take notes during remote consultations. Some stated that they could stay more focused and recall the conversation better as they felt that the “*conversations evolve*”, compared to consultations in person with a doctor.

Other patients indicated that they felt more comfortable asking “*challenging*” questions in a face-to-face setting, such as “*why is this the best treatment option for me?*”.

These insights can be viewed in the context of the recent update to NICE Guidelines regarding embedding shared decision making into routine practice (June 2021²). Many of the recommendations guide healthcare professionals on how to create safe spaces for patients to ask questions and provide specific techniques for communicating the benefits and risks of treatment options.

NICE guidelines also promote the importance of healthcare professionals considering patient preferences and individual needs as part of the decision-making process. Increasingly, techniques such as ‘teach back’ or ‘ask 3 questions’ are being used to help assess the patient’s understanding during consultations in remote settings. The use of shared decision-making aids or tools is also proving effective in helping patients better understand their treatment options and, in many cases, these result in patients feeling more satisfied with the outcomes. However, none of the patients on our Panel reported being introduced to digital decision aids as part of their remote consultations.

Adapting consultations to meet patient preferences and needs

The Panel made the case for the importance of flexibility as part of discussions with healthcare professionals during remote consultations. Certain topics were considered appropriate as part of an online discussion e.g. medications, side effects and ongoing issues. However, there was widespread support for the important role that face-to-face appointments play in areas such as physical examinations to identify new conditions, together with the 'holistic' patient view that in person appointments provide to healthcare professionals.

“The news isn’t always good. So if you’re sat in your own home, to me that’s a much better place to receive bad news rather than having to come out to see a waiting room full of people. I wouldn’t want that at all.”

While some patients may feel more comfortable in their home setting when receiving bad news or dealing with inevitable wait times and delays, home settings are not always a comfortable space for everyone. Many patients felt that healthcare settings are better equipped to make them feel more comfortable and open when it came to having a high-quality conversation with their healthcare professional. Many of the Panel noted that there could be several instances in the home settings that compromised their feelings of privacy.

The differences of opinion on home vs in person consultations led to a consensus that healthcare professionals should consider patients' preferences and needs when determining the format of the consultation.

Panel members highlighted the individual capability of patients as a fundamental factor in governing any decisions regarding the format of a consultation, and this is equally an important consideration for shared decision making³. There were questions relating to the ethical side of remote consultations, for example concerns for elderly parents who suffer from dementia. In instances like these, it was felt that a face-to-face consultation would allow for more nuance in the conversation and provide a significant benefit to healthcare professionals from non-verbal cues.

There was overwhelming support for the importance of taking a tailored approach to the format of consultations, reflecting the need for patients to make the choice that is right for them.



Technology limitations

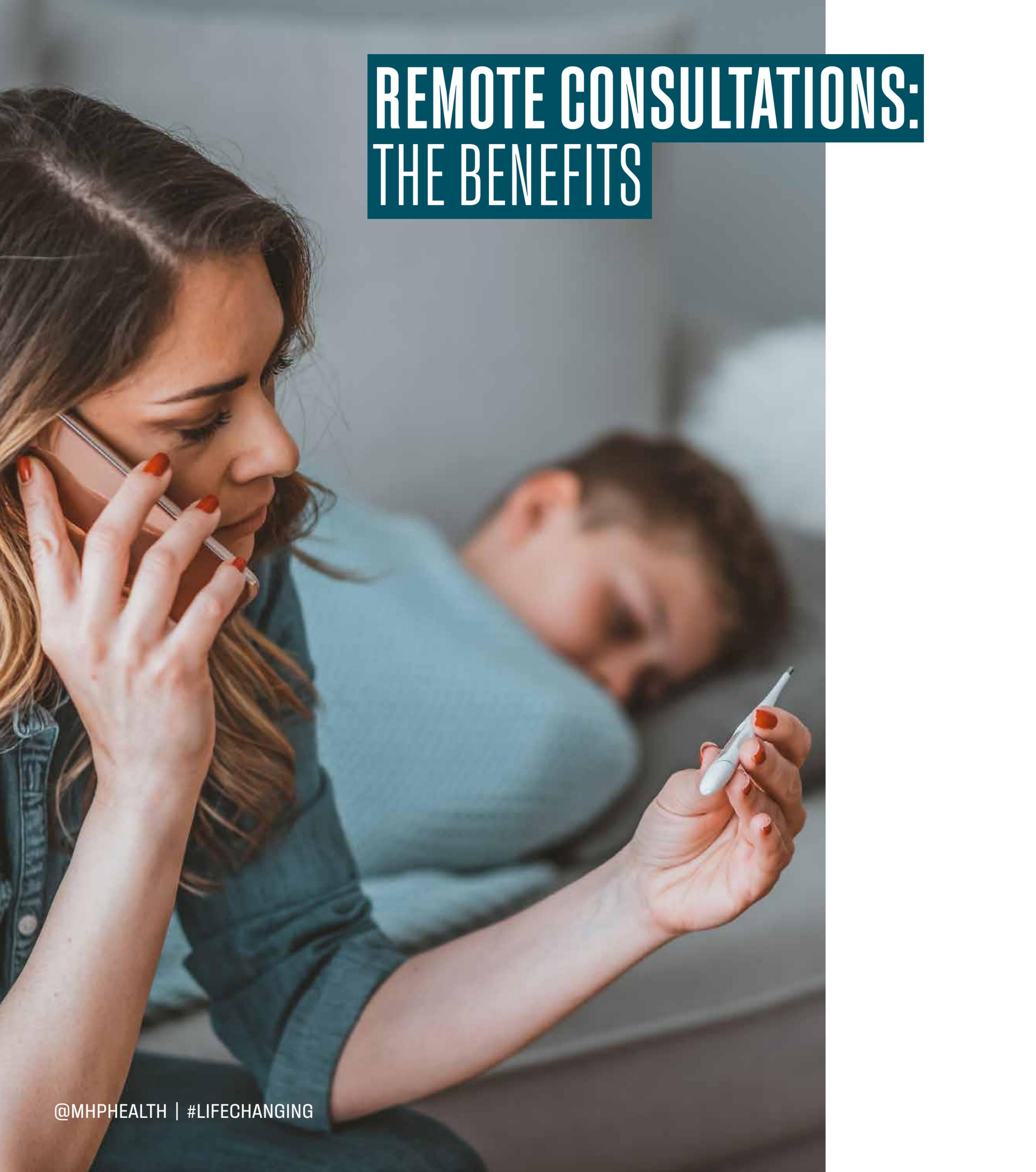
“But for some of us who are older, we need that reassurance... we have experienced primary care and secondary care at its absolute best for many years and, at the moment, I see us taking a backward step, until they get so many digital issues sorted out.”

The Panel discussed the drawbacks of the increased reliance on telephone call backs as part of remote consultations. The telephone call back model was called out by patients as being “inherently flawed” and requiring “a significant redesign”. Several patients shared that they would call their GP surgery and be told that the doctor would ring them back but would not be given an indicative time. Should a patient miss the call, they are often required to start the process all over again. This ‘stop-start’ form of care can be disruptive to patient interactions.

Patients commented on the preference for digital consultations rather than telephone conversations as it offers the option for the healthcare professional to see their patient. There was significant disparity in services offered to patients - some Panel members had never been offered a video call and others did not understand why they had been offered a telephone consultation over a video consultation, or indeed a face-to-face appointment.

Several of our Panel members reported that no technology instructions had been shared, which meant that potential technical issues were not raised or troubleshooted in advance. Patients reported on several occasions waiting in excess of 90 minutes to see their healthcare professional.

REMOTE CONSULTATIONS: THE BENEFITS



The Patient Voice Panel participants noted a range of benefits related to remote consultations:

- + Enables the involvement of carers and other family members who may not have been able to attend during the pandemic.
- + Facilitates the involvement of more than one healthcare professional at one time, which may not have been possible during a face-to-face setting. This is particularly relevant to patients with co-morbidities.
- + Maintains regularity of consultations that may not have been geographically or physically possible.
- + Offers time-saving benefits and efficiencies for the patient, carers and healthcare professionals.
- + Helps to manage financial barriers to care as patients are not required to pay for transport or miss work.
- + Minimises exposure to infection, notably COVID-19, but also protects patients and clinicians from other infections.
- + Inclusivity benefits for patients with mobility issues that may struggle to access face-to-face care.
- + Provides superior security and comfort to the patient, particularly when considering the uncertainty of waiting times prior to a consultation.



I had my usual face-to-face appointment with my consultant to receive some scan results. I was concerned that they might reveal a secondary cancer, so I brought my husband along for support. My son lives in the United States, so in normal circumstances he would be unable to join. However, my consultant arranged a Zoom link so that my son could also be present virtually - this was very much appreciated.”

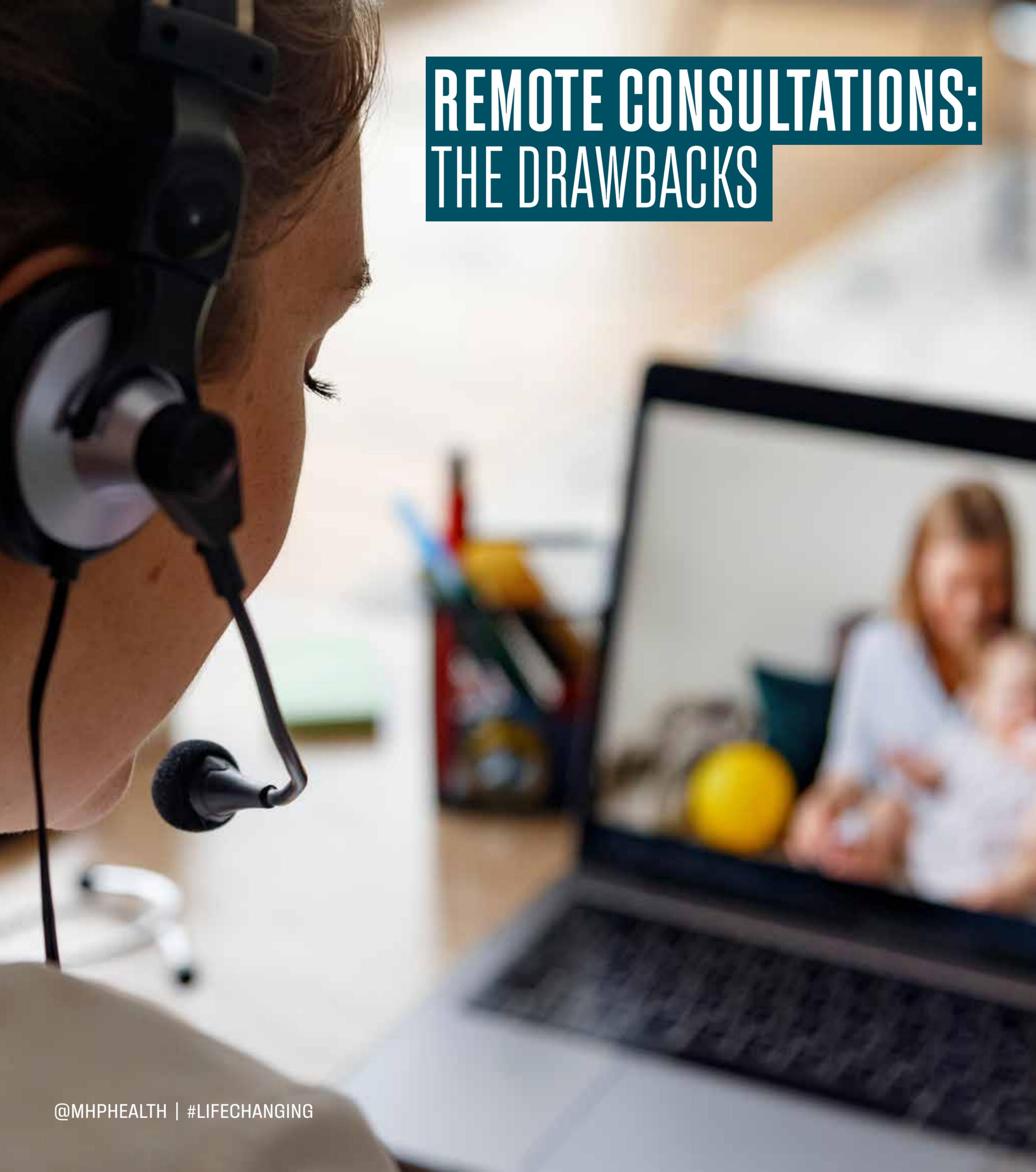


I am a patient myself and care for my son who has comorbidities. Remote consultations are extremely helpful as, in both cases, we are able to speak with a number of different consultants in the same online meeting, which would be much harder or impossible to arrange physically.”



I am a carer for my adult son. On average, we have to attend several appointments a week. We have found that remote consultations have been helpful at relieving some of the burdens associated with travel and cost, in addition to the physical and mental impacts of travelling. Via telephone, both my son and I can join easily and if my son is asleep, I am able to speak on his behalf as his carer.”

REMOTE CONSULTATIONS: THE DRAWBACKS



The Patient Voice Panel noted the following drawbacks related to remote consultations:

- + Significant delays at several time-points e.g. between contacting the surgery and getting a response or receiving a call back, prolonged waiting times in the virtual waiting room, in relation to telephone connectivity and delays in resolving any issues.
- + Lack of supportive information to guide patients on using the technology and what to expect from the consultation process.
- + Can introduce reliance on internet services and phone connectivity, which can be particularly challenging for certain groups, such as older patients and patients with learning disabilities.
- + May result in a breakdown of communication; there is an increased tendency for patients to feel they are being rushed, a concern that may also apply to face-to-face consultations.
- + Concern over the suitability of remote consultations for certain appointment types e.g. examinations.
- + Increased challenges with ensuring translators are present during remote consultations.
- + The effectiveness of a telephone or digital consultation is disproportionately dependent on the personality and disposition of the health professional conducting it.
- + Privacy may be compromised during remote consultations.



From speaking to other patients, most practices appear to have the e-consult process. However, it's not uncommon for it to take up to a week to receive an acknowledgement of an initial application and a further three weeks to receive a response from a healthcare professional."



Telephone appointments just take time. I find that nine times out of ten, I make a telephone appointment, but I am then required to visit my GP, before getting referred for a specialist appointment, all of which delays things quite a lot.”

It can take you up to four weeks to get a response from a healthcare professional and I don't think that is good enough.”

THE ROLE FOR INDUSTRY

We asked our Panel what they believed to be the key actions required to ensure that remote consultations provide effective support for patients when making decisions about their health and care.

Five key themes came out of the discussion, providing opportunities for industry to support patients to participate in high-quality shared decision making in an increasingly digitised healthcare system.

01

Co-development of strategies and tools to support the assessment of digital needs and preferences of care models for patients. Digital and telephone systems must have clear troubleshooting strategies to assist patients with technical difficulties.

02

Benchmarking initiatives to improve consensus on measuring the quality of shared decision making. This is critical to ongoing assessments regarding the quality of remote consultations and the ultimate impact on patient outcomes.

03

Considering the unique aspects and nuances of shared decision making in remote vs face-to-face settings when developing and optimising existing shared decision making tools.

04

Collaborating with patient advocacy groups when developing supportive guidance for patients and healthcare professionals to ensure that the patient perspective is reflected in the types of consultations that are best suited to remote consultations.

05

Creating patient engagement strategies targeted at specific groups, particularly the underrepresented communities who often have poorer outcomes, to ensure more equitable uptake of shared decision making in remote settings.



IN CONCLUSION

While patients on our Panel expressed a range of views and experiences in relation to remote consultations, there is a compelling argument to indicate that remote consultations have the potential to positively improve some aspects of shared decision making. With the £2.1 billion recently pledged to digitally transform the NHS, we can expect to see an increase in connectivity and adoption of digital tools that will be crucial in supporting patients as part of a radical reshaping of the model of health and care delivery.

However, different patients inevitably have different perspectives. The consultation methods for each patient should be agreed with consideration given to the patient's knowledge and understanding of their own individual health needs, alongside healthcare professional clinical judgements.

As our research highlighted, not all patients will be able to decide on the most appropriate care format for them so they may require a default face-to-face consultation. The role of the healthcare professional working together with patients to agree the best care format is critical to addressing the polarisation currently evident between different patient communities.

The insights from the Patient Voice Panel have highlighted that the role of shared decision making is integral to evaluating the benefits of remote consultations. It is an essential factor in ensuring decisions are based on lived patient experiences and it is a critical step in achieving the ultimate ambition of today's NHS - positioning patients as equal partners in their own care.



APPENDIX METHODOLOGY

Patients were recruited for the MHP Patient Voice Panel via the Patients Association e-newsletter.

Thirty-four people expressed an interest in participating in the Patient Voice Panel. Based on the responses to the patient questionnaire, participants were selected to ensure the cohort was ethnically diverse, including patients from under represented and marginalised groups, different age ranges, carers and patients with a balance of rare and chronic conditions.

Twelve patients were selected for the Patient Voice Panel. Four of the twelve participants also identified themselves as being carers for family members. Eleven patients participated in a 2.5 hour Panel in October 2021 and responses were based on patient experiences of primary and secondary care.

Panel members:

- + **Gender:** n=7 female, n= 5 male
- + **Age:** The mean age of Panel members was 60 and ranged from 22-89
- + **Ethnicity:** White British (n=7); White Other (n=1); Asian British (n=1); Asian Indian (n=1); Mixed multiple ethnic groups (n=1) White Irish (n=1)

Region participants lived in: South West (n=3); South East; London; Yorkshire and the Humber; East Midlands (n=8); North West (n=2); Scotland (n=2)

Participants experienced a wide range of health issues including:

- + Asthma - Chronic obstructive pulmonary disease (COPD), Chronic fatigue syndrome
- + Lung cancer

- + Physical and multiple mental health conditions
- + Long term effects from polio and breast cancer
- + Dyslexia, Psoriasis, Reflux Gastroesophageal, Obsessive compulsive disorder, Autism (not diagnosed)
- + Prostate cancer
- + Psoriatic arthritis
- + Atrial Fibrillation, Cardiomyopathy, Vasculitis, Fibromyalgia
- + Type 2 diabetes
- + Allergic bronchopulmonary aspergillosis, a chronic lung condition
- + Several long-term health conditions (not specified)
- + Women's health issues

Participants were asked the following four questions:

- Q1.** If you've had experience of digital consultations:
- a)** Was anything positive about it because it was virtual?
 - b)** Was anything negative about it because it was virtual?
- Q2.** What do you think are the **benefits** of digital consultations for shared decision making?
(Supporting people to make decisions about their health and care?)
- Q3.** What do you think are the **drawbacks** of digital consultations for shared decision making?
(Supporting people to make decisions about their health and care?)
- Q4.** What do you think are the **key factors** that are needed to ensure that digital consultations best support people to make decisions about their health and care?

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