

PE1460/H

OMISSION OF SEVERE SHORTAGES AND THE DEMOCRATIC DEFICIT OVER CHRONIC PAIN

From: Dorothy-Grace Elder, founder member of the Scottish Parliament's cross party group on chronic pain.

The “non reply” to Susan Archibald’s petition from the Scottish Government’s “Quality Unit” is an insult to pain patients. Those who read carefully will note that it fails to tackle the petitioner’s points, which she brought to Parliament at considerable strain to herself. This pain sufferer requested radical action. None of this old waffle shows that. It merely parrots the same old spin from the shoddy Update Report plus “the patter of tiny feats”; small stuff people have heard for several weary years. The Chronic Pain Steering Group, Healthcare Improvement Scotland, a “Quality Unit”. So many well-funded bodies – but NO radical action. They should be ashamed to produce such smoke and mirrors. Dragged in once again is the old mention of the Chronic Pain Service Model, a wish list which has been around for years but can’t be actioned as all these bodies don’t tackle the dire lack of funding from Boards or Government. We’ve long had all this propaganda: a petition was decided on because THERE IS NO MAJOR MOVE FORWARD.

There’s even lavish praise for Bath facilities, without mention of sending pain sufferers on 1,000 mile gruelling return journeys at a recent cost of £1.1 m. Or that we also have highly skilled, though overstretched, pain staff in Scotland – we just need more funded. Patients are sent to Somerset because of Scottish shortages in day services, as well as having no residential service.

Astonishingly, health secretary Mr Alex Neil’s very welcome promise of an inpatient centre in Scotland over this petition isn’t mentioned. Why not?

Are people behind scenes kicking this into more long grass, with an “assessment” spun out for another seven months? In short, campaigners knew all the stuff mentioned yet again. A petition was decided on because THERE IS NO MAJOR MOVE FORWARD. A poster for pharmacies? Is that radical? Weary regurgitation of old propaganda` indicates a smug mindset against any radical reform, at least from officialdom. Elected politicians need to show their mettle. It’s been five years since the GRIPS report, 12 years since Parliament responded to public demand and set up a pain campaign. This non reply offers only more years of let downs and failure.

Anger over the controversial “Update Report on Scottish Chronic Pain Management” is largely because its inadequacy and omissions of bad news are symptomatic of the bureaucratic attitude towards chronic pain for years. That’s despite the vast number of sufferers and the strain on the few staff coping with rock bottom resources.

The sufferers’ cause is tied up between the quango Healthcare Improvement Scotland and the Scottish Chronic Pain Steering Group, both heavily linked.

(Please see Democratic Deficit below) The needs of understaffed clinics or primary care improvement are being swamped by bureaucratic talking shops and spinning on small “improvements” at the edges, demonstrated by this shabby Report. The Report serves as an example of several years of secretiveness/avoidance over the worst facts.

The two bodies (above) don't tackle the key factor- lack of funding by health boards and Government, without which no radical change will happen and “planning” moves will remain in the long grass.

Equally, drastic shortages –affecting both patients and staff – are not exposed and discussed. Patients, public, Ministers & Opposition must be told the reality. We're dealing here with a condition officially estimated to affect some 700,000 in Scotland, to varying degrees, with only a tiny minority referred to NHS pain specialists and no obvious encouragement of GPs to do so. Chronic pain is not benefitting from empire building on bureaucracy – meetings, conferences, a Report - instead of investment in front line services. That is why I appealed for strong political leadership at the Public Petitions Committee. We have had a good first move from health secretary Alex Neil over promising a Scottish inpatient service to prevent sending some patients 1,000 mile return trips to NHS Bath. (The Report did not criticise sending to Bath) But day services remain critical - and primary care. Thanks go to the Committee for the excellent hearing you gave to Susan Archibald and I.

Report omissions

The quango Healthcare Improvement Scotland (HIS) issued the Report, by the lead pain clinician and themselves. HIS is the “health watchdog”. It gets £20 million in public money for thorough “scrutiny” of health issues, using, HIS claims, “the strongest evidence”. **We'll see.**

The Report was published October 26, the data and missing facts - submitted by Health Boards- appeared six weeks later on December 7, briefly. Once seen, it was clear that data figures contained some bad news which had been excluded.

The figures appeared after complaints about lack of facts. They were online, not analysed, in large spreadsheets unsuited to patients or public and placed on a website little known to the public, from which the data swiftly became unfindable. (Error warning) The new health secretary intervened over the Report this January, stressing the need for transparency “all should be easily and freely seen by the public”.

Some of the essential points left out of this "audit" are budgets, clinic staffing numbers or staff time, patient numbers and clarity on waiting lists:

Budgets: Report did not reveal existence/or not of budgets for treating CP. But Data sent by Boards showed ten out of 14 did not list a budget. Scottish Government policy is that chronic pain is a condition in its own right.

Clinic staffing: Report did not give numbers or staff time, using instead tick boxing (P 9) which meant a fraction of staff time (e.g. 0.3) had a full tick, equal to a WTE or full timer. That made things look better. QUESTION: Who chose tickboxing?

But the Data showed all Boards had sent staff time. QUESTION: Were they asked for patient numbers? Can the Committee be shown the original questionnaire?

With difficulty, an outsider could add scores of fractions to the equivalent of around 72 WTEs to over 35,275 patients, though not all review patients were in the figures so this is a minimum. HIS refused, by email, to give their calculation when I asked.

So public or patients were left to work it out – if people could even find the data. Obvious mistake risk, one volunteer against a paid quango team on that Report.

Patient numbers. Report excluded these for adults but (P12) not for children's services.

Data revealed the Boards DID supply adult patient numbers for all new referrals and for some "review"/continuing patients. The Report stated, P6, referring to it being an Update on the Grips Report of 2007/8: "Healthcare Improvement Scotland has since conducted a detailed audit of the provision of pain management services and the numbers of patients seen by these services for the period 1 April 2010-2011..." But the Report excluded the figures to which it referred. So a proper ratio of staff to patients was impossible, also consideration of staff holiday & illness. Such ratios are normal in health reports. Was exclusion because the ratio would be remarkably bad? QUESTION: Who decided to exclude?

Waiting lists: It's normal in Health to give patient numbers and waiting times, but no numbers were given for first or second appointments. On the latter, waiting times are particularly controversial. QUESTION: Again, who decided to exclude second visits, especially known examples such as psychologist or physio shortages?

The Report claimed (P7 & P9) that the average for a first appointment was eleven weeks, but data showed six out of 14 areas didn't send times, so was a true Scottish average possible? Three of the six claimed guaranteed waiting times – but did not list weeks. Lothian, with one of Scotland's largest numbers of pain patients (Over 6,000) had no guarantee and gave no waiting times. The Report did not specify some waiting weeks were missing. QUESTION: Were Boards asked for waiting lists in patient numbers and, if not, why not?

Numbers were available under a separate FOI query by Jackie Bailie MSP. (Some 3,000 pain patients waiting for first and second appointments) HIS, when asked, said they were dealing with 2010-11 and the FOI question was in

2012. But the answer – not the question – was in March 2012 – HIS did not respond on whether this might indicate 2010-11 or say if they had 2010-11 patient waiting numbers.

Critical shortages: The Report did not highlight or detail severe shortages in the five pain clinic disciplines – doctors, nurses, physiotherapists, psychologists, occupational therapists . These were in the data sent by Health Boards for the Report work. Yet stress was put repeatedly on Scotland having “multidisciplinary chronic pain management services”, an unacceptable term once you saw the data.

Examples of severe shortages were already known by the Report’s “oversight” body – the linked Chronic Pain Steering Group. Example: Greater Glasgow and Clyde had continuing waiting lists for a clinical psychologist, reaching “SEVENTY- TWO WEEKS to EIGHTY - TWO weeks.” QUESTION: Why were such examples ignored in the Report?

“Multidisciplinary services” should not be claimed when they aren’t in reality. Traders can’t advertise five course banquets if they serve only soup.

EXCLUSION OF PATIENTS - DEMOCRACY DEFICIT ONE:

This was an “Update Report” on this quango’s predecessor body Quality Improvement Scotland’s GRIPS reports on chronic pain in 2007/8. Not only is the placatory, non-urgent spin tone very different, but GRIPS set up patient focus groups and consultations. If there was, for the Update Report, patient involvement, there is no sign of it. Patients’ experiences of waiting times, referrals, etc should have been essential. Exclusion of the public should be assessed against HIS’s “legal duty of user focus”, Priority 1, on their website:

“Healthcare Improvement Scotland User Involvement and Person centredness strategy”, 2011

Priority 1: Involve patients and the public in all aspects of our work and demonstrate the impact of their views in everything we do.

Healthcare Improvement Scotland is covered by the Duty of User Focus. This legal duty aims to ensure that users of public services are involved in the scrutiny of those services and in identifying areas for service improvement. In order to involve users in all aspects of our work, we will:

1. Involve users in our governance structures
2. Involve users in the design of scrutiny
3. Use feedback from users to inform our scrutiny activity
4. Involve users in carrying out scrutiny
5. Make sure that our scrutiny reports are clear and accessible
6. Involve users in improvement activity
7. Establish arrangements which will demonstrate continuous improvement in our user focus approach.

“Healthcare Improvement Scotland aims to be regarded as a leader in user and public involvement. This means that we need to ensure that our own approach to involving people is at the forefront of good practice...”

QUESTION: WERE ANY OF THE ABOVE PLEDGES FULFILLED OVER THIS REPORT? Nothing was accessible for the public in any normal form. Take Point 5: “Make sure our scrutiny reports are clear and accessible”. Exclusion of key facts from the Report was followed by access to the facts/data being made difficult to impossible. For weeks, the material was effectively buried (Please see also “Refusals of information” at end.)

THE SCOTTISH CHRONIC PAIN STEERING GROUP: DEMOCRACY DEFICIT TWO

The Steering Group is the body charged with improving chronic pain services. Its composition, transparency standard and attitude are therefore vitally important. It is trusted to plan services and reveal problems and shortages. This body was assigned by someone to “oversight” of the Report by Healthcare Improvement Scotland. But the Steering Group and HIS are hugely interlinked.

People may not realise that the quango now has NINE people involved with the Steering Group. (Membership list is online)
So the Report’s authors were effectively “overseeing” and approving themselves.

The Report’s co-author, with HIS, is chair of the Steering Group. (Dr Steve Gilbert is listed under HIS). There are only three “patient/public” representatives, one being from the quango.

The Steering Group also contains six Government officials, and several bodies accountable to and /or funded by the Scottish Government. There are also doctors, a nurse consultant, pharmacist, physiotherapist, etc. all NHS workers except for only one doctor from a University. HIS was formed in April, 2011, but the new quango’s numbers have risen steadily on the Steering Group. Two years ago, the predecessor body, Quality Improvement Scotland, listed only three Steering Group members, with two others “in attendance”. Now, it is six from the new quango with three others “in support”.

“Quango rule” plus Government agencies is not conducive to challenge in this cosy set up. Concerns about the atmosphere and lack of any radical moves have been mentioned – only privately.

The Steering Group meets only four times a year, but its composition is important regarding lack of inclusiveness beyond the Report issue. Critically, this Group is informed of shortages. Instance: They were told by a clinician member that patients were waiting “between 72 to 82 weeks to see a pain psychologist in Greater Glasgow and Clyde”. (From the Steering Group minutes, August 2012) Long delays had continued (from previous years). As the Update Report covered 2010-11, why were such severe examples excluded?

An independent “oversight” body on any Report usually questions robustly and missing facts are queried. Major problems might have been avoided had there been independent oversight, rather than virtual in-house approval.

The Group’s exceptional shortage of independent influence/voices, especially for patients, is worrying as patients want real change. Also, no union identifiable to speak for staff under great pressure in pain clinics.

While Government bodies are well represented, the Scottish Parliament or its Cross Party Group on Chronic Pain, which has campaigned for 12 years, has never been invited. When the CPG voted for representation in Sept 2012, (non MSP) resistance came from within the Steering Group.

New HIS appointees are added swiftly to the Steering Group - the latest being three part time HIS “facilitators”, each on one day a week’s work for the chair.

QUESTION: Who makes appointments to the Steering Group?

QUESTION: Who picks patients or public representatives?

QUESTION: Who decided that the Report be overseen by this Group, and not by a totally independent body?

The Scottish Public Appointments Commission doesn’t appoint or regulate them. Has the Group evolved into a closed shop over normal inclusiveness?

VAGUE CLAIMS IN REPORT

Primary care: Professor Steultjens of Glasgow Caledonian University has particularly challenged the statement on P11 that patients not referred to specialist clinics “may be being effectively managed in primary care”. No backing evidence is included – and primary care is a particular concern. A range of GPs and patients were not consulted for this Report; again, bland spin attempting to make all seem rosy is not appropriate.

Funding for voluntary groups: On P11, it’s stated: “Other voluntary organisations also support patients with chronic pain, with some funding coming from the Health & Social Care Alliance self management fund” Not mentioned is that the Alliance, funding over 80 conditions for self-help, has long had no dedicated budget for chronic pain self help, despite Government recognition of CP four years back. The Alliance is on the Chronic Pain Steering Group, another link with the introverted set up.

Pain Association Scotland, although being the only charity running self-help groups in some NHS areas, failed to achieve Alliance funding over a year ago. The Alliance, pressed on why they had no pain budget, eventually produced a list of some of the conditions they fund, saying these had an element of pain. But such conditions had gained funding previously without pain being highlighted. The Alliance had added fresh typing on pain to former descriptions.

ACCESS TO PAIN MANAGEMENT PROGRAMMES - PMPs

Report: P7: "Over 75% of the population now have access to a PMP in their NHS board area" This is hardly borne out by the data, showing missing disciplines, etc.

CHILDREN'S SERVICES

The Report, P12, estimates there may be around 80,000 children who suffer chronic pain, saying: "There are multidisciplinary children's pain management services in the children's hospitals in Glasgow, Edinburgh and Aberdeen." But the figures, either fractional or zero, for all five pain disciplines in the three children's hospitals, do not bear out the "multidisciplinary" ridiculous exaggeration. For example, Aberdeen had only half the time of a paediatric pain nurse per week– the four other disciplines are missing.

CONFUSING AND MISLEADING

While the Report chose not to reveal that ten out of 14 Boards listed no budgets, there is also no mention of Government refusal for direct funding for clinics. The previous health secretary, in writing to the CPG in January 2012, refused direct funding - the authors knew this. So pain treatment is in a double bind.

But on Page 5, the Report claims: "The Scottish Government has now funded additional support to drive forward implementation of the Scottish Service Model for Chronic Pain". SPIN? WHAT DOES THIS MEAN?

The average person might believe this is significant funding for the front line. Some believe it covers more admin and the three part time "facilitators" from HIS, each working one day a week for the lead clinician.

Refusals of information

Healthcare Improvement Scotland refused by email to give the cost of the Update Report. But £58,000 for "chronic pain scrutiny" is online in their budgets.

This secrecy is continuing - even in a Parliamentary reply to an MSP. (See below) Jackie Baillie had asked for the BUDGETED and final cost. The question was not answered although the £58,000 budget is shown here in the quango's written evidence to the Parliament's Health and Sport Committee last year (foot of P1)

http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/NHSBA10_NHS_Healthcare_Improvement_Scotland.pdf

Jackie Baillie (Dumbarton) (Scottish Labour): *To ask the Scottish Government what the (a) budgeted and (b) final cost was of the (i) Update Report on Scottish Pain Management Services, published by Health Improvement Scotland on 26 October 2012, and (ii) the data report published on 7 December 2012.*

Mr Michael Matheson MSP: *The update report (October 2012) and subsequent additional data (December 2012) were planned and accounted for*

within Healthcare Improvement Scotland's overall budget and did not require any additional or external funding. There were no publication costs for either report as they are electronic publications.

(S4W-11952)

I asked HIS's communications dept and a project officer to produce, for clarity, their figure for staffing—they refused, by email. So patients, public, researchers, disabled activists or anyone would be left to struggle through huge spreadsheets of fractions to calculate the truth about pain services the quango was paid to produce. HIS would know it would be easy for an outsider to make mistakes and the effort it would take. I hate to think of the public up against such a bad attitude.

Complaints about missing facts in the Oct 26 Report and requests for the figures were raised from October 31. Figures/data eventually appeared online.

Dec 7 – briefly, then an “error” warning – couldn't be opened - thereafter “hunt the needle in haystack” began. I had to ask HIS for a paper copy – they sent this.

The chosen, little known, website is described as: “The Knowledge Network is a major electronic library available to all NHS staff in Scotland and a range of NHS partners” The data was in two large spreadsheets. Even some academic researchers couldn't find it. Now, a link is on the home page, weeks later, after Health Secretary Mr Neil called for transparency. HIS did not, at first, put the Report on their own website, later they did – but not the data. Now, both. I'd contacted HIS with questions from Dec 6 – 21.

Eventually, instead of answering basic questions, HIS offered to meet me sometime in the New Year– after their bosses returned from a 17 day break. To what purpose if they couldn't answer basic questions from Dec 6 – 21?

Future Reports

The situation over this Report would make anyone concerned about other Reports by the “health watchdog” – currently set to “scrutinise” treatment of the elderly in hospital, prison health, etc, potential life or death subjects. In future, it might be best to consider Health Reports being entrusted to independent people – eg. Universities – either entirely or in oversight. There should also be a commitment to have no involvement of spinners. The Update Report has all the indicators of spinning in its persistently contrived gloss over of acute problems and the soft spin terminology used.

QUESTION: during the up to seven months delay in its publication, who precisely worked on this Report?

Conclusion: A poor report and the hidden facts showing major problems were subsequently buried from public view in an electronic Boot Hill. And later questions were met with obstructive blocking. Totally against “Duty of User Focus”.