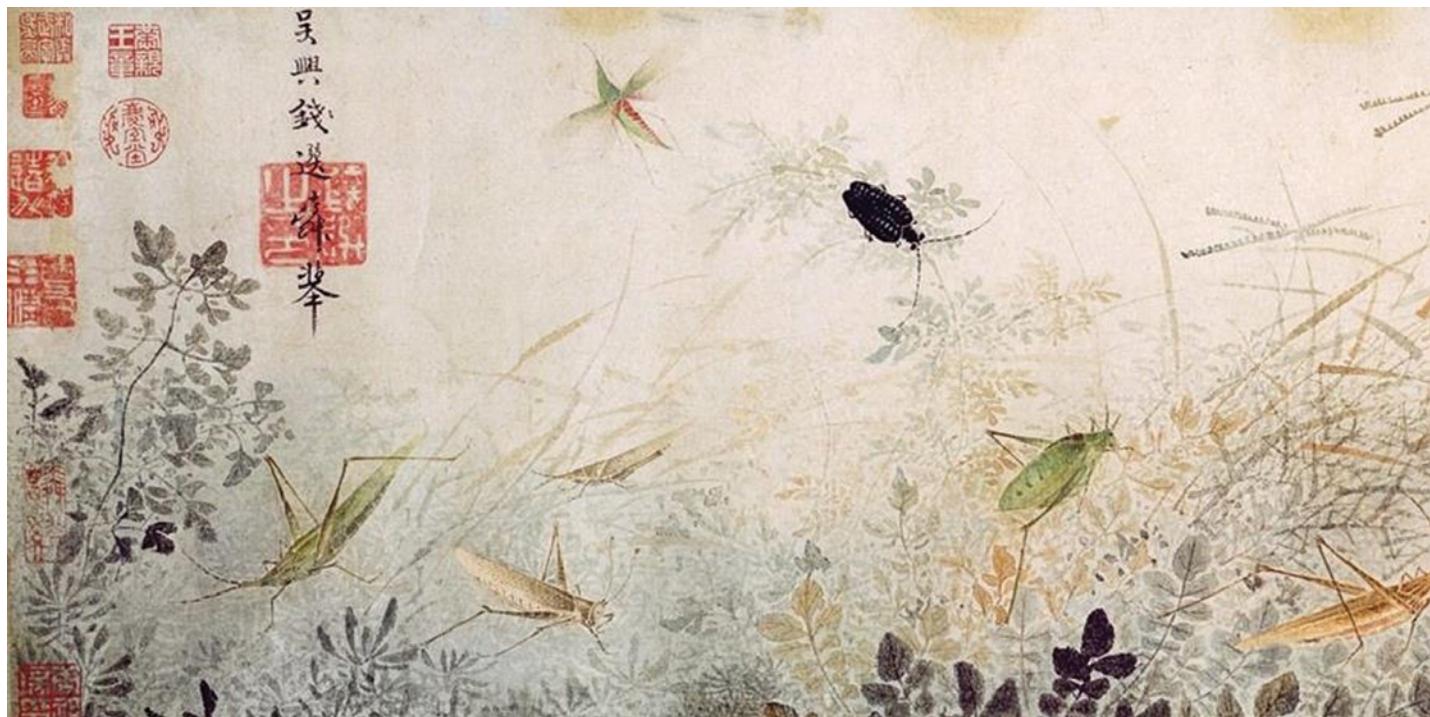


DECEMBER 2021 VOLUME 19 ISSUE 4

PAIN NEWS

A PUBLICATION OF THE BRITISH PAIN SOCIETY



- Treating pain NICEly part 3
- Where have the clinics gone?
- Pain Services in Scotland
- History of Western Pain Philosophy
- PROMS at Kings
- White Dwarves and menopausal symptoms
- Pain has an element of blank

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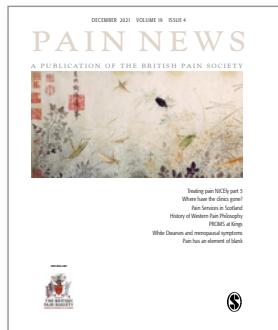
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Part 3: Treating pain nicely: caring for the individual in the crowd

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Rajesh Munglani and Paul Wilkinson

Physicians pour **drugs** of which they **know little to cure diseases** of which they **know less**, into humans of **whom** they **know nothing**. – Voltaire (1694–1778).

How should we define health and disease?

In an ideal world, individuals would seek treatment when they feel unwell, and clinicians seek to treat patients to restore and maintain health.¹ However, the boundary between the states of being in health and suffering from a disease is overlapping, partly due to intrinsic and wide variability of presentation of symptoms in the human population, and an individual's expectation of what is 'dis-ease', suffering or health.

The concepts of health and disease, and especially in regard to pain, typically involve both major subjective and some objective measures; why people seek medical treatment, and whether and at what point clinicians and, indeed, health services and, indeed, society regard them as 'ill'. The concept of disease includes the processes of not only describing and explaining, but also considering the point where Clinicians investigate and treat. Hence, how we define disease, health, and reaching the point of consideration of treatment is not a matter of mere theoretical or philosophical interest, but ultimately critical to help promote people's well-being and to live a good life.

Some definitions

'Disease' literally means 'dis-ease' or 'lack of ease'. There is no philosophical or scientific distinction between diseases and other types of complaints, for example, small stature or obesity. However, in principle, the notion of 'disease' is useful in practice as we can attempt to focus on specific problems that afflict a human being and suggest medical treatment to ameliorate or cure such symptoms.

'Illness' is more subjective and incorporates subjective feelings of pain and discomfort. 'I feel ill' is an accepted statement but 'I feel disease' sounds odd. Critically, the concept of 'illness' incorporates behavioural aspects, for example, 'illness behaviour,' which are usually thought to be

undesirable and unwanted within a particular culture, and often precipitate the seeking of help from those who have the role of healers or health care providers within a society.

'Sickness' involves concepts of the more social aspects of ill health. The related concept of the 'sick role' may relieve one of social responsibilities, such as avoiding work or family responsibilities, and may also relieve some of the blame for being ill, though not usually for why one becomes ill in the first place.

Disease conditions are understood primarily scientifically and then usually, following investigation, are treated. In contrast, there are further judgements to be made before assigning someone as sick. Typically, Clinicians identify the underlying biological criteria to assess the presence of a disease state. Despite the desire for objectivity, empirical judgements are made on what is biologically 'natural' and also what is considered normal functioning for an individual. Boorse's² view defines health as the absence of disease, where a disease is an internal state which either impairs or limits normal functional ability.

But defining various disease conditions requires a series of normative value judgements by the Clinician and society. Disease is also therefore a divergence from these clinical and social norms.

However, normativism is subject to criticism, for example, are alcoholism or morbid obesity disease states? Drapetomania used to be commonly diagnosed among American slaves in the 19th century who displayed the tendency to run away. We may conclude that a condition should be considered a disease if it both causes harm or causes diminished function of an individual, and the condition results from some failing biological process. But this approach excludes many from being diagnosed with depression or pain, that is, they would not be considered disease states due to being prevalent in the general population.

The concept of (good) 'health' is even more complex. The World Health Organization (WHO) (1948) defines health

*a state of complete physical, mental and social well-being and not merely the absence of disease. Is an ideal state of health often beyond what is 'normal' or the typical lived experience within the general population?*³

Some disease categories, often based on value judgements, are not agreed among clinicians. These include chronic pain, fibromyalgia (FMS), chronic fatigue syndrome (CFS) and mental illness. Sufferers present with a wide array of complaints in multiple bodily systems. The definitive cause or basis of these conditions remains uncertain, therefore they are thought of as unproven because of the lack of evidence of a discrete pathological disease condition.

Evidence-based medicine

'Evidence-based medicine' (EBM) describes a movement which arose from the early 1990s by a group at McMaster University in Hamilton, Canada, as a reaction against what was perceived as an over-reliance on clinical judgement and experience in making treatment decisions for patients. EBM is defined as use of current best information in making decisions about the care of patients in general. It does not allow clinical judgement and experience to count as 'best evidence'.

This has led to the model of 'Hierarchies of evidence' that categorise different research methods with respect to their supposed quality:⁴

- 1++** High-quality meta-analyses, systematic reviews of randomised controlled trials (RCTs) (including cluster RCTs) or RCTs with a very low risk of bias;
- 1+** Well-conducted meta-analyses, systematic reviews of RCTs or RCTs with a low risk of bias;
- 1-*** Meta-analyses, systematic reviews of RCTs or RCTs with a high risk of bias;
- 2++** High-quality systematic reviews of, or individual high-quality non-randomised intervention studies (controlled non-randomised trial, controlled before-and-after, interrupted time series), comparative cohort and correlation studies with a very low risk of confounding, bias or chance;
- 2+** Well-conducted, non-randomised intervention studies (controlled non-randomised trial, controlled before-and-after, interrupted time series), comparative cohort and correlation studies with a low risk of confounding, bias or chance;
- 2-*** Non-randomised intervention studies (controlled non-randomised trial, controlled before-and-after, interrupted time series), comparative cohort and correlation studies with a low risk of confounding, bias or chance;

- 3.** Non-analytical studies (e.g. case reports, case series);
- 4.** Expert opinion, formal consensus.

Evidence produced by RCTs has thus been called the 'gold standard' of evidence in EBM. RCTs are powerful experimental designs and that is their power because bias and confounding are controlled by the process of randomisation. But in our view, 'gold standard' over-states the case and ignores possible fundamental weaknesses. In fact many variables profoundly affect a patient's probability of response to the treatment in question and recovery depends on factors such as gender, age, comorbidities, genetic factors, compliance with the treatment regime and psychological factors. These factors are critical in the individual clinical setting rather than when assessing a group. Indeed, in this light, observational studies that identify so-called significant individual variables may be more powerful and indeed clinically relevant.

Typical treatment patients differ from those chosen to take part in RCTs. For example, many RCTs will routinely exclude elderly patients and those with comorbidities but ultimately the treatment will be marketed to more complex patients. Such a process may over- or under-estimate the size of the treatment effect but in particular miss significant responses in some.

Case reports are seen by some as problematic in the era of EBM, because they may focus on unusual manifestations of illness and disease, rather than its presentation and treatment in a more uniform group of patients that might provide generalisable treatment regimes.

The ultimate clinical goal is to treat the individual; this means that medicine is often described as a 'science of particulars' or more 'an art rather than a science'. The art and method of diagnosis is critical to the practice of medicine. The issue is the uncertainty, variation and complexity of the human condition, and applying the symptoms and signs to signify a particular disease condition. Thus, tensions exist for the Clinician diagnosing and treating an individual with their particular comorbidities and expectation, subject to the ill-defined concepts of illness, wellness and societal values. The problems and uncertainties are clearly obvious. Furthermore, no therapy is 100% effective and is partly dependant on the Clinician, who may initially choose a suboptimal therapy for a patient before finally selecting the appropriate one. Furthermore, intolerable side effects of an otherwise extremely efficacious treatment may limit the effect and compliance for a therapy and so require careful clinical judgement when considering an individual treatment recommendation. This means an apparently less efficacious treatment, with fewer side effects, may be preferentially chosen.

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Table 1. Sequelae for low back pain in Global Burden of Disease 2010.⁶

- Condition**
- Severe acute low back pain without leg pain. This person has severe low back pain, which causes difficulty dressing, sitting, standing, walking and lifting things. The person sleeps poorly and feels worried. Disability weight 0.269 (0.184–0.373).
 - Severe acute low back pain with leg pain. This person has severe low back and leg pain, which causes difficulty dressing, sitting, standing, walking and lifting things. The person sleeps poorly and feels worried. Disability weight 0.322 (0.219–0.447).
 - Severe chronic low back pain without leg pain. This person has constant low back pain, which causes difficulty dressing, sitting, standing, walking and lifting things. The person sleeps poorly, is worried and has lost some enjoyment in life. Disability weight 0.366 (0.248–0.499).
 - Severe chronic low back pain with leg pain. This person has constant low back and leg pain, which causes difficulty dressing, sitting, standing, walking and lifting things. The person sleeps poorly, is worried and has lost some enjoyment in life. Disability weight 0.374 (0.252–0.506).

Outcomes

How do we measure the effectiveness of treatment? Many measurement systems exist. We can use patient-reported outcome measures, or PROMs, and these are well established.

Disability-adjusted life years, or DALYs, measure burden of disease and have a unique role. It is a measure of the effectiveness of interventions, developed by Harvard University for the World Bank and WHO in 1990 and used to measure global disease burden and formulate health policy.⁵ If a person dies due to a disease 20 years sooner than expected, this adds 20 DALYs to the global disease burden. If someone ends up paraplegic for the last 20 years of life, the DALY given is only 12 as the weighting given to this patient's paraplegia is approximately 0.6, that is, $20 \times 0.6 = 12$. The DALY weighting given to pain is variable. Some examples are given in Table 1.

While DALYs measure the 'burden of disease', they fail to take account of societal and cultural influences, that is, the context in which disease or disability occurs. DALYs measure ill health rather than suffering (can a dead person, with a DALY weighting of one, suffer?). Furthermore, a new illness in a person who is already handicapped contributes less to the measure than its occurrence in a healthy person. This tends to be counterintuitive clinically where the overall suffering may be compounded by comorbidities. How does one measure disability of new pain or major injury in someone who already is troubled by depression and prior migraines or brain injury? Unfortunately, DALYs are used by some national and international societies in strategising health care and prioritising spending. In our view, their use may tend to diminish the weight of the suffering experienced by an individual patient and therefore the amount of health care resource which might be targeted for that condition and patient.

The purpose of this section is to highlight the limitations of diagnosis, especially when the biological basis is ill understood. That diseases are recognised within a population and societal norms; furthermore, the assessment of disease burden ill health, sickness and wellness are ill-defined rather than distinct categories. In this uncertain context, we turn to National Institute for Health and Care Excellence (NICE) assessment of the treatments and the symptom of pain which suffers from being diagnostically one of the most poorly defined disease states.

Truth is singular, its versions are mysteries.

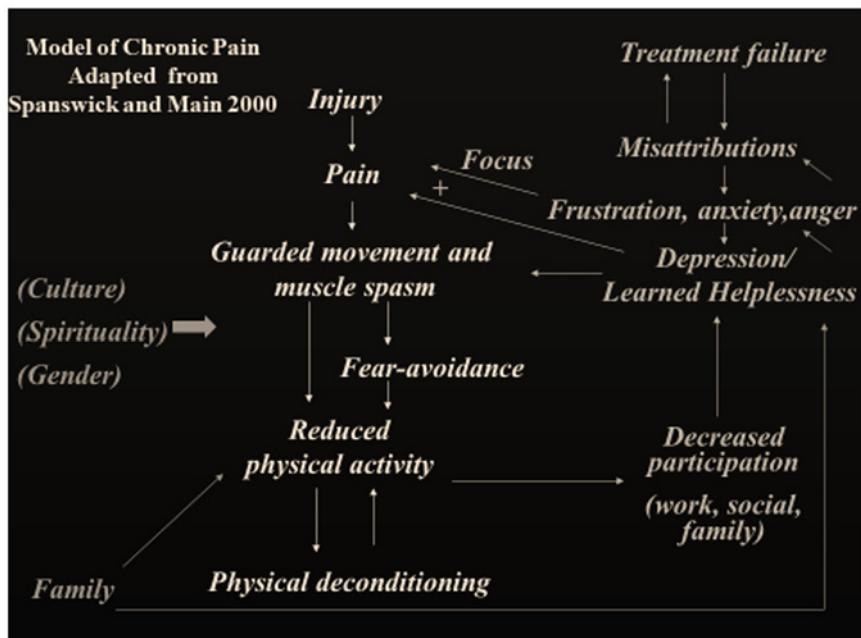
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NICE guidance on the treatment of pain

It is easy to provide corrosive criticism of positivist strategies used by NICE in the field of pain.⁷ Sadly, these approaches have been elevated to an almost unassailable position of influence which in our view is unwarranted. So how do we move on?

It is worth reminding ourselves, and others, of the complexity of the chronic pain state and what we are trying to achieve as practitioners. Even a simple model (Figure 1) is but a small fragment of what is considered pain.

There are factors intrinsic to the person and also a variety of external factors that include social and family interactions. The focus of pain treatment is to help the individual journey to a better place, ideally a position of wellness. Aims include improved acceptance and understanding of their condition, reduced distress and psychological consequences, decreased disability and improved social function.

Figure 1. A model of chronic pain.

Any expert working in the field of pain would know that, when considered across groups of patients, treatments such as paracetamol, non-steroidal anti-inflammatory drugs (NSAIDs) or opioids, neither primarily evaluated for long-term use, are nowhere near as effective as they would be in acute pain.

It is known that meaningful long-term trials in chronic pain are few for a variety of logistic and cost reasons. Furthermore, the development costs of medicines, from molecule to market, may be around £1 billion, with a small percentage of those developed finally making it through to marketing authorisation and into the hands of the patient. Clinical trials on generic medicines will not be undertaken for these very reasons. There would also be insurmountable difficulty in undertaking trials requiring individuals to be studied over years.

In chronic pain, 'background noise', that is too many uncontrolled confounding (comorbid) factors, would likely threaten or occasionally enhance small treatment effects that likely do exist in some.

An urgent challenge for practitioners in pain practice is to promote a conversation on how we use and critically evaluate our professional knowledge for the good of the individual. The

educational and social literature have extensive academic theses on alternative paradigms. This would say that over-emphasis on scientific knowledge neglects hermeneutic, aesthetic, critical, moral, creative and other forms of knowledge, reducing human behaviour to technicism. If we were to adopt a co-constructive approach on the example of use of painkillers in chronic pain, we would welcome and use the differing perspectives of NICE and Cochrane. They would not be competing but help enrich our understanding and signpost limitations of the methodology. We might draw further on the extensive literature which would indicate that the commonly used painkillers have all undergone extensive trials in acute pain. Data show that they have strong biochemical grounding to justify their use as painkillers. This new proposed paradigm would allow patient experiences, clinician and patient testimony, case studies and give more weight to n-of-1 studies and enriched-enrolment studies. We submit the patient would benefit from inclusion rather than exclusion of evidence.

There are many phenomenal logical and conceptual approaches in the social literature that we could find helpful for us to decide what, using new language, is trustworthy treatment and what is not. We might attempt to import new concepts to assess our observations such as credibility, dependability, transferability, auditability and plausibility. There is

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considerably more work to be done on this in order to identify the best frameworks to evaluate our practice.

It is an interesting caveat to put the evidential boot on the other foot. What happens if we begin to use co-constructive methods from educational and social sciences to ask the question of whether the NICE process effectively captures evidential sources and builds a coherent picture of how we need to practice real-world pain management?

For example, one of many concepts that could be used might be that of authenticity. This can be defined in a number of different ways.

Ontological authenticity means that the research should provide a comprehensive and fresh understanding of the subject matter potential, reducing 'cultural blindness'. There should be educative authenticity that the research should generate a new appreciation of chronic pain outside the expert field.

Catalytic authenticity means that the research should lead to specific and appropriate courses of action, and tactical authenticity, that is, it should at its heart have beneficence. Other than potentiating cost-savings, treatment withdrawal and confusion, we find it difficult to conclude that the NICE methodologies for chronic pain would score highly on this basis. Put simply, we conclude the NICE guidance adds little or nothing and in fact may do harm when it comes to helping the individual. This would not be surprising, given the fundamental flaw of the positivist methodology is the incapacity and futility of trying to control the experimental environment in chronic pain. We acknowledge that this approach is at its best in assessing individual treatments, whereas companies have invested heavily in new technologies and medicines and purposefully and prospectively undertaken trials to assess group responses. This latter approach, in the form of RCTs, performs at its worse in areas like chronic pain.

Consider the analysis in the NICE document related to pain management programmes. Although individual components are effective, there is limited evidence of overall effectiveness. This is not surprising when the NICE process omits to consider key evidence. Individual department PMP outcome data are not considered. Consensus statements highlighted in the British Pain Society and other publications are not given weight. There is absolutely no patient narrative or evidence of the transformation of individual lives.

Without getting into arguments as to whether chronic pain fits the criteria of 'a complex system', in pain practice, we face many of the same types of issues that are considered in

complexity theory. We consider multiple complex relationships that overlap and interconnect. We operate in a non-linear environment, sometimes chaotic with a dynamicity of social, family, psychological and medical issues. In our complex pain system, we at times 'nudge' individuals towards a better place through their reactions to our interventions.

Journalistic etiquette does not allow us to say that under some pressure a major trial lead stated that the main thing that had been learnt through a highly expensive pain trial was that the experimental approach was not the right way to go forward in the future. There were many criticisms of this trial that should not have removed it from NICE processes but it became a major influencer on a NICE publication because primary entry criteria were met.

There is a fundamental epistemological failing in NICE guidance when applied to a complex system such as chronic pain. We note that the financial ombudsman can intervene when a financial advisor or body provides misleading or flawed advice, quoting from the website, the individual 'can be compensated for the distress, inconvenience, pain and suffering'. The headline news that there is no evidence that components of the WHO ladder work in chronic pain is hugely misleading and there is serious risk of NICE guidance doing harm to the individual through evidential 'tunnel vision'. Where in NICE is the methodological self-criticism? Where is there evidence of accountability?

It is now important that all members of the British Pain Society work together to highlight these problems and think deeply about how to find better ways to gain commissioning and consumer confidence in our precious professional knowledge. This will certainly mean ensuring a paradigm shift from the group response to the individual patient.

I didn't say it would be easy, Neo. I just said it would be the truth.

I'm trying to free your mind, Neo. But I can only show you the door.

You're the one that has to walk through it.

Morpheus, *The Matrix*

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Where have all the clinics gone?

Rajesh Munglani

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SAGE

There is little doubt that the vast majority of pain in the community is never seen or treated by the medical profession or a health/complementary care practitioner. These facts are unsurprising given that 14–28 million people out of approximately 67 million people in the United Kingdom suffer from persistent pain. Not all of this requires our attention; however, it is estimated that approximately 15% of the UK population suffer with significant intrusive persistent pain.¹ Even the more intrusive pains are typically managed in primary care by general practitioners. Indeed, 22% of all 300 million general practitioner consultations in the United Kingdom are for the symptoms of pain.²

There is a considerable financial and societal benefit not only in enabling people to manage their own pains, but evidence for an overall improvement in the quality of life through the process of self-empowerment. The de-medicalisation of pain symptoms is part of the long-term aim to help patients reduce overall disability.

It is therefore a noble aim of all Pain Services, whether provided in primary, secondary or tertiary care, that eventually all such patients are helped to a point of self-management. Despite these laudable aims, it is clear that some patients need considerable help; this can be in the context of GPs, community pain clinics and musculoskeletal clinics. But some patients with complex needs do need access to Specialist Pain Clinics in either specialist or secondary care services, having access to Consultants in Pain Medicine along with specialised teams often including Psychologists, Physiotherapists, Pharmacologists and others. For the most complex patients, they may require highly specialised services including the use of spinal-cord stimulators, specialised injections and infusions. Certain highly specialised and nationally recognised clinics focus on particular conditions such as pelvic pain or CRPS. Such highly specialised services involve a detailed, time-consuming assessment by a multidisciplinary team, but there is evidence of an improvement in outcome in individuals with an otherwise intractable condition.

In recent times, there is increasing evidence for increasing waiting times for and reduced capacity of specialist services to manage this group of patients with more distressing and disabling symptoms. A report in the Pharmaceutical Journal in

February 2020 by Dawn Connolly uses a freedom of information (FOI) request to document the average waiting times from referral to such services and treatment across the United Kingdom. In Scotland, the waiting times were given as 40–112 weeks for NHS Highland. The waiting times in Wales were over 20 weeks. In England, the wait at one trust was reported to be 35 weeks.³ In *The Times* on 17 June 2021 Professor Dominic Harmon reported the dire situation in Ireland and cited a shortage of specialists, exacerbation by COVID-19. In the newspaper article, it was reported that 11,932 patients were waiting for treatment in January 2020 with over a quarter waiting in excess of 18 months for treatment.⁴

In terms of national strategy, leaving patients with avoidable persistent chronic pain will increase the overall disability-adjusted life years (DALY) for the condition and population. That is, there is a significant increase in the overall burden of suffering of the population. This is because more severe suffering of persistent pain is multiplied by the duration of suffering, which impacts the overall weighting given to the condition.

We have as a country of course spent a lot of money on COVID-19, and we accept the NHS budget is finite, and yet there is evidence that there has been a longer trend rundown of the number and capacity of these specialist services leading to reduced access, favouring instead self-management or access only to general practitioner or community pain clinic care. There is nothing wrong with the latter, so long as this is appropriate for the individual patient in question and does not prevent access to specialist care for those patients who need it. In many cases, only specialised care may reduce persistent pain and suffering. We have to be careful that the wholesale transfer to care in the community does not lead to prolonged suffering in some patients due to ineffective management.

In this issue, we highlight concerns that patients with complex needs which can only be addressed by more specialist care are simply not able to access such secondary and tertiary level specialist services. The focus is on Scotland but applies to all parts of the United Kingdom and consists of firsthand accounts by Members of the Scottish Parliament

(MSPs) and patients, all having firsthand experience and/or serving on specific Scottish Parliamentary Committees focusing on pain. One cannot help but conclude that there is a perception of the under resourcing or *running down* of such specialist services.

The role of the BPS

In 1979, the Intractable Pain Society was created and in 1988 the British Pain Society evolved from this beginning as the membership became multidisciplinary. It is good to regularly remind ourselves what the purpose of our Society is:

The British Pain Society is the oldest and largest multidisciplinary professional organisation in the field of pain within the UK ... [Persistent Pain] is commonly distressing and commonly highly disabling. It is devastating for individuals who suffer. Many cannot work and lose their jobs.

Treatment of pain is a fundamental human right, yet sadly there is an enormous gap between the care people require and what happens in [clinical] practice. Our alliance of professionals works collaboratively with patients and industry partners to advance the understanding and management of pain. We strive to reduce the suffering of people enduring daily pain.⁵

It has been shown that patients who wait more than 6 months for treatment experience deterioration in health-related quality of life and psychological well-being.⁶ There is also little doubt that effective treatment of persistent pain will reduce the burden on primary care and specialist services generally.⁷

As Editor of *Pain News*, I consider it my role, and part of the remit of the BPS and indeed its overwhelming responsibility, to highlight such national strategic failings and lack of service provision even if politically sensitive, when it impacts patient care and leads to avoidable and needless suffering.

We have been here before. The irony is that effective treatment of pain has been already shown to lead to an overall reduction in healthcare expenditure on patients who are complex. Starving specialist pain services of resources now may actually simply be committing our society to increasing overall future expenditure both in healthcare and social costs. This current cost-cutting is short termism and in my view economically incomprehensible; the current apparent strategy is likely to prove futile for many of our most desperate suffering patients and it needs to be rethought.

Oh, when will they ever learn?

Pete Seeger 1955.
Track 4 on Bitter and the Sweet (1962)

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Jenny Nicholas



I cannot believe its Winter already! How this past year has flown.

You will have noticed this past year some changes to *Pain News*, and the Editorial team continue to develop your Newsletter with added content and ideas, which we hope you enjoy!

This issue sees a new section on 'Pain News Roundup' prepared by our Associate Editor Margaret Dunham. This section will feature a roundup of all pain, health and political news impacting on pain. Please let us know what you think!

Speaking of news, I would like to take this opportunity to share that the Durham University 'GOTT: Gabapentinoid and Opioid Toolbox: Ten Footsteps Training Programme for Pain Self-Management' project has been shortlisted for the Bright Ideas in Health Awards 2021.

Here is a sneak preview of some of the articles we have in store for you this issue ...

- Our Editor, Raj Munglani, and colleague Paul Wilkinson open the issue with a discussion on 'Treating pain nicely: Caring for the individual not the crowd'.
- Dorothy-Grace Elder and others share with us what is currently happening with 'Pain Services in Scotland'.
- Carsten Bantel introduces us to the 'Western Models of Pain – A brief history and a short outlook'.

- 'Are the biopsychosocial and self-management models still relevant' Leila Heelas invites you to discuss this interesting topic.

We finish this issue with a poem titled 'Wartime Christmas'.

We do hope that you enjoy this issue of *Pain News*, and we are always glad to hear your feedback!

Have your say

We would welcome your view and letters on any of the topics we have covered in this, or previous issues of *Pain News*.

We also welcome articles, so if you have a story to share, please contact us at newsletter@britishpainsociety.org. We would be delighted to hear from you!



Little Russian ox cart in winter by Ivan Aivazovsky (1866). In the romantic style. Public Domain.

President's message

Arun Bhaskar

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Dear Friends
I trust this finds you well.

The predictions for another wave of Covid in winter are happening in parts of Europe and also in the United Kingdom; however, it would seem that the healthcare system is better equipped to deal with it. I hope that this would be the case as many Pain Services were forced to shut down and personnel redeployed to deal with the cases overwhelming A&E and intensive care. Hopefully, with the vaccination and booster doses, the number of seriously ill patients who require hospital admission and critical care support would be reduced, but it would seem that it could be well into 2022 before we would be in a position to say that the worst is over. Let us also hope that resources are supported to continue running Pain Services to deal with the ever-increasing backlogs of patients with persistent pain.

At the recent Annual General Meeting (AGM) on Wednesday 8 December, following the election process, we were delighted to welcome Dr Tacson Fernandez as a newly elected Council Member. We look forward to him joining Council.

It would seem the decision to have a hybrid meeting for the 2022 Annual Scientific Meeting (ASM) in June is the correct one as it gives the flexibility to have the meeting unless there are significant and catastrophic reasons. Having said that, most people are vaccinated and the need to have the social contact and networking is also important as we all have had enough of virtual meetings and the associated 'Zoom fatigue'. It would also give the opportunity for those who want to have the scientific programme, but not willing or wanting to attend the meeting in person for whatever reasons. It gives me great pleasure to share that the Scientific Programme Committee has been meeting regularly and has managed to get some high-profile and exciting speakers for the plenary sessions and work is underway in finalising the parallel sessions on what is promising to be a very exciting programme which would cater to all members of the multidisciplinary society. I would like to reiterate my request from the previous communication that you please consider attending the ASM and supporting the British Pain Society (BPS) to ensure that the BPS continues to function as a truly multidisciplinary society.

The Patient Voice Committee has expanded its membership and I am looking forward to working with them alongside the Faculty of Pain Medicine and the Royal College of General Practitioners as well as the various specialist bodies including the Royal College of Nursing, Chartered Society of Physiotherapists, British Psychological Society and Pharmacological Society to make pain as part of the healthcare agenda. The Faculty of Pain Medicine (FPM) and BPS had been involved in some of the talks to be part of the decision-making process, but more work needs to be done. Dr Ayman Eissa, Hon Secretary, has put forward a plan on how to engage with various stakeholders involved in healthcare delivery including the private healthcare providers and nursing homes as well as the medical technology companies and the pharmaceutical industry. You will be hearing more about this in the coming days from our Hon Secretary.

We are now reaching the end of a rather challenging year and I am wishing and hoping that 2022 brings a bit more stability and we can aim to have some 'normalcy' back in our daily life. I wish a Merry Christmas and a very Happy New Year for 2022.

Pain News roundup

Maragret Dunham Associate Editor, Associate Professor, School of Health & Social Care, Edinburgh Napier University

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Crises, controversies and creativity.

Welcome to our new news roundup section about the world of pain, living with pain and managing pain ... The world has become a lot smaller, in particular following COVID-19, through the accelerated use of remote communication interfaces such as Zoom, Microsoft Teams and similar. These have had a massive effect on the way we connect both personally and professionally. The implications for health care delivery and pain services are paradoxically both damaging and potentially monumentally beneficial, hence we anticipate a growing body of policies, evidence and new platforms to support these. Yet the work of our lab-based colleagues continues with some interesting and novel developments to report from the United States.

New analgesic drugs are like 'hen's teeth'; they are expensive to develop or may be bundled up with fear of side effects. Remember the new 'Cox-2' drugs that were going to be 'o so safe and effective' and the subsequent revelations of associated cardiac events? Hence, there is much anticipation at the University of Arizona Health Sciences' Comprehensive Pain and Addiction Center, from the findings of a study of a new 'non-opioid' sodium channel blocking drug that shows promising results in rats. Wouldn't it be marvellous if this can become part of the repertoire of opioid alternatives, again with fewer side effects than current options.

It is important to be cautious in pain medicine, and all medicine, when there are so many 'snake oil' salespeople out there in the currently unregulated 'wild west' of the Internet. It is also possible to miss an amazing and potentially revolutionary

study by Professor Samuel Strupp and team at the Northwestern University in Chicago, USA; whereby mice with spinal injuries, given a single injection of a new therapy, walked again. So do keep an eye out for the paper in the November issue of *Science* and watch with anticipation if hopefully this translates into successful human clinical trials.

We are on completely new territory about how COVID-19 may affect future health and adversely impact populations. We are also living in a globally ageing population where investment into everyone's future health and well-being into old age must be seen as a public health priority.

In this new section of *Pain News*, we hope to share the novel, innovative, amusing and interesting happenings in the world of pain.

If you have anything interesting, please do not hesitate to share for the next issue m.dunham@napier.ac.uk

In the meantime, keep safe.

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Pain services in Scotland

Dorothy-Grace Elder, *Founder Scottish Parliament Cross Party Group on Chronic Pain, Former MSP*

NHS chronic pain treatments face reductions in Scotland in favour of ‘self-management’ under a controversial move away from specialist services bit by bit. This has caused outrage from patients. They need clinicians to fight what they call ‘shocking harm’.

Specialist pain services were built up over many years, making life bearable and lessening suicide risk. But the Scottish Government wants to ‘reduce long-term reliance on specialist services and treatments that demonstrate limited health outcomes’, the First Minister wrote on 1 September 2020.

But for over a year, the Government has refused to name the threatened treatments they claim are ‘limited’ in clinical value. Patients say expert treatments such as injections and Lidocaine infusions, chosen by experienced clinicians to suit individuals and some off-label, transformed their lives, stopped breakdowns and suicide attempts and even enabled some to remain in work and escape poverty.

Scotland has around 40,000 patient visits annually for various Clinic treatments and 20,000 new patients in normal times. But official figures for return patients aren’t published. Only first referrals are shown quarterly – these are better as they are prioritised within 18 weeks but return patients have no waiting time limits.

Some 5000 injections were cut over recent years in Scotland without public consultation. But 9100 continued in pre-Covid years. The revelation that it is a 3-year waiting list for injections in one area came to a patient through one Board letting slip the information. A local official wrote that waiting times for injection renewal, due every 6 months, were 3 years overdue in NHS Lanarkshire.

A letter to a patient, Liz Barrie, disclosed that her board was currently treating, in autumn 2021, patients due treatment in autumn 2018. Ms Barrie was told that she faced a delay of another 18 months. This was despite the NHS knowing she had twice attempted suicide after past delays, before the pandemic.

Short staffing hit Lanarkshire long before Covid, and this 3-year wait illustrates that Covid is not entirely to blame. Scottish clinic services were being run down and understaffed years ago and there were regular complaints to Government.

If Scotland now forces thousands more sufferers to self-management, which has variable standards, it is feared that England, Wales and Northern Ireland could be influenced to save money and gain more hours from pain consultants and anaesthetists who work part-time with chronic pain. The Scottish Government’s intentions are not made clear, even to Members of the Scottish Parliament (MSPs).

While the Scottish Parliament’s committees are open, producing Hansard-style reports, with meetings on Parliamentary TV and public and media present, the Scottish Government runs separate private but influential ‘advisory’ committees on health policy. These meet behind closed doors and won’t admit public or media. The appointees to the National Advisory Committee on Chronic Pain (NACCP) are mainly Government and health board officials, four charities which receive Government funding, and recipients of Government grants. The NACCP appears to be secretive, and it is hard to discern where they initiate any policies or if this committee simply reacts to what Government wants.

How to run down services

The NACCP committee system started in 2009 and has been reproduced under various names. It still contains several appointees from 12 years ago. The suggestion has been made that, for Scotland, it is a good move to have a Government committee, and that puts them ahead of England. However, our experience in Scotland contradicts that. There is particular concern about reduced anaesthetist influence on chronic pain policy decisions. They no longer have key Committee appointments, like chairing or being lead clinician for chronic pain.

The new NACCP chair, appointed early in 2021, is not a pain clinician or anaesthetist. The lead clinician appointed for all

Pain services in Scotland

Scotland is a physiotherapist from Grampian area. Two years ago, a GP and another physiotherapist were given Government appointments on pain. These promotions do seem geared to promote self-management rather than specialist clinic services. Anaesthetists, who founded modern chronic pain services, may have steadily lost influence. Several years ago, there used to be three anaesthetists on previous advisory committees, now there is only one, an academic. Pain nurses are no longer appointed.

Beware the buzz term ‘co-production’!

Plans for a Covid recovery ‘Framework’ were compiled by officials from the Government’s Clinical Priorities Unit which serves the NACCP committee. This year, for the first time, the Government let 10 independent pain patient representatives – unconnected with Government-aided charities – join the committee. They were recruited by what is sometimes referred to as ‘the Government’s own charity’, the Health and Social Care Alliance, which receives over £4 million a year. The Alliance informed patients several times that they’d be in a ‘co-production’, with equality with officials and doctors in designing improvement plans and having access to information. But once elected to the NACCP, patients reported they did not seem to be involved. They were not allowed to see written recommendations to Ministers about chronic pain services for the patients they represented and could not access some key documents. Three resigned within a few months, seeing no progress. Later, more withdrew after they reported pressing for information and discussion, saying they cannot approve plans they have not seen.

Ian Semmons Chair of Action on Pain UK, who founded AOP as a patient

He was elected by fellow patients to the NACCP after years of voluntary pain work in Scotland. Action on Pain UK is entirely independent and does not take funding from the Scottish Government.

He said,

The situation in Scotland is serious. It is disturbing that the Scottish Government states that it involved pain patients as members of their National Advisory Committee for Chronic Pain. Sadly, this has been shown to be pure window dressing. I am anxious that they do not continue to pretend patients were ‘involved’ by them and I have now resigned from the NACCP. I will continue years of work with the independent and voluntary Cross Party group on Chronic Pain which has worked for patients properly for 20 years.

Kathleen Powderly Chronic Pain Patient and Professionally Qualified Nurse

She said, ‘Patients need specialists in Chronic Pain’. In Nicola Sturgeon’s ‘Programme for Government’ published in September 2020, she states on chronic pain that her Government will:

... build on the value of self-management and reduce long-term reliance on specialist services and treatments that demonstrate limited health outcomes. (P69)

Yet time and again they refuse to name treatments they want to replace with self-management. I would question the evidence they have. Specialist services get good results; the problem is they’ve been subjected to limitations for years.

Since our election as Patient Representatives I have found the experience extremely challenging because we expected a positive and constructive relationship with openness and transparency. We were denied sight of documents such as the written policy recommendations sent to Ministers, although we sent our patient views, hoping for some inclusion. A diagram sent to us was no substitute for clear recommendations.

We were being stifled in our role as patient representatives. We were called to only two full meetings of a Govt policy committee, a third was cancelled. We have asked for proposals to be shown since February and I cannot approve of proposals unseen.

Patients do not deserve extra stress caused by this sort of behaviour, as stress exacerbates chronic pain.

Liz Barrie Patient



Liz Barrie researched how patients needing injection renewal were being treated in Scotland. Injections are the treatment method clinicians chose for her and she says they 'restore life'. She is a former nurse suffering from a back injury years ago. Mrs Barrie is in extreme pain, as it is 22 months since her last injection, due every 6 months but can take 18 months in Lanarkshire. She has made it public that, over the years, she had twice attempted suicide because of treatment delays long before Covid. In normal, pre-Covid years, Scotland provided some 9100 injections throughout the country. Only NHS Lanarkshire admitted their return figures of up to 3-year recent waits in a letter.

Ms Barrie said,

I was concerned at the way our voices as patient representatives on the Government's advisory committee have been ignored. The biggest fear is that key treatments will be removed and run down and that is why everything is being kept secret.

I am now 22 months past my last injection, but I was speaking for many others who are at suicidal levels of suffering. NHS Lanarkshire knows of my past suicide attempts through delays. But I've just heard from them that NO treatments are being reinstated currently until further notice. So I am really struggling, with no hope for the near future.

Patients were invited to only two full committee meetings on new pain service policy and then dropped. We put forward proposal after proposal but these were ignored. We were asked originally to volunteer by the Government-funded charity, the Alliance. We were assured we'd be in a 'co-production' but there was no co-production or equality. We still haven't been shown this new 'Framework' for patients. We weren't told what was being recommended to Ministers for services to patients we represent. I think they just wanted to pretend patients were involved as a 'tick box'.

The Scottish Government plans a public consultation but wouldn't even allow patient reps to be involved with the questions, something patient reps on other groups usually do. The Alliance, the Government-paid charity which first claimed we'd be consulted and have equality, also produced a 'survey' but did not discuss it with us in advance.

Lives are being risked through lack of treatment.

Every single impact of whatever is in the new 'Framework' will come back to the patient.

Although we were at the table, details of this Framework were not shown to patient reps, so we fear treatments seem likely to be cut and self-management imposed. That will mean more mental health harm and risk more suicide attempts.

Monica Lennon Member of the Scottish Parliament for Central Scotland, Co-convenor of the Scottish Parliament's Cross Party Group on Chronic Pain



Patients have the right to speak up and not be silenced:

The co-production model in this case was misused and appeared only as a tick box exercise for the Scottish Government. Any opportunity to take on board the lived-experience of individuals who are trying to manage their chronic pain must be taken seriously and listened to intently. Transparency is key and patient representatives must not be excluded or intimidated at any part of the process.

I am desperately worried about my own constituent, Ms Barrie and others I know who are feeling vulnerable after experiences they endured following their roles as patient representatives on the committee when trying so desperately to get help.

Urgent action needed to tackle Britain's Health Crisis

Alex Neil *Former Cabinet Secretary for Health and Wellbeing in the Scottish Government*



The founding principle of the National Health Service (NHS) is that treatment is based on clinical need, not the ability to pay.

That principle is being eroded on a daily basis. Because of the crisis in the NHS throughout the four nations of the United Kingdom, thousands of patients are now paying for private healthcare because they cannot get access to the treatment they need on the NHS.

The length of waiting lists and the consequent knock-on impact on waiting times are forcing patients to go private because they cannot suffer the pain of waiting for months or even years for treatment.

People suffering from chronic pain are unable to get the regular injections they need, patients on waiting lists for hip and knee replacements are being told it could be years before they get their operation, too many cancer patients are having their lives put at risk because they are waiting too long to get their scans and treatment, the percentage of Accident and Emergency patients waiting more than 4 hours before they are seen is the highest it's been since records began.

The Covid-19 pandemic has had a devastating impact on the NHS and its ability to cope.

The so-called post-pandemic recovery plans produced by the four UK Governments to get the NHS back on to an even keel read more like wish lists than plans. They fail to rise to the magnitude of the challenge facing the NHS. They also fail to address many of the underlying issues facing the NHS even before the pandemic; epitomised by patient outcomes in the United Kingdom being among the worst in Europe, including survival rates for cancer, stroke and heart conditions.

What needs to be done to rescue the situation?

Clearly more money is needed. The average spend per patient in the United Kingdom is way below that of comparable countries, including Germany and France. This has resulted in significantly fewer doctors relative to our population, fewer nurses and fewer allied health professionals such as radiographers.

Top priority therefore must be to address the dire shortage of resources available to the NHS to do its job.

The additional money promised for the next few years is welcome although not enough to deal with the on-going demands of the pandemic and address the longer-term needs of the NHS.

Tackling the dire shortage of medical staff must be the top priority.

Urgent action needs to be taken to stop the exodus of existing staff from the NHS. The ridiculous situation where some staff are being hit with huge tax bills for doing extra work, coupled with the unresolved, long-standing problems with NHS pension schemes which force people to retire early, need to be sorted.

Pay and conditions for all medical staff need to be improved further to incentivise people to stay and encourage agency staff, including locums, to work full-time for the NHS.

A major recruitment drive is needed to reduce the work pressures on existing staff, for example, by incentivising retired doctors, nurses and allied health professionals to return to work on either a part or full-time basis.

This was tried by some local NHS organisations during the pandemic, to varying degrees of success. Unfortunately, too often it was done half-heartedly. For example, the Royal College of Surgeons in Scotland recently reported that only 15% of its retired members had been contacted to ask them to return to work, hardly an ambitious effort. Similarly, I know of many nurses who responded to the NHS appeal for them to return to work during the pandemic but didn't even receive an acknowledgement of their interest, let alone any follow-up.

This must change. The NHS needs to recruit as many additional staff as it can get and to do so quickly. We also need to significantly increase the number of people being admitted to our medical schools so that we solve the strategic staff shortages on a permanent basis.

As well as too few staff, we have too few beds in the NHS. A situation that has been exacerbated by the Covid crisis. At the time of writing, the number of Covid patients in hospital in the UK is hovering around 7,000. We must assume that figure will not drop significantly in the short-term.

The United Kingdom has one of the lowest ratios of beds to population in Europe. This is one of the reasons why we have been missing our Accident and Emergency 4-hour target for so long.

The problem of delayed discharges for patients who are medically fit to leave hospital but not able to return home exacerbates the problem of a shortage of beds. Many 'solutions' to this problem have been tried but none so far have been greatly successful. I suggest that the best way to solve this problem is by creating 'convalescence' units which are in close proximity to acute hospitals where these patients can be properly looked after until they are able to go home.

The other big shortage which needs urgent action is the lack of enough up-to-date equipment, especially for the purposes of diagnostics.

Quick diagnosis is key to success but too often cannot be done due to the combined shortage of qualified staff and

modern equipment. If the NHS is to recover, then this issue also must be addressed with urgency. There should also be a roll-out of the artificial intelligence capabilities which can provide fast and reliable diagnosis.

Throwing more money at the NHS of itself won't be enough to solve its underlying problems. The additional resources should be part of a much broader plan for addressing the long-term strategic challenges which the NHS faces, including the ageing of the population and the increasing costs of new medicines and new technologies. Systemic change is needed.

The role and resources of the primary care sector isn't just essential for achieving better outcomes for patients but is a prerequisite to solving many of the problems of the acute sector, including the long-term crisis in Accident and Emergency services.

We should learn from other countries, such as the Netherlands, where the 24/7 local availability of primary care services has resulted in A and E attendances which are one quarter of those in the United Kingdom, in relation to population sizes.

We should adopt a similar approach.

The Alaskans' reform of their health services has also shown how important it is to make primary care services much more patient-oriented. The triaging of patients ensures that patients are routed to the most appropriate health professional who can deal with their complaint. Much better use can then be made of the general practitioner's (GP's) time and those patients who need access to their GP get it very quickly and, where necessary, for a longer period of time than hitherto. This system has resulted, for example, in much improved diagnosis for patients, resulting in improved patient pathways for treatment and better outcomes. We can learn a trick or two from Alaska.

Given the geography of Alaska, some patients live hundreds of miles from their GP. The use of remote technologies is therefore essential for diagnosis and treatment; another example of where we could do better.

The culture of the NHS should also be changed for the better, starting with the abolition of arbitrary targets which distort the delivery of patient-centred care.

We had the ridiculous situation recently when the UK Health Secretary tried to set a target for what percentage of patients GPs must hold a face-to-face appointment with. This is a decision for the GP in consultation with each patient. There is no evidence to support the need for face-to-

Urgent action needed to tackle Britain's Health Crisis

face appointments with any specific percentage of patients. Such a decision is dependent of critical factors like urgency, geographical access, whether a telephone or zoom consultation would be adequate, and so on, it is a nonsense for a politician sitting in London to issue a decree that all GPs must meet a politically set target for face-to-face appointments. The success of GPs, like the NHS itself, should be judged primarily by the outcomes they achieve, not some arbitrary target concocted by the Secretary of State.

The management structures in the NHS are also crying out for reform. In Scotland, for example, we now have 22 Health Boards, 31 Health and Social Care Partnerships and 32 local councils; a total of 85 different organisations involved in the delivery of these services to a total population of 5.4 million people. This is not an exhaustive list as there is a labyrinth of

other committees, regional boards, and so on; a huge structure which badly needs to be de-layered and streamlined. It also needs to be much more localised and accountable to the people it is meant to serve.

The quality of management in the NHS is also a problem. With such a top-heavy structure there aren't enough good managers to go around, a situation which is aggravated by the lack of enough medical staff promoted to managerial positions.

These are just some of the issues which need to be addressed to make the NHS fit for the 21st century, and if we are to avoid people having to use their life savings to purchase private medical care because they can't get the treatment they need when they need it in the National Health Service.

Western models on pain: a brief history and a short outlook

Carsten Bantel *Anesthesiology, Critical Care, Emergency Medicine, and Pain Management University of Oldenburg, Klinikum Oldenburg Campus Rahel-Straus-Strasse 10, 26133 Oldenburg, Germany*

Genesis of thought

Probably ever since humankind has acquired its ability to reason, we have sought to understand and explain nature, the universe and of course ourselves. In this quest, many hypotheses that mean ‘ideas that propose a tentative explanation about a phenomenon observed in the natural world’ have been formulated, modified or discarded.¹

Those that survived scrutiny and fit the purpose of the people at the time were often further developed into representations, maps or models of the phenomenon in question. At least in theory, such modelling allows additional investigations and easier communication.² Not surprisingly, therefore, our history is full of models and many of them even found their way into our culture, religion and subsequently our daily life.

Take the first book of the bible, for example. It can be seen as an early model of how people thought our planet and ourselves were created.³ But interestingly and more to the point of this article, the First Book of Moses also already mentions pain, or more precisely why we might suffer from it. The pain of childbirth, for instance, is depicted as the direct consequence (punishment) of man’s original sin (Genesis 3:16). Pain thus gets a very negative connotation here. This idea was then further advanced by many authors, but probably most eloquently by John Milton in his epic ‘Paradise Lost’: Without our fall, he mused, we wouldn’t feel pain. According to Milton, pain and mortality thus define us as man – created by God but no longer divine.⁴



Paradise Lost – Gustave Dore Public domain

However, pain as described in Genesis (Genesis 17:11; Genesis 34:25) is also part of a contract (covenant) God makes with man. Therefore, despite its evilness it, too, contains something positive, something we can rely on, something that keeps us close to God. Now, these of course are religious interpretations of life and as such they are notoriously difficult to test and hence to either disprove or affirm. They therefore belong entirely to the private realm of any individual person, their subjective beliefs and convictions.

Nevertheless, as probably everybody has experienced firsthand, beliefs and convictions can only take us that far. Sooner or later a point is reached where more universal and especially verifiable, that is, objective, answers are needed.

Here scientific approaches have proved themselves as valuable alternatives to pure religious thinking.

The Greek beginning

Not surprisingly in the Western world it was the Greeks who left an early mark. They introduced thoughts, methods, and terminology we still use today.

Where once superstition and ignorance ruled, they began to develop knowledge based on logic and observation. This approach led thinkers quickly also to focus on how we, our bodies and minds might interact with our environment, and what the consequences of this interaction might be.

According to Morton Hunt, it was Alcmaeon (around 600 B.C.) who first acknowledged a central role of perception, that is, the awareness of things through the physical senses, in this regard.⁵ Sense organs, he conjectured, send their perceptions to the brain where they are interpreted and become knowledge. Because of this first model of knowledge acquisition Alcmaeon is generally considered the father of epistemology, the study of how we obtain knowledge.⁶

About 150 years later, two other philosophers (Protagoras, 481–411 B.C. and Democritus, 460–371 B.C.) introduced the notion of perception as being subjective and hence private.

Western models on pain: a brief history and a short outlook

This ‘private object’ argument was afterwards extended to pain and has haunted the view on it ever since.⁷

However, Protagoras and Democritus also anticipated McCaffery ('pain is whatever the experiencing person says it is'), when they held each perception as being true for the perceiver.⁸

Soon afterwards even the greatest of all philosophers dedicated a good deal of thought to the nature of pain. They came up with ideas, which every modern pain physician is to some degree familiar with. Here are some examples: Socrates (470–399 B.C.) and Plato (428–348 B.C.) introduced the ‘body and soul dualism’ and acknowledged that data obtained from the senses (‘sense data’) might sometimes be unreliable.⁵

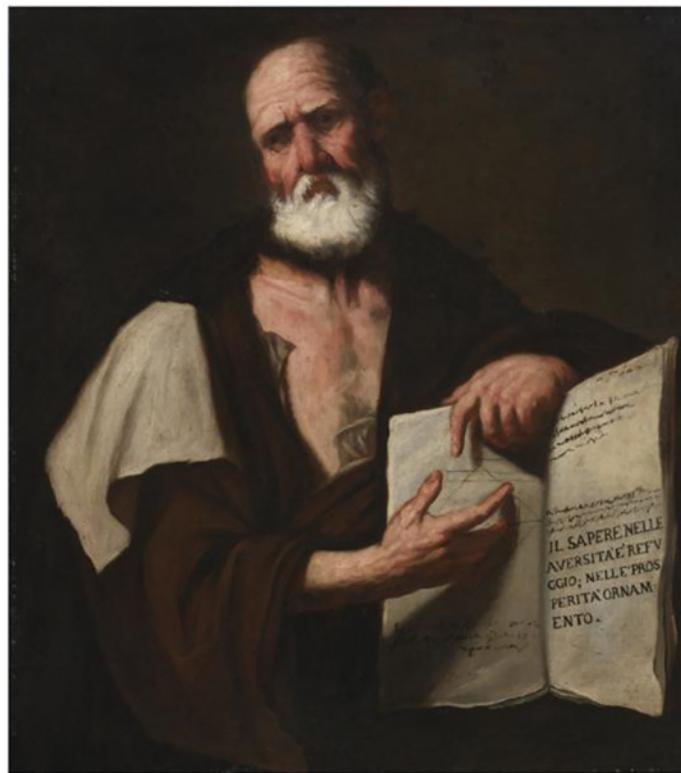
With this they laid the foundations for the later development of pure biological (physiological) pain models to explain our pain experiences.

This was additionally emphasised by Plato’s statement that ‘we are slaves of our bodies’ and that only knowledge can free the soul from this prison. In this bodily (biological) approach to pain, he nevertheless allowed the possibility of bodily sensations being controlled by the mind, or that through the mind a sufferer might be able to alleviate his or her suffering. Isn’t this something patients learn in present-day pain management programmes? And does this not also imply an important role for the brain – if we assume it to be the seat of our mind? The latter, of course, was not as obvious to the old Greeks as it is to us today.

However, it was the godfather of all physicians, Hippocrates (460–370 B.C.), who probably made this connection for the first time when he mused that ‘only the brain creates pain’. Even now we are just at the beginning of understanding how that might work.

It was then Aristotle (384–322 B.C.) who advanced this ‘proto-biological’ thinking about the senses further when he distinguished five special (hearing, taste, smell, sight, touch) from common senses.⁹ Although he was not sure about the sense organ for touch, he speculated that the objects of the special senses can only be perceived by specialised organs, for example, the eyes or ears. Conversely, he thought of common objects such as number, size, shape, rest, or movement as only being sensible through different (non-specialised) organs. Aristotle even talked about phenomena present-day neuroscientists would describe as ‘threshold’ or ‘adaptation’. With his work, Aristotle thus anticipated something like the specificity theory that we will come to see later.

Before we gradually move on to the developments of our times, Epicurus (341–270 B.C.) is also worth mentioning here. This is because in trying to understand what motivates people he came to see pleasure and pain as the single most important forces. As he said, the former we try to attain, the latter to avoid.⁵



Aristotle – Luca Giordano Public Domain

Modern ideas

The times we usually regard as the beginning of modern thought on pain probably did not start exactly with Rene Descartes (1596–1650), but he certainly is its most prominent figure.

Who does not know his famous sketch of a young man kneeling at a fire, the heat transmitted via a long tube from the back of his foot, passing the leg and back all the way up to his brain? It set the tone for an era of physiological (mechanistic) discoveries about pain generation in the periphery and its transmission to the brain.

However, it needs to be stressed that most models I am going to introduce below are strictly speaking models of acute pain. Comprehensive physiological models of chronic pain are still sparse.

Physiological (mechanistic) models

Nineteenth and 20th centuries have seen something similar to a quantum leap in our understanding of pain mechanisms. Some of the most important are discussed below.¹⁰

Specificity theory. This theory holds that noxious (painful) stimuli are sensed by specific sensors in the periphery. These sensors then generate a signal, which is transmitted to the spinal cord and further to the brain via specific nerve fibres. Charles Bell (1774–1842), Johannes Muller (1801–1858) and Maximilian von Frey (1852–1932) were the first to postulate the presence of such peripheral pain receptors. These were finally discovered in 1906 by Charles Sherrington and termed ‘nociceptors’. Upon their stimulation, for instance, through surgical skin incision, ‘nociceptive pain’ is generated. The finding of nociceptors as well as receptors for pressure, heat, and cold finally helped completing Aristotle’s hypothesis on the presence of specific sense organs.

Intensity theory. The core of this theory is the assumption of a stimulus threshold. A signal is hence only generated if the stimulus intensity is above that threshold. However, the threshold can be crossed by two different mechanisms: (a) the application of a single suprathreshold stimulus and (b) the summation of a burst of rapidly applied subthreshold stimuli in the spinal cord (‘central summation’).

Although formally not belonging to intensity theory, which lost appeal after the discovery of nociceptors, the physiological phenomena of ‘wind up’ and ‘central sensitization’ can be viewed as its extension. Central sensitization in particular is thought to play an important role in the development of chronic pain.

What are they, then? *Wind-up* develops in neurons of the central nervous system (CNS; spinal cord, brain) after exposure to repetitive high-intensity peripheral stimuli. As a consequence, the strength of the incoming signal is augmented and prolonged. However, wind-up usually seizes after the peripheral stimulus is discontinued.

Central sensitization is very similar to wind-up. It also develops as a consequence of a continuous barrage of nociceptive stimuli entering the CNS. Although it, too, augments the incoming stimulus, it does not cease after stimulus discontinuation. It therefore progressively increases the pain experience and it is thought the underlying mechanism of ‘hyperalgesia’ (a painful stimulus is felt even more painful) and ‘allodynia’ (experience of pain in response to the application of a non-painful stimulus).¹¹

Pattern theory. To some degree, pattern theory is similar to intensity theory, the difference being that, according to intensity theory, pain is dependent on the stimulus intensity, whereas it is dependent on the firing pattern of neurons in pattern theory. Hence, the nociceptive signal here is encoded into a spatial and temporal firing profile of the stimulated neurons. Such encoded signals are then transmitted to the brain where they are deciphered and translated into what becomes the painful experience.

Gate Control Theory. Probably the best-known and most influential modern theory on pain, however, is the Gate Control Theory from Melzack and Wall, which they published in 1965.

The novelty of this theory was that for the first time it described an integration and modification of the incoming signal with and through other signals at spinal cord level. If, for instance, an injury occurs in the periphery (skin), the noxious stimulus is sensed by nociceptors and transmitted via C- and A δ -fibres to the spinal cord. There it is transduced onto secondary neurons, which then carry it to the brain. Melzack and Wall suggested this simple pathway to be much more complex in reality. They mused that the original nociceptive signal is integrated with and subsequently modified by signals that are (a) transmitted from the periphery to the spinal cord via large A β -fibres (e.g. touch), (b) generated by specific spinal interneurons and (c) descending from the brain stem (descending pain modulating pathways).

These modifying mechanisms, they held, form something like a gate for the incoming nociceptive information. Consequently, only stimuli that are intense enough are carried upwards to the brain while all others are filtered out and hence controlled by the gate in the spinal cord.

Integrated models

All these models can explain to some degree how pain is generated and why we suffer from it. However, they also work under the assumption that some form of bodily injury took place. By and large, they were not designed to explain pain in the absence of injury. This is something that integrated pain models try to achieve. They also try to overcome the dichotomy of body and mind that rules our views on pain ever since the times of Socrates and Plato.¹²

Neuromatrix model. According to this model, incoming nociceptive information is modified by the activity of various regions of the central nervous system, which are often summarised as ‘neuromatrix’. Among these

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regions are the spinal cord, brain stem, thalamus, limbic system, insular, somatosensory, motor and the prefrontal cortex.

The product of the action of the neuromatrix on the original nociceptive signal is called ‘neurosignature of pain’. In becoming aware of it, this neurosignature is thought to underlie a person’s painful experience. Therefore, the peripheral signal can only start the process that ultimately leads to a neurosignature; it cannot create it on its own. Moreover, once a neurosignature is created, it is memorised so that next time a comparable signal enters the CNS a similar painful sensation is felt (‘pain memory’). However, in addition to the introduction of a potential mechanism that explains ‘pain memory’, the neuromatrix model also defines cognitive-emotional factors to critically influence our pain experience. This follows from the involvement of those brain regions that are crucially involved in cognitive and affective processes.

The bio-psycho-social (BPS) model. Although the neuromatrix model acknowledges the critical involvement of cognitive and emotional factors in the generation of pain, it is not quite a fully integrated model. This is because (a) it still heavily relies on biological, that is, physiological, factors and misses, for instance, social aspects as explanatory variables for painful experiences, and (b) it is predominantly a theory on how pain is generated and offers little on how it might be treated comprehensively.

This is achieved with the bio-psycho-social model. Although many predecessors such as John Bonica or Roy Grinker, who even used the term ‘bio-psycho-social’, had thought about all-encompassing integrated medical models, it was not until George Engel’s paper, ‘The need for a new medical model: a challenge for biomedicine’, published in *Science* in 1977, that the concept left the field of psychiatry for which it was initially intended and became widely accepted in all parts of medicine.

With this model, for the first time the complex interactions of biological (physiological), psychological and social factors were taken into consideration as variables for disease processes and their treatments. The model is now also explicitly mentioned in the new International Association for the Study of Pain (IASP) definition of pain from 2020:

According to this definition, ‘pain’ is ‘An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage’.

The IASP explained the definition further by adding six key notes and the etymology of the word ‘pain’:

1. *Pain is always a personal experience, that is influenced to varying degrees by biological, psychological, and social factors.*
2. *Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.*
3. *Through their life experiences, individuals learn the concept of pain.*
4. *A person’s report of an experience as pain should be respected.*
5. *Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.*
6. *Verbal description is only one of several behaviours to express pain; inability to communicate does not negate the possibility that a human or a nonhuman animal experiences pain.¹³*



The Madness of Fear – Francisco Goya. Public Domain

Old challenges and new horizons

The last 100 years have therefore seen tremendous progress in our understanding of pain generation and its pathways.

This notion was further highlighted by recent news from the Nobel Prize Committee. While I was writing this article they coincidentally announced the awardees for the 2021 Nobel Prize for Medicine – or better Physiology. This year’s prize will be going to David Julius and Ardem Patapoutian who dedicated their work to the understanding of how the body perceives temperature and touch, respectively. They both laboriously tested DNA fragments to finally identify ion channels specialised for this purpose. At the end of their endeavours, David Julius found TRPV1 and TRPM8 receptors, while Ardem Patapoutian characterised Piezo 1 and 2 proteins.

Through Julius' work, we know that the capsaicin-sensitive TRPV1 and the menthol-sensitive TRPM8 proteins are the heat and cold sensors of our body. Especially TRPV1 receptors are now further implicated in the generation of inflammatory, neuropathic and visceral pain. At the same time as Julius did his work in San Francisco, only a few hundred miles south in La Jolla Ardem Patpoutian independently worked on a similar project. He ended up uncovering how our body senses touch, body position ('proprioception') and motion through Piezo 1 and 2 proteins. These proteins have subsequently been shown to be involved in mechanical pain as well.



The Sense of Touch – Jan Brueghel the Elder. Public Domain

What a great achievement their work was! Especially as both scientists have contributed to close a knowledge gap that Aristotle had identified 2,500 years earlier when he spoke about the senses but could not come around how the perception of touch might work.

However, as good as this Nobel Prize is for the field of pain medicine, sometimes, when I follow the news or read professional articles I get the impression there aren't that many riddles left for us to solve. All seems said and done – except, a great proportion of patients are still suffering from intractable pain, leaving us physicians often struggling to find an answer for them; any answer.

Why is that? What, despite all progress, are we missing here? Hey, in the end, it is just pain we are talking about. Nothing substantial, not cancer, not COVID, no cardio-vascular or cerebro-vascular disease, not even a broken bone. Just a subjective experience a lot even find hard to talk about. And, come on, we have morphine and steroids. That's pretty strong. If they don't respond as we wish them to do, they are either drug seekers or mentally sick.

Dear reader, you will have noticed that I am just trying to provoke you in stating, admittedly in an abbreviated way, what I

hear almost daily, from health care professionals, managers, relatives, the public and even my patients.

So let's be serious again: What are we missing? Why do we find it so difficult to close the gap between the biology of pain and our patients' experiences?

One thing I notice when sickness and disease are mentioned in the media, when patients are talking about their pain and therapists about mechanisms, the overwhelming dominance of the biological approach to pain. Interestingly, the Nobel Prize for Medicine itself proofs my point as psycho-social research is never even considered here. Pain therefore is nearly always seen as being representative of either biological or, to a lesser degree, psychological pathology. In reality, this means in almost all cases pain is viewed as having a bodily cause that subsequently, almost linearly, leads to perceptual changes. This is what Murat Aydede in his paper 'What is a Pain in a Body Part?' calls the *perceptual-representational model* of pain.¹⁴ It relies heavily on the old concept of *body-mind dualism* which, once again, Socrates, Plato and Aristotle had endorsed. Body-mind dualism means that the body (=physiology) and the mind (=psychology; old: 'the soul') constitute two separate entities that might or might not interact.

The philosophical and linguistic difficulties this model produces are discussed by Aydede in depth, and he finally revokes it. Apart from these theoretical considerations, perceptual-representationalism also brings with it some practical difficulties: First, with this approach the main organ that defines a patient's pain experience, the brain, often remains obscure. It is hence under-represented when causes and treatment options are considered. Second, when discussing pain with patients and with colleagues, it often remains unclear what pain really is. This is at the core of Aydede's paper which, I can admit, was an eye-opener to me. Third, in simplifying pain as a pure perceptual phenomenon, we additionally miss several other aspects that are equally important for the patient in pain. Among those are (a) linguistic issues. In focusing on perception, we might oversee and even deny other expressions of and for pain. (b) pain concepts. Despite being now even acknowledged in the IASP definition of pain and with a tradition that reaches back to at least Ludwig Wittgenstein, it still remains uncertain what our pain concepts are, how we communicate and, most importantly, how we acquire them.¹⁵

Furthermore, based on Joanna Bourke's work 'The Story of Pain', where she convincingly showed the influence of culture and religion on pain perception and communication, this and

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the political circumstances of patients demand further exploration.¹⁶ How do, for instance, the increasing isolation of people, the technological advances, the resource deprivation, and environmental changes influence the way we experience pain? Why is it that pain so often is belittled, its sufferers stigmatised and ostracised, as I have mockingly stated above? Has it something to do with the ‘politicalness’ of pain? Something Elaine Scarry discussed, when she mentioned the pain of torture victims, and something that I often notice when some of my female patients open up and talk about their experience with domestic violence or psychological trauma.¹⁷ Who is it that benefits from the pain others suffer? What is achieved by it?

That leads me to my final question. What will be our future role as pain therapists? Doctors in the classical sense, as prescribers or interventionists? Will we be something more like generalists, bringing together aspects of the work of psychologists, social workers, educators, activists, and lobbyists? Will we be something completely different? Or, maybe might we even vanish? I think apart from discovering cellular pain pathways, these are the challenges that lie ahead of us. As pain therapists, we now have to ask ourselves a question Barack Obama so eloquently raised in his acceptance speech at Grant Park on 4 November 2008:

[...] we have come so far. We have seen so much. But there is so much more to do. So tonight, let us ask ourselves: If

*our children should live to see the next century; [...], what change will they see? What progress will we have made?*¹⁸

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Are the biopsychosocial and self-management models still relevant?

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A discussion paper

Background

In a recent British Pain Society Philosophy and Ethics of Pain meeting, a critical lens was applied to the self-management model. Self-management of long-term conditions was a concept developed in the United States, which was transported to the UK health service in the 1990s. The premise is that experts develop self-management practice, compliance of the patient ensures benefit and individuals are invited to adopt healthy behaviours.¹ There is an assumption that self-management (behaviour change) is accepted practice and by some it is viewed as synonymous with the biopsychosocial (BPS) management of persistent pain.² It is acknowledged that self-management concept and the biopsychosocial model are separate entities but for the purposes of this article there will be an assumption that they are interlinked. There are a number of interpretations of self-management: one definition is that the

core processes involve problem-solving, decision making, effective utilisation of available resources, reduced healthcare utilisation, changing behaviour and fostering partnerships with healthcare practitioners who act as supervisors.³ The BPS model as applied to pain acknowledges that pain may be present in the absence of positive tests and results and that the pain experience is influenced by contextual, biological, psychological and social factors.⁴ It has been suggested that biopsychosocial management is essentially psychologically informed practice with the intention of changing attitudes and behaviour of patients (and therapists).⁵ Some authors have proposed that self-efficacy is a key tenet of self-management whereby an individual is able to make decisions in the light of their own situation and can be developed by practice, observation of modelled skills and managing emotions.⁶ There is a plethora of literature related to self-management interventions for persistent pain and it is usually a key aim of pain rehabilitation: however, evidence for such approaches (using a traditional hierarchical grading system) is low to moderate.⁷ Given this, should it still be part of accepted practice in pain services?

Self-management and neurobiological education

The self-management concept may utilise pain neurobiology education to decrease fear and enable return to physical activity. It is argued that delivery of this message to wider society is also required but is a neglected element of the BPS model.⁸ Social media networks are an important influence and may act as barriers or enablers. Where there have been efforts to shift cultural perspectives, profound health care improvements have occurred.⁸ Initiatives such as 'Flippin Pain', which is a public health campaign which is co-designed with people living in pain. The intention of the campaign is to use pain neuroscience education to develop knowledge and skills for people living in pain. It is an excellent example of the desire to drive social change in the understanding and management of pain. Pain neuroscience education has been criticised, however, when applied in a reductive way with emphasis on

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pain neurophysiology education.⁹ Indeed, it has been argued that this in fact conflates the model with the biomedical model.² Although psychological factors are noted to be important in pain neurobiology interventions, some are focused on pain neurobiology education with reference only to the biology of emotion,² meaning that mental wellbeing factors may be left unaddressed. For example, reference might be made to the sensory discriminative and affective-cognitive-evaluative regions of the central nervous system involved in pain processing¹⁰ but without further exploration of the psychological impact and sequelae of living with persistent pain. Mescouto suggests that mental health is briefly noted in studies of biopsychosocial interventions for low back pain but aspects such as shame and guilt were not acknowledged.² These emotional responses have been found to be important in qualitative research about the experiences of living with persistent pain.¹¹ Mescouto concludes that ethnography or critical qualitative approaches may better investigate the complexities of the experience of living with low back pain.²

BiopsychoSOCIAL

Mescouto highlights that social aspects such as isolation have not been explored in detail in a critical review of biopsychosocial physiotherapy literature. Mardian et al.⁹ propose, with reference to the US healthcare system, that the biopsychosocial model should be transformed to the sociopsychobiological model. They suggest that despite acceptance of the biopsychosocial, biomedical practices are still deeply entrenched in healthcare, also citing the prevalence of neurobiological education strategies in teaching related to BPS management. The authors state that psychosocial therapies are in danger of reinforcing the biomedical model where healthcare providers are active, physical therapists move body parts, or healthcare providers deliver massages and give injections. Perhaps not all these elements are relevant to current clinical practice in the United Kingdom, but these points provide food for thought.

It is argued that a sociopsychobiological model could be transformative by attending to the more macro level of suffering and vocational activity. Mardian highlights that pain experience is formed within a social context and suggests that social isolation as a result of persistent pain is akin to threats to survival, triggering an alarm response. Such threat responses may be amenable to public health, population level intervention, where psychological, movement-based therapies, mental health and substance disorder treatments could be delivered as part of a self-management approach to treat the whole person. These recommendations are far from revolutionary and not dissimilar to a UK multi-disciplinary pain service; indeed, an

inter-disciplinary pain rehabilitation intervention was later described in the paper as novel practice, which perhaps reflects differences in UK and US healthcare systems.

Further suggestions of the sociopsychobiological model were that co-morbidities such as obesity, poorly controlled diabetes and poor sleep could be addressed by an approach fostering intra/interpersonal and coping strategies which require active involvement.⁹ The importance of this is exemplified by data from the UK biobank which indicates that age and gender-adjusted risk of death is increased in people with chronic widespread pain who are obese compared to those of healthy weight,¹² and individuals with chronic widespread pain are at increased risk of mortality, which may be due to high body mass index (BMI), low physical activity levels and dietary factors.¹² Another factor may be related to suicide as higher rates have been reported in people living with fibromyalgia compared to the general population.¹³ Pain rehabilitation may address the health problems associated with physical inactivity. The benefits of activity in terms of reduction of co-morbidity are highlighted in the Moving Medicine campaign <https://movingmedicine.ac.uk/why-movement-matters/why-moving-matters-2/> This campaign invites clinicians to foster a motivational interviewing approach to achieve adherence to physical activity in people attending for clinical consultations. But does a lack of motivation provide an explanation for the causes of physical inactivity in people living with persistent pain?

The premise that personal responsibility is the key target in some interpretations of self-management is a limitation because this fails to acknowledge the 'social' context. Marmot's report on health inequality states that community environments shape health via service provision, safety, access to outdoor space and leisure facilities, housing and education.¹⁴ These factors move beyond behavioural change via knowledge and skills acquisition, as assumed in the self-management model. Fletcher et al.¹ note that inherent tensions arise in self-management models in relation to control, power and responsibility. Public Health England emphasises the importance of policy change in government, education, environment, employment and healthcare and recommends moving to an active society.¹⁵ Cited successes are outdoor spaces for exercise created in Finland and campaigns such as Change4Life – posited as illustrative of good marketing, although it is unclear whether social media influencers and role models such as Joe Wicks and Marcus Rashford may have had a greater impact. The Capability, Opportunity, Motivation-behaviour (COM-B) evidence-based model for behaviour change acknowledges that opportunity in the form of an increase or a reduction of a feature in the environment may influence behaviour. An example may be the introduction of

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cycle lanes in the post-Covid United Kingdom. However, a change such as this is only a small step in the right direction. Marmot moves away from personal responsibility and calls for action on all social determinants of health which include education, occupation, income, home and community.

Self-management and lived experience

Doebl et al.¹⁶ conducted a narrative synthesis of qualitative data and reported that participants identified that moral support, multidisciplinary fibromyalgia clinics, problem-solving and ongoing support for self-care were important. These aspects could be considered elements of self-management. Qualitative exploration of the experiences of physiotherapists and people with joint hypermobility syndrome (JHS) found that the usual 6 sessions of physiotherapy did not meet the needs of people living with JHS,¹⁷ and people living with fibromyalgia or JHS have identified that they would like longer-term access to treatment due to the fluctuating nature of the conditions.^{17,18} This may be satisfied by access to intensive multidisciplinary treatment as noted earlier, but it represents a resource challenge in the National Health Service (NHS) where discharge usually follows intervention. The desire for ongoing care is at variance to the philosophical underpinning of self-management where the explicit intention, in some interpretations, is to decrease healthcare reliance. Many pain services encourage group cohesion as a method of prolonging the support derived from participating in a group programme. Third sector involvement and social prescribing may also go some way towards bridging this gap, although participants in studies have resorted to paying for private treatments where public sector physiotherapy provision has been unavailable.¹⁸

Lous Heshusius, an academic living with persistent pain, writes that self-management programmes separate the person in pain from the societal context within which they live. She notes that complexity and diversity of need is not always recognised and that principles are superimposed onto her life in a simplistic manner. This perhaps indicates that there is a danger in applying self-management principles in a manualised or fixed manner without adapting to nuanced, person-centred requirements. Managing diverse requirements in a group setting requires high-level skills, flexibility and responsiveness of the clinicians to meet complex needs of individuals. These (arguably under-rated) skills are routine clinical practice for advanced practice clinicians delivering group pain rehabilitation programmes using a psychologically-informed approach. Pain services might wish to consider how complex needs might be met. Examples from our practice include build-up sessions to gain physical and social confidence prior to joining a group programme, individual treatments where requested, adapted

communication strategies for people with particular learning needs, treatment in quiet areas and going out to meet people in the car park where there is anxiety around attending in a hospital setting. In clinical practice, it is not always possible to offer self-management as described in the introduction, such as when support has been provided over many months for people with complex social circumstances where multiple agencies might be involved.

Despite criticisms of self-management, Heshusius reported that group programmes offered solidarity and social contact without fear of stigmatisation.¹⁹ This fellowship, derived from a community of others with shared experience, was highlighted as being part of a healing journey in a meta-synthesis of qualitative research.²⁰ Participants in the qualitative literature described elements of self-management as important to them, specifically – having strategies for managing pain and taking an active role in healing with reference to exercise, goal setting, managing emotions and pacing. Factors such as humanity of healthcare practitioners, a reconnection with mind, body, self, a sense of inner calm, personal growth, validation of pain experience, being an equal partner in healthcare, having autonomy and acceptance were other themes related to healing.²⁰ The National Institute for Health and Care Excellence (NICE) guidelines for chronic primary pain do not include qualitative research findings although there were lay members of the guideline committee. It might be useful to consider how we include this kind of evidence into treatment recommendations for persistent pain.

Summary

Criticisms of the self-management model refer to a pain neurobiological education being applied in a reductive way with a failure to recognise the full impact of emotional responses to pain. Self-management is considered synonymous with biopsychosocial management; it is argued that interventions and practice which purport to be biopsychosocial are still inherently biomedical. Social aspects of the pain experience such as social isolation are not considered and a sociopsychobiological model has been called for. A public health approach may mitigate for some of the long-term health impacts of physical inactivity. This assumes responsibility of the individual and implicitly assumes motivation is required. Failure to recognise the social context in shaping health is a limitation of the self-management model: changes in social policy may be required to tackle social determinants of health. Self-management interventions may be overly simplistic and fail to recognise the full complexity and diversity of experience. Healthcare practitioners may wish to consider how treatment offers can be diversified in order to meet the needs of service

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users. Despite these limitations, people with lived experience value access to multi-disciplinary treatment where (self-management) strategies are developed for living well with persistent pain and where there are opportunities to encounter a shared community of experience.

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Chronic pain patient-reported outcome measures: a survey of current UK practice

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In 2008, the Chief Medical Officer in England acknowledged the burden of chronic pain on the UK healthcare system stating, 'each year over 5 million people in the UK develop chronic pain, but only two thirds ... recover'. He went on to comment that 'more needs to be done to improve outcomes for patients', thereby highlighting an inherent need for services to measure the effectiveness of care provided.¹ Nearly a decade prior to this, the published report from the Clinical Standards Advisory Group (CSAG) 2000 had revealed shortcomings within the provision of UK pain services.² Although there had been an improvement in the provision of inpatient pain services, the quality of care provided in chronic pain was said to vary widely with many doctors still working in isolation. This coupled with long waiting times to be seen by pain services highlighted the need for improvement. In a bid to initiate change, the 3-year National Pain Audit 2010–2012 was commissioned by the Health Quality Improvement Partnership (HQIP).³ As part of the national audit, Patient-Reported Outcomes Measures (PROMs) were used as a tool to measure effectiveness of care.

In 2015, the Faculty of Pain (FPM) in collaboration with multiple medical bodies, published the 'Core Standards for Pain Management Services (CSPMS) in the UK'.⁴ This report refers chronic pain services to the importance of outcome standards that should be met. For example, the 18-week wait limit to see a pain consultant, reflecting the clinical deterioration observed in patients awaiting treatment.⁵ Waiting times are likely to be affected by the efficiency and effectiveness of therapies and new to follow-up patient ratios have been used as a marker of service effectiveness with high rates of follow-up appointments used to highlight problems in care provision.⁶ Logical deduction may conclude that outcome measures assessing efficacy of treatment can be employed to highlight areas of inefficiency, thus making a case for the routine use of PROMs.

The core standards set out by the CSPMS relating to outcomes in outpatient-based pain services state that services

must record performance outcomes related to caseload, new to follow-up outpatient ratios, waiting times from referral to treatment and patient experience ('Friends and Family Test').⁴ However, collecting outcomes related to clinical effectiveness of pain management therapies was only a recommendation of the document and not a core standard.

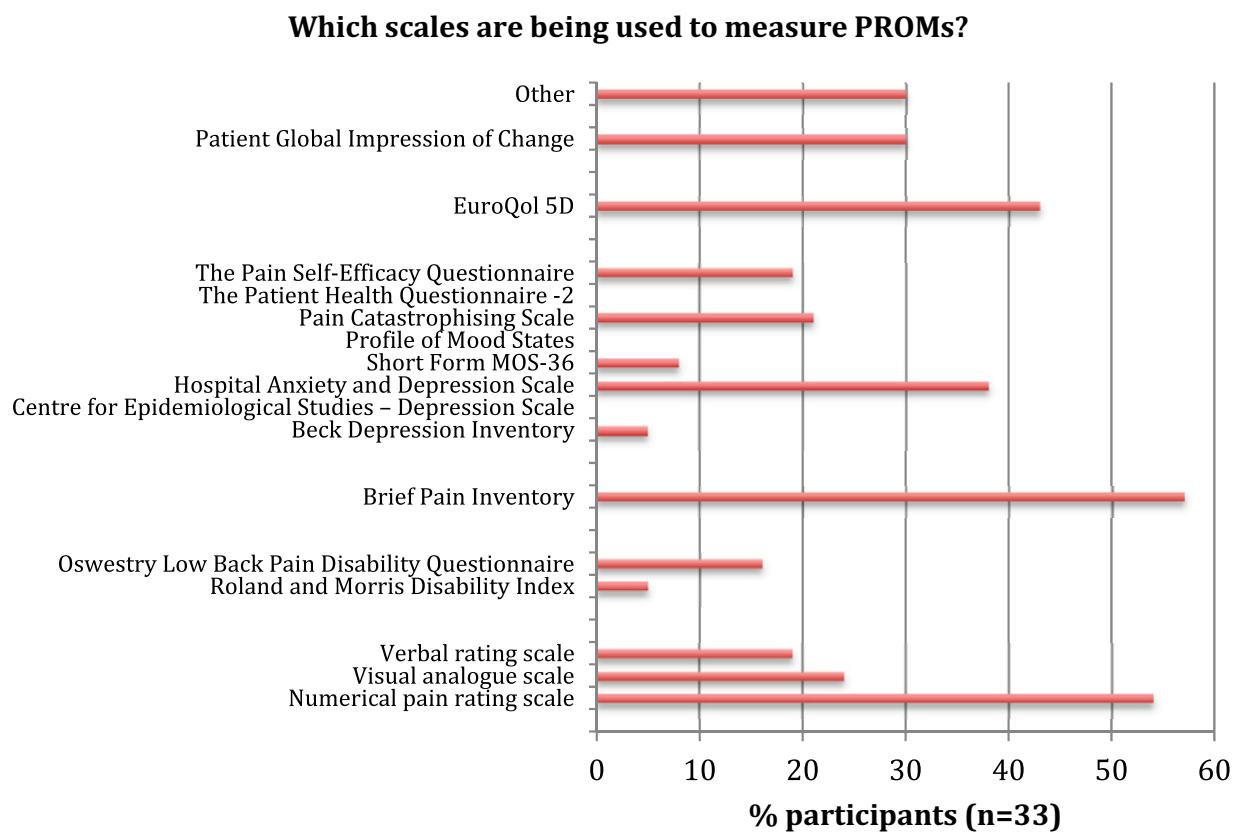
Although the National Health Service (NHS) has used performance indicators, such as the 18-weeks wait, for many years to assess quality of service, historically it has not used outcome measures to assess service effectiveness.⁷ But there is now a move towards outcome-based commissioning, encouraging value for money and improved outcomes for patients. Some clinical commissioning groups (CCGs) are now requesting outcomes to inform commissioning decisions.⁷ In response to this, the FPM with the British Pain Society (BPS) prepared the document 'Outcome Measures' to guide pain services in selecting outcome measures that could be used. They stated that no single scale can expect to meet all needs due to the variation in treatments offered and populations treated.⁷ This probably reflects the complexities encountered in trying to measure patient outcomes in the chronic pain population and the barriers faced if trying to compare services against one another.

The chronic pain management service at King's College Hospital (KCH), London, at the time of writing, did not routinely collect PROMs data. In a move to follow current recommendations and create a robust service for the future, the department decided to explore collecting PROMs. During the planning process of introducing this change, several questions were raised, including: is it common practice now for UK pain services to use PROMs?; what PROMs are commonly being used?; when are outcomes being measured?; who is collecting the data?; and what is the perceived impact to services from collecting PROMs data?

Using this information, a patient questionnaire containing PROMs was to be integrated into routine practice at KCH.

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Figure 1. Bar chart showing % use of the PROMs scales (as recommended in the FPM Outcome Measures document Jan 2019) by respondents routinely recording PROMs. The scales are grouped into the following domains; pain quantity, pain interference, physical functioning, emotional functioning, quality of life and patient-reported global rating.

**Method**

An anonymous questionnaire was developed using the online platform 'Survey Monkey' (see Appendix 1). Question 3 explores which scales are being used by pain services to collect PROMs data and is based on the shortlist of scales analysed in the FPM 'Outcome Measures' document.

Consultants registered to the UK Pain Consultant Google Group and UK advanced pain trainees registered to the trainee WhatsApp group were invited to complete the survey in November 2020. The Survey Monkey automatically sent a reminder to potential participants after 14 days to encourage completion. The survey was closed after 3 months. Consent to participate was implied by the voluntary action of completing the survey.

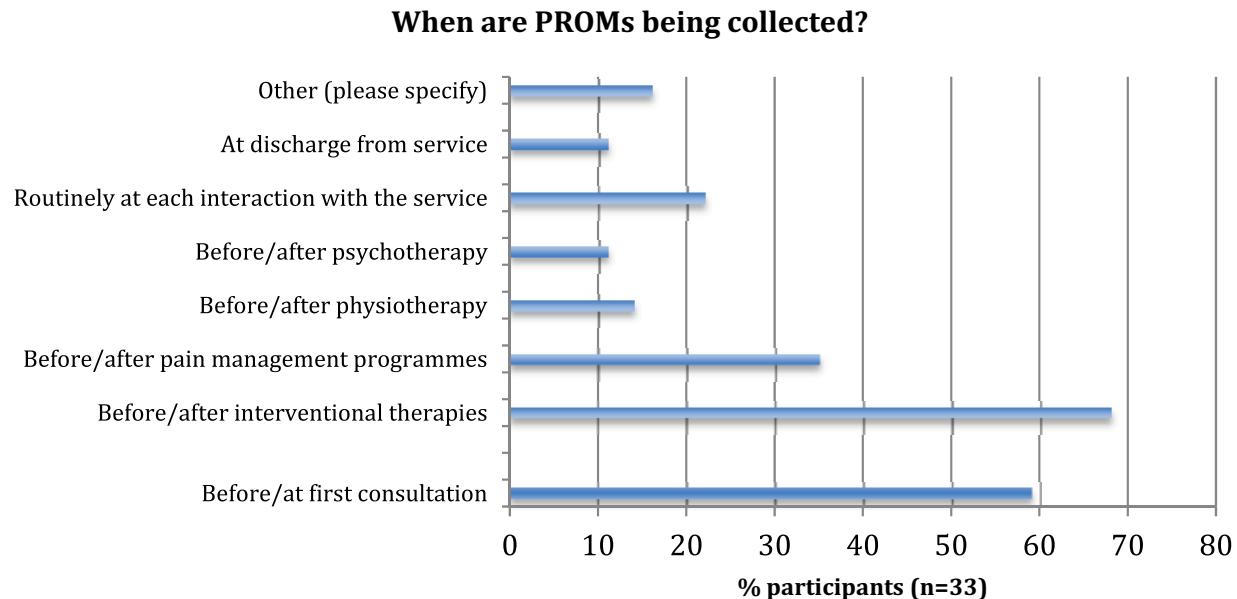
Results were entered into a Microsoft Excel spreadsheet for analysis.

Results

A total of 40 respondents completed the survey, of which 80% routinely collected PROMs data in their service. Of those who did record PROMs, 47% had been collecting them for >5 years, that is, before the publication of the FPM's CSPMS.

The scales commonly being used to collect PROMs data by those pain services routinely recording them are shown in Figure 1. The top 3 commonly used scales in descending order are the Brief Pain Inventory (physical functioning), Numerical Rating Scale (pain quantity) and EuroQol 5D (quality of life). Other scales commonly chosen to assess the impact of pain on the patients' life are Hospital Anxiety and Depression Scale (emotional functioning) and Patient Global Impression of Change (global rating tool).

Some departments described using a binary scale of simply 'success or failure,' whereas another service employed scales

Figure 2. Bar chart showing what proportion of respondents measure PROMs in different clinical situations.

not listed in the FPM document, including GAD-7 (anxiety), PHQ-9 (depression) and PSQ-3 (sleep). One service has developed its own scale (e.g. Northwest Pain Group PROM) and another describes a more simplified 7-point scale assessing changes in pain, medication use, sleep, physical function, mood, global perception of change and adverse effects of treatment.

As Figure 2 shows, the most common times to collect PROMs are before/after interventional therapy (68%) and before/after first consultation (59%). Very few services collected outcomes at each service interaction (22%) and only 11% of respondents stated that they measure outcomes at the point of discharge.

The majority of respondents stated that the physician/specialist pain nurse routinely collect PROMS data (54%, see Figure 3). Two respondents reported that they had a data coordinator in their service, although one of the services currently had an unfilled position.

Figure 4 shows that of those respondents who routinely collect PROMs data in their service, only 35% felt that they have seen a change in their service as a result of the information gathered. This feels like a missed opportunity. Some did plan to make changes to their practice based on the data collected but had yet to do so.

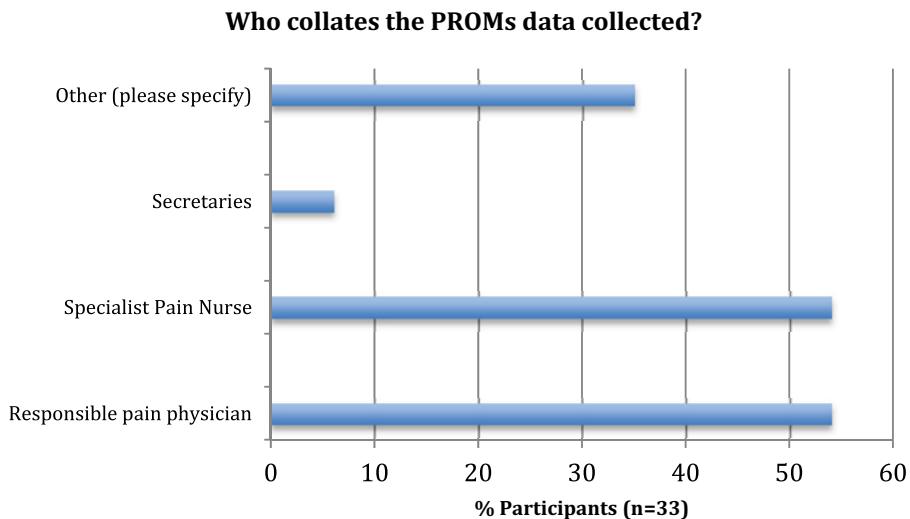
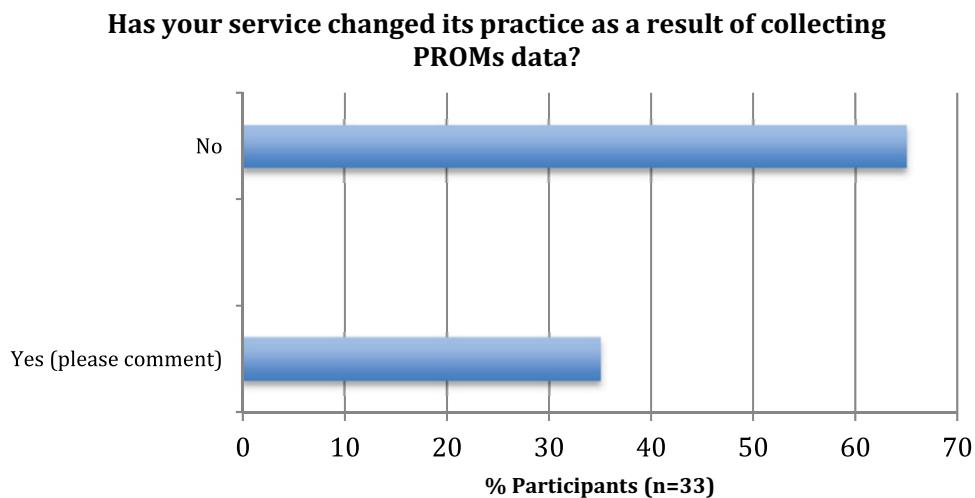
Table 1 groups the types of change seen within pain services as a result of responding to the PROMs data collected.

Discussion

Before discussing the findings of this survey, it should be noted that they should be interpreted cautiously for a number of reasons. The response rate was low in relation to the number of pain clinicians invited to complete the survey. In addition, the survey was kept anonymous in a bid to enhance the uptake of the survey. This included the location of the pain service. Therefore, there is a chance that multiple clinicians from the same service may have completed the survey. Clinicians within the same service are likely to have unified practices, such as measuring outcomes, so risk skewing the results. Overall, it is likely that the findings of this survey may not be a true representation of the activity of pain services in the United Kingdom. However, it was felt the survey results could be used to direct a general discussion about the use of PROMs in pain services.

Initially, it may be surprising that a fifth of respondents stated they do not routinely measure patient-reported outcomes as part of their practice. It could be misinterpreted that they are treating their patients blindly. But, as part of follow-up visits, the clinician will informally ask the patient about response to treatments given and so likely modify management strategies as a result of what the patient reports. The difference is that a

Chronic pain patient-reported outcome measures: a survey of current UK practice

Figure 3. Bar chart showing the proportion of respondents in relation to who collates the PROMs data in their service.**Figure 4.** Bar chart showing what proportion of respondents believed their service had changed its practice as a result of collecting PROMs data.

scale has not been used to measure the change. However, those clinicians not routinely measuring outcomes may be persuaded to adopt the use of PROMs by the growing pressure of services to justify their practice and treatments to commissioners.

A large proportion of clinicians who collect outcome data as part of routine practice have been doing so for more than 5 years. This certainly predates the FPM 'Measuring Outcomes'

document and is also likely to predate the 'CSPMS in the UK' document. This could reflect the complexity of managing chronic pain patients and the laudable attempt of clinicians to find something concrete to measure, thus proving that their treatment is effective and justified.

Based on the most commonly used scales to measure PROMs reported in the survey, our service may be justified in following common practice and choose to use the BPI,

Table 1. Summarising the areas of change commented on by respondents in response to collecting PROMs.

| Area of change | Examples |
|------------------------------|---|
| Service development | maintaining an acupuncture service; developing a pain rehab programme; support appointment of a psychologist |
| Pain interventions | abandoning less successful treatments |
| Tailoring patient management | identifying patients likely to benefit from PMP; adjusting medication; identifying targetable psycho-social issues. |
| Patient information | improving quality of informed consent process |

PROMs: Patient-Reported Outcomes Measures.

EuroQol 5D and NRS to measure outcomes in our patients. However, combined this generates data from 22 to 39 questions, depending on whether the long or short BPI is used. The difficulties and impracticalities of collecting such data on a regular basis for each patient start to become apparent. Not only does it rely on patient motivation and underlying agenda to answer the questions as truthfully as possible, but then somebody needs to find time to interpret and collate the data if it is to be used to successfully influence management. It becomes apparent why some of the respondents' comments expressed a need to simplify the measure of outcomes. Furthermore, a common theme expressed was the lack of resource, to not only collect the data, but also analyse and use it to guide the service. This frustration is exemplified in the finding that over half of both clinicians and pain specialist nurses are collecting and collating the outcome data themselves. In an overstretched service, it is easy to see why measuring outcomes may be kept brief or not done at all.

Another challenge facing PROMs may relate to the accuracy of the data captured. This may be in part due to the difficulties in defining meaningful change when using PROMs. With this in mind, the argument voiced by one of the respondents for binary categorised outcome measures starts to gain some credence. The simplicity of simply responding 'success/failure', 'yes/no' has some appeal. Furthermore, deciding on appropriate timings to measure outcomes to detect a change, if there is one, may also present a challenge. Too early and an improvement that takes time to develop and be appreciated may be missed. Too late and any relationship between intervention and effectiveness may be difficult to establish. Perhaps with regular use a clinician may get a feel for the strengths and weaknesses of the PROMs employed, and it may be that they can then be tailored to the individual service to maximise their use and best represent their patients' pain experience. However, this probably has to be done with some caution as it may reduce the validity of the measure. Overall, as

the FPM recognises, 'No single scale can meet all needs: the choice of outcome/s for a service depends on the treatments offered, aims of treatment, and on the population treated'.⁶

Although, on the face of it collecting, collating and interpreting PROMs accurately seems challenging, the benefits have the potential to be far-reaching if done well. The comments made by some respondents, regarding how the PROMs have helped mould their service, reflects their usefulness. The authors of a systematic review, examining the impact of PROMs in the treatment on non-malignant pain, eloquently created a concept map depicting five key areas in which PROMs are suggested to impact on clinical practice (Figure 5).⁸

However, the current literature on PROMs doesn't allow a comprehensive understanding of how PROMs do actually impact on clinical treatment, due to the level of evidence available and the degree of gross conflict within that evidence.⁸ Despite this, the following table summarises the possible value of PROMs in each key area as identified by the current literature described in the systematic review by Holmes et al.

It should be noted that although the benefits of using PROMs described in Table 2 may entice a clinician to adopt them into their routine practice, it should not be done with blind acceptance. For each study that supports the use of PROMs in a key area, there is a study that finds no benefit in its use, thereby justifying some scepticism surrounding the use of PROMs, and raising concerns about the objectivity of the data provided by patients.⁸ If patients' treatment and service structure is to be influenced, it is essential that PROMs should track patient progress accurately.⁸ This can only be feasible if using a validated and trusted tool. The FPM 'Outcome Measures' document does address this point to some degree by reviewing each measure's reliability and validity, so helping guide the clinician in their decision of which PROM to adopt.

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Figure 5. Concept map showing the three stages of treatment where PROMs impact on clinical practice, as described in the systematic review by Holmes et al.

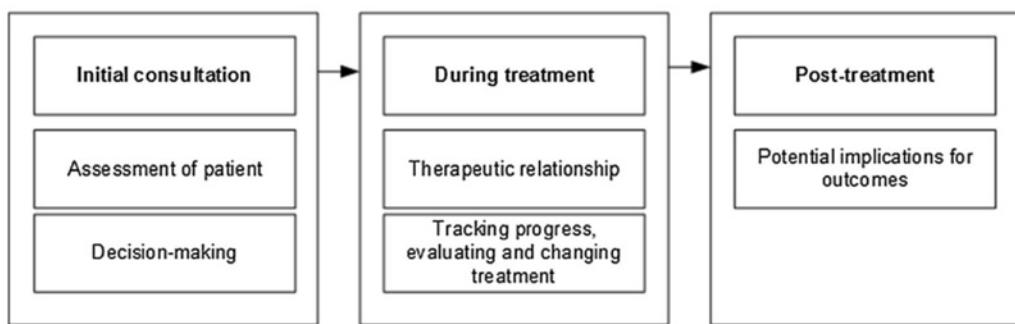


Table 2. Describing the potential benefits identified in current literature of measuring PROMs in the 5 key areas of clinical practice.

| Key area | Possible benefit |
|--|--|
| Assessment of patient | Helps to understand patient's pain; acts as a screening tool and improves diagnosis. |
| Decision-making | Setting goals for patient; enabling shared decision-making for course of treatment |
| Therapeutic relationship | Enhanced patient engagement and communication |
| Tracking progress, evaluating and changing treatment | Change to medication; contributing to referrals to other clinicians |
| Potential implications for outcomes | Improved pain levels and patient satisfaction in patients with liver disease, cancer and mental health issues. |

Summary

It appears to be common practice in the UK to record PROMs with the majority of respondents following current recommendations. However, there is no consensus as to which are the PROMs scales to use with services using a huge range. The decision process is likely to be guided by local population, service characteristics and clinician preference; the FPM 'Outcome Measures' document acknowledges an expected lack of homogeneity.

Common times to collect PROMs are at first consultation and following interventional therapy, but very few collect data at discharge. This suggests that very little data is being collected on the global effectiveness of services at managing patients' chronic pain. Perhaps this is an area that could be looked into further by services.

A limiting factor to PROMs collection and use is poor resource availability to facilitate data handling and analysis. This

may be the reason why many respondents report routinely collecting PROMs, but few report changes to practice based on the data collected. Another reason may be scepticism surrounding the accuracy and usefulness of the data provided by PROMs. Current literature doesn't help dispel a lack of trust and it feels a much more robust evidence base is required if commissioners are to justify the weighting put on patient-reported outcome measures to guide their decision to commission pain services.

KCH service update

Since writing this article, we have introduced PROMs into our pain service. A link is sent to the patient via text message the day before their clinic appointment (face to face and telephone). Clicking on the link takes the patient through to the questionnaire. We decided to collect:

1. Brief Pain Inventory
2. Pain Catastrophising Score

- 3.** Pain Self-Efficacy Score
- 4.** Patient Health Questionnaire 9 (Depression screen)
- 5.** General Anxiety Score 7
- 6.** EuroQol EQ5-D

Mental health screening tools are used in addition to the pain PROMs to identify patients who might benefit from psychological input. We are currently using PROMs at a patient level to inform each outpatient consultation but are not yet in a position to analyse the data at a service level.

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Appendix 1

Outcome Measures Survey in chronic pain

<https://www.surveymonkey.co.uk/r/DPSGNGY>

In response to the ‘Outcome Measures’ document jointly produced by the FPM and BPS in January 2019, we are in the process of introducing routine measurement of patient-reported outcomes into our service.

We are interested to hear about your experiences of using PROMs and the effect they have had on your service.

We would be most grateful if you could take 2 minutes to complete this short survey.

- 1. Does your pain service routinely use any patient-reported outcome measures (PROMs) as part of monitoring patient management?**

- (a) Yes
- (b) No

- 2. How long has your service collected PROMs data?**

- (a) <1 year
- (b) 1–5 years
- (c) >5 years

- 3. If outcomes are being measured, which tools do you use?**

Pain Quantity

- Numerical pain rating scale
- Visual analogue scale
- Verbal rating scale

Pain Interference

- Roland and Morris Disability Index
- Oswestry Low Back Pain Disability Questionnaire

Physical Functioning

- Brief Pain Inventory

Emotional Functioning

- Beck Depression Inventory
- Centre for Epidemiological Studies – Depression Scale
- Hospital Anxiety and Depression Scale
- Short Form MOS-36
- Profile of Mood States
- Pain Catastrophising Scale
- The Patient Health Questionnaire-2
- The Pain Self-Efficacy Questionnaire

Quality of Life

- EuroQol 5D

Patient-Reported Global Rating

- Patient Global Impression of Change

Other (please state)

- 4. In what clinical situations is PROMs data being collected?**

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- (a) At first consultation
 - (b) At clinic appointments
 - (c) Before/after interventional therapies
 - (d) Before/after pain management programmes
 - (e) Before/after physiotherapy
 - (f) Before/after psychotherapy
 - (g) Routinely at each interaction with the service
 - (h) At discharge from service
5. Who collates the PROMs data collected?
- (a) Responsible pain physician
 - (b) Specialist Pain Nurse
- (c) Secretaries
 - (d) Other (please state)
6. Has your service changed its practice as a result of collecting PROMs data?
- (a) Yes (please comment)
 - (b) No
 - (c) Only recently started collecting
7. Any other comments?

White dwarfs and menopausal symptoms



Credits: ESA/Hubble, NASA, and G. Piotto et al.

Sir

I have been a senior counsellor at North Devon Hospice for very many years and part of my role is to support our staff. This has included helping those coping with the menopause, and in particular, having hot flushes while working.

Surprisingly, an observation which has particularly helped a colleague recently, was a finding from the Hubble telescope. An international group of astronomers have concluded that, in the final stages of their lives, white dwarfs can slow down their rate of ageing by casting off outer layers and burning hydrogen on their surfaces. This causes them to appear more youthful than they actually are.^{1,2}

She loved the mirroring of her personal experience with something that was observed far out in space. It made her feel connected and comforted and, in some indescribable way, less alone.

Yours sincerely
Christa Friend

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Pain has an element of blank

Pain News
2021, Vol 19(4) 180
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Emily Dickinson (Public Domain)

Pain – has an Element of Blank –
It cannot recollect
When it begun – or if there were
A time when it was not –
It has no Future – but itself –
Its Infinite realms contain
Its Past – enlightened to perceive
New Periods – of Pain.

When we are ill or in pain it is very difficult to remember a time when we weren't ill or in pain. The visceral power of physical pain – but this might also be extended to psychological pain as well – prevents us from imagining or envisioning a time without it, whether in the past or the future.¹

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Public Domain

Led by a star, a golden star,
The youngest star, an olden star,
Here the kings and the shepherds are,
A kneeling on the ground.
What did they come to the inn to see?
God in the Highest, and this is He,
A baby asleep on His mother's knee
And with her kisses crowned.
Now is the earth a dreary place,
A troubled place, a weary place.
Peace has hidden her lovely face
And turned in tears away.
Yet the sun, through the war-cloud, sees
Babies asleep on their mother's knees.
While there are love and home – and these—
There shall be Christmas Day.

Joyce Kilmer - 1886-1918.

Joyce Kilmer was born on December 6, 1886, in, New Jersey. His best known poem, "Trees," was included in his second collection, *Trees and Other Poems* published in 1914.

Kilmer last poetry collection was published in *Main Street and Other Poems* (1917) in which year he also enlisted in the U.S. Army to serve in World War I, he continued to write poems while fighting in the 69th Regiment. He died of a gunshot from a gun shot wound on 30 July 1918.

<https://poets.org/poet/joyce-kilmer>

Winter Landscape



Winter Landscape - Paul Gauguin 1879; Paris, France : Impressionism (Public Domain).

Paul Gauguin was a French Post-Impressionist artist, whose work deeply influenced the French avant-garde and modern artists, such as Pablo Picasso and Henri Matisse. As a descendant of the Peruvian nobility, he spent his early childhood in Lima, Peru. This nomadic upbringing aroused his curiosity for exotic lands and cultures, which would eventually lead him to Tahiti and Martinique. Gauguin discovered art relatively late in life. He was married and working in Paris as a stockbroker when he befriended painter, Camille Pissarro. By 1879 he was Pissarro's unofficial pupil and patron, and after the stock market crashed in 1882, Gauguin decided to become an artist full-time. His early paintings were mainly Impressionist

landscapes influenced by Pissarro and Paul Cezanne, who he met through Pissarro.

His ability to fuse a variety of cultural influences and sources resulted in unique artistic creations. In 1893, Gauguin returned to France where he found little success and struggled financially. In 1895, he moved permanently to Tahiti. There, he continued to struggle with illness and poverty, and in 1898 he even tried to commit suicide. Gauguin was largely unappreciated during his lifetime, and only after his death, he received recognition for his experimental use of color and innovative Synthetist style. (Public Domain. WikiArt)

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- ✓ From over 31 million patient treatment days³, Myopridin has a well-documented safety profile with no known potential for addiction^{4,5,6}
- ✓ Myopridin may support the de-prescribing of other medicines commonly prescribed for low back pain and neck pain, that are associated with abuse and dependence^{7,8}
- ✓ Myopridin 3mg tablet TDS costs £7.80 for a 10 day course of treatment
- ✓ Dosing is simple with no need to titrate and treatment can be extended if required^{1,4}



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Reducing muscle tension
Improving mobility¹

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Prescribing information

Myopridin tablets containing pridinol mesilate. Consult Summary of Product Characteristics before prescribing. For the treatment of central and peripheral muscle spasms: lumbar pain, torticollis, general muscle pain, in adults. **Dosage and administration** 1.5–3 mg pridinol 3 times daily. The duration of administration is decided by the treating doctor. Administration is independent of meals, with the onset of the effect being faster when taken before meals. Tablets should be taken with sufficient fluid (e.g. 1 glass of water) and not chewed. **Contraindications** Hypersensitivity to the active substance or to any of the excipients, glaucoma, prostate hypertrophy, syndrome with urinary retention, gastrointestinal obstructions, arrhythmia, first trimester of pregnancy. **Special warnings and precautions** Use with caution in the elderly, and in patients with severe renal and/or hepatic insufficiency, because higher and/or longer-lasting blood levels must be expected. In patients who suffer from hypotension, the risk of circulatory problems (fainting) may be increased. Myopridin contains lactose. Patients with the rare hereditary problems of galactose intolerance, total lactase deficiency or glucose-galactose malabsorption should not take this medicinal product. **Interaction with other medicinal products** Myopridin potentiates the effect of anticholinergics such as atropine. **Pregnancy and breastfeeding** Myopridin is contraindicated during the first trimester of pregnancy and should be avoided during breastfeeding. Myopridin may only be used later in pregnancy after careful consideration, under medical supervision and only if absolutely necessary. **Side effects** The following adverse effects may occur, particularly during concomitant administration with other anticholinergic medicinal products: dry mouth, thirst, transient visual disorder (mydriasis, difficulties with accommodation, photosensitivity, slight increase in intraocular pressure),

redness and dryness of the skin, bradycardia followed by tachycardia, micturition disorders, constipation and, very rarely, vomiting, dizziness and unsteady gait. Other side effects occur in fewer than 1 in 100 patients. Prescribers should consult the Summary of Product Characteristics in relation to the treatment of overdose and for details of other side effects. **Effects on ability to drive and use machines** Owing to potential anticholinergic effects on eyesight, greater caution is advised when driving vehicles and operating machines. **Presentation and Basic NHS Cost**: Presented as a white round tablet diameter 9 mm with a score on one side. May be divided into equal doses. 3 mg x 20 tablets (£5.36) 3 mg x 100 tablets (£26.16). **Marketing Authorisation Numbers**: PL 49452/0010 **Legal Category** POM **Date of Last Revision**: May 2020 **For further information, please contact**: Mibe Pharma UK Ltd, 6th Floor, 4 Coleman Street, London EC2R 5AR, United Kingdom

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UK/MYO/20/001a Date of preparation: Oct 2020

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