

Scottish Parliament Cross Party Group on Chronic Pain

Meeting: September 14, 2021. Minutes approved at March 2 2022 meeting.

MSP Rona Mackay chaired and welcomed everyone.

Election of office bearers: MSP Co-conveners, Rona Mackay, Monica Lennon, Miles Briggs. Voluntary Secretary: Dorothy-Grace Elder. All elected unanimously.

2021 marked the 20th year of this CPG's continuation in six Parliaments, as a totally independent group. We had welcomed independent patients being appointed to the Government's National Advisory Committee on Chronic Pain in January 2021. But what happened behind closed doors in this private committee, which has no MSPs and is closed to public and press, has raised more concerns. Patient Liz Barrie reported to the CPG.

PATIENTS FELT INTIMIDATED

Liz explained she and others had been "very keen" to be among the first independent patients on the National Advisory Committee on Chronic Pain, unconnected with paid officials or charities getting funding from the Scottish Government or Boards. But she said that the treatment of patient representatives had been "absolutely atrocious."

There had been no protection for patients. Liz found it was made impossible to represent patients properly. She pointed out that patients were assured when they were asked to volunteer - by the Government funded charity the Alliance - that they'd work equally with officials and others in a "co-production" to improve services. "We'd be shown all documents and were there to promote patients' views to shape the services. But co production did not happen." She was grateful to the many patients who voted for them to be representatives but wanted them to know their reps did not -and could not -support plans they were not allowed to see. (Three patient reps left by summer, 2021, one citing failure to protect women patients from disturbing online posts by a male)

Liz and others explained what happened:

0 Agendas were set by officials. The patients were invited to only two meetings of the NACCP, the third was cancelled. The Alliance also cancelled side meetings without explanation, People felt they were being used to appear that there was patient approval of proposals they were not allowed to see. (This was not normal co-production)

0 Patients were asked to give their views but subsequently not allowed to see what was being recommended in a document to ministers over services. Points gathered by Liz on behalf of patients were not minuted.

0 They were not allowed to see the Framework document - for services to the patients they represented - before it was printed. "We put forward proposal after proposal but were ignored." Clinical Priorities claimed that in December they'd let patients see the draft days

before distribution– but did not add that was AFTER it was printed! The patients did not - and could not - approve it.

0 The Alliance appeared very close to the officials. They also did not ask patient views on the “Survey” they sent out. Nor were the reps asked about suitability of questions for patients in a public consultation, (something which usually involves patient reps on other organisations) Liz said she thought happenings showed treatment of patients with “contempt”

“One senior official asked the patients to send her any questions we had. We compiled eight standard questions. Not one was answered.”

REVEALED: PATIENTS WAITING THREE YEARS FOR INJECTION RENEWALS DUE EVERY SIX MONTHS. (Note: Ms Barrie approves suicide attempt references)

As return patient waits were not published, Liz set out to find how bad waits might be. In NHS Lanarkshire, she said she was not the only patient who was now “19 months past my last injection which should happen every six months. Now I am being told I may not be seen for another 18 months from now – taking me to over three years. My board area (NHS Lanarkshire) knows I have twice attempted suicide over delays of 18 months in the past long - before Covid.” She referred to a letter which an NHS Lanarkshire official had sent, stating they are only now (Sept 2021) treating patients due injection renewal in Sept 2018, So Covid (March 2020) was not wholly to blame. As we now knew there were three year injection waits in Lanarkshire for uncounted return patients - anywhere else?

Are Ministers told what is done in their names- or are officials obeying orders? Threats to patient volunteers.

Liz also discovered that patients pleading for injection renewal who wrote to Ministers got a reply from Clinical Priorities which omitted to tell them in April 2021 that injections could be renewed from July 29, 2020. The Faculty of Pain Medicine had permitted resumption of injections, under safety rules, because of patients reaching “insufferable” pain levels. But injection patients in Scotland weren’t told if they wrote to Ministers and Clinical Priorities officials replied.

Liz got such a letter from Sharon Robertson of Clinical Priorities on April 23 2021. She spotted the missing update facts. This meant Scottish injection patients were nine months behind English patients in being told. As a patient rep, she raised this at a small private Alliance meeting on April 27, 2021. Dr Harden, chairing, refused to discuss at this meeting. Liz asked to know why officials had not told patients who needed urgent pain relief, who continued suffering. She was backed by other patients including Kathleen Powderly and Ian Semmons, chair of the charity Action on Pain, appealing for discussion.

Liz commented on Scottish numbers: "As a patient representative, I raised the issue that there are around 9,100 injections in normal years. I was brushed aside. But two patients who supported me were threatened with expulsion for over two months afterwards. I thought it our job to raise issues and protect patients." Liz explained: "The official who

signed the letter I got as a patient, leaving out the change, Sharon Robertson, was at that meeting and didn't say a word."

It was agreed patients should be informed - but the reps wanted urgent discussion on how to relieve the pain of those already left without help. But two of the patients who urged discussion were later forwarded emailed threats by officials, threats to dismiss them as patient volunteers on the committee. Liz added:

'It is absolutely appalling that people who are chronically sick were being bullied by people we thought we were in partnership with. That is not permitted in any area of employment so why is it allowed with patient volunteers? There was absolutely no empathy whatsoever."

Patients felt very alone. The Alliance, which had been paid to "help the patient reps" did not intervene.

Patients Kathleen and Ian confirmed to our CPG meeting that they received emails threatening to dismiss them from their voluntary roles. The letters were sent by Clinical Priorities officials Sharon Robertson and James O'Malley, apparently in the name of a stranger to pain patients, Lynne Nicol, Deputy Director (Interim) DHQI: Healthcare Quality & Planning. There was no sign that Ms Nicol was at the April 27 meeting and patients had never met her. Patients assumed hearsay claims were made.

After two months of refusals to say exactly what they'd done to justify threat of expulsion, Kathleen was accused of uttering a tut and an eye roll.

Liz said the whole experience was "terrible" for sick people in pain. "All of us live in an unwell state every day. I've never seen treatment as bad as that anywhere else in my life. We must get chronic pain away from Clinical Priorities to a different part of the civil service"

"There is absolutely no empathy whatsoever." Liz commented: "Every single impact of whatever is in the "new Framework" will come back to the patient. We were at the table to try to improve services but were blocked. We wrote reams but we were bombarded by blockages". The Alliance had not spoken up for the patients. Parliamentary questions also did not get proper answers. Liz said people were suffering mentally as well as physically, including suicide risk.

"Our biggest fear is that patients are going to have pain treatments removed without being consulted. If a Framework which cuts treatment services gets passed by the back door - as patients have not approved it -we could be looking at more people thinking of ending their own lives." The fact that Return patient waiting times were still not published, despite encouragement on openness from the UK statistics regulator five years ago, is a major problem. Lack of return facts helped lead to three year waits kept under wraps.

Liz mentioned that " We've had a core minimum data set that didn't include waiting times for return patients." (The Scottish Government paid £257,000 for this dataset to the Dundee University dept which has three members on the NACCP). Liz added: "We have to

address waiting times and change from only new patients being recorded - there are many more return patients." (40,000 returns to 20,000 new patients annually, pre-Covid)

The CPG chair Rona Mackay, thanked Liz and expressed the meeting's overall view: "We are thoroughly shocked."

Patients backed Liz's evidence:

Kathleen, a nurse, said: "I was personally threatened along with Ian. I was accused of a great big long ream of things but nothing specific. It was a horrible experience, including the whole process of two months of being kept waiting to find out what I had done. It was really horrible."

She had submitted to MSPs copies of emails she was sent after refusal of discussion on April 27 2021 of injection patients left without treatment. Officials admitted there was no recording of the meeting or anything said. But one email sent to Kathleen and signed by Lynne Nicol, a stranger to patients who was not known to be at the April 27 meeting, claimed: "Your behaviour at the meeting constituted aggressive or abusive behaviour. Specifically we consider you made rude and derogating remarks against Dr Harden that we feel were inflammatory and unsubstantiated – these did not treat Dr Harden in a fair manner, with dignity or respect. We have a duty of care to ensure employees and stakeholders are engaging in a psychologically safe space.

"If your engagement with us and other stakeholders continued in this manner, we would need to review your place as a member of the National Advisory Committee for Chronic Pain."

But after two months, officials could not name any "aggressive, abusive or rude remarks" they claimed Kathleen made. Finally, they admitted they were accusing her of a tut or rolling her eyes. But officials reporting patients to Ministers over a tut or an eye roll by a patient has not been ruled out.

Chair "no one should be treated like that."

Hussein Patwa: I am one of the patient reps on the NACCP. There are procedural anomalies with this committee. As a committee supposed to cater for the needs of people with chronic pain, they seem to do this in a very strange way. The Framework seems to be the sole agenda item, not what is happening this year. There's no recognition of the current or long-standing challenges or the increases from long Covid." He'd stood for election hopeful of getting things done rapidly. "We have never had a rational, satisfactory, well evidenced or balanced explanation from Clinical Priorities as to why they are treating us the way they are."

"Nor had the patients - who are supposed to benefit- had the option of questioning and appealing a decision." Hussein added: "As Liz said, we have never had proper time for patients to speak. Patients were once asked to speak for the first few minutes of the agenda – but the rest of the meeting was what officials put on the agenda, that seems back to

front. Wouldn't you want patients to be able to question things after they've been announced? "

He was among those who questioned what use the Alliance was to the situation. "The way of using the Alliance as a conduit to gather patient input and then feeding that back through representatives, then by extension to the committee, would seem over convoluted, not making the best use of representatives and officials' time and not really achieving the purpose." He thought there is "an unfair imbalance as to who gets support or any degree of thought as to how people are helped on the ground and how services will be improved. I certainly want to support the motions. "

Monica Lennon MSP said the situation was "beyond urgent. People's lives and mental health are at risk. We've had these conversations before with ministers. So we really need to have a meeting. Maybe Liz and Dorothy-Grace could go along."

She pointed to strong support for the patients in the Parliament though most did not realise how bad things now are for the patients, saying "We have a lot of solidarity. I counted about eight MSPs here tonight. We leave our politics at the door. We're here to help patients. We stand as one group united and we will take forward these motions across Scotland. Whatever you need from us we will take that forward. I would like if the health secretary came with some suggestions." She thought that first, "we desperately need to get the return patients waiting times counted."

Dorothy-Grace Elder pointed out that Clinical Priorities were involved with about nine different conditions apart from chronic pain, including heart disease and diabetes and they've now been given Long Covid issues. They compiled answers to parliamentary questions, wrote letters for ministers and now also decided /rejected Freedom of Information queries. The FOI involvement was particularly upsetting.

Rona Mackay MSP said: "I personally think that we should ask for a meeting with the health secretary - a face to face - as soon as possible. We don't know how much he knows. He needs to know the background."

Jackson Carlaw MSP. "The whole thing tonight has been one long ghastly déjà vu experience. The experience of those who have been on that NACCP committee is exactly the experience of all the mesh women who at first went through the same. This was being dismissed , finding that their evidence was being changed underneath them, thinking that they were only there to tick boxes.

Eventually they had to disassociate themselves from the report which went out, finding that whole chapters were removed. Dr Wael Augur resigned after a whole chapter was removed. Hearing now about the kind of censoring of individuals who might want to come forward is also eerily familiar.

I found that depressing because we had discussed that in Parliament and there were assurances of protocols had been learned and the experiences of those involved would be considered."

MESH SURVIVORS – IS IT GOING SMOOTHLY ON BEING SENT TO TREATMENT IN AMERICA?

Two mesh affected women, Lisa Megginson and Nancy Honeyball said that Mesh patients were having great difficulty obtaining pain relief. They'd welcomed the decision by the Scottish Government to allow women to have mesh removed in America but did not realise the difficulty of being assessed in Scotland, where the mesh had been inserted and where they'd lost trust.

Lisa Megginson, Tayside

She was referred to a Doctor in Tayside on October 1st 2018, eventually seeing her seven months later at the end of April 2019, to be told "I had to be seen by the pain team before I could be referred to a mesh centre for help. Five months later, end of Sept 2019, I eventually saw someone from the pain team to be told they can't help me as I am seeking the surgical route. Without assessment or examination I was discharged. My husband and I were gobsmacked. I was left with being pumped full of drugs.

I have had an array of tablets from the GP who didn't know what to do with me I then begged for pain patches but the GP said he had to write to the pain team. They refused, saying I couldn't have them as they were for certain pain. This went to and fro for another 3/4 months. I spoke to another GP, who prescribed patches without a problem. They have helped more than any tablet has. I don't know what would happen to my mental health without them. And here I am nearly 3 years from that referral and still awaiting mesh removal and still suffering."

The Alliance had been involved with the original committee on Mesh, which was ended after patient anger.

Lisa added that the Alliance had started another group about data so she asked to join as they were looking for one patient rep. Lisa said she is involved with Scottish Mesh Survivors and thought this should be useful "But the Alliance refused me, saying I was on other groups. I emailed saying that might be useful as I knew how these things worked. But the Alliance still said I can't be on this group because I am on other groups." They wanted someone who had no involvement"

Rona commented: "that is quite astonishing."

Nancy Honeyball, Dunoon.

Most want to go to America and the health secretary said "yes it'll all be funded " but he next said "but don't make appointments just now."

"What he means is go through the whole thing again. The consultants I would be sent to here are the ones I have no faith in. Nobody in Scotland can remove what I've got.

Put it this way: animals are treated better. I shouldn't have to have this stress. If I didn't have my husband, I would not be here." Nancy and Lisa stated they'd both written to the

health secretary but had no reply. " I had mesh inserted in 2010 after the birth of my two children. We were not told it was mesh, just that it was this magnificent device which would change our lives for the better! In 2014, suffering severe pain, I asked for pain management. I was referred to a Scottish surgeon but I am still waiting for an appointment. In 2016 after having breakdowns I contacted Dr Agur in Kilmarnock who basically saved my life. He gave me the strength to fight on.

We are continually fighting for appointments somewhere and if you are in chronic pain and take opiates which knock you for six, it is hard enough trying to stay awake without having to always fight for appointments.

Scottish mesh patients are having appointments cancelled all over. I had a call last week for an appointment in Glasgow as an urgent referral. Just ten minutes later the woman called back to say appointment cancelled, have to see you -impossible over a call. The hospital rang back, offered another appointment that day, then it was cancelled.

Rona said MSPs can ask Parliamentary questions about mesh.

Monica suggested "I was convener of the Women's Health CPG - suggest a joint meeting even early next year."

* **Lidocaine patches:** Greater Glasgow & Clyde health board is cutting back on patches – to save money. Patches were the most some had during lockdowns. The meeting invited Mr Quesir Mahmood, from the manufacturers, to tell us the price to the NHS. This is around £72.40 for the Versatis brand and £61.54 for Ralvo, each for 30. The meeting did not think these prices should prohibit issue to those they suited. The members thanked Mr Mahmood for appearing.

CENTRE FOR INTEGRATIVE CARE (CIC)

Some CIC staff had been withdrawn and moved to parts of other hospitals recently while other units were also sharing their custom-built hospital, created by public donations in 1999. Greater Glasgow & Clyde health board told the CIC these moves were temporary, lasting two to three weeks. Rona Agnew of the Friends of the CIC said that, although there was huge demand by patients, she said of the CIC: "We feel it is being closed by stealth. Some patients were now in "a desperate state" unable to get treatment."

The NHS staffed hospital used to be open to suitable patients throughout Scotland but several years ago the ward was closed, making it an outpatient clinic, now accessible by Greater Glasgow & Clyde patients. There was large public protest and consultation responses but these were ignored and the ward closed.

Carla Kaspar, a medical researcher, said she was currently in contact over dozens of younger people, all desperate, some "suicidal", whose GPs had recommended the CIC, " but all had been denied on grounds that their post code wasn't within Greater Glasgow and Clyde." GPs had a great struggle with paperwork to try to refute these turn downs, almost all unsuccessfully.

Kathleen Powderly said that the CIC help was needed throughout Scotland more than ever, to help with drug addiction, chronic pain and long Covid. Monica Lennon MSP believed this was all due to “deprioritising chronic pain”

Chair Rona Mackay MSP said inquiries must be made – starting with MSPs writing to the GG&C Board asking about their future plans for the CIC. If the response was unsatisfactory, they could then take the matter further to the health secretary. Agreed.

The motions passed were:

ONE: The meeting called on the Scottish Government to remove chronic pain policy and issues from the Clinical Priorities Unit urgently, transfer to a different department and set up an external investigation into this Unit’s dealings with vulnerable patients and request a mechanism for proper patient representation during and after transition.

TWO: The meeting called on the Scottish Government to make certain that Return patient waiting times are collected, not just new first-time patients who get priority, Returns being around 40,000 patient visits compared with 20,114 new patients in a normal year, the regular refusals on information on returns over the years having contributed to cases of three-year waiting times now being proved by patients, with extensive increases in suffering. Also, transfers to other Board areas should happen at times of shortages.

MSPS present: Rona Mackay chairing, Monica Lennon, Jackie Baillie, Paul O’Kane, Jackson Carlaw, Miles Briggs, Clare Adamson. (7)

Non MSPs: Lorraine Purdie, Alex Thorburn, Liz Barrie, Gordon Barrie, Ian Semmons, Kathleen Powderly, Jenny Gow, Lisa Megginson, Heather Baxter, Hazel Borland, Quesir Mahmood, Dorothy-Grace Elder, George Welsh, Catherine Hughes, Anne Hughes, Faith Ougham, Dr Jackie Mardon, Alison McColl, Stuart McIver, Anne Simpson, David Caulfield, Rob McDowall, Paul Aitken, Hussein Patwa, Barbara Melville, Pauline Firth, Steve Kent, Nancy Honeyball, Carla Kaspar, Dr Patrick Trust , Anne Marie Diamond, Rona Agnew, Gillian Gray, Pete McCarron, Susan Archibald, Nicola Mills, Fiona Kelly Paulo Quadros, Alex Stobart, Fiona Robinson, Hazel Young, Christine Martin, Patricia Kanyandekwe (Patsy) John Mack, Nichola Maclean, Robert Mack, Alex Gallacher, Andy Stuart, John Thomson. (49). 56 in total.

This CPG has a total of 11 MSP members who support hundreds of thousands of pain sufferers: Jackie Baillie, Rona Mackay, Monica Lennon, Miles Briggs, Pam Glancy-Duncan, Paul O’Kane, Jackson Carlaw, Clare Adamson, Sandesh Gulhane, Neil Gray, Alex Cole-Hamilton. Thanks to all.