SCOTTISH PARLIAMENT
CROSS PARTY GROUP ON CHRONIC PAIN AGM
MINUTES OF MEETING
Held on Wednesday 15 June 2011 at 6.00 p.m. in Committee Room 5
Refreshments from 5.30 p.m.

Attendees

Scanlon, Mary – MSP & Convenor	Hughes, Sally – Napp Pharmaceuticals Ltd.
Baillie, Jackie – MSP	Johnson, Janice – PSALV (Psoriasis Scotland Charity) – Person with Pain
Eadie, Helen – MSP	Kay, Thomas – Backcare
Wilson, John – MSP	Ma, Andrea – Co-secretary of Cross Party Group on Chronic Pain, Pain Concern
	McGinn, Gordon – Lead Clinician for Greater Glasgow & Clyde Pain Service
Archibald, Susan – Archibald Foundation	Paton, Bill – Chair of ABPI Scotland – Scottish Pain Industry Group, NAPP Pharmaceuticals Ltd
Atkinson, Phil – Editor (Scotland Health Association (Holyrood Communications)	Dr. Roche, Pat – Project Coordinator of EOPIC
Bishop, Doreen – Backcare	Ross, Douglas – Assistant PA to Mary Scanlon MSP
Cadden, Helen – NHS QIS Public Partner for Healthcare Improvement Scotland	Simpson, Anne – National Osteoporosis Society Development Manager (Scotland)
Dr. Dunbar, Martin – Consultant Clinical Psychologist	Sizer, Phil – Pain Association Scotland
Dr. Gilbert, Steve – National Lead Clinician for Chronic Pain in Scotland	Sparks, Linda – Clinical Specialist Physiotherapist, Chair of Physiotherapy Pain Association (North)
Given, Alison – Grunenthal Ltd.	Wallace, Heather – Co-Secretary of the Cross Party Group on Chronic Pain, Pain Concern

Apologies

Paterson, Gil – MSP & Former Co-Convenor	Dr McMenemy, Michael – Project Lead MSK Programme, SALUS Occupational Health & Safety
Dr. Simpson, Richard – MSP & Former Vice-Convenor	Onions, David – Person with chronic pain
	Onions, Pat – Carer for person with pain
Auld, Sandra – ABPI Operations Director	Quadros, Paulo - Intlife
Barrie, Janette – Nurse Consultant for Long Term Conditions	Quinn, Des – Vice Chair of Fibromyalgia Association UK.

Dr. Cameron, Heather – Physiotherapist Professional Lead at NHS	Rae, Colin – Lead Clinician for the Managed Clinical Network in Chronic Pain in Greater Glasgow & Clyde
Elder, Dorothy-Grace – Editor & Founder of the Cross Party Group on Chronic Pain	Rafferty, Judith – Lead Clinical Nurse Specialist
Falconer, David – Director of Pain Association Scotland	Prof. Smith, Blair – Professor of Primary Care Medicine
Green, Katy – Arthritis Care, Area Development Manager	Thomson, Diane - Pfizer Pharmaceuticals Ltd.
Dr. Johnson, Martin – RCGP Clinical Champion in Chronic Pain	Watson, Jacquelyn – Nurse Specialist
Logan, Irene – Fibromyalgia Friends Scotland	Williams, Lars – Consultant in Anaesthesia & Pain Management
MacPherson, Fiona – CNS Chronic Pain	Dr. Wilson, John – Consultant in Anaesthesia & Pain Medicine
MacFarlane, Janet – Fibromyalgia Association UK – Regional Coordinator for Scotland	
Dr. McDonald, Ross – President of the Scottish Chiropractic Association & Chiropractor in Discover Chiropractic	

1. Mary Scanlon MSP welcomed everyone to the meeting and introduced MSP's: John Wilson representing the SNP, Jackie Baillie representing Labour and herself representing the Conservatives.
2. Everyone agreed that the focus should be on early detection of chronic pain and other relevant items should be the Aims & Objectives of the group.
3. Three Convenors were elected and seconded. The Co-Convenors are John Wilson MSP, Mary Scanlon MSP and Jackie Baillie MSP. There will be no need for a Vice-Convenor. The secretarial duties will be shared between Pain Concern and the Parliament.
4. The minutes of March 10 were agreed as an accurate account of the proceedings.
5. Mary Scanlon invited the members of the group to come forward with ideas for the agenda of the group over the next term of parliament, in order that the group can campaign on behalf of people with chronic pain. Please contact Heather Wallace or Mary Scanlon to raise any issues of concern.

5.1 Pat Roche pointed out that there are many banners that chronic pain campaigning could fall under. Mary Scanlon emphasised the importance of a focused approach. Jackie Baillie agreed that parliamentary action is more important than words, especially to maintain services in the current financial climate. An agenda is something all cross party groups should have, and the group could look at all the political parties' manifestos and pick something out from those.

5.2 Mary Scanlon compared chronic pain to mental health in that it's a spend to save policy – the savings outweigh the costs over time. Helen Cadden voiced concern that people with chronic pain could be pushed back to work without being ready, especially as it can be a hidden disorder. Susan Archibald said the priority must be to allow people with chronic pain who want to work back into work.

6. **MCN Update Gordon – Lead of Service in GG&C:** Due to Dr. Gilbert's absence the group proceeded to the Managed Clinical Network update which Dr. Gordon McGinn led. Dr. McGinn introduced himself as Dr, Gavin Gordon's replacement as the National Lead of Greater Glasgow & Clyde and explained that the National Lead Clinician of the Managed Clinical Network is Dr. Colin Rae who was unable to attend the meeting.

6.1 The MCN has been funded for two years, and Camilla Young is the facilitator. It has 5 subgroups: pathways, standards, audit, IT and Education, which runs training courses in primary and secondary care. Although having just started in the post, Dr McGinn thought the MCN was functioning very well and that it would continue for at least the next two years. There is a general desire to roll out the MCN model nationwide. Martin Dunbar said this wasn't the case with executives however, but campaigning needs to be done on the issue as it is proving successful in Glasgow. Evidence on this needs to be gathered to strengthen the group's case.

6.2 Helen Cadden reported on the first meeting of the Scottish pain research community – SPaRC – held on the 31st March with 80 delegates. Clinicians want this to be an annual event, and funding for next year's event is secure. Martin Dunbar highlighted one thing to come out of this event which was the agreement of the work program for the SIGN guideline, which will look at non-medicinal treatments and measuring pain. Helen Cadden said the guideline would be focused on primary care, given that a guideline on living with malignant pain already exists.

6.3 Helen Cadden also updated on the educational subgroup of the national pain steering group, at which Dr. Colin Rae will speak on using the GRIPS report to advise educational reforms. Bill Paton said that Steve Gilbert was keen for the audit group to be reinstated, and Bill thought that from his experience running the audit group in Glasgow, it could improve patient journeys. Mary Scanlon recalled a meeting in May 2006 and how much progress has been made since then.

7. **Chronic Pain Steering Group – The Newly Appointed National Lead Clinician on Chronic Pain – Dr Steve Gilbert:** Mary Scanlon welcomed Steve Gilbert in his new post, and commended

him for raising chronic pain with a petition to parliament originally. Mary invited Steve to update on his role and also to advise on taking action.

7.1 Dr. Gilbert has been in the role for a month and a week. He has a support team in Healthcare Improvement Scotland – two admin staff, a project manager and a medical project manager. Dr. Gilbert is also working with Craig Bell and Rachel Dunk in the Scottish Government, and noted that Will Scott is moving into other areas, but achieved a lot for chronic pain.

7.2 Dr. Gilbert reported that his team were working on a business plan and briefing paper on the pain management service model, to present to regional planning executives of the Scottish Health Service on 30th June. He intended to present an economically attractive package, which would save money in the long term by treating pain properly. He expressed optimism, and said the results would be posted on the chronic pain website.

7.3 Data needs to be gathered on whether health boards have implemented the recommendations of the GRIPS report. A snapshot survey revealed some progress, and an ongoing program of data collection to provide concrete evidence of the benefits of pain management programs. As such the audit group is being reinstated with the next meeting in September.

7.4 Communication is important – clinicians on the ground need to know what the lead clinician, steering group and cross party group are doing, and the website is suitable for this. Communicating with the public and press is important too. Healthcare Improvement Scotland represents a cut from 20 to 6 programs from Quality Improvement Scotland, with pain now a part of long term conditions. Dr. Gilbert attended the long term conditions meeting the day before, where the emphasis was on patient-centred care. The LTCAS has to represent chronic pain as a large component of many long-term conditions.

7.5 **The SIGN guideline:** The steering group has had its first meeting with SIGN with a view to setting up a guideline on chronic pain care. The emphasis would be on training non-specialists in pain to reduce treatment with drugs and injections, in favour of non-pharmaceutical management. The SIGN guideline would have an impact in medical schools and internationally.

7.6 **Scottish Pain Research Community (SPaRC):** The first meeting was on March 31st, which featured ground-breaking research from around Scotland, and communication between clinicians and people with pain. Opioid use is first on the agenda. More dialogue is needed and feedback to

Dr. Gilbert. On the community website, more regional information is needed for patients to access, especially in remote areas.

7.7 **Education and Learning Needs Analysis:** A small sample replied to the Baccus survey, mostly from Fife and Glasgow, with feedback which could help GPs. Lots of educational resources exist across the UK, including those of Pain Concern.

7.8 **Children:** Dorothy-Grace Elder wrote an article critical of children's pain services. The steering group is trying to get a business case approved in this area. Mary Rose from Sick Kids in Edinburgh is coming on to the steering group, and it is going to be given a high priority.

7.9 **Tele-health** is an opportunity for chronic pain, looking at the diabetes service especially. It empowers patients to take control of their own treatment course. **Residential pain management** gained publicity with the number of patients being sent to Bath reported. Both the rate and cost of referrals to Bath is increasing, making it an expensive way of managing people's pain. The majority of patients are referred from Dundee due to the lack of a pain service there. This strengthens the case for pain management programs around Scotland. Recruitment to these might be an issue, as existing ones struggle to recruit psychologists, OTs and physiotherapists. Mary Scanlon asked if there was an update on Nicola Sturgeon looking into whether a residential unit could be justified in Scotland. Dr. Gilbert said that had been delegated to him, and reported that the steering group thought that this would take away attention from providing ordinary pain services around Scotland. The cost is also high, at £10k per patient in Bath, although it's £5k in Bronllys in Wales.

7.10 Mary Scanlon inquired whether Dr. Gilbert could come back with an update on equality of access to MCNs on pain across Scotland. Dr. Gilbert replied he would post an update after 30th June on the managed knowledge network website. Some money from government will remain to start up MCNs, but the rigid structure of MCNs may put health boards off. Dr. Gilbert cited the service implementation group in Fife as an alternative, which employs people already working in pain for some of their time. They have been able to see people more promptly, and hope to have outcome data by September/October. Gordon McGinn agreed that referrals to Bath may not need residential care and are referred due to the lack of local services, but felt that it would be worth getting confirmation of this from the centre in Bath. Dr. Gilbert said he would do this, and noted that Bath record outcome data from their patients.

7.11 Helen Cadden highlighted the Pain Association having to close down its services in areas

where NHS provision is lacking. Phil Sizer of the Pain Association confirmed its self-management training service in Ayrshire had closed due to lack of funding. The service was akin to a non-medical pain management program, which was popular with patients and clinicians, but after 6-8 years operating for free it was no longer tenable. Helen Cadden expressed concern that this left gaps in pain management provision in parts of Scotland. Dr. Gilbert said this was the opposite of the aim of the LTCAS, which is to encourage third sector provision of services.

7.12 Jackie Baillie expressed interest in the Welsh model if it shows that the government has responded to pressure. Given the current climate, gaps in provision will be difficult to fill. Dr. Gilbert recommended checking figures with Mike Winter, director of NSD. Mary Scanlon suggested freedom of information requests as an alternative way of getting information on the national picture.

7.13 Pat Roche proposed that the allied professions could be educated to themselves fill the gaps in provision, and encourage self-care. Mary Scanlon thought this could be included in the SIGN guideline, but this doesn't automatically lead to clinicians adhere to SIGN guidelines. Anne Simpson of the Osteoporosis Society agreed, and provided examples of patients calling their helpline and reporting sub-standard pain management by their GPs. Mary Scanlon highlighted new end life assistance bill, and thought that fear of pain is a major factor in support for the bill.

7.14 Helen Cadden said the voluntary sector is important in helping working age people in chronic pain back to work, and quoted a figure of £10.4bn as the cost of chronic pain to the economy. Anne Simpson wondered why GPs seemed reluctant to refer on patients who ended up coming to charities for help. Dr. Gilbert referred to the difficulty of keeping up-to-date with different specialities, and the time pressure on patient appointments. In medical school, painkillers are taught rather than other means, and GPs may have little time or desire for education. Going straight to the public allows patients to ask their GPs about pain management techniques, as happened in Australia with back pain.

7.15 Heather Wallace of Pain Concern reminded the group that they had an opportunity with the RCGP in making pain a priority over the next five years, with Martin Johnston the clinical champion for chronic pain. Mary Scanlon asked why **chiropractors** seemed so scarce in Scotland. Gordon McGinn gave examples of patients who had developed cauda equine syndrome as a result of manipulation. Linda Sparks commented that manipulation generally doesn't help people with chronic pain, and tends to make symptoms worse. Gordon McGinn thought physiotherapists had a

wider range of therapies than chiropractors who tend to diagnose a twisted spine. Mary Scanlon expressed concern that chiropractors may make symptoms worse, and suggested inviting one to the next meeting as it would be an important and interesting debate. Linda Sparks pointed out that manipulation is better for acute pain, and its effectiveness varies with the type of pain and symptoms.

7.16 A patient's perspective was provided by Helen Cadden, who receives manipulation for cauda equina syndrome, but not at the site of her injury. It helps to relieve symptoms, but the NHS has never paid for it. Linda Sparks added that it is unlikely to see a physiotherapist weekly on the NHS, and there are numerous self-management techniques. Steve Gilbert had invited the chiropractic and osteopath councils to the SIGN guideline but hadn't heard back. The evidence base isn't good for either practice, and the British Chiropractic Association unsuccessfully sued Simon Singh for libel when he pointed this out. At the same time, any treatment helps where the practitioner gives the patient time, attention and perhaps lays hands on them. It's difficult to separate different alternative therapies from each other. Aromatherapy is funded in Edinburgh and it's hard to find evidence for that. Rapid or weekly access to physiotherapy would be great, but patients in primary care can wait 8-12 weeks to see a physiotherapist due to a lack of funding for them.

7.17 Mary Scanlon pointed out that she could learn aromatherapy in 6 weeks but chiropractic takes a four year degree. Steve Gilbert proposed that the ideal scenario is having the right information at the onset of their problem. Treating people can give the impression that they are being fixed, and that decreases self-management, which is the long-term focus.

7.18 Mary Scanlon again expressed concern about manipulation making symptoms worse, to which Linda Sparks clarified that this is manipulation in general, not chiropractors specifically. Steve Gilbert added that a physiotherapist without chronic pain training may exercise the patient which makes pain flare up, but doesn't do lasting damage. He sees patients who say they don't want to see another physio as the last one almost killed them. Pat Roche said she would support bringing in a chiropractor knowledgeable in chronic pain, but that chronic pain treatment is not simply the kind of manipulation chiropractors tend to do. Physiotherapists can focus on soft tissue as opposed to bones and joints, which is important.

7.19 Mary Scanlon didn't want the group to be exclusive to different types of practitioner. Heather Wallace agreed that chiropractors need educating as much as GPs. They use imaging which can scare patients who think that they can't move normally without damaging their spine. Steve Gilbert

said a range of health professionals can give out these negative messages, and that he intended to work with radiologists on the language of their reports.

7.20 Mary Scanlon informed the group that the procedures committee expect cross-party groups to have three meetings per year, with the next two in October/November and February/March [see below for date and time of next meeting]. A chiropractor may be invited. The purpose of the group is to inform parliamentarians. Attendees were asked who they would like to invite to the next meeting. Attendees were reminded of the focus of the group over the next few years, which Steve Gilbert could help inform by identifying gaps in current chronic pain care provision. Steve Gilbert said he'd pass on his next report to Pain Concern to distribute before the next meeting of the cross-party group. Mary Scanlon thanked everyone for coming.

Thank you to Medtronic Ltd for providing refreshments for the group.

The next meeting of the cross-party group on chronic pain will be at 6-8pm, with refreshments from 5.30pm, on Wednesday 26th October 2011, in committee room 5.

Appendix: Agenda of the 15th June meeting

1. Welcome

2. Discussion of the aims and objectives of the cross party group on chronic pain.

3. Election of Office-bearers
   - Co-Convenors
   - Vice-Convenor
   - Co-Secretaries

4. Minutes of Last Meeting Held 10 March 2011

5. Matters Arising

6. The Managed Clinical Network update

7. Chronic Pain Steering Group – The New Appointed National Lead Clinician on Chronic pain – Dr Steve Gilbert will be speaking tonight

8. Any other business