

Approved Minutes CPG on Chronic Pain, Wed. October 26 2016

**SCOTTISH PARLIAMENT'S CROSS PARTY GROUP ON CHRONIC PAIN.  
Minutes of the meeting on October 26, 2016.**

**Welcome:** Patients, hospital staff and other health professionals and carers were welcomed by MSP Elaine Smith, who chaired the first part of the meeting. Some present mentioned a smell of paint or varnish in the committee room, Elaine became unwell with this, having to leave. MSP Rona Mackay took over chairing the rest of the meeting.

**OFFICE BEARERS ELECTED:** The meeting welcomed our new office bearers who were elected unanimously and thanked for their commitment. All have concerns about long-term conditions. The fifth Parliament sees the 16<sup>th</sup> year of the group's work. (All Holyrood's CPGs had to delay meetings from the March dissolution of Parliament until the autumn.)

Co conveners: Elaine Smith, MSP; Labour, long term campaigner for pain patients; Rona Mackay SNP, special interest in chronic pain; Miles Briggs MSP, Conservative Public Health spokesperson. Deputy convener: Anas Sarwar, MSP, Scottish Labour Health Spokesperson.

Voluntary secretary re-elected: Dorothy-Grace Elder.

(Other MSPs supporting as members include Alex Neil, former Health Secretary; Willie Rennie, Scottish Lib Dem leader; Donald Cameron, Conservative Health spokesperson; Jackie Baillie, Labour, former co convener; Bill Kidd, SNP, former co convener.)

**Minutes approved of our meeting on March 2, 2016.**

**LIGHTBURN HOSPITAL PROPOSED CLOSURE, and REMOVAL OF BEDS FROM THE CENTRE FOR INTEGRATIVE CARE (CIC).**

Campaigners stressed that these two hospitals are among the few facilities dedicated to long-term conditions, including chronic pain. MSP Anas Sarwar, Ivan McKee MSP and Campaigners from "Save Lightburn", Gerry McCann and Tanith Muller of Parkinson's UK and Catherine Hughes and Christine Martin of the CIC campaign, spoke strongly against these cuts. They deplored such serious threats to services being rated "minor change" by Greater Glasgow & Clyde Health Board.

The backing of the majority of the Scottish Parliament against the threats to services was won in September 2016 through a motion by Anas Sarwar MSP. (Cuts and closures proposals not only affected Lightburn and the CIC but cleft surgery in Edinburgh, maternity care in the west of Scotland and the children's

ward in the Royal Alexandra Hospital, Paisley.)

Anas, now deputy convener of the CPG, told the meeting: "Parliament voted for all cuts proposals to be called in, classed as major change and handled personally by the health secretary rather than be controlled by Boards. Otherwise, the will of Parliament is being defied. I will continue the fight, whatever the setbacks"

CIC patient Christine Martin said protests must be sent to Government "showing condemnation of the term minor service change as entirely wrong and insulting over the proposed closure of Lightburn Hospital and the downgrading of the CIC to an outpatient clinic." The following resolutions were sent to the Health Secretary and the Public Health Minister by Elaine Smith MSP.

Resolution 1: The proposals to close Lightburn Hospital and remove beds from the Centre for Integrative Care (CIC) are harmful and unnecessary. These service changes should never have been categorised as 'minor service changes' and the group urges that such decisions be categorised as 'major service changes' in future, and as such should be dealt with by the Cabinet Secretary for Health and Sport.

Resolution 2: To urge the Scottish Government and the Scottish Health Council to halt the flawed engagement processes that pertain to Lightburn Hospital and the CIC. The Cross Party Group on Chronic Pain condemns these processes as farcical, and recognises that a number of MSPs and patient representatives see the process as undemocratic and biased.

NOTE: Please see below the letter sent on the CPG's behalf by MSP Elaine Smith to Shona Robison, Health secretary and Aileen Campbell, public health minister. Note that the reply is by the Scottish Health Council, not the ministers. The reply does not answer specific examples of poor engagement raised at the CPG meeting, such as health board officials dominating meetings, including sending the official who is the architect of the cuts to chair patient meetings at the CIC. And only two meetings over Lightburn.

**WAITING TIMES AT SCOTTISH CHRONIC PAIN CLINICS.** Provisional Waiting Times are now published quarterly on the Information Services Division (ISD) website after a long, difficult campaign by the Cross Party Group which had to use FOI legislation after numerous refusals.

The quarterly figures now issued by ISD have proved difficult to understand, even for NHS personnel as well as patients.

Provisional results are that the "guarantee" of new clinic patients being seen and treatment starting within 18 weeks of referral by a GP to a specialist NHS pain clinic is not being met in all 14 health board areas, large and small. DG Elder has investigated with ISD who said they would try to make future figures more clear. Figures are "developmental".

To simplify, several thousand new patients not seen within the 18 week timeline in a quarter have to be added to the 5,000 or so new patients referred during the next quarter. (Scottish totals). Only six boards out of 14 usually report 100 per cent compliance with seeing all new patients on time. But compliance is not good news for return patients, numbering thousands more.

The secretary confirmed that return patients are not being counted. The CPG has had return patients stating that they are being pushed further down the waiting lists. NHS Lanarkshire is 100% on time with new patients but return patient Liz Barrie from Lanarkshire, present, had a letter confirming that giving priority to first time patients meant more delay for her, as a return patient.

She said: “Some time ago it took me two years from GP referral to get in front of a specialist. I was then offered a successful treatment. But I had to wait another two years to see the same excellent consultant. There are still only two pain consultants for the whole of Lanarkshire, which has one of the highest incidences of chronic pain. Funding and staffing are what needs to be tackled, not tick boxing to pass targets for first time patients”

She said “The staff try everything to help but there’s just too few staff and a huge number of patients”

The Group applauded Liz when they were informed that she had made huge efforts to cut prescribed medication on top of her injections. She thought it wrong that Lanarkshire had barred patients from using the CIC as complementary methods were working for her, albeit that she could not access the CIC due to her Board’s refusal to fund Lanarkshire patients.

Another Lanarkshire patient, Fiona Robinson, who had over a year ago gained the assistance of the CPG in ending huge gaps between renewal of her Lignocaine injections, (at a conventional service) said she was again concerned about delay. “Treatment on time gives me a life; it is wonderful. But delays are once more feared” she reported.

## **SECURITY & HIDDEN MOVES**

Difficulty for patients, MSPs and health professionals gaining basic information to try to help chronic pain patients was criticised by the meeting as a continuing problem. The secretary said experience was that lack of openness was puzzlingly extreme with chronic pain, even compared with other health issues.

The meeting discussed having to use FOI to gain Waiting Times. When the CPG asked the secretary to FOI all 14 Boards when Waiting Times were refused last year, 13 out of 14 Boards responded. Only NHS Dumfries & Galloway kept refusing, even under FOI legislation. The CPG then asked the

secretary to complain to the Scottish Information Commissioner.

DG Elder reported that total effort lasted many months and a volunteer was up against paid officials. But she gathered detailed evidence and the complaint was won. NHS Dumfries & Galloway were found to have breached FOI Scotland legislation on two sections. The Commissioner drew attention to proving that this board held its Waiting Lists all along, while their Chief Executive wrote to the CPG claiming they did not have them (which the Commissioner later proved wrong) Huge delay resulted. The CEO eventually wrote saying that the Information Services Division, ISD, In Edinburgh had agreed with a request from NHS D & G that ISD would handle the FOI. The CPG queried this as the FOI was for NHS D & G - who had compiled figures originally and sent them to ISD. Full circle. The CPG was then forced to re-apply to ISD. More delay.

As a patient group, the CPG was put through a long and unnecessary ordeal for asking a question about Waiting Times for patients.

The Commissioner was limited to a finding on FOI, not on the status of Codes of Conduct and ethics in public life.

But the Commissioner's investigation also revealed that, while being refused Waiting Times wrongly, the Group's FOI had also been subjected to secretive actions thwarting their request. Some 27 NHS staff had their time interrupted by behind scenes moves stretching from NHS Dumfries & Galloway to their contacts in Edinburgh. An email trail released by the Commissioner to the CPG showed this. Members present thought this outrageous and called for a complaint to be lodged with the head of NHS Scotland requesting that this be investigated to ascertain if Codes of Conduct and ethical standards in public life had been breached. Patient John Thomson complained that it was shocking to see NHS time wasted rather than aiding patients. Action: MSP representative to forward a complaint from the CPG.

The honorary secretary was thanked for pursuing this from November 2015, a difficult task.

ATTENDANCE: 45 people.

MSPs PRESENT

Elaine Smith, Anas Sarwar, Rona Mackay, Ivan McKee

STAFF OF MSPs

Roseanna Murphy, Greens, Douglas Pattullo, Conservatives.

## NON MSPs

Gerry McCann, Tanith Muller, Peter McCarron, Dr Andreas Kelch, Dr David Weeks, Heather Goodare, Catherine Hughes, Anne Hughes, Fiona Robinson, Nicola McEvoy, Mairi O'Keefe, Maureen McAllister, Laura Clark, Anne Murray, Christine Martin, Mary Craig, John Thomson, Moira McGuigan, Ian Little, Mohammed Nadeem, Tasneem Nadeem, Janette McDowall, Ken McDowall, Irene Loudon, Martha Heaney, Dr Jacqueline Mardon, Carol Fairley, Carol Carter, Patricia Donnachie, Elaine Hamilton, Arlene Byrne, Geraldine McGuigan, Liz Barrie, Gordon Barrie, Dorothy-Grace Elder, George Welsh, Rosalind McMillan, Alison McGinty, Sheila Gillies.

## ORGANISATIONS REPRESENTED

Parkinsons, UK and Scotland; Leuchie House respite centre; Arthritis Care Scotland; Save Lightburn Campaign, Centre for Integrative Care Campaign.

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On 9 Nov 2016, at 11:26, Smith EA (Elaine), MSP wrote:  
FAO Cabinet Secretary for Health & Sport and Minister for Public Health & Sport

Dear Shona and Aileen,

### **Cross Party Group on Chronic Pain**

Having partially chaired the first meeting of the CPG on Chronic Pain as a co-chair this session I have been asked to write to you following the meeting.

Current CPG MSP Members are myself, Alex Neil MSP, Willie Rennie MSP, Anas Sarwar MSP, Rona Mackay MSP, Miles Briggs MSP, Jackie Baillie MSP, Donald Cameron MSP and Bill Kidd MSP.

At the meeting on 26<sup>th</sup> October the CPG including a number of MSPs, medical professionals, and representatives of health charities passed resolutions stating:

Resolution 1: The proposals to close Lightburn Hospital and remove beds from the Centre for Integrative Care (CIC) are harmful and unnecessary. These service changes should never have been categorised as 'minor service changes' and the group urges that such decisions be categorised as 'major service changes' in future, and as such should be dealt with by the Cabinet Secretary for Health and Sport.

Resolution 2: To urge the Scottish Government and the Scottish Health Council to

halt the flawed engagement processes that pertain to Lightburn Hospital and the CIC. The Cross Party Group on Chronic Pain condemns these processes as farcical, and recognises that a number of MSPs and patient representatives see the process as undemocratic and bias.

In addition, a number of serious flaws in the consultation process were highlighted by patients who were in attendance and include:

- Stakeholder Groups being dominated by members of Greater Glasgow and Clyde Health Board. E.g. Seven out of the thirteen members that attended the Lightburn Stakeholders Group were minuted as Board members.
- The exclusion of patients who were members of the local anti-cuts campaigns from both Stakeholder Groups.
- The introduction of patient public partners who were not from either hospital
- The exclusion of expert clinical staff from Stakeholder Groups
- Patients were concerned that the CIC's Patient Panel is chaired by Catriona Renfrew, the architect of the cuts to the CIC, and has met only twice. E.g. The September meeting never surpassed the first item on the agenda as a result.
- concerns that Catriona Renfrew prejudged the engagement process by stating in media interviews that Lightburn Hospital is "past its time"
- Scant publicity to alert patients of the changes to Lightburn and the CIC.
- Public meetings regarding Lightburn were held at Tollcross, a distant venue difficult to reach for many of Lightburn's disabled patients.
- Information regarding the nature of the National Service for Chronic Pain (NSCP) has been confusing. Patients reported at first being told it will be located at the CIC, then patients have said they are now being told the two situations are not related.
- In addition, more clarity about funding arrangements for the NSCP is required as it appears the new plans for a facility with less in-patient beds are costlier than the current set up within the CIC.

I would be grateful therefore, for your comments on the issues raised in order to inform the Cross Party Group Members.

Thank you

**Elaine Smith MSP**

**On Behalf of the CPG on Chronic Pain**

**c.c. Daniel Connelly, Service Charge Manager, Scottish Health Council**