

## 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)

03.10.2022

### Date Annual Return Submitted

27.10.22

**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]

14.09.2021

### 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.

**MEETING Sept 14, 2021**

**Seven MSPs, 49 non MSPs, 56 total  
MSPs Rona Mackay, chairing. Monica Lennon, Jackie Bailie, Paul O’Kane, Jackson Carlaw, Miles Briggs, Clare Adamson.**

The Group was re-established and office bearers elected. It has now marked its 20<sup>th</sup> anniversary of founding in 2001 and is one of the longest running CPGs.

**“Atrocious attitude to patients”**

Patients had been cut out of involvement on planning new services since May 26, 2021 by Govt and Alliance, who both stopped meetings without explanation. Patient rep Liz Barrie reported as one of 10 “lived experience” patients invited by the Government-funded charity, the Health & Social Care Alliance, to serve on the Government’s National Advisory Committee on Chronic Pain. (NACCP) Patients had wholeheartedly volunteered, hoping for positive results.

But Liz said it was an “atrocious” experience, used to tick boxes that patients were invited, although denied proper involvement. There was no sign of compassion or care for patients,

The Alliance had said in advance that the independent patients would be in a “co-production” equal with officials. They would see all documents and facts to help them write service improvements. But they found no co-production, facts not given. They could not approve a report they’d worked on but were not allowed to see, being without word for six months and then sent it only after it was printed.

At a side meeting on April 27, 2021 Ms Barrie produced written proof that Clinical Priorities had not informed patients that a ban on pain relief injections had been lifted nine months before in July 2020. Patients urged discussion –refused by the chair, Dr Harden.

Later, Clinical Priorities officials sent emails threatening expulsion to two of the patient volunteers who pushed for discussion of patients left without treatment. Patient rep Kathleen Powderly said she was threatened with expulsion over “a tut or eye roll”.

In contrast, no action taken against a male on the committee sending disturbing online posts to women patients who spoke up. There was no safeguarding, rules were written but ignored.

MSPs expressed shock and urged the health secretary to meet patients,

The meeting passed two resolutions:

\*Urging the Government to remove the Clinical Priorities Unit from involvement with chronic pain and transfer to another part of the civil service.

\*Urging that return waiting times be published for 40,000 patients, as some could wait up to three years

**Mesh patients**

Lisa Megginson and Nancy Honeyball reported continuing lack of pain relief, and massive delays in being assessed for mesh removal. Lisa also reported that the Alliance had sought Mesh women for a role but refused her application because she was on other Groups, including the campaigners Scottish Mesh Survivors,

Mesh campaigner MSP Jackson Carlaw said the attitude to chronic pain sufferers was “a ghastly déjà vu experience, similar to what mesh campaigners endured”. The mesh women at first felt dismissed, thinking that they were only there to tick boxes. Eventually they had to disassociate themselves from the report and start again. Mr Carlaw said rejection of individuals who volunteered services was also “eerily familiar”.

### **Lidocaine patches:**

There was concern that some areas wanted to cut use of Lidocaine patches to save money even for Mesh patients. The meeting invited Mr Quesir Mahmood, from the manufacturers, to tell us the NHS price. This is around £72.40 for the Versatis brand and £61.54 for Ralvo, each for 30. Patients did not think these prices should prohibit issue. Patches were all some had when treatments stopped during lockdowns.

### **MEETING 02 March, 2022**

6 MSPs, 50 Non MSPS. Total 56.

MSPs: Monica Lennon, chairing, Rona Mackay, Miles Briggs, Jackie Baillie, Clare Adamson, Pam Duncan Glancy.

Three MSPs met Health Secretary Humza Yousaf and public health minister Maree Todd on February 21 2022, a meeting requested from August 2021. The three pointed out that the original request was for patients as well as MSPs. They were Rona Mackay, Monica Lennon and Pam Duncan Glancy. Mr Yousaf promised to meet CPG patients in future.

The MSPs stressed the suffering caused by lack of treatment for chronic pain and arthritis & MSK conditions and how patient reps considered they were badly treated on the Govt advisory committee.

Mr Yousaf promised to consider a request for waiting times for return patients to be published. The Ministers also promised openness and transparency from now on,

### **New Pain Framework Report**

Patient reps called the report “waffle” not an action plan.

It was hard to discuss a report without hard facts such as patient and staff numbers or any investment.

Patients were excluded from knowing what was in it until printed. Patient reps were elected for two years but invited to only two meetings in four months.

All meetings stopped after May 26 2021 with regular contact over. But the presence of the patients for two meetings was used to tick a box. Patients still haven't got answers to questions on what will happen to lidocaine or injection treatments.

### **All health boards on pain clinic results**

The voluntary secretary had contacted all boards and obtained new info under FOI.

Specialist services such as outpatient injections and lidocaine infusions were again down. Fife used to be the only area which provided neither but now Ayrshire & Arran have also cut.

### **NHS Highland retiral.**

Kirstin Laing, an NHS Highland pain patient, thanked the CPG for their support of Highland outpatient services on which she, her husband and hundreds relied. The group backed her efforts to get the Board to accept the offer by Highland pain pioneer Dr John Macleod to maintain treatments part time after he retired. The voluntary secretary said that Dr Macleod had a great service and possibly shortest waits of all, which must be protected. Secretary contacting Highland MSPs.

### **Guest speaker: Dr Elke Loeffler Designing and delivering effective co-production.**

Dr Loeffler is a leading expert and author on co-production. She assured the group that, properly done, it is a good way forward with equality for the public in planning all kinds of services. It should never be “top down”. Patients agreed that what they went through was definitely not proper co-production.

### **Other work done by the CPG –**

Numerous appeals for information and patient cases;  
Some members attended other CPGs supporting patients on shared concerns: e.g. Long Covid, Arthritis, Women’s Health,  
Some patients compiling a detailed complaint to OSCR, the charity regulator on the Alliance on several factors.

### **AGM AND MEETING October 3, 2022**

MSPs: Miles Briggs (chairing) Rona Mackay, Jackson Carlaw, Jackie Baillie, Clare Adamson.

MSPs Rona Mackay, Monica Lennon, Miles Briggs elected co-conveners

Dorothy-Grace Elder elected voluntary secretary

Miles Briggs MSP, welcoming, said that after 20 years, the CPG continued to attract new members, currently welcoming new people from the Western Isles, Highlands and Borders and the cities,

**Highland success** He was delighted that Highland patients had won their effort to retain services from Dr John Macleod after his retiral, to which Kirstin Laing had alerted our group at our March meeting.

### **Meeting with health secretary and public health minister.**

The meeting was told that our MSPs had tried hard to gain a meeting with Humza Yousaf and Maree Todd.

This was now set for November 7 but the health secretary again did not invite any patients, only the MSP conveners – Rona Mackay, Monica Lennon and Miles Briggs.

MSP Jackson Carlaw said this wasn't fair and that the health secretary must involve patients.

Patients pointed out that this would be the third time this year that the health ministers excluded patients. In February, a meeting was confined to MSPs, in June, he agreed to just a 45 min meeting with three patients as well as Conveners- but cancelled the meeting. November: no patients again. The conveners had pressed for patient presence and the Health Secretary promised he would meet the group at some time.

It has been made impossible for patients to continue contributing positive work to Government as officials and the Alliance have not communicated for many months,

### **Snooping on patient activists**

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 any Govt health branch, this was reported to Clinical Priorities and Govt PRs/spin doctors. No question was answered – her queries were used only to snoop on what she was doing and trying to find out, to help patients.

The emails from other Units were sent to and collected by the Clinical Priorities Unit, from whom Data Protection officials obtained them.

**Example: Dorothy asked Public Health Scotland (PHS) and the “Modernising Patient Pathway” team to explain patient pathways. Both did not reply but clyped to 13 different officials what she asked. They also alerted that Dorothy and a patient from the Government NACCP group were on the radio. They told spinners in case of criticism of Govt. PHS claims to be independent, covering Scotland’s health statistics and we are told to trust them.** Other health units such as the Quality & Safety team, the Patient Safety Commissioner office and Clinical Priorities also clyped, without permission, to numerous other officials when DGE sent any query, however small. Some of this outrageous 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?**

**What is so shady about chronic pain plans that patients face spying?**

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 right away to do what the Govt official wanted and stop the patients talking. Incredible for a charity, even though they get £6 million from the public purse.

### **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 he considered will not be published.**

Patients had asked, since late May 2021, what was happening with the NACCP committee they were elected to for two years. It wasn't until late July 2022 that they were told the committee had ended. No consultation.

The meeting passed two resolutions, citing that this was the fourth time they had urged for Clinical Priorities to 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 patients and covert compliance with Government officials.

### **MSP Members of The Group**

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

**SNP: Rona Mackay, Clare Adamson. Lab: Jackie Baillie, Monica Lennon, Paul O'Kane, Pam Duncan-Glancy, Con: Miles Briggs, Jackson Carlaw, Dr Sandesh Gulhane. Lib Dem: Alex Cole-Hamilton,**

### **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.

<b>Individuals</b>	Prof Martyn Steultjens John Thomson Leigh Mackie Lord George Foulkes Dr Colin Rae Margaret McInnes Annemarie Ward, Councillor Frank McAveety Rob Friel Katherine Kilgour Fiona Collins David Caulfield Rob McDowall Prof Jim McEwen Bailie 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 Jim Eadie Marion Scott Irene O'Neill John Mutch Dr Andreas Kelch, Lesley Riddoch Martha Heaney Anne Cassels Irene Logan Linda Tierney John
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	<p>Lawrence Dr Martin Johnson Dr Helen Jackson 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</p> <p>Frank Mawson Pete McCarron Marion Scott Olive McIlroy Lisa Megginson June Greenhorn Nancy Honeyball Karen Neil Claire Daisley Pauline Firth Janice Castlemilk Lorna Kettles K. Humphreys Jean Rafferty Marie Fallon Michael Grieve Selina Mehra 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 Gillian Watt 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 Liza Horan Nan Black Lucie 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 Baiiiie Soryia Siddique Isabella Smith Paul Smith Alex Neil Hussein Patwa Marion Brown Jim McBeth Peter Gordon Lorraine Purdie Stuart Mclver Barbara Melville Brian Whitters Jane Ormerod</p> <p>Jacqui Tweddle Peter Kearney Andy Stuart Mary Teresa Johnson Marie Steele 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 Mahmood.</p>
<p><b>Organisations</b></p>	<p><b>Organisations</b></p> <p>Action on Pain UK</p> <p>ME Action</p>

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 Friends Scotland

FFU-Scotland (Fibromyalgia)

Fibromyalgia Action UK

BMA

Independent Federation of Nurses in Scotland

Cope Scotland

RCN

Campaign for a Safe & Accountable NHS in Scotland

Healthcare Improvement Scotland

Leuchie House respite centre

National Osteoporosis Society

Royal College of General Practitioners

Intlife

Scottish Neurological Society

Marfan Association



	<p>Femme Fatigue</p> <p>Glasgow Caledonian University</p> <p>CPG on Arthritis &amp; Musculoskeletal Conditions</p> <p>Equality Council</p> <p>Open Democracy</p> <p>Friends of the NHS Centre for Integrative Care</p> <p>Open Government.</p>
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### **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.

<b>Convener</b>	Rona Mackay MSP
<b>Deputy Convener</b>	Co Conveners: Monica Lennon MSP, Miles Briggs MSP.
<b>Secretary</b>	Dorothy-Grace Elder, voluntary secretary
<b>Treasurer</b>	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.**

We do not seek funding. Voluntary Secretary gives services free.

### **Convener Contact Details**

<b>Name</b>	Rona Mackay MSP
<b>Parliamentary address</b>	Scottish Parliament Edinburgh EH99 1SP
<b>Telephone number</b>	0131 348 5789