Airing Pain Programme 61: Deciding together

How shared decision making works in practice, plus, making IT work for people in pain and healthcare professionals.

*In this edition of **Airing Pain** we hear about how people in pain can take an active role in their care through shared decision making and technological tools. 'Being collaborative is fundamental' for managing pain, says Dave Tomson, a GP working on the MAGIC Programme (Making good decisions in collaboration). He speaks to Producer Paul Evans at the British Pain Society's (BPS) Annual Scientific Meeting in Manchester about the advantages and challenges in developing an approach to medicine where decisions are made by doctors and patients together.*

Technology can play a transformative role in empowering people in pain, but there are also pitfalls to be avoided. Jason Davies discusses the pros and cons of 'telemedicine' as a pain specialist working in the remote Argyll region of north western Scotland.

Other members of the BPS Special Interest Group on Information and Communication Technology discuss the things patients and doctors should be looking out for when using online resources and the cultural change needed to make technology work – people in pain empowered to take responsibility for their pain.

Paul Evans: You're listening to ***Airing Pain***, a programme brought to you by Pain Concern; a UK-based charity working to help support and inform people living with pain and healthcare professionals. This programme has been funded by Pain Concern's friends and supporters.

Now, do people with chronic pain really have a say in how we're treated? Are we given the right information to make informed decisions? Are our views as experts in how our pain effects our lives really taken on board? And do the different disciplines in the health profession who manage us treat us as conditions or as individuals? Indeed, do they communicate with each other at all?

These issues were addressed at the British Pain Society's annual scientific meeting in Manchester, when Dave Thomson, a GP in the North-east of England, spoke about shared decision making and his involvement in the MAGIC programme. And that's an acronym for 'making good decisions in collaboration.'

Dave Thomson: The MAGIC programme has been an implementation programme in hospitals and general practices to try and work with front-line staff, and with patients, so that they are making better decisions together: by sharing information, looking at the pros and cons of different options and arriving at a decision that's best for the patient, that fits.

Evans: So where are the barriers to shared decision making?

Thomson: There are lots. I mean, for good shared decision making, you need good information. So one of the challenges is we don't have good information about lots of the things that we do. What is the relative benefit of exercise programmes versus cholesterol lowering drugs? Or in a pain context, we have very poor evidence about how many people given an opiate for muscular skeletal pain will improve, versus the number of people who will improve using exercise as their way of coping with their pain, or improving their pain. So one problem is evidence.

The second problem, I think, is that many professional, many clinicians, are uncomfortable – in a number of ways – with really opening up the dialogue to being shared. So some may believe that patients won't be able to understand the details or the complexities of the science, if you wish – the evidence. Some may think that there's not enough time to do it adequately, and that it's the patient’s job to trust them. So I think there are a variety of barriers at a clinician level and then I think there are some barriers or challenges for patients. So some patients may wish to put themselves in the hands of a clinician and simply say, you know, ‘tell me.’

Evans: ‘Doctor, fix me.’

Thomson: ‘Doctor, fix me.’ And of course [they] may actually even be resentful of the idea of a doctor saying, ‘well, actually, I'm very unlikely to be doing most of the fixing here. Most of the fixing is gonna [sic] be you and, what I can do is help you understand better and worse ways of handling your condition, but in the end, if you don't do the exercises, or do the stretches, or do the pacing, that's in your court.’

And so shared decision making is actually an invitation for patients to be much more engaged themselves. And some of the barriers are around patients that want to be passive, want to be held, want to be simply looked after.

Evans: But to share a decision – it means that we both have to be informed about the other, if you like. I, as a patient, need to know how you can help me and how I can help myself.

Thomson: Yeah, yeah, yeah. We need a number of things. We need the information that we can share together about what works and how well it works. We also need to understand what matters to you. If you think about any decision, what's best for you might not be best for someone else. It might be that, you know – if we take a very simple example like taking a cholesterol lowering tablet, a tablet that lowers your cholesterol – which there's very good evidence is likely to reduce your risk of heart disease.

But it means taking a tablet every day and it has the potential for side effects. And some people believe, you know, ‘I don't think, for me, taking tablets is what I like to do. I'm prepared to take that extra risk.’

The science would say everyone above a certain age with other risk factors should take one of these things; but the science doesn't take into account your preferences. So, a good shared decision has to be about what matters to you.

And you may not know what matters to you in terms of this particular decision, until you've started to explore the territory with someone. So your preferences at the beginning of a conversation about a treatment option may actually change as you understand the pros and cons – the benefits and risks – of any one option.

Evans: That's a good example, because I am that person on the verge of taking a cholesterol lowering tablet.

Thomson: OK.

Evans: I'm at the point where I'm getting pretty fed up of the medical profession arguing amongst themselves and giving me conflicting advice.

Thomson: OK

Evans: Mainly through the media. Not through face-to-face health professionals.

Thomson: Yeah. Yeah.

Evans: So, does the medical profession need to get its own shop in order before asking me to help out on my decisions?

Thomson: Well, yes and no. I think, in a sense, understanding that there are not such clear options – welcome to the real world, patient. If you thought that you would come to me and I'd tell you, ‘it's very clear – this works, this doesn't work, it's all very straight forward’ – probably you've never experienced chronic pain. But I know you have had chronic pain and that is a field where we know very little, where we're discovering lots, where lots of it’s conflicting and there are lots of different ideas going round – so it's messy; it's not straightforward.

And actually the science around lots of things is not straightforward. And at some level, if we are going to both be adults, we both have to accept that it's actually a bit messier. I can pretend that it's all nice and straightforward and treat you like a child, and you can pretend to be a child and accept my... unquestioning... you know, advice. And that's a world that, you know, we've maybe been in, but it's not a world that I'm interested in working with patients in.

Evans: And that's not shared decision making.

Thomson: No, no. Shared decision making, you have to share some of the messiness. The fact that it is not straightforward. And in pain it's particularly tricky, I think, because we have very poor evidence. And sometimes we find it difficult – patients and clinicians find it difficult to actually agree, about what the nature is, of the problem. And if we can't even agree about the nature of the problem, and the meaning and understanding we attribute to that, that wraps up that problem, then we're in trouble in terms of discussing what might options be.

But I think what we need to do is, we need to try. We need to start that conversation, we need to start the effort of treating each other as adults. Of exploring together what we do know; arriving at shared meaning, shared understanding and then beginning to say, 'well, you know, if that's where we're starting, these are some of the options and this is what we do know about these options.' And beginning to then be in a more collaborative place. And certainly in chronic pain, being collaborative is one of the fundamental... you know, we really need that more than in many things.

Evans: That was Dave Tomson. I'll just remind you that while Pain Concern believes the information and opinions on ***Airing Pain*** are accurate and sound, based on the best judgement available, you should always consult your health professional on any matter relating to your health and well-being. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

Yes I know, I say that in every edition of ***Airing Pain***. But I think it's particularly relevant [to] the amount of information and disinformation available to us at the click of a mouse key on the internet and social media. How can we trust what we find on search engines? and how can current and developing internet technology be used in the management of chronic pain? These are just some of the issues that a new special interest group of the British Pain Society will address.

I went along to the launch of this information and communication technology group at the Society's annual scientific meeting; where I spoke to Meherzin Das, who's clinical lead of [the] Dorset Pain Management Unit, and chair of the [ICT] group, along with David Barrett, one of the committee members, and John Worth, founder of Know Your Own Health, a provider to the group community.

John Worth: The internet and IT services can be very powerful in supporting people with long-term conditions with pain and so on. But what's key is that actually it doesn't replace human – warm, human, equitable support – but what it can do is, it can create the conditions and the foundations within which things can be organised better. Information can be exchanged better. People can go and find, you know, the information that they're looking for and access the type of support that they want. That's the sort of... the thrust of the work that we're doing.

Evans: That's the thrust of it; but what does it mean to the patient?

Meherzin Das: Speaking as a clinician, ICT has a lot to offer, in terms of complementing clinical work done in hospitals and community care settings. So the website that John's set up for us, for example, which is Soaring Above Pain within the Dorset Community Pain Service, helps patients by providing lots of handouts, data sets that they've got from clinicians, so patients have those to access at home and can track their own goals and own progress and therapy, and set up what they'd like to, as part of their recovery process from pain. And I use that word ‘recovery’ in inverted commas, because it has different meanings to different people, but it's very much part of learning to soar above pain; learning to get a handle on, a grip on their pain and learning to live life meaningfully despite being in pain.

David Barrett: Listen, what we've done is to use the technology to enable patients to communicate [with] or see doctors online, but without having to leave their homes. So if someone is in particularly bad pain and can't get out to see their doctor, they're able to do that online and still get the information and feedback from the doctor in a face-to-face situation, but using a technology that's available these days.

Evans: I guess it's particularly valuable – as you say for people who can't leave home – but [also] for people in rural areas.

Barrett: Absolutely. I think this concept of tele-medicine has been used out in the wilds of Scotland for some time and it's certainly going to be useful to that patient group, I would have thought, for sure. And what we've done with my clinic for pain is to take that model that's been used – that was mainly for cardiac patients – but we've taken that model and extended it to be used in the pain area.

Evans: Taking the human face away from a doctor/patient consultation; is that a good thing or a bad thing?

Barrett: Well it's not taking the human face away because they'll be able to see each other, as you would with a – lets for example a Skype or a Face Time discussion. So you can see the doctor, the doctor can see you, and the beauty of it is it can be recorded and stored on the patient's home page if you like, for the patient to review at a later date. So if they've missed something that the doctor said, they can go back and look through the video again and pick that up and put it into action. So that's the start of it. And linking it into what John's company does, is to lead patients down the path of self-management, using this as a tool to help the patients, rather than using it to drive what happens. So it's an assist to the doctor and the patient, rather than taking over.

Worth: Yeah. I mean you can't assume that technology is going to answer the problem. It isn't going to answer the problem. What you need to do alongside the introduction of technology is to introduce, work around, systemic change and cultural change within the practices that you're kind of delivering. So it doesn't happen overnight: it's something that needs to be introduced to people, to patients, to citizens, who are more used to kind of just rocking up at a surgery and asking to be fixed. The opportunity with IT is to create an infrastructure that enables people to start to view their options and things that are available to them. Which include clinical services and other kinds of support that they might be able to get out there.

Evans: I glibly said it's removing the face, if you like, of the doctor. In actual fact it could be viewed as bringing the doctor to you, rather than you having to go to the doctor.

Barrett: Yeah, I think that's certainly true. From my own personal experience of seeing my own GP, we sit there in a room, we don't make any eye contact. He's looking at his computer screen and talking to me and writing notes! Now this is clearly...with my clinic for pain, you haven't got any choice. You have to see the doctor face to face, so that you're both looking at each other with eye contact. So, I mean, in fact in some ways this might be even better than the situation in the doctor's office.

Evans: There is no hiding.

Barrett: Absolutely! And it's all recorded too, so it's there for everybody to see. And the CQC, as you can imagine, love that!

Evans: CQC?

Barrett: Care Quality Commission.

Evans: You've just finished all the development work and you're going live. Now what does that mean – how will it be rolled out?

Barrett: Well, it means doing some trials with a number of patients and making sure we can get rid of all the bugs that will inevitably be in the system and making it as easy as possible for people to use. Obviously we developed it in house and we know how it works – we know it inside out – but of course the patient won't know that, so we're going to have to trial it with real life patients and then see how things go from there and make the changes and improvements. And I think some of the ideas that John has got also will feed very much into what we're trying to do.

Wroth: The IT aspect is really just the means by which you set up infrastructure to enable people to access the care and support that they want. So, David's solution might be one option of many within a range of options open to a person who's managing pain on a daily basis. What we're interested in primarily is what happens to that person in between their clinical appointments. So, you know, if you imagine between March and October – what happens to that patient? Between the March appointment and the October appointment, what are they doing in between times? They’re self-managing. What options have they got that are available to them to increase and improve their self-management, to increase their levels of confidence and their skill and make good informed decisions about the types of medications and treatments that they might, or that they could be receiving.

Evans: You see, I think the term IT – information technology – is an outdated term. It is no longer static.

Wroth: What you're saying is absolutely right. What we're looking at, in all walks of life, whether you're catching a plane or wanting to do your shopping, digital services are kind of prevalent – and they're going to be more and more prevalent within healthcare. So what do you need to do to enable digital services to work well within the very complex nature of healthcare?

And, our understanding, and the work that we're doing, is to identify how you manage the interdependence between digital services, clinical services and the work that people need to do to self-manage their long-term health conditions. So those are three core components that need to work side by side. It's a really exciting part of the whole healthcare landscape. It's something that's in policy, but [that] very, very few people know how to deliver or know what to commission at the moment. There's an inevitability that that's the direction we'll travel.

Barrett: And I think the key to it is not to use it as a substitute for other means of treating patients, but as an aid. And that's, I think...hopefully we'll take the fear away. It's not something that's going to take over people's lives. It's going to be part of their lives and to help improve their quality of life.

Jason Davies: I'm Dr Jason Davies, I'm a consultant anaesthetist in Oban and I run the pain service for Argyll.

Evans: Oban, that's the far north of Scotland?

Davies: It's about a hundred miles north west of Glasgow. At the moment there is an initiative to try and see if we can better deliver our services to the more remote parts of our community, which are not well served, it would be fair to say, at the moment. And also that the work is done, pretty much, all by the patient. You know, if they want to gain access to these services – for instance, if you live on Islay or somewhere like that, you have to go to Glasgow. And Glasgow is better to travel to because you can actually fly there, so it's a less onerous journey. But it would be better if we could deliver, if they didn't have to travel as much. I'm not saying that they wouldn't have to travel at all, but if you could actually deliver something effective – and I think that's the key word – deliver something *effective* locally then that, I would think, has got to be a good thing.

Evans: But is travel the only benefit?

Davies: Not necessarily. I mean, you know, obviously you're delivering a sort of secondary care-type service – a more comprehensive service, perhaps, to the patients – but you're also supporting GP's. So you're educating, you're supporting – there's lots of collateral benefits that you get as well.

Evans: And face-to-face consultations.

Davies: Well, I like the idea of actually seeing the person! And I think, with the limited experience that we've had by telephone – it may be that I'm a bit of a dinosaur in that respect – but I like to see people, I like to touch people and moving into tele-medicine, which has got to be the way to go – there is no doubt about that – it's a different experience for me, but it's also a different experience for people as well, because I think people like to be seen!

Evans: It also, I guess, puts patients a little more in control.

Davies: Which is where we want them. Because we know that if they take care of themselves, they take an active interest in policing their pain, then they do much better.

Evans: So it's something of interest for you.

Davies: It has to be an active experience for them – yes, yes.

Barrett: I'm going to try and see if I can link up to our office in a minute, to show you how the thing works... and it's just like a normal face-to-face conversation. Any notes that the doctor makes would appear in here, and if he's prescribed something, we run an internet pharmacy, so you could actually buy that from the pharmacy now. But it's also got the patient information leaflets.

This may be a bit difficult in the north of Scotland, but within a ten-mile radius of where you live, it will identify all the back-up services that you need. So if you want, let’s say an acupuncturist near your house, then it'll give you the address and phone number...

Davies: Probably not as useful for us.

Barrett: No, exactly!

Davies: When it's up and running, it all sounds great. But how do you get from the point of not having anything, to the point where – I mean, we do have broadband access to all the islands because that was a Scottish Government priority.

Barrett: Broadband access and a laptop, you can do this anywhere.

Davies: Tele-medicine is the way ahead for us, because we can't physically be everywhere. Telephone is OK, it gets information, but you lose a lot of visual clues, you lose a lot of non-verbal communication, which can be quite relevant in terms of the consultation. I mean at the moment the patient questionnaire that we're using is a handwritten questionnaire.

The questionnaire gets sent out, the patient fills that in with various scoring systems and what not, that comes back, and then we have a telephone consultation. Often that will either be quite clear where they're going, or what needs to be done, or what advice needs to be given. Sometimes it's not and you have to bring them in. But you're bringing them in primarily because you want to see what's behind this sheet of paper!

Barrett: And there's no reason why you couldn't do that with this system online.

Wroth: The work that's going on is to produce a range of key bench marks across – not just this group – but across the whole of healthcare delivery. It's a major priority within NHS England itself, you know, the information directorate, and the way in which data is managed, that information is managed, and so on, is something that has increasing importance.

You know, within healthcare, we're working with a knowledge economy as much as we are with a healthcare economy. How do you manage that knowledge; how do you ensure that the quality of the information that a person is accessing is good. Anybody can type in a medical term and come up with a range of search returns. They have no way of knowing the valuable quality of the information that's there; and part of the job of people like myself and the work that we do and that this group does, is to enable people to access trusted, filtered information that is validated across a range of different groups and inputs

Evans: Well, is it enough to know that if it's part of the British Pain Society, then it can be trusted?

Das: Ah, no, because there's a phrase that says, 'In God we trust, all others must bring evidence!' So I think the British Pain Society's as accountable as any other organisation and for that purpose we've set up a whole bench-marking system by which we can validate other websites, if they want to be recognised by the British Pain Society. We're actually working to revamp our own website as well, to create a better web presence for the society – to make it a much more user friendly website. So anyone anywhere living with pain, or clinicians working with pain, can come to us and actually say, 'how can you help us?' And we can help them straight away.

We've got a whole benchmarking process underway – there's been a consultation which John's been a part of, David's been a part of as well. We've come up with seven criteria that we need other websites to meet: so, we want to know people's intervention capabilities; we want a website to tell us what they can and can't do – limits; so not to claim the earth, if they can't actually deliver.

Websites need to be inclusive in terms of their development, in terms of including service users – engaging them not just as a reference group, but as part of the development of each web tool. Reference materials need to be included, because if you were publishing in a journal, you couldn’t just say, ‘this is what I think.’ You’d have to evidence that. And websites don’t have enough of that, so we need that to be revamped and done up.

Websites need ongoing evaluation and that has to be published, so users know what that’s all about. Website user statistics need to be included as well. And disclosure of responsibilities has to be used in line with the HSCIC Information Governance Level 2, which, I’m reliably informed, all of us should be adhering to. And it has to be accessible for people with sensory difficulties.

So, all those seven benchmarking criteria need to be fulfilled for an external website to be recognised and nominated by the BPS as one that we would recommend.

Evans: So, is there something like the old kitemark that patients and professionals can recognise…?

Das: …can rely on? Absolutely! And we’ve also developed a social networking policy, because we believe that social networking should also happen responsibly within the BPS. So, that’s been all the way to Council and ratified, so we’ve got that in place. And we hope you’re following us on Twitter, as we speak, because that’s up and about.

Evans: So if I’m a patient and you have set me a care plan, how do I know that that is relevant for me?

Das: Right… so Paul, I’ll take it one step back, if I may, and say that in actual fact care plans should be set up with patients in collaboration. So we’d never set up a care plan for you: it’s very much with you, depending on the goals and objectives you want to meet as part of your treatment.

So, in the field of pain, there aren't any PROMs available – and PROMs stands for patient reported outcome measures. So other fields have them in terms of what outcomes are patients looking for – individual patients – but pain doesn't have them. So at Dorset Community Pain Service we're working very hard to set these up and we have four cornerstones of therapy and those are personal development goals, such as, emotional development; physiotherapy – and physical development and fitness lead that, things like that; we have medication, understanding pain, as a third one; and then we have relaxation and working with leisure activities, hobbies, things like that. So those are the four cornerstones and, within that, patients identify what they want to work on.

So the thing that we're trying to set up is to have that linking all the way from when a patient goes to their GP and says, 'help – I'm in pain!' So GPs will those which we'll feed to all our 104 surgeries in Dorset and then when we receive their referral forms, patients will identify what they want to work on. When they come for an assessment will stamp that in and make sure that's really what the person wants to work on. Then, when they go away and work with self-management with the website that John's developing, we'll have those on the website as well.

So, all through the patient's journey, we're working with the same objectives that the patient has identified, because all too often happens is there's a disconnection between what GPs believe, what consultants believe and what someone else wants and the patient is nowhere to be seen in the middle of that. So we're going to do away with all of that and have goals that the patient identifies, because they're the centre of the process.

Evans: So, I go along to my GP in Dorset, we identify that I have pain and then what happens?

Das: The GP would say, 'what about the pain is the worst thing for you? Is it the pain itself? Is it that you're worried about pain? What do you… how do you live your life? Has it stopped you from doing things?

Evans: Oh no – but I'd go to the GP and say, 'I want to get rid of my pain.'

Das: Absolutely. And that's the GP's job. Because we talked to all of the 104 surgeries we have… we have staff going out to 'educate' – in inverted commas – all the GPs on pain management. So the GPs now know that it's not just about getting rid of pain: it's about living life around pain, intractable pain. So GPs then share that message with patients from step one. The patients no longer come into the pain service saying, 'get rid of my pain' – they're actually saying, 'can you lessen my pain, decrease my pain? and how do I learn to live with my pain?' So that's the message we're sending out.

Evans: And that's a very powerful message.

Das: It's a very important message, sadly, because, till we have a magic solution or a magic bullet to take pain away, you know, we're left with self-management. So we have to do our very best to let patients somehow learn to cope with their pain.

Barrett: It's about helping the patient to learn how to take responsibility for their pain, rather than the doctor taking over that responsibility and handling it on their behalf. This is about the patient taking control and managing their own lifestyle according to what they *can* do, as opposed to focusing on what they can't do. I think that's the key to it for me, is helping them achieve, rather than not achieve.

Evans: Yes – self-management doesn't mean, 'go away and get on with it'. It means, 'let's find a way of living with this and putting pain further down the list of issues.

Barrett: Yes – and there are a whole lot of other organisations there to help the patient achieve that: it's not one person on their own. And I think what Meherzin has achieved in Dorset is to bring all those agencies together for the benefit of the patient, not the benefit of the doctor. That's what's making a difference there, I believe.

Evans: Dave Barrett at the launch of the British Pain Society's Information and Technology Special Interest Group.

Don't forget that you can still download all editions of ***Airing Pain*** from our website: that's painconcern.org.uk, or you can obtain CD copies direct from Pain Concern. If you'd like to put a question to our panel of experts or just make a comment about these programmes, then please do so via our blog, message board, email, Facebook, Twitter, all the contact information is on our website, once again it's painconcern.org.uk. There you'll also find details of ***Airing Pain's*** companion magazine ***Pain Matters***, which is available as an online subscription or direct by post.

Last words to Meherzin Das, Clinical Lead at Dorset Pain Management Unit and Chair of the British Pain Society's Information Technology and Communication Technology Special Interest Group…

Das: You know, my heart goes out to every single person with pain because I think there courage is absolutely inspirational, because if I was living with pain non-stop, I don't think I would want to be in pain either. And I say to all my patients that I'm inspired by their brand of courage each and every single day.

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