Airing Pain Programme 98: IASP Global Year of Excellence in Pain Education & Bristol PMP

What is the IASP Global Year of Excellence in Pain Education, and how does pain management research benefit the patient?

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The International Association for the Study of Pain (IASP), formed in 1973, is the leading forum of scientists, clinicians, healthcare providers and policy makers supporting and promoting the study of pain and using that knowledge to improve pain relief worldwide.

Each year IASP focuses on a different aspect of pain that has global relevance. In 2017, IASP focused on pain after surgery, and joint pain was the focus of 2016. In this programme, Paul Evans speaks to Dr Paul Wilkinson, task force lead for the 2018 Global Year for Excellence in Pain Education.

IASP hopes to advance the understanding of pain in the areas of government, professional and research education and ultimately create strategy to communicate the gaps in pain education globally.

Paul also speaks to clinical psychologist Dr Nicholas Ambler, patient trainer Lisa Parry and assistant psychologist Sareeta Vyas at the Bristol Pain Management Programme to find out if there is a correlation between investment in pain management research and development and patient benefit.

Paul Evans: This is ***Airing Pain***, a programme brought to you by *Pain Concern*, the UK charity providing information and support for those of us living with pain and for health care professionals. I'm Paul Evans, and this edition is funded by *Pain Concern's* donors and friends, assisted with an educational grant from Grünenthal.

Dr Paul Wilkinson: If all health care professionals in the field of pain did one hour of education for one day in just one year, in terms of the number of people that would be reached, it would make a very significant difference.

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Evans: The International Association for the Study of Pain, or IASP as it's known, brings together scientists, clinicians, health-care providers, and policymakers to stimulate and support the study of pain and translate that knowledge into improved pain relief worldwide. They have nominated 2018 as the Global Year of Excellence in Pain Education.

Dr Paul Wilkinson, who is Director of the Pain Management Service in Newcastle in the UK, is lead for the international task force for the project.

Wilkinson: The Global Year for Excellence in Pain Education is divided into four main areas:

- Patient education
- Professional education
- Public and government education
- Pain education research

The cornerstone of the Global Year for Excellence in Pain Education will be a web-based resource which will have educational resources for professionals, for patients, for public and government and to facilitate education research. But resources are not much good on a website; we have to lift them off the website and there will be strategies to try to communicate the needs, the gap in pain education through the world.

One key example would be that there is an absence of minimal essential training for healthcare professionals in pain management in hospitals and healthcare institutions.

There was an important publication in Canada and [it] was being replicated in other countries that showed that the educational provision to healthcare professionals was less than [to] vets. Obviously, the inference there was that maybe animals were getting the better deal than humans. So that was a strong statement for what needed to be done in in pain education.

Evans: So how will the Global Year address that?

Wilkinson: It's got a multi-prong specialty covering the different areas of education.

With patient education, we are providing a series of resources that will improve patient education, using the most up-to-date research.

For professionals, there is a launch of a number of curricula and resources to try and help professional development. In addition, we want minimum essential training for all health care professionals.

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Related to public and government education, we want to carry the messages to government and make public aware of the problems that the patients suffer with and the lack of resources through the world.

Finally, as well as trying to bridge the gap between what we now know and what we do, we would actually like to know more, so pain education research is an important part of the Global Year.

Evans: Now you're based in the UK, you work in Newcastle with the NHS. Is there something you can learn from other countries, sharing of information, if you like, and other countries can learn from you?

Wilkinson: Absolutely. The dissemination of different experiences is an important part of the Global Year for Excellence in Pain Education. The International Association for the Study of Pain values this in part of its work. There are positive experiences of treating different conditions in different parts of the world. It's really important that new developments are shared across countries and between countries.

Evans: When we speak again in a year's time, what do you hope will have happened?

Wilkinson: I hope that every person with pain in the world would know the kind of resources that are available to help them. We want governments through the world to recognize pain as a disease and to provide the resource to ensure the well-being of their population.

Evans: You brought up an interesting point of governments recognising pain. Well, is chronic pain a condition, or was it just a result of some other condition?

Wilkinson: Well, there are two types of pain, broadly speaking, acute pain and chronic pain. These may not be the best terms, but that's what we use medically. Acute pain is pain that follows injury. It's closely related to injury, it's proportionate to level of injury - as the injury heals, the pain resolves.

What I think people don't know, is that where pain persists, yes it may be due to a problem, it may be due to a rheumatological condition (rheumatoid arthritis) that's not resolved, but most commonly, it occurs in its own right. It's a disease in its own right, there are changes that occur in pain parts of the nervous system, which mean that when injuries heal, instead of the pain going as injury gets better, the pain unfortunately stays.

Sometimes we recognize these injuries because we know the accident occurred. But sometimes these injuries are small, they occur through our lifetime and lead to persistent back pain or persistent neck pain, taking away the life that we'd had previously.

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In fact, one of the starting points of the Global Year is to try to improve our understanding of pain *better* through patient stories. So the Global Year of Excellence in Pain Education is starting with patients, putting patients in the middle.

Evans: That education side from the patient's point of view, explaining what pain is and what's available there, that's something that I hope we in *Pain Concern* can contribute to this Global Year of Excellence in Pain Education.

Wilkinson: Absolutely. And I hope that this will contribute significantly to education in promoting the Global Year.

Evans: That's Dr Paul Wilkinson, lead of the International Association for the Study of Pain's task force of their Global Year of Excellence in Pain Education. You can keep up to date with all that's happening throughout the year at IASP's website which is https://www.iasp-pain.org

And don't forget that *Pain Concern* contributes substantially to patient and healthcare education through its information leaflets, helpline, magazine, campaigns and of course these ***Airing Pain*** podcasts. This is 98 by the way – that's nearly fifty hours of information about living with and managing chronic pain, from leading authorities in their field – be they healthcare professionals and researchers or expert patients. You can download all editions from *Pain Concern's* website which is www.painconcern.org.uk

It's probably best not to listen to all 50 hours' worth in one go, which brings me to the small print that, whilst we in *Pain Concern* believe the information and opinions on ***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. He or she is the only person who *knows* you and your circumstances and therefore the appropriate action to take on *your* behalf.

Now, advances in pain medicine and pain management can cost an awful lot of money in terms of research and development and they can take years to roll out. But is there a correlation between investment and patient benefit? Pounds per points on the pain score if you like?

Dr.Nick Ambler: There's a goldmine here. It really is something that could make a massive difference to the way in which people sustain the gains, sustain the momentum of a pain management programme. That's our feeling, there really is something to mine into here.

Evans: That's Dr Nick Ambler. He's a Clinical Psychologist and a lead of the North Bristol Pain Management and Self-Management Programmes at Southmead Hospital in Bristol in the UK. And this is Lisa Parry.

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Lisa Parry: I'm a patient that's been through a self-management programme within the hospital here and at the end of that, we were asked if any of us were interested in volunteering to help present the programme. I had found it so beneficial for myself, that I thought it would be maybe a good thing for me to do.

Evans: Nick, you're one of the leads on the pain management programme, I'm not sure I've come across patients being actively involved as teachers.

Ambler: It's something we started around 2008/2009, as part of a multi-centre project across the country regarding long term conditions. [The project] involved not just involvement of a patient tutor in providing information and personal experience, but the sharing of the delivery of the whole course, which was a big leap for us then. Quite a few of us were concerned about how well that would work out, but we quickly found that it works spectacularly well within the context of reorganizing our service to have a middle tier.

I think most people have a grasp of what a pain management programme is nowadays, which from our point of view is quite an intensive form of support for people to learn self-management strategies with chronic pain. We created a middle tier for people that are really just ready to have a go at it. They already understand the basics of it, they're not ambivalent about wanting to try that stuff out. We designed a shorter course, where you basically hit the ground running with that.

Evans: Now, I guess that it's not unusual to have a so called "Expert Patient" in just to talk to people, but actually to teach them… what are the issues there?

Ambler: I think the concerns everybody had really from people volunteering to come forward were "What do you want me to do, is it right that I should be doing this? I need to know what's going to happen, I need to know precisely what I need to say".

From the health professionals' perspective, concern at having gathered a hell of a lot of experience before, you're in a position where you can deliver pain management program, [but] it kind of felt as if that experience was being not being acknowledged. You do need that as a health professional, but what they *lack* is a day-to-day understanding of what it's like living with pain, they don't have personal reference points.

With every element of course delivery, there's the stuff that will resonate for Lisa because she's had to face those challenges in ways that I haven't, so I can't constantly refer back to that. They're not a model of how well somebody can adapt themselves despite having pain every day. Lisa brings all of that stuff into a course in a way that I can't.

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So the thing that we needed to tackle fairly early on, was setting up a training course which provided the basic rudiments and also to define the role, because there are clear distinctions in the way in which the patient tutors operate within their share of the course and the way in which the health professionals operate.

Basics that we all observe though, is when you're doing one of these courses, we have an understanding which is our own, that we try not to dictate. So we've had this mantra of "Ask Don't Tell" which is basically - explore issues with people, but don't try and tell them how to live their lives. The learning experience of taking part in one of these courses means rubbing shoulders with others in the same situation, learning as much off them and learning by trial and error, prioritizing what you want to change. All those things are going to be a unique thing for each individual taking part.

Evans: Lisa, tell me about your pain journey.

Parry: Basically, I was fit and active, working for Bristol University at their Veterinary School, a very physically demanding job and one day I bent over at work and I then couldn't walk. At the time I was just bent over in pain, I'd had what I think they used to call a slipped disc, a bulging disc and was expecting a fairly quick recovery from that which didn't actually happen and I just could not do the job I was employed to do basically. I had to give up working then and it's been kind of finding my way back from a bit of a dark place, from that point onwards, living with pain. It's pretty constant, but now having done the self-management program, I'm able to manage that to a level where I can continue to do the things that I want to do now.

Ambler: I think anybody living with the situation that Lisa's just described, faces lots of choices. They may not recognize those choices straight away.

For example, what do you prioritize if you only have so much energy and focus left to you in a day because you've had a terrible night's sleep and you can't move around very well. You could be thinking about managing a bit of the housework perhaps, or go to see someone or reading or something like that. What are you going to do? And what are you doing, for example, to maintain your fitness, against the fact that the pain that's going on is probably complicating things with muscle tension, so if you're inactive, it's harder to get to sleep. So, when you make that choice, it will have consequences.

If you do some more housework, it's going to have a beneficial effect in one area, but not in another. If you decide to, say, call a friend or go see someone, likewise.

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Evans: In some ways, it is a little bit of self-control as well, because if I'm feeling well today, or if Lisa's feeling well today, she could go out and run a marathon. It might *not* be the correct thing to do, so you have to control your thoughts and actions.

Ambler: Yes, the topic of pacing is one of the things that people reflect back on at the end of course saying "I really needed to do something about that…" which is odd, because at the beginning of the course we generally ask people "who understands the importance of pacing?" and everybody says they do.

They all say "Yes, it's really important" and so the next question that follows from that is "who is pretty good about applying it?

Evans: Lisa, how easy is pacing?

Parry: Really, really difficult [laughs]. Not for me now, now I've kind of got the hang of it. But at the beginning, really difficult to think "I'm going to do a *minimum* amount of something" to enable me to then get through the rest of the day. So I'll do a minimum amount and then I'll put a rest break in, or I'll take a short walk, or I'll do something else and I'll go back and do another small portion a bit later on.

You're fighting that instinct to get the job done, which is how I was brought up - if you start a job you should finish it. I think that's perhaps how a lot of people are, you want to get things done. To break that cycle is really quite difficult at the beginning, but once you do, it's fantastic and it has actually enabled me to do far *more*, long-term than if I had tried to keep going on this cycle of "do it all" and then be off my feet for four days.

Evans: Nick, I suppose you have to keep (for want of a better term) patient trainers on message, it has to be within your curriculum?

Ambler: Yes, and there is always a sense with these courses that we don't have enough time to get through all that we want to get through. There's a degree to which one adapts each course, according to what crops up for that group of people. Some have bigger priorities, for example, around the way in which frustration and anger can come out in everyday life in relationships. That wouldn't normally be part of our curriculum for the course, but sometimes we bring stuff in about that and run a session on that.

Lots of groups have real issues with sleep, it's something my colleague, Sareeta, knows a lot about. There's other groups [where] that's less the case and so we might magnify or play that down. But we do have core set of things that we need to get through.

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I think as well, one of the disciplines for health professionals that we have to do, is for us not to be telling long, elaborate, metaphorical stories about why a point is important, when you have somebody sitting next to you who can talk from the heart about what they did in a much more succinct way. So, to an extent, the health professionals need to rein it in, not just the patient tutors!

Evans: Sareeta, Nick has just dropped you in it by talking about the sleep course. The Sleep Management Programme, that's not the same as the Pain Management Programme?

Sareeta Vyas: No, it's a separate course that we run so people could come along to improve their sleep either before they attend a pain management programme or a self-management programme or after. It's really a time just to focus purely on improving someone's sleep. We've adapted the cognitive behavioural therapy approach for insomnia to cater for people in chronic pain.

So making their area for sleep as comfortable as possible, maybe putting in some routines of winding down before they go to sleep, putting in some consistent bedtimes and wake up times. We also look at thoughts that might be happening at night, because we know that a lot of people do their thinking at night and that can be quite distressing if their thoughts go to things that keep them awake.

But the most powerful part of the course is what we call sleep compression or sleep restriction. The idea of sleep compression or sleep restriction is actually reducing the amount of time that you are in bed so that the sleep pressure builds up throughout the day, so that once you do get into bed, you get off quicker. You may still wake up throughout the night, but the times that you are awake for are reduced and people report feeling their quality of sleep has improved as well.

It all sounds quite difficult because a lot of people really struggle with that. Initially you're actually reducing the time that you're spending in bed by a quite significant amount, so that can be really, really challenging to stay awake longer in the evenings and when every part of you wants to get into bed.

It's a really difficult kind of intervention to go through and that's where the group comes together really well. There might be several people in the group that are doing that together and so when they come back to report on how the week's been, it's something that can they can think about together and think of ways of how they can keep going with it.

Evans: At what stage do people come on the pain management course Nick?

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Ambler: I would like to think people come when they feel that this is the right thing for them. So you meet people fairly early on after an injury, similar to the way that Lisa described. They could be expecting, reasonably, that they might recover [e.g.] I don't need to be doing something like this, because I'm going to be better by this time next year.

Parry: My attitude going into doing my course was, even if I just learned one new thing that will help me to make an improvement; that would be enough. Obviously, I picked up lots more than that.

Evans: So you went from patient to patient tutor…how did that happen? How did you make that transition?

Parry: At the end of the course, we were asked as a group, if anyone would be interested in doing it. I actually had a Patient Tutor on my course, who I felt just made everything valid. It was real, it she'd had personal experience; she understood what we were saying. That was really important to me to have her, there so I just felt "Oh I'll give it a go. I might not be able to do it, I may not even get as far as the meeting about it". But I did and I did the training course, I then actually went and sat in on a course. I didn't actually present or give any sort of teaching as such, but I was observing and watching what they were doing and then after that I did my first course.

Evans: What was that like?

Parry: Scary as can be [laughs]. Really scared, quite nervous, just with a group of people coming in that obviously you've never met before. Explaining to them that it was my first time and be nice to me, basically! But yeah, it was absolutely fine.

Evans: So did you feel the love, the empathy coming back at you?

Parry: Yeah, oh *absolutely,* they were really fantastic. Because I'd said "This is the first time I've done this". They were just like "It's really good, you're doing fine" and that gave me a massive amount of confidence to keep going and to enjoy what I was doing.

Evans: So we've heard all about this empathy, this love - it's a two-way thing for the patient tutor and the patient. What happens when they part company and the pain management programme is over?

Ambler: I think usually there's a hope on the part of the health professionals, that this is the beginning, the platform after which people will power on. They have a grasp of what's involved, but they haven't resolved everything, they haven't got to the perfect place for

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coping yet and that they will use what they've learned off each other in this part of the programme to take things forward.

But sadly, when you meet people later on, that often turns out not to be the case and one of the things that we've been trying to do differently in the last five years has been to change the way courses end. This all came from an incident that happened in that first group that Lisa was describing and it was when we met for a follow-up meeting three months after that course had finished. Do you remember what happened Lisa?

Parry: Yeah, one of the girls in the in the group basically took Nick to one side and said “Oh what do we do now, you can't just leave us, we're feeling like you've abandoned us” kind of that scenario and was sort of demanding “What do we do, what are we going to do?”.

Ambler: At this point, it's not just me, health professionals who run courses tend to squirm. They have, in a sense, got to close this off now. That's part of our process, because we need to be moving on, we've already prepared the next course and we can't be doing with bids for keeping the whole thing going.

But in that situation, my squirming and wriggling led to me pushing it back to that group of people to figure out what they were going to do to keep it going. But the thing that was different, was the question was about them *collectively* rather than individually and that group of people decided they will carry on meeting without me, but they invited Lisa to carry on with them, as someone who knew and that's pretty much what happened isn't it?

Parry: Yeah and we still meet now. That was about six years ago from that first course. They decided they were going to get together every two weeks to meet up for a couple of hours, just to see how everyone was doing, to make sure people were still managing and they weren't struggling with anything, they asked me to go along.

We had our Christmas party last Friday for a couple of hours and yes, we've continued to meet.

Ambler: [It's] more than just the social contact though, they kept going with the business side…

Parry: Oh yeah, we still goal set. We took goal setting as our main focus because we're constantly trying to move forwards. There are things we need to do and there are things we want to do. I think we all felt, through that first course, that that was a really beneficial thing for us so we carried on doing it.

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Ambler: This became something that we learned from, because we figured out that this group of people were doing something that seemed clearly to be of great value to them. When I had reason to meet with them sometime after this, they'd resolved a whole load of problems which I would have expected to come back either into a General Practitioner's clinic or into the pain clinic.

But they'd sorted that those problems out amongst themselves, crises really. So what we learned was to try and change the way we ended courses. Rather than think of the whole process as packing up the tents, the circus is leaving town, which is really what's going on in the health professional's head, to see it instead as the health professionals leaving the party, but we're going to keep it going, we're not finished yet.

So, we changed the way in which we close off the course. We don't think about the concept of closure in the same way as would normally happen in a group programme. Whilst the course is underway, we spend a bit more time really building an idea that they can act as therapists for each other, within the course. [It's] kind of co-counselling, which is the way we've worked out goal-setting, how to run goal-setting.

Rather than the health professional being in command of the whole process, what we do at the start of the course is try and get across the process by which you can be a counsellor to the person sitting next to you, to be a co-therapist and how you can look after each other. Also to really underline the importance of social contact as being one of the best protectors against relapse with chronic pain. Which is part of why that particular group were looking after each other so well, supporting each other when one of them was having a difficult spell

The kind of dialogues we have towards the end, we start to plant the idea, just past the halfway point, that they can carry on without us and then build towards an endpoint where a decision should have been reached by those in the room about whether or not they want to, and how they're going to keep going in the absence of the health professional.

Evans: You're fairly unique in what you're doing here, with patient tutors. How do your colleagues, the rest of the world if you like, take that on-board?

Ambler: I think they're intellectually interested and we've been able to present the findings that we've had. Considering that usually, you get less than 50% of people coming back for a routine follow-up at the end of a course (that's not just something locally, you find that around the country); we got 70% of people involved in this networking between each other, willingly engaging with that process, which I still scratch my head in amazement about.

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So there's plenty pointing to this being quite a phenomenon that should really be taking off, but I think when you're under pressure of service delivery, getting through the numbers, you stick to what you know. It's difficult to take risks and perhaps that's contributing to the kind of sense of a slow burn with this.

There are plenty of people that want to talk and are interested in it, but there hasn't been the sense of, "there's a gold mine here". It really is something that could make a massive difference to the way in which people sustain the gains, sustain the momentum of a pain management programme, that's our feeling. There really is something to mine into here.

Evans: That's Dr Nick Ambler, Clinical Psychologist and a lead of the North Bristol Pain Management and Self-Management Programmes in the UK and also Assistant Psychologist Sareeta Vyas, who runs the Sleep Management Programme there.

So, casting our minds back to the International Association of the Study of Pain's 2018 Global Year for Excellence in Pain Education, here's something for healthcare professionals and policy makers to think about. The person with pain is not just a patient, but potentially is a valuable resource to help others. In the words of our patient trainer, Lisa Parry.

Parry: It has absolutely changed the way I approach things. I've got so much more confidence in myself, in the abilities that I have. It's still a learning process for me, I find every course that I do, somebody will come in with something new and I'll learn from them. It just constantly helps me reaffirm my own self-management and just giving me the confidence to try new things and make the move forward in life that I really want.

Contributors:

- Dr Paul Wilkinson, Director of pain management services in Newcastle and lead of IASP 2018 international task force
- Dr Nicholas Ambler, Clinical Psychologist and lead of NHS North Bristol Pain Management Programme
- Lisa Parry, patient and patient trainer at NHS North Bristol PMP
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