

## Draft Minutes, **CPG for Chronic Pain, March 14, 2018.**

Welcome by Co-convenor Miles Briggs, MSP, chairing.  
Minutes approved of meeting on October 4, 2017.

### **Waiting Times and suicide risk.**

There was disturbing news that, in January, NHS Grampian chronic pain patients had been told that waits had increased to 40 weeks. That's for new patients on a promised 18 week maximum. Return patients can wait even longer but are uncounted at present. Grampian and Moray are areas which report return patients with suicidal impulses due to excessive waits of a year, 18 months or 22 months since last treatment renewal. This is due to long term short staffing.

But a NHS Lanarkshire patient at the meeting, Mrs Liz Barrie, said she had attempted suicide this month (March) after being 12 months since her last injection – required every six months, her clinicians said. (Written permission to use Ms Barrie's name). Fearing the total wait would be 18 months or over –her past experience – she swallowed about 40 pills and “lay down to die”. Ms Barrie, a former nurse, warned that while NHS Lanarkshire was one of six Scottish boards whose statistics looked “good”, seeing all NEW patients within 18 weeks, the hidden plight of return pain patients needed urgent investigation. But this remained unknown publicly as returns aren't counted throughout Scotland. Prioritising new patients made the waits worse for returns going to the same small staffs. She believed returns weren't submitted to ISD because their numbers would show the waiting times were even worse.

She has had years of pain from a severe back injury. A wife and mother, Ms Barrie pointed out that extreme pain blanks all but the need to stop the agony. “ I didn't want to see my family suffering more with me in distress daily. Pain had already taken my career, and my normal life. But I know the injections work and restore me to near normal life but I could never get them in time”

“When you're in excruciating pain all the time, you don't think. You can't even stand properly” Her husband found her and he and their daughter rushed her to A&E. She was hospitalised over a weekend. “It is entirely to do with staff shortages that I had reached wanting to end my life. The clinicians are very good, they try hard and it is not their fault but they are clearly under –resourced and have a huge workload”

“Knowing a procedure of about 20 minutes could stop the worst of the pain and I could get back what is left of my life, but ending up suffering a year, 18 months or more between appointments is beyond cruel.”

She said her husband, who was with her at the meeting, had no advance idea she would speak on impulse after hearing about Grampian. “But I had to show how dangerous it is to keep return patients hidden, meaning no action to help us”

The treatments can help her cut down or even stop opioids and other pain drugs. The meeting expressed outrage and praised Ms Barrie for her bravery in speaking up to help others.

Members said people should be ashamed that anyone was driven to try to end their lives because of staffing shortages which stopped them reaching help that was there.

**Action point:** The meeting urged immediate action; MSPs to ask Parliamentary questions; MSP co-convenor Miles Briggs would contact the deputy CMO, who chairs the Government's CP Advisory Committee, and ask what they were doing about suicide risk. Alex Neil, a Lanarkshire MSP, will raise this with the NHS Lanarkshire CEO.

Group secretary DG Elder to contact the lead clinician for chronic pain, Professor Blair Smith.

Note: later replies from deputy CMO Dr Gregor Smith, chair of the Government's National Advisory Committee, did not specify any direct or urgent action they would take on prevention of suicide due to excessive delays in pain treatment. One recommendation was that patients contact the Samaritans or Breathing Space. ( They cannot tackle NHS waiting times.) Prof Blair Smith said it "would be beyond my remit, as Lead Clinician, to add to Dr Smith's reply on these matters". Blair Smith is appointed for half a day a week.

#### WAITING TIMES FOR RETURN PATIENTS - FIRST INFORMATION

The meeting welcomed speakers Scott Heald, Head of Profession for Statistics at the Information Services Division (ISD) and Fiona MacKenzie, Service Manager, Service Access and Waiting Times, ISD and NSS who had volunteered to meet us. The speakers expressed their deep concern for the harrowing experiences of Ms Barrie, which gave insight. They hoped that the return facts they sought would help. Ms MacKenzie volunteered to contact the Scottish Suicide Programme Board, which analyses and releases statistics to aid suicide prevention.

The slides shown at the meeting are a "must read" new work for the CPG's information and benefit to patients.

**Return patients:** From Slide 11 onwards, Scottish chronic pain information is highlighted, especially on the new work on Return patients. See info below. The meeting agreed it was clear from the presentation they gave that ISD had put a lot of work into this and work is ongoing until the autumn. These are developmental statistics.

On previously unknown RETURN waiting times patient numbers, this is the first time any information has been revealed, with its limitations explained. Slide 20 shows of the sample "During January to September 2017, 974 people across Scotland had their first return appointment following their first attendance at a pain management clinic". Only half of these "new returns" were seen within 26

weeks (over six months). Alex Neil MSP asked about the others - long standing return patients, mostly waiting far longer –as Ms Barrie’s evidence had shown. ISD has not looked at these figures yet but will do, the source of this data is from an activity dataset and not a waiting times dataset as most boards do not count return waiting times for this chronic condition, which can need a lifetime of repeat help. This sample of nine months, with roughly 300 new returns per quarter, indicates up to 1,200 first return patients annually. So how many more who are not first returns but long term?

The speakers outlined the many challenges in obtaining and interpreting waiting times statistics, even for new patients. Some 12 out of 14 health boards send new patient (physical clinic) waits to ISD, only six boards send pain psychology clinic figures (mental health including suicide prevention). Issues were often due to boards' problems with resources and IT.

There are also problems around how patients are counted. For example: if someone is given lignocaine, they may not be counted as a pain patient as lignocaine is not registered as a pain treatment in this context. There are also problems around how Health boards allocate appointments, over which ISD has no control.

Patients felt that being uncounted equated with lack of help as their plight of excessive delays was hidden. The CPG has for years campaigned to get returns counted.

But the speakers mentioned ISD's own public consultation had resulted in the majority of respondents requesting return appointment facts.

Some members asked ISD to resume including when treatment time started for new patients under RTT and also to make it more clear in summaries that e.g. the 72.3% was not 72.3% of all referrals but only of patients seen **on time** within 18 weeks. ISD speakers were thanked for their extensive work and presentation. Also, for already keeping the promise to the CPG and the UK Statistics regulator to restore facts missing from two Summaries last year and to investigate return waiting times for patients.

The meeting agreed this helpful new contact with ISD, in exchanging views and giving patients a voice, has been a valuable outcome from a previously upsetting situation.

A motion was passed, fully supporting ISD’s work on trying to gather return patient figures, the vital data element in tackling the reality of the pressure on NHS clinics and bringing to light “invisible patients”. The meeting called for all Boards to count returns.

Action Point –Ms MacKenzie and Mr Heald invited the CPG to collect any other questions for ISD and forward them. DG Elder forwarded all questions.

### **Confusion over £187,500 Dundee University dataset.**

Members asked if ISD, as Scotland’s leading health statistics body, was involved with a new £187,500 chronic pain services dataset being compiled by Dundee University from last year. They are not involved. ISD had only heard this was happening recently. The Dundee work is overseen by the National Advisory Committee for Chronic Pain, several of whose members are with Dundee

University. The Advisory Committee had opposed collecting return patient information. But ISD is now doing that independently, after a CPG campaign and ISD's own consultation showed the majority wanted these figures. Return patient facts are the priority for patients to show the full pressure on pain clinics. Miles Briggs, CPG co-convenor, was told in an answer to his Parliamentary question that Dundee is compiling a three-year study of pain services in three areas: NHS Tayside, Lothian and Fife involving "quality outcomes."

Some members said they could not understand its purpose as short staffing was the problem which affected all outcomes.

During its first year, the Scottish Government gave Dundee University £187,500. ISD was asked how much they had for their return patients study –£30,000 they said, which they are financing from their own funds.

Some members queried why the SG had invested £187,500 in external additional data. Dundee University's website shows that there are two researchers and a supervisor, Dr Paul Cameron, a Dundee University linked member of the Government's Advisory Committee.

Another query was on why Tayside, Lothian and Fife had been chosen instead of other areas, including some with very severe problems (NHS Grampian was mentioned) but these were not answerable questions by anyone present.

ISD has proactively contacted Dundee University to arrange a meeting to learn more about this project.

## **MESH CAMPAIGN**

The meeting welcomed leaders of the remarkable MESH campaign, including Elaine Holmes, Olive McLroy and their journalist champion Marion Scott.

These pioneering patients paid tribute to Marion Scott for her huge work and continuing dedication. Her journalism had helped the campaign founders, Elaine and Olive, make Scotland start and lead a global campaign for huge numbers of sufferers. Speakers said that what started with surgical procedures to treat bladder problems and pelvic prolapse ended with many having their lives wrecked, some in wheelchairs, unable to walk, suffering appalling chronic pain. There are hundreds in Scotland and could be hundreds of thousands round the world. Some are suing.

As Elaine put it "Our lives were wrecked by the original aim of saving only about £200 through using mesh". Searing levels of pain, family lives wrecked and suicides had resulted. The Mesh women warmly thanked leading MSP campaigners present for their support for years, including Alex Neil, Jackson Carlaw, Neil Findlay, Rona Mackay, John Scott and Johann Lamont and said the Public Petitions Committee had been outstanding in its aid. Elaine remarked: "More than 100 MSPs signed our pledge poster for a "no mesh whitewash", and for that we are very appreciative. We are not on our own".

Marion Scott and Neil Findlay MSP said: "This is a massive scandal, looking like being the worst ever in the NHS."

The women thanked Alex Neil who, when he was health secretary, intervened and launched a moratorium on the use of mesh – but Mr Neil, who stopped being health secretary in 2014, was later shocked that his intention of a ban was lifted and mesh was being used again by some surgeons.

An interim report of a Review Group had been welcomed by the campaigners – but when they saw the final report, they were “horrified” and, along with many MSPs, called it a whitewash. There had been consensus for the interim report. But the independent Chair resigned for 'personal reasons' after 2.5 years - and only 4 months before the final report was published. A new Chair, who is a current serving NHS Medical Director, was appointed. The campaigners said the final report bore little resemblance to the interim version.

### **How women campaigners were excluded.**

After years of work while suffering extreme pain, Elaine and Olive resigned from the changed review group “in disgust”. “We were not invited to any meetings for 10 months and no meeting minutes were shared”. They said they were told there was no new evidence by one of the Scot Govt officials in the 'independent' review group, when the women said there was. “Evidence tables we had repeatedly asked for were not handed over. With heavy hearts, we resigned from the review group as it had lost its independence and transparency - it had lost its way. But our names were published as members against our express wishes. We believe this was to make the report look more palatable. We feel badly let down.” They found the UK Health “Watchdog” MHRA worse than useless.

The women were well aware they were patients up against big business in mesh. An expert surgeon, Dr Wael Agur, also resigned. His views concerned the risks mesh implants posed to women. “His evidence challenging the cherry-picked studies was dismissed, ignored or buried in lengthy annexes.” The campaigners said this doctor bravely decided to speak out publicly.

Shona Robison, health secretary, endorsed a “review of the review” process, due to be published in July – when Holyrood is in recess. But the campaigners wanted a proper ban.

They remarked: “Ms Robison has somewhat prematurely said the outcome will not change the conclusions of what we say is the whitewash final report. If the process of the review is flawed, then the content is flawed.”

Unexpectedly, a pain patient present, who is not involved with the Mesh campaign said that, late last year, she had surgery but claimed that she was not told until after the operation that mesh was used. She would not have agreed and believed that all patients had to be asked in advance under new rules. She was asked to provide more information later to specify.

The Mesh campaigners objected to ISD’s work on the review and submitted twelve questions challenging flaws they saw in the ISD study. DG Elder forwarded.

### **Thyroid conditions: Women's voices ignored.**

Speakers Elaine Smith MSP and Lorraine Cleaver (both sufferers) have long campaigned against poor treatment of thyroid sufferers - 95% are women. Many patients believe this is part of old attitudes towards conditions where most patients are female. The speakers said many are being denied types of medication which restore them to normal life. Some have to buy on the internet. In general, thyroid conditions have no priority despite their devastating harm to lives. Treatment is usually with medicines that have been tested on men. Some experts feel unable to speak out for fear of damaging their careers. Evidence from women is often dismissed as 'just anecdotes'. Endocrinologist Dr Anthony Toft wrote a recent paper condemning current guidelines. He had changed his mind radically on his previous thinking. Dr Toft is a former president of the Royal College of Physicians of Edinburgh and the speakers drew attention to Dr Toft's "counterblast" to establishment thinking as part of their campaign.

Dr **Anthony Toft's** counterblast article can be googled under Dr Anthony Toft, for the Royal College of Physicians of Edinburgh, on Thyroid Hormone Replacement.

### **NHS CIC**

Continuing concerns have been raised about the Scottish Health Council's report on the responses to the consultation and the lack of democratic accountability, said patient campaigner Catherine Hughes. The final report defined the change to the CIC as a minor, not major, service change. There does not seem to be any right of appeal over the Council's report. The closure of the ward mostly affects women, as 80 per cent of inpatients were women. It also, by removing beds, denies years of access to patients throughout Scotland. The ward was very popular, with over 300 patients annually. Although it is around a year since the beds closure, against public protests, there is no sign of any other service moving into the space. The hospital is now for outpatients. Ms Hughes pointed out that this cutback came at a time when the latest SG report sought to reduce opioid prescribing, and the CIC had specialist help from its NHS trained clinicians for those who could not tolerate certain drugs.

### **Support for our Group's work from the Presiding Officer.**

The meeting was pleased to hear a letter of warm support from Ken Macintosh MSP, the Parliament's Presiding Officer, following our successful rejection of an attempt to stop publication of return patient information. Extract: "Your CPG on Chronic Pain has long been one of the most productive of all the groups. I can assure you I will continue to do what I can to support Cross Party Groups."

ATTENDANCE: 7 MSPs: Miles Briggs (chairing), Rona Mackay, Alex Neil, Johann Lamont, Neil Findlay, Elaine Smith, John Scott.

34 Non MSPs: John Thomson, Peter McCarron, Mary Craig, Linda Mawson, Marion Scott, Jim McBeth, Elaine Holmes, Olive McIlroy, Moira Mahoney, Kathleen Powderly, Fiona Robinson, Lorraine Cleaver, Janice Morgan, Evin

Morgan, Fiona MacKenzie, Scott Heald, Liz Barrie, Gordon Barrie, Janet McComiskey, Janice Maclean, Efi Fenning, Dr Moira McGuigan, Dr Jacqueline Mardon, Alan Robinson, Jim Eadie, Anne Hughes, Emma Trottier, Rob McDowall, David Caulfield, Catherine Hughes, George Welsh, Dorothy-Grace Elder, Geraldine McGuigan, Arlene Byrne. Total attendance: 41.