PCN ROUNDTABLE

ADHD: HOW PCNS CAN MANAGE THE DEMAND

Rising demand for ADHD assessment and treatment is pushing up ICB spending and prompting some to restrict Right to Choose pathways. As waiting lists grow and shared care with private providers becomes more complex, six experts join Pulse PCN editor *Victoria Vaughan* to discuss what role PCNs can play.

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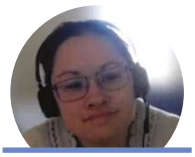
DELEGATES

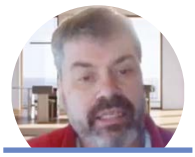
Dr Asfia Aftab
PCN health inequality lead and GP partner in South Birmingham



Dr Beckie Akroyd
GP, Bexhill-on-Sea, East Sussex

Dr Chibby Orjiekwe
Clinical director, St Helens South PCN, Merseyside

Dr Katherine Wallek
GP partner and mental health lead, Foundry PCN, Lewes



Dr Matt Prendergast
Clinical director, PCN North, Southampton

Simone Wilson
Chief operations officer, GP co-operative South Doc Services, Birmingham

CHALLENGES

Victoria: What are the main challenges for PCNs and general practices when it comes to ADHD?

Simone: The private boom is causing quite a lot of issues within primary care in our system.

I've spoken to a private company and been quite shocked at how quick [it is] – you can do an hour with somebody virtually and, bang, you've got a diagnosis. And what then happens is they've got that sheet of paper, they go to their GP and start asking about medication, and their GP doesn't necessarily know what's happened in the assessment.

Asfia: The explosion in neurodiversity has been quite stark in the last few years, and it has thrown us off course a little bit.

Here, the wait time for young people is 13 months by which time some are not in the age group anymore. And for adults, we're looking at two to three years on the NHS, but with Right to Choose, it could be weeks.

But then there's this kind of abyss, because a lot of our practices are saying we're not going to share that care. We just don't have the expertise or the capacity, to be honest.

I think publicity has a lot to do with it. We need to manage expectations in terms of the spectrum and who needs reasonable adjustments; who needs clinical input and where that lies. If it does lie in primary care, we need a lot more support than we're getting at the moment.

Katherine: We're just trying to mitigate the explosion of people that are presenting thinking that they have ADHD. Since January, we've referred 131 adults under the title of neurodevelopmental referrals – which includes the autism spectrum ones as well but it's mainly ADHD – and 69 children.

Through Right to Choose, provider numbers have gone up, but waiting times have also gone up. And it's really difficult not to refer people, because if they're presenting saying that they're having issues because of their ADHD or whatever they perceive to be their ADHD symptoms, then we can't just turn them away and say we're not going to refer them.

I can probably count on one hand the number of people that have come back and said they weren't given a diagnosis. So yes, the numbers are enormous and growing.

"I'm suspicious that private providers sometimes drive activity by income rather than necessity.
Dr Matt Prendergast

Matt: The current situation is really bad for a number of reasons. We've gone from a desert to an oasis and then back to a desert again. We had no service, effectively, and then Right to Choose came on board, and we had a great service.

The landscape has been very difficult recently because Hampshire and the Isle of Wight [integrated care board] has restricted Right to Choose because of cost. The waiting lists for our local provider are three to four years, so that's not an effective resource for use, really.

I work at the University of Southampton, which is an NHS practice on the campus, and I've got a huge amount of patients either waiting or with established ADHD and on various medications. I think we've referred about 500 in 15 months, and we've had two rejections. That might suggest that the bar is too low or that we're underdiagnosing – I'm not quite sure, but certainly the screening seems to be fairly liberal.

It is under-resourced. In our area, they're proposing a single point of access so that everything goes through that, but that doesn't increase resource, it just streamlines the process.

At the moment, the process is really difficult because patients go to a Right to Choose provider and then told they're on a waiting list and they have no idea when they'll be seen, so they don't know where to go, and they continually come back to us.

What has been very frustrating up to now is that all the Right to Choose providers have different ways of accessing their services. So if you decide to go to one provider, they will have one form and another provider will have a different one.

We've started refusing and have a standard form that we sent to them all, including our local provider. But that doesn't help the patient. It helps the doctor.

I do think for some people, an ADHD diagnosis and medication is transformational. For others, it's less clear. Certainly, the diagnosis has been driven by need, but also by publicity. And to a large extent, I'm suspicious that private providers sometimes drive their activity by income rather than perhaps necessity.

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SHARED CARE

Victoria: What's the current approach with private providers? Shared care, for example, is a problem for GPs across the country, isn't it?

Matt: We do shared care. Many don't, but we do. We only do it with approved providers. Our specifications are that they must be in the UK and must have a prescriber – and that would generally be a consultant, so they're backed by a consultant psychiatrist.

We have to have a consistency there and we insist they stay on. We can't diagnose, and it's supposed to be a specialist, so they can't then just hand it back after a quick diagnosis.

Victoria: Is the shared care with Right to Choose or private providers as well?

Matt: We do it with everybody, as long as we think they're reasonable.

Victoria: Do you find that there's a difference between Right to Choose through the NHS and the private providers in terms of the burden on you?

Matt: Some providers are keener to divest their patients than others. And it's not clear when they should discharge their patients to NHS care. It's really unclear.

Now, clearly, if someone's been on the same dose for 10 years and never changed, it's probably reasonable. But after the second appointment, when they're still titrating the dose, that will be unreasonable.

So, it's a mixed picture, really, and again, there's no consistency from one provider to another.

Katherine: We made a decision in November 2024 not to accept shared care agreements from private providers, only to accept the ones that were given to us by the NHS pathways and Right to Choose pathways, because we just couldn't cope with the volume.

But it was also because we couldn't guarantee safety with the patients that were coming through the private pathways. They'd quite often come to us, and we'd agree to do a shared care agreement, and they'd start having medication from us, but then wouldn't carry on with their follow-ups from the private psychiatry teams because it's obviously expensive.

We also didn't want to offer a two-tier service where we're allowing

We're delivering ADHD services through enhanced access via a hub-and-spoke system.

Dr Chibby Orjiekwe

people to jump a queue so those that could afford to see a private provider would go to a private provider and then come back to us for us to do the prescribing.

It caused a quite a lot of upset with a lot of patients. We did honour the legacy shared care agreements that we'd agreed to before November 24.

At the moment, we're kind of firefighting. We triage all of our patients electronically via a software called Anima and we've created links to send to patients because we've got so many every day asking for a referral for an ADHD assessment. So we send them the link for the questionnaire and links for how to look at the Right to Choose list, and then they'll send back the information to us.

It's an incredibly work-intensive problem. The mental health support coordinators and our social prescribers spend an inordinate amount of time sitting with patients and doing the referral forms with them because they find it really difficult. And then the secretaries will do the referrals. And then the pharmacists are looking at these shared care agreements that come back.

We don't have any additional funding for all of this at the moment, but we are spending an awful lot of our time and resources on ADHD.

Asfia: We're using our care coordinators a lot. I thought we would bring them in for long-term conditions, but they're spending more time with neurodiverse patients.

We use them as a stop gap with all the delays – assessment or treatment – and to help with everything else in life. It's helping to reduce the chaotic issues.

Simone: In Birmingham and Solihull, there is potential for ADHD patients. Looking at the integrated care board (ICB) and the community services, there is definitely interest but nothing has actually hit the ground.

There's lots of talk on this subject, but nothing ever actually goes live.

Beckie: Because of the Right to Choose spend in Sussex, the ICB gave money to PCPC (primary care provider collaborative) who have started a pilot in three areas of deprivation within Sussex – ADHD Primary Care Connect. It is very new. We only started on the first of April.

Basically, it's upskilled general practitioners to be GPs with an extended role in ADHD.

I'm not aware of many other areas that have GPs working independently in this way. Most other areas where there's a GP who is working in diagnostic services they are within community paediatrics or a psychiatry service. So, it's going to be a really interesting pilot. If it works, it's going to be a model that others can follow.

Chibby: With everything we do in the NHS, justice should prevail. So if you have a service that runs well in one area, it should be equally replicated in another area without any consideration for how it's going to financially impact that area because they need the service.

We've done quite a lot of work in Merseyside to understand the problems with patient access and the workload for GPs and get an integrated solution for ADHD.

We're piloting [a service] in our PCN, which is the biggest of four PCNs, delivering services in enhanced access and the other three PCNs are doing something similar. We do 4.5 sessions a week in enhanced access. Essentially, we've got a hub-and-spoke system. The hub is the main provider, which is Modality, and we are the spokes. We are taking some people onto the spokes to ease workload for them and obviously providing a service that would help these patients.

PCN MODELS

Victoria: Two interesting community-based models of ADHD care were mentioned by both Beckie and Chibby there. Can you explain more?

Chibby: We're fortunate to have a proactive project lead. She's the transformational lead for mental health. As a PCN, we've developed a team, which includes a clinician, pharmacist, mental health practitioners and care coordinators and social prescribers.

We are looking in our PCN to get a neurodiversity practitioner (NDP), but we're going to leave that for the next quarter of the year. One of the PCNs has put it to advert, and they've got a few interested. So that's good progress, because when you look at the Locally Enhanced Service (LES) [from Cheshire and Merseyside ICB], it specifies that you don't get full remuneration without having that neurodevelopmental practitioner.

Looking at the actual LES, it's well written. It's a very overarching document – a 20-30 page document that covers everything to do with the identification of patients and aligning with NICE guidelines. It gives a job spec for an NDP – usually Agenda for Change band four to five – and the competencies that they need to actually achieve.

It talks about the training and development that clinicians need. We're fortunate in our PCN because we've employed our own mental health practitioners or nurses, so they're actually helping with the triage and management of stable patients from our main provider.

We're only looking after established patients with ADHD who have not been able to go through the pathway with Modality. They are all stable patients. I think as the year progresses and we get our neurodevelopmental practitioner, we'll start to look at assessments.

We're also working quite closely with our secondary care provider, Mersey Care, who will do MDTs and take on those very complicated patients to manage properly.

We want to be very careful that we're getting the assessments right so we've scheduled 45-minute appointments for an initial assessment. It gives the clinicians time to get comfortable with the training that they've had – because they've all had two or three training days to actually onboard ADHD assessments and treatments for patients.

The other thing with the LES is that you do have to evaluate the service. They want to know the number of patients who have been reviewed within a six-month period and a one-year period. That then attracts the payments, which obviously are put back into helping the patient. So it's not viewed as a profit for the organisation; it's to actually develop it a bit more.

Victoria: Thank you. Can you explain more about what's happening with your pilot, Beckie?

Beckie: It's a 12-month pilot and it's only adults.

There are three hubs – Brighton, Crawley and Hastings – in areas of

extreme deprivation. Some of the areas covered by our PCN in Hastings are in the 5% most deprived in the country, which often surprises people, so that's where they've targeted because we know that neurodivergent individuals are under-employed, and because of the genetic links of ADHD and autism, that then persists, and so you end up with multi-generational poverty.

I've done seven or eight assessments. Of the patients I've seen, fewer than 50% finished secondary school education due to the difficulties they had, but they never received the support or a neurodevelopmental diagnosis that they needed.

Our aim is to make robust assessments. The danger for some of the Right to Choose providers is that the assessments may not be robust, and therefore may not be defensible, and therefore causing concerns with shared care, etc.

We all did the UK Adult ADHD Network course and then had three further days from Sussex Partnership Foundation Trust – the local mental health trust – from one of their consultant psychiatrists and nurse practitioners who work in their ADHD service in order to be able to diagnose and manage ADHD.

At the moment, we don't have the pathway set up for medication or wraparound support, but that will be there, and we will be prescribing and have non-medical wraparound support available.

The core training was together for all three hubs, and then each of the hubs runs independently because they're within their own PCNs and they can decide how they do it.

"I'm not aware of many other areas that have GPs working independently in this way.

Dr Beckie Akroyd

Within our PCN, we have a care coordinator who basically chases the ADHD patients to fill in their developmental questionnaire and a repeat the ADHD self-report scale if we haven't had one already. One of our practices has a neurodevelopmental practitioner who was in place before this existed because the PCN CD had recognised the high level of needs for neurodivergent individuals. She's a therapist by background and is very helpful with wraparound support and doing low-intensity therapies, etc, as well as support groups, which can be huge.

I had a question for Chibby, actually – what's the assessment that you're doing in 45 minutes?

Chibby: We're looking at their initial care plan, looking at the challenges with medication, wanting to find out the complexity of the patient, whether they actually just have ADHD on its own, or whether they have

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Having a GP with a special interest would be worth its weight in gold.

Dr Katherine Wallek

other diagnoses. So, reading or going through all that and understanding their journey.
As a GP, I think 45 minutes is quite a long time with the patient, but if you're still piloting a service, you want to make sure that you get it right. I suspect that subsequent assessments will be a lot less. If somebody's been through this service a few times, then you can shorten those assessments.

Beckie: We have two and a half hours for an initial diagnostic assessment. That's 90 minutes with the patient and 60 minutes of admin time because our reports are 10-12 pages long.

There is full consultant supervision. We have integrated the neurodevelopmental team through the mental health trust with each of these hubs and the PCNs. We also have a full MDT. You can have an optional drop-in Teams meeting MDT for discussion of hard cases, and you have full support of the consultant who can read your reports or chat with you if there's any diagnostic uncertainty.
In our PCN, seven of our eight surgeries are part of it. To be involved, the surgeries had to agree to being okay with sharing care. One surgery has opted out because they were worried about what would happen if the pilot came to an end, and then who would they be sharing care with? It will have to just be subsumed under the Mental Health Trust if the pilot ends, but they weren't confident to go ahead.

FUTURE

Victoria: What's the future? Is there any sign of any movement from ICBs regarding their cap on Right to Choose referrals, for example?

Matt: I don't think there's going to be any movement on the cap for Right to Choose because it's budget and most ICBs are very constrained with budget. So if you take it away, you rob Peter to pay Paul, really.

I think what we can do is find cheaper models and advocate those within the envelope that is currently there. I don't want to speak for her, but someone like Rebecca's probably going to be a big advocate of enhancing the budget and I can only agree with that to some extent. If it's in the same healthcare envelope, then what's going to give? That's the problem.

Beckie: I wouldn't necessarily say that the budget needs to be enhanced. It just needs to be better used. We know that a pound in general practice is worth £14 in secondary care – that's a well-quoted statistic. We can do as good, if not better, for cheaper. And that's part of the reason for our pilot – we can do it well. We know our patients, we know we have the ability to look at more areas of their life. We're not just single organ specialists, etc, and that is what it is supposed to be.

If the Right to Choose funding had been put into local services earlier on, I don't think we'd be in quite such a bad position. The trouble is that literally all that money is being funnelled to a private provider who is often working for profit, rather than it being reinvested in the local area.

Asfia: My main concerns are identifying access. Maybe we could look at self-referrals. I know it might seem a bit far-fetched, but kind of similar to the BUMP (Birmingham and Solihull United Maternity and Newborn Partnership) maternity referrals that go directly, maybe something in that vein.

Victoria: What about training in terms of your own skill sets and your staff? Do you feel you could do assessments and diagnoses in the PCN?

Katherine: Well, we can go through the referral and the self-assessment questionnaire with the patient, and come to a pretty reasonable conclusion that a patient has got ADHD, but we haven't had any formal training. This is all stuff that we're picking up as we're going along.

I think we could do with some training. Certainly, having a GP with a specialist interest in neurodevelopmental / neurobehavioural problems would be worth its weight in gold. Referring everyone on the Right to Choose pathway feels like a sticking plaster and it's just not sustainable.

Asfia: In Birmingham and Solihull, we honestly have incredibly limited support. If we could have a mental health practitioner that was trained up in that area, we could work closely together.

Simone: We talk about left shift and putting resources into community and GP surgeries – well, forget about funding, what about actual people?

I'd be quite happy for someone to come into our PCN and help us. But the left shift scenario doesn't seem to be mandated in any way, shape or form – not in Birmingham and Solihull. There is no movement in our trust at all – even asking for consultants for an MDT, there's nothing.

I really think the transformation needs to come from all system partners, not just primary care, because that will really move things along a bit more.

Chibby: This all informs the neighbourhood agenda – a culture of shifting funding to the right place. We have to think about it in that way. What is right for the patient rather than what is right for the provider?

In the NHS, we are very good at looking at our budgets and saying, 'We're going to make a saving here,' but, you know, what is cost-effective?

If you get a patient through the pathway properly, they'll be more employed, they'll contribute to society properly, they won't be involved in criminality – surely, that's the saving, isn't it? Let's look at it that way. We are very myopic with our views and opinions, and that is where the problem lies.

And yes, a pound in general practice is worth £14 pounds in secondary care. I know that very well as a CD because we've had to decommission some of our services with a secondary care provider – a mental health service – and we've employed our own mental health nurses. We're getting value for money and patient satisfaction has gone up. This is why we've got the confidence to make them part of our ADHD pathway.