PCN ROUNDTABLE

EARLY CANCER DIAGNOSIS

Primary care leaders joined Pulse PCN editor *Victoria Vaughan* to discuss challenges and progress in early cancer diagnosis

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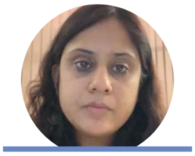

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Victoria The early cancer diagnosis specification came into the contract in 2020. What has that meant for your PCN and how has it worked in practice?

Sarah At Medics PCU we couldn't have delivered what we have if I didn't have a cancer lead that was clinical in my PCN and buy-in from my GPs. It's a fantastic deliverable, but an awful lot of work. Obviously 2020 was a very difficult time. The specification was paused while many of us were doing vaccinations. But we worked well with system partners and Cancer Research UK (CRUK).

We asked our practices to complete an audit. From that we found that one of our practices had a really good approach, leading on the referral process. It was not a coincidence that the year before they had worked with CRUK. We set up a small task group of three GPs, who met every month to thrash out the best referral practice pathway. There are lots of other elements but that's the biggest piece.

You need to take that time. It's just not doable otherwise.

Shanika I completely agree with Sarah. We were lucky that one of our GPs was the previous CCG cancer lead and did a lot of work with Macmillan, so she brought in a Macmillan cancer co-ordinator who helped to drive it by getting practice engagement, sharing resources and sharing data on cancer screening and how it looked at a practice level and at a PCN level. I know we've got data on Fingertips, but when you have someone who's mapped it for your PCN and they present what the practices are looking like, it really helps.

We evaluated our safety-netting tool and found it was not as effective as we hoped. Soon after that, we had a clinical effectiveness group run by Queen Mary University London (QMUL) in east London. It developed a new safety netting tool that was rolled out across all the practices and put on all the clinical systems. It's really helped drive the early cancer diagnosis. But without this system support it's very difficult on an individual PCN level.

Binodh We are a PCN with three large practices, so we identified three GPs to represent their practices as cancer leads and employed a cancer care co-ordinator. The cancer co-ordinator made links with the East Sussex Cancer Alliance and the Macmillan team and we did presentations to educate our clinical colleagues and the admin team about running searches, identifying people and inviting them to screening programmes. A key thing we did was to encourage one admin person from each practice to become cancer champions. They liaised with patients and made the connection between the cancer care co-ordinator and the practice. We hold a monthly meeting to discuss updates. We've improved a lot. At the beginning, there was a lot of chaos about doing FIT tests and not having blood tests together for the local trust.

Baldeep In terms of our PCN and the wider borough at Hammersmith and Fulham, being the cancer lead, I had the benefit of data. It is slightly older, I could go into meetings with each PCN and show them their position in the borough and the wider situation.

In terms of the PCN DES, I found it worked well to break things down for each practice into small manageable chunks with an action plan so it wasn't overwhelming. Otherwise, you're trying to boil the ocean with this big chunky piece of work.

One of the interesting things we did was significant event analyses (SEAs). They helped develop a community of practice in the PCNs. And they've helped change practice, with things like safety-netting and reviewing cancer diagnosis. A lot of good work has come out of that.

Bal The PCN DES has started to focus our minds. Working at scale, working with other practices has been really useful. But we also have to be very critical of ourselves. The reality is the outcomes for our patients. Since the PCN DES came into place, [outcomes] have deteriorated. Health inequalities for cancer have got worse. If you speak to our secondary care colleagues, they're very critical of primary care – and there may be reasons for it. They're critical of the fact that we shut up shop. I speak to a lot of professors of oncology, who say, [some] cancers are now irretrievable. [They're seeing] the late stages of cancer a lot more. That's something my friends in oncology are really disheartened about.

Cervical screening was a big success for general practice over many years. Now something has changed – suddenly, people have lost confidence in coming to us to get smears done. We need to be critical of ourselves. Have we focused on the wrong things? Have we sat in rooms talking to each other, but not talked to people outside us? And [4.6 million people did not take up their latest test] – it hasn't been good enough because they're not coming forward.

Being critical about the PCN DES, we've become very insular in how we're looking at cancer. Yes, we're talking to Macmillan, but not to people who are commissioning cancer care. Very few of us are having good conversations at scale with oncology departments, cancer trial patients and people who are commissioning the screening procedures.

> **We revamped our safety-netting tool which has made a big difference to early diagnosis**
>
> Dr Shanika Sharma

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We need public health in England to raise general awareness about red flags and the purpose of screening

Dr Baldeep Syan

Our cervical screening and breast screening programmes are commissioned at a national level. We haven't got any traction in those conversations so far.

Shanika These points are really important. Our cervical screening rates in Barking and Dagenham were historically lower than the national average anyway. But, during the Covid pandemic, we noticed they were dropping even further. We got together as a PCN, and made some videos in different languages, to target hard-to-reach populations – people from Asian or Eastern European backgrounds. We did videos in many languages and encouraged practices to send them out.

The link with health inequalities work is really important. We're currently working with our public health partners. We put a bid in for health inequalities money across Barking and Dagenham. One of the projects aims to encourage breast screening in elderly patients, and to explain to them the importance of breast screening. The proactive approach for cancer screening has been identified as a priority in our borough-wide partnership. I agree this must be done outside the PCN. It has to be across the board with public health at the local authority, with secondary care, with community services all on board.

The SEAs also identified that some things are beyond the control of primary care. It identified a lot of problems with diagnostic pathways. There were patients who were referred for a CT scan by primary care, but never had the scan, or it wasn't safety-netted.

Binodh Bal, this is exactly what we are thinking about. We have extended our hands towards the commissioners, the secondary care cancer delivery manager and the CRUK team. We have a quarterly meeting with all of them, and that's when we have the SEAs and discuss difficult cases.

This has helped improve relationships between each of us. Now, through the cancer champions, the secondary care managers have access to the practices. We've asked them not to reject referrals, and if they need more information, the champions provide it. Sometimes we have to go outside the specifications, but at the end of the day, these small things make a big difference later on.

Sarah I'm interested to see what people think about the impact of telephone triage over the last three years. Are things not being picked up because patients aren't being seen face to face?

Bal There is a concept in primary care that 'every contact counts'. We say 'Yes, I know you've come for your ear infection, but do you realise it's really important to have your smear?' I think there is a distance growing between primary care. Maybe we need to re-evaluate.

In our practice, which is in a very deprived area, our screening rates were very good but they dropped off. We attributed it to telephone triage. We've gone back to fully face-to-face appointments, and guess what? Our screening and vaccination rates are coming up because you remember 'the contact counts' and the doctor has a pastoral role. It's been a conscious decision to view the triage machine as another tool rather than a replacement, which is how it was viewed in Covid. Seeing your patients does reduce health inequalities. That's a reality. We know that.

Binodh We also are reducing our use of telephone triage. We are going face to face. And nurses have never stopped seeing patients face to face – neither did healthcare assistants. A really small number of people have telephone contacts. Our chronic disease monitoring has gone down a bit, but it's picking up. [Those face-to-face contacts are] an opportunity to emphasise the importance of all these screening programmes.

To improve access, we have set up a group of three nurses who are offering extra sexual health sessions for women at weekends. There's at least one clinic every three weeks, from 9am to 1pm, where women can drop in or make an appointment. Improving access is key.

Sarah My cancer lead's practice has completely switched back to face-to-face appointments. But our PCN has five practices that all work in their own way, as does each clinician. There are various members of PCN staff such as paramedics and physician associates who are predominantly working by telephone triage, so we can't change that.

Baldeep Public health in England needs to play a role in this as well, in raising awareness. I read a statistic the other day that a full-time GP will have eight or nine cancer cases diagnosed in one year. It's not a lot if you think cancer's going to be present in one in two people. We need campaigning for patients to be aware of what red flag symptoms are, when to present to their GP, why we do screening, and what the purpose of screening is. I don't think there's enough at the moment.

Victoria This year there was an added focus on improving referral practice, particularly in disadvantaged areas where early diagnosis rates are lower. What work have you done on this?

Binodh Our cancer care co-ordinator is working with our learning disabilities care co-ordinator and we've got another care co-ordinator who looks after people who are vulnerable and in care homes. We have produced a leaflet, which is really straightforward, so that people with learning disabilities and their carers can understand about cancer screening programmes.

We are using cancer co-ordinators to contact carers and introduce themselves, asking permission to visit and talk to them in person. We've worked with our integrated care system (ICS) lead because this is one of our programmes to improve health inequalities and increase cancer diagnosis in people with learning disabilities, serious mental illness, and people from ethnic and Asian and African backgrounds. These are the main areas we are concentrating on.

We are working with public health in our area too. It gives us loads of information about pockets of deprivation.

Shanika There are loads of research studies. Locally for lung cancer we've got SUMMIT, an early cancer detection and lung cancer screening study from University College London run by University College London Hospitals NHS Foundation Trust. As part of this, people are being offered a low-resolution CT scan and we've caught quite a lot of cancer diagnoses through that because we have an area of high lung cancer prevalence.

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Also, we've been working closely with local voluntary sector organisations to tackle health inequalities. As part of our health inequalities bid, a chunk of funding was given to our voluntary sectors organisation lead and they've developed a programme of locality leads. There is a health inequalities lead in each of our six PCNs in Barking and Dagenham. Their role is to map the assets in the community and bridge those gaps between different workers – care co-ordinators, social prescribing link workers and all the other wider members of the PCN team.

Whatever we do in primary care, some people won't come to us so we need to go to them.

Bal One of the most amazing successes – which has been a sea change – is the ability for PCNs and practices to employ care co-ordinators. The amazing thing about the PCN DES is being able to locally look and get these ARRS roles on.

Shanika, Baldeep and Binodh are six or seven months ahead of us but I've got the ambition to get there. For me as an old GP that's an amazing legacy for the PCN DES – to be able to employ some of these care co-ordinators in practices. We'll get the dividends of that as time goes by. We've just done a piece of work to get people on board with that.

Kanchan We have a designated cancer care co-ordinator who's taking the lead on this. We support her.

But from what I'm hearing today, I think our services are a little bit disjointed. I'm only involved in our PCN part and not in the wider Dudley area.

It would be helpful to co-ordinate care more with other PCNs because there's always something to learn from other areas to increase our uptake of screening.

Our cancer lead is doing a lot to increase the uptake of breast cancer. We are sending out messages to increase our first breast screenings because we found that our rates were really low – maybe about 40% when nationally they are about 70%.

I also find that secondary care and primary care in our area are not working together at all. Even if we see more patients face to face, our secondary colleagues are still doing telephone triage.

So for two-week cancer referrals, secondary care would first do a telephone consultation. The upper GI referrals do well, as do referrals for obstetrics and gynaecology.

But others like neurology are getting appointments after two or three months.

I feel we all have to work more together, not just in primary care.

Victoria So in some cases the two-week referral results in a secondary care phone call rather than a face-to-face appointment?

> **We're looking at governance structures for our diagnostic centres. For instance: who picks up the results?**
>
> Dr Binodh Chathanath

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Kanchan Yes. So we are not in any way guaranteeing a patient will get whatever investigation they need within the two weeks of referral.

Victoria Is this something others are experiencing?

Shanika We looked at this with our SEAs escalated it to our local trust. We said look, GPs are sending people for scans. The trust did an internal enquiry and found problems. We were able to troubleshoot through this but it's really important to keep the process going. I completely agree about the two-way conversation. Unless we have that relationship [between primary care cancer leads and secondary care], it's not really happening. That integration is pivotal to move this forward.

Bal When we talk about health inequalities, some are in accessibility and pathways. Shanika, you say you've got access to scans. We don't have that in Oldham. There is variation nationally in diagnostic access, irrespective of diagnostic centres. And the elephant in the room is why have you got access to CT scans, Shanika, and we have not? The conversation about health inequalities [is not just] outcomes; it's also diagnostics. We're lucky in Oldham, we've got a rapid diagnostic centre. We put a bid in and we're very proud of that.

Binodh We've got two rapid diagnostic centres for East Sussex. We are still looking at governance structures. One problem is this – who is going to pick up the results?

Baldeep I'm the clinical lead for our rapid diagnostic centre at West Middlesex Hospital. We've got north-west London fully covered with GPs to access rapid diagnostic centres. We're a two-week wait. It works well and supports our local GPs. They're not worrying 'does the patient have cancer or not, how am I going to investigate it?' It can go down a vague symptom pathway if it doesn't fit along another pathway. Binodh, you mentioned the issue of who picks up the results. Once the GP has referred a patient down a two-week wait pathway it's the responsibility of clinicians at the diagnostic centre to pick up the results and carry out the necessary tests.

Shanika We have a rapid diagnostic centre. I find it helpful and valuable because, as you've mentioned, patients are getting more complex. They don't perfectly fit into one cancer diagnostic pathway so it's nice to have the rapid diagnostic centre. I'm a GP trainer and my trainees value it as well when they've got that sort of uncertainty, when they're wondering is this upper GI, is this lower GI, where do I send this person?

Also, there's an additional safety net. The other thing we've picked up on our SEAs was a couple of individuals who were referred down one cancer diagnostic pathway, and were found to be clear, but then ended up having a cancer in another organ which wasn't followed up. How do we make sure these people are looked after and their care is streamlined and communicated between the different streams?

Baldeep For our pathway, we have a filter function test. Our referral criteria are vague – to accommodate that GP gut feeling. Then we have a requirement for function tests to be done – a FIT, a CA125, other blood tests. Usually in those you can pick something up. They help decipher where the patient should go.

Bal With the case Shanika mentioned, if you're a gastroenterologist and the patient has vague lower abdominal symptoms, you examine them and if there's a mass, you refer them. But you can't do that in telephone triage. It is a reflection on secondary care – it seems to be behind us in moving back to the face-to-face consultation. Maybe we need to be more forceful to get them back on board with this.

Victoria What would you like to see in next year's DES and for the future in terms of cancer diagnosis?

Bal I'd like the whole system to be accountable for cancer outcomes, not just my part of the system for my cancer care. We need to be much more ambitious. Let's put the whole pathway in the DES, cancer care for everybody involved in the pathway, not just a referral actioned in two weeks.

Baldeep There should be work linking primary and secondary care for cancer, and for diagnostics. I think early cancer diagnosis in the DES needs to span the breadth of patient education and diagnostics. And also treatment summaries and making sure treatment happens. We're lagging behind all that. [The DES] needs to be a lot broader.

Sarah I am a great believer in investigating the referral pathway. I assumed each practice would do each referral pathway differently but there's even more variation than that. Actually each GP does it differently, and so do locums and other members of staff. From the data we've seen in our PCN, things aren't being picked up in primary care any more. Cancers are being diagnosed with other presentations, and also not through screening. [The DES] needs to revisit what it asked in the first place because I would argue that many PCNs haven't done that.

Shanika There should be a standardised approach up and down the country in terms of access to diagnostics, access to rapid diagnostic centres. It's unfair if a PCN doesn't have access to rapid diagnostics because it is not commissioned for the PCN and it has to be done at place level. Also we need to make sure cancer diagnosis is a priority for place-based partnerships and for integrated care boards (ICBs).

Kanchan My wish list is more integration pathways between secondary care and primary care. The other significant problem we have faced is coding. We depend on coding – being able to pick up how well we are doing. Coding is not being done properly and is a huge issue in our area. There's no consistency in practices or even in different PCNs and how we pick up the referral rate and all those things.

Binodh The most important issue is stability. [We must] remove uncertainty about the DES and the contract. That's a big risk for me as a CD – what's going to happen in 2024? We've got so many people employed through the additional roles reimbursement scheme (ARRS), and I'm cautious every minute because I'm answerable to all these people.