# Scottish Parliament

# Cross Party Group on Chronic Pain

## Minutes of the AGM held on Thursday September 18, 2008

## (Committee Room 4, 1800-20:00)

## AGENDA

1. Election of Office bearers:

- Convenor
- Co-Convenor
- Vice Convenor(s)
- Treasurer
- Secretary

2. The purpose of the Group

3. Minutes of meeting held on February 26, 2008.

4. Matters arising.

5. NHS QIS and its role after the GRIPS report: what is the way ahead? Dr Mike Serpell, consultant in pain medicine, will introduce this topic and update the group on developments.

6. The Managed Clinical Network: Dr Gavin Gordon, consultant in pain medicine will update the group on the work being done in Glasgow and Clyde.

7. Impact of the 18-week referral to treatment target.

8. The Chronic Pain Policy Coalition: an update on recent activities.

9. Scottish Medicines Consortium.

10. Any other business.

## Present

- Scanlon, Mary – Convenor
- Paterson, Gil – Co-Convenor
- Atkinson, Phil, Holyrood Communications
- Bannister, John, Ninewells Hospital
- Basler, Michael, NBPA, Glasgow Royal Infirmary
- Bishop, Doreen, BackCare Lothian Branch
- Brett, Mick, Medtronic
- Cadden, Helen, NHS QIS public partner
- Colvin, Dr Lesley RCA Scottish Board
- Craig, David, Southern General Hospital
- Deehan, Maureen, Grunenthal
- Dinwall, Andrea, Pfizer
- Dunbar, Dr Martin, Stobhill Hospital, Glasgow
- Gilbert, Steve, Queen Margaret Hospital, Fife
- Gordon, Gavin, Victoria Infirmary, Glasgow
- Green, Katy, Arthritis Care
- Elder, Dorothy Grace, Past Convenor Cross Party Group
- Hughes, Sally, Napp
- McMenemy, Mick, GGHB Back Pain Service
- Mcpherson, Fiona, CSN, Western General Hospital
- McWhirter, Graham, Medtronic
- Marples, Ivan, Western General Hospital,
- Edinburgh
- Mauntford, Jonathon, Medtronic
- Quadros, Paulo Intlife Pain Management Services CIC
- Ritchie, Andrew, Morhamburn
- Thomson, Diane, Wyeth Pharmaceuticals
- Thomson, John, Patient
- Waddell, Helen, Pain Concern
- Wallace, Heather, Pain Concern
- Wilson, John, Royal Infirmary of Edinburgh

## Apologies

- Barrie, Janette, Nurse Consultant, Long Term Conditions, NHS Lanarkshire
- Hester, Joan, British Pain Society
- James, Sabu, Monklands Hospital
- Lafferty, Gerry, Patient
- Lopes, Victor, Edinburgh Dental Institute
- Mackenzie, Pete, NBPA, Southern General Hospital
- Power, Professor Ian, Edinburgh University
- Prowse, Professor Morag, Napier University
- Rafferty, Judith, Ninewells Hospital, Dundee
- Smith, Professor Blair, Aberdeen University

Mary Scanlon MSP (Con) opened by welcoming everyone to the meeting. Ms Scanlon then proceeded to introduce the other MSPs present:

- Gil Paterson MSP (SNP)
- Christine Grahame MSP (SNP and Convener of the Health and Sport Committee)
- Richard Simpson MSP (Lab and member of the Health and Sport Committee)
- John Wilson MSP (SNP)

Ms Scanlon then acknowledged the attendance of Ms Dorothy Grace Elder, former MSP and past convener of the Cross Party Group (XPG), before noting that Dr Peter Mackenzie (Chair, NBPI Southern General Hospital Glasgow) had withdrawn due to illness.

Item 1: Election of office bearers

1.1 Ms Scanlon then moved on to the first item on the agenda: election of office bearers.

1.2 Mary Scanlon and Gil Paterson were once again nominated for the posts of Co-Conveners (seconded and accepted). Dr Richard Simpson was nominated for the post of Vice-Convener (seconded and accepted). Helen Waddell and Heather Wallace (Pain Concern) were nominated to form the CPG Secretariat (seconded and accepted).

Item 2: Purpose of the Group

2.1 Ms Scanlon then commented on the “excellent turnout” of MSPs. This, she stated, illustrated the level of interest in chronic pain. She then paid tribute to Ms Dorothy Grace Elder and her work in setting up the CPG. Ms Scanlon added that CPG membership was made up of those on the frontline of pain services – who were best able to advise Scottish lawmakers on issues and concerns facing those with persistent/chronic pain in Scotland.

Item 3: Minutes of meeting held on February 26, 2008

3.1 Minutes accepted.

Item 4: Matters arising

4.1 Continuing the meeting: the next item discussed was the meeting between the Cabinet Secretary for Health and Wellbeing Nicola Sturgeon and Dr Pete Mackenzie to discuss the way forward for pain services in Scotland. Given Dr Mackenzie's absence, Ms Scanlon asked for anyone else present at the meeting to provide feedback.

4.2 Several representatives (who had either been present/or were able to indirectly report on the progress of the meeting) stated that it would appear that the Cabinet Secretary has made a commitment to recognise chronic pain as a long-term condition. Those assembled were also informed that the Cabinet Secretary also made a visit to the Southern General Hospital where she was able to meet four or five (Outpatient Department) patients who were able to discuss their conditions with her. Dr Gavin Gordon (Victoria Infirmary, Glasgow) also informed the CPG that the Cabinet Secretary had subsequently spoken at a Pain Association meeting. Continuing, Dr Mike Serpell, Consultant in Pain Medicine, informed the Group that the Cabinet Secretary's speech before the Association had been "very supportive" and that it would appear that the "government spotlight" was now on the condition.

Item 5: NHS QIS and its role after the GRIPS report

5.1 Dr Serpell informed the CPG that GRIPS 2 was ready for launch; that the foreword had been supplied by Ms Sturgeon, Cabinet Secretary for Health and Wellbeing. Dr Serpell added that NHS QIS' Jan Warner was interested in launching the document soonest to ensure a continued spotlight on pain.

5.2 Dr Serpell stated that there now was momentum behind addressing needs of patients with chronic pain, adding that the consensus of opinion was that it was important to maintain this momentum. Conversation then moved onto the topic of "lobbying". Here Dr Serpell noted that the CPG had no autonomy outside Parliament. One option, he suggested, was forming a subgroup within the Chronic Pain Policy Coalition (CPPC). A further option, he offered, was the formation of lobbying groups within Managed Clinical Networks (MCNs), for example: Diabetes, Cancer MCNs. He then observed that it would be up to the CPG to decide the avenue that would best serve its needs.

- Action points:

5.3 Dr Serpell then reiterated that there was an impression of optimism, adding that there were five items of ongoing activation:

1) Education: NHS QIS is active - including in competencies in prescribing.

2). Information technology: current debate on pain pad as a tool. (Pain pad: a database developed by Ian Merrylees where core data is generally filled in by healthcare workers).

3). Local MCNs – West Coast MCN under the chair Dr Gavin Gordon.

4). Pain pathways – setting up of Pain Management Pathways (PMPs) mooted.

5). Telemedicine.

5.4 Ms Dorothy Grace Elder then asked for clarification on exactly what had been promised by the Scottish Government - in terms of funding and timescales.

5.5 Dr Gavin Gordon (Victoria Infirmary) stated that MCN had been set up on the back of the McEwen Report. Glasgow Health Board, he stated, had applied to set up a Pain MCN given that provision already in place locally was virtually the same as that of an MCN. He then stated that the funding would be £100,000 over two years, noting too that in terms of finance - budgets had been devolved back to health boards to manage and implement.

5.6 Ms Dorothy Grace Elder – referring to the £100,000 mentioned by Dr Gordon – stated that this was in fact "old money", that no new sums had been put in place for an MCN.

5.7 Dr Gordon stated that the West of Scotland MCN was pilot and that he hoped other healthboards might contribute.

5.8 John Thomson (patient) observed that, while it was "fine to have specialised pain clinics", the onus was also on GPs who actually deal with people in community settings to learn about pain. It was also necessary, he continued, to get chronic pain onto the chronic conditions indication in GP clinics. Here it was also observed that this might be something Holyrood lawmakers might like to look into.

5.9 Dr Gordon stated GRIPs is a Scottish report, however, he acknowledged that much of the provision is concentrated in the West of Scotland. A concentration of services is required *across* Scotland, he said, before observing that some good work was being conducted in the south of Scotland, adding that Highland was close to putting in place two posts.

5.10 While agreeing that MCNs are important, Dr Richard Simpson stated that one needed to decide how many were required. He also offered that there was a need to get GPs involved, adding that consideration also should be given to addictions and the pain link: basically how to manage pain in someone with an opiate addiction.

Referring then to funding (raised by Dorothy Grace Elder and Dr Gordon), Dr Simpson stated that having been in government in the past – the current Scottish administration is dealing with "a tight Spending Review". There is money, he said, and this could come from the two per cent efficiency savings.

5.11 Ms Christine Grahame MSP then offered up a three-part question for consideration:

i) Referring to data collection, she asked what is available across NHS boards?.
ii) Resources: what resources were available to NHS boards – both in terms of financial as well as personnel.
iii) Resources – this time available from the voluntary sector.

5.12 Ms Grahame then stated that it might be useful for MSPs to know how many (if any) chronic pain consultants were within their constituency/region. She then suggested that the CPG might consider (as has been done before by other CPGs or organisations) that the CPG organise a night with MSPS. For example, patients from Perth or the Borders would have the chance to meet with three to four MSPs from their region. This, she said, would allow patients to raise awareness among MSPs and would ensure that the issue of chronic pain did not "gather dust". One should, she said, use GRIPS to target MSPs, adding that it might be useful for consultants to be present to make contact with MSPs too.

5.13 Ms Grahame then stated felt that she had felt "rather uninformed" on the matter of chronic pain and thanked Ms Scanlon for inviting her to the meeting.

5.14 Moving on, Helen Cadden (NHS QIS public partner) stated that QIS was committed to standards. However, while the public demanded a unified chronic pain service, there appeared to be no evidence-base to come up with unified standards for health boards to work with. In short, she said, there was no consensus among clinical staff across Scotland which made it difficult to come up with the standards everyone wants.

5.15 Responding, Dr Richard Simpson stated that the CPG could ask NHS QIS what the problem is:

i) If standards are not being adopted – then why (are there standards but which cannot be agreed upon).

ii) Use the CPG/MSP(s) to drive forward.

iii) What are the gaps – here a letter could be written to an MSP (with the required detail) and this could also help drive forward the adoption of (unified) standards.

5.16 Dr Gordon then stated that there were differences in what constituted standards. One also had to consider not just clinical

standards, but also administration. What was required, he concluded here, was a business plan on how best to tackle this. NHS QIS could perhaps step in and drive forward.

5.17 Ms Grahame then took the floor once again. She reiterated the questions that she had asked earlier during the course of the meeting (regarding data, resources/personnel). She then stated that if the CPG wished to drive chronic pain up the agenda then they should plot a "campaign". By way of example, she stated that the CPG could lodge (or encourage) a petition with the Public Petitions Committee on a specific issue and this might be referred up to the Health and Sport Committee.

5.18 Referring to back pain services, Dr Mike Basler (Glasgow Royal Infirmary), stated that great moves had been made to recognise chronic pain. However, what MSPs still needed to know was that sometimes their constituents did not receive the same treatment as the same person "down the road". In terms of the back pain service in Glasgow, he stated that a GP in Glasgow can self-refer a patient in two weeks. A patient from Paisley would not, however, receive such a service – and this is despite both patients being within the same health board area. Telemedicine (a topic raised briefly earlier on in the meeting) should also be used he stated. He concluded by referring to a patient from Mallaig who required treatment – stating that this patient should be able to receive treatment locally rather than having to be referred to Glasgow.

5.19 Ms Dorothy Grace Elder then reminded the CPG that it was six years since the SPICE (Scottish Programme for Improving Clinical Effectiveness in Primary Care) report on pain services was published. It was also six years since the first Health Committee voted for chronic pain facilities throughout Scotland. Referring to the 2004 McEwen Report on chronic pain services in Scotland, more work, it was felt then, was required to improve chronic pain care provision. Today, she said, real political work is still required given health boards in Scotland are still sending patients elsewhere (Manchester, Bath) for treatment.

5.20 Dr Richard Simpson stated that the CPG should call on the Cabinet Secretary for Health and Wellbeing to do something concrete in this area.

5.21 Dr Mike Basler pointed out that the GRIPS report was accompanied by a CD-ROM which contained information on health boards and the sort of services provided.

5.22 Christine Grahame MSP reminded Dorothy Grace Elder that (according to her statement) that the first course of action had been taken in 2002, six years ago. There was now, said Ms Grahame, a number of new MSPs – who could be informed of the gaps and about how they could work for patients (suffering chronic pain). She then informed the CPG that FOI (Freedom of

Information) is another useful tool and this could be used to determine what is happening in Scotland's health boards.

*(Items 6.1-8.2 supplied in written format by Dr Gavin Gordon given that the CPG had little time to discuss)*

Item 6: The Managed Clinical Network: Update supplied by Dr Gavin Gordon, consultant in pain medicine, on the work being done in Glasgow and Clyde.

6.1 The MCN for pain management in Glasgow and Clyde is taking shape. Although a difficult concept to define, it is easy to state the way in which it works.

6.2 Our Health Board oversees the process which starts as a series of meetings in which all interested parties including the voluntary sector and patient representatives as well as primary care and community groups get together to map out how we can improve pain services in our area. This provides a structure and an impetus to change things collectively.

6.3 We have identified five areas we wish to tackle.

- Planning and strategy: To set out our stall for the next two years and beyond
- Standards: So we can assess our service and its progress.
- Education: In theory for as many groups as we can – from patients/carers to doctors at all levels.
- Pathways: To simplify the patient journey where possible
- IT: To underpin all the above developments.

6.4 The MCN in Glasgow and Clyde was supposed to be a pilot for Scotland. To that end I asked for anyone interested in contributing from beyond our Health Board to contact me so we might develop generic guidance for anyone thinking of setting up a similar service elsewhere. Given the demography of Scotland I want to avoid the temptation of thinking that what is good for Glasgow is good for the rest of the country. So far I have had one volunteer (from Tayside) when I hoped to have more. If you know of anyone who might be interested please contact me.

Item 7: Impact of the 18-week referral to treatment target (Dr Gavin Gordon)

7.1 The new Scottish Government has introduced targets for patient services under the heading 18RTT. By the end of 2011, they wish all patients to be seen i.e. attend for consultation and treated within 18 weeks for referral – hence 18 weeks referral to treatment or 18RTT. My concern is the definition of treatment, which for us is a process rather than an event. No information is as yet forthcoming on how this will be defined but my concern is that they will focus on physical treatments like injections, which by no means benefit

everyone and ignore other, perhaps more important areas such as physiotherapy, psychology etc. which may have long waiting times. Of course these last two specialist treatments (and others) at least in our health Board are the forgotten ones and I would be loathe to sign up to the notion that because patients can seen and injected, say, within 18 weeks, that this represents much progress if the same patients are still waiting far longer for other treatments.

7.2 I (Dr Gordon) would like this flagged up and wonder if the MSPs might be in a position to carry this point forward or find out how this is being tackled.

Item 8: Scottish Medicines Consortium

8.1 The SMC though not by any dint of our efforts have agreed to include Lidoderm Plasters as second line treatment for Post Herpetic Neuralgia. This will get the medication onto formularies and probably make life easier and probably less painful at least for some. Similarly, our Health Board, who has long opposed the inclusion of the moderately strong painkiller Tramadol on its Formulary has now agreed to its entry.

8.2 One area worth exploring is whether we can mount an alliance to promote pain management beyond the cross party group to a wider audience and perhaps tackle the issue of submissions or background research to the SMC in the first place.

8.3 Taking questions from the floor: on the Scottish Medicines Consortium (SMC), Dr Gordon was asked about Coproxamol. Dr Gordon stated that the license had been withdrawn, however, it would appear that it was still available on private prescription. He concluded with the statement that he would refer the matter back to his pharmacist and inform the CPG.

8.4 Gil Paterson MSP, referring to waiting times, asked Dr Gordon if he had any solutions. Dr Gordon stated that he had mixed feelings on targets. He also stated that some waiting times – such as for psychology – had been hidden.

8.5 Dr Simpson asked if there was a SIGN guideline on pain. If not, he said the CPG could approach SIGN. Response from the floor indicated that there were no such guidelines (apparently SIGN does not have recommendations for the pharmacological management of pain).

9 Chronic Pain Policy Coalition

9.1 The Coalition's newsletter had been circulated to members of Cross Party Group.

10 Action points

10.1 Concluding the meeting, Ms Scanlon stated that action would be taken on the following points:

- An event would be organised in the Garden Lobby (probably spring next year)
- Ahead of any such event – an update on pain services in each health board area would be required (Pain Concern's Helen and Heather asked to action, reminded that data is contained in CD-ROM accompanying GRIPS report).
- Cabinet Secretary Nicola Sturgeon to be invited to address Garden Lobby meeting.
- SIGN/NHS QIS to be approached on the matter of clinical standards.

10.2 Ms Scanlon then stated that one in five Scots experience chronic pain. This is a huge drain, not just on the NHS but also in terms of benefits.

10.3 There is therefore a need, she observed (taking up Christine Grahame's points and advice) to ask PQs, seek further information on SIGN/clinical standards. There was also a need for a Member's Debate on Chronic Pain.

10.4 There would be a staggered campaign to raise awareness about chronic pain. The last debate, she reiterated, was six years ago. There were now new MSPs in the Chamber. The campaign programme would therefore take in the following elements:

- Member's Debate
- Garden Lobby Event
- Petition

10.5 On MCNs, Ms Scanlon concluded the meeting by stating that MCNs such as the one led by Dr Gavin Gordon (West of Scotland) could be rolled out throughout Scotland.

## Garden Lobby event has been confirmed as 22nd April 2009, 6pm-8pm

## The Cross Party Group is grateful to Medtronic for sponsoring the cost of refreshments and to Napp, Grunenthal and Pain Concern for sponsoring travel and administration costs