Airing Pain Programme 136: Pain Management During the Covid-19 Pandemic – Lessons Learnt

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How technology developed for the COVID-19 pandemic has changed the working practices in pain clinics and the benefits of patients working together with doctors.

Paul Evans: In the two or so years when COVID-19 was at its most critical, well hopefully anyway, the face to face relationship between doctors and patients was one of the first casualties. Now, with restrictions relaxed have we returned to the status-quo? Or has what was developed at breakneck speed, with necessity being the mother of invention, lead to new working practices? So what did we learn that would actually improve the management of chronic pain into the future? Dr Cathy Price is a consultant in Pain Medicine with the University Hospital Southampton NHS Foundation Trust.

Dr Cathy Price: It's going to take quite some time I think before we truly learn and understand what the pandemic has taught us. I feel first of all that we can implement change at a very rapid rate when we need to. So we had to go from delivering face to face services to everything being online in a couple of weeks. We learnt from that how to use a lot of technology that probably would have taken years to introduce. And we also learnt what patient preferences were with that. When we introduced this locally what we learnt was what we could safely manage at a slower rate and what we absolutely needed to continue delivering. So we took a really evidence-based approach to deciding who to prioritise but made sure that the people who we couldn't see at that moment were safe and checked up on them.

We also looked at what was the impact of remote consultations at all different aspects of the patient journey? In the service we found that really the education sessions that we invite people to could be very safely delivered online and that infact people preferred them because they didn't have to drive and didn't have to sit with other people because they were afraid of picking up bugs themselves and it was much more convenient. And people like me, my medical appointments didn't need to be delivered in a clinic so that saves people sitting around waiting for hours, and then we also learnt that the vast majority of psychological interventions could be safely delivered online. What we also learnt was that it wasn't a great

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idea to try and do rehabilitation online because people need that face to face reassurance and modelling of what needs to be done.

Paul Evans: What do you mean by that?

Dr Cathy Price: So to understand what the movement looked like and how to do this safely we really needed to see it in action because many people learn by doing. So the physiotherapy side, particularly, said: 'we're not doing this remotely and minute more than we have to.' So in terms of delivery of a service we learnt quite a lot. In terms of impact then the referrals from primary care (primary care as you know had to reform and reshape many times) and when we were merging services and splitting them apart trying to do different cohorts I think many people got lost in that process. It was difficult to get through to general practices so what we learnt was that primary care services needed to be different, you needed to have better access than just remotely and that trying to do it all with a lot of triage was sometimes not in patient's best interests.

The other thing that we have learnt is the intense loneliness that people have experienced. When you phoned people in the middle of the pandemic they were just glad to hear a voice and glad to do something. I would say that dropped off very quickly as soon as everybody could get out but its really left its mark, so that one of the biggest impacts that we all know about is that impact on people's wellbeing - emotional health I think is going to be with us for a long time. We've been fortunate to at the same time in primary care be able to provide more staff who can support people's wellbeing. For example social prescribers, health and wellbeing staff and primary care mental health workers. So there is more infrastructure but what I've learnt is that all needs really careful management, grouping and leadership to make it work for patients.

Paul Evans: I think with the online consultations, you think there may be a future in that or there is a future in that. Putting my glass half full about the COVID epidemic, if you tried to get that through in a non-epidemic time it would take you donkeys years and there would be so much opposition to it but largely it has worked and people like it.

Dr Cathy Price: Yes. There are definitely some people who it's very bad for. It's about trying to get that balance though isn't it. You're absolutely right that we would never have done it at the rate of change that we did but it was something I thought was really needed and had

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been needed for a long time. I'm not sure it's terribly fair to ask people to get on two sets of buses to come all the way and then sit for an hour on a seat. By that time I think they're not up to processing very much at all. I'd much rather do things in the comforts of people's homes if at all possible.

Paul Evans: What are the downsides of that?

Dr Cathy Price: Well firstly that not everybody can grapple with technology. Even if you provide iPads, which we managed to get, not everybody can use them. People have got communication difficulties - and I don't mean people who are speaking a different language because actually that was relatively straightforward. More people who may have sensory loss or language difficulty really struggle. So you really need to be sure that people can understand and are finding it useful and not just being polite.

Paul Evans: You mentioned physiotherapy. A doctor can work out a heck of a lot just by watching them walk from the door to the seat in the consultation room.

Dr Cathy Price: It absolutely can't be done online, can it? You're absolutely right and I think that's the bit that sometimes is missing so that's were you need to sometimes allow space to be able to speak to people. Physiotherapists especially, a lot of it is on observation.

Paul Evans: That's Dr Cathy Price. I want to take you back now to an edition of ***Airing Pain*** we made in the Autumn of 2019, so just a few months before COVID 19 grazed its ugly head. 'Experts by Experience - Working Together in Pain Management Programmes' was a workshop running in parallel with the British Pain Society's 'Pain Management Programme Special Interest Group' national conference in Bristol, in which patients and practitioners from four different pain management centres around the UK shared their experience of working together. You can still listen to that edition of ***Airing Pain***, it's number 119 at Pain Concern's website which is *Painconcern.org.uk.* But here's a flavour:

Primrose Granville: Unemployment is one thing but not being employable is a totally other story. It's a case of 'you are useless' and this happened around the same time when our lovely former Prime minister David Cameron came up with the word 'scroungers'. And here I was, on benefits, a scrounger.

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Penny: If you just help one person it’s so worthwhile I had a lady and she was in such distress and anxiousness when I first met her and all she wanted was someone to listen to her and to feel validated that her pain is real. It really is there.

Primrose Granville: And I turned up Week One, Two and then in Week Three that gentleman there who is trying to hide, Rob, who you all know, changed my life with five simple words: ‘I still live with pain.’

Penny: And it’s rewarding if you see someone who is down here to suddenly be in a better place. It’s worth it just for that one person.

Primrose Granville: I’m going to live with this for the rest of my life, but I’m going to have a nice life. I just do things differently and that’s what pain management has done for me. The best part though, is being on the team. You feel so valued.

John Bremner: If only I had had some of this information earlier in my pain journey. Why didn’t I get this earlier I might not have been there in this state if I had had information earlier?

Lindsay: To those who are considering volunteering I would wholeheartedly recommend you to get involved. It is so rewarding and so fulfilling. Very best of luck to you all and please remember to be kind to yourself.

Paul Evans: That was an excerpt from an earlier edition of ***Airing Pain***, number 119, and as I mentioned you can listen to the full edition at the Pain Concern website. And the voices were of participants in the ‘Experts by Experience Working Together in Pain Management Programmes Workshop’ just a few months before we were hit by the COVID-19 pandemic. Of course, a lot of water has gone under the bridge since then, to put it mildly. The workshop was facilitated by consultant and clinical psychologist Dr Nick Ambler of the North Bristol NHS Trust. He and his team were working to create a more personalised form of management and support for people living with chronic pain. Two years on from that workshop, he and colleagues shared their experience with delegates at the 2022 British Pain Society Annual Scientific Meeting.

Dr Nick Ambler: We convened the pain management programme conference in Bristol and I was very keen to run a workshop that would showcase the involvement of service users in

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service delivery and service organisation and that's what we did. It was all about the patients.

Paul Evans: And why was it so good?

Dr Nick Ambler: Well I think it's a refreshing change to take part in a pain science meeting run by the organisation that most represents the practitioners working in the area. It's nice to hear the involvement of patients alongside that meeting. Very much in tune with what we're trying to achieve as health professionals - but as partners rather than in the more traditional way of thinking about the work as being 'we develop the technologies of pain care and we have recipients of pain care lining up to try it out'. We don't think in that way in pain management work and that felt like a chance to more appropriately reflect that evolution taking place in the involvement of service users.

Paul Evans: I wasn't aware that there were many health professionals there. I guess there was you and there was Martin Dunbar.

Dr Nick Ambler: There were probably about twelve of us in the room. I guess our target was really to talk more to the patients. So my main focus really was to try and persuade others who had been involved themselves or were curious about it to come along and hear from people who were involved in delivering services in different shapes and forms in different sites around the country, to hear about how they do that and whether or not it works.

Paul Evans: But its not just about people with pain helping people with pain. It's also about people with pain helping health professionals manage people with pain.

Dr Nick Ambler: It's supposed to be a partnership, In my profession when you're learning about consultation methods, one of the tricks of reflecting how well you're getting on is to ask within yourself. What does it feel like this discussion I'm having with this client? Does it feel like a wrestling match or a dance? To try and have that picture and approximate where your position is. Because if it feels like a wrestling match it's probably not going very well and you need to think about doing something different. If it feels like dancing then you're in tune with each other and that's a fair reflection of a process rolling forward in the right way. So with that in mind the way in which we work in partnership with patients should feel like the organisation and delivery of pain services is like a dance, where it's good to see the people

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who need our help and to be working out what they need and how its suited best to them with them rather than to be second guessing.

Paul Evans: I guess the idea is that patients leave with a smile on their face and doctors are left with a smile on their face.

Dr Nick Ambler: Well that's a big ask Paul, and I'm not sure we'll get that when dealing with pain but a sense of feeling heard, definitely. The reverse is where somebody is coming away maybe with a list in their pocket which didn't quite work out, or didn't feel like they were able to express themselves or that they've been patted off. Those things are quite commonplace nowadays and with healthcare under pressure there is a real risk of that worsening not improving But it is worth it for healthcare professionals to focus in on how well they're getting on in a sense of finding common ground and hearing what people want. Changing the way they approach things to try and smooth out that kind of discussion so it doesn't feel quite so tense, but I think tension is still prevalent in those kind of consultations.

Paul Evans: Well we're at the British Pain Society Annual Scientific Meeting 2022. What were you telling the great and good of the scientific world about that?

Dr Nick Ambler: Well if I tried to tell them I don't think we'd get very far. I've been asked to present something along with my colleague Nicola O'Brien about service user involvement and different kinds of pain service. But for both of us at the core of that are pain management programmes and the way in which working in partnership with people who had been former patients but had volunteered to come back, taken part in training and received some supervision to develop them into the role. How that's different, what you would have as a health professional if you embrace the idea of that, what you need to put into it, what's expected of you. Some clarity about how it works rather than just trying to sell the idea of it, that's what we were talking about today and I hope it was somewhat provocative. But my intention was to say 'you can't make an omelette without breaking eggs', which is an old expression about there are crunch moments as you try and move things forward. The issue really is of something which we have a strong sense of commitment to which is valuable but yet to really take off in pain services and more generally in healthcare.

Paul Evans: Well the title of your talk was harnessing patients to deliver care. Now that word deliver is quite an important word.

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Dr Nick Ambler: Can I, before we get to the delivery take the harness off which is what I did at the beginning of the talk. I don't think harnessing anybody is a good idea and we switched the title to working in partnership to deliver services. Do you find 'deliver' is a bit of a provocative thought?

Paul Evans: Well the word deliver doesn't involve me as a patient. You talk about breaking eggs, who are the eggs here?

Dr Nick Ambler: Colleagues.

Paul Evans: So do you think that deliver is the wrong word?

Dr Nick Ambler: I wish I hadn't mentioned about breaking eggs, I don't want anyone to get broken. Delivery does reflect a sort of sense of somebody having something to give and they're being a passive recipient so no in that sense it's not a good word. But we did, in the talk, cover at some length the transition from the traditional kind of 'bring your problems and I'll fix them' kind of encounter that exists in the relationship between doctors or health professionals generally and patients to one of shared decision making, joint exploration and a sense of trying to work on the things that the person most wants to work on and then reaching decisions through a shared understanding.

Paul Evans: Those traditional views - they are traditional and they still exist. Doctor sits there, patient sits here. 'Doctor I've got a bad shoulder. Fix it.' It takes education for the doctor but also for the patient. Lets assume the doctor wants to change things but how do you change the patient viewpoint?

Dr Nick Ambler: I'm imagining here a general practitioner that this is happening to at primary care level, and so I'm thinking that from the doctor's point of view there is a little voice in their head saying 'why do you keep asking me that because you know that I can't?' That is not a friendly thing to say in the consultation. And instead, I'm not sure you're asking me the right question here Paul (this is an imaginary consultation). It's been 3 months since you last asked me that. We've been round the roundabout of trying to find a means of fixing this pain and I had been thinking ahead to our discussion today about how we look sideways at that, kind of differently. If you can bear with me a few minutes I'll explain a bit more about what I mean. Would you like me to do that?

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Paul Evans: A few minutes is the problem.

Dr Nick Ambler: Again, a mantra for those undertaking training around this - this is about spending time to save time. Think back to where we were a moment ago. This is a repeat consultation. This is a revolving door process. This person has been in the room sitting in the chair asking for help for this injured shoulder. Whatever is going on with the shoulder, several times previously I suspect, and there hasn't been any sense of moving forward with that so we need to try a different route. It would be a matter of trying to divert in a direction that is probably more productive.

Paul Evans: Pain Concern has done research and is continuing research into patient doctor consultations and they have developed their navigator tool that puts patients and doctors on the same plane. The doctor has to do his or her homework and the patient has to do his or her homework also.

Dr Nick Ambler: So a preparedness to have a different conversation that is ideally better set up if both sides know what that change in direction is. And the tool can help it from the patient's side. Training in the consultation process in the different format from the health professional side is also a useful idea. If one or other really doesn't get it it's much more of a struggle.

Paul Evans: Well there is an elephant in this room and we're going to have to talk about it and that is COVID. In the workshop we met - that was 2019 - 3 years ago and we've had COVID since then. Now, how has that affected what you were trying to put into place in 2019?

Dr Nick Ambler: Well it was a very unsettling period that's for sure. In the beginning many of us were diverted into other priority areas to deal with the pandemic, to deal with all the other pressures which existed in the hospital. All outpatient activity was blocked for some time. Many pain clinics really had to shut down and the concern at that stage was where we would pick up as we got going again. But even before that happened there was a push within those of us running pain management programmes to go online and to try to meet the demand in a different way. And I think with that, the beginnings of something different had emerged in extreme circumstances so increasingly we were able to go back to more traditional roles, I think, within about a year of the onset of the pandemic hitting the health service. We were up

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and running with our online course well before then. And they were something which I guess we weren't particularly under pressure to understand well before then but now have become very much part of the array of things that we do. And we are in a different phase now where we are able to things again about getting going on an outpatient basis. We have got a backlog of work to pick up with. The consequences of that are going to play out for quite sometime. But we've jumped forward in our understanding about access that is made available by the means of working with people. That's evolved in a different direction. I'm not going to tell you that face to face working is less preferable than working online. I don't believe that for one minute but I'm really glad that we've learnt about how to approach this in an alternative way and I think if nothing else right now, in the NHS we are going through a refresh phase looking again at how to do what we can do with a load of work to catch up with. And it demands new thinking and reasoning and that's what I find encouraging about what has been a very difficult situation.

Paul Evans: I would guess that one of the issues with that word refresh is that everything we learnt in the last two years, that was just a temporary thing and back to the old ways.

Dr Nick Ambler: I can't imagine that's going to happen. I don't see evidence of that around. There has been this opening to improve access. So we have, for example, introduced first contact being by zoom if possible so it's possible to come into our service with a face to face contact initially but the initial screening is done by zoom calls, by preference. That's enabled us to pick up more quickly with people. I think one of the initial things that you experience when you're coming into the service is the sense of a long wait. Well, that's less the case because of what we've learnt about online consultations. But we blended that with face to face follow up, where that's possible, and we've continued with a segment of service which is not face to face open to those people that would prefer to approach it in that way.

I think new stuff has come out of this - grim as it has been - it has shunted things forward with a lurch. We are still under pressure but we're doing things differently now and I don't think we can go back.

Paul Evans: I think the word of question that came up in your talk earlier was 'disheartened'. Are you disheartened?

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Dr Nick Ambler: Not at all. There's a sense of a lot of effort being expended. I might've felt set back because today I'm talking about the thing that you and I were talking about three years ago when we last met in Bristol and in a sense I can't see that there's been a jump forward in the involvement of service delivery in a way I would've hoped and visioned at that stage but realistically we've had three years of COVID and we're facing a very different situation now. This offers an enormous amount of potential input and I see with this and with the idea of a refresh perhaps a better chance to get a more firm footing with that. I was at one of the talks this morning about virtual reality and how that might be been incorporated. Talking to Owen Williamson afterwards about the slow pace at which - something that I think is really quite helpful for acute pain - the slow pace at which that's moved forward. He was reassuring in a sense. He said: 'You know you need to understand on average a new piece of technology that's going to help things along clinically can take on average seventeen years to be implemented.' I shouldn't feel disheartened really. I am accustomed to taking the ideas and rehashing them but also with a new sense of the changed situation to continue to draw attention to this as a huge potential asset of volunteers being alongside health professionals, working in partnership for delivering services. I guess we need another term for that. But the broader term is actually co-production - the idea that you're creating something, you're finding a way with something and to take that forwards in a sense that that is part of the way out of this difficult situation. Its an evolution and naturally takes a lot of time. I feel encouraged by that but there's still plenty of work to do.

Paul Evans: That's consultant and clinical psychologist Dr Nick Ambler of the North Bristol NHS Trust pain management programme. He and his team guest edited issue number 78 of ***Pain Matters*** magazine about delivery of pain management throughout the COVID-19 pandemic. You can get details from Pain Concern's website which is Painconcern.org.uk and you can download all editions of ***Airing Pain*** from there and find a wealth of support and information material about living with and managing chronic pain, including more details about this edition of ***Airing Pain***. Now, as in every edition of ***Airing Pain*** I like to remind you of the small print that whilst we in Pain Concern believe the information and opinions in ***Airing Pain*** are accurate and sound, based on the best judgements available, you should always consult your health professional on any matter relating to your health and wellbeing. They are the only people who know you and your circumstances and therefore the appropriate action to take on your behalf. It's important for us at pain concern to have your feedback on these podcasts so that we know what we are doing is relevant and useful and

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to know what we are doing well or not so well so do please leave your comments or ratings on whatever platform your listening to this on or the Pain Concern website of course. That will help us develop and plan future editions of ***Airing Pain***. Back to this edition of ***Airing Pain***. We heard Dr Cathy Price earlier talking about how pain teams have adapted to working through COVID-19 restrictions so what would she like to keep from those two years?

Dr Cathy Price: I'd like to keep the flexibility - our team meetings are so much better since they've been online. Haven't had grumpy people turning up at 8.30am in the morning having fought their way through two hours of traffic, for example. I'd very much like to keep that flexibility. When people have been booked in face to face and I can't see why I say 'what would you have wanted' and they say 'we'd have been perfectly happy at home', so we need to really step back and think. I'd like to keep a lot of that technology. I fear we'll be told it's too expensive and we won't have as good access as we have had. I'd like to keep all of the different ways that we've communicated with people. I've got much better at text messaging, sending links, doing video consultations – much, much better. And people have as well. They have been really open to it. I'd like to keep that openness I think.

Paul Evans: How do you make sure that all the good things aren't rolled back?

Dr Cathy Price: What we've done is done an evaluation to really make sure that you've asked people how it has gone and what they've felt. You learn from that and you keep asking again and again. Look to see whether you've got lots of complaints, also use patient feedback as well and ask the right questions.

Paul Evans: Cathy Price. Going back to that experts by experience working together in pain management programmes workshop just before COVID hit - Nick Ambler.

Dr Nick Ambler: The person that hit the right tone at the beginning who works with us at Bristol is Primrose Granville, who I thought did a really inspiring talk about how she had found it incredibly useful taking part in a programme, changing her life and then continuing to do that. So I have to say one of my main memories from the period of time when we were all locked in watching TV, which is pretty much all I did when I wasn't at work. Seeing the local news, seeing Primrose out on the street in one of the suburbs of Bristol where the uptake of vaccinations was very low, stopping people on the street and persuading them to have jabs.

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And I thought well my immediate reaction was - isn't that just Primose, she's phenomenal. Then I thought well I don't want to lose her. Someone has found her and taken her away from our service and immediately felt quite defensive about that. It just shows you the kind of people that come forward and they know the impact they can have. She was interviewed on TV about why you're doing this. And she said: 'Well I've realised how important this is and if I can use the way I present things to persuade others to do it I'm going to do that.' I identify with these people. It's a poorer suburb of Bristol in the sense of average income so I need to talk to them. I'm the one who should be talking to them. And doesn't that nail it actually. That's exactly right. That totally reflects the way in which we became involved with Primrose in trying to improve the way we do things in the pain service.

Paul Evans: And that is patients being involved in a team.

Dr Nick Ambler: Being part of the team.

Paul Evans: Nick Ambler. And so we let Primrose Granville, part of that team have the last words of this edition of ***Airing Pain***.

Dr Primrose Granville: I have been on two pain management courses, so I went to one in the old days. That course didn't do anything for me. It was purely instructional. I felt like I was in high school again being forced to do maths which I hate. And I got nothing from it whatsoever, absolutely nothing. Fast forward a couple of years, anyone know Dr Greenslade? Yes, so we had a really long conversation. It ranged from articles in the Guardian to articles in The Sun where he was actually trying to convince me to go on a second course and I was like no I'm not doing that, give me the magical pill and I'll be fine. Give me surgery give me anything. And he was like 'no you've had the surgery, you do need to go on another pain management course, I promise you its different'. And I turned up Week One, Two and then in Week Three that gentleman there who is trying to hide, Rob, who you all know, changed my life with five simple words: I still live with pain. Those were the five simple words that literally changed my entire life. And then he started talking about all kinds of things that he did and I'm like I was stuck and I still live with pain. And I remember leaving the room with my pain friend and we used to be a lot of trouble on the course. You know we were the talkative ones. And we were sitting in my car because I was taking her home that evening and we were like 'so we can do stuff'. The pain was controlling my life and one of the things I wanted to do was, my only goddaughter lived 146 miles up the M4 and the A13

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in deep Essex. Why her parents choose to live there, I don't know. And I wanted to be able to get in my car and do the journey from beginning to end and just not stop. And he spoke about going down the M5 to Cornwall and how he had to stop several times. And I was like, oh my God, stop several times. But I heard him out and it was like wow so he changed my life with his examples but he got me with those five words and I thought 'hmm'. And you know the end where they give you that long questionnaire that we all have to fill out, the big long one that looks like an epistle. So when you get to that last question that said: 'Do you think you could volunteer here?' or something like that. And I consulted with my friend and she said it's too much and I said I'm going to try and I ticked the box. And they phoned me the following week and I was like they don't hang about so I kind of wanted to see what it was like from the other side. To find out if I could impact somebody else the way Rob has impacted me. His simple example, his simple words. His: 'I still live in pain but I actually have a life that I enjoy.' And I'm glad I met Rob because I'm glad that I actually volunteered because I felt valuable. I was turning up on Wednesday and when I wasn't well they missed me. And that's my why. I feel like I'm doing something that's worthwhile to someone else. Who would've thought the words 'I still live with pain' would mean anything to anybody? I wouldn't have thought it would mean anything to me. But it does now because it was the moment that I decided I'm going to live with this for the rest of my life, but I'm going to have a nice life. I just do things differently and that's what pain management has done for me. The best part though, is being on the team. You feel so valued. It's a case of somebody wants you there. For me being that messenger is a lot more important than the message.

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