

PUTTING PAIN ON THE AGENDA

THE REPORT OF THE FIRST ENGLISH PAIN SUMMIT

An initiative of



KEY RECOMMENDATIONS

A

Clear standards and criteria must be agreed and implemented nationally for the identification, assessment, and initial management of problematic pain

B

An awareness campaign should be run to explain the nature, extent, impact, prevention and treatment of chronic pain to the wider general and NHS community

C

Nationally-agreed commissioning guidance must be developed and agreed, describing best value care in chronic pain to reduce unwarranted variation

D

A data strategy for chronic pain should be agreed through creation of an epidemiology of chronic pain working group

Background

Alleviation of pain is one of the most basic medical acts, and is a key aim of healthcare. However, in spite of tremendous advances in medicine, this seemingly simple goal remains elusive.

Around one in eight people live with chronic pain nationwide. Although the majority of people living with pain learn to live well in spite of it, a substantial proportion develops problem pain with progressive disability leading to loss of independence and poor quality of life. Untreated, intractable pain can destroy the lives of those living with it and those who care for them. It is strongly associated with depression and people with severe chronic pain die younger than others. The burden on health services of poorly-managed chronic pain is great. The cost of chronic pain to the national economy in terms of benefits paid and lost work is vast, with estimates running into the tens of billions of pounds each year.

Chronic pain – persistent pain lasting longer than three months – can affect any part of the body. It can affect people of any age, including children. Examples include back and joint pain, headache, abdominal pain, pelvic pain and nerve (“neuropathic”) pain. Sometimes the underlying cause for chronic pain is unknown, for example fibromyalgia or some types of chronic pelvic pain. In other cases the condition causing the pain is identifiable, for example pain due to arthritis, or persistent pain in cancer survivors or following major injuries. However, once chronic pain is established in the nervous system, treatment of underlying causes will not necessarily remove the pain and specific treatment is required.

Making progress

Over recent years, multiple national reports have focused on this issue, describing the extent and impact of chronic pain, and highlighting necessary areas for improvement. Several consistent major themes have emerged over time:

- Chronic pain is a major public health problem, affecting large numbers of people with great impact on those affected, their families, the health service and the wider national economy
- Pain, including chronic pain, is one of the key reasons that people seek healthcare, yet pain is often overlooked by health professionals and those providing care in clinics, hospitals and care homes, and documentation is poor
- Chronic pain education for most health care professionals is weak at both undergraduate and postgraduate levels with the exception of pain medicine training in anaesthesia
- People with chronic pain would often benefit from early effective intervention to prevent disability, but those in need are not consistently referred for specialist treatment, and waiting times are often long
- Services for people with chronic pain are of inconsistent standard and quality and are not always available for those who need them. This is particularly true for centres specialising in treating children with chronic pain

The Chief Medical Officer's 2008 Annual Report, which included a chapter on chronic pain entitled: Pain: Breaking through Barrier, was a landmark publication in this field. For the first time a national government report tackled this issue and made a number of recommendations. Close working between professional and voluntary organisations, the Department of Health and NHS bodies, has enabled progress on implementation in a number of areas:

2008 Recommendation	Action taken
The Health Survey for England should routinely collect data on the impact of pain on quality of life	The Chronic Pain Policy Coalition and the Department of Health agreed the inclusion of a chronic pain questionnaire in the 2011 Health Survey for England
All chronic pain services should supply comprehensive information to a National Pain Database	A collaboration between the Health Quality Improvement Partnership (HQIP), the British Pain Society and Dr Foster has delivered a comprehensive National Pain Audit to discover the quality and coverage of pain services
A model pain service or pathway of care with clear standards should be developed by experts	The British Pain Society has led on with creation of Map of Medicine pathways for the commonest presentations in chronic pain
Inclusion of assessment of pain and associated disability in the Quality and Outcomes Framework	After representations led by the Chronic Pain Policy Coalition, the National Quality Board have asked NICE to develop pain management (young people and adults) as one of the library of national NHS Quality Standards
Training in chronic pain should be included in the curricula of all health professionals	A joint approach by the Faculty of Pain Medicine and the British Pain Society led to the Department of Health funding free chronic pain training modules as part of the NHS e-learning programme

Another major development was the decision by the Royal College of General Practitioners to make chronic pain a clinical priority area for 2011-14, appointing a Clinical Champion to develop and oversee the work. As well as recognising the need to address the problem of chronic pain, this decision acknowledges the important role that primary health care can play in identifying and supporting people with chronic pain.

Further developments

In recent years, researchers have begun to discover the changes in the brain, spine and system that take place in chronic pain. This work has begun to explain the physical basis for the experience of chronic pain, as well as identifying new targets for treatments. Screening tools for musculoskeletal pain have been refined to target care effectively and the quality of the evidence base underpinning treatment is slowly improving.

At the same time, there has been growing awareness among policymakers at a national and international level that more needs to be done at policy and health system levels to enable the breakthrough that people with chronic pain need. In Australia, Canada, USA, Portugal, Scotland and Wales, national reports have been produced focusing on chronic pain, setting out overarching strategies to tackle the problem. In 2010, the First International Pain Summit was held in Montreal, Canada, resulting in the Montreal Declaration that access to pain management is a fundamental human right. In this country in 2012, the government recognised “chronic pain as a long-term condition, either in its own right or as a component of other long-term conditions”, setting out that people living with “persistent pain should have a timely assessment in order to determine the cause of the pain” and be offered appropriate treatment.

First English Pain Summit

In November 2011, the British Pain Society, Chronic Pain Policy Coalition, Faculty of Pain Medicine and Royal College of General Practitioners came together to produce the first English Pain Summit.

Through patient stories, presentations from professionals, panel discussions and workshops, the Pain Summit agreed that many of those living in pain are denied the benefit of appropriate management and improved outcomes due to the patchy commissioning of services and a lack of national directives and resourcing. Data from the National Pain Audit confirmed that many areas fail to commission effective specialist pain services that might underpin local systems and champion the cause of people in pain.

Outcomes from the Pain Summit

All the organisations that came together agreed that the principle aim of any future activity should be to enhance the quality of life of people living with chronic pain. To achieve this, Summit attendees were challenged by the four keynote speakers to deliver a number of goals, including:

- To reduce the time to satisfactory diagnosis and treatment of chronic pain from an average of 2.8 years to a few months, aspiring to be the best in Europe (Professor Sir Bruce Keogh, NHS Medical Director)
- To ensure that chronic pain becomes a “high street” disease, recognised and visible to all, with equitable access to treatment, care and education (Professor Sir Liam Donaldson, former Chief Medical Officer 1998-2010)
- To create integrated systems to eliminate the perpetual pinball currently faced by many people in pain (Earl Howe, Parliamentary Under-Secretary of State for Quality)
- To create the right conditions to support people in pain to remain in, and return to, fulfilling work (Dame Carol Black, National Director for Health and Work 2005-2011)

The Summit agreed that there needs to be a sustained focus on public health surveillance of those with, or at risk of developing, chronic pain; prevention of chronic pain where possible and access to rapid treatment and support to reduce the impact of chronic pain. Robust data is needed to feed into local Joint Strategic Needs Assessments to inform commissioning. People in pain often have multiple co-morbidities and models of service delivery are needed that reflect this as well as dealing with chronic pain as a single condition. Commissioners of services need to work across the health and social care divide to address the needs of those in pain and their carers to ensure equity. Success in improving services for people with chronic pain will depend on the provision of high quality education for healthcare professionals based on a clear needs assessment. Finally, the Summit agreed that to equip the system effectively with the knowledge and skills to effect change, education of the general public, employers and patients and metrics to act as a dashboard for improvement are also needed.

Recommendations for action:

In the months following the Pain Summit, continued stakeholder consultation and engagement further developed the priorities for action identified on the day. These are:

A

Clear standards and criteria must be agreed and implemented nationally for the identification, assessment, and initial management of problematic pain

B

An awareness campaign should be run to explain the nature, extent, impact, prevention and treatment of chronic pain to the wider general and NHS community

C

Nationally-agreed commissioning guidance must be developed and agreed, describing best value care in chronic pain to reduce unwarranted variation

D

A data strategy for chronic pain should be agreed through creation of an epidemiology of chronic pain working group

These recommendations are discreet, achievable and measurable, and their implementation would make a substantial contribution to the work to reduce the impact of pain on individuals and society.

Within each are steps that could be taken, that are feasible and specific enough to have demonstrable impact. All four organisations responsible for the delivery of the Summit will collaborate to deliver these, with each taking a lead role in one area to ensure a strong governance framework.

Detailed analysis of recommendations

A

Clear standards and criteria must be agreed and implemented nationally for the identification, assessment, and initial management of problematic pain

This work should be led by the Faculty of Pain Medicine and should:

- build on the relevant British Pain Society Map of Medicine pathways
- be based on the best available evidence and embed the principles of supported self-management throughout
- encompass all people who have a painful condition whether it is part of another condition, part of someone with multiple health conditions (multi-morbidity) or as a single problem
- be agreed and subsequently promoted by multi-professional, patient and research organisations working in this area
- draw upon the lead the Faculty of Pain Medicine has taken on developing educational standards on pain
- form the basis of the NICE Quality Standard on Pain Management
- be included as core modules of the NHS e-learning for health modules on chronic pain and demonstrate impact through both the quality standard and training standards for healthcare professionals
- support the development of a needs-based assessment tool to help healthcare professionals, patients and carers to identify what education and training is required to support current and future roles

B

An awareness campaign should be run to explain the nature, extent, impact, prevention and treatment of chronic pain to the wider general and NHS community

This work should be led by the Chronic Pain Policy Coalition and should:

- be based on the best available evidence and include messages to help prevent chronicity, reduce disability and promote self-management
- target key groups individually, including the general at-risk public, health and wellbeing boards, occupational health services, commissioners of health services and employers
- request NICE hold a public health scoping workshop to develop nationally accredited guidance on public health activities, to address the population, environmental, social and organisational determinants of chronic pain
- be considered for development into discreet health promotion packages for dissemination by specific community-based professionals, such as community pharmacy and the fitness industry
- help employers and workplace agencies understand how best to support employees so that those with chronic pain can contribute as confidently and productively as possible

- promote and signpost the large number of self-management resources existing for chronic pain and the organisations that support these, including the use of online, printed and telehealth-based media

C

Nationally-agreed commissioning guidance must be developed and agreed, describing best value care in chronic pain to reduce unwarranted variation

This work should be led by the Royal College of General Practitioners and should:

- be based on the best available evidence from a range of sources, including identifying and showcasing examples of current excellence wherever possible
- focus on and prioritise interventions that give the highest health gain. This should be established through comparative research at all points in care pathways
- involve health service commissioners, public health practitioners, health professionals and patient organisations in its development
- embed the principles of supported self-management and shared decision-making
- harness the findings of the National Pain Audit and develop its reach including the use of primary care data as a driver for improvement
- focus on commissioning for outcomes, including agreement on standard metrics for measuring performance of pain services
- seek accreditation through the NICE/NHS evidence process which involves patients and lay members
- include guidance on incorporating a local appraisal of the extent and impact of chronic pain on health as part of the statutory Joint Strategic Needs Assessment
- consider how to improve the accuracy of programme budgeting data, to better understand the true spend on pain services nationally
- ensure education and training needs are met to deliver the guidance

D

A data strategy for chronic pain should be agreed through creation of an epidemiology of chronic pain working group

This work should be led by the British Pain Society and should:

- bring together epidemiologists and public health specialists nationally with an interest in chronic pain and its impact
- define core data items and sources, including the chronic pain data produced by the Health Survey for England 2011, to enable on-going surveillance of the extent, severity and impact of chronic pain
- generate an accurate burden of disease calculation, including identification of groups most affected and characterising unmet need and those most likely to benefit from interventions
- involve close working with Public Health England (PHE) and the Quality Observatories (including the evidence and intelligence function) to agree and review

key national data sources relevant to this area. PHE and the Quality Observatories could focus on the development and interpretation of such datasets to produce and promote a clear and workable methodology for local public health teams to gather relevant information to systematically include the extent and impact of chronic pain on the local population routinely as part of the Joint Strategic Needs Assessment

– further develop the scope of the National Pain Audit to support this work

The Chronic Pain Policy Coalition will ensure that the lead organisations are held to account for delivery in these areas within realistic timescales.

References

Blyth FM. (2008), Chronic pain – is it a public health problem? Pain 2008; 137:465-466.

Donaldson Sir L. (2008), Chief Medical Officer 2008 Annual Report. Chapter: Pain: Breaking through the Barrier.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/AnnualReports/DH_096206

HC Hansard, Vol 539, cols 680W, 1 February 2012

International Association for the Study of Pain, Declaration of Montreal (2010)
<http://www.iasp-pain.org/Pain/DeclarationOfMontreal.pdf>

Maniadakis N, Gray A. (2000), The economic burden of back pain in the UK. Pain 2000, 84:95-103.

National Pain Audit
<http://www.nationalpinaudit.org>

Services for patients with pain: Report of a CSAG committee chaired by Professor Alastair Spence.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007468

Author

Dr Cathy Price, Lead Author

Contributing authors

Dr Benjamin Ellis, Ms Ann Taylor and members of the Pain Summit Steering Group:
www.painsummit.org.uk/people/steering-group

For further information please contact
Rachel Downing, Project Manager

Chronic Pain Policy Coalition
Policy Connect
CAN Mezzanine
32-36 Loman Street
London SE1 0EH

020 7202 8580
rachel.downing@policyconnect.org.uk

www.painsummit.org.uk
www.policyconnect.org.uk

Printed on recycled paper

Sponsored by the following
members of the Chronic Pain
Policy Coalition:



© Policy Connect 2012
All rights reserved



This work is licensed under the Creative Commons
Attribution-NonCommercial-NoDerivs 3.0 Unported
License. To view a copy of this license, visit
<http://creativecommons.org/licenses/by-nc-nd/3.0/>
or send a letter to Creative Commons, 444 Castro Street,
Suite 900, Mountain View, California, 94041, USA.

Designed at Richard P Chapman Design Associates

