**Listen to THIS Podcast - Episode one: Access to primary care and improving healthcare systems**

Kristina Wanyonyi-Kay: Welcome to Listen to THIS. Examining how we can improve quality and safety of healthcare.

In this series, we’ll dive into both current and longstanding healthcare challenges and we'll shine a light on some of the work that has been done to address them.

I'm your host, Kristina Wanyonyi-Kay. I'm a Research Programme Leader and Senior Research Associate at the Healthcare Improvement Studies Institute.

And in this episode we are turning our attention to a topic that's generating a lot of conversation in healthcare. So there are growing workload pressures and staff shortages and a decline in patient satisfaction in primary care in the UK.

So how might increasing access to care and changing how pathways are navigated by patients impact their experiences of the healthcare system? And what does extended access look like for a patient? And what do we actually mean by pathways?

I’m joined by THIS Institute Fellows…

Patrick Birch: Hi, my name is Patrick Burch, I'm a GP in the Peak District and until recently was a THIS Institute PhD fellow and my work has been looking at continuity of care for patients when they're seen outside of their usual practice.

Georgia Black: My name's Georgia Black. I'm a reader in Applied Health Research at Queen Mary University of London and I'm just finishing my postdoctoral fellowship with the THIS Institute. My research is all about cancer pathways and particularly considering issues of patient safety.

Sean Manzi: And I'm Sean Manzi, I'm a senior researcher with Dartington Service Design Lab and Postdoctoral Fellow with THIS Institute. My research is focusing around mental health service provision, particularly in relation to eating disorders and the interfaces between different services.

Kristina: Thank you guys and very much. Looking forward to a conversation.

So we have three broad questions that we want to discuss today.

It's looking at what these access pathways are, what the trade-offs have been in order to create these pathways and how patients might experience them. And then we also want to talk about the system level approach to all of this.

Now, before we get into the questions, I'll just talk about a few of the key sound bites we've heard around how access to care is changing. So, since last year's plan to improve pathways by NHS England, we hear that there have been significant improvements.

There are now 360 million appointments, which is 57.5 million more appointments than there were before the pandemic.

Three out of five people are having their appointments face to face and nine out of 10 of these appointments are actually being booked on the same day. So this sounds great, but we really want to dive into whether this is actually what's happening on the ground and the actual practicalities of this.

So I'm moving over to you, Patrick, because you are at the coalface and you're a researcher. What are the actual extended access pathways that are available and how is it all working?

Patrick: Yes, so extended access was a concept that was coined in 2015 and the idea was that there would be additional GP appointments available outside of a normal general practice, so generally in the evenings and at weekends. Originally it was for patients for whom it was inconvenient to come in during the day and they would be able to access these more convenient appointments.

Since then, because of issues with capacity, my work and others’ has shown that actually it's being used as a kind of overflow. So patients that aren't able to get appointments in their usual practice are having to go and be seen in other places.

So it's not being used as it was originally intended for, but it is providing additional appointments.

Kristina: That's quite interesting that this is doing something, but there is still the existing patient load that are still struggling to get the kind of care that they want.

It makes me start to think about your area of work, Georgia, which is around diagnostic pathways. What is the implication of this for patients who are actually looking for a diagnosis and not necessarily going in for something routine?

Georgia: I have several concerns. It's really interesting hearing about Patrick's research. The primary concern for me is one of continuity. So I just want to clarify that I'm not a clinician or a GP, but it's my understanding that a lot of diagnostic processes happen with repeated appointments and in the time between appointments.

And if you are sending patients to an extended provision one day, and then you're hoping that they might come back and see a GP in their practice and then they're going somewhere else, then it's really hard for GPs to do the skilled work that comes from using methods like the test of time. So just seeing if someone gets better or if their symptoms change over a period, and being able to maybe test out whether medications help them, for example.

It's really hard to do that if you're fracturing your service between several different environments.

Kristina: That's quite interesting that it's not necessarily a one size fits all, but we also have to think about are we doing enough to find more generic ways of making sure everyone is finding their place in access to primary care for what they need.

So, Sean, your area of work is. It's a slightly different patient group. Do you think some of the pathways that Patrick has outlined work for the group of people you've researched?

Sean: So it's really interesting, this idea of extended access and trying to create additional capacity within the system, when it's trying to create extra capacity within existing pathways. But for those people who are trying to provide, for those who already need care and would have already been accessing services, this is not actually allowing for new capacity within the system.

These are not new pathways, this is not providing any additional services for what we call the ‘demand’ - the total amount of people who need to come in and access the services. This is just for those people who haven't already been able to get an appointment but need one.

I think there's a real discrepancy between the activity levels that they're trying to meet within care services and the demand that is trying to access those care services or should be accessing them, but doesn't, because there isn't either a way into those services for them because the referral routes are blocked, they can't get a referral into the service because a service might not be taking referrals at the moment, or they don't quite meet the right criteria.

So there isn't a service available to them. So there's lots to do around redesigning new services.

Kristina: So a lot to consider. So that the demand, it's not necessarily just numbers, is it? It's actually who makes up this new group of people coming into their services.

I'm quite interested inequalities and I'm quite concerned about how these services actually impact on those groups that are particularly hard to reach or particularly having more challenges. So, Patrick, are there some groups of patients that you're particularly concerned about when you think about these new pathways? Are we trading off on certain groups or certain groups being hard done by what's been put in place?

Patrick: The short answer to that is yes. I think whenever you create new systems and new pathways, it suits some groups better than others. So arguably, when extended access was created, creating appointments, the evenings and weekends was arguably better for working people, for instance, who couldn't access GP during the day. But then that excludes a lot of these sites away from the practice.  So then you may be advantaging that group, but then you may be disadvantaging people that can't travel.

And I think one of the things about if you create additional pathways, so if you have a service like general practice, where anyone can turn up with any problem, then I guess the barrier for entry is relatively low and you can turn up with very non-specific things that are going on.

If you create a specific service for a specific group of people with specific problems, that automatically excludes some people. My experience is that it’s those people who are often the most vulnerable, who don't fall nicely into a box, into a specific pathway.

A disadvantage by this creation of new things that are specific to one group or another as opposed to just general systemic capacity increase, in that when you give something one hand and you help one group, it takes away from another in some ways.

Kristina: So I think there's also a resource question here and I'm going to go to you Sean, around that because you do a bit of modelling work. Are they considering everything when they start to think about these new pathways and what do you think they should be putting into the models that they use to plan?

Sean: Actually determining total demand is really difficult. Actually understanding who out there is not receiving the service that they need...we can do this...we can do broad guesstimates and this is what public health tried to do, WHO informs looking at…what do we think is the prevalence within a given population with certain characteristics…and we can make an estimate for county wide.  For example, in Devon we'd expect to see a prevalence of, I think currently reported to be from the last quality outcomes framework around about 13% of people having depression, for example. That's a large number of the population. Our services are not set up to deal with that level of demand.

So trying to then understand who needs it most is what we try to do and trying to put them into the boxes of what services do we have available and who can go where and dealing with the activity that we have at the moment. But for most people they're really complex as well.

As Patrick was saying, one service does not fit everybody and lots of people have multiple different needs and trying to provide in a system that likes to treat one thing at a time and to predict what the actual demand is for that is...well, we haven't found a good way to do it properly yet, which is why they use activity and try to work back from who they're seeing.

Kristina: Lot of complex things to consider in predicting things is quite difficult. But this is also an area that, Georgia…you've done work on this on natural exclusion of people from pathways and more specifically, I'm interested in the urgent side of things.

So we could potentially think about people broadly in terms of their demographic and social circumstances. But what about people who have urgent conditions. What should we be thinking about in terms of modelling and being sure? Because we do have some estimates on how…predicting what the outcome might be if we don't get them into the system in good time.

Georgia: If a GP suspects that a patient might have cancer or they're just worried about them, then in the UK or across the four nations, we have various policies to expedite investigations that will find cancer.

And the main one in England that we're all aware of is what used to be called the two-week wait pathway, or the urgent suspected cancer referral pathway. The timelines have shifted a bit, so you could still expect to be seen within two weeks, but you should have been told whether or not you have cancer or you've had it excluded within 28 days. And so you could imagine that's pretty snappy. But 28 days is quite a long time to wait if you've been told by your GP that you might have a cancer.

And I just wanted to highlight that those clocks starting and stopping. That urgent timeframe is really open to gamesmanship, completely understandably, by the NHS.

What happens frequently to patients is they're actually referred once or twice or even three times. I've seen through my ethnographic work that patients are sometimes accepted onto a cancer pathway and then immediately discharged because the GP is filled in the form wrong and they send it all back to be filled in again.

So urgency is a really unquantifiable thing. The actual risk level of a lot of these patients being referred urgently is really only around 3% risk of cancer. So we've made a set of policy decisions that are being implemented and whether or not we've got them right is definitely a matter for more research, crucially, but also for public debate.

Kristina: I don't know if others have any thoughts on that, on how relative urgency is and what that might be like. Patrick…probably have something to say about that.

Patrick: George is right. There are whole papers written about what urgency is, or discussions about what is urgent and what isn't. But I think of a practical example…if I'm on call as a GP, I've had this in the last few weeks where there's been limited capacity. Say I've got two appointments the end of the day and someone rings up and it might be a child who's got a temperature, or someone is struggling to breathe.  And then I had a woman who'd rung up in the morning and had felt breast lump in the shower. You think, well, “I can't fit all three of them in. The child with the temperature, or the person struggling for breath could potentially deteriorate over the next 24 hours and actually die.

The breast lump can wait physically; psychologically, it's awful for that woman to have to wait, to then be dealt with.” And then do you then say, well, “book the next routine appointment”, which is two weeks away, which is often what we end up saying. Or do you say, oh, “I'll try and fit you into an urgent appointment the next day or on Monday”, so Friday, but then, you know, that's going to take capacity away.

And so we're constantly juggling with these, having to make these calls about what is and isn't urgent. And it is ultimately, it's by the condition, but it's also by capacity as well. So it's not hard and dry, cutting fast. If I'd have had two appointments that day, the one with a breast lump would have got it.

Georgia: Patrick makes such a good point that quite often when we measure metrics to do with patient care, we think of one patient and how long it's taken the GP or how long it's taken for them to be referred.

But actually the quality of their care and the quickness, if you like, of their care is always so dependent on the volume of patients that's coming into a service. There are these great bottlenecks into certain bits of the service which really affects those numbers.

It's not like an orderly queue that's just chugging along at a predictable rate. There are these peaks and troughs. Healthcare has to somehow adapt to accommodate all these people in different ways. And sometimes that means changing your thresholds.

I mean, really in quite significant ways, where one person would be urgent one week and they get deprioritised the next week.

Kristina: And I think that's the question is: how flexible we are in terms of adapting. And also, do we have the data?

And I'm looking at Sean, you might have some thoughts on that, but I just want to throw some statistics your way so that you can tell me what you think. So the BMA has been monitoring waiting times, and one big part of the Recovering Access to Primary Care Plan was to cut out the bureaucracy and improve the referral. So they want GPs to spend less time on paperwork - we'll hear from Patrick if that's actually happening – and to be treating patients so as to cut the bureaucracy out/ so that we often hear about the 18-week wait and we know that it's been failing.

The last statistics were that we now have an average of about 13.6 weeks’ wait for a large number of people. I'm not sure how many millions, but it's in the millions, maybe over 3 million. But that's much worse than what was happening before the pandemic, which was about 7.5.  Does this mean anything?

Sean: When we're talking about these on average, o average we've got a 13-week wait. For some people that'll be much shorter, for others it will be much longer.

Averages are funny beasts. And when we're talking about millions of people, the level of variation that we see. I'd really like to see these statistics reported with a what's the top end and what's the bottom end on these? Don't just give me an average and you've managed to fudge the population somehow to give you a nice low average. Let's take out some of the top end.

Mental health…you have extremely long waiting times. Are those numbers included? Are we just looking at primary care when they're quoting these? You know, particularly since the change that we've seen since the pandemic, there is a backlog to get through.

Also, we've seen a change in the capacity of our services and the way that services are functioning and the way they're structured. There hasn't been the increase in capacity that is needed. The workforce numbers are not increasing at a rate that's necessary to keep up with the increases in the actual demand of people coming through.

So it's a lot of different complex factors coming together. We're not seeing a very quick downward trajectory in waiting times.

Georgia: One of the ways these statistics might be changing is that what counts as a patient contact might have changed too. Sometimes you're given a telephone appointment and sometimes there's a triage appointment before the telephone appointment, where there wouldn't have been one previously. You'd have had a clinic appointment.

So I think it might be interesting to start looking at how long it takes you to see a human being. And I don't want to be gloomy about this. I think COVID really produced some innovation. I did a project funded by the Health Foundation that looked at changes to colorectal cancer pathways. And actually a lot of virtual clinics suit people with mobility problems or children at home or caring responsibilities.

And if you don't need to come all the way into hospital just to be told that your tests are normal, then some people are really grateful for that.

So it's not all bad, but I think it's really changed the way some of these statistics look and changes what they measure and what they mean in terms of experiential concerns for the patient and those reassuring moments where you're being given care face to face.

Kristina: And I think this is quite a good time to start thinking about your specific area and what you could probably add to the suite of system level changes or any localised strategies that are in place to improve access.

What do you think? But before we get into that, also I would really like to hear from Patrick as to whether the bureaucracy has been cut down and he's doing less paperwork in general practise and getting treat patients.

Patrick: That's not something that I've noticed, I have to say. I worked in Australia about 10 years ago for a couple of years and we had almost no paperwork at all there. So I'd see 40 patients a day, 30, 40 patients, and I'd do about 10 minutes’ paperwork for all of them. Almost no communication from secondary care unless the patient brought a letter in and patients could see multiple different GPs and you know what happened.

So I think it's important to say that bureaucracy is seen as bad, but it depends what the point of the bureaucracy is and what the notes are there for. They do that, you know, in the UK, for all it's the faults of the NHS, it is quite a joined up system when it works. And that has an enormous amount of advantages.

When I can look at what investigations the patients had done in hospital and what the consultant thinks about what's going on with them, there's a lot of advantages to that. Now, I completely agree that some stuff does need to go, but getting rid of everything, you don't want to throw the baby out of the bathwater.

Kristina: Well said. What about you, Georgia, what are your thoughts on any other improvements or how do we simplify the processes?

Georgia: That's a great question. Two things spring to mind. One is more on the more technological front. There's a lot of technology that is made that really slows down clinicians time or administrators time. Patrick's right. You've got to document things both for the patient safety and for legal reasons and for continuity of care.

But I know there are a suite of technologies emerging that fill these things in for you. Not all of them are brilliant, really. Create systems that distribute the responsibility for care much better so that if things are missed they get picked up quickly by different members of the team.

So that's one great white hope that I'm nursing currently. And the second is a back-to-basics answer, which is don't rely on technology, but give GPs in particular, although other clinicians too, a bit more flexibility.

I mean, I know that some primary care practices are really good at, for example, giving double appointments to patients that need it, but I do a lot of research with groups that find access to primary care difficult.

People with a learning disability, people who need an interpreter, people with particularly low health literacy, people with complex health conditions, they just need longer. It's really simple. And sometimes the really simple solutions are the ones that are overlooked. I know the reason why it's overlooked. It's really hard to find time.

But also…going back to our economics and cost question, I think sometimes there are savings to be made in giving patients a longer appointment once so that they don't have to keep coming back and so on. But I'm not an economist, so that might not be true.

But it's a hunch that has come from many different studies that expose the same problems, that GPs are highly skilled people, but trying to do difficult things very fast, and that's really hard.

Kristina: I think it's a very credible hunch. Sean, what do you think?

Sean: Definitely. All the evidence shows that bring two specialists together to provide a single appointment that will take slightly longer than a single appointment, but shorter than two appointments in the same place at the same time is much more efficient in terms of the time for the patient that they only come to one appointment. It's more efficient in terms of the time for both the clinicians, health professionals, to come together into one place at the same time.

And it produces better decision making as well, because face-to-face interaction between clinicians can actually result in them having a discussion about the patient and with the patient that they then get additional information, additional insight that wouldn't have been possible in two separate appointments and you get a better outcome. They often problem solving as they do working together.

We so often everything's so siloed in the NHS that you go in, you see one person in a room. Multidisciplinary teams and multidisciplinary working has to be the way forward in the future, particularly dealing with complex care needs.

Kristina: No. And I think that's a really exciting prospect. I think everywhere we think about multidisciplinary teams as being an option, even in surgical care. Because it's such a complex process and you want everyone talking and singing from the same hymn sheet and bringing people together.

I don't know if, Patrick, you see yourself sitting in a room with all the other specialists discussing a patient's care, chronic disease patients coming together. I think during the pandemic it seemed like that was happening to some extent with the complex outcomes of COVID, it seemed like people who had cardiovascular conditions and were being managed by their general practise needed to have consistent care. But I don't know how sustainable that could be, but it would be a great idea.

I'm going to open you up to discuss, to say anything, so I'll come to Patrick, any thoughts?

Patrick: I think one of the things that we haven't really talked about is the issue, well, the issue of what is capacity and is increasing capacity and extending access, is that going to solve problems?

And I think one of the things that I haven't said is that not all appointments are the same. Georgia touched on the issues of continuity and people seeing different clinicians and different things. And part of the bureaucracy that we have to deal with is created by the fact that people see multiple clinicians.

Now, Sean's mentioned the benefits of Multidisciplinary Teams (MDT) working and there are massive benefits, especially with complex patients, but with a lot of patients, and they can be patients with multiple morbidities, a lot of older patients that don't fit into a neat pathway, it needs somebody to take charge of that patient and decide when you're not going to put them in the pathway and what you're going to do with them.

And that is where continuity of actually seeing the same individual, it may not all be written down. A lot of it will be in the clinician's head and getting to know that patient, understanding them from a patient centred point of view, where what would take six or seven or eight appointments in different systems, seeing different people, can be done with two or three appointments, with the same clinician that's willing to take on board the patient's point of view and manage risk and not funnel them into a pathway.

And I think if I could change one or two things within the health system, primary care system, would be to have experienced GPs who are willing to take a patient-centred perspective and hold risk, giving continuity to those patients that will benefit from not being put into a pathway or multiple different pathways.

Georgia: Just to echo a similar point, I think something that risks getting lost is the idea of clinicians having the freedom to just keep the patient with them for a little bit longer, to keep responsibility for their patient a little bit longer.

There's an awful lot of pathways which are really just about very brief contact and then handing the patient on to someone else. Not so much in primary care.

But I understand the example that Patrick gave that if you initiate a pathway for that patient then you're perhaps missing the point and that careful risk management might be much better for the patient. But it happens in secondary care too, that patients are very quickly moved on from one department to the next.

And some of my THIS Institute research really highlighted this, that we lack enough generalists in secondary care who are willing to, or even if they're not generalists, to act like generalists so that they can perhaps, for example…you might have been referred for a suspected cancer, but the clinician spots an early dementia.

So how much can you do as that cancer clinician before we discharge them back to the GP or can you initiate some process for them, some referrals and testing before letting go of them? So just allowing people to do the most they can to avoid that endless ping-ponging around the system for patients which we know of.

Patrick: I was going to say there is an optimal point with that as well though, because I'm sure you see in your work, Georgia, that you can have clinicians that hold on to the risk for too long and then patients don't get referred and there is an optimal and a right and wrong way to do it, but it is making judgments ultimately.

If I have someone come into me and they've had, I don't know, sixty-year-old man that's had diarrhoea for a week, is there a chance that's bowel cancer? Yeah, there is. He's had it for a week and no other symptoms. Do you follow the pathway that says…and the pathways will say he's had diarrhoea for, I don't know, X number of weeks, three weeks. And that's an arbitrary cutoff.

It's because they know if they refer people at two weeks they'll have too many negatives and if they refer at four, they may have got a few too many positive. And some of it's down to money.

We can't afford to do that many scopes so we'll have to make the cuts of three weeks or four weeks and someone's making those decisions. And actually sometimes the clinician's best place to make that. And if we become too risk averse, we overwhelm secondary care which already isn't coping.

But if we, then if we have to be careful, we don't go too far the other way as well. It's a very difficult balance to be had by both by the clinician themselves and should be in consultation with the patient and also what the system can deal with.

Georgia: Yeah, not only that, but the funding models don't really reflect it. In secondary care the funding models are set up for a very small number of contacts and in primary care, not at all because it's a cancellation model.

You're absolutely right, Patrick. And of course if you miss that cancer for the man with diarrhoea, then all hell breaks loose for you and the patient feels something was missed. Even though you were doing such careful, patient centred care.

Sean: It's really difficult with the continuity of care aspect in work that was done around eating disorders and care we’re seeing for the same patient group, those with anorexia. They were seeing across Devon – and this is excluding primary care – they were seeing 70 different services, unique services across Devon and that's an enormous number for what is just one geographic region for one patient group and the complexity of their care over time and the different services that they need to interact with.

And part of what we're trying to do really is to say no one GP, no one clinician, can hold all that information about that care pathway in their heads. We have these idealised care pathways of where people should go. That's not the reality of what actually happens in practice.

So what we're trying to do with some of these system approaches is to actually go, okay, here's the reality, let's try and look at this reality of what's happening. Then we go, wow, we didn't expect it to be this complex. We knew it was.

And this is what everybody shies away from. So there's a whole lot, I think, in what we can do in health service improvement at the moment…is to help understand those realities of complexity which will help us afford better continuity because we can make better informed decisions about what rationalised pathways might look like.

How we start putting together care packages, doing care planning that goes beyond just a single referral and do healthcare in a more intelligent way that isn't so reactive, but that takes a lot of information.

Kristina: It's quite difficult when we talk about being able to have continuity of care and our data systems are fragmented or to be able to have consultation back and forth about complex care, and we don't have the mechanisms to do that.

So many important points brought up here. We talked about system approaches, we've talked about rationalising pathways, we've talked about being more flexible but at the same time not being too reactive. We've talked about inequalities, certain groups who are actually not necessarily benefiting from all of these new access pathways.

A big thank you to all the guests who joined us today: Patrick Burch, Georgia Black, Sean Manzi. I’ve been your host, Kristina Wanyonyi –Kay and I hope you’ve enjoyed listening to Listen to THIS.

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