

CROSS PARTY GROUP ON CHRONIC PAIN IN THE SCOTTISH PARLIAMENT  
MINUTES OF MEETING  
Held on Wednesday 26 October 2011 at 6 pm in Committee Room 5

Attendees

Eadie, Jim – MSP	Dr. Gilbert, Steve – National Lead Clinician for Chronic Pain
McLeod, Fiona – MSP	Dr. Johnson, Martin – RCGP Clinical Champion for Chronic Pain
Dr. Simpson, Richard – MSP	MacGregor, Breck – Policy Officer, Pain Concern
	MacPherson, Fiona - CNS Chronic Pain, Pain Clinic, Western General Hospital
Dr Atherton, Rachel - Clinical Psychologist with Highland Chronic Pain Management Service	Martin, Christine – patient representative
Archibald, Susan – Archibald Foundation	Meek, Ros – Director, ARMA
Atkinson, Phil – Health Policy Scotland	Onions, David – Person with chronic pain
Barratt, Paul – Director, Edinburgh Osteopathic Surgery	Onions, Pat – Carer for person with pain
Campbell, Lin – patient representative	Paton, Bill – Chair of ABPI Scotland – Scottish Pain Industry Group, NAPP Pharmaceuticals Ltd
Clubb, Malcolm - Policy Development Pharmacist, Community Pharmacy Scotland	Quadros, Paulo - Intlife
Cottom, Sonia – Pain Association Scotland	Quinn, Des – Vice Chair of Fibromyalgia Association UK
Dr. Dunbar, Martin – Consultant Clinical Psychologist	Rae, Colin – Lead Clinician for the Managed Clinical Network in Chronic Pain in GG&C
Edmonds, Julia - Regional Representative of the British Acupuncture Council	Richens, Helen – Policy Officer, Pain Concern
Elder, Dorothy-Grace – Editor & Founder of the Cross Party Group on Chronic Pain	Simpson, Anne – National Osteoporosis Society Development Manager (Scotland)
Forde, Jacqueline – Director, Health Inequalities Alliance Ltd.	Thomson, John – patient representative
Fotheringham, Graeme – Vice Chair, ABPI Pain Group	Wallace, Heather – Co-Secretary of the Cross Party Group on Chronic Pain, Pain Concern

## Apologies

Baillie, Jackie – MSP & Co-Convenor	Prof. Macfarlane, Gary – Epidemiology; Deputy Head of Institute of Applied Health Sciences, University of Aberdeen
Scanlon, Mary – MSP & Co-Convenor	Dr. McDonald, Ross – President of the Scottish Chiropractic Association & Chiropractor in Discover Chiropractic
	Dr McMenemy, Michael – Project Lead MSK Programme, SALUS Occupational Health & Safety
Barrie, Janette – Nurse Consultant for Long Term Conditions	Prof. Prowse, Morag – Dean, Napier University; Non-executive Director, NHS Lothian
Bishop, Doreen – Backcare	Dr. Roche, Pat – Project Coordinator of EOPIC
Cadden, Helen – NHS QIS Public Partner for Healthcare Improvement Scotland	Prof. Power, Ian - Anaesthesia & Pain Medicine, University of Edinburgh, Edinburgh Royal Infirmary
Cruickshank, Stephen – patient representative	Sizer, Phil – Pain Association Scotland
Grieve, Claire – patient representative	Williams, Lars – Consultant in Anaesthesia & Pain Management
Grieve, Michael – carer for person with pain	Dr. Wilson, John – Consultant in Anaesthesia & Pain Medicine
Logan, Irene – Fibromyalgia Friends Scotland	

1. Richard Simpson MSP welcomed everyone to the meeting.
2. Fiona MacPherson corrected a comment in the minutes that aromatherapy could be learnt in six weeks; it now involves a masters course. It is also seen as a package of care rather than a treatment in its own right. Otherwise, the minutes of the June 15<sup>th</sup> meeting were agreed as an accurate account of the proceedings.
3. –
4. –
5. 5.1 Steve Gilbert (SG) is preparing a business case presentation to NHS regional planning chief executives. This emphasises shifting the balance of care to primary care, ensuring patients are treated swiftly for their pain. This aspect makes economic as well as medical sense, as it would prevent unnecessary treatment, investigations and referrals to secondary care services. The presentation is based on figures from SG's audit of Scottish pain services, which updates and expands the last GRIPS report. They show variable secondary care across Scotland, with four areas having a single doctor providing the pain service, and

varying levels of multidisciplinary clinics in the other boards. SG has also visited health boards for the business case, to gauge current provision, and challenges and opportunities in each board. Reaction to the business case varied between different boards.

5.2 The chronic pain steering group is continuing to focus on its priorities of education, research, audit, tele-health and the establishment of a SIGN guideline in chronic non-malignant pain. Research, led by Blair Smith, is progressing towards a national study of opiate prescription. The SIGN guideline is currently under development and will come for public consultation next year. The community website is receiving input from a number of sources, including ALISS about self-management resources.

5.3 Christine Martin (CM) expressed surprise that health boards have leeway to place different levels of priority on pain services. SG responded that this is due to pain being seen as part of other conditions in the past, and though there is current endorsement from government, health boards retain autonomy in spending their budget. DGE commented that appealing to health boards was putting the cart before the horse, and if government isn't backing a cause then health boards won't. Obesity and smoking campaigns get tens of millions whereas chronic pain gets next to nothing. SG replied that neurology used to be in a similar state, but funding increased once clinical standards were introduced. DGE replied that governments won't respond without campaigning, there is no chronic pain funding from LTCAS, and recognising pain in its own right doesn't seem to have made a difference. SG advised that a lot of campaigning and hard work are necessary to make a difference, but that getting funding for nationwide pain services overnight is unrealistic. CM showed the meeting a staff magazine from NHS Western Isles as an example of health boards mismanaging public money.

6. 6.1 Chronic pain was made a clinical priority by the RCGP following on from the CMO report in 2009. Clinical priorities are targeted by the RCGP to raise profile, awareness, and quality of care. Increasing the evidence base for pain is vital due to the lack of it currently. Education of GPs is key, and MJ has been visiting GPs around the UK to gauge needs in this area. British GPs are the best in the world at preventative medicine, but to involve them more in chronic pain, early detection and management must be prioritised. Chronic pain is recognised as a chronic disease in Scotland, unlike in England. Recovery is not the end target; in fact the IASP's new gold standard is a 50-70% reduction in pain. The stakeholder group of the RCGP in chronic pain sets the strategic direction and looks into funding of the clinical priority.
- 6.2 The BPS has developed five pathways, for neuropathic pain, which will mirror the NICE guideline, spinal pain, non-inflammatory musculoskeletal pain, pelvic pain and initial assessment and management. The latter is key because of the importance of correct assessment from the outset. SIGN have also developed a pathway on this. The pathways will be hosted on an IT system, and on the map of medicine,

and hopefully published in the British journal of anaesthetics. Evidence base isn't essential for inclusion in the pathways, and each pathway has a patient group. MJ will be involved in the implementation strategy, as it will mostly concern GPs. A key concern is categorising those with problematic pain – 49% of primary or secondary GP consultations are to do with chronic pain, compared to 6% for diabetes. The four Ds will be used – disability, drugs, distress and dolorosa (pain). Screening questions will be used before GPs see patients. If a patient's outcome on the questions is positive, they will take a dolo-test, where they rank their pain and other measures on scales. This is done every few weeks. Pilot tests have been encouraging, indicating quality of life can improve without a reduction in pain.

6.3 Another potential development is a charter for the treatment of pain patients, modelled on the end of life care patient charter. This would include pain as the fifth vital sign, mandatory basic assessments of pain and quality of life scores.

6.4 Co-codamol is the second most prescribed drug for chronic conditions in the UK, but GPs are severely lacking in guidance on its use. RCGP are developing guidelines for GPs with the BPS.

6.5 The Pain Summit in Westminster is largely for England, as they are the only UK country not to have a pain strategy. A UK-wide summit in 2-3 years is a target. Northern Ireland are having one in March, and one in Scotland is a possibility.

6.6 NICE have a new library of clinical standards, with pain management as a generic topic for the first time, which covers pain assessment and standards.

6.7 DWP are running a pilot in Leicester, where people with chronic pain are being assessed for neuropathic pain. One in seven people have had undiagnosed neuropathic pain, which again highlights the need for proper assessment.

6.8 Co-creating health is a program which encourages self-management across a range of conditions. The COPD program has seen a 20% reduction in readmissions, and it is popular with patients, so it may translate well to chronic pain.

6.9 MJ invited attendees to approach him about working together.

6.10 Fiona McLeod MSP (FM) was appointed chair of the meeting after Richard Simpson left for a prior engagement.

6.11 Martin Dunbar asked if RCGP is UK-wide in scope, which MJ confirmed it is.

6.12 DGE asked whether MJ was encouraging GPs to refer patients to pain clinics. MJ replied that the key thing is to get GPs referring appropriate patients, and dealing with other patients in their surgeries or elsewhere in primary care. Des Quinn asked whether the NICE neuropathic pain guideline are moving care away from GPs towards pain clinics. MJ responded that the guideline specifically concerns the

pharmacological management of neuropathic pain in the community, and as such isn't changing advice much. It assumes a correct diagnosis however, and doesn't advise on the primary assessment pathway. HW added that NICE guidelines are designed for non-specialists, and should the advice be followed without success the patient should then be referred to a pain clinic. MJ commented that the use of pregabalin is currently indefensible as the population it is used on are not confirmed as genuine neuropathic patients, because they haven't been assessed for it. The priority should be enabling people to assess for neuropathic pain, so that only people with it are given the drugs to stop them entering secondary care. SG added that in Fife it was mostly primary care that was prescribing pregabalin and oxycodone. Only a fifth to a third of neuropathic pain sufferers respond to pregabalin, so some patients are being kept on the drug unnecessarily. SG proposed education should focus on understanding pain and non-pharmacological management, and health trainers and physiotherapists should see patients early on. As such the emphasis should be on increasing expertise on pain in primary care and even patients themselves, rather than increasing secondary care services.

7. 7.1 Rachel Atherton (RA) is clinical psychologist on NHS Highland's chronic pain management service. The service's inception may well have been helped by the GRIPS report recognising pain as a condition. The service works with primary care as much as possible, disseminating skills and knowledge to healthcare professionals, while still working with some people individually. Patients referred are given a questionnaire about their condition, which is popular, as patients feel listened to. Due to the geography of the area, the first contact is a telephone triage within 4-5 weeks. This is cost-effective and efficiently dispenses advice.
- 7.2 The service runs a weekly multidisciplinary clinic, individual and group physiotherapy, individual psychology, and theatre procedures. There is also a pain management programme, which is half a day for 11 weeks, and has a cognitive behavioural emphasis. In addition Phil Sizer from Pain Association Scotland runs a monthly class. The service is hitting its waiting list targets despite having 50% more referrals than it was funded for. It is vulnerable to staff absence due to low staffing levels however. Resources are being moved online, and the service is keen to make use of the variety of resources from other organisations.
- 7.3 Heather Wallace (HW) asked whether a residential pain management service is necessary in Scotland. RA replied that whereas patients make long round trips to the clinic in Inverness, some are unable to, but they still just need an outpatient service.
- 7.4 SG agreed that the service was vulnerable to absence with only one medical doctor. Outreach, online resources and up-skilling people are important aspects of overall strategy given the small number of medical professionals working in pain services.
- 7.5 FM asked if the service worked with the voluntary sector in delivering services such as exercise classes.

RA replied that it had been discussed and approved of but not prioritised yet.

8. 8.1 Update from Colin Rae (CR), lead clinician for the Managed Clinical Network (MCN) in Glasgow. The MCN is a very useful framework for clinicians, and improves links between levels of care. The service only sees a very small proportion of people with chronic pain. Accessibility of clinics is an issue even in an urban setting. Improving this would further stretch secondary care services, and without further funding would be very difficult.

8.2 The MCN has a pathways group, which is looking at referral criteria for different members of the multidisciplinary team. Waiting times are an issue for all members. Improving access to primary care through outreach is a priority, but a huge task with such a big population. A meeting will be held looking at clinical standards, which would contain what the service was achieving and what it should achieve. There is an education subgroup which undertakes learning needs analyses, and provides learning programs such as one starting in March 2012 for primary care professionals. The IT group looks at improving communication within the team and with primary care. Having an MCN has raised the profile of what is a small speciality, and it has provided a focus for clinicians to evaluate the service.

8.3 DGE advised that only Glasgow has taken up an MCN, due to the pump-priming lasting for only two years, and that this represents the only money offered for chronic pain services. DGE added that money is available, like the £14m reallocated to the Commonwealth Games from the e-health and flu contingency budgets, but if you don't ask you don't get.

8.4 HW informed the group about the founding meeting of Pain UK on 1<sup>st</sup> November 2011. It's an umbrella body of UK pain charities with a large user involvement. HW added that the co-chairs of the group are keen to receive parliamentary questions.

8.5 FM returned to the issue of campaigning as a group, and told the group her opinion that cross-party groups are forums rather than campaigning organisations. DGE replied that the description of the group included promoting the interests of the patients.

8.6 DGE asked Sonia Cottom (SC) of Pain Association Scotland whether they applied for funding recently. SC replied that they applied to LTCAS for funding, as LTCAS had received government funding for self-management programs. Pain Association Scotland provides self-management to chronic pain patients, but were declined. DGE advised that she asked LTCAS some months ago whether they had any budget for chronic pain, and was told they didn't, which SC commented still seemed to be the case. FM advised that a parliamentary question could be asked if the grant criteria excluded funding for chronic pain. SC added that Pain Association Scotland wrote a letter to Mary Scanlon some months ago on this topic, but haven't received a reply.

8.7 John Thompson, a founder member of the group, commented that very little progress has been made in the eleven years of the group, and very little done for patients.

8.8 Paolo Quadros (PQ) asked if there was a national figure of the number of patients being helped for chronic pain, to track progress of new measures. FM replied that a parliamentary question could be asked on this. Martin Dunbar advised the figures do exist these days. SG added that these figures are all in his audit, but that he had to wait to present the business case before publicising the figures, which he aimed to do mid-late November. PQ asked if there was a measurement of how much people are helped. SG referred to epidemiological evidence of the help of pain management in improving function, reducing healthcare use, and returning to work. In England there is a nationwide audit by BPS and Dr Foster of pain services, but not in Scotland. There is also a musculoskeletal framework which uses IT to collect quality of life scores before and after service use, which could translate to chronic pain.

8.9 PQ asked if there was any data comparing the effectiveness of different therapies for chronic pain. HW commented that the majority of pain is treated by GPs, so the priority is educating them. MJ added that a study in the Lancet on the aptness of physiotherapy for different patients is very relevant. Measuring outcomes in pain is the biggest topic internationally, and agreement on best interventions is rare.

8.10 SG returned to the campaigning issue, and advised that the chronic pain policy coalition (CPPC) is a campaigning group outside of the English all-party group, with advantages that no MPs are required, and with less constraints on members. An outside group to the Scottish cross-party group could involve charities and patient groups. HW added that with Pain Association Scotland joining Pain UK, there would be a more united voice campaigning on chronic pain. MJ advised that the CPPC was formed in 2006, and most campaigning in England has been done via the CPPC, such as instigating the Pain Summit. DGE advised that a cross-party group taking an exclusively party-political line would be unacceptable, but campaigning in general is acceptable. FM recommended that the secretariat consult the Scottish Government Corporate Body on the purposes of cross-party groups, and that the group could hold a meeting specifically on funding streams of chronic pain services.

8.11 DGE proposed that the group ask the Scottish Government whether they will consider direct funding to aid chronic pain facilities in Scotland, which are patchy and inadequate, in view of their commitment to the chronic pain cause, as approaching individual health boards and relying on their budgets may not be adequate. SG advised that the group had previously asked Andy Kerr this without success. A new administration may be more receptive though. DGE reiterated that the Scottish Government should be sent a letter, as should the LTCAS, asking their budget situation regarding chronic pain. SG asked to have until the middle of December to report back to the group on the outcome of his business case

presentation to the regional planning chief executives, to see if that leads to a commitment to institute pain services. FM asked the group whether they wanted to take a vote on DGE's proposal. The proposal received 15 votes which was a majority. FM asked the secretariat to follow up the vote, thanked the speakers and everyone for coming, and called the meeting to a close.

9. Date of next meeting

6-8pm Wednesday 8 February 2012

Refreshments kindly provided by Medtronic Ltd.

## AGENDA

1. Welcome
2. Minutes of last meeting held 15 June 2011
3. Matters arising
4. EU position on the prevention and control of non-communicable diseases  
*Alison Given – Grunenthal Ltd*
5. Chronic Pain Steering Group update  
*Dr Steve Gilbert – National Lead Clinician for Chronic Pain*
6. Presentation  
*Dr Martin Johnson – Update on his work as Royal College of GPs Clinical Champion for Chronic Pain*
7. Pain Management in the Highlands  
*Dr Rachel Atherton – Clinical Psychologist, Chronic Pain Management Service, NHS Highland*
8. Any other business
9. Date of next meeting  
*6-8pm Wednesday 8 February 2012*