

Webinar 18th January 2021

Chronic pain in primary care; the case for annual review

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Slides: <https://prezi.com/view/BvtH2F19ID4FBbc7AO9f/>

Dr Tomlinson has been a full-time NHS GP in Hackney, London since 2001 with time out for voluntary work in Afghanistan in 2003/04 and an academic fellowship in 2014-6. He has an MA in Human Values and Contemporary Global Ethics and a PGCert in Medical Education. His special interests include the social determinants of health, patient advocacy and the relationships between doctors and patients. He is author of <https://abetternhs.net> on how issues such as continuity, kindness, shame and trauma impact on patients and doctors.

Hackney is a young, socially diverse but largely deprived community. There are at least 40 different languages spoken by our patients. My interest in chronic pain, trauma informed care and poverty medicine have come out of my experience, particularly of trying to do a better job for the patients I and my colleagues and trainees find most difficult and challenging. Rather than running away from these I decided to make it the main focus of my interest and research. I have found this incredibly helpful.

There are four things I would like us all to think about as I describe what I have been doing. The first is: how do we define and label chronic pain? This second is: in primary care, what would you want to comprise in an annual review for a chronic pain patient? If you were such a patient, what would you want to discuss with your doctor? And if you were a commissioner what would you find the most useful things to be documented? Thirdly, what audit standards should we have for our chronic pain patients? Should 100% of them have an annual review? Should 50% (or more) have a self-management plan? Should a certain percentage be referred to specialists? The fourth area for discussion is about social justice. We know that chronic pain overwhelmingly affects people who suffer poverty, of female gender, of colour, or people who have experienced complex developmental or inter-partner violence. How do we do better for these groups? *It is notable that none of these issues are mentioned in the new NICE guidelines for the management of chronic pain.*

A register for chronic pain patients

All of the doctors in our practice of 13,000 patients will admit that they struggle with patients with chronic pain. They spend a huge amount of time with them and don't often feel that they have achieved very much. They are also aware that as well as having chronic pain they are often in difficult social situations, including domestic violence or past experience of this, problems with immigration status, poor housing – it's never just chronic pain. The average number of contacts per patient per year in the practice is 11 but for those with chronic pain it is 33, more than any other patient group. So why do we need a register of chronic pain patients? We have never had one before and I think few if any other practices will have one. But we need to know the scale of the problem: what proportion of our 13000 patients have pain? - and are we doing a good enough job for them? Are they being managed well, appropriately and fairly? Can we monitor changes and improve quality?

We have registers for other long-term conditions like heart disease, diabetes, asthma and COPD. Once you have a register you can call in every one of these patients for an annual review to make sure that their condition is well controlled. So first of all I searched the practice database for all patients with a code of chronic pain including chronic low back pain, fibromyalgia, CRPS etc. The initial search came up with nearly 400 patients. I did a further search for patients on opioids, gabapentinoids and tricyclics of whom the total was nearly 600. I went through nearly 600 sets of notes to select those who should have a diagnosis of chronic pain. This came up with 540 patients which counts for 4% of our practice. For comparison, the figures for other long-term conditions are 670 for diabetes, the same number for asthma, nearly 900 for depression, and over a thousand with hypertension. This puts chronic pain as the fifth most prevalent long-term condition in our practice by a long way. (The sixth is upper tier mental illnesses like bipolar and schizophrenia at about 300)

Deciding whether someone should have a code for chronic pain is really difficult. Often there will be a problem list in the notes going back to the 1970's which might have about 50 different entries including everything from a UTI to a migraine to a sprained ankle to hypertension. A typical example:

	Problem	Onset Date
K	Migraine	20-Feb-2017
L	Somatization disorder	31-Aug-2016
M	Somatization disorder	14-Apr-2016
N	Helicobacter breath test positive	05-Apr-2016
O	Stress incontinence	10-Dec-2015
P	Microscopic haematuria	03-Sep-2015
Q	Eye symptoms	12-Jan-2015
R	Irritable bowel syndrome	11-Dec-2013
S	Gastroscopy NEC	13-May-2013
T	[D]Chest discomfort exercise related	2012
U	Helicobacter pylori gastrointestinal tract infection 29.4.13	28-Dec-2012
V	Depressive disorder NEC	11-Jul-2012
W	Dizziness symptom	27-Oct-2010
X	Counselling	27-Oct-2010
Y	Helicobacter breath test positive	09-Apr-2008
Z	Chlamydial infection of genital organs NEC 22.11.07	21-Nov-2007
1	Menorrhagia	30-May-2007
2	Fertility problem	19-Sep-2003
3	Dyspepsia	19-May-2003
4	Depressive disorder NEC	21-Aug-2001
5	Introduction of gamete into uterine cavity NOS	25-Jul-2000
6	Panic disorder	01-May-2000
7	Secondary infertility unspecified -9yrs	12-Jul-1999
8	Acne vulgaris	18-Nov-1998
9	Fertility problem	01-Sep-1998
	Infertility - female NOS	01-Sep-1998

I looked to see how many entries might refer to the same pain condition e.g. lumbago, backache, back sprain etc. and whether these codes might recur repeatedly, whether people were prescribed drugs or referred and so on. So I had to come up with a pragmatic

definition for chronic pain which I described as *pain that is persistent, hard to bear, and results in repeated practice attendances*. This is different from the idea of chronic primary pain* - could we use this as a code? So, for example, if someone with multiple back pain presentations had had a scan which showed disc degeneration or arthritis, you could call this secondary pain, or you could say that that is such a common finding that it's the behaviour and the experience of that pain which makes it chronic. So we will go with the above pragmatic definition as we in our practice have decided on, and will use in our coding.

The annual review

We decided that each of our nearly 550 patients with chronic pain should have an annual review. This should be with their usual GP; every patient should have their own GP that they have had the opportunity to get to know and trust, and have developed a relationship with over time. For some this may have meant having the same doctor for more than 30 years. Secondly they should have the opportunity to look critically at the problems listed in their medical records and agree that chronic pain works for them (or anything else) and that all the other problems listed, such as PTSD anxiety or IBS, are appropriate. So it's about building relationships and establishing trust. The third thing would be a review of all medications, especially those for chronic pain. If you take the example of COPD or asthma your regular medication would be inhaled corticosteroids and occasional bronchodilators, and a course of oral steroids or maybe a nebuliser for a flare-up. But the way we have often treated chronic pain is like leaving the patient with COPD on their rescue pack, like oral steroids, all the time. We would also go into things like goal-setting, self-help, signposting and offer of referral to specialist services. This would be a 20 or 30 minute appointment. Regarding audit standards: 100% should have their own GP; I would be grateful for other suggestions.

Trauma and chronic pain

In general trauma isn't what happens to you; it is what you are left with afterwards and what people *have* experienced, which is so common in chronic pain: disbelief from family, friends, colleagues and professionals so they feel to blame, it is their fault, and rejection. The perception of not wanting to be seen or heard adds to their feelings of shame and unworthiness of care, commitment or love. That is why chronic pain and trauma overlap so much. How do we respond to this? It is important to note that people with chronic pain and trauma both adopt the same coping strategies such as addictive behaviour: any activity that gives short-term pleasure or relief, that people crave and find hard to give up, despite long term harm, can be called an addiction. Whenever you are dealing with addiction you have to think, not so much about 'why the addiction?' but 'what is the pain that underlies that addiction?' Things like excessive exercise, gambling, working excessively, OCD etc. It's not just addiction to medicines; quite a lot of these patients are not on any medicines at all but have addictive behaviours about the pain of trauma underlying the pain. Indeed we might think more in general about the causes behind the causes of ill health in general e.g. poor diets, overeating etc.

*Chronic primary pain is defined (by the WHO) as pain that persists for longer than three months and is associated with significant emotional distress or functional disability and that cannot be explained by another chronic condition. This new definition applies to chronic pain syndromes that are best conceived as health conditions in their own right. Examples of chronic primary pain conditions include fibromyalgia, complex regional pain syndrome, chronic migraine, irritable bowel syndrome and non-specific low-back pain. Chronic secondary pain syndromes are defined as pain that may initially be regarded as a symptom of other diseases having said disease being the underlying cause.

Salutogenesis

Salutogenesis is anything that makes you feel better or makes pain more bearable.

I have this picture in in my consulting room:



Social security wraps round everything else. It includes personal safety, money, work etc.

Human relationships: one of the effects of trauma is to drive disconnection from your body, other people in the world around you. Anything which can help people to reconnect can help them to recover and cope

Biology includes everything you put in your body including medication

Body is everything you do with your body; exercise, dancing, painting

Mind is your feelings, emotions and memories

Discussion*

I want you to think about these four issues:

1 How should we define and label chronic pain?

2 Annual review for chronic pain in primary care: would you be happy to have someone like me go through your medical records and put it in your problem list, bearing in mind that you will be invited to have a discussion about it at your annual review?

3 Audit standards for chronic pain: are they needed? What should they be – mine or something different?

4 Trauma informed care for chronic pain: how can be sure of this and that care is attentive to issues of social justice like poverty gender and race

What you call something is important and influential. Chronic pain is such a rubbish name, like heart 'failure'. People interpret 'chronic' not as something that goes on a long time but simply 'bad'.

The annual review is an opportunity to share someone's problem list with them and ask: "does chronic pain work for you or should we think of something else?" In its defence it enables us to have a cohort which we can follow up and make sure that we are providing good care.

I agree that 'chronic pain' carries a negative suggestion; it doesn't sound as if you are going to get better. And because it shares aetiological factors with all the other functional disorders, could we call it 'functional pain'? Even if it has a primary cause but a functional overlay ... if we started calling all functional disorders functional [?- unclear word} then it would improve research because we have to find the causes behind the causes ... [unclear recording] ... a perception or sensation... pain, could be motor, or physiological ...with IBS ... and get the word functional in there ...

When I was a lad if we said someone's symptoms were called functional it always meant 'all in the mind' – psychological, psychogenic or whatever, or worse 'hysterical', but it does have a new meaning now. I quite agree that chronic is not a very good definition to use for patients but it does have the advantage that nearly everybody involved in treating pain knows what they are talking about when they use it and it has got too well established to change easily.

In our session last month Tim was talking about the necessity for patients to accept that their pain isn't going to go away, and it occurred to me that the former name of the BPS was the 'Intractable Pain Society' which was abandoned because it was thought to be far too negative, but is it possible, from the point of view of acceptance that pain ain't going to go away, that the word 'intractable' should be re-introduced? The other word that is often used nowadays is 'persistent pain'.

A pragmatic definition of chronic pain is pain of any cause that involves frequent consultations in primary care. I am sure there are people who just quietly tolerate it at home.

**Contributions 'from the floor' in italics. Not all of these were clearly audible and representation of them involved either guesswork or insertion of '...'*

But I wanted to suggest that chronic pain should not be of any particular aetiology. I was beginning to think that it was all trauma but found lots that wasn't, or I couldn't make that link. Some people were saying "it's just unbearable" and I was interested to learn what it is

that makes pain so painful and it's the persistence and the difficulty of bearing it that makes it chronic.

As a pain patient I quite like your idea of asking the patient what term they would like you to use and is the best for them because we are all different.

I too live with chronic pain; the term implies that it is going to last a long time or that it is never going to get better. I think the negativity arises from the pain and not the words we use for it. We spend a lot of time trying to qualify it in some way. My experience of pain didn't change when it was labelled chronic; it was still just my pain which lasted a long time. There was no difference for me with that transition I like that focus on what it means for that person and if it resonates with them and is how they would refer to their pain or would rather call it something else. Better to focus on the experience of that person I think those conversations are so much more valuable than whatever it is that we ultimately call it. The pain is the defining feature of it. Patients need to express themselves in a way that's not conscripted by a definition.

When talking about patients I always hear about them being difficult or challenging but rather than labelling the person in this way (which I know from experience to be hurtful) we should recognize that it is the situation they are living in which is challenging. I know we are challenging to health care providers but it is all the other factors that are a cause of that

At the beginning I said that my motivation for getting into chronic pain was born out of frustration with these patients and feeling I was going to burn out. I couldn't enjoy myself as a doctor if I was going to spend my whole time being annoyed with my patients. The longer you work as a GP the more patients with long-term conditions you collect ... there are patients you find really difficult and I want to help you feel different about them. Doctors do struggle with patients and not just their presenting problems. Being aware of that is a way to change your practice and become more deeply engaged with the topic.

That is an important distinction between the person and not the situation and that needs to be addressed, but I would also say that patients do encounter a lot of difficult healthcare professionals! ... I do sometimes perceive a barrier...

If the doctor or healthcare professional really can't figure out what to do next and are fed up then they may label the patient as 'difficult' or 'challenging' - or worse still 'manipulative'. If we have a patient with a boil or something easy to sort out we really love them, but people with complex needs can be really hard and frustrating if you can't do anything.

I come from a palliative care background and frequent experience of Cicely Saunders's concept of total pain. It's a lot easier to prescribe; I sometimes think that prescribing is a self-soothing technique for physicians! I don't prescribe; I'm a music therapist. Even in palliative care I do find patients labelled as 'difficult' - it's quite unconscious and the doctors aren't bad people. Part of my job is to point out that we are avoiding this person and labelling them because we don't want to feel the feeling that we can't fix this, 58 which can lead to burnout. The understanding has to come through dialogue and meetings like this with all the stakeholders ... it has to be understood and unpicked relationally together.

I think it's unlikely, given the comments we have heard, that you [Jonathon] will be able to come up with an easily identifiable word to use, whether it be chronic, functional etc. I like the idea of allowing the patient some choice. But in the end the whole point is the discussion with the patient about the chronicity, long-termness or intractability of the pain. As a clinician, the longer I have been doing chronic pain the more I am persuaded that it is not something we can do very much about, and attempts at reducing the pain are pointless, and until the patients get a grasp of that we won't succeed. Otherwise it does lead to burnout, and frustration for patients. Often sitting for half an hour with the patient and

discussing this and getting them to accept that although chronic pain is horrible that's what they have got: it fits in entirely with their symptoms and history and makes perfect sense to me as a clinician; I have lots of patients like you and although we can't fix the problem, by helping you to understand it there are lots of ways we can help you to move ahead. I suspect that is what you are doing as a GP?

The way I came up with this idea of looking at the problem together was that when patients came in asking for a report for their benefits I would say – sure, but we have to look at this together and agree what your active significant problems are. And we would often discover that there were many things still very much active hidden in their past problem list. For instance someone might have come in a year ago about an episode of incontinence but it is an ongoing thing that they were embarrassed to keep coming to talk about; or that they had had a bout of depression but hadn't mentioned it since, perhaps because they had had a bad experience with another GP. Or as well as chronic migraine they had suffered other kinds of pain which weren't recorded in the active problem list. So it was an incredibly useful use of time, not just to get an accurate list of problems for their benefit report but also for building a relationship of trust – “ I'm going to share your medical records with you and you are going to play a part in deciding what ought to be there” That's a form of validation; it's hearing and believing you, which allows so much other therapeutic stuff to happen. “It will also help you when you are putting your PIP application in, and help us to make sure you come for a review every year. You may prefer to call your pain arthritis or a prolapsed disc and that's OK.” Even if you call it functional pain and accept that it has something to do with what happened to you when you were growing up it doesn't mean that it doesn't need care or physio or immunosuppressant therapy or whatever.

To comment on what Tim said [para before last]: traditionally one gave a drug or an injection to 'kill the pain' and you might not be able to do that, but you can always reduce suffering by the comforting, the listening, the exploring and encouraging other activities, perhaps getting a knitting group together. How to monitor this: - maybe there is a measurement of suffering...!

[Zoom chat comment: - 'could you deliver all this in a half-hour review?'] The answer is yes: we can set our own Directly Enhanced Services: a local commissioning group can decide that they are going to fund GP's to do something special such as chronic pain which is a major issue for them, and show them the work I have described on its prevalence. If you offer an annual review most GPs would vote for it

Some sort of guidelines would be useful.

[Zoom chat comment: 'what is the point of an annual review if there is nothing you can do?'] People will say that and do about other conditions such as asthma and diabetes. But chronic pain often comes with other things like anxiety and depression or dissociative symptoms; or other issues they might want to discuss. Or they might have issues around their goals.

From the point of view of a psychologist one of the values of an annual review would seem to be the opportunity to think about how the patient is approaching their pain. People having 30 consultations a year are probably searching for solutions we don't have to give them. So we could say: let's think about what you are looking for in all these consultations and what it is like for you when you come hoping that I might have something else to offer that is going to get rid of the pain. And it's a chance to open up a different conversation about seeking solutions, which is what we all want, and turn the direction towards something else like quality of life – to look at the workability of the way we are approaching their pain

It's a good opportunity to pick up on other stuff. I can think of lots of patients ... like one I saw the other day who has been coming to me with chronic pain for years who finally came out to me that she was experiencing domestic violence which had been going on for years but it had taken all that time to build up the trust to enable her to do that. She hadn't made an appointment for this - it was only because she had been invited proactively. Doctors will often do everything they can to avoid seeing patients with chronic pain; an invitation for an annual review says 'I really want to see you' – not –'Oh my god, not you again'.

An annual review could make a profound change to peoples' lives. If people feel really cared for – especially if the questions are not just about medication etc. I have seen patients with a really good relationship with their GP who have reduced their medication and have sought mental health support when they hadn't previously felt able to trust that.

I want to come in on a different tack: I am actually a very biomedical physician and have always approached things in a very biomedical and reductionist way. I spent this morning working with a colleague on analysis of a trial we did in March on myeloma following stem cell therapy and investigating which patients got pain and quality of life impairment and which didn't. Among other things we were looking at biomarkers and genetic predispositions., and we have identified genetic variations and mutations which predispose some patients to express more pain than others. This is nothing new and we have known about it, but that is what I like doing. I am a retired professor of health and medicine so that has always been my background. I have been accused of being a physician with holistic tendencies so that is why I am in this group!

My point here is to question you about your initial discussion about the role of trauma: you go through patients' histories and find a recurrent underlying theme of trauma. Whether that has a causative or an explanatory effect on pain you presumably discuss this with them. So my first question is: what percentage of your patients actually accept trauma as a factor either in the causation or multiplication of their pain problem, and my second is: if you look at all the patients in your practice, you must have a lot of them with a trauma history but don't express pain. So what makes one patient express pain because of a trauma background but others somehow cope with that ... or they may have other issues such as chronic breathlessness. Have you looked at that? I want to understand the physiology of it, which is probably the wrong way, but that is where I come from.

When I first got into this I took 50 patients in a row over a three month period with complex trauma and lots of associated problems, and drew up a big table showing what kind of trauma they had and what kind of problems they came out with later, to see if I could make any relationship between the two. It included things like IBS, irritable bladder, chronic constipation, pain, anxiety and depression, dependant and non-dependant substance misuse. I couldn't find any particular relationship connecting type of trauma with type of symptoms. About a third of them had chronic pain; the commonest shared problem was anxiety and fearfulness, followed by depression, and less frequently things like constipation and IBS substance abuse – more dependant than non-dependant which I wasn't expecting. That was my experience and you will find similar results in the literature.

I think trauma causes hyper-arousal, hypo-arousal, toxic shame and dissociative symptoms, which lead to coping strategies which are usually addictive in nature. Hyperarousal with an overactive autonomic system is also associated with autoimmune diseases. There is about six times the incidence of SLE and rheumatoid arthritis, which are painful conditions in themselves, in people with a history of trauma. There is 3 or 4 times the incidence of diabetes and heart disease in people who have had four or more instances of adverse childhood experiences. So we know that it is associated with disordered immune, neurological and other systems. Why one person should get back pain and another IBS is an unanswered question. I nearly included the latter under chronic pain; nearly all with severe IBS have a trauma history.

The other question was do these people accept their situation and are they able to talk about it? The most important thing is that safety and trust have to come first before people are able to have a discussion about this. I have been in the same practice for 20 years and I have had some patients for most of that time who are only just about getting the courage to talk about it. There is a huge fear that [briefly inaudible] which you have to take seriously.

I am a GP without Jonathon's years of experience but for the last couple of years I have had the experience of chronic pain myself and have seen things from the other side. I was really excited by that whole concept of an annual review. But I do have mixed feelings about it. The first thing that occurred to me was, having read things Jonathon has written and heard him speak; and had actually had the privilege of talking to one of his patients recently, that what Jonathon was talking about was what was on the wall of his consulting room and something he probably does at every consultation, and does that in the format of serial consultations which have built up confidence and trust with his patients over years, and that is good quality care. Contrasting that there is a danger that when we hear someone like Jonathon speak we make the assumption that this is the standard of care that is going on in every consulting room, and when we talk to some patients we learn that is not as universal as we might have hoped. This idea of the annual review and, perhaps more importantly, training people for it could be a good way around that.

When you asked us at the beginning what would go into an annual review I started jotting a whole lot of things down, and when I put your picture of a hand up I realised that all of them came under one of those fingers or the wrist ... physical health ... mental health ... etc. A huge amount came under social security: finance including housing and food, safety at home, relationships, social support, engagements, relationships with secondary care, but also medication and side effects; and perhaps most importantly life. Pain can so often be a barrier to life. Perhaps you might include thinking to the future including crisis planning. So I love the idea; I think 30 minutes rather than 20 might be more realistic ... One of the things that struck me that might be a barrier was that although most GPs you talked to were keen on this, whenever I float my ideas past my colleagues they all sort of smile supportively and then say that's great but we just don't have the time. And that is where the power of doing things comes from the way Jonathon does over a series of consultations in that relationship building manner.

There is some good evidence that if you offer patients a choice in how long they want their consultations to be we seem pretty close to getting it right. But we are afraid of doing that. Offering 10-, 20- or 30-minute appointments for annual reviews turns out to be cost saving in terms of time.

I read a while ago that early trauma altered the morphology of the brain, including shrinking the hippocampus. Some work on people coming back from Vietnam showed that the one guy out of a group who had seen the same horrible things who got PTSD was shown by a scan to have a small hippocampus. They didn't know whether it was a result of his experience or whether he had had it before. So they went back to his home town and scanned his brothers, and they all had small hippocampi. It turned out that they had had a horrible early life; from birth they had been deprived, neglected and beaten. So it seems that there are physical effects that can lead on ... that aren't just about emotions. Chronic anxiety and depression are associated with hormonal changes

The concept of salutogenesis and health creation has a potential to change pain and improve quality of life. It seems to me that the system we have at the moment is unsuited to people with complex issues. We need specialists in the wider context of health creation but most people who come on to my wellbeing programme have acquired many diagnostic labels from the many specialists they have seen on the way there and there seems to have been little or no communication between them. I remember someone saying to me many years ago that no-one is unlucky enough to have eight different sets of diseases. So we

must look for the core issues for these people. We need a more systems way of thinking and a more collaborative approach instead of the multi-specialist pathway so people don't get multiple labels. The NICE document does nothing to move in this way – there is nothing about communication. There is a long list of things that I don't like. Talking about care plans does nothing to enable people with pain . I hate the idea of care plans for people in pain instead of a collaborative approach.. Going down the pathway of health creation is a much better way

[Parts of the recording from this point become increasingly distorted and some of what follows involves either guesswork as to peoples' words or inserting [...] where this is not possible]

I totally agree. I remember a Pain Society meeting where one of the presentations was about the [?] of chronic pain which never occurs on its own. Once you have chronic pain plus anxiety plus IBS you can practically guarantee that you have other issues. The thing with trauma informed care when you recognise how prevalent it is and how it impacts on life and relationships including relationship with a doctor which may be threatening and influenced by experience of power and authority. It's important to recognise that they are struggling and it's not just about the pain, it's about relationship.

Is there anything else that should be in an annual review?

Perhaps something that ought not to be there is pain scores. My own view would be that we know they have chronic pain, it is well established, the patient knows what it is like and the clinician hopefully has some inkling of what it is like and the question is: how are you coping with it? Pain scores are arguably unhelpful and may give a wrong target.

I don't use them in chronic pain patients. It doesn't really ask anything useful. I assume that patients who come and see me have pain that is very severe, because that is why they are there. The more informative thing is how they are coping.

I hadn't realised till this evening that the annual review is something I have been doing for about 39-odd years by offering patients long-term review in the clinic, particularly if they aren't having any active therapy. The choice after they have finished a course of active treatment that either has or hasn't worked is either to discharge them or give them an annual review. Over the years I have accumulated a huge number of patients – probably over 100. In each clinic I have on average 2 or 3 patients who are coming for their annual review. I wouldn't tell an audience of my fellow pain clinicians because I think they would frown and my hospital manager would be aghast to know we were bringing people back year after year which would be seen as a failure of treatment. But it is vital support which enables you to [...] and to encourage engagement with helpful agencies. I am all for it but I think people doing it have to fully understand chronic pain. Given what we have said about the challenges of helping people with chronic pain, it is something we have to be cautious about landing on clinicians who may find chronic pain a difficult thing to manage.

An annual review can be an opportunity to see someone when they are not in crisis. If all your care is reactive and you are just waiting for something to happen, every time you see that patient things are awful. If you have a proactive plan for review it can be an opportunity to talk to someone when the pain isn't 11 out of 10 .

I kept patients under review but not necessarily annually. One important aspect of this was that it showed that I care and realised that the problem wasn't going to go away, and this knowledge could be very therapeutic. I never used pain scores – if a patient used them I would think they had been got at by one of my colleagues. It's not how people view pain. It does beg the question as to what pain clinics do – what their role should be in the long term.

Perhaps pain clinics should be doing an annual review, and be a point of contact where they can discuss their pain.

I really like critically reviewing the notes and co-creating a shared problem with that person. It establishes that relationship of collaboration and working with that patient on the problems which are relevant and important to them. It is such a great foundation to build upon. One with that is an annual review is that a lot of people never get to see the same GP - whether that is just a local issue or more widespread. It seems to me that if you are having that annual review with someone you get to know each other and build up on the foundation of trust, but if they see a different person the next time there isn't that continuity of care but this could be a useful function of a pain clinic. I see numerous patients who get to a point where I can't personally help too much other than to help them to navigate care across different areas of the system. If they can't see the same GP or they don't trust them or anyone else in any other area of specialism, my role with those people is to see them for a regular six-monthly review of how things are going, and coming up with a long-term plan which can be a really valuable way of working round the issues of continuity of care

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The first box for the annual review template asks who is your usual GP. The second would be something about diagnosis and coding of active problems and agreeing that it makes sense to the patient. For a lot of pain patients we have agreed to use complex [...] or something similar ... trauma [...] The next bit would be to ask if they have been offered social prescribing or wellbeing advisors to help with benefits. I thought of having a section asking have you discussed past trauma but I am not sure that that is useful. Then medication, referrals, [...]

What about asking about activities – have they improved, how is their day to day quality of life, with some sort of comparison as time goes on – whether even if they still have the pain if they are enjoying life a bit more.

Can I come back to the issue of pain scores: I agree that in chronic pain asking about severity on a score doesn't help much but it does have an important role in acute pain. If you look at something like the brief pain inventory [... Two people talking ...] To come back to your more global, holistic approach, one of the things I did in our department about ten years ago was to design a holistic needs assessment tool. This would try to encapsulate in 45 questions the kind of things you have been talking about in your review: things like independent living and dependence on other people. I was moving in that direction and you have put it into context for me.

There should be something in the review about the positive upbeat stuff. Like this is where you are now; what do you think might help you – like Betsan's knitting for example, all the social stuff and that could be part of the structure. They may not want to but they may say; "I didn't want to do it last time but now I might try." - to have an ending on a positive, let's go kind of note. So it's not all just medical questions.

I totally agree that the emphasis should be on the positive side and improving relationships. There is one thing that will come up if this is spread among GPs generally, and we haven't talked about much, is the kind of potential for conflict within these encounters which can be bad for both patients and doctors, around dependence on medication. One of the potential barriers I can see as being an obstacle is that many patients will assume they are being called in for a medication review and will think someone is going to try to get me off my opioids or gabapentinoids etc. That is a problem for many in our patient population who have come to see it that way And if you put that paragraph into a template there will be a lot of GPs who will view that in that kind of context; there has been a huge amount of pressure on them both locally and nationally to reduce peoples' medication or bring them off it, and

supposedly as part of an agreed shared care plan with that person, which they will accept very much against their will. That shouldn't be an obstacle but it is certainly something that will have to be addressed in the training.

One of the reasons for this search was that we had been told we must reduce our use of opioids and gabapentinoids. Our very good GPs and clinical pharmacist got struck straight away into ringing up and inviting everybody on these to come in for a medication review. I protested and said: wait a minute - the problem here is not the drugs but of chronic pain, and if we are going to make progress we need to provide better care for this, and you can't just take away the drugs without it. So they said "what are you going to do about it?", so this is what I am doing. Your fears are justified and this is my response in the hope that we can reduce the use of drugs.

Another reason for doing this work is about advocacy: if we can say we have 540 patients with chronic pain who attend our practice on average 33 times a year, we can say this is what GPs are dealing with and we need more resources for it, like having financial advisors and clinical psychologists in the practice. Advocacy is really important if we want to provide adequate care for people with chronic anxiety and depression as well as pain. So you need to find the numbers and as far as I know nobody else is doing that.

In the context of social justice, the advocacy needs to be for people who are finding their pain hard to manage because they are isolated, poor, or in unsafe relationships and so on.

When Jonathon was talking about the predisposition of people with a history of trauma to suffer chronic pain it occurred to me that studies of the prevalence of pain in the general population have demonstrated that it is far more prevalent than would be suggested by the number of people who actually seek help for it. So I am wondering about the people that don't consult their doctors. The number who get to a pain clinic is relatively miniscule compared with that huge number. So why do some people seek help for chronic pain and others don't? Perhaps it's not the people who have the worst pain that go to their doctors but those who are most distressed – possibly also those who are most dependent and help-seeking. So I wondered whether things like trauma predispose people to be distressed by pain, rather than predisposing them to experience it in the first place.

In her book *The Story of Pain*, Joanna Bourke writes about the social life of pain which is of course really important, and the social work of diagnostic labels. It's extremely common to find when looking after people with chronic pain that their families bring them in because they can't cope with them. "You've got to do something about mother because she keeps going on about her pain". That is where issues of poverty and overcrowding and toxic stress and so on. So what makes pain unbearable is really important. It's not just the genes.

When I started researching the therapeutic benefits of knitting I received literally thousands of stories from all over the world and they were often profound life stories. It led me to wonder why some people were happy to live lives with vast numbers of problems and others were defeated by seemingly minor issues. There seemed to be some core issues for people who weren't coping like social isolation, lack of rewarding occupation, meaning and purpose, and one that was very big, lack of anything successful in their lives. When I was a community physio I used to go round day after day visiting people who had loss of identity, a lot of stress in their lives, with low self-esteem and confidence. It's interesting that you see all these life stories and encounter some people had gone through horrific things but feel they have a good life. But for others it seems to be the other stuff going on in their lives that has tipped the balance

Points from Zoom chat

Wouldn't you label someone with arthritis as having chronic pain? Because it is ongoing pain that is hard to cure. They might not go to their GP often because they have tried that and have now found their own ways of managing it. But wouldn't they still have chronic pain?

In palliative care we talk about "Total Pain" which again, might not be right but the model is holistic and you can talk through the different aspects; physical "ouch", mind stuff, relational/social and "spiritual" stuff

Some people find some kind of diagnostic label helpful in terms of benefits and workplace modifications,

As GPs we often think about the power of working side by side with people through serial encounters over years but perhaps we miss that isn't peoples' expectations when they attend. Needs to be made clearer by practitioners about goals and timescales.

Repeated feedback we get in secondary/tertiary care is that people would value (on the whole) some contact with a health care professional as pain changes and life changes and they aren't able to discuss any arising issues with a trusted professional. The GP sounds like a really well placed person to bring together concerns. Other clinicians might not piece it all together.

Would annual reviews help to shift from a 'fix it' mentality to more of a 'live with (and live better)' framework like in other chronic conditions?

I was the patient that visited the GP about 20-30 times a year but I never had a review of my pain or even my meds and every time I went I often had a new symptom that required a new med in most cases! Turned out MOST of my symptoms mounted up because of the increasing opioid meds I was on! Annual review would hopefully have spotted this long before the critical life threatening state I ended up in! (NO BLAME BY THE WAY!)

I think a needs assessment would be helpful, housing, benefits, peer / digital support, sources of social support, physical activity, what is currently helpful, what has been tried already, is there anything else- diagnostic, mental/ physical health. One of our rheumatologist developed a kind of passport called Moving Forwards for people with FM. It had notes about these things, including medications tried, physio, pain clinic etc. It belongs to the person with pain and they take it from primary care and into secondary care services.

Annual review would include offers of referrals to social prescribing, clinical pharmacist, psychology, pain-service

I appreciate that you don't like ACEs screening, it is such a sensitive area that does require trust and relationships, and too often it can just be used as data collection. From my own experiences, I resisted learning about the links between trauma and pain because of the associated stigma with both - it's like a double whammy of judgment and stigma, with women in particular often blamed for past trauma and blamed for their pain - and not wanting to be victimized again.

The thing about self-management is that being told (in the wrong way) to "self manage" can be felt by someone with complex trauma as more rejection, shame-inducing etc.

Aren't there are also patients with chronic pain due to physical deformities, structural problems? Who don't necessarily have past trauma or psychological needs, just physical pain and need hcps to support them to find ways to cope with that?

Of course not all pain comes from trauma. But perhaps wellbeing interventions might work for all

Considerable FND research shows that trauma is not always a factor. Research in respect of aetiology will be important if long term solutions are to be found.

ACES and repeated and complex trauma fairly ubiquitous in our practice population and highly prevalent in our attending patients. When we do e.g. a minor surgery clinic we then see people, often with similar experiences, who seem to be doing okay in life. What often seems to make the difference, and there is some evidence for this in terms of reducing adverse outcomes from ACEs, is strength of relationships and connection. The doctor can be one of those relationships

There could be more emphasis on links to social prescribing in a partnership equal way —I think Mike Dixon has written recently about this Relationships are key in all of this