

Cross-Party Group on Chronic Pain

Date and Time October 3, 2022 at 6 pm Meeting & AGM

Minute

Present

MSPs. Chairing: Miles Briggs, Rona Mackay, Jackie Baillie, Jackson Carlaw, Clare Adamson

Non-MSP Group Members

Annemarie Ward, Faith Ougham, Liz Barrie, Irene Logan, George Welsh, Peter McCarron, Dorothy-Grace Elder, Helen McDade, Gordon Barrie, Kirstin Laing, Dr Patrick Trust, Brian Whitters, Alex Stobart, Stuart Mclver, Hussein Patwa, Jason Carter, Jacqueline Mardon, Fiona Kelly, Ian Semmons, Kim Dam, Cass Macdonald, Marion Scott, Jacqui Twedde, David Caulfield., Alex Thorburn, Tina Jordan, Jane Ormerod, Amber Welsh, Anne Marie Diamond, Ian ? (not Semmens), Shaben Begum, Eva Thomas-Tudo, Laura Wilson, Arlene Byrne, Carla Kaspar, Lisa Megginson, Catherine Hughes, Rona Agrew..Hazel Borland, Helen Goss, John Thomson, Marian Kenny, Geraldine McGuigan

Apologies Christine Martin, Dr David Weeks.

Agenda item 1

Miles Briggs MSP, chairing, welcomed everyone, saying that, after 21 years, the CPG continued to attract new members, currently greeting new people from the Western Isles, Highlands and Borders and the cities, The group is entirely independent of Govt or Party funding and is patient-run. Draft Minutes of the previous meeting were approved as correct.

Agenda item 2

AGM: MSPs Rona Mackay, Monica Lennon, Miles Briggs were re-elected co-conveners .Dorothy-Grace Elder was re-elected voluntary secretary.

Agenda item 3 This meeting concentrated on exclusion, secrecy, lack of information and snooping on patient activists

Patients not included by health secretary. Patients excluded three times by health ministers.

Our meeting learned that Health Secretary Humza Yousaf had asked to meet our conveners – but not patients- on November 7.

Patients pointed out that this would be the third time in 2022 that the health secretary and his deputy had missed out patients. He did not blame time shortage– as he would meet MSPs. Our conveners urged he meet at least some pain sufferers - originally, he said he'd come to our whole CPG. Patients had not been told what was happening to pain services for over a year and were anxious.

In February, Mr Yousaf confined a meeting to three MSPs and his officials. In June, he agreed to a 45 min meeting limited to only three patients as well as Conveners -later, he cancelled that meeting. Now, patients were not to attend the latest private meeting in November.

MSP Jackson Carlaw said this wasn't fair and that “the health secretary must involve patients.” The conveners had pressed for patient presence.

He had also not responded when patients wrote to him in August 2021 asking him to investigate bullying concerns and actions by the Scottish Government's Clinical Priorities Unit and the Alliance charity. The unit had sent emails threatening to dismiss two patient volunteers who had urged discussion on untreated pain sufferers. One woman patient was threatened with dismissal over a “tut or eyeroll.” Patients also did not get action on lack of safeguarding over some women patients on the Government committee being upset by disturbing online posts by a male on the committee who was appointed through officials, not patients.

Agenda item 4

Snooping on patient activists What is so worrying about chronic pain plans that patients face rather bizarre spying?

The voluntary secretary produced email proof of snooping on patient activists which she obtained from Data Protection. This showed that, when she asked a question of a Govt health branch, this was reported to Clinical Priorities, however tiny the query was. No question was answered – queries were used only to snoop on what she was trying to find out, (to help patients.) Data Protection wrote that they'd obtained these emails from the Clinical Priorities Unit which had been sent to them by other units they'd contacted.

Example: Dorothy asked Public Health Scotland (PHS) and the “Modernising Patient Pathway” team to explain patient pathways. Both gave no answer but 13 different officials were emailed what she asked. Officials also emailed that Dorothy and a (very ill) patient from the Government NACCP group were on the radio.. PHS claims to be independent, covering Scotland’s health statistics. Other health units such as the Quality & Safety team, the Patient Safety Commissioner office were also informed, without permission, when our CPG sent any query. But no-one sent answers. Some of this time waste by Edinburgh health officials was at the height of the Covid crisis in 2021, while exhausted NHS staff struggled to save lives. Is there a black list or snoop list of patients for information denial?

Separately, Freedom of Information revealed, among other matters, emails showing that the Alliance charity had been told by a Clinical Priorities official to stop pain patient representatives “communicating” with each other outside of Alliance meetings. The Alliance agreed by email right away to do what the Govt official wanted . Patients were unpaid volunteers. This charity gets £6 million from the Scottish Govt annually, from the public purse. The complaint to OSCR by patients continues.

Secrecy and discourtesy

It was reported there had been no increase in transparency since the health secretary promised more openness in February. And return patient waiting times will not be published. Patients had asked, since late May 2021, what was happening with the NACCP committee they were elected to by other sufferers as patient representatives for two years. It wasn’t until late July 2022 that they were finally told the committee had ended after just two meetings to which patients were invited in four months.

Motions: The meeting passed two resolutions, citing that this was the fourth time over the years they had urged that Clinical Priorities be replaced by another part of the civil service, their latest involvement over patients being snooped on being utterly intolerable. They also urged that the Government-funded Health & Social Care Alliance be removed from chronic pain involvement over their lack of help to our patients and their closeness to Government officials.

Agenda Item 5:

Clare Adamson, MSP for Motherwell and Wishaw, drew attention to “Burning Nights” an Edinburgh conference on CRPS - Complex Regional Pain Syndrome- from which some suffer terribly. She hoped that some CPG members would attend in November - or contact at any time. The meeting thanked Clare for her concern. Contact by email at ordinary times support@burningnightscrps.org

Highland success The chair said he was delighted that Highland patients had won their effort to retain part time services from Dr John Macleod after his retiral, to which Kirstin Laing had alerted our group at our March meeting.