

**PE1460/O**

Dorothy-Grace Elder Letter of 6 May 2013

**HEALTHCARE IMPROVEMENT SCOTLAND RESPONSE TO QUESTIONS FROM PUBLIC PETITIONS COMMITTEE OVER THE 'UPDATE REPORT'**

Please note: red type is analysis from DG Elder. But first, MSPs & others said the Update Report was heavily "spin doctored".

Extract below shows it was going through the PRs and spinners ("communications") of HIS by August 2012. Publication delayed until October 26.

Were independent researchers and statisticians used by HIS? Who, precisely, worked on this Report?

From the Chronic Pain Steering Group minutes, 22 August 2012:

SG gave an update regarding the benchmarking report, noting that it is in the process of going through Healthcare Improvement Scotland's communications unit processes, and once completed will be ready for publication. The anticipated publication date is early to mid September. The finalised report will be circulated to the steering group in due course by SR. Action (7): SR

But this letter below of March 2013 shows continuing avoidance of openness by the "health watchdog".

**Healthcare Improvement Scotland responses (in bold) to additional questions from the Public Petitions Committee (in plain text) from HIS letter to the Public Petitions Committee.**

Question:14. During the evidence session it was argued that the data that underpins the Update Report had been hard to source (e.g. col 988), indicating that the data was not always clearly available for those interested in it. Also, the data spreadsheet has been updated following the publication of the Update Report, as additional information has become available. Whilst there are notes and coding to show where this has happened, it does make it more difficult to analyse it against the Update Report. In addition, in the text box entitled "Key to protected data", there is a reference to the publication of an accompanying letter with additional information.

**The Update report on Scottish Pain Management Services was published on the 26 October 2012. This report is a follow-up to the Getting to GRIPS with Chronic Pain in Scotland which was published in 2007 and reissued in 2008, with an endorsement from Nicola Sturgeon, the then Cabinet Secretary for Health and Wellbeing. The Update reports on pain management across NHSScotland using data collected from April 2010 to March 2011 and provides further information on provision of Pain Management Services across Scotland, identifying any gaps and variation.**

No answer on the “accompanying letter” point. No answer on extreme difficulties with data hidden & links disappearing from the MKN website same day; only robotic repeat of background previously stated many times.

**(“Answer” continues) In addition to the publication of the Update report, underpinning data was subsequently published on 7 December. Although this was published in the interests of transparency, the underpinning data was never designed as public facing documentation.**

So why weren't key facts in the report? Admission there had been no intention to let patients/public see the reality of services reported by Boards. Facts removed included staff time & patient numbers, real waiting times and 10 out of 14 boards listing no budget for chronic pain treatment. These were in the data. “Transparency” was not volunteered by the quango. Data was produced after protests by members of the CPG for Chronic Pain. Health secretary Alex Neil intervened, calling publicly for transparency. Following that, the quango published the data 7<sup>th</sup> Dec., six weeks after the Oct. 26 report.

15.Question: Was the data spreadsheet published at the same time as the Update Report in October 2012, and if so, where? **The Data Spreadsheet with explanations was posted on the Managed Knowledge Network website on 7 December 2012. The data table was posted on the Healthcare Improvement Scotland website on 8 January 2013.**

Report published Oct 26, data Dec 7. This shows HIS withheld publication for a month from their better known website, while the data remained unfindable on the obscure MKN website, which removed home page links immediately after publication Dec 7. Both report and data were effectively buried from public sight for a month. To deflect controversy?

16.Question: How many times has the data spreadsheet been updated since the publication of the report?

**There has been one update to the data spreadsheet since the publication of the report.**

17.Question: Please can you provide a copy of the letter referred to in the “Key to protected data” **The freedom of information response letter is available from the Scottish Parliament’s Information Centre, bib. Number 54547. Please see below:**

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**“Jackie Baillie (Dumbarton) (Scottish Labour): To ask the Scottish Government further to the answer to question S4W-10857 by Michael Matheson on 16 November 2012, for what reason there are no plans to publish the data underpinning the Healthcare Improvement Scotland Report, Update Report on Scottish Pain Management Services.**

**(S4W-11396) Michael Matheson: The information requested is being collated. I will write to the member as soon as the information is**

**available and a copy will be placed in the Scottish Parliament Information Centre (Bib. number 54547)."** This is a PQ, not FOI? A missing letter link which may be FOI, on the update report, was mentioned briefly on Dec 7 on the MKN site - from Derek Feeley, NHSS director general. Unopenable from Dec 7, "fix soon" but no reappearance, link removed.

18.Question: Please can you provide a copy of the questionnaire that was sent to Boards as part of the audit, as it is occasionally unclear what the data in the table is referring to? **Please see Appendix 1.**

19.Question: Why did you choose to present the data from the audit in the way that you did in the Update Report, for example, why not report specifically on the number of whole time equivalents in each area?

**The data was presented in this way to be consistent with the presentation of the data in the GRIPs report of 2007. In GRIPs the number of staff was reported, but not the (Whole Time Equivalent) WTE commitment they had to the pain service.**

But the update report contained neither staff numbers nor WTE timing/commitment. Boards detailed WTE – excluded from the Report.

The inconsistency was with detailing WTE commitment for children's services, but removing WTE for the much larger adult patient numbers, where shortages would show up more. Detailed WTE times sent by Boards were changed to tick boxing in the Report, giving a better impression, wrongly. A fraction, e.g. 0.3 of a nurse or physio's time, thus gained a tick equivalent to a full timer. Who permitted this device? Who executed or approved the complicated change, wasting time and considerable work by Boards?

**Answer continues: The key statistic provided in the section on Provision of multidisciplinary pain management is: "The average waiting time for a first appointment to a pain service was 11 weeks from referral." (p 9)**  
**Wrong. See next page**

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20.Question: There is no additional information or context provided alongside this statement. It could be read as providing a waiting times average across all NHS Boards. However, it appears from the data spreadsheet that the data on waiting times was provided by seven out of 14 NHS Boards. Calculating the total of the figures provided by those seven Boards and then taking an average, the figure of 10.8 was achieved, which was presumably rounded up to 11 for the report. **Even though the clerk's question has uncovered the truth, the HIS answer still repeats "average waiting time...11 weeks" without tackling only half the Boards were used to imply Scottish average.**

21.Question: In hindsight, should the Update Report have been more explicit about the limitations of the data concerning the 11 week waiting time figure for a first appointment to a pain service? **Not answered.**

**Answer continues: Although waiting times were included in the data collected, this was not the primary purpose of the report. An FOI request by Jackie Baillie MSP in 2012 was able to collect accurate data on waiting times in all NHS Boards, **What does this mean as the Report ignored FOI findings HIS now agrees were accurate?** and it should be noted that patients may have chronic pain for a long time and either self manage or have treatment with their GP or other secondary care specialties, such as orthopaedics, rheumatology, neurology etc. before being referred to a specialist pain service.**

Another case of waiting times manipulation? An “average” of eleven weeks was presented as if it was a Scottish average, while ignoring FOI returns showing that some areas had 30 weeks or more waiting times, totalling over 3,000 patients waiting for first and second appointments. The FOI answer to Jackie Baillie MSP was in March, 2012, publicised in the media. The Report was published October 26. So why was any reference to FOI figures excluded? Was it because these “accurate” figures would harm the 11 weeks “average” spin? People should be questioned further and held responsible, as hospital boards have been over waiting lists. Patients ignored. Comments on people receiving prior treatment (most do) aren’t useful. GP & clinic notes should exist. But patients were not surveyed. GRIPS had patient & staff survey/focus groups. Why the inconsistency of excluding patients from a purported “Update” of previous practice?

22.Question: Multidisciplinary pain management programmes (PMPs) are also covered in Table 1 of the Update Report, with a “tick” presumably referring to a PMP being available. If this is the case, Table 1 suggests they are in five NHS boards. However, when considering the data spreadsheet it appears there are six NHS Boards providing a multidisciplinary PMP. In addition, the Update Report states that access “to all elements of a PMP can range from 4 months to over 1 year”. Such figures do not appear to be provided on the data spreadsheet.

5.“Access to all elements” mainly means second appointments. This should have been a priority area, due to known concerns over 2<sup>nd</sup> visits. But the inadequate questionnaire did not tackle this and the report brushed aside with “range from 4 months to over a year”. How far over? Up to 82 weeks in one of the “better” services – Glasgow - on pain psychologists, a “2<sup>nd</sup> appointment” discipline. HIS knew example below, reported to the CP Steering Group, with its nine HIS people, including the report’s author.

From: Healthcare Improvement Scotland.

Written Update from Stakeholders to the Chronic Pain Steering Group meeting, 22 August 2012 from Dr Colin Rae, MCN lead clinician.

NHS Greater Glasgow & Clyde Chronic Pain MCN

"In the secondary care pain service, Clinical Psychology waiting times continue to be very long, currently between 72 and 82 weeks. Negotiations are ongoing between the Clinical Services and RAD directorates on how this can be tackled."

23.Question: Please can you clarify what the figures on the NHS Boards with

multidisciplinary PMPs mean?

**There has been a transcription error and the Pain Management Programme in NHS Borders has not been highlighted. We will correct this. No answer. Q is about all, not Borders.** It is difficult to define waiting times for a Pain Management Programme. After initial assessment at the pain clinic, it may be appropriate to trial self-management, medication and physical treatments. Following these approaches it may be appropriate to go on to a pain management programme, consisting of education in self-management, physiotherapy and psychology techniques. Embarking on a pain management programme, while other management techniques are still being trialled and the patient is not necessarily ready to accept learning to live with pain is less likely to be helpful. Thus the data on waiting times for the Pain Management Programme were estimated by telephone discussion with clinicians & are not included on the spreadsheet. Why not? Dates when individuals were assigned to actual PMPs should be known.

24.Question: Are the data on access to all elements of a PMP available on the data spreadsheet and, if not, how were they arrived at? **No answer.**

**The section Provision of multidisciplinary pain management begins with more information on multidisciplinary PMPs and then states: “PMPs are now available to 75% of the Scottish population in their NHS boards.” (p 10) Wrong. See below:**

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25.Question: The data spreadsheet indicates there are six NHS Boards with multidisciplinary PMPs. Presumably the 75% population coverage refers to the total population of these six NHS Boards taken as a percentage of all NHS Boards. However, undertaking this calculation using the figures in the data spreadsheet, results in a figure of 64.9%. Also, the data spreadsheet provides data for the Argyll and Bute area, within that of the NHS Highland figures. Whilst NHS Highland is noted in the data spreadsheet as having a multidisciplinary PMP, the Argyll and Bute area is denoted as having no such access. This raises the prospect that there may be differences in access to multidisciplinary PMPs within NHS Boards as well as between them.

26.Question: How was the figure indicating the coverage of multidisciplinary PMPs across Scotland calculated and how does it relate to the information in the data spreadsheet?

**As noted above data on NHS Borders was not included by error. This will be corrected. No answer. Second time question on how figures were used not answered. No answer on the 64.9% instead of 75%. Again despite six boards presented as if an average of 14, no comment. And resort to second irrelevant mention of Borders. (This is shocking stuff, treating public and Parliament with contempt, at public expense. That anyone gets paid to produce rubbish like this is worrying)**

27.Question: Was there any additional data indicating coverage of multidisciplinary PMPs within NHS Boards? **No**

GRIPS reported five PMPs in 2007 figures. See end of this document. An increase to just six in 2012 was not a very favourable “update” – excluded.

28.Question: Do you have any concerns as to whether access to existing PMP services is equitable for the whole population of a Board area?

**There are issues in accessing services for many patients with chronic pain. These are most obvious in the North of Scotland & the Islands, but also affect patients travelling from West Lothian to Edinburgh and in other areas. We have emphasised that it is for the NHS Boards to consider how they are going to meet the guarantees on access to psychological and AHP services. Is there any urging of Boards by HIS or Govt. to supply funding for CP? No urging of GPs to refer as clinics are too short staffed.**

29.Question: Regarding referrals of patients to the residential PMP in Bath: Where do the figures in the Update Report for the cost of referring patients to the residential PMP in Bath come from, as there is no reference to such costs in the data spreadsheet?

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**The data were provided by National Services Division of National Services Scotland who are responsible for commissioning this service on behalf of NHS boards. (Costs were £1.1 million for 119 patients, excluding travel, over 3 – 4 years. Patients included some children and one person sent on 1,600 mile return journey from Shetland)**

30.Question: Table 3 of the Update Report shows the provision of staff for children and young people’s chronic pain clinics in March 2011, and the number of referrals and reviews over the period 2010-11. However, this information is not detailed in the audit data spreadsheet.

31.Question: What is the origin of the data in Table 3 of the Update Report?

**The Questionnaire was circulated separately to the children’s services and the full data is provided in the update report. So why was childrens’ data detailed as received, but adult figures from Boards changed to tick boxing? Why the inconsistency of two different systems in one report: childrens’ services revealing, the larger adult services concealing WTE staff time, patient and staff numbers? What benefit was this, other than to make adult services appear to look better by tick boxing? Who decided to change to tickboxing? The “presentation” spinners or the authors or anyone else?**

32.Question: There are a range of factors that are reported in the data spreadsheet, and presumably were part of the audit, but are not covered in the detailed findings section of the Update Report itself. The factors include: referral to spinal cord simulation ; administration ; budget; telephone

consultations; waiting list initiatives.

33.Question: What was the purpose of including these in the audit, what did the data from each show, and why were they not discussed as part of the detailed findings section of the Update Report?

No answer. This key question shows that the work of Boards on five important areas was censored completely from the Report. Perhaps the most important was on budgets and the resultant exclusion.

**Budget we were interested solely to find out if there was a defined budget for the pain management service.**

You did find out – but did not publish the results. Data shows Boards revealed ten out of 14 did not declare a CP budget. As budgets are crucial, why was this essential information excluded from the Report? The questionnaire was headed “Snapshot of Scottish pain services”, meaning all clinics; no reference to being “solely” for pain management budgets for a minority of clinics.

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**(Continued answer by HIS on Budgets) In most Health Boards there is no separate budget and the funding comes from separate directorates, such as Anaesthetics, Rehabilitation, Neuroscience, Psychology, Primary Care etc. This was to be expected.**

Why was it “to be expected” four years after the Scottish Govt. accepted chronic pain as “a condition in its own right” and five years after GRIPS? That ten out of 14 boards didn’t list a CP budget contradicts the Report’s persistent claim of improvements and “co-operation by Boards”. Comments about funding still coming from other depts accept clinicians continuing to spend time “begging and borrowing”.

EXTRACT from GRIPS below, shows that in 2007, EIGHT areas reported having a specific budget – now, FOUR. Report claimed to be an “Update” on GRIPS – so why wasn’t the budget information updated? Questionnaire didn’t even ask sums. Was total “redaction” on budgets because it indicated budget areas had reduced?

In normal reports, naming boards helps push Boards which didn’t supply a budget and commended others who did. The Boards named themselves in the data – the Report removed this honest response. WHY? **GRIPS: Ability to identify specific budget for their chronic pain services per NHS board** Of the 8 service providers who reported having a specific budget for their service, only 4 were able to state the amount of money involved.

**Referral to Spinal Cord Stimulation**

**This is a very interventional technique requiring surgical implantation of electrodes next to the spinal cord. The usefulness of the technique is**

debatable, although some patients can have considerable benefit. The purpose of gathering the data was to see if there was variation in referrals and it was not commented on in the report as it only affected 38 patients. A separate review of spinal cord stimulation and other interventional techniques is underway, through the three centres where these techniques are carried out (Aberdeen, Dundee & Glasgow). So was there variation even with 38 patients and 3 centres? In 2007/8, GRIPS found three Boards at six sites across Scotland using Spinal Cord Stimulation. Why no comment?

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## Administration

Administrative support is essential to running a pain management service; to ensure that patient enquiries are answered, that clinics are efficiently run, to provide secretarial support and to communicate treatment plans to the other healthcare professionals looking after the patient. Most services replied that they had some administrative staff. Those that did not had some unofficial assistance, which ensured that letters were typed, but may not have been ideal. This data was fed back to NHS boards for local use.

Why ask boards this if you didn't name areas which had some admin help/ no help/ unofficial help? Why not aid clinics by highlighting shortages? What data was "fed back to boards for local use" if comparisons were publicly excluded?

Highland Pain Service are carrying out an innovative method of conducting their first appointment by 'phone & they keep records of how many patients are reviewed in this way. Several other services use the 'phone to review patients but don't keep records. **Is a first appointment in Highland always with a clinician?**

## Waiting List Initiatives

This information is of specific interest to the pain services and health boards. These are extra clinics, funded by Waiting List Initiative money. Some boards did not use this.

Which boards? Why aren't they named? And why wouldn't patients, public, local MSPs, etc. also have an interest in being informed?

CONCLUSION: That non answers and lack of transparency continue is particularly worrying, five months after the original trouble over non transparency in a report. An "update" was skewed into a PR exercise detrimental to the chronic pain cause in glossing over the rock bottom state of service resources. Nor did it "identify gaps in services" clearly or have robust recommendations for any radical change.



Snapshot of Scottish Pain Services 1/4/10 - 31/3/11

NHS Board	ayrshire & arran	patient numbers			
		services	wte's	new	review
Medical					
Nursing					WL in weeks
Physio					
Psychology					
OT					
pharmacy					
MDT PMP	Y/N				
primary care	Y/N				

meeting WL guarantee	Y/N	WL in weeks	
WL initiative clinics	Y/N	number/month	
Referrals to a residential Pmp			
Referrals to SCS/IT therapy			
Paediatric	Y/N		
admin			
management			
audit	Y/N		
budget	Y/N		
Pain Assoc	Y/N		
Other volunt	Y/N		
<b>website info</b>			
service description	Y/N		
meds	Y/N		
interventions	Y/N		
physio	Y/N		
psych	Y/N		
pain info	Y/N		
links	Y/N		