

Airing Pain Program 39: National Pain Audit

The state of pain services in England and Wales: the National Pain Audit's findings revealed.

At the launch of the National Pain Audit at the Science Museum in London, Paul Evans talks to people who took a leading role in its development about the need for an audit and what their findings suggest needs to be done in the future.

For the first time, the Audit will make available to patients and healthcare professionals detailed information on local pain management services. Richard Langford and Cathy Price of the British Pain Society discuss the report's findings, including the need for more pain clinics to adopt the minimum international standard for interdisciplinary services. This would enable them to take a biopsychosocial approach to pain management, which, as Richard Langford explains, can make a crucial difference to patients. Cathy Price also discusses how pain clinics could do more to help patients remain in or get back into employment.

We also hear from Christine Hughes and Jean Gaffin, who have both been involved in the campaign for better pain services, about the problem of inconsistent service provision and the need to work towards a national standard.

For more information on the National Pain Audit and to find out about your local pain services visit: www.nationalpainaudit.org

Paul Evans: Welcome to **Airing Pain**, a program brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain. This edition has been funded with an educational grant from Pfizer Ltd.

Each year over five million people in the United Kingdom develop chronic pain, but only two thirds will recover. Much more needs to be done to improve outcomes for patients. That was the stark announcement by the Chief Medical Officer for England in 2009. In response, the British Pain Society, in partnership with Dr Foster Intelligence Limited, and funding by the Health Care Quality Improvement Partnership, undertook a national audit of pain services. Their final report was published in December 2012. I went along to the launch of that report at the Science Museum in London.

Richard Langford: For those of you who that might not have met me yet, my name is Richard Langford, I'm President of The British Pain Society, and it's a pleasure to welcome you to this event this evening, on behalf of really the three organisations that have been involved in delivering the National Pain Audit. So welcome and thank you so much for coming this evening.

It's the final report which encompasses the work which took place in two phases: the first phase being an evaluation of an audit of the disposition of pain services around the countries, England and Wales; and the second phase was to recruit patients who were in clinics for the first time, enquiring about their history and co-morbidities and their incoming

pain scores, quality of life, etc., and then following them up six months later to find out what treatments, broadly speaking, what treatments they'd had and broadly some of the outcomes.

Evans: Why did we need a National Pain Audit?

Langford: There was a reasonable amount of pain epidemiology in the press, suggesting the sort of range of percentages of the general population that suffer with daily pain or chronic pain. But we didn't have a great deal of information on where pain services were placed and their composition in terms of staffing in order to deal with the pain problem which we recognised was quite significant, with an estimated 7-8 million people living with pain in the United Kingdom.

So we wanted to enquire about where the pain services were, what they looked like, and, also, there was very little information on how patients fared once they were referred to a pain clinic. So it was felt that all of that would be useful, and very particularly what triggered this national pain audit and indeed was the impetus to the approval for the funding was the fact it was suggested in the CMO's annual report in 2008.

Evans: Chief Medical Officer?

Langford: Chief Medical Officer – yes.

I would like, personally, and on behalf of the community of patients in pain, with people living with pain, some of whom are present with us today, representing patient organisations and people with pain – on behalf of them, on behalf of the British Pain Society and others to thank those who were on the Scientific Advisory Committee, the Project Board and the Governance Committee. But I would particularly like to draw attention to Dr Cathy Price, who was both a leading author on the final report and also chaired the Scientific Advisory Committee, and Dr Steven Ward, who chaired the Project Board itself, both of whom are here with me now. So with that I'll hand over to Cathy.

Dr Kathy Price: Thanks Richard. I haven't got such a loud voice as Richard, or maybe I have, maybe my kids will tell me otherwise. I just wanted to run through some quick highlights of the pain audit to represent what's happening in pain management in England and Wales, as best we can.

Successive reports from government suggested that we didn't know how well pain services were doing. When people tried to find out a bit about them, it wasn't clear who they were seeing, how many of them there were and the outcomes from them. Patients didn't know how to find them, GPs didn't know how to find them, and so, at the very least, some sort of geography to the pain services was needed. Then the reports recommended that we also find out a lot more about them.

Evans: What have you found out about them?

Price: There're quite a lot of them actually. The main things are that they seem to be seeing people who have a very poor quality of life – much worse than if they had one single condition. So it suggests people have got multiple health conditions. We found overall 161 different providers in England and Wales – of those, 214 different clinics – so some people

are really scattered about. We also found that 28 primary care trusts in England didn't appear to have any pain services at all and perhaps they were borrowing from other areas.

So there's a great big variation in actual services – there was an even bigger variation in the type of services. And for pain services the standard is multidisciplinary clinics. And we found that in England only 40% of clinics could truly call themselves multidisciplinary. It's a bit higher in Wales – about 60%. And that means that they are not really able to offer the full range of treatments or get the most effective outcomes of care.

Evans: So is your aim to name and shame or to kick people into action?

Price: [laughs]. From my perspective it is to highlight where there is variation. To highlight where there is apparently less than good practice – it's then up to the people in those areas to decide what they want to do. But unless you name people, then, probably nothing ever happens. We found that clinicians have been trying to get multidisciplinary services and yet their voice has not been heard. We hope that the National Pain Audit will give that voice to them.

Evans: Right, okay, we are not going to name and shame – where's the best place to have chronic pain in England and Wales?

Price: [laughs] It looks like it's somewhere around Gloucestershire and Ipswich are around some of the best services, so, particularly the South West, and Suffolk area seem to be doing well with pain services, as does the far North East of England.

Evans: So – those are the places to go if you're hurt?

Price: [laughs] Well, I suppose that they could be – but we'd hope the other services can get to their level.

Dr Steven Ward: If patients and their GPs don't know about the services, where they are, who to refer to, what's on offer, and occasionally, if they don't recognise the benefits that can be accrued from referral, then there is a significant issue for patients. And I think we recognise, both us as professionals and patients and the patient organisations, recognise that there can be serious delays in the time to referral in the patients' journey from the first development of a serious pain problem through what was on one occasion, in a separate survey, found to be a seven-year period during which the patient suffered their pain before they were referred to specialist pain services.

And it's not unusual for these patients, this group of patients, to be sent from pillar to post, first of all, maybe with what ultimately turn out to be – but very well intentioned – but turn out to be investigations that – necessary investigations – but they don't actually lead to anything that helps, treatment that helps the pain.

And also because patients in this group often have complex problems: we talk about pain being a biopsychosocial phenomenon, so it has the biological aspect, so the actual mechanisms of it, the anatomical damage, the pathology that maybe responsible for it, but there is also the psychological impact of the pain, and on the person's psychological profile – in other words, they may well become depressed and anxious, they will potentially have sleep problems – all sorts of things affect their mental health, and similarly, mental health

can indeed lead to chronic pain. So the two are inextricably linked. So, there's the bio, psycho and social: the terrible impact that this can have on relationships, on family, on carers and indeed, of course, the societal impact, the costs, but also of course, for the individual, the impact on their ability to work or get back to work. So it's a very wide ranging problem that our pain patients have.

Price: People reported that pain had the highest impact on work out of all areas, so we absolutely need to take notice of that, part of the problem is that by the time people come to pain services, they come too late and they've lost everything. We've started, locally working with Remploy vocational rehabilitation specialists. They are going into local employers, trying to prevent people losing their jobs and finding new jobs for people. This has been a new approach pioneered in Southampton mirroring some work done in Cardiff in the mental health services there. It's been very successful to date and I'd encourage others to adopt that model. Other services have worked collaboratively with other vocational rehabilitation specialists and they do see a difference. So one of our recommendations is that services need to do this.

Evans: It would appear to me that if pain is a biopsychosocial disease, then if you don't address all three issues, in your pain service then it falls short?

Price: Absolutely. And for many people, I think this is the confusion for many people, in the primary care population, people manage pain – they learn to manage it relatively well and it's not troubling them too much. But when it starts cutting into their life significantly, it starts taking over and impacts – on what we found highest – on work, and then on activity, and then on social life and friendships, overall mental wellbeing. And when it's got to that level then you can't just try and treat the pain itself, you've got to look at the pain and its effects and the biopsychosocial approach is really the gold standard for doing that. So, unless you try and do that with this population, what we've shown is that indeed the population is that which has got multiple needs, and yet the services haven't got everything that they need to be able to deliver fully effective care. It feels to me like many are struggling – many people know what they should be doing but it seems very hard to ask or to develop the need for that. We hope that the National Pain Audit will have at least highlighted that there is a need for a biopsychosocial approach with a multidisciplinary model.

Evans: The fact that patients have been pushed from pillar to post – does that mean that pain isn't viewed as the problem itself – just as a by-product of something else?

Ward: Well, I would hate to generalise on that. But I think that certainly on occasion, we might interpret the patient's history and experience as one in which practitioners – again, with all good intention – focus on the disease or on what they think might be the cause, with obviously good intention, with a desire to treat the root cause.

But, of course, if that isn't found to be genuinely the cause of the pain, or actually there isn't an abnormality there, because pain can occur either long after the original condition has healed up – such as shingles or a surgery or a trauma, or other conditions like a stroke, or whatever, spinal cord damage – that can lead to long standing pain problems, and the focus may be on the original disease or on the on-going disease, for example, diabetes, without enough focus on the pain.

So, some people are very keen to see that pain is regarded as a condition in its own right. I think it is sometimes a condition in its own right. There is no obvious remaining... or maybe no cause ever that can be identified for it – that doesn't mean that the pain isn't real – it's very real. Equally, there can be a condition that is ongoing, where the pain is indeed a symptom if you like of – I'm a pain doctor – but it could be a symptom if you like of somebody else's disease like a diabetologist, a diabetes doctor's disease. Absolutely the diabetes has to be addressed, but the message I would like to get out is that whether we regard pain as a condition in its own right or not, pain should always be addressed in its own right – that regardless of the patients other conditions – pain needs to be addressed, and, while trying to improve the patient's physical or mental health, the pain itself needs to be treated. In fact, it's the most common reason for a patient to go and see a doctor, but mystifyingly, it's also pretty common that the patients come away with everything being managed except the pain.

Christine Hughes: I'm Christine Hughes. I'm the secretary and a trustee of Pain UK, an umbrella organisation that represents those charities where pain plays a significant part of the condition that they represent.

Evans: Now you're at the launch of the National Pain Audit report tonight. Were you surprised at the paucity of pain management services throughout the UK?

Hughes: I wouldn't say I was surprised, Paul, because having worked in this field now for seven or eight years, I realise how poor they are. But, yes, when I started I was shocked and I haven't seen a vast improvement over those six years. I think there is more awareness and I think there are people working extraordinarily hard, like the BPS and the CPPC, to improve services and raise awareness. But it's not happening fast enough for a lot of people who do suffer appalling pain, and who often aren't asked about it.

Evans: What do you think the next step should be for the report writers or the report publishers?

Hughes: The thing that is important is to be able to go nationwide, if you like, and the only way that we can do that is if NICE do take up the quality standard and provide guidance. And then we will have a national standard that people could then hold up to commissioning bodies and ask them – you know – the basic question, why aren't you providing this? And so I think that is probably where this has to go.

Evans: Now you're a volunteer for pain UK, which is an umbrella organisation, if you like, covering people like Pain Concern?

Hughes: Yes, we have 23 full member charities which range from quite big charities like Arthritis Care, right through to very small ones like Vulval Pain or Pelvic Pain who are really, almost, one man charities. Our average charity has – I must get this right – but I think it is 5.6 full-time members of staff. But I think that the majority of them actually have, less than one member of staff. So these are charities where people are working extremely hard, mainly using volunteers, and they can't hit all the buttons, which is why it's very important that we hit pain for them. I'm talking about things like the Polio Federation, I'm talking about the Limbless Association, I'm talking about the Spinal Injury Association as well as lupus, and fibromyalgia, and, you know, rheumatoid arthritis...

Evans: And these are all people who should be affected by the National Pain Audit report?

Hughes: Yes, they should, it will help all of them, even though most of these charities are fighting very hard for services for their particular condition. You know, if you have endometriosis, you need somebody fighting for a better understanding of that.

But, at the same time, there will be pain that will not be resolved just by treating the endometriosis, and for those people these services, these that the pain audit has highlighted are really important, and that goes for every condition I've mentioned. You know, if you lose a limb through diabetes or an accident or whatever, you have phantom pain, or you may have appalling post-operative pain. And you need good pain services to deal with that. And that is not directly linked to not having a leg, which might be more about having a prosthesis than anything else. So, yes, it's something that overrides nearly every long term condition and we need both things running alongside – good services for rare, long-term conditions, as well as good pain services.

The thing that stuck out for us was really the people's report of their quality of life with pain. The Europe poll score was about 0.4 was very low indeed, and what that's telling us is that people have got many health problems and that it's on a par with those sorts of conditions, long-term, severe neurological conditions and forms of dementia, in terms of people's general experience of life, [people coming to] specialist services.

One of the things that came out of the audit is the high health care use that patients have before they come to a clinic. We found 16% of patients had been to A&Es, which was much higher than we were expecting. After they had been to a service it had dropped down to 9%. Hospital beds are very costly, especially unscheduled care visits, and so to me that could potentially pay for a service in itself, if we were able to address those emergency visits.

It's very hard to create a case of need when the majority of care is for social care, and we shouldn't really have the divide that we do. However, pain services exist within health services and we have to create the case of need from within the health needs. If people are frequently attending hospital, that suggests that their needs are not well met and it's expensive because poor quality care costs more. And I think that we can have sufficient [evidence] there to demonstrate that we can cover costs.

Evans: And the other thing is that – when I go to my GP, he gets paid for my diabetes, but he doesn't get paid for my pain.

Price: Absolutely right, it's been a source of quite great frustration, really, that we have not been able to get some sort of quality outcomes framework register for pain. I think that's because it's been very hard to define and set some reasonable quality standards. I'm hoping that the quality standards that we've developed with the National Pain Audit can be highlighted to NICE, and indeed that's what we've recommended to NICE, and that those over time can be incorporated into QUAF, or whatever succeeds QUAF in the future.

Jean Gaffin: My name is Jean Gaffin, and I've been hanging around the pain world for quite some time. I first got interested about 25 years ago, 24 years ago, and I became chief executive of arthritis care, where I was constantly, constantly, constantly meeting people living with the pain of rheumatoid arthritis and osteoarthritis. Nobody bothered very much. Then I went to work in the hospice movement where dealing with pain was a priority. When I

finished that job, I saw an advert for the chair of a patient liaison committee, the Pain Society, and I've been hanging around pain ever since trying to increase understanding of it, increase management of it, and, through the Chronic Pain Policy Coalition, get parliamentarians involved, so now we've got an all-party group on pain. So we're very, sort of a, mish-mash really of concern and interest.

Evans: Now we are at the National Pain Audit launch this evening, what were your reactions to it?

Gaffin: I think it's an incredibly important piece of work, not just because it's an examination of how many pain clinics there are, or how few there are really, relative to the needs of the population, because they have done this very important research. Nothing new, but just reinforcing, and more scientifically perhaps than what we have done it before, just what the burden of pain is, to people living with chronic pain, in terms of work, in terms of quality of life and so on.

And I gather that there are going to be more statistics coming out from another National Survey and I hope in the end we will build up a real head of steam – not easy in this world of cuts – to try and meet the needs of people living in chronic pain, which has been under managed for so long.

Evans: What surprised me was that the people who wrote this report, the British Pain Society, they had trouble in finding out all the statistics. Where do we patients stand on this?

Gaffin: Absolutely, you know the sign posting of services is minimal. I happen to be a trustee of my local hospice, and we had a clinical governments meeting in which two cases were brought to our attention, where there was an inappropriate referral to the hospice.

These were two patients, and I'm not talking about the last weeks or months of life, two patients who were in such pain that the GP didn't know how to cope and there was no pain service that the GP knew about in the area. And so they ended up at an outpatient appoint with our hospice doctor, rather than in a proper pain service. I'm sure our doctor dealt with them, by the way, extremely well, I'm sure. But that isn't quite the point. Because that's not what speciality palliative care should be about, just pain relief.

Ward: As you've heard, this is just a step on the way now. This is the dissemination of the report, but the next step will be to make sure that it lands on the doormats of those who will hopefully engineer the changes that we need to see.

Evans: You are really speaking to the converted now – to me, to other members of the British Pain Society, to other people listening to this program who have persistent pain – what about the people who can really affect our lives, the politicians? What are they going to do about it?

Ward: Well, I think they need to answer that. We are leaving no stone unturned in terms of trying to access the politicians. We have sent the press release to a number of politicians who sit on the Chronic Pain All Party Parliamentary Group for chronic pain. We may have the launch this evening and the publication of the report with release by the Department of Health and HQUIP this evening and tomorrow. We won't let it rest there, and we will be

asking questions and we hope there will be some parliamentary questions in the follow up to the publication of this report.

We have indeed, sent copies to the Chief Medical Officer and Medical Director of the NHS in England and the Undersecretary of State for Health. So, we hope in that way to continue our lobbying of politicians and policymakers, our contacts in the Department of Health, who are responsible for drafting policy and advising ministers – we hope that through this continuous drip feed of data, information and canvassing, lobbying, that we will make our mark and we will improve the experience for future pain patients.

Charles Dobson: I am Charles Dobson, I work in the Department Of Health, and among other topics I have current responsibility for the policy on pain.

Evans: What does that mean?

Dobson: it means advising ministers. It means helping to facilitate the things which will improve pain services for patients. Say, for instance, I helped to secure funding for the National Pain Audit we've heard about today and also for the question in the health survey for England 2011 on chronic pain.

Evans: What did you make of the National Pain Audit review today?

Dobson: I think it's very impressive, it's a wonderful piece of work which obviously involved a tremendous amount of effort from everyone involved and it's told us some things that we thought we knew already and it tells us some things which perhaps we didn't know before.

Evans: Like?

Dobson: The very low quality of life on average of patients who responded to the questionnaire and who attend specialist Pain Services.

Evans: You're a civil servant – your masters are the ministers – what would they do about it?

Dobson: They have set out a new vision, if you like, of the relation between ministers and the NHS at the coal face, through the NHS commissioning board as an intermediary. So, in the new landscape, ministers will set very broad priorities and the commissioning board will then decide where they need in particular to take national action.

Now, one of the five outcomes in the NHS outcomes framework is improving the quality of life of people with long-term conditions. And all the evidence we have shows that you couldn't possibly do that without in particular helping people with pain and people suffering with musculoskeletal disease. So – it seems to me a no brainer – that the NHS commissioning board will want to take action on pain and on muscular – skeletal disease. And it's very encouraging that they have within the last few days, advertised that they want to lead the commissioning board with this particular responsibility for musculoskeletal disease, so that will address one key component of the pain agenda.

Evans: That was Charles Dobson of the Department of Health.

Now before we end this edition of **Airing Pain**, let me remind you of our usual words of caution that, whilst we 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 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.

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Final words from this launch of the National Pain Audit final report go to Professor Richard Langford, President of the British Pain Society, Christine Hughes and Jean Gaffin, who represent patient organisations:

Hughes: What surprises me is how little we actually know about what is available for pain patients out in the big wide world of the British NHS, And I think this is the biggest problem for patients. Information, I think, is key and people go to their GP and very often, the GP, well, one doesn't ask them about their pain, and, if they do find out about their pain, probably has not got the kind of knowledge – because it is a very specialised area – to help them on their pain, or know where to refer them. And because there's so little knowledge out there of the services you could actually have a very specialised pain unit, fairly close to that GP and there's a good possibility that he won't even know about it.

So it's about spreading information about what is available as well as what is good practice in the hope that we can then, in this new world of the NHS, commission new and better pain services across the country so that there is access for everybody. I think also quick access, because undiagnosed pain will become chronic and will become a disease in its own right.

Langford: Pain is now listed as a long-term condition in the long term conditions agenda. And so we hope that with all of our efforts, raising awareness of pain, and, indeed, lobbying policymakers and politicians and now, very much, commissioners, that we will see that pain rises more in the priority list.

Gaffin: I'm encouraged and have been for the last 15 or 16 years by the accumulation of data, which hopefully, eventually, will be powerful enough to influence commissioners. We're not quite there yet, but I hope that we will be eventually to be able to do that.

Contributors

- Professor Richard Langford, President British Pain Society
- Dr Cathy Price, British Pain Society
- Steven Ward, British Pain Society
- Christine Hughes, Secretary of Pain UK
- Jean Gaffin, Honorary Member of the British Pain Society
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