
NOTE: All CPG minutes have to be in this new format, Parliament says. This puts attendance first. What happened was first previously.

Cross-Party Group on Chronic Pain

Date and Time March 15, 2023 a 6pm online.

Minute

Present

MSPs. Rona Mackay, Rachael Hamilton, Clare Adamson,

Invited guests

Linda Pollock, deputy director, Healthcare Improvement Directorate

Clare Morrison, Director of Community Engagement, Healthcare Improvement Scotland

Non-MSP Group Members

Ian Semmons, Faith Ougham, Margaret Coats, Anne Marie Diamond, Hazel Borland, Geraldine McGuigan, Lorna Farrell, Claire Daisley, Dr Jackie Mardon, Nancy Honeyball, Jean Rafferty, Irene Logan, Liz Barrie, Gordon Barrie,, Pete McCarron, Leigh Payne, Clare Morrison, Linda Pollock, Amber Welsh, Brian Whitters, Pogie Manson, A.Simpson, Dorothy-Grace Elder, David Caulfield, Rob McDowall, Marion Scott, John Thomson, Leigh Mackie, George Welsh, Ailsa Collingwood, Grant Downie, Lorraine McQuarrie, Evelyn Reid, Catherine Hughes, Anne Hughes, A. Sutherland, Andy Stuart, Bailie Soryia Siddique, Linda Mawson, Sharon Turnbull, Alison Carey, Martin Roberts, Fiona Shannon, Alex Stobart, Carole Torsney, Helen McDada, Helen Goss, Stuart Mclver, Marianne Scobie. 49

Apologies Jackson Carlaw MSP, Kirstin Laing, Clare Jacklin, Annemarie Ward, Monica Lennon MSP, Sandesh Gulhane MSP.

Agenda item 1

(Meeting noted there was industrial action at Holyrood that day and several MSPs could not attend -some offices closed.)

Welcome by tonight's chair, Rona Mackay MSP. She was delighted to hear of new members from organisations started by patients – “More than Fibro” which was founded by Sharon Turnbull, Coatbridge for those with fibromyalgia. Ehlers-Danlos Scotland joined and there were new members from the Centre for Integrative Care. The chair congratulated Western Isles patient Brian Whitters who was featured in a Scottish Government video encouraging early detection of cancer.

Agenda Item 2 Minutes approved of meeting of October 3, 2022.

Agenda item 3 WHAT'S HAPPENING TO PAIN SERVICES? Patient representatives replaced by recruiting through a marketing firm.

It was explained that the voluntary secretary had to use Freedom of Information - FOI - to find out what was happening with chronic pain.

We have not been sent key information about Govt plans for chronic pain services.

New plans were made “behind scenes” for about a year. We invited Linda Pollock, interim Director, Healthcare Directorate, Scottish Government to inform us. She attended on her own, which was appreciated. Much of the meeting involved points from patients over what is seen as continuing secrecy over the implementation plan. People said it was unclear how the “implementation plan” would be implemented. Critically, there was no mention of funding. Even Versus Arthritis had said last year there was no mention of investment by the Scottish Government and the plan was too slow (about two years of talking).

Ms Pollock gave a diagram presentation. She stressed they were working with “clinical networks” and Public Health Scotland to have transparency over data and working with NHS Inform to improve access. A “Pain Management Taskforce” had been set up. She said this had been through “ independent engagement” with an outside firm, The Lines Between. (The firm was commissioned by the Government’s Clinical Priorities Unit)

Ms Pollock promised to write back with answers not covered tonight Mainly, time was for patient questions.

WHY WERE VOLUNTEERS REPLACED BY PAID PEOPLE INCLUDING ADVERTISING ON FACEBOOK?

The revelation that a marketing firm had been used to recruit a “patient panel”, excluding known pain patient representatives and groups, shocked many who pointed out that our group wasn’t told in advance of any recruitment. We have elected patient reps and 22 years volunteering experience via Holyrood.

This was discovered by our CPG voluntary research - Scottish Govt then confirmed. Reminder: we are all volunteers, with no funds.

A patient panel of 16 “seldom heard” people is already set up behind scenes. FOI documents show it was stipulated by Government officials that anyone with experience of groups or advocacy (help) for patients, was to be rejected: “Thank and close”.

This new report (we were not sent it) was commissioned after EIGHT previous pain reports, most of which were not actioned. This Report and “lived experience” patient panel organising was paid by more public money (Around £40,000). The marketing firm’s adverts in 2022 aimed to form a “pain patient panel” .This will **advise on future pain services for all**

Scotland, which has 800,000 affected including around 60,000 serious cases.

We don't know if there was proof of conditions suffered by all 16 new recruits being used to influence the future for Scottish pain patients. Each received £200 if they attended four meetings. But recommendations are all selected by over 20 officials and Government appointees. Patients are not allowed at their meetings!

Ms Pollock said she had NOT known that Facebook had been used for recruitment adverts

Ian Semmons, chair of the charity Action on Pain UK, expressed concern that the Director had not been told by anyone. He said: "In 26 years of running Action on Pain, I've never known a switch from volunteers to paid patients" But Ms Pollock added that she had confidence in the report.

Results of this report showed three out of 16 who claimed they had chronic pain stated it had "no impact" on their lives. That is strange.

Seven said "little impact" and only six out of sixteen reported "high impact" Overall, ten did not know about specialist pain services. So how can these be judged?

(This report contrasts with another report by Healthcare Improvement Scotland showing only one in 92 pain sufferers claimed no life impact. That is a more normal result)

Brian Whitters thanked Ms Pollock for coming and asked: "Could you give us an understanding of why chronic pain patients (from interested groups) were deliberately excluded?" He also asked for a definition of "seldom heard" patients but examples weren't given. Linda Pollock replied: "The Government had not aimed to exclude patients at all. We have not been trying to exclude people. They based things on what patients had told them."

She said they had held a public consultation and some(CPG) patients had been members of a previous government group - the National Advisory Committee for Chronic Pain.

Patients pointed out that ten were elected to that past committee by other patients as their representatives for two years – but the ten were cut out after two meetings' in four months, Questions went unanswered and there was perception that questioning people were resented. Ian Semmons, who had been on the committee, said: "They tried to dismiss patients who asked a lot of questions." Two patients were threatened in emails with dismissal after they wanted discussion of a mistake by officials. Patients

wondered: Did a change to recruiting only “seldom heard” patients without experience mean fewer questions expected?

Patient Liz Barrie said it was welcome that Ms Pollock had attended as there had been no consultation with patient representatives like Catherine, Ian and herself who had been on the previous Govt committee, had worked on the Framework but now weren't told what is happening to implementation. Patients couldn't approve the Framework -they weren't allowed to see it before it was printed.

Liz said that patients had “been regarded very, very poorly long before Covid.” Liz's clinician said she needed six monthly pain relief injections “But these were delayed some 2.5 years well before Covid. Pain was so bad you could jump off a bridge”

Linda Mawson objected to diagrams rather than real facts about implementation. “ Everything seems to be going round and round in circles. It's the same old, same old.” She thought involving payment vouchers and Facebook advertising was shocking. “I find it insulting to people who suffer for years, as I do. All I can see are more pie charts and more graphs going nowhere. It's undemocratic.”

Health secretary Yousaf brushed off

Voluntary secretary Dorothy-Grace Elder said her enquiries showed that “officials are recommending on services for patients but even the patient panel recruits are not included to sit with officials at meetings. They are kept separate” .

Dorothy said that ministers needed to hear direct from patients. The then health secretary, Humza Yousaf, had promised to meet pain patients but did not do so three times last year, confining meetings to a few MSPs. But FOI showed his office had emailed Clinical Priorities on July 1, 2022, He wanted to know why officials “looked to exclude patients from the working group” (the new Pain Taskforce) Mr Yousaf warned this would be criticised . Dorothy added “emails from Clinical Priorities then claimed they weren't excluding sufferers -just keeping them separate!” But she said “Officials just chucked his view aside, brushed off the cabinet secretary. Sadly, emails show he gave up trying for numerous patients- but did ask officials appoint one patient representative to the Taskforce. “But officials still did not appoint from the patient panel! They recommended a consultant previously known to officials to be a patient representative!” Dorothy commented “Officials have taken over. But all this is paid by public money.”

Secrecy The names of over 20 officials dealing with pain are not given. Only the chair, Lynne Nicol, was named in FOI returns. The rest are

hidden. Ms Nicol is “head of openness” in health. Patients wondered how many of the new Taskforce may be the same people who had been on the former Govt committee, who had been named.

The several sub committees also keep most names anonymous – so patients don’t know who is recommending on changes that may affect 800,000 lives in Scotland

CPG Chair Rona Mackay MSP asked Linda Pollock about long standing questions of the CPG. One was over whether specialist treatments like infusions and injections would be cut or reduced.

(Note: Scottish Govt stated in Sept 2020 they aimed to “reduce reliance” on specialist services.)

Ms Pollock said “I know specialist injections vary across the country. But Government doesn’t make the decisions - these are clinical decisions- but we are trying to gather data. I’m not aware specifically of cuts.”

The chair also asked: “For about ten years, this group has asked for return patient waiting times to be published.”

Ms Pollock said these were still not published “ but we are working with Public Health Scotland on how to do that”

Director not informed Ms Pollock said she did not know about Facebook being used in patient recruitment adverts. Ian Semmons expressed concern that the Director had not been told. The one patient representative was not named.

But Ms Pollock said she was “very comfortable” with the report work,

Catherine Hughes and Jean Rafferty said person- centred care was not happening in Scotland with pain patients. Jean waited a year to see a physiotherapist- pre covid. Catherine had to go to London NHS nine times in a year although journeys were agonising. She commented: “I am disgusted at the way Liz, Ian and myself were treated on that (previous)committee. It was shocking. They wanted to say they’d involved patients although there was no co-production. It is discrimination that in this new committee (The Taskforce) patients were deliberately kept out of meetings. Our voluntary patient reps (in 2021) were democratically elected by votes from many other patients, there’s no sign of that now”

Clare Morrison Director of Community engagement, Healthcare Improvement Scotland. (HIS)

They conducted wider engagement with 92 pain patients from 14 health boards. (Note: our CPG which has patients from numerous boards was also not told of this recruitment.)

Patients said that key concerns included lack of understanding from some health professionals on impact on lives, lack of being believed. (The HIS work confirmed much of the same findings from most of eight previous reports on chronic pain.). “Gathering views on Chronic Pain | HIS Engage” is, however, a serious report worth reading.

Agenda item 3 Complex Regional Pain Syndrome help.

MSP Clare Adamson asked if the CPG could have a future speaker on Complex Regional Pain Syndrome, a very painful condition. Ms Adamson said that her son, as a teenager, had developed this condition after an injury at rugby. She and her son attended last year the first Scottish conference of the Burning Nights charity which helps CRPS sufferers. Clare had also met at another event Dr Carole Torsney who understood the CRPS condition. Dr Torsney was also concerned that the vast majority of studies of chronic pain have been with men, leading to moves which might not be relevant for women. Women sufferers form the majority! Clare asked if the CPG would like a speaker about CRPS and to hear about Dr Tornsey’s fascinating work. The chair and the meeting agreed warmly.

.The chair said conveners and the voluntary secretary would much welcome future suggestions of speakers.

And contact for the charity helping CRPS Email: support@burningnightscrps.org. Telephone/Help line: 01663 795055 (UK)

Agenda item 4. Voluntary Secretary Report

DG Elder said she’d already made points so she would report briefly that her application for a "core participant" place for our patients at the Scottish Covid Inquiry had taken much time but wasn’t successful although she could compile written evidence. Patients had reported concern that the Health & Social Care Alliance had been named to represent all disabilities. She had no objection to anyone giving evidence but representing all disabilities was different. The Alliance is Government funded for many millions.

But the Glasgow Disability Alliance - a separate body, name coincidental - offered to represent pain patients if we wished. The meeting agreed.

The voluntary secretary pointed out that her work was made arduous, involving months of free toil unpicking the huge amount of secrecy in health over chronic pain and moves regarded as unacceptable. Did the meeting approve a future formal complaint if we do not get answers? Approved.