

Chronic Pain: Patient Voice and the NHS Long Term Plan

Chronic Pain Policy Coalition 2019 Pain
Platform Follow Up Report

Chronic Pain Policy Coalition

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FOREWORD

The CPPC is delighted to present its report following the 2019 Pain Platform meeting held in the House of Lords in June 2019. We have gathered the thoughts and recommendations raised during the Pain Platform and incorporated them into this document to help further the development of patient centric pain policy in England.

Many people, whether they are aware of it or not, will have someone in their lives who is affected by chronic pain. That may be an elderly relative suffering from a musculoskeletal condition, a friend who has endured bouts of pain from fibromyalgia, or a co-worker whose pain has arisen following a surgical operation. This is not an exhaustive list and highlights just a few of the many types of pain that can impact a person's physical capabilities, mental wellbeing, job prospects, family and friends and their overall ability to live their life to the level they would want.

We know how pain impacts people and we know that it can vary, as pain is as emotional as it is physical. This report touches on the scale of the problem at hand. However, this is all information we know. So why is the issue of pain still systemic in our society?

The CPPC has examined this matter before and we have seen progress. For example, the publication of the FPM's Core Standards for Pain Management Services in the UK. We have also seen a commitment to improving MSK services in the NHS Long Term Plan, ensuring direct access to MSK First Contact Practitioners and expanding the number of physiotherapists working in primary care networks.

However, attendees from our English Pain Summit in 2011 might ask why not enough has changed since then? Whilst many of the challenges in pain policy we saw 8 years ago still exist, there is hope for a brighter future.

This report emphasises that we do have the resource and guidelines that we need to alleviate the impact

chronic pain has on those living with it, as well as their carers, their GPs, family and others. The burden chronic pain has on the NHS and our economy can be alleviated through implementation of such guidelines.

This report will show new data that consolidates much of what we already know, with in-depth patient interviews, and importantly clinicians. We will give examples of cases where existing tools have been used to improve the lives of those living with chronic pain.

The Pain Platform and this report act as a call to action to policy makers to ensure the guidance we already have is fully accessible and implementable, and to place pain patients at the heart of care across all settings.

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The CPPC would also like to thank all those who attended the 2019 Pain Platform, who have contributed to the debate and furthered the development of positive chronic pain policy for those living with the condition.



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INTRODUCTION

On the 25th June 2019, the Chronic Pain Policy Collation (CPPC) hosted a patient centric Pain Platform meeting exploring the burden of chronic pain in England, and how policy in the area can be improved. The meeting took place in the House of Lords and was chaired by the Rt Hon. the Lord Luce, Vice-President of the CPPC.

The objectives of the meeting were developed by the CPPC Advisory Group: a multi-disciplinary group of patients, clinicians and policy experts working in pain. The meeting had three objectives:

- To propose policy solutions that would improve the outcomes of those living with chronic pain
- To act as a call to action for policy makers to engage with the pain community on these issues and facilitate implementation of solutions
- To facilitate the sharing of helpful policies from around the UK that may inform the broad pain policy landscape, and act as solutions to the challenge in England

Seldom has there been a greater need, or opportunity following the NHS Long Term Plan, to examine and improve policy for those living with chronic pain. The burden of chronic pain on the individual and society is often overlooked, but the evidence lays bare the severity and the prevalence of the problem:

- In 2011, 31% of men and 37% of women in England reported chronic pain. Of these, almost 25% said that their pain had kept them from usual activities (including work) on at least 14 days in the previous three monthsⁱ

- A person living with pain may have a very poor quality of life – often much worse than other conditions, and as bad as significant neurological diseases such as Parkinson’sⁱⁱ
- Lack of effective pain control represents a significant burden for the NHS. For example, in the National Pain Audit (2010-2012), 20% of respondents attending specialist pain services reported visiting A&E in the past six months, all of them had previously seen their GPⁱⁱ

The Department of Health and Social Care in England recognises chronic pain as a long-term condition in its own right and as a component of other long-term conditions. One might therefore expect there to be measures addressing the unmet need in this areaⁱⁱⁱ. Unfortunately, for too long there have been challenges in confronting the burden of pain for patients and society in the NHS in England.

The Pain Platform meeting was attended by stakeholders from across the pain community, including patient organisations, individual patients, clinicians, professional bodies such as the Royal College of General Practitioners and the Royal College of Nursing, the private sector, NICE, NHS England, Public Health England and Parliament.

This report builds on the themes of the 2019 Pain Platform and will make a series of recommendations that need to be implemented in order to improve the delivery of chronic pain management across the UK. This report therefore, acts as a call to action to policy makers in government and the NHS, to implement these recommendations, and to ensure the needs of those living with chronic pain are met.

THE IMPACT OF CHRONIC PAIN: THE POWER OF DATA

There is a lack of useful healthcare associated data in chronic pain. As there is no registry, chronic pain has not been recorded adequately across all care settings, leading to poor prevalence estimates. Further, there is minimal social impact data. Generating data of this nature is important to support the creation and implementation of good pain policy. This not only benefits the individual living with chronic pain, but also the patient body as a whole. Data can help to quantify the problem of chronic pain and guide decisions about how to solve the complex issues it presents.

Research has continued to highlight the impact of chronic pain on patients, and in a new piece of research conducted by Adelphi on behalf of Arthritis and Musculoskeletal Alliance (ARMA), light has also been shed on the clinician's perspective too^{iv}.

Sue Brown, CEO of ARMA, presented this brand new data at the Pain Platform. The objective of the research was to understand the patient journey for people living with chronic pain. A series of interviews with patients and Healthcare Professionals (HCPs) was conducted to understand the issues and the possible impact caused by potential inequity of access to services within chronic pain. The findings resulted from a bespoke survey conducted via qualitative 60-minute telephone interviews with 24 patients and 20 health care professionals during April and May 2019.

The survey found that management of chronic pain in the UK appears to be deficient and inconsistent:

- Living with chronic pain affects all aspects of patients' lives; it places a huge 'mental burden' on patients, exacerbated by a lack of clear answers about how best to manage daily life
- Patients often face delays and setbacks to gain access to healthcare support services and treatment
- GPs also face hurdles at almost every stage of treating and managing chronic pain and are aware that there are inconsistencies that vary from location to location across the country
- Access to specialist pain services is difficult and is inconsistent across the UK. Overall satisfaction with support for chronic pain is fairly poor and patients have mixed experiences of services

HCPs and patients alike readily suggest improvements to provide support and equity of treatment and management approaches:

- HCPs would like to see more joined up care for chronic pain patients – ideally through a multi-disciplinary team (MDT) approach
- The optimum treatment model would treat pain with the same significance as a condition in its own right as with other long term conditions, and aims to work in partnership with patients
- Almost all patients, and most HCPs, felt that an annual pain review would be beneficial

The research concluded with the following recommendations:

1. Ensure patient involvement
2. More equitable access to specialist services
3. MDT approach to co-ordinate care
4. Advocacy for pain to be afforded the same priority as any other serious condition
5. Regular review for chronic pain
6. Quicker referrals
7. Improvement in provision of information for patients and GPs

The data that ARMA presented at the 2019 Pain Platform consolidates the statistics on pain. For example, in the British Pain Society's (BPS) National Pain Audit, 66% of people attending A&E seeking help with pain had more than three visits to an HCP in the preceding six monthsⁱⁱ. It is clear that pain is not being managed to the level expected by patients, and also clinicians. Despite the community being well aware of these problems, guidelines and resources do exist which ought to alleviate the issues. This report will further explore some of these resources.

Further Research is Required

We still lack extensive data to highlight the scale of chronic pain in England, particularly from a socio-economic perspective. The Government's own calculations of the prevalence of chronic pain range so widely that it is difficult to imagine how, as stated in the English NHS Long Term Plan, the health service can truly take a population based approach to health and in this instance chronic pain^v.

The CPPC would like to note that it is encouraged by other elements of the plan such as its commitment to ensure that patients will have direct access to Musculoskeletal First Contact Practitioners (FCP). However, we would note that many individuals' chronic pain is not caused by a musculoskeletal (MSK) condition. As such, we do not feel that the plan goes far enough in preparing for the provision of a broad range of chronic pain services from a population based health perspective.

One way this might be resolved is through timely and proper implementation of the SNOMED codes as well as a chronic pain patient registry. If used in the correct manner, HCPs will be able to code those entering the health system with chronic pain. This will feed into a database which would then be analysed and reported back to NHS England in order to adequately plan for pain management services.

Conclusion

This chapter has highlighted that whilst data on the impact of chronic pain is essential to ensure policy makers and healthcare professionals understand how pain affects people's lives, it is equally important to have robust prevalence data to plan for health and social care intervention.

Accurate prevalence and impact data will enable NHS England and local government to adequately plan for the provision of chronic pain services across the country. It is likely that there is variation in needs between the regions, rural areas and cities, as evidenced in the ARMA survey findings.

Research into the socio-economic impact of chronic pain on the NHS and the economy will also help to ensure chronic pain remains high on the political agenda. Ultimately this would act as a catalyst for meaningful action amongst policy makers.

THE NEED TO IMPLEMENT APPROPRIATE PAIN POLICY

We heard from a number of contributors at the Pain Platform that the right policy and approach to pain management does exist, and that it is not expensive or challenging to implement. There are a variety of resources and guidelines that have been designed to assist both the patient and the professional in the chronic pain pathway. Guidance and policy have been developed by a number of notable bodies including, but not limited to, the British Pain Society, the Faculty of Pain Medicine (FPM), the National Institute for Health and Care Excellence (NICE), the General Medical Council (GMC), Scottish Government and NHS Scotland. Yet, despite this helpful work, the issues mentioned in the previous chapter such as quality of life impact and poor provision of pain services, remain.

The Need for an Annual Review

Dr Martin Johnson, Co-Chair of the CPPC and chronic pain representative at the RCGP, presented on the merits of ensuring those living with chronic pain when they have regular reviews of their pain and its management.

The minimum standard of an annual review for people living with chronic pain, in a primary care setting, would help individuals to adjust and manage their pain in the most appropriate manner. Reviews may therefore go some way in reducing the adverse impacts on an individual's life of their chronic pain and also the adverse effects of certain pain medicines. The actual frequency of the review will need adapting to individual circumstances.

In 2016, the CPPC commissioned a survey which received 1027 responses^{vi}. The survey was simple in its approach: respondents were asked whether they had chronic pain and how often their pain medicine was reviewed. Of the 90% of respondents who said they have chronic pain, just over 30% had either never had a medicines review, or not had one in the last 1-3 years. This, as well as ARMA's study findings, and the experiences of much of the pain community, indicates that not enough individuals are having simple reviews of their overall condition and their medicine.

There is a major issue in that such a review is not currently mandatory for all pain patients, especially those being prescribed powerful pain medicines. Pain reviews should be taking place at least annually as more newly diagnosed patients may require more frequent reviews initially. Pain reviews are not mandatory despite the numerous policies and guidelines that recommend such an intervention:

- Both the FPM's Core Standards for Pain Management Services and the GMC's guidance, 'good practice in prescribing and managing medicines and devices', state the importance of reviewing patients and their medication regularly^{vii,viii}.
- The FPM's Opioids Aware, is a resource for patients and HCPs to support prescribing of opioid medicines for pain^{ix}.
- The Quality Prescribing for Chronic Pain document was written by the Scottish Government and NHS Scotland to promote quality improvement in the prescribing of analgesic medicines and to integrate this

with non-pharmaceutical therapeutic approaches to management of chronic pain^x.

In his presentation at the Pain Platform, Dr Johnson discussed the need for all those living with chronic pain to have reviews, but not just those taking medication to control their pain. The Pain Platform attendees also raised the possibility of engaging patients to ensure they have an annual pain review with the HCP that best suits their needs at that time. The GMC guidance suggests that a pharmacist may be able to carry out a medicines review if a GP does not have time. Other HCPs able to carry out a review might include a practice nurse, occupational therapist or a physiotherapist.

With the room in agreement, Dr Paul Cameron, National Chronic Pain Coordinator, Scottish Government, commented that this was a reason to have a national approach, so that all stakeholders look to drive the strategy forward.

Outcome Measures

In the foreword to this report, pain was described as both an emotional condition and a physical condition. With that in mind, the importance of measuring pain accurately has become essential to the methods deployed to manage it.

Dr Ganesan Baranidharan, a consultant anaesthetist from Leeds Teaching Hospitals NHS Trust, led a joint FPM and BPS group, to develop a practical guidance document of outcome scales appropriate to pain management^{xi}. Dr Baranidharan and his team undertook this work to assist pain services in selecting appropriate outcome measures. The measures, it is hoped, will improve patient care and allow benchmarking against other services and targets, helping to bring uniformity locally and nationally.

Dr Baranidharan, who presented at the 2019 Pain Platform, explained that whilst pain is a complex emotional experience, and has a multitude of effects on people, the outcome measures offer guidance which can be utilised regionally and nationally to mitigate variation when setting outcome measures.

Dr Baranidharan and the room discussed the importance of setting up a national chronic pain registry. It was agreed that the outcome measures would be required to establish this. National registries, although expensive, would be a huge assistance for the future of pain management, notably in mapping out equity and inequity.

With more guidelines set to be published in the near future, including NICE's Chronic Pain Guidelines, Public Health England's review of prescribed medicines that can cause dependence and the Medicines and Healthcare Regulatory Agency's work on opioids, there must be assurance that they will be adhered to correctly^{xii,xiii,xiv}.

Conclusion

It is clear that guidance exists to support optimal management of pain patients in England. In the next chapter we will explore success stories in the provision of chronic pain services that have occurred in two UK localities. This demonstrates that we do not need to focus efforts on producing new guidance, instead only to use the policy currently available and adapting it where necessary for the NHS in England.

The 2019 Pain Platform agreed there is the need for a national oversight group to ensure that these policies are implemented across England and the rest of the UK without variation, and that future policy is supported by the necessary data.

EXAMPLES OF BEST PRACTICE

This report has outlined the issues that those living with chronic pain face. It has also identified that, for the large part, tools which can be used to alleviate the impact of chronic pain are not being utilised.

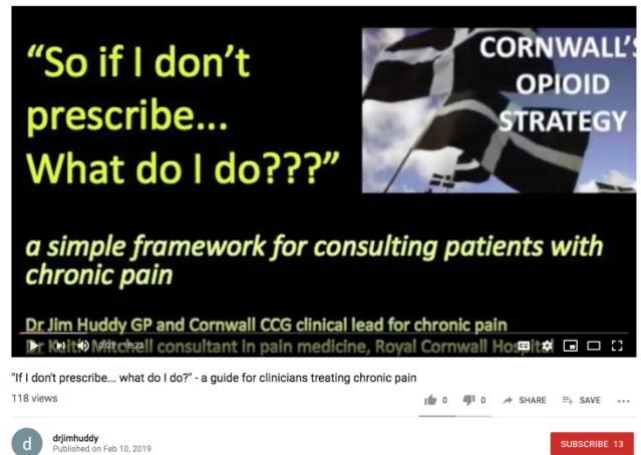
At the 2019 Pain Platform, the room heard from two speakers about how their approach resulted in positive patient outcomes using existing tools. Both approaches use the methods derived from guidance and tools which were already available to them.

Existing Tools to Assist Pain Management Delivery

Dr Jim Huddy, the chronic pain lead at NHS Kernow Clinical Commissioning Group (CCG) in Cornwall and Sean Jennings, someone who lives with long term pain, presented at the 2019 Pain Platform on Cornwall's approach to pain management.

Dr Huddy discussed two areas in particular which have helped his local area's aim of deprescribing opioid medication and improving pain management: better guidance dissemination and social prescribing.

Firstly, Dr Huddy and his team realised that whilst guidance was available and effective, it was not always accessible. Although written information contained plenty of useful information, the team in Cornwall decided that resources needed to be more digestible. Dr Huddy and his team, therefore, began to make and disseminate videos. This year a key focus was on a video entitled "*If I don't prescribe what do I do*"^{xv}.



This was a framework for primary care consultations. The central idea was to encourage GPs to carry out more active listening to understand each patient's situation and possible motivation for change. GPs would then introduce the idea of a pain cycle, a self-care tool and a healthcare needs assessment form to identify what patients really wanted from their pain management.

Patients were asked which of the following best describes the impact pain has on their lives:

1. Lack of physical fitness and difficulty exercising
2. Social isolation
3. Not knowing how to self-manage chronic pain
4. Medications – either they're not working or they have side effects
5. Understanding why persistent pain happens
6. "Boom or bust" – tendencies to do too much on a good day and then paying for it the next
7. Weight or eating well
8. Sleeping difficulties
9. Managing mood changes or depression, anger, anxiety or worry
10. Relationship difficulties with partner or family
11. Remaining in work, or returning to work and/or training
12. Financial/money worries

Through identifying the greatest areas of impact, the team in Cornwall was able to identify patient-centred goals. The CCG then began to look at social prescribing through local pain management programmes.

Sean Jennings spoke about his experience with the pain management programme. Here, he learned how mindfulness and exercise could help him manage his condition. Thanks to the availability of a system in which Sean was able to gain exposure to these tools, Sean has started to gradually reduce his pain medicines intake. Sean is now approaching 18 months of no pain medication and is managing with the tools he learnt on the programme.

A National Unified Strategy

Dr Paul Cameron, National Chronic Pain Coordinator, Scottish Government, presented at the 2019 Pain Platform on his experience of shaping pain policy in Scotland, and key learnings for England and how these can be implemented.

Similar to Cornwall, Scotland has been able to build on existing resources to deliver positive outcomes for those living with chronic pain in the country. Dr Cameron discussed key pieces of guidance, developed from the SIGN Guidelines 'Management of Chronic Pain in Primary Care'^{xvi}.

In 2017, the "Quality Prescribing in Chronic Pain: A National Guideline" was published. In 2018 both "Management of Chronic Pain in Children and Young People – A National Clinical Guideline" and "Health Care Needs Assessment of Adult Chronic Pain Services in Scotland" were published^{x,xvii ,xviii}.

What is unique in Scotland is not so much the success of the guidelines themselves, but that in 2017, a National Advisory Committee for Chronic Pain (NACCP) was set up that assisted the country-wide implementation of these important guidelines. The group has the following remit:

- Guiding the improvement of chronic pain management at all levels of health and social care
- Developing a dataset to allow for effective measurement/quantification of chronic pain services across Scotland, and Quality Performance Indicators (QPIs)
- Raising and maintaining the profile of chronic pain
- Advising the Scottish Government on chronic pain to inform effective national policy development

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- Oversees subgroups and reports to Scottish Ministers

The NACCP is chaired by the Scottish Deputy Chief Medical Officer and consists of members from National Officers, Service Users, the Third Sector, NHS Chief Executives Group, Integration Joint Board (IJB) Chief Officers Network, Scottish Board of Anaesthetists, Scottish Public Health Network, and any others as required.

Such a group would be applicable across the whole of the UK. Dr Cameron commented that it is crucial to have a UK Westminster government-supported national oversight committee to advise on and monitor improvements across the full spectrum of need (i.e. primary, secondary, tertiary care, and include social/vocational care).

The full spectrum of care is covered in the Scottish Chronic Pain Service model. The service model is underpinned by the belief that people who live with pain jump between different levels of management as their pain, and their lives, change. With this in mind, individuals with pain will continually need support across all levels of care from community health services which give advice on how to manage pain, to specialised pain services. The focus on community services in Scotland is replicated in Cornwall's pain management approach.

Furthermore, unlike the case in Cornwall and Scotland, who have conducted a needs assessment, Wales and Northern Ireland are still lacking a needs assessment for chronic pain to help focus efforts to what patients most require.

Conclusion

Cases like Scotland and Cornwall are proof that with the right execution and organisation, existing pain guidelines can be used effectively to improve patient outcomes. This report will go on to recommend that a service model, similar to the one in Scotland, and an oversight group, similar to the NACCP, is set up with scope across England. This will ensure that the tools used to greatest effect across the country, and those recommended in various pain policy and guidelines, are properly implemented.

CONCLUSIONS AND RECOMMENDATIONS

The beginning of this report gave examples of new data that emphasise the problem of chronic pain. Individual patient and clinician testimony have consolidated the fact that the issue of chronic pain can no longer be ignored. Not only is the impact of pain on the patient's quality of life severe, also the service provisions are not performing at an adequate level across the country. It was made clear at the Pain Platform that there is also an appetite for improved education on self-management.

This report has stated that the current system could improve, given that we have the right policies and guidelines in place to alleviate the burden of pain on the individual. That might include pain reviews to manage pain medicine prescriptions or validated outcome measures to set country-wide patient-centred pain targets. The barrier, however, lies with the fact that these guidelines are not always being effectively implemented or monitored and adhered to, often due to lack of national oversight. Where guidelines are adhered to, we see success, such as in Scotland and Cornwall. However, these cases of good practice are few and far between. Principally therefore, it is clear that we need a mechanism whereby the existing guidelines and tools will be accessible and implementable across the whole of the UK. Once this has been achieved, the likelihood of equity in access to appropriate and beneficial pain management services across the country will improve.

As such, the themes raised in this report have followed the key discussion points that stemmed from the 2019 Pain Platform. The following recommendations seek to collate these discussion

points. The CPPC hopes that these recommendations will be taken forward by policy makers and supported by all those who attended the Pain Platform, and those who have an interest in chronic pain policy.

Recommendations

1. The Department of Health and Social Care in England should convene or commission a National Advisory Group on chronic pain. The group, which would be multidisciplinary and driven bottom up, would develop the framework for a national strategy on pain in England.
2. Representatives from the health and social care system, particularly primary care, must come together to explore how to make the Annual Review for individuals living chronic pain a reality.
3. A needs assessment form should be developed, similar to the one used in Scotland, across the rest of the UK. This will help to focus efforts towards what those living with chronic pain need and want the most, as the individual will be able to indicate what they want to achieve from their pain management, including support for self-management.
4. In order to ensure the retention of individuals in the work place, there must be efforts to establish policy designed to keep individuals in work as appropriate, and support them back to work if possible. This would benefit from leadership from the Work and Health Unit.

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