

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.)

October 2016

DATE OF MOST RECENT AGM

October 5, 2020 by Zoom

DATE ANNUAL RETURN SUBMITTED

October 30 2020

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

October 9 2019

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: May 11, 2020 by Zoom due to Covid-19 lockdown Chaired by Miles Briggs MSP

Present: 5 MSPs, 36 Non MSPs

This meeting said that lockdown had brought to a head the need for urgent reform of the “ undemocratic and secretive way” chronic pain policy has been run for years.

The meeting called for urgent reform of the National Advisory Committee for chronic pain. Patients felt “completely abandoned” during lockdown. This key committee had not reached out to them and had proved unhelpful for eleven years. There was no contact or apparent plan to help. Pain clinics closed without word, with no pain relief for those dependent on lidocaine infusions and injections - which could only be given at specialist clinics. Patients testified about having to go to England for pain relief and pay privately - around £860 - £960 first time, about £650 subsequently. Fiona, a patient who had made the “agonising journey” of around 500 miles return and Nan, the mother of an adult patient, told of extreme suffering. Nan’s son was in lockdown with his two small children who should not have to see his agony.

Chris Bridgeford, chair of Affa Sair, a patient group of over 500, believed patients were “subjected to deplorable levels of suffering” because the Scottish Government officials had regarded chronic pain relief as “non-essential”.

Mystery over pain treatment refusals.

Fiona pointed out that while Covid precautions were the reason given for banning brief hospital attendance for infusions, she had been offered three days in hospital “under sedation” with morphine, but no pain treatment. She said that 3 days in hospital carried far more risk than a two hour infusion which would curb pain for up to six weeks.

Another patient , Lynn, had gained infusions for a different condition – so why not chronic pain? Some speculated the worst case would be that pain services could be cut – like some “terrible experiment” if officials got away with stopping injections and infusions for months of lockdown, despite the suffering caused, then some may try to stop clinic help permanently.

Liz Barrie warned that the attempted suicide rate was bound to rise the longer people were forced to be without treatment. There were already signs that services were being cut quietly without consultation, Patient Irene, a fibromyalgia sufferer, told of how, after 15 years of successful injections, the New Victoria in Glasgow had stopped this service last year and offered her only self-management, which she had already trained in but it was a tool, not a replacement for relieving the worst of pain.

Th MSPs agreed that chronic pain problems in Scotland had become magnified through lack of policy management.

Kathleen and Catherine asked why, when they also intended to reduce opiates, there was also a mindset which didn’t seek alternative help from doctors at the NHS Centre for Integrative Care who were NHS trained experts.

Chris Bridgeford proposed “Pain relieving infusions and injections should be resumed forthwith to relieve the intolerable pain suffered by those patients reliant on these types of treatment. By not allowing treatments to go ahead, advisors and government can do considerable harm to patients. Many will be despairing, some to the point of suicidal thoughts/attempts due to the agony suffered without the type of help that works for them”

MEETING: June 15, 2020 by Zoom. Chair: Monica Lennon MSP

Present: MSPs: 4; Non MSPs: 49

The intervention over lockdown suffering by international star Annie Lennox publicised the plight of chronic pain patients in Scotland round the world. She personally suffers. Annie is chancellor of Glasgow Caledonian University. She wrote on her website:

Unlike the barbarism of the Middle Ages - in the 21st century, it should be considered indecent and inhumane to leave people to suffer intolerable pain without their usual relief, while we actually do have the means to treat it. I very much hope this situation can be taken seriously and responded to as soon as possible.

“Without medication or clinical treatment, life becomes torturous and untenable. Due to the Covid 19 lockdown situation, NHS chronic pain clinics have been closed for months with no word yet on when they will re-open, which is sought urgently In Scotland in particular. Will years of complaints over waiting times and underfunding continue to be ignored? Annie Lennox.”

This meeting was dominated by questions to the guest: Prof. Jason Leitch, Scottish Government National Clinical Director, who is “in charge of patient safety and patient centred care “ He asked for questions in advance and patients put work into this. However, there was general concern that few actual answers were given and little information. Questions included patients being left without clinic treatments for three months by June 15 and feeling abandoned as it was known that treatments like lidocaine infusions had to be renewed every five to six weeks, Fiona Robinson asked why Covid risk was blamed for not allowing her a two hour pain relief infusion – wasn’t the offer of three days in hospital under morphine sedation – but not pain relief – riskier?

Why was pain relief being avoided when other types of infusion did go ahead during lockdown? This was asked by Lynn, who obtained infusions of another kind.

Prof Lynch said, while that “wasn’t like me” he stressed again they were dealing with a public health emergency”. But he promised that Covid 19 would not be used as an excuse to cut services.

Nan Black outlined that £2,450 had to be raised by her family to send her son hundreds of miles to Yorkshire for private treatment because pain relief wasn't available in NHS Scotland or privately here. He couldn't answer on money return queries but advised she write to the Scottish Government.

He referred to the Faculty of Pain Management, which had said in mid May they believed treatment would begin restarting at NHS clinics in six weeks. (end of June) The meeting said there was no sign of this in Scotland. (It took till late Sept/October)

Members raised the key issue of the National Advisory Committee on Chronic Pain (NACCP) which was called secretive and asked why, in the 21st century, did Scotland have a committee meeting in private, barring public and media, with no patient representatives but four charities which all gained Scottish Government money? Various members cited the NACCP had not helped clinics, shortages and let patient waiting times crash from 89.8% being seen on time in 2011 to only 60.5% in 2018-19, pre Covid. No sign of achievement.

Prof Leitch said that the Alliance was organising a patient panel but was told that the CPG had not been informed how this would work. Moreover, the Alliance had been on the NACCP for years and were party to the situation. Irene Oldfather of the Alliance said they were willing to work alongside the CPG but the meeting objected to the patients being segregated from the committee influencing their treatment. It was agreed that the Conveners write to the Scottish Government expressing serious concerns including about the NACCP continuing private meetings and engaging only with charities which received Scottish Government money.

It was decided the voluntary secretary should compile another round of patient views and continue her work to gain help for suicide risk pain patients and further research on FOI.

Meeting & AGM October 5 2020. Zoom. Chair: Rona Mackay MSP

MSPs: Six MSPS, 48 Non MSPs

The chair welcomed Joe Fitzpatrick MSP, Minister for Public Health and Dr John Harden, the new chair of the National Advisory Committee on Chronic Pain. Patients put questions to both.

There was wide concern that many still did not know, after seven months, when clinics would be open fully for them/their next appointments and that pain risked return to a pre-NHS situation of “pay or no treatment”.

The minister and Dr Harden said that the health secretary's letter to Boards put chronic pain among the priorities. Patients stressed they felt “abandoned” during lockdown with no clinic treatments The Minister and Dr Harden agreed “it must not happen again” that there were no services during lockdown if there was a second wave. The meeting welcomed this announcement but needed details. People were

glad there was a new chair of the NACCP and hoped the review of this committee caused real change as it had shown no help to any of the problems outlined.

Treatment times doubling There was anger that some treatment times had more than doubled despite the number of operations being greatly reduced, presumably giving anaesthetists time. Managers are discarding clinicians' decisions on patients needing five or six week renewal. Managers are imposing 12 weeks, meaning some patients may be forced to return to private medicine in England, as Fiona has had to do three times in lockdown and Nan's son has had to do five times, (both NHS Lanarkshire) Many more will suffer if unable to pay – a pre NHS situation.

The minister and Dr Harden were asked to investigate waiting times being increased/doubled and prevent clinicians being over ruled by managers. And will there be recompense for those forced to pay privately?

Return to private medicine? Jenny Gow said she had to get a second job to pay privately for pain relief for her 22-year-old daughter because NHS Grampian cannot give injections in time. The family paid £1,120 for two injections this year and likely to pay a third time because NHS Grampian can only supply one a year. Ms Gow said the clinician thought the young patient needs three to four a year. Grampian also has no infusions. This young woman had to give up work she loved due to excruciating pain.

The meeting was told that “no decisions had been made” on treatments which may be at risk yet these are still not being named. But overall policy has declared pain services “will build on the value of self-management and seek to reduce reliance on treatments that do not deliver long-term health outcomes” Patients rejected this and stressed the high value of injections and infusions in giving them a life again.

FOI shows treatments already cut. However, FOI new disclosures show some key treatments have already been reduced without consultation being known. Injections have been cut in Scotland from 14,500 in 2015/16 to 9,100 in 2019 (pre Covid). That's a heavy loss of over 5,000 injections for successful pain relief lasting possibly up to six months. Lidocaine now involves under 2,000 infusions throughout Scotland.

FOI also showed continuing huge variations in treatments throughout Scotland. Some gave both infusions and injections, others gave one of these. But NHS Fife pain services were the only ones refusing both infusions and injections and they have long been represented on the NACCP.

The CPG still hadn't been told since February how a proposed Patient Panel will work and why it's planned to keep patients separate from the NACCP. That is viewed as wrong and unworkable.

THE PROBLEMS WITH THE NACCP

The voluntary secretary thought that Dr Harden being from outside the NACCP atmosphere should be an asset to fresh thinking. The meeting was told this Committee is viewed as not being patient friendly, not supportive of clinics and uncommunicative. The CPG did not know of NACCP achievements. A major point, such as the creation of the Scottish Residential Service, was through a 12-year patient campaign backed by the Scottish Parliament unanimously and agreed and promoted by then health secretary Alex Neil.

There are ten/eleven paid officials, and four charities which get SG funds. It meets in private, excluding public and media. Patients called for charities unconnected with state money to be appointed.

The Alliance (£4 million plus their staff/running costs) provides Govt money to the other three – Versus Arthritis £369,563 for one five-year project, Pain Concern £90,206; Pain Association £28,128 last year; (source: Alliance website) All four charities get funding for promoting self-management. Can their views on treatments be unbiased?

The minister and Dr Harden were asked to look at the overall democratic deficit.

Annual General Meeting

The meeting re-elected MSP co-conveners Rona Mackay, Monica Lennon, Miles Briggs, Elaine Smith.

Dorothy-Grace Elder was re-elected voluntary secretary and Chris Bridgeford elected as assistant secretary.

Other work by CPG volunteers:

Meeting, with 3 CPG members, January 2020 with civil servants at their invitation.

February -18 members met at the Alliance's invitation over their plans to have a Patient Panel. Only seven members from other groups and charities present. The CPG did not want patients to be separated from discussions by the NACCP

June – The voluntary secretary has been trying for two years to add the suicide risk for pain patients (agreed by the WHO, etc) added to Scottish Government work on suicide. SAMH has now set up a group for us and six members attended a friendly meeting.

Sept: The voluntary secretary obtained and researched FOI applications she had made to 14 Scottish Boards on cuts made to lidocaine infusions and pain relief injections. These cuts were imposed without sign of consultation with patients

It showed that, over the last four years, service cuts had removed over 5,000 injection appointments in Scottish pain clinics and lidocaine infusions were used in only seven out of 14 Boards.

Service with least provision is NHS Fife, the only Scottish area with neither infusions nor injections for chronic pain. They also do not transfer patients to other areas if they request these treatments, replying just “no” with no explanation.

MSP MEMBERS OF THE GROUP

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

Elaine Smith, Lab,
Miles Briggs, Con,
Rona Mackay, SNP,
Monica Lennon, Lab,
Tom Mason, Con,
Alex Neil, SNP,
Donald Cameron, Con,
Anas Sarwar, Lab,
Willie Rennie, Lib Dem,
Jackie Baillie, Lab,
Bill Kidd, SNP,

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	Dorothy-Grace Elder Prof Martyn Steultjens John Thomson Anne Murray Lord George Foulkes
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	Dr Colin Rae
	Margaret McInnes
	Councillor Frank McAveety
	Karen Neil
	Claire Daisley
	Elaine Holmes
	Olive McIlroy
	Nancy Honeyball
	Rob Friel
	Robert Dickson
	Frances Boyle
	A Floyd
	Katherine Kilgour
	Fiona Collins
	David Caulfield
	Rob McDowall
	George Welsh
	Catherine Hughes
	Ooi Thye Chong
	Prof Jim McEwen
	Bailie Josephine Docherty
	Maire Whitehead
	Dr David Weeks
	Bill Sinclair
	Claire Schiavone
	Laura Clark

	Maureen McAllister
	Anne Hughes
	Margaret Coats
	Tasneem Nadeem
	Mohammed Nadeem
	Akhtar Javaid
	Lara Grant
	Margaret Searle
	Lyssa Clayton
	Helen Campbell Ian Brogan
	Anne Simpson
	Margaret6 Wyllie
	Karen Hooten
	Dr Sheila Inglis
	Jim Eadie,
	Marion Scott
	Irene O'Neill
	John Mutch
	Kathleen Powderly
	Marion Butchart
	Marian Kenny
	Dr Patrick Trust
	Dr Adreas Kelch
	Nicola Mills
	Alan Watt
	Linda Mawson

	Frank Mawson
	Pete McCarron
	Lesley Riddoch
	Michael Grieve
	Jim Scanlon
	Martha Heaney
	Jean Rafferty
	Anne Cassels
	Christine Martin
	Jacquie Forde
	Irene Logan
	Arlene Byrne
	Linda Tierney
	Fiona Robinson
	Geraldine McGuigan
	Janice Connelly
	John Lawrence
	Dr Martin Johnson
	Dr Helen Jackson,
	Dr Mike Serpell
	Dr Sabu James
	Liz Barrie
	Gordon Barrie
	Anne Hughes
	Alasdair Barron
	Paulo Quadros

	<p>Kenny Boyle</p> <p>Phil Atkinson</p> <p>Helen McCluskey</p> <p>Lloyd Mawson</p> <p>Bailie Soryia Siddique</p> <p>Vicky Bulman</p> <p>Nan Black</p> <p>Andrew Druagh</p> <p>Carla Kaspar</p> <p>Steve Kent</p>
Organisations	<p>Action on Pain</p> <p>Affa Sair charity</p> <p>Chartered Society of Physiotherapy Scotland</p> <p>Royal College of Physicians & Surgeons of Glasgow</p> <p>Scottish Mesh Survivors campaign</p> <p>Community Pharmacy Scotland,</p> <p>Complementary & Natural Healthcare Council UK</p> <p>Fibromyalgia Friends Scotland</p> <p>FFU-Scotland (Fibromyalgia)</p> <p>BMA</p> <p>Independent Federation of Nurses in Scotland</p> <p>Versus Arthritis</p> <p>Scotland & UK</p> <p>Cope Scotland</p> <p>RCN</p> <p>Grunenthal</p>

	<p>Novartis</p> <p>Healthcare Improvement Scotland</p> <p>Leuchie House chronic conditions respite centre</p> <p>National Osteoporosis Society,</p> <p>NHS Highland</p> <p>NHS Lothian</p> <p>NHS Tayside</p> <p>NHS Lanarkshire</p> <p>Royal College of General Practitioners</p> <p>Royal Pharmaceutical Society</p> <p>Intlife</p> <p>Scottish Neurological Society</p> <p>Marfan Association</p> <p>Femme Fatigue,</p> <p>Glasgow Caledonian University</p> <p>Equality Council</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.

Convener	Co conveners: Elaine Smith, Rona Mackay, Miles Briggs, Monica Lennon, Re-elected October 5, 2020.
Deputy Convener	n/a

Secretary	Voluntary secretary Dorothy-Grace Elder Re-elected October 5, 2020, Chris Bridgeford elected assistant voluntary secretary
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Treasurer	n/a
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FINANCIAL BENEFITS OR OTHER BENEFITS RECEIVED BY THE GROUP

Please provide details of any financial or material benefit(s) received 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.

Details of material support should include the name of the individual providing support, the value of this support over the year, an estimate of the time spent providing this support and the name of the organisation that this individual is employed by / affiliated to in providing this support.

Groups should provide details of the date on which the benefit was received, the value of the benefit and a brief description of the benefit.

If the Group is not disclosing any financial information please tick the box to confirm that the Group has considered the support received, but concluded it totalled under the threshold for disclosure (£500).

SUBSCRIPTION CHARGED BY THE GROUP

Please provide details of the amount charged and the purpose for which the subscription is intended to be used.

n/a

CONVENER CONTACT DETAILS

Name	Elaine Smith MSP
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Parliamentary address	Scottish Parliament Holyrood Road Edinburgh EH99 1SP
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Telephone number	0131 348 5824
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