

PE1460/P

Dorothy-Grace Elder Letter of 11 June 2013

From: Dorothy-Grace Elder, witness to Petition 1460 and CPG member regarding Letters from Michael Matheson MSP (May 31) and Healthcare Improvement Scotland, (May 17).

Susan Archibald's petition on behalf of the Cross Party Group on Chronic Pain is an outstanding example of the value of having a Public Petitions Committee. Health Secretary Alex Neil has gone out of his way to listen to campaigners, produced proposals speedily and gratitude goes Jackie Baillie MSP for her vigilant representations to the committee as a co convener of the CPG and to all speakers in the excellent debate on 29th May. A proposed end to some major injustices suffered by chronic pain patients for years is now in sight. But vigilance remains.

Questions remain and the PPC evidence hearing on 25th June is of key importance for the future. Mr. Glennie, the new CEO of Healthcare Improvement Scotland, (HIS) promised full future transparency on 30th April (preceding his letter of 17th May) and at the CPG meeting on 29th May, he reiterated that facts had to be made known. Mr. Glennie is taken at his personal word – he was not at HIS when problems started. However, following two years of problems harming the pain campaign, the evidence session should show if all at HIS are willing to change from spin, obscure replies, defensiveness, shortage of patient involvement, so everyone can move forward . I'd respectfully suggest a few question areas - this submission touches on ministers not being informed, the need for more patient representation and changed excuses from HIS. Aim: clear the air, "hands up"; move to constructive work.

LETTER FROM MICHAEL MATHESON, PUBLIC HEALTH MINISTER TO THE PPC, May 31, 2013.

Funding P2

Can the committee please clarify on how improvements in pain services will be accelerated regarding funding as this part of the letter may be misinterpreted: "Through implementation of the model, we consider that the costs of treating pain will likely be reduced and that Boards would be able to reinvest any such savings into their chronic pain services" I think this is meant as a bonus result, and the intention is to accelerate by, as P5 states: "The health secretary has promised to include development of CP services in NHS Boards local service delivery plans from 2014." Will this mean Boards should allocate funds speedily rather than wait for implementation of a model by "end of 2015"? Currently, the model applies to a minority of Boards.

Continuing stress on creating Managed Clinical Networks or Service Improvement Groups (seven out of 14 so far, most being new) is somewhat confusing – as this is only seed money and no radical changes possible without Board funding for staff, etc. Note that even with the only long term MCN in Scotland, GG & Clyde (four years) delays of well over a year exist on some second appointments.

QUESTIONS ON SHORTAGE OF PATIENT REPRESENTATION. Intensive Pain Management Services – Bath. P5

Last par: Mr. Matheson raises good news on Susan Archibald's inclusion although the NSD body is temporary –on Scottish inpatient options replacing Bath. Can the committee please consider questions on the severe lack of appointments of a range of public and patient representatives on lasting official bodies dealing with chronic pain? EG: The Chronic Pain Steering Group has only 3 representatives of patients out of some 30 members. One is from HIS and another from Pain Concern, a small charity which did not support the petition or CPG campaigning.

Officials recommend appointees to Government and the same people are usually appointed to most bodies & events involving chronic pain. More patients need to be involved, especially as most official bodies aren't open to the public.

NOTE: However welcome, Susan's inclusion occurred AFTER the PPC started hearings on her petition –she was not invited originally, the first meeting was over. The wider point remains that there's a lack of a variety of patient voices on official bodies dealing with chronic pain, despite "user focus" claims.

17th May letter from Healthcare Improvement Scotland.

Mr. Glennie states correctly that the meeting of 30th April arranged by cabinet secretary Alex Neil and involving petitioner Susan Archibald, CPG secretary Jacquie Forde and myself was a positive meeting overall, at which the health secretary promised among other things, an end to sending pain patients those huge journeys to Bath and acceleration of service improvements.

That does not detract from the PPC's need to get answers in the evidence session from HIS and see if attitudes now show promised transparency by all.

Ministers not informed.

During the April 30 meeting it was confirmed that the health secretary had not been informed of the severity of key shortages in chronic pain, although he asked for this. Example: that waiting lists for appointments with a pain psychologist had reached 72 – 82 weeks in Greater Glasgow and Clyde was notified to him by the CPG on April 30. He expressed shock. Some officials present were on the Chronic Pain Steering Group, which received this information last year.

Mr. Neil immediately asked officials to enquire and action is being taken to reduce these vast waiting lists. So the overall issue is not only that the public weren't told the reality of shortages vis a vis the Update Report, Parliament and even the health secretary wasn't told and given the chance for early intervention.

Information on shortages had to be researched voluntarily by the CPG, with difficulty. The cross party group has always been willing to work positively with anyone but has not had the chance until now.

The annex to Mr. Glennie's letter is over events which happened before he joined HIS and contains some of the usual HIS responses which, especially after the Ninewells controversy, should not have happened.

*There is an apology only for the data being unfindable, ignoring the bigger issue that much of the data should have been in the Report by HIS, and that it was almost entirely bad news that was excluded.

Why was there “extensive correspondence?”

*That HIS had “extensive correspondence with Dorothy-Grace Elder during December 2012, offered to meet with Ms Elder on several occasions ...but this was declined” Not an accurate reflection – I object.

The correspondence was because HIS failed, over 15 days, to give proper answers to some very basic questions – similar to what the PPC has faced. That’s why I mention it.

I first contacted HIS (no result) on Oct 31. Renewed contact – this time with their Communications team – between December 6 and Dec 21. In those 15 days, HIS gave mainly unacceptable replies/no answers/fudge. This was not the responsibility entirely of the Coms team.

HIS management knew - on Dec 7, Coms team emailed to say my questions were sent to Directorate of Scrutiny and Assurance. The lead clinician for Chronic Pain was also informed. (I have names)

Problems continued Dec 7 – 21. even a refusal to give HIS’s total of WTE time sent to them by boards. I was told this “could easily be summed”. Not so for scores of fractions, not accessible for public and patients. I added up 72 WTEs to minimum of 35,250 patients (several thousand returning patients not in stats)

On Dec 20, I was offered, rather than answers, a meeting with the lead clinician. Next day, Dec 21; the offer was renewed from Scrutiny Directorate JW...to meet “early in the New Year” after her return from the Christmas holidays of Dec 21 – January 7! (As stated when I was a January 8 witness to the PPC) Totally unacceptable. A flurry of emails had gone round four to five officials without result. This indicates a serious attitude problem over public accountability of a quango in receipt of over £19 million in public money. This must end. (I have all these emails if you wish to see them)

Reference to “no similar enquiries” from sources other than me, I was responding to a build up of concern from patients, campaigners, also some health professionals upset that shortages they suffered were not exposed in the Report.

I started questions as a member of the CPG, then as “playing the dodgems” worsened, as a journalist. Their predecessor body, QIS, was open about chronic pain. Why the secretiveness clamp down over the past two years?

PPC question on choice of data items within the Update Report and their presentation:

“Staffing was not reported within the Update Report primarily due to the fact that, at the time, considerable staffing developments were being introduced in some areas which would have provided a distorted and out of date picture” Previous excuse was inconsistency with GRIPS. New excuse equally unacceptable, as developments happen during most Report compilations and are covered in notes.

GRIPS gave staff numbers; the Update report gave neither numbers nor WTE, though Boards gave them WTE figures. So inconsistencies with GRIPS throughout,

especially the non-involvement of patient groups (GRIPS had these) Conclusion: WTE excluded as it was part of bad news.

Extent of National coverage:

They have at last admitted their claim of 75% of the Scottish population covered by improvements means 64.9% - a maths mistake might be error but could it be a “genuine error” not to clarify this covered only half of Scottish Boards, not 14?

Waiting Times – “were collated similarly”. Does this mean non disclosure that six boards didn’t submit times, though the claim was made of an “average of eleven weeks” looking like a 14 Board Scottish average? **Also under Waiting Times** “The intention was to focus on the extent to which SSMCP were available throughout Scotland rather than to undertake a detailed stocktake...”

This is a new excuse for omitting Board figures on waiting times. The Questionnaire did NOT specify the Scottish Service Model CP plan, being headed “Snapshot of Scottish Pain Services”, as sent to the Committee – meaning all clinics, not the few with a Service Plan in place.