Preventing cardiovascular disease
What patients tell us

Report from a patient and carer involvement event

11 March, 2020

> “Primary care is the first point of contact for most people with a health concern. We have a real opportunity to reduce the numbers of strokes and heart attacks by managing and preventing some common conditions. However, it can’t just be about getting more people to see their GP. A large part of our programme is about how to make new things happen, which is why we wanted to bring patients into the conversation to help us work out the best ways of doing that.”

Dr Matt Kearney
GP and Programme Director,
UCLPartners

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Responding to COVID-19

Following this event, the COVID-19 pandemic came upon us. In response, we have adapted our work. We are now developing a primary care support package, focused on CVD and other long-term conditions.

We have been able to use the insights gathered at this event to help inform our wider primary care work and have conducted virtual involvement activities to ensure patient and public involvement remains at the heart of all we are doing.

Introduction

Two-thirds of premature deaths in our local population are caused by cancer or heart disease. Nationally, cardiovascular disease (CVD) is responsible for more than a quarter of all deaths, with around 36,000 people under the age of 75 dying from it each year.[1]

There are excellent interventions that can prevent many heart attacks and strokes if the underlying high-risk conditions are spotted early enough. Three of these conditions are:

- High blood pressure
- Irregular heart rhythm or pulse (known as atrial fibrillation)
- High cholesterol.

What's the problem?

Unfortunately, these underlying conditions may have no obvious symptoms, making them hard to detect. So in many people they are not treated correctly, or not identified in the first place. There are also health inequalities in this area. People in the most deprived areas are four times more likely to die of cardiovascular disease than those in the least deprived areas.[2]

What are we doing about it?

At UCLPartners, we want to tackle this by finding new ways of identifying and treating these conditions within primary care, so that we can prevent strokes and heart attacks at scale. As a first step, we wanted to develop a better understanding about patients' experiences of being tested and treated for these three high risk conditions. That's why we held a patient and public involvement event.

About the event

In March 2020 we held a patient and public involvement event, attended by approximately 30 people with these conditions, and carers. The participants came from across the UCLPartners region, representing a diverse range of age, gender, and ethnicity although we did not record demographics.

At the event, we facilitated group discussions and one-to-one interviews and recorded what people said. The conversations on the day form the basis for this report, with people's views divided into six themes.

The event also aimed to test conclusions around patients' information needs from the National Voices report Surfacing Unmet Need.[3]

The report presented findings from a survey of National Voices' charity members on the unmet needs of patients, service users, carers and their families managing long-term conditions. Report author Sarah Brooke shared the report's findings at the event.

We will use the insights and information gained to better identify people with high blood pressure, atrial fibrillation and high cholesterol and, ultimately, to prevent strokes and heart attacks.

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[1] British Heart Foundation (2020) Statistics factsheet. www.bhf.org.uk/what-we-do/our-research/heart-statistics

[2] Public Health England (2019). https://publichealthmatters.blog.gov.uk/2019/02/14/health-matters-preventing-cardiovascular-disease/

[3] National Voices (2020) Surfacing unmet meet. www.nationalvoices.org.uk/publications/our-publications/surfacing-unmet-need

The need for clear information

Patient-focused information plays a crucial role in educating and reassuring patients and their loved ones about conditions, treatments, risks, benefits and practicalities. Many patients and families find it hard to take in information during a consultation and need to access information at their own pace, when the time is right.

At the event, patients' views varied. Some preferred to simply follow their doctor's instructions, while others described a 'fear of the unknown' and wished they had received more information. Sometimes, loved ones sought information on patients' behalf.

Some offered examples of poor information interfering with adherence to treatment. For example, a patient might stop taking a critical long-term medication (such as blood-pressure treatment) if no one had explained that they may not feel any different day to day once they started the medicine.

Patients raised health literacy as a significant issue. Many found it hard to understand information such as blood pressure readings. Those who did struggled to find consistent information (for example, about statins). Some highlighted a need for accurate, up-to-date information targeted at an appropriate reading level – especially in communicating complex concepts, such as risk.

> **There is a very good information sheet in the packet. If you read it, it's good enough.**

> **Information? What information? All I was told was 'Take these tablets once a day.' That's all the information I was given.**

> **I think it would be good if there was some sort of information sheet – not just on the medication, but on general lifestyle, just to remind people.**

CASE STUDY: HIGH CHOLESTEROL

Anita

In terms of my health, I've been knocked about a bit! But I like to stay active and be useful as it helps me feel like a person and not just a sick person.

After I had head and neck cancer I didn't feel well for a long time. I was tired and run down. Of course, it could have just been because I'd had major surgery, but the GP ran loads of tests, and that's how they found that I had high cholesterol and put me on statins. Once they discovered what it was, it was all very straightforward.

I have other conditions too, so I take seven tablets a day. I have to order them – I either take the form to the doctor's or I do it on the computer. Some are delivered by courier, which means waiting in.

I go to see my consultant two-to-four times a year, but if there's something wrong, I go to my GP. There are two doctors in the practice who know me, who I feel comfortable with. I would like to see them every time but it's very hard to get appointments. I've had to wait a long time to see the person I want to see.

If I see another doctor, they have to get their information from the computer, so they're talking to you while they're looking at the screen. I don't feel as comfortable and I probably don't open up as much.

Overall I am happy with my care, though I would like different services to work together better. It can get tiring having to tell your story over and over again. If I wasn't so looked after by my main consultant, I would be more proactive. But because I know that I've got such excellent care, I can just relax.

The importance of trust

Patients said their anxieties about health conditions were compounded by fears about treatment and wider concerns. Many experienced strain associated with attending and coordinating appointments, monitoring symptoms, managing medications, adopting lifestyle changes and so on.

Some were worried about the impact of medications. Others reported that fears of side-effects (particularly with statins or anticoagulants) put some patients off from seeking medical help in the first place, or not following their treatment regime. One suggestion to tackle this was better patient information. Others shared fears about misdiagnosis, or of returning for check-ups in case of poor results.

For some, concerns about funding sources and the influence of financial incentives on clinical decisions made it hard to trust that clinicians were always acting in the patient's best interest. Some described a fear of healthcare generally, explaining that those finding it hard to adjust to a new diagnosis may be resistant to taking treatment. For them, a strong trusting relationship with the GP was essential.

> **If you have a good relationship with your GP and trust them, you're less likely to be worried about your health.**

> **I take eight different medicines a day and I don't think I've ever read the packet. I just trust the doctor.**

Person-centred care

Person-centred care involves focusing on the whole person, taking into consideration what matters most to them, and tailoring communication and interventions to their individual needs, priorities and values. Some patients felt that clinicians did not always see the person behind the condition and simply delivered instructions rather than having a conversation.

People with long-term conditions wanted clinicians to recognise the expertise that develops through managing one's condition 24 hours a day. They wanted a more holistic approach that looked at their overall health and the impact of their condition on their daily lives. They argued that the length of GP appointments encourages a focus on just condition at a time.

Some patients raised a need to streamline tests such as blood pressure and cholesterol, arguing that providing multiple tests at the same time would save time for patients and clinicians alike.

Many felt that ad hoc check-ups with community pharmacists (for example, for blood pressure) could provide reassurance. However some noted that if the reading was high, they would have to make a separate appointment to see a GP, requiring two trips rather than just the one.

> **I think what would be easier is having kits available for people to self test.**

Enabling self-management

Most long-term conditions involve extensive self-management efforts and many patients at the event were eager to play an active role in their health, given the right support. Some reported leaving appointments wondering if the doctor had told them everything they needed to know or whether there were gaps in their understanding.

Patients discussed various self-monitoring options, including home testing kits. One proposal was more community health coaches, to support patients and reduce demand for primary care. Other suggestions included roadside testing booths, self-testing pods in GP practices and chemists, and individuals purchasing machines to use at home.

Many wanted to know more about how weight, diet and physical activity could impact on their condition and how they could improve their health – if only through signposting to a reliable source. For treatments involving long-term medication, patients wanted to understand more about the risks of not adhering to treatment or lifestyle advice, and of developing related conditions.

> **If we had a national message of the month, like 'Have you checked your blood pressure?', it could increase public awareness.**

> **They should give the patient a leaflet and say 'Here is the British Heart Foundation website: it will tell you what to eat, how much exercise you need – everything you need to do.'**

> **My son was just told 'You need to take these tablets.' Luckily, my daughter was there. She asked all the questions, so she got the information he needed about weight, diet and exercise.**

CASE STUDY: HIGH BLOOD PRESSURE

Rodney

I had a family history of men dying young with cardiovascular problems, so my GP checked my blood pressure in my mid-twenties. When I was told it was high and given medication, I was relieved. I thought 'Aren't I lucky!' Unlike my uncles who died in their forties, I had some advance warning.

I'm now fitter in my sixties than I was in my forties. Between the ages of 42 and 54 I couldn't work at all. Now, most of my medical problems have been resolved.

I'm on an awful lot of medication – I take over 30 different medications every day – but now I order everything online, that cuts down massively on GP appointments. In the past, my orders often had missing items, but this hasn't happened lately. I'm quite happy to go to the pharmacy because it's a nice walk, but to my amazement, they have started delivering which is very convenient.

My GP is very good. She likes to know what's going on at my different hospitals and helps me coordinate everything. She's quickly resolved occasional difficulties.

I find in every health issue there's a bit of DIY involved – taking my blood pressure, making phone calls or looking things up online. Both my GP and my kidney consultant said, if my blood pressure goes down, I can stop taking one tablet without consulting anyone. I don't mind being proactive. I do wonder how do older people who are less clued up manage it.

I actually think I've been incredibly well looked after. I haven't been completely free of problems, but I feel very lucky.

CASE STUDY: HIGH BLOOD PRESSURE

Jacob

I take my blood pressure medication and do three blood pressure readings every morning, along with testing my blood sugars.

I've had Type 1 diabetes for over 70 years, since I was diagnosed in 1950 at the Royal Free with 'the sugar', as it was known then.

Most diabetics die of a cardiac condition, so at the diabetes clinic they always measure my heart performance. Three years ago they put me on a running machine and afterwards they told me I had very high blood pressure. They gave me a holter monitor to measure it over 24 hours and then told me I needed blood pressure-lowering medication. I took the news as a matter of course.

My character is formed by the diabetes: if I'm told to do something, I do it. I have a sense of responsibility to those who've looked after me, too. So it's not my job to export my illness to everybody else – it's for me to deal with.

I think the reorganisation of healthcare has made it more fragmented. It would be nice to get back to a situation where people had close confidences with their GP and pharmacist, so there was more continuity and trust. Appointments can be a bit chaotic – the hospital will try to change things at the last minute.

But I'm not complaining. More than one doctor has said to me 'You should be dead', and I'm aware of how much I've been given. If I get through to tomorrow, I'll be absolutely delighted.

Patient–clinician relationships

Among patients at the event, there was widespread sense that a trusting relationship between patient and clinician lay at the heart of their experience of healthcare.

Good communication skills were seen as imperative. Some identified a poor 'bedside manner' as a key barrier to attendance or adhering to treatment. Some felt they were 'bothering the doctor' by making appointments. Others described a power imbalance.

Some patients saw the appointment as a one-way journey, with the patient sharing their information and in return receiving a diagnosis and medication. They wanted a more equal discourse, with healthcare professionals bringing their clinical expertise and patients bringing their expertise of what works for them.

Others were concerned about possible changes in healthcare systems – some suggested more service delivery could move into community pharmacy, but this view wasn't shared by all. Others wanted to see a consultant for conditions such as atrial fibrillation rather than their GP.

All these views were balanced by an acknowledgement of the pressures facing clinicians at present and empathy with individual healthcare professionals working within a challenged system.

> **We don't know everything, but we know how we feel and what would make things easier.**

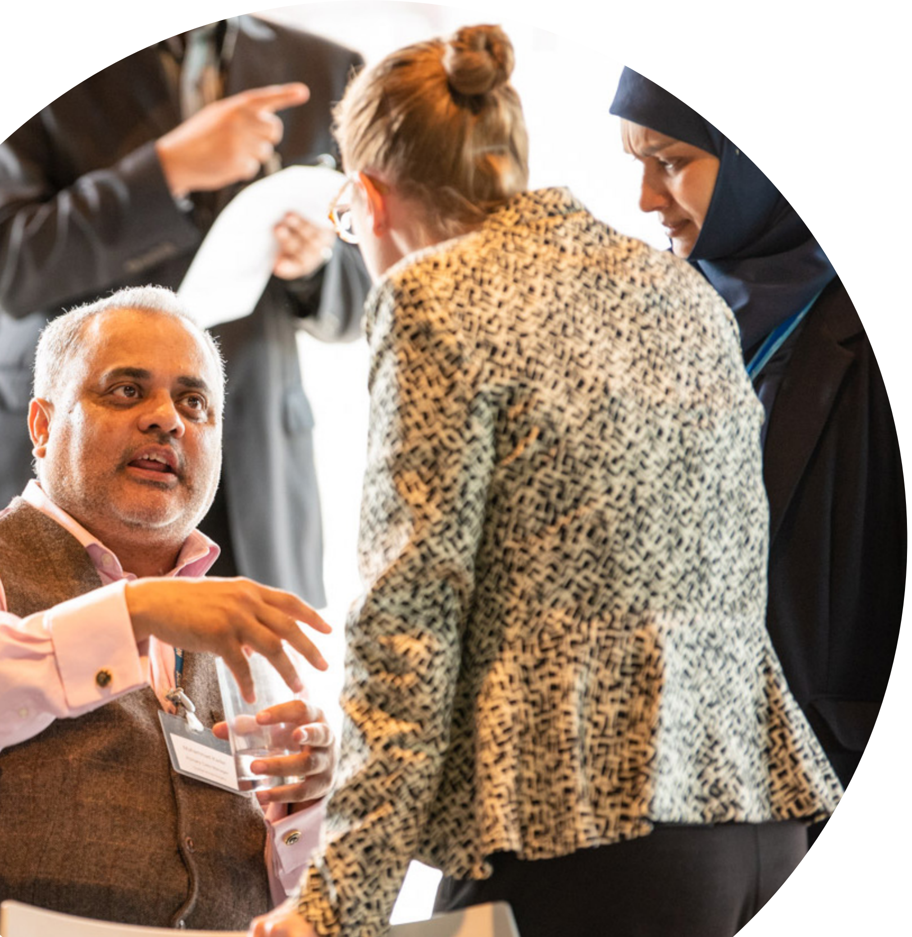
> **We are so concerned about ourselves but we must look after doctors too because they're going through a very stressful time.**

> **Each time I go, I have a different doctor so there's no relationship. That doesn't make me feel confident.**

What next?

The rich insights gained from the conversations at this event will be used to shape our programme on delivering proactive care for CVD prevention and other long-term conditions.

This event highlighted important areas for us to consider as we develop our programme of work on CVD prevention:



- **Holistic care**
  Patients raised concerns that the current system doesn't lend itself to providing holistic care. Some told us they felt their overall health and the impact their condition had on their daily lives was not given enough consideration in appointments they attended. We will be exploring ways to support the system to provide high quality, streamlined care that meets these needs
- **Signposting to support**
  One common concern was a lack of clarity in where to go for accurate information and support. We will be investigating options to improve patient access to this support
- **Access to testing**
  Many patients expressed a desire to be empowered to manage their own health when it is safe to do so. They suggested a wide range of options to enable them to monitor their health, including home testing kits. When testing by a healthcare professional was needed, patients said they wanted this to be streamlined to avoid multiple appointments. We will work with our partners and innovators to find the best solutions to this issue.

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