

Cross-Party Group Annual Return

Name of Cross-Party Group

Cross-Party Group on Chronic Pain

Date Group Established (the date of establishment is the date in this parliamentary session that the Group held its initial meeting, where the office bearers were elected and not the date that the Group was accorded recognition. All Groups should hold their AGMs on, or before, the anniversary of this date.)

14.09.2021

Date of Most Recent Annual General Meeting (AGM)

01.11.2023

Date Annual Return Submitted

28.03.2024

Date of Preceding AGM [this date is required to aid clerks in verifying that the most recent AGM has taken place within 11 to 13 months of the previous AGM]

03.10.2022

Group Meetings and Activities

Please provide details of each meeting of the Group including the date of the meeting, a brief description of the main subjects discussed and the MSP and non-MSP attendance figures.

Details of any other activities, such as visits undertaken by the Group or papers/report published by the Group should also be provided.

March 15, 2023: MSPs 3, non MSPs 49. Total: 52

Three MSPs: Rona Mackay, chairing, Rachael Hamilton, Clare Adamson. Industrial action at Holyrood that day affected MSP attendance.

Non MSPs 49. Total present: 52

Rona Mackay MSP, chairing, welcomed more new members – including “More than Fibro” and Ehlers-Danlos Scotland.

Secrecy continued as a major concern. The meeting was called after the revelation that officials had excluded patient volunteers, replacing them with paid people recruited by a marketing & recruitment firm. Paid £200 each. This shocked many. For almost a year, our group and others hadn't been told of pain patient recruitment. Our voluntary secretary had to use FOI to discover that Clinical Priorities officials had commissioned a “patient panel” and report costing £40,000. (PQ statement)

FOI disclosed instructions from Scottish Government officials that anyone who was a “patient advocate” was not to be included. Also excluded was anyone with language difficulties needing an interpreter. There were objections to exclusions and to the report's “unusual” figures.

It claimed 3 out of 16 said pain had no impact on them and only 6 out of 16 had “high impact”. By contrast, Healthcare Improvement Scotland found only one in 92 claimed no impact.

FOI showed the "Pain Taskforce" has around 20 officials but no patients are allowed at meetings on patient services. The one “patient rep” is not from patients but a doctor appointed by officials.

The meeting was deeply concerned that changes which might affect 800,000 sufferers in Scotland

could be recommended by officials with no patients present to challenge. Even the paid recruits were kept separate.

Linda Pollock, interim director, Healthcare Directorate, was a speaker but said she did not know that some advertisements for pain sufferers were on

Facebook. Ian Semmons, chair of Action on Pain, stated: “In 26 years of running a charity. I've never known a switch from volunteers to paid patients”

Waiting times: One patient reported a year's wait to see an NHS physiotherapist, another waited 2.5 years between injections meant to be six monthly and another was sent to NHS England for help.

The meeting agreed that, if matters did not improve, a formal complaint should be made.

June 20 meeting

MSPs: 6; Non MSPS 33; total attendees 39

MSPs: Monica Lennon chairing, Miles Briggs, Jackie Baillie, Paul Sweeney, Clare Adamson,

Minister Jenni Minto (speaker, briefly)

The recently appointed public health minister Jenni Minto attended.

The previous health secretary and deputy twice met three MSP conveners, but no patients. Ms Minto was welcomed as the first health minister to visit in four years. She apologised that she could only stay for 30 minutes but listened.

Secrecy: Patients informed her of their serious concerns over lack of inclusion and lack of transparency.

They asked the "Why" to such questions for later response.

*Patients did not know who was on the Taskforce making recommendations on their services. FOI showed around 20 officials and no patients.

*The minister's officials had not given patient groups information for a year during which they

set up a "Pain Taskforce" and seven working groups. Why were these unnamed?

*Patients were now asked to comment on a second year of work but had no information about the first year.

*FOI disclosed that patient "advocates" (supporters) were not to be recruited. Although it's claimed they wanted "little heard" patients, those needing an interpreter were also excluded,

*Volunteer patient reps elected by fellow sufferers were replaced by people selected by a marketing firm and paid £200 each. "Patients" were advertised for on social media,

*A retired consultant had been appointed by officials as a patient rep, not a patient.

The minister said we could write to her as she had little time tonight. But she had officials taking notes. Linda Mawson said ""There is nothing solid about the Framework plan, no clarity, no practical proposal. Is this just another talking shop?

Ms Minto said "I don't want this to be a talking shop. I don't think there has been any secrecy. My officials will answer questions as I have to go to another engagement"

After the Minister left, official Nicki Motiang said there was no new budget money for staffing or other help for chronic pain services with Boards, This greatly concerned the meeting, as patients fear cuts to specialist pain services. The meeting agreed to keep up pressure to get proper funding for clinics, and to challenge lack of information. The meeting was summed up by an email sent by experienced members with chronic pain :

Meeting & AGM: November 1, 2023. MSPs 4; non MSPs 52 total 56

Four MSPs: Miles Briggs, Rona Mackay, Monica Lennon, Clare Adamson.

Election of office bearers: Convener MSPs Rona Mackay, Monica Lennon, Miles Briggs re-elected

Voluntary Secretary: Dorothy-Grace Elder re-elected.

MSP Rona Mackay, chairing.

Inspiring speakers: Dr Carole Torsney on her research on sex differences in dealing with male and female pain sufferers. And Victoria Abbott-Fleming of Burning Nights pain charity Complex Regional Pain Syndrome. MSP Clare Adamson on family experience,

Secrecy

* Discussion again centred on secrecy , officials on the “Pain Taskforce” and on seven sub groups remain nameless.

*Concerns again raised about NHS Highland, where Highland’s top rated specialist pain service is already losing some treatments, despite opposition from patients. Only existing patients are allowed injections and infusions - not suitable newcomers. Again, little information on the future.

*Patients still not allowed to sit with officials when officials discuss their patient services.

*The man whom women pain patients complained about making disturbing online posts against some women patients in 2021 has now been re-appointed to speak for patients.

*Despite protests, there are still no patients allowed to sit with officials on the Taskforce.

CPG voluntary work with the Parliament has become harder - the Parliament’s IT people would not allow us to open this meeting’s recording, which everyone had agreed as usual should record for minutes. This meant the voluntary secretary had work doubled, contacting many to check names and content.

Work all year*

*Our voluntary secretary was invited to address the STUC congress in Dundee in April, seconded by UNITE on a motion against secrecy and for FOI strengthening backed by Glasgow NUJ.

She received unanimous backing against FOI decisions being made by any department being questioned under FOI (as happens with pain),

*The secretary compiled numerous FOI requests pain services and five review appeals after scant FOI information, which is handled by Clinical Priorities.

*Other research meant hundreds of emails and letters plus individual contact with concerned patients.

*Some members attended two identical “briefing” meetings of one hour with officials but there was a shortage of answers.

Some members also attend CPGs on Women’s health, Arthritis & MSK conditions.

MSP Members of The Group

Please provide names and party designation of all MSP members of the Group.

Monica Lennon (Labour)

Jackie Baillie (Labour)

Pam Duncan-Glancy (Labour)

Clare Adamson (SNP)

Miles Briggs (Con)

Jackson Carlaw (Con)
Dr Sandesh Gulhane (Con)
Alex Cole Hamilton (Lib Dem)

Non-MSP Members of The Group

For organisational members please provide only the name of the organisation, it is not necessary to provide the name(s) of individuals who may represent the organisation at meetings of the Group.

Individuals

Prof Martyn Steultjens
John Thomson
Leigh Mackie
Hazel Borland
Sharon Turnbull
Alison Carey
Eddie Phillips
Prof Richard Simpson
Lord George Foulkes
Margaret McInnes
Annemarie Ward,
Councillor Frank McAveety
Rob Friel
Katherine Kilgour
Fiona Collins
David Caulfield
Rob McDowall
Prof Jim McEwen
Baillie Josephine Docherty
Maire Whitehead
Dorothy-Grace Elder
Bill Sinclair
Claire Schiavone
Tasneem Nadeem Mohammed
Nadeem Akhtar Javaid
Laura Grant
Margaret Searle
Lyssa Clayton
Helen Campbell
Ian Brogan
Anne Simpson
Karen Hooten
Marion Scott
Irene O'Neill
John Mutch
Dr Andreas Kelch,
Martha Heaney
Anne Cassels
Irene Logan
Linda Tierney
John Lawrence

Dr Martin Johnson
Dr Mike Serpell
Alasdair Barron
Lloyd Mawson
Vicky Bulman
Drew Searil
Susan Archibald
Alan Watt
Billy Hillhouse
Helen McCluskey
Anne Murray
Christine Martin
Linda Mawson
Frank Mawson Pete McCarron Marion Scott Olive McIlroy Lisa
Megginson June Greenhorn Nancy Honeyball Karen Neil
Claire Daisley Gillian Watt Pauline Firth Janice Castlemilk
Lorna Kettles K. Humphreys
Jean Rafferty
Marie Fallon
Michael Grieve
Iain McPhee
George Welsh
Sue Lavery
J.Canning
Lynn Laidlaw
John Russell
Russell Malcolm
Dr Bill Macrae
Amber Welsh
Miriam Smith
Fiona Stalker
Graeme Houston
Lorna Farrell
Marion Macmillan P T Weir Marian Kenny Donald Macaskill
Elizabeth Roper Heather Ann Baxter
Christine Macdonald
Adam Stachura
Owen Hughes
Rab Wilson
Rona Agnew
Carla Kaspar
Steve Kent
Nan Black
Keir McKechnie
Craig Smith
Kathleen Powderly
Dr Patrick Trust
Irene Loudon
Dr Malcolm Maclean
Ming Robertson
Frances Boyle
Hazel Young
Ooi Thye Chong
Catherine Hughes
Anne Hughes
Fiona Robinson
Margaret Coats

Des Quinn
Arlene Byrne
I.J. Tierney
Geraldine McGuigan
Janice Connelly Irene R. Logan
Josie Isles
Dr Jackie Mardon
Anne Marie Diamond
Dr Mary Loudon
Liz Barrie
Gordon Barrie
Dr Sabu James
Greg Halliday
Lynsay Brasington
Lauraine Macdonald
Ruth Lewis
Kay Hildersley
Prof Colin Howie
Paulo Quadros.
Kenny Boyle
Katharine Kilgour
James Sandeman
Claire Stevens
Marion Butchart
Elric Honore
Alex Stobart
Nicola Mills
Margaret Wyllie
Ian Semmons
Karen Hooton
Irene Loudon
Dr Malcolm Maclean
Ming Robertson
Frances Boyle.
David Caulfield
Carole Brown
Joanna McParland
Claire Watson
Claire Headspeath
Dr Kirsty Proctor
Baiiie Soryia Siddique
Isabella Smith
Alex Neil
Hussein Patwa
Marion Brown
Jim McBeth
Peter Gordon
Lorraine Purdie
Stuart Mclver
Barbara Melville
Brian Whitters
Jane Ormerod
Jacqui Tweddle
Peter Kearney
Andy Stuart
Mary Teresa Johnson
Marie Steele

	<p>Claire Daisley Miriam smith Dr Karen Gardiner MWCraig Polly Firth, Dr Elke.loeffler Alex.Thorburn Cass Macdonald Fiona Kelly Helen McDade, Helen Goss Lucinda.Roberts, Dr David Weeks Kim Dams Qesir Mahood</p>
--	---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

<p>Organisations</p>	<p>Action on Pain UK ME Action, Inclusion Scotland Faces & Voices of Recovery UK Glasgow Disability Alliance Scottish Care EDS UK – Ehlers - Danlos Support UK Chartered Society of Physiotherapy Scotland Royal College of Physicians & Surgeons of Glasgow Scottish Mesh Survivors campaign Complementary & Natural Healthcare Council UK, Fibromyalgia Action UK, More than Fibro, BMA Independent Federation of Nurses in Scotland Cope Scotland RCN, Campaign for a Safe & Accountable NHS in Scotland Leuchie House respite centre National Osteoporosis Society Royal College of General Practitioners Intlife, Scottish Neurological Society Marfan Association Femme Fatigue Glasgow Caledonian University, CPG on Arthritis & Musculoskeletal Conditions, Equality Council , STUC, NUJ, Friends of the NHS Centre for Integrative Care.</p>
-----------------------------	------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Group Office Bearers

Please provide names for all office bearers. The minimum requirement is that two of the office bearers are MSPs and one of these is Convener – beyond this it is a matter for the Group to decide upon the office bearers it wishes to have. It is permissible to have more than one individual elected to each office, for example, co-conveners or multiple deputy conveners.

Convener	Monica Lennon MSP (Co-convenor) Miles Briggs MSP (Co-convenor)
Deputy Convener	N/A
Secretary	Dorothy Grace-Elder (Voluntary)
Treasurer	N/A
Financial Benefits or Other Benefits Please provide details of any financial or material benefit(s) the Group anticipates receiving from a single source in a calendar year which has a value, either singly or cumulatively, of more than £500. This includes donations, gifts, hospitality or visits and material assistance such as secretariat support.	
None	
TO BE COMPLETED BY THE CONVENER	
COMPLIANCE WITH SECTION 6 OF THE CODE OF CONDUCT (Please tick all boxes that apply) I, Convener of the Cross-Party Group on Chronic Pain, hereby declare that, in line with the requirements of Section 6 of the Code of Conduct, this CPG has:	
5 MSP Members from 3 different political parties	Yes
Held at least 2 quorate meetings in the last 12 months	Yes
Held an AGM within 11-13months of the date of registration or the last AGM	Yes

Submitted an annual return form within 30 calendar days of the AGM	Yes
Provided Standards Clerks with 10 calendar days' notice of all meetings	Yes
Provided minutes of all meetings	Yes
Signed	<i>Monica Lannon .</i>
Date	15/03/2023