

Minutes of Cross Party Group meeting and AGM October 5 2020. Zoom.  
Chair: Rona Mackay MSP.

55 attended.

The chair, Rona Mackay MSP,  
welcomed as guests 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 said 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 over the years.

**Treatment times doubling** There was anger that, after slow re-  
openings, some treatment times had more than doubled, despite the  
number of operations (requiring pain clinic anaesthetists and staff) being  
greatly reduced, presumably giving anaesthetists time.

Managers are discarding clinicians’ decisions on patients needing five or  
six week renewals on, for instance, Lidocaine infusions. Managers are  
imposing 12 weeks, meaning some patients may be forced to return to  
private medicine in England once in 12 weeks.

Fiona has had to travel three times in lockdown so far and Nan’s son  
has had to go to England 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?

Carer 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 are 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.

Liz Barrie, pain sufferer and a former nurse, pointed out that she and many other patients had been denied her NHS pain relief injections which “restored her life” because they contained steroids. She was concerned to see that SG official advice still stressed that as the reason for refusal.

Liz pointed out that steroid treatments were now being used to help some Covid patients in intensive care. Matt Hancock had talked of a new drug but Liz said it wasn't new, had been around since 1967 but is an anti-inflammatory. Dr Harden said Liz had “hit the nail on the head” and thanked her for highlighting this.

He said that doctors were learning much more about Covid as they went along. In his 25 years as a doctor, he'd never seen such huge change. The remaining problem in his view was that she would be treated in a theatre and there was risk of Covid, even in a few hours. Liz said the risk was to mental and physical health through not being treated. She had never been given her injections in good time, long before Covid. Her clinician said she needed two a year – “but that never happened”.

She was already six months over re-treatment time but short staffing meant she had never had renewal on time and that required investigation, not just blame on this emergency.

### **Truth needed, not spin.**

Several patients including Marion Scott challenged on why there was such variation in services throughout Scotland and called for equality and the truth being told.

Andrew, husband of a chronic pain sufferer, said “It breaks my heart to see my wife 's pain”. He called for truth over services. He had moved to Glasgow to be told at one hospital that they no longer gave lidocaine infusions there and could not tell him where else the patient could go in Glasgow. The CPG secretary contacted the Board, who then assured Andrew that the Board continued Lidocaine infusions. But the CPG secretary then obtained FOI facts, showing that they had cut to only five lidocaine treatments in a year before Covid.

As four treatments a year are needed, that helped only one or two patients in Scotland's biggest health board. Cutbacks in this major treatment had been huge – done silently behind scenes. Few would know to query with FOI – had the CPG not challenged, the patient would have been left with spin, believing a service continuing with previous strength.

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.

The minister, Joe Fitzpatrick promised with regard to self management and treatments that decisions “should always be made with the patient, it needs to be a two-way process”

### **FOI shows injections as well as Lidocaine infusions already cut quietly in Scotland.**

Voluntary Secretary DG Elder reported her FOI investigation. 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 CPG patient

campaign backed by the Scottish Parliament unanimously and agreed and promoted by then health secretary Alex Neil.

Currently, there are ten/eleven paid officials on the NACCP 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.

Other work by CPG volunteers: Meeting, with 3 CPG members, Hughes, Elder, Welsh in January 2020 with civil servants at their invitation.

February -18 CPG 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 over two years to have 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 five 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.

Six MSPs: Rona Mackay, chairing, Elaine Smith, Monica Lennon Tom Mason, Donald Cameron, Joe Fitzpatrick (guest) six

NON MSPS: Dr John Harden, Rona Agnew, Steve Kent, Liza Horan, Carla Kaspar, Margaret Coats, Hazel Borland, Fibro Action UK, Mariam Smith, Dr Jackie Mardon, Josie Isles, George

Welsh, Dr Mary Loudon, Arlene Byrne, Liz Barrie, Catherine Hughes, Anne Hughes, Kathleen Powderly, Amber Welsh, Irene Logan, Jo Lego, Jill Stewart, Chris Bridgeford, Jenny Gow, Nan Black, Lucie Black, Dorothy-Grace Elder, Marion Scott, Donna Philp, Mark Macleod, Drew Searil, Anne Murray, Rob McGowan, David Caulfield, Vicky Chapman, Alison McColl, Christine Martin, Faith Ougham, Anne Simpson, Dr Kirsty Proctor, Kathleen Robertson, Susan Archibald Pauline Firth, Fiona Robinson, Anne Diamond, Marion Butchart, Dominic Wake, . Government officials – three – listened in. 48. Total: 54.