

## THE SCOTTISH PARLIAMENT'S CROSS PARTY GROUP ON CHRONIC PAIN. Minutes of Meeting on March 2, 2016

The meeting was chaired by John Finnie MSP, co convener, who welcomed everyone. Attendees included people from Argyll, Aberdeen, East Lothian, Lanarkshire, Edinburgh, Glasgow.

The minutes of our November 18 meeting were approved unanimously. A progress report on the new National Residential Service from the lead clinician was distributed but is also attached to covering email.

### PAIN CLINIC WAITING LISTS CONTROVERSY

The secretary reported that she had written Freedom of Information requests to 14 health boards asking for patient waiting lists at chronic pain clinics. The CPG asked her to do so after the figures were still withheld, a year after being promised for November 2015.

Claimed reasons were that ISD (Information Services Division) and the Government's Ministerial Steering Group withheld for coding problems, etc. No future date was set for release.

DG Elder reported that, under FOI, most boards sent figures without problems,

But she was concerned that these were only "first appointment" lists, not the full picture, which should include return patients.

But there were secrecy moves, even under FOI. NHS Forth Valley and NHS Dumfries and Galloway claimed exemption on grounds of the information already being publicly available.

DG Elder told them this exemption did not apply as the figures weren't published. She thought that Dumfries and Galloway and Forth Valley should know that, as people from their areas were on the Ministerial Steering Group which had agreed not to publish by last November. Forth Valley apologised and sent the figures.

But Dumfries and Galloway officials continued defiance of FOI. In fact, their officials never sent the lists and caused a runaround totaling 70 calendar days (around 45 working days, FOI requires response in 20 working days) They received the request on Nov 25 2015 and by January 20<sup>th</sup> 2016 after DG Elder dismissed the exemption claim, their chief executive, Jeff Ace, wrote saying he had passed the FOI request to ISD. It was not until February 4, 2016, that DG Elder received the figures breakdown from ISD. These figures had originally been compiled by Dumfries and Galloway. DG Elder said this was unacceptable behaviour wasting the time of a volunteer through the actions of paid people in a health board. She did not believe that FOI requests can be passed on or that a Board should have involved ISD in their attempt to defy FOI legislation and ignore the legitimate request of a Parliamentary Cross Party Group trying to aid patients. DG Elder was very concerned that any member of the public, perhaps with less knowledge of FOI, could face such extreme secrecy levels.

The meeting agreed and backed unanimously a complaint being sent to the Scottish Freedom of Information Commissioner. Action: DG Elder.

## PUBLISHED WAITING LISTS ARE NOT GOOD NEWS.

Update: on March 8, the figures were made public –Google the ISD website. The waiting lists showed health boards failing on chronic pain targets for first appointments (usually much better than repeats which are still not produced). Four Boards seriously broke the legal guarantee of all first time patients being helped within 18 weeks, with considerable numbers over the time. Two other Boards couldn't produce figures. (NHS Highland & NHS Western Isles). People in pain in the Western Isles have had no area pain management for over two years, since their clinician retired.

**Scotland:** In just the last three months of 2015, a total of 580 patients in Scotland were waiting over the 18 week limit, with some 2737 being seen within 18 weeks. The worst waits were in Ayrshire & Arran, where only 14 out of 333 patients were seen within 18 weeks.

Ayrshire & Arran: 319 patients waited over 18 weeks. No explanations given by any boards.

Borders 32 patients out of 62 over 18 weeks

Grampian 138 patients over 18 weeks

Forth Valley 70 over 18 weeks

Highland - no figures.

Western Isles – no figures because no pain management service for last two years.

(Several other boards exceeded 18 weeks but as they were between one and 16 patients, the above are the worst)

## UPDATE ON CENTRE FOR INTEGRATIVE CARE (CIC)

CIC patient Catherine Hughes updated on the campaign to protect the CIC. The Health Secretary, Shona Robison, had invited Catherine to have an hour's discussion with her about the CIC. Catherine said she had waited a year for this meeting, first proposed via Nicola Sturgeon in December 2014, finally arranged for December 9 2015. But the evening before, Dec 8, she was notified that Ms. Robison wouldn't make it. Her deputy Maureen Watt was substituted, with time cut to 30 minutes. Catherine said she found this late change "devastating" as she had done much preparation and Ms Robison had appeared sympathetic. The meeting with Ms Watt mainly featured the repeated claim that no changes were planned for CIC services and no closure but key questions are still unanswered. And there are growing doubts (see below) She appreciated Ms Robison was busy and asked for a future meeting, which was declined.

Catherine felt that the refusal of Ministers to intervene over a hospital described by them as a "national resource" was harmful, as Boards were ignoring patients' wishes and basic democracy.

However, the Public Petitions Committee (PPC) had serious concerns and agreed to continue Catherine's petition on the CIC to the next Parliament. The Committee had been strongly supportive of patients' rights and had challenged NHS Lanarkshire in particular concerning over ruling the 80.6% Public Consultation majority in favour of continuing access to the CIC hospital and two outreach clinics at Coatbridge and Carlisle. Officials called by the

committee to explain their actions “raised more questions than answers” in the committee’s view. Committee MSPs expressed concern that a service was being closed to Lanarkshire over “scientific effectiveness proof” when an overwhelming number of patients said CIC services were effective for them.

Catherine believed that repeated assurances by Scottish Health Ministers and Greater Glasgow & Clyde Health Board (GGC) that there were “no plans to change services at the CIC” as well as no plans to close were in doubt following evidence by Catriona Renfrew, Planning Director, GGC. Ms Renfrew made it clear that there would be reviews of two different aspects of the CIC. She believed the CIC was viable at present, due to GGC patients. But the loss of three health boards recently meant they “had to look at how we reduce costs to reflect that loss of income. We cannot afford the service to go on exactly the way it is at the moment”

She also wanted to review the “effectiveness” of treatments, comparing this with Lanarkshire’s review of “scientific” effectiveness. Ms Renfrew said that her board last looked at CIC services about 10 years ago. Then, “public and patient anxiety and anger” had made them continue to provide.

But they would now “look at the work other health boards have done in revisiting our own conclusions”

Catherine viewed this statement showed the true danger the CIC was in, as “other health boards” had withdrawn patients. She pointed out that there was still no clarity over the Scottish Government’s statements that a wing could be built onto the CIC to take the new Residential Chronic Pain Service. A later email from Catriona Renfrew of GGC said: “[There is still a discussion on options for the new service either within the building or in an extension](#)”.

Much discussion followed. Elaine Smith MSP was thanked for appearing twice at the Public Petitions Committee to give strong backing to the CIC and express alarm that Lanarkshire patients were being removed from its help, including the future closure of the CIC outreach clinic in her constituency, Coatbridge & Chryston. She said the need for its services should be on the opinion of doctors and patients “It should not be at the whim of whether funded or not by a health board”

It was estimated that over 50 doctors had referred patients to the CIC recently but funding was rejected by Lanarkshire officials. Dr Richard Simpson MSP said the Government had to clarify what had priority: a doctor’s professional judgment or funding by a board. As the CIC was a tertiary service meant for all Scotland, it could be a case for central Government funding to ensure access.

It was pointed out that Lanarkshire and other Boards still had to pay for CIC services until Service Level Agreements ended in two years or so, even if no patients were sent.

John Wilson MSP was thanked for his stalwart support of patients at the PPC and said: “We shouldn’t rely on health boards making arbitrary decisions”. If the CIC wasn’t given national status (for funding) we will end up with other services being impacted upon”. (See below)

Dr Pat Roche had heard, at the PPC meeting, Lanarkshire Board officials’ defence of withdrawing services and said that, as a pain management

specialist and a scientist, she thought this was not scientifically presented and she thought it was “disgraceful of the Lanarkshire board to have judged the CIC effectiveness on the evidence base for Homeopathy alone. The Centre of Integrative Care integrates several forms of health therapy which do have strong and internationally accepted scientific evidence of effectiveness based on modern measures of outcome. The Lanarkshire board’s defence excluded this evidence”.

#### LATEST LETDOWNS FOR PATIENTS

By ending CIC services, Lanarkshire has potentially added hundreds more first time patient visits to their conventional NHS pain clinics, impacting on “return” chronic patients, who have no timescale protection, unlike first timers. Mrs Liz Barrie of East Kilbride attended to confirm that she was now eight months over the time she should have received a repeat injection but said Lanarkshire HB was so short staffed in pain clinics they still couldn’t give her an appointment. She needed these injections only twice a year but was forced instead to rely on a heavy drug dosage including morphine. This highlighted the plight of “return” patients; and a letter from Lanarkshire HB confirmed that first time patients were getting priority and return patients having to wait more. (Only first time patients are under an 18 week legal guarantee) Ms Barrie stressed that the pain clinic staff were excellent, just too few of them.

Tracy Robertson, a young wheelchair-using patient from Mallaig, attended with carers to say NHS Highland pain patients needed help urgently. Last year, she was in such pain she had to cancel her respite break. (Note: Highland could not even send waiting lists)

Lorraine Cleaver, a petitioner on thyroid problems, attended to say that she found similarities between lack of action by the Scottish Government on chronic pain with what she had encountered over inaction and lack of understanding of thyroid issues and demanded that long term conditions were raised up the agenda and firm action taken.

DG Elder reported the latest news over NHS Grampian twice breaking its promise to patient campaigners "Afa Sair" to re-open their local clinic in Elgin. At present, Moray patients make a 140 mile round trip to Aberdeen for about 20 minutes of help. But having broken promises for December and February, NHS Grampian now claim re-opening in March but would not specify a date by time of our meeting.

#### WHISTLEBLOWER CALLS FOR END TO HEALTH SECRECY

Rab Wilson recently launched a campaign to protect NHS whistleblowers properly: Action for a Safe & Accountable People’s NHS in Scotland. (ASAP) Rab is a former psychiatric nurse who exposed secrecy and a catalogue of errors surrounding suppression of 50 serious incidents, including 20 patient deaths at NHS Ayrshire & Arran. His investigations led to a Healthcare Improvement Scotland probe criticising the health board for “material

weaknesses in management” and improvements resulted. Rab was not surprised that, even with chronic pain, there was secrecy. With other nurses, doctors and health workers, ASAP demanded that secrecy and “a culture of fear” in health is ended. Staff must feel safe to whistleblow in patients’ best interests. Current whistleblowing “protection” moves weren’t worth the paper they were written on. Rab said that Boards had been allowed to appoint “whistleblowing champions” from within, and not advertise for independent new people. He called this “Putting the foxes in charge of the chicken coops”. He is urging MSPs to support ending “gagging clauses”, confidentiality clauses paid to departing NHS staff preventing them speaking out about patient care or potential wrongdoing. “These were supposed to end but they are still being paid out”

Rab stressed that Scotland had no health regulator. Healthcare Improvement Scotland was sometimes called this erroneously – they aren’t. The country needed its own independent regulator urgently.

#### REPLIES FROM PARTY LEADERS

DG Elder reported that she had compiled an updated briefing on chronic pain and, as the CPG had decided, had written to the leaders of all five Scottish Parties, asking them to consider the need for more help for chronic pain patients in their 2016 manifestos. All five – Nicola Sturgeon, Kezia Dugdale, Willie Rennie, Patrick Harvie and Ruth Davidson - replied personally, thanking the CPG for the briefing. All promised to forward our request to their manifesto teams for consideration. Highlighting the issue was our aim.

#### MEETING THANKS

Kathleen Powderly, of Grampian area, thanked the night’s chair John Finnie MSP for convening the meeting and Dorothy-Grace Elder, hon. sec. for her 16 years of “hard work for the CPG and pain patients”. Catherine Hughes thanked the Group for acting on the threat to the CIC hospital and its service to chronic pain sufferers and said that the Public Petitions Committee, the CPG and its volunteer secretary DG Elder had shown that the Parliament was best hope. John hoped all would continue in the next Parliament.

Attendance: Six MSPs John Finnie, chair, Elaine Smith, Dr Richard Simpson, John Wilson. Part of the time Jim Eadie and Alison Johnstone .

29 Non MSPs: John Thomson, Jacquie Forde, Pete McCarron, Rab Wilson, Catherine Hughes, John Lawrence, Tracy Robertson, Mary Robertson, Mairi O’Keefe, Donna Stevens, Heather Goodare, Dr Jo McParland, Lorraine Cleaver, Martha Heaney, Linda Mawson, Dr Jacqueline Mardon, Dorothy-Grace Elder, Anne Hughes, Dorothy Mackie, Sandra Mostafa, Richard Marsh, Mary Travers, George Welsh, Dr Pat Roche, Fiona-Frances Adam, William Banyard, Liz Barrie, Gordon Barrie, Fiona Steele.

Organisations: ASAP-NHS (Action for a Safe and Accountable Peoples' NHS in Scotland), Leuchie House Respite Centre, Glasgow Caledonian University, Centre for Integrative Care, Complementary & Natural Healthcare Council, Edinburgh University, Edinburgh Health Forum, Allergan.

Apologies: Bill Kidd MSP, Michael Grieve, Liz Porterfield, Scottish Government, Lord Foulkes, Prof. Martijn Steultjens, Susan Archibald, Christine Martin, Gaby Stewart, Ian Semmons, Jackie Baillie MSP, Irene Logan, Fiona Robinson, Arlene Byrne, Tasneem Nadeem, Claire Schiavone, Paulo Quadros.