

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

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A report of the Pain Summit 2011

# PAIN SUMMIT 2011

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# SUMMARY

## Overview

The Pain Summit 2011 took place on Tuesday 22 November at Central Hall, Westminster.

The Summit was well attended by a wide variety of delegates, ranging from health care professionals to commissioners, academics and patient groups. The morning session included addresses from Earl Howe, Professor Sir Bruce Keogh and Professor Dame Carol Black, combined with accounts from patients and professionals and two panel discussions. Delegates then split into smaller groups to attend workshops on the themes of 'Education', 'Public Health: The Wider Context of Pain' and 'Quality Commissioning' in order to discuss the issues that these subject areas raise for chronic pain.

In the afternoon, delegates heard from four speakers about current measures aiming at improving the lives of those living with chronic pain: The Health Foundation's Co-creating Health Initiative, Pain UK, the British Pain Society (BPS) Pain Patient Pathway Mapping Guidelines, and the role of the Royal College of General Practitioners (RCGP) Clinical Champion for Pain.

After brief reports of the workshops, Dr Beverly Collett, Chair of the Pain Summit Steering Group, spoke about next steps for the Pain Summit, before the day was concluded with remarks from former Chief Medical Officer Professor Sir Liam Donaldson.

## Recommendations

### Education

The education workshop discussed what measures and initiatives need to be taken to raise awareness of the educational needs of patients, carers and professionals who encounter people living with pain (including employers) and to highlight to policy-makers and commissioners the key opportunities and challenges in developing educational initiatives for these groups.

Some of the key recommendations arising from discussions were:

- There needs to be cross-collegiate working, together with patient organisations, to map out current provision and gaps.
- An across-England gold standard educational provision needs to be agreed and the level of variation from this measured.
- The media needs to promote positive messages about coping using positive role models.
- We need to be sure that we understand which communities we are trying to reach and use appropriate platforms to do so.

### Public Health

The workshop on public health looked beyond the clinical encounter to consider the wider context of chronic pain and to consider how the tools and skills of the public health and other non-clinical communities can be used to help reduce the impact of chronic pain on individuals and society

Some of the key recommendations arising from discussions were:

- Public information – an information campaign to focus on the commonalities between chronic pain and other long term conditions.
- An agreed national prevalence/incidence data report needs to be established that is based on agreed definitions.
- Joint Strategic Needs Assessments – treating chronic pain as a long term condition and undertaking systemic local needs analysis and planning could result in better outcomes.
- There should be a NICE quality standard on pain management and this should include self-management principles. It will be key to ensure that any quality standard is put into practice.

### Quality Commissioning

The workshop on quality commissioning aimed to reach principles which could be used to better commission pain management at a clinical commissioning group level and to determine how to achieve a large scale improvement in clinical commissioning groups which is achievable now.

Some of the key recommendations arising from discussions were:

- Training should allow clinicians to make a biopsychosocial assessment of pain.
- Clinicians and people living with pain should collaborate to assess health needs linked to pain and empower people to improve self management.
- To increase community-based specialist-led services where assessments are made to determine how people living with pain are best treated with the fewest number of steps.
- An information strategy linked to public health is needed to inform clinical commissioning groups and to increase public awareness of ways to prevent chronic pain and improve self-management.

### Next steps

The work that began in the Summit workshops will be continued and will form a large part of the Summit's final report, which is due to be published in spring 2012. This report will be targeted at those who are designing and delivering services for people living with pain. The report will contain recommendations on all three workshop topics: education, public health and quality commissioning.

The Pain Summit Steering Group will then plan a three to five year programme of work, which may entail further summits, in order to achieve the agreed outcomes.

# REPORT ON THE PAIN SUMMIT 2011

### Introduction

The first English Pain Summit on 22 November 2011 opened with the challenge to consider what the pain community should do over the next three to five years to reduce the impact of chronic pain on individuals and society. In opening the Summit, the facilitator of the day's events, Deborah Hall, likened the challenge ahead to a game of chess, stating that addressing the variation in pain services across the country cannot be achieved overnight. A long-term plan therefore needs to be developed which contains robust actions that will deliver better, more cohesive services to people living with pain.

The Chief Medical Officer's Annual Report 2008 increased awareness of pain as a public health issue. The initial impetus for this Summit was partly due to a reflection of the work done in Australia to achieve a shift at a variety of levels in health care policy. The Australian Summit led to a considerable national increase in the awareness of pain, had a high media profile, and from this, Pain Australia was formed. Given the Chief Medical Officer's report in England and the work that had been achieved to date as a result, it was felt that an English Pain Summit could have a similar impact amongst policy-makers, health care professionals and commissioners, patient groups and others.

### Setting the scene

In his keynote speech, Earl Howe, Parliamentary Under-Secretary of State for Quality at the Department of Health, referenced the Australian Pain Summit and how it had stimulated the collaboration that had led to today's event. Earl Howe confirmed that Government recognises the enormous collective burden of pain and the impact it has on many levels of society – individuals, friends and family, business and the economy. This impact was echoed in many of the later speeches and presentations, and underlined the fact that the solution cannot be delivered by organisations working in isolation.

He noted that the variation in the provision of services to people living with pain is also recognised by Government. Addressing this is a challenge for the NHS at a time of great change.

Earl Howe spoke of the Government's plans to change the structure of the NHS to remove over-centralised management and replace it with national 'scaffolding' that ensures delivery



**“The successful management of chronic pain requires seamless integration between primary, secondary and tertiary care. Patients should not be left on their own to navigate the spaghetti junction of providers, assessment, treatment and support.”**

**– Earl Howe**

of high-quality services whilst allowing sufficient flexibility to meet local needs. The Government's challenge is to create an environment for innovation and excellence to flourish. He described the scaffolding as consisting of:

- Evidence-based clinical guidance from which the NHS Commissioning Board will promulgate commissioning guidance.
- Pain management being included in the proposed library of NICE quality standards.
- National and local indicators to show how well the NHS is delivering good outcomes. One such indicator relates to the quality of life of people living with pain.
- Putting clinicians in charge of commissioning services. Not only do they know the needs of their patients, but they also talk the same language as the provider organisations. They are therefore in the best position to redesign care pathways and commission joined-up services.

In his keynote speech, NHS Medical Director Professor Sir Bruce Keogh echoed many of the themes raised by Earl Howe. He described the variation in pain relief that he had witnessed between three hospitals and acknowledged that there is a major educational issue to address, a theme that was examined in more detail, including in workshops, later in the day. Sir Bruce also spoke of the legal issues which have complicated the administration of pain relief and in particular the concerns that health care professionals face following the Shipman inquiry.

In the UK, 7.8 million people live with chronic pain. Fifty percent suffer from depression, whilst for people with a long term condition, 50% of their loss of quality of life is due to the pain that they live with. Changing services so that people are better able to live with their pain is not only good for the individual and their friends and family, but also for business and the economy; if the NHS could get more people back to work, provided that is what they wished to do, then we could avoid the estimated £5-10bn loss in productivity to the economy. Better pain management keeps people in work. Being able to work improves people's self-esteem, makes them more financially independent and reduces their reliance on other people. The NHS therefore needs to focus on pain, if not for compassion and humanity, then for economic reasons.

People are not only living longer, but are living longer with a



**“...I think it goes as far back as the Greeks who felt that the broader aspects of medicine and surgery were about three things; they were about the prolongation of life, the relief of pain and the correction of deformity...I put relief of pain in the middle of those three because prolongation of life turns into prolongation of death if we don't deal with pain properly.”**

**– Professor Sir Bruce Keogh**

range of long term conditions; only 13% of people who live with pain have that as an isolated condition whilst 46% of people living with pain have three or more other long term conditions. This makes their care and treatment more complex.

Sir Bruce referred to the recently published National Pain Audit which provides further evidence of the variation in access to pain services across the country. For example, 28 PCTs commission no pain management clinics, and while 64% of the identified pain clinics in England claim to be multidisciplinary, only 40% could provide the evidence to support their claim. The results provide clear evidence that pain is not at the top of the agenda in many parts of the local NHS.

The NHS reforms provide delegates with the opportunity to look at how to address some of these issues. Sir Bruce invited delegates to gather their thoughts and define what is needed to make the NHS 'good' in terms of treating people with acute and chronic pain and to then come back and tell him and Earl Howe how they can help deliver the services that delegates want for people living with pain.

Possibly the starkest fact that Sir Bruce gave was the time between presentation with chronic pain and receiving a satisfactory diagnosis and treatment: in Europe it is 1.9 years, whilst in the UK people have to wait 2.8 years. However, he challenged delegates not to accept European standards and to aim higher.

**“...I don't aspire to European mediocrity. I'm sure none of you in this room aspire to European mediocrity and I know Earl Howe doesn't. So let's not set our sights on some kind of European average. Let's set our sights on being the best.”**

**– Professor Sir Bruce Keogh**

### The impact of pain on individuals and society

Kiera Jones and Hollie Sturgess spoke powerfully and eloquently about how pain affects their lives. Kiera, a chemistry PhD student, described how she can no longer work in a laser laboratory, full-time, as part of a group of academics with a busy and active social life. With no diagnosis for her pain, her future is uncertain as she doesn't know if it will go away or get better, or whether she will be able to pursue a career as a scientist.

Simple things like doing the washing-up have become a challenge, with the choice of either doing them and then being in pain, or having to rely on someone to do them for her. She described the isolation of being in the house on her own for most of the day, and her frustration of not being able to live the life she once had.

Seventeen-year-old Hollie was diagnosed with Complex Regional Pain Syndrome just before she started her GCSE years. She explained the problems she encountered in missing school due to appointments and her pain, how she couldn't always concentrate if she was able to attend school, and of her desire to go to college and university which has been put on hold for twelve months. She revealed that she can no longer be spontaneous and has had to miss many things that other teenagers take for granted: for example, going paint-balling for her friend's birthday.

However alongside the negative impact that pain has had on her life, Hollie was also keen to point out the positives. She has discovered new skills and is now considering a career in journalism, having written articles for the last two years, and wants to use her story to inspire others. Although unable to take part as hoped in the 2012 Olympic Games as an athlete, Hollie will be running the largest independent media centre for the Paralympic Games.

One of Hollie's key messages, though, was how lucky she had been in finding a pain doctor who believed her pain, echoing the variation in services highlighted by the two keynote speakers.

Consultant in Paediatric Anaesthesia and Pain Medicine Dr John Goddard then spoke of the impact on parents whose children live with pain. He described their feelings of guilt and frustration, of



**“Now I have to carry out . . . a cost benefit analysis of every activity I do. Will the enjoyment I get from it outweigh the pain that I'll have to pay for it?”**

**– Kiera Jones**

how lives are put on hold and of their inability to plan – even for the short term – because they cannot tell how their child will feel from day to day.

Twenty-five to thirty percent of children and adolescents live in pain, most commonly with headaches, musculoskeletal problems or abdominal pain. Not all need to be seen as their pain is not severe or troublesome; however 15% of children and adolescents in the country do see their GP with pain and there is huge pressure for diagnosis.

Multidisciplinary teams are needed as drugs are not the answer, but such teams are relatively expensive to commission. Dr Goddard suggested that some services could be commissioned nationally, operating as a hub and spoke model to ensure not only coverage across the county, but also consistency of services.

However, education is a key aspect that needs to be addressed in order to deliver high-quality care. Education of non-specialists is fundamental if we are to manage patients well in primary care. Veterinary surgeons receive more pain training than health care professionals, although the British Pain Society (BPS) is actively trying to improve the content and volume of pain training.

There are no training centres for physicians in paediatric pain as the clinical services are insufficiently well established to enable them to be trained. There are no accredited doctors, nurses, physiotherapists or psychologists in paediatric pain. This, Dr Goddard believes, robustly demonstrates the need for specialist commissioning of paediatric pain services in order to facilitate the training of health care professionals.

In the panel discussion, in response to being asked what single thing would have made a difference, Kiera suggested improved communication from the outset and being told that you can have pain for no particular reason so that you can begin to develop coping strategies and accept it. For Hollie it was being treated more as a person and not a number.

As Kiera and Hollie had done earlier in the session, Patient and Public Representative Neil Betteridge spoke of isolation, focusing on how older people living with pain can be affected. Despite the expense of heating bills, the alternative of paying for taxis to go out because public transport is not an option means

**“Everything I do now has a price in pain. . . it's not really the pain itself that's the problem. It's the consequences of the pain that have the biggest disruption on my life.”**

**– Kiera Jones**

that many people choose to stay at home, leading to further isolation and an increased potential for depression and obesity. He suggested that technology could go some way to addressing isolation, although it was agreed by all the panellists that this was no substitute for meeting up with other people to share experiences. There is also a key role for patient groups to play, and for health care professionals in ensuring that people living with pain know how to access them.

Specialist Consultant in Rheumatology and Senior Clinical Adviser at Arthritis Research UK Dr Benjamin Ellis reflected that changing demographics mean that older people and people of working age are increasingly finding themselves in the same cohort. He believes that the use of language is important; being able to explain and reassure people that there may not always be a cause for the pain will allow them, as Kiera said, to begin to adjust to living with pain.

A common problem that people living with pain have is the lack of a test to 'prove' their pain and the frequent lack of a diagnosis. The panellists talked of how blood pressure and blood sugar levels can be measured and diagnoses given quickly. However, for people living with pain, there is no test and frequently no diagnosis, and they can face scepticism from employers and work colleagues. The lack of a diagnosis means that they cannot return to work or school and explain why certain modifications may be needed to enable them to work or study. Increased awareness of the issue is needed within employing and teaching organisations. Neil described how living with pain is like a relationship and at any one time one party can be stronger than the other. Pain can be seen as an invader and people living with pain need to be able to take back control. Giving it a name is part of that process.

The panellists agreed that unless you live with pain you cannot fully understand what it is like. Dr Ellis confirmed that whilst training, health care professionals are not told what it is like to have pain, yet understanding this is crucial if you are to help people.

In looking at what schools could do to mitigate the impact of pain on individuals, as with the NHS, it was noted that there is currently variation in the approaches taken. Some schools are very accommodating but others are not; raising awareness of

**“Being in pain doesn’t have to define who you are.”**

**“I had a mixed experience with the NHS – my pain management doctor was the first healthcare professional to believe my pain. Others did not believe I could be in so much pain.”**

**– Hollie Sturgess**

pain with teaching and administrative staff would go some way in addressing this.

Deborah Hall reflected that it is not just the physicality of pain, but also the psychological impact. Dr Ellis agreed, saying that for many of his patients the low mood, depression, fatigue and sleep deprivation is as big a component of the impact of pain as the pain itself. Focussing on the pain itself is not the most helpful thing and it is as important to look at non-medical support as it is to look at medical support.

Finally the panel were asked what one thing would lead to a wider appreciation of pain in society:

- Use of the media to increase awareness and to help people understand that just because you cannot see pain, it does not mean it is not there.
- Treatment starts with identifying what the person most wants to achieve and helping them to achieve it.
- There is always something positive that can be done but you need to seek help yourself.

**“It’s like someone ripping my heart out. I feel so helpless. I’m supposed to be able to help my kids and I’m helpless. I feel so helpless. A great, big F on my report card. I could run away but I don’t.”**

**“We realise as parents we have to fight an awful lot to get our children anywhere, to get them diagnosed, to get them recognised, to get them treated.”**

**“If I could only get a good night’s sleep, I actually feel I could get through with my pain. When I’m exhausted it’s the last straw.”**

**– Anonymous**

### Pain, work and wellbeing

The impact of pain on the ability to work was highlighted in the first session and expanded on by National Director for Health and Work Professor Dame Carol Black in her presentation. She described how desirable and possible a healthy, engaged workforce is and how living with pain should not stop someone from working if that is what they want to do.

Dame Carol also spoke of the role that employers have to play in understanding the issue and ensuring that they have a well-managed organisation that provides the necessary adaptations to enable people with a long term condition to work; too often there is the assumption that people with a long term condition cannot work. Too often health care professionals and employers do not ask people living with pain what is needed to make it possible for them to be in good work, or to stay in good work. This needs to change.

Research in 2006 showed that, of the top ten health problems impacting productivity, three (back/neck pain, other chronic pain and arthritic pain) specifically relate to pain. Solutions, Dame Carol said, depend on collaboration between Government, health care professionals, employers, employees and would-be workers, and trade unions.

Of the approximately 27 million people currently in employment, 26% have a health condition or disability and 2.4% are collecting a sick certificate. Of those who are inactive (approximately nine million), 48% have a health condition or disability. Of those who are unemployed (approximately 2.7 million), 29% have a health condition or disability. Understanding what allows people living with pain to remain in employment is important so that it can be replicated and allow more people with a health condition or disability to work if they wish to do so.

Many chronic conditions are associated with pain and require:

- Good clinical care at GP and secondary care level
- Vocational rehabilitation
- Well-informed work-conscious health care professionals
- Flexibility and adaptation in a health-promoting workplace.

However, Dame Carol reflected that the achievement of these criteria is variable across the country and so people living with



**“Employment is nature’s physician and is essential to human happiness.”**

**– Galen (129-200)**

**“Work is generally good for physical and mental health and wellbeing.”**

**– Waddell and Burton (2006)**

pain may be unable to work or to return to work.

The Fit for Work Services trial in Leicester, which aimed to reduce sickness absence and avoidable job loss through coordinated services, found that, for one in four of the 222 people discharged from the service, pain was a significant barrier to returning to work.

Dame Carol ended her presentation with five principles for all stakeholders to focus upon:

1. What people can do, not what they cannot do.
2. Early intervention is essential.
3. Imaginative job design is key to rehabilitation.
4. Think beyond the physical symptoms (they are often associated with psychosocial problems).
5. Assess the direct and indirect costs of pain-related absence.

**“With treatment modification and work support, we have had some real successes in returning people to work.”**

**– Dr Rob Hampton,  
Clinical Director,  
Fit for Work Team Social  
Enterprise**

### Delivering services for people living with pain

The final plenary session of the morning looked at how services are delivered.

Jo Cumming outlined the work of the Arthritis Care helpline she manages. Over 10,000 calls were received in 2010 and 62% of these were from people who had problems managing their pain. Common themes were:

- Callers requesting guidance on self-management.
- Callers asking for help with understanding treatment, and in particular the effects of medication.
- Callers showing little awareness of the benefits of exercise and a lack of referral for physiotherapy.
- Callers needing emotional support.
- Callers receiving no advice on healthy eating or referral to a nutritionist.
- Callers with little awareness of pain clinics and services that are available
- Callers seeking support to remain at work.
- Callers not being offered cognitive behavioural therapy or other counselling services.

Many of these themes demonstrate the lack of communication and variation in services that earlier speakers highlighted. Jo concluded by saying that greater access to information to help people understand what services and support are available to them is urgently needed.

Dr Ollie Hart is a GP in Sheffield. He explained how pain is now seen as a long term condition in its own right and so there should increasingly be systematic management of people living with pain as there is for diabetes, for example.

However, in order to be successful, there needs to be an integrated system to assist GPs in the systematic management of people living with pain. He described this wider primary care team as consisting of:

- Mental health workers
- Health trainers
- Physiotherapists
- Occupational therapists
- Patient-led support groups.



Commissioners need to decide:

- What is the role of primary care, in its widest sense, in the management of pain?
- What services need to be commissioned?
- What skills do GPs need to have, and what tools and support services will they need?
- What self-help resources are needed for people living with pain?

Dr Hart described a pyramid of care with self-management at the bottom, then primary care services and finally specialist services at the apex. Resources need to be targeted to ensure that care is maximised.

Professor Richard Langford, President of the BPS, reflected that Dr Hart had looked at the development of primary care services, leaving specialist services within the secondary care setting, and agreed that this was the model that should be adopted. Not everyone will need to access specialist services, so it is appropriate that the focus for secondary care should be on those people who do need that level of care.

He expanded further on the role of specialists in disseminating best practice and acting as local leaders in the development of pain services, with a particular role in local education and training. He also spoke of the need for multidisciplinary teams within specialist services to be at the forefront of being able to assess, refine and manage complex pharmacological interventions.

Another role for specialists is in the surveillance of disease prevalence in order to predict future requirements for the commissioning and provision of both primary and secondary care services.

Earlier speakers had mentioned the increase in life expectancy and the fact that people are living with long term conditions for longer. Professor Langford reflected that improvements in the treatment of cancer are also prolonging the lives of cancer survivors, which in turn has led to an increase in demand for high-quality pain services. He also spoke of advances that have led to better survival rates for injured military personnel and

**“It’s about getting through the system to get to the person you need but you don’t always know who you need.”**

**– Anonymous**

civilians, but to those people then living with worse injuries.

He agreed with Dr Goddard's suggestion that due to the relatively small numbers of patients who need access to these specialist services, centralised commissioning of specialist services may be more appropriate, with local commissioners focusing on primary care services and self-management.

The panel then discussed the current barriers to early treatment and Professor Paul Watson spoke of the need to ensure that resources are targeted at those who will not respond to simple advice and analgesia. Screening of people living with pain to ensure that they access the right care pathway is important. However, this will require integrated commissioning of services to ensure seamless service provision as close to the person as possible.

It was agreed that the evidence shows that current services do not empower patients to ask the right questions. Jo spoke of how even expert patients have problems navigating the current health system and finding out what services are available to them.

Meaningful engagement of people living with pain in the development and commissioning of services is vital. Dr David Paynton, National Clinical Commissioning Lead at the Royal College of General Practitioners (RCGP) Centre for Commissioning, confirmed that engaging the public in local commissioning decisions is a key element of the NHS reforms, and increasingly there will be a shift of investment from secondary care to services in local communities.

It was acknowledged that there are already a number of levels of care to reflect the wide spectrum of pain needs; however, Professor Langford said that care must also be tailored to the individual's needs. He went on to state that education is needed so that people know what to expect from their pain – what is normal and what is not – so that they are empowered to seek help when they need it. The role of charities and support groups is vital in raising awareness.

“Empowered patients choose best.”

– Quality commissioning workshop

## Workshops

Workshops focusing on three of the main themes of the day (education, public health and quality commissioning) took place before and after lunch. Each started with a series of short presentations followed by tabletop discussions.

### Education

#### Topics for discussion:

- Identifying the knowledge base and the best ways of delivering it.
- How to influence learning institutions, public and employers to deliver pain education.
- The skills required of those providing education.
- Benchmarking education with other chronic conditions.
- Establishing educational standards and how these can be realised.
- Marketing and use of new technologies for education.
- Getting out to schools and speaking to young people to prevent disability and pain at source.

#### Key recommendations:

- There needs to be cross-collegiate working, together with patient organisations, to map out current provision and gaps.
- An across-England gold standard educational provision needs to be agreed and the level of variation from this measured.
- The media needs to promote positive messages about coping using positive role models.
- We need to be sure we understand which communities we are trying to reach and use appropriate platforms to do so.
- We need to link with key current campaigns, such as Olympic Sport For All, Help for Heroes and Back to Work.
- We should make use of existing standards to drive improvement, such as Essence of Care Benchmarks.
- We should give clear unambiguous messages, such why 'Pain as the 5th Vital Sign' is important.
- We should be clear about which educational initiatives will deliver a faster route to diagnosis of chronic pain as the main issue.

## Public health

### Topics for discussion:

- How can data be used at a local and national level to influence the public health environment and outcomes in chronic pain? This would include consideration of Health Survey for England, Joint Strategic Needs Assessment, Quality and Outcomes Framework, National Audit and others.
- What could be done to tackle the problem of chronic pain under the umbrella of health promotion? This would include prevention, social marketing, general public education (including in schools), promotion of self-care and considering how the problem of chronic pain fits in with the wellbeing agenda.
- What are the public health and policy levers for change? This would include the roles of various bodies within the new NHS framework, in particular thinking about the role of health and wellbeing Boards, but also considering the Quality and Outcomes Framework (QOF) and Quality Standards, thinking about the role of primary health care, local public health and any role for Public Health England.

### Key recommendations:

New areas for work:

- Public information:
  - Beliefs, attitudes, social and cultural norms underpin the propensity for people in pain to develop chronic pain syndromes with accompanying disability.
  - Altering maladaptive population norms can help reduce the progression to disability (secondary prevention) without 'medicalising' those people in pain who are coping and functioning well.
  - There are a number of avenues to distribute this information, such as community pharmacies, libraries and third sector organisations.
- Establishing indicators and data:
  - Need to establish an agreed national prevalence/incidence data report that is based on an agreed definition.
  - The definition needs to be carefully determined and must measure things that are relevant and appropriate, and not simply 'pain'.
  - It was noted that impact should be considered, along with indicators of ability to cope – such as self-efficacy.
  - There was some discussion as to whether this should

distinguish between people for whom pain was attributable to some other condition and those for whom it was the primary diagnosis.

- Other indicators include work retention, prescribing data and whether schools have systems to support young people in pain.
- More work is to be undertaken on this area.

Opportunities to work within existing frameworks:

- Joint Strategic Needs Assessments
  - This is at the core of local health planning, and work in NHS Kirklees was presented as an example of how treating chronic pain as a long term condition and undertaking systematic local needs analysis and planning could result in better outcomes.
- Wellbeing agenda
  - Many of the public information messages have shared commonalities with work being done by people working on the wellbeing agenda.
  - Engagement with emerging health and wellbeing boards will help to move chronic pain up the local authority agenda.
- Quality and monitoring frameworks
  - It was recommended that there should be NICE quality standards on clinical pain services and that NICE should also have a quality standard on self-management.
  - Additionally self-management principles should be embedded into the quality standard for pain.
  - However, it was noted that the key challenge is getting quality standards put into practice and that contract enforcement and use of the commissioning for quality and innovation payment framework may be important.
  - A review of other quality standards/guidance could be an opportunity to identify gaps in pain management in the context of other conditions.
- There is a need to engage the Care Quality Commission to ensure pain management is adequately accredited and standards and processes appropriately monitored for providers. Early engagement of the nascent Public Health England will be an important opportunity to ensure that pain is on their radar.
- The Quality and Outcomes Framework (QOF) was thought to be one of the ways of driving up standards of pain management, but it was noted that previous attempts to integrate pain within the QOF had not been successful and that this could be difficult to achieve.

## Quality commissioning

### Topics for discussion:

Using back pain as a starting point (though this can be extrapolated into other areas of pain medicine):

- What evidence based changes should a clinical commissioning group (CCG) implement in primary care for people with back pain?
- What evidence based changes should a CCG implement in the pathway of care for people with back pain outside primary care?
- How will we align the responses to the above questions to Quality, Innovation, Productivity and Prevention (QIPP) (specifically shared decision-making and self-care support)?

### Key recommendations:

- Training should allow clinicians to make a biopsychosocial assessment of pain. Clinicians and people living with pain should collaborate to assess health needs linked to pain, develop tailored care plans and empower people to improve their self-management.
- Increased consultation time to also allow risk assessment for chronicity so that clinicians look at both primary and secondary prevention.
- An increase in community-based clinical specialist-led services where assessments are made to determine how people living with pain are best treated with the fewest number of steps.
- Need for an information strategy linked to public health to both inform clinical commissioning groups and to increase public awareness of ways to prevent chronic pain and improve self-management.
- Improved information for people living with pain, particularly on the services that are available.
- Explore whether certain services could be commissioned less.
- Empower patients by:
  - Making a good diagnosis early.
  - Helping the individual decide if they have a treatable condition and give them treatment options, or, if a non-treatable condition, to give them management options.
  - Discussing the risks for the future.
- The best pool of such information is with the people who are living with pain and have learnt these skills already, and the people who create the environment within which they live and

work such as employers and teachers. Commissioning efforts should focus on creating the environment where these experts can have a commissioning conversation.

### Looking to the future

Dr Dimple Vyas, Consultant in Pain Management, spoke of The Health Foundation Co-creating Health Initiative, a programme which aims to embed self-management support within mainstream health services across the UK and to equip individuals and clinicians to work in partnership in order to achieve better outcomes. The programme is based on the recognition that the health care system for all long term conditions has to change from being a health care system to being a health support system. This is achieved by the co-delivery of the programme by patients and clinicians.

The programme consists of three strands:

1. A self-management programme for individuals which helps them to actively manage their pain.
2. A collaborative consultation skills programme that is delivered to all clinicians to assist them in adopting a different way of working.
3. A service improvement programme which allows the necessary processes and tools to be put into the system and to be embedded into everyday practice. Feedback is then used to make any further changes.

The results of the programme were that:

- Individuals had more confidence in managing their pain and a better quality of life
- Clinicians had greater job satisfaction because people living with pain are making progress
- There were benefits to society – the NHS is assisting people in returning to work and reducing feelings of isolation and low self-esteem.

Sean McDougall introduced the work of Pain UK, a newly formed charity aiming to provide a stronger, more powerful voice for people living with pain. Pain UK is an alliance of charities dealing with pain in different parts of the body. By uniting voices and

working with commissioners and professional bodies they hope to increase awareness and improve services. Signposting people to information and services will also be an integral part of their work.

Dr Andrew Baranowski spoke on the BPS Pain Patient Pathway Maps which are due to be available on Map of Medicine. Five pathways are being developed, involving 50 people from a variety of backgrounds including people living with pain:

1. Spinal pain – this complex pathway moves from the early management of spinal pain through to guidance on the complex cases, including guidance on when a variety of interventions are appropriate. It also looks at stratification of risk of chronicity enabling appropriate support and intervention to be provided.
2. Primary assessment and management – giving guidance for practitioners on the correct techniques for assessing pain and supporting early management of those living with pain. Ensures appropriate management and support, and encourages self-care. Timelines are included to ensure patients are not 'lost' in the complexity of NHS systems.
3. Neuropathic pain – this pathway expands on the NICE guidelines and includes a full range of interventions and support.
4. Pelvic urogenital/pelvic pain – this pathway has been one of the most complex but is nearing completion.
5. Musculoskeletal pain – looks at the presentation of widespread aspects of pain that are seen.

Based on evidence and NICE guidelines, they also include an element of common sense to ensure the best possible pathway for people living with pain. Other pathways have been discussed and will be developed in due course.

Dr Martin Johnson spoke of the huge challenge he faces in his role as Clinical Champion for Pain at the RCGP. It is estimated that 45% of all chronic conditions management consultations in primary care involve chronic pain. Accurate pain assessment is paramount. Get that right, he says, and the rest should follow. He will be working to ensure that GPs see chronic pain as a long term condition, not as a symptom.

Medicines management is a significant programme of work. The second most commonly prescribed drug for long term conditions

in the UK is co-codamol. However, there is no system to manage this prescribing in the same way as there is for the prescribing of anti-hypertensives, for example. Prescribing is fundamental to the role of the GP and the RCGP will take the existing BPS guidance on prescribing opioids and set it in a primary care-relevant format.

### Next steps

Chair of the Pain Summit Steering Group Dr Beverly Collett commented on the energy in the room and thanked delegates for their hard work and enthusiasm. She confirmed that the Summit is the end of the beginning and that we now need to develop consensus about what the problems are and to work collaboratively to achieve the agreed outcomes.

The first step will be the production of this factual report of the day which will be circulated to delegates and published before Christmas. The work that has been started in the workshops will be continued and will form a large part of a final report. The final report will be targeted at commissioners, policy-makers and educators: that is, those people who are designing and delivering health services for people living with pain. It is anticipated that the report will be published in spring 2012 with a launch in the Houses of Parliament.

The Pain Summit Steering Group will then plan a three to five year programme of work, which may entail other summits, in order to achieve the agreed outcomes.

To support the development of this work programme, Dr Collett invited all delegates to join the Pain Summit NHS Network, which has been established to facilitate ongoing discussion and information sharing which will feed into the programme of work.

Following publication of the final report, the challenge will then be to ensure that it is turned into reality, and does not merely sit on a shelf. Introduction of a quality standard for pain management would help to ensure that this does not happen.

A considerable number of people and organisations had contributed to the planning and success of the day, and Dr Collett gave her sincere thanks to them for all their hard work.



### Closing remarks

It fell to former Chief Medical Officer and Chair of the National Patient Safety Agency Professor Sir Liam Donaldson to close the Summit. Throughout the day the issue of pain as a symptom, or an illness of unknown causation, and the profound impact it has on all aspects of life were eloquently described from a number of viewpoints. Sir Liam summed up the challenge ahead as securing change to benefit the many, not just the lucky few.

He described a five-point plan that needs to be developed, echoing many of the points that had been made throughout the day:

1. Undertake a burden of disease analysis to be able to describe the scale of the problem.
2. Ensure chronic pain is seen in the eyes of the public and the media as a 'high street' disease so that people realise it is a common disease, not a rarity.
3. Embed chronic pain within an NHS performance framework, and ideally more than one.
4. Showcase centres of excellence.
5. Achieve universal use of pain as a clinical metric in the same way blood pressure is regularly recorded.

Finally, he commended the progress that had been achieved and the passion to improve the experiences of people living with pain. He encouraged delegates to continue to raise awareness of pain in fresh and original ways so that it is not lost in the plethora of challenges facing current and future commissioners, educators and policy-makers.



# THE PAIN SUMMIT 2011

## About the Pain Summit 2011

The Pain Summit is a joint venture organised by the Chronic Pain Policy Coalition (CPPC), the British Pain Society (BPS), the Faculty of Pain Medicine, and the Royal College of General Practitioners (RCGP).

### The British Pain Society (BPS)

The British Pain Society is the largest multidisciplinary professional organisation in the field of pain within the UK. Our membership comprises medical pain specialists, nurses, physiotherapists, scientists, psychologists, psychiatrists, general practitioners, occupational therapists and other healthcare professionals actively engaged in the diagnosis and treatment of pain and in pain research for the benefit of patients. Our multidisciplinary nature is pivotal in making our society a uniquely relevant representative body on all matters relating to pain.

[www.britishpainsociety.org/](http://www.britishpainsociety.org/)

### The Chronic Pain Policy Coalition (CPPC)

The Chronic Pain Policy Coalition is a forum established in 2006 to unite patients, professionals and parliamentarians in a mission to develop an improved strategy for the prevention, treatment and management of chronic pain and its associated conditions

[www.policyconnect.org.uk/cppc](http://www.policyconnect.org.uk/cppc)

### The Faculty of Pain Medicine

The Faculty of Pain Medicine is the professional body responsible for the training, assessment, practice and continuing professional development of specialist medical practitioners in the management of pain in the United Kingdom. It supports a multidisciplinary approach to pain management informed by evidence-based practice and research.

[www.rcoa.ac.uk/index.asp?PageID=853](http://www.rcoa.ac.uk/index.asp?PageID=853)

### The Royal College of General Practitioners (RCGP)

The Royal College of General Practitioners is a professional body for GPs. It represents a GP voice, seeks to improve patient care, and provides training for GPs. Between 2011-2013, chronic pain is a clinical priority for the RCGP.

[www.rcgp.org.uk/](http://www.rcgp.org.uk/)

### Sponsorship

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