

MINUTES: CROSS PARTY GROUP ON CHRONIC PAIN MEETING AND AGM
June 25, 2014

Note: All Holyrood's CPGs had unexpected problems on June 25 and some cancelled because Parliament sat until 7.15pm. Our CPG went ahead, the conveners asking DG Elder to chair the first informal part of the meeting, until they arrived.

The Group warmly welcomed the appointment of a new clinical lead on chronic pain - Professor Blair Smith, who talked informally and answered questions. He is well known to most of the CPG but to recap: Blair is an academic General Practitioner and Professor of Population Science at the University of Dundee. He also practices clinically as a Consultant in Pain Medicine at Ninewells Hospital. He chairs the Research Sub group of the National Steering Group on Chronic Pain and the Scottish Pain Research Community (SPaRC) and his own research is published widely.

Blair outlined his background, starting as a GP in the Peterhead area, and his long interest in the need for improvements for those suffering chronic pain.

He recalled that he joined the CPG and supported our aims from early days, recalling that he had supplied research to help the first debate on chronic pain held in February 2002, which had 130,000 responses and started Parliamentary focus on chronic pain.

He was happy to see that a key CPG aim he supported, creating the first Scottish Residential Centre of Excellence, had now been accepted by the Scottish Government and that the first patients are due from January 2015 at Glasgow's Gartnavel Hospital. This would spare patients needing 2 – 4 weeks of treatment from being sent as far as Bath in Somerset. Blair confirmed his role would involve helping the new residential service when he could.

He agreed to numerous points made by CPG members, especially patient members, that the extensive waiting lists for Chronic Pain Day Clinics, (Level 3) were of urgent importance as well as improvements for GP/Primary Care Services. Replying to questions, he said he had, like the CPG, believed that the Steering Group would pursue the Level 3 problems as well as primary care. Members referred to the Healthcare Improvement Scotland Report which revealed patients waiting many months, sometimes up to a year or over two years to see some specialists.

Blair pointed out that he was assigned to only half a day of work per week as lead clinician. He hoped that his University commitments might give him more time later but said that he was part of a team being funded for the Steering Group as a package. This consists of Paul Cameron, physiotherapist, from Fife on 2 full days a week in a new post of National Co coordinator; Mary Harper; chair on half a day and Emma Graham as administrator.

Members expressed concern about Blair's "half day" working time. This was the first time they'd heard that, having assumed the new lead clinician would be on two days per week, like his two predecessors.

Blair heard from the CPG that the new Glasgow South hospital complex would treat teenage and young adult chronic pain patients, both residentially and at day clinics. He had not been informed of this by officials and would welcome hearing from the CPG.

Action: DG Elder to forward to Prof Blair Smith details of youth chronic pain services from Greater Glasgow & Clyde Health Board announced in 2013 and 2014.

Blair received applause and was thanked by everyone for speaking to us on a busy day for him and wished well.

Meeting formal AGM– Co conveners Jackie Baillie MSP and John Wilson MSP arrived from the late Parliamentary sitting. Jackie Baillie chaired.

Jackie Baillie and John Wilson were unanimously re-elected as co conveners.

Jackson Carlaw MSP could not make the AGM but had intimated he was ending his term of office. Members recorded appreciation of Jackson's years of service and support and were glad to learn that he wished to remain a member. (Applause)

Jacque Forde, voluntary secretary, was resigning due to recent health problems which prevented her attendance at the AGM. She wrote that the Group had made "remarkable achievements for pain patients", thanked members for their support of her and wished to remain a member. The Co conveners recorded thanks to Jacque for her hard work. (Applause)

Dorothy-Grace Elder was elected voluntary secretary unanimously.

Minutes of the AGM of May 29, 2013 were approved unanimously.

Minutes of the CPG meeting of April 1 2014 were approved unanimously.

Meeting: normal business.

The co conveners were given details of Prof Blair Smith's talk earlier and agreed with the CPG's concern over his contract being for half a day a week. They had no knowledge of this, nor of there being a new appointment to the Steering Group of a chronic pain coordinator for two days a week. Several members said a major problem was that there was little transparency about the Steering Group and it was extremely difficult to find out what they, or the Service Improvement Groups (SIGs) were doing.

The meeting heard that no minutes of the Steering Group had been published since December 2013 to date (June 25), but there had been two subsequent meetings in February and May 2014. Also, ten out of 14 of the Service Improvement Groups had still not made public their plans to improve services in local Boards. Plans had been promised for publication since April in a Parliamentary reply by Michael Matheson, public health minister, to Jackie Baillie MSP.

Jackie Baillie said lack of information from the National Steering Group was long standing and unacceptable. She was particularly concerned to discover if the local SIGs would deal with the priority issue for patients of long waiting lists for appointments at pain clinics. Members agreed that this must be addressed as a priority, following the Healthcare Improvement Scotland report in April 2014 showing waiting lists of, e.g., up to 2.5 years in some areas for a clinical psychology appointment.

The meeting agreed to send questions to the new chair of the Steering Group, Dr Mary Harper and a copy of the CPG's briefing on the current shortages.

Action: DG Elder, Secretary.

Secrecy.

The above led to a discussion on secrecy. Several patients have already lodged complaints over the failure of SIGs or Edinburgh officials to respond or provide information when they tried to volunteer as patient representatives for SIGs or the Steering Group. But a health professional outlined a similar experience and had become so concerned she travelled from Aberdeen to inform of facing "remarkable secretiveness" after asking about the local Grampian SIG.

Ms Kathleen Powderly, a former NHS nurse and midwife, now an acupuncturist, wanted to know what Grampian's SIG would do. Grampian was of particular concern to the HIS report, which stated that it had, at 31 weeks, the longest waiting times for first appointments in Scotland.

Ms Powderly said she had served on the SIGN guidelines for two years, was enthusiastic about SIGs, and wanted some information for patients and herself, having contemplated volunteering. She said what resulted shocked her as, repeatedly, she encountered extreme reluctance to provide information. She'd had "seven wasted months, including being passed from pillar to post, with no one willing to provide ordinary information" The first few months involved no reply to emails (a pattern similar to non replies to patient volunteers, two CPG members pointed out). Ms Powderly re-contacted, and the Chronic Pain Co ordinator, Paul Cameron, referred her to the website www.chronicpainscotland for local SIG information. But Grampian was among the ten SIGs which haven't put their plans online. All she sought was an informative call or email. Instead, she was next invited to two meetings with Grampian's SIG leaders. She found

this “a waste of everyone’s time” as basic questions still weren’t answered. She also ended up concerned for patient representatives, as to whether they are encouraged to speak up.

Ms Powderly instanced that two patient representatives were invited by officials to one meeting with Ms Powderly and a doctor. But one patient informed her that they couldn’t discuss the SIG they were on, without saying why. Ms Powderly was concerned that two pain sufferers had been troubled to travel to a meeting at which both sat silent, apart from one patient saying that the doctor should not be asked questions about the SIG. Only the doctor spoke but while being reluctant to discuss, revealed that the Grampian SIG will not deal with Level 3 waiting lists (31 weeks for first appointment in Grampian) Their chosen priorities are instead Level 1, patient leaflets/info and Level 2, GPs.

Ms Powderly found the whole atmosphere unacceptable and emerged concerned that patients who had been selected by the SIG leadership may not been informed that asking questions of an NHS doctor is acceptable!

From being enthusiastic over SIGs, Ms Powderly said her experience ended with serious doubts over how they are run, after finding secrecy and “extreme unwillingness” to inform the public on what should be a positive helpful matter. She wondered if this atmosphere affected all SIGs and the Steering Group and what had gone wrong. Her experience was that volunteers may be discouraged if they weren’t picked by the system.

The meeting thanked Ms Powderly for travelling from Aberdeen to express her concern after discovering about the CPG. The meeting agreed to add questions on information blocking and selection of volunteers to their questions to the chair of the Steering Group.

Action: DG Elder

Next meeting: In view of the referendum in September, members were warned that the next meeting date is likely to be delayed to another month.

Action to arrange: DG Elder.

Tea, coffee and biscuits paid personally by DG Elder. (£60)

