

## **SCOTTISH PARLIAMENT CROSS PARTY GROUP ON CHRONIC PAIN.**

Minutes of meeting on April 24, 2019, at the Parliament.

Welcome from Rona Mackay MSP, chairing. She thanked people for attending in large numbers despite the health secretary's office cancelling her appearance.

Just five days before 24<sup>th</sup> April, the cabinet secretary's office cancelled, saying they had forgotten she asked them to change to October 9. The chair and the CPG secretary were thanked by the meeting for extra work in trying to rectify and inform. Some patients travel several hundred miles. Ian Semmons, chair of the charity Action on Pain, said his round trip of 700 miles plus a hotel stay – paid personally -could not be cancelled at such short notice. He would have to return in October.

Minutes of previous meeting in October 2018 approved.

### **ARE CHRONIC PAIN PATIENTS AND CLINICS BEING SIDELINED ONCE AGAIN? Fear of losing out on a fair share of £535 million waiting times funding by the new Scottish Access Collaborative.**

There was concern about how the Scottish Access Collaborative's stated aim to cut waiting times was being handled regarding chronic pain. There's £535 million for extra resources for various conditions plus £320 million in capital monies, total: £855 million from the Scottish Govt. Yet so far, chronic pain clinics have been given a total of just £27,000 out of £855 million. So will patients be short changed again?

The voluntary secretary had been enthusiastic about the Collaborative, as a new body being involved for a change. Yet past influences prevailed, in her view. She spent two days at "workshops" in Stirling organised for the Scottish Access Collaborative but, like some others, found avoidance of spelling out the huge burden on understaffed specialist clinics. As another participant remarked: "There was a clear agenda to steer the meetings towards primary care being helped rather than the clinics and their waiting times".

This was a very "inhouse" project without independent external oversight.

The "design workshops" and a report were organised by the Digital Health Institute/Glasgow School of Art, who are funded by the SG. The DHI/GSA people said they weren't knowledgeable about chronic pain but were being advised by the Government's Clinical Priorities unit from the National Advisory Committee. These are not bodies our CPG has found helpful to chronic pain waiting times or clinics. The sessions included many officials but were light on patient voices.

Those mentioning waiting times problems in Scottish areas were told such facts were not required... in a waiting times project! ISD written facts on waits were cut out of a later submission by the CPG. Separately, a patient who sent a letter was asked to remove mention that waiting times in his area had reached over 40 weeks for new patients (18 weeks is the maximum) Our secretary and a clinician objected to the exclusion of essential facts about chronic pain clinics. It was claimed that only "a small number of patients" attended chronic pain clinics, with even the number of new patients annually – over 20,000,

excluded as well as any estimate of return patients. But the draft report which excluded facts was approved by the National Advisory Committee, on which Clinical Priorities has places.

The number – 20,117 new patients in 2018 – was inserted in the final report after an appeal to the DHI/Art School people by the CPG. Return patients are not included. These may run into tens of thousands – the claim of “small number” is entirely wrong.

The final report does call for more investment, workforce help, etc. CPG discussion involved anger that patients’ future appeared shaped by officials. But the influence to swing facts away from the clinics has resulted in a decision by officials to concentrate on primary care, without known plans. There was long discussion with this ending:

The CPG passed a unanimous vote of no confidence in the National Advisory Committee on Chronic Pain and the Clinical Priorities Unit for failure to help chronic pain patients over the years – proposed by Ian Semmons, seconded by Kathleen Powderly. This is the second time in three years the CPG has complained formally about these organisations. One earlier complaint was over a Clinical Priorities official emailing statisticians to try to stop return patient numbers being published, an interference overturned by the UK Statistics Regulator in 2017.

### **MESH SUFFERERS**

Mesh patients said that red tape in Scotland was delaying and obstructing the offer by Dr Dionysios Veronikis, who has world class experience of full mesh removals, to come to Scotland from Missouri to share his knowledge with Scottish surgeons and help patients. This is a remarkable offer, patients said. MSP Rona Mackay said she was confused as to why there had been no progress as there was an allocation of money and she would ask the health secretary why there was no progress.

One patient, Claire Daisley, said that in Scotland she would shortly have her bowel and bladder removed, which horrified her but surgeons here reckoned that would alleviate her pain. Although she had been informed that mesh had been removed, she believed some of it was still there and was the cause of continuing excruciating pain. She did not want to lose vital organs if remaining mesh was to blame.

Marion Scott passed a message from a mesh sufferer requesting a treatment and care pathway but nothing is in place. Former health secretary Alex Neil had tried to stop mesh procedures completely but two boards had continued. Dorothy-Grace Elder said the mesh disaster was similar to the silicone implants scandal of twenty years ago, when the Medical Devices Agency in London refused to condemn silicone despite Canada, America and France ceasing procedures at the time. The Agency’s successors, the Medicines and Healthcare products Regulatory Agency, were now involved with mesh. They are undeveloped.

### **WAITING TIMES -INFO FROM INFORMATION SERVICES DIVISION (ISD)**

Scott Heald, Head of Profession for Statistics and Fiona MacKenzie, Manager, Service Access, extended an invitation to the CPG on chronic pain to be represented on ISD’s Governance Group. Members thought this a progressive, inclusive idea from ISD and CPG patient FR volunteered. She had a distinguished business background until chronic pain forced her to end a career she loved.

The meeting learned that the Dundee University dataset work on chronic pain has now been transferred to ISD to complete, who will receive fees. Members queried why as much as £257,000 had already gone to Dundee University, more than any money for the pain clinics who got only £27,000, but the ISD representatives were not involved with such decisions. The CPG was aware ISD had not been informed of the project originally. ISD has worked on gaining numbers of return patients, investing £30,000 from their own funds.

The Dundee University project has studied three health board areas over chronic pain since 2015, costing £275,000.

ISD now has to roll out the project to all Scotland, including all 14 boards. ISD reckons they will have good quality data within about 18 months from now.

ISD will endeavour to include workforce data and return patient numbers. They remain committed to previous promises to the CPG. (return patient figures were not mentioned in the original Dundee University commission by the Scottish Government)

### **DATA GATHERING CUTTING TIME FOR PATIENTS?**

Discussion moved to the time taken away from patients while clinicians fill in more forms; The ISD team pointed out that while all health boards may be using the same technology, the way they choose to use it varies considerably between boards.

Ian Semmons, chair of Action on Pain, related that a pain physiotherapist he knows spends one day a month recording statistics. Multiply this time with the other pain professionals and he could see how disruptive data collection can be in a clinical setting, unless it is vital data, which he did not think the original Dundee work was. Members pointed out that this dataset would deal with quality outcomes of patient treatment.

But how to achieve quality when understaffing was still untackled?

Fiona MacKenzie hoped the new data collection would work seamlessly within the normal working day in clinics. The ISD leaders were thanked for their help, especially as Scott had newly returned from sick leave.

### **CONCERN OVER LACK OF OUTSIDE VIEWS.**

The meeting was glad to hear that ISD, as an independent body, had taken over the Dundee University project. The CPG had voiced previous concern that the Dundee project was another example of moves on chronic pain being limited to a small circle. The contract was awarded by a Scottish Government grant, so did not require to be put out to tender.

Three persons involved with the dept at Dundee University which received £275,000 are on the Scottish Government's National Advisory Committee.

### **CENTRE FOR INTEGRATIVE CARE (CIC)**

The Parliament's Health & Sport Committee asked our CPG and the CPG for Arthritis and Musculoskeletal Conditions for patient and professional views over the CIC, the loss of the ward and stoppage of Scotland-wide access, despite protests from patients. This is the follow up to the petition by Catherine Hughes. Her health is increasingly poor and she is unable to access the past care she received as crisis beds have been removed from the CIC, and all inpatient access is barred. She has campaigned for the CIC for 15 years. Members

thought the hospital might have been lost entirely without Catherine's dedication.

Catherine thanked our co conveners for letters of support.

**Action:** Due to Catherine's illness, the voluntary secretary has agreed to gather views and write a Report for the health committee. This will take several weeks of work.

### **MIGRAINE**

The meeting learned that Alex Neil MSP was involved in trying to raise the importance of migraine and the extreme pain many suffer. Over one million in Scotland suffer from migraine yet there were only three specialist treatment centres covering Scotland, of which a Lothians Clinic has now been stopped, leaving Glasgow and Aberdeen as the main centres. The voluntary secretary recently attended a special meeting at Holyrood organised by migraine sufferers and Mr Neil. More action by charities is needed to draw attention to the huge problem in Scotland.

### **ATTENDANCE**

MSPs Rona Mackay (chairing). Tom Mason, Miles Briggs (earlier part of meeting)

Non MSPs: David Caulfield, Rob McDowall, Dr Jacqueline Mardon, Claire Daisley, Marian Kenny, Lorna Farrell, Olive McIlroy, Elaine Holmes, Catherine Hughes, Gillian Watt, Sharon Mercado, Anne Simpson, Colin Simpson, Liz Paterson, Marilyn Weir, John Mutch, Sian Guest, Hilary Basely, Scott Heald, Fiona Mackenzie, Christine Macdonald, Kathleen Powderly, Dr Mary Loudon, Anne Hughes, Dr Line Caes. Dr Lauraine Macdonald, Dr Greg Halliday, Ruth Lewis, Dr Linsay Brassington, John Thomson, Peter McCarron, Frances Boyle, Carole Brown, Anne Marie Floyd, Fiona Robinson, Alan Robinson, Marion Butchart, Sarah Barbour, George Welsh, Dorothy-Grace Elder 43 total.