

PE1460/J

Petitioner Letter of 11 April 2013

Susan Archibald: petition PE 1460

Here are my findings from replies to my current chronic pain petition.

I would like to highlight in the beginning that I am specifically concerned of the fact at no point has anyone in an official bodies considered what impact lack of progress on chronic pain help is having on patients, their families and carers. Not a mention of how, by not providing appropriate treatment or service, this breaches the Public Sector Equality Duty, Human Rights Act 1998, Equality Act 2010, UN Convention on the Rights of Persons with Disabilities, UN Convention on the Rights of the Child. I begin with the responses from the Scottish Government Quality Unit and Healthcare Improvement Scotland, because they are shocking.

Scottish Government “Quality Unit”

I was deeply concerned by the response I received from the Scottish Government.

“As for all long term conditions we are committed to ensuring that people can access high quality, safe and effective services as close to home as possible, with access to specialised when needed.” This is not the current case as so many are not being referred and the whole reason for this is because there is a lack of service and resources, the whole reason I had to bring my petition to the Scottish Parliament in the first place. This material is merely something that has been copied and pasted out of a document. Safe? How can this be seen as safe? People in left in agony without the proper support or treatment is a form of torture or in humane treatment under the Human Rights act 1998 so I was seriously unhappy with this part.

“We are committed to providing services closer to peoples home” If people in their own health board areas can't access local pain services then the Scottish Government are not providing this statement above. Having a residential unit in Scotland this would redress another point I made about travel and negative impact it has on patient and family, once again they don't understand my concerns around Bath as no one has considered how the Equality Duty, Human Rights Act, Risk Assessments, Impact Assessments. And this came from the “Quality Unit”?

“I understand the petitioners concerns regarding the provision of residential pain services in Bath. There are a very small number of people in Scotland who require this level of specialised treatment. Approximately 30 people per year are referred to the service in Bath, who provide well established and highly valued service by those who use it. Bath are able to provide a range of specialised services which are tailored to meet individuals specific needs including programmes developed specifically for the children” Once again with

no reference to how far people have to travel, no consideration how long patients have to be away from their families, or how inhumane this is. And let me be very clear I don't care whether it is one person or 30 a year the fact still remains you are allowing this to happen is beyond me. Maybe there needs to be an investigation into all this as am seriously shocked by this attitude to people in pain.

30 patients a year has no relation to the numbers needing residential help. The Welsh residential service has treated hundreds of chronic pain patients from their population. Wales – 3 million people. Scotland – 5.2 million. We have many more at the worst end of the pain spectrum.

I am glad to have turned to elected members to see if there is a real difference. The low standard of this reply shows that the many thousands suffering chronic pain **desperately** need support and action from elected MSPs, your committee and the Health Secretary.

This is not a proper reply my petition. It was extremely difficult for me as a pain sufferer to gather my evidence and more importantly to reveal some of my most darkest moments to help get better services for my peers yet many of the concerns I raised have not been answered or swept under the carpet and all the hard work of key members from the chronic pain cross party group in preparing this petition and the petition committees work to be treated like this is not right.

A big point in my petition was that Scotland should have it's own inpatient service instead of people suffering from chronic pain being sent to Bath. After the public petitions hearing, Mr. Alex Neil promised to create a Scottish centre which was really terrific news.

But the officials in this Government quality unit don't mention the health secretary's promise!! Now how did that happen? They talk up the Bath hospital, just like that Update Report did. No regard for Human Rights? My petition warned that Scotland is breaking Human Rights legislation by subjecting people suffering terrible pain being sent hundreds of miles away when there should be a centre here. Now I am seriously concerned for a quality unit to not have picked up on this. It is beyond belief not to mention the Health Secretary's move. I seriously have to question the experience and knowledge of this response from officials. It is not good practice to ignore breaches for a start.

Healthcare Improvement Scotland response

This letter does NOT address my petition it basically wants to highlight everything in the GRIPS Report and Update Report. I found it quite bizarre for a PAID body's response as the Update Report was very inaccurate and misleading, let alone where to find half the information in them. Just like the Quality Unit, they don't or

won't answer points and both show the same thinking – no proper action. These bodies are too close and must change.

Looking at the other responses (see end of my letter) I found I am not alone in fighting for real change as others who have responded have been involved with this work for over 30 years or more and still feel services are patchy, inadequate, understaffed see below for full details.

Healthcare Improvement Scotland still seems unable to deal with the truth. Why are they getting £19 or £20 million a year to show up problems, when they cover them up?

Bearing in mind the recent scandal at Ninewells I have to ask seriously about the Chronic Pain Update Report:

Come on almost five months after the Update Report was hammered for removing facts on shortages, the same attitude continues with them dodging answers or giving unbelievable replies or no replies at all. They are treating **pain sufferers and the committee** with contempt, but the committee's and clerk's questions have shown up how bad news from the audit was removed or twisted time and again.

Another waiting times scandal?

Item 19 in the letter: The claim of 11 weeks average was presented as if it is a Scottish average but is from only seven boards out of 14, without explanation. FOI showing waiting lists of up to 33 weeks was not used. But what's this? HIS ignored FOI figures they now call "accurate" but their incredible excuse now seems to be that **these figures existed somewhere. Beyond belief!**

So why did they not mention or link? FOI figures were in March 2012, Report was 26th Oct. Plenty of time to include.

Item 24/25, Claiming 75% of the population was covered by Pain Management Programmes without saying this meant six boards and the figure was 64.9% not 75%. Same spin technique – no warning this meant just six out of 14 areas.

They admit on Point 14 that "the underpinning data was never designed as public facing documentation".

So Facts taken out of the Report but in the data never supposed to be seen. They published data six weeks after report - only after the health secretary stepped in and the cross party group on chronic pain demanded answers.

Item 19: (On tickboxes replacing Boards WTE figures) Question:

“Why did you choose to present the data from the audit in the way that you did in the Update Report – why not report specifically on the number of whole time equivalents WTEs in each area?”

“**Answer**” “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 WTE commitment they had to the pain service”

INCREDIBLE REPLY! The report didn't have staff numbers or WTE commitment. But the Questionnaire asked about WTEs. And Boards detailed WTE figures – removed from the Report. So how was it consistent to have no figures at all? Inconsistency was giving WTE for children's services but vanishing WTE from the adult clinics, Report changing to tick boxes which gave a better but false impression as a fraction of time was ticked same as a full timer.

Dorothy Grace Elders own research showed this in her letter: she calculated 72 WTEs equal full timer's from the data to 35,250 patients minimum as big review numbers were not put in by all boards, including Glasgow. So likely thousands more. Also, illness and holiday times would crash small number like 72. Which would lead to even more problems by increasing waiting times, **breaching HEAT targets**, costly referrals to other boards.

HIS refused to give a figure. Rubbish answers says it all throughout – like they forgot to include data, they find it difficult to define waiting times for pain management programme, etc OMG just gets worse.

But here are five answers from Boards ignored:

Item 32 and 33, the clerks ask about a bunch of questions put to boards on five subjects - referral to spinal cord stimulation; administration; budgets; telephone consultations; waiting list initiatives. Question says: “They were reported in the data spreadsheet but not covered in the detailed findings of the Update Report itself” The clerks ask:

Item 33 “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?”

(I'd say “what was the purpose of all the questions in the whole questionnaire if you're going to get rid of replies which don't suit you?”)

In this five, censorship of info on budgets was particularly disgraceful. Even in this unacceptable “answer” to the committee, HIS still does not state that ten out of 14 Boards listed no budget for chronic pain. Just “most boards”. Like the Ninewells

Report was changed from “35 elderly people on trolleys and wheelchairs in corridors” to “some elderly”.

The Update Report was so bad for chronic pain sufferers, denying them and MSPs information on their local services. Health Boards were asked to send in their statistics, a lot of work.

Report was held up for months and publishing dates kept changing. None of this letter shows any support for doing anything radical to help pain sufferers, as my petition requested.

PATIENTS SENT TO BATH

Look at the conclusion of the HIS letter, over which they refuse to tackle point d) of the petition which appealed for a Scottish inpatient centre to replace patients being sent far as Bath. Same as the Quality Unit, HIS ignores the public promise by the Health Secretary Alex Neil to create the first Scottish inpatient centre. He made that promise in January.

Why, by March 14, did HIS do the same as the Quality Unit and also ignore this good news?

Trying to keep out bad news and spin good news was HIS's method in the Update Report. I find it a bit sinister that two sets of officials dealing with pain ignored the one big piece of good news in years.

Would make anyone wonder if they will work against Scotland getting it's own inpatient centre and just keep people suffering on those hundreds of miles of journeys to Bath. They also say nothing about my petition's request on funding for pain centres in Scotland.

(d) change its (Govt.) policy to provide direct funding to ensure radical improvements to the service can be made including establishing a residential unit in Scotland to prevent Scottish pain patients being sent to Bath in Somerset for treatment. GRIPS made this a priority in 2007 and officials have failed to act in six years. This was no “update” report.

As for the petition's point that funding of our present (day) pain clinics be addressed, HIS also cops out of this. So no “view” on any positive action but they had the view by removing facts from their Report that they should not let people know that ten out of 14 boards had no budget as they kept this out!

The KEY part of this letter is the work of the clerk to the petitions committee and the questions raised by the committee.

15. 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.”

So the spreadsheet was posted 7th Jan n the spread table was posted on own website 8th Jan. Why? Is the spreadsheet and table same document if so why are they calling it different names? This means HIS kept out the data for a month on their own site while folk couldn't find it on the other website.

This is very misleading and confusing to anyone as I had to go and check both sites to find out that the spreadsheet and the data table are the same thing but here it looks like it is 2 different things. They just cant or don't want to communicate. I still don't understand why they would want to do a report based on figures from 2010/11 why not 2011/12 is it possible to ask for tables or spreadsheets from 11/12 as could it be they went with year before because figures were better?, patient waiting times, breaches, HEAT targets, staff were being sourced but then pulled because of funding priorities? So many questions ????

Avoiding answers to honest questions are a disgrace to any public body. I know about health reports as I have served for years on health and disability organisations. But I've never seen as bad a level of it as I have from the “health watchdog”.

As this is the second time HIS are being challenged over facts and figures I think the parliament should intervene as the chronic pain sufferers in Scotland deserve better and trust to get to the bottom of this. I have to call on the committee for help as I really need to ask who are they accountable to? I seriously think someone has to intervene as I would be embarrassed to put a shoddy response out like this. Once again HIS like Scottish Government Quality Unit have given no mention to anything I had to say about the way people are being treated, or to the Acts and Duties that are being breached as stated in the beginning of my response to petition committee I put it at the top so it will be seen. We need a debate in Parliament on chronic pain, with a vote this time and an investigation into how the “health watchdog” operates at public expense.

The KEY part of this letter is the work of the clerk to the petitions committee and the questions raised by the committee

14. The clerk asked “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.”

No answer on this. This was extremely difficult to find so how would they have expected patients and the public to find it? I did try to find it on the 7TH. I tried the next day to go in but it had disappeared.

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As the charity Action on Pain said:

“Clearly the current fragmented service cannot be allowed to continue with the obvious need to develop and implement an effective replacement paramount”
The recent Health Improvement Scotland report on pain services did in our opinion, and that of many others, do a disgraceful dis-service in the ability to achieve an effective service. Proved to be inaccurate and misleading, had it been accepted on face value then the future of people with chronic pain in Scotland would have been badly compromised. That such a report was allowed to see the light of day causes Action on Pain serious doubt as to the integrity of those behind it in introducing an effective pain management service for Scotland. We therefore call for the whole process to be opened up to include greater Independent patient representation in any future decision making”

Pain Association Scotland

I include a quote from their letter below which clearly highlights the work of the late Dr Pete McKenzie who was so committed to introducing a new service model but it seems, meeting after meeting, once again we see barely any implementation and some parts still have no improvement.

“As I am constantly reminded by Government they cannot tell Health Boards what they do and have to do or implement with the funding they receive”

That is why I specifically asked for in section (d) **change its policy to provide direct funding to ensure radical improvements to the service can be made including establishing a residential unit in Scotland to prevent Scottish pain patients being sent to Bath in Somerset for treatment** as this could be seen as a way for Scottish Government to redress this by funding directly to introduce good practice to tackle inequalities of services and inhumane treatment provided by the NHS, as by not providing the same services to all in each health board they have entered into the scary territory of breaching the following acts and duties bound in law as I have stated at the top of the page. The Pain Association continues:

“The fact that Jackie Baillie (Dumbarton) (Lab) calls for common sense to be applied we all know that that will never happen or it would have by now. Despite the fact that the late Dr Pete McKenzie introduced and had agreement for NHS Boards for a new Service Model this has seen subsequent and numerous amendments in the hope to unify the delivery of services in Scotland. We have, as Jackie Baillie argues and we have argued for years, for the size of country and population we have you would think this would be possible”

Health and Social Care Alliance

I have included this quote from their letter **“We are concerned that this has had the knock on effect of creating a significant variability of provision across Scotland which may have a negative impact in ensuring the best possible treatment for chronic pain in each area. The ALLIANCE supports the petition in calling for a greater emphasis to be placed the management of chronic pain in primary care. In 2007, the NHS QIS (now Healthcare Improvement Scotland) “Getting to GRIPS with Chronic Pain in Scotland” report³ noted that “the provision of chronic pain services within Scotland is patchy and fragmented particularly for core secondary services. Service provision and access to services varies considerably between and within NHS Boards and we found little evidence of needs assessment or strategic planning for chronic pain services.”** This also picks up on the postcode lottery service I described in my petition drawing back to 2007, now come on this clearly shows how very little has been achieved in the service and provision in 6 years. It’s not good enough and what a disgraceful way to treat the patients that rely on these services as they are trapped in agony with no vision “light at the end of the tunnel” of being able to get their pain under control which would then have a knock on effect on both their social and working lives.

Dr Martin Johnson response – chronic pain champion, Royal College of General Practitioners.

“It has been discussed widely how much chronic pain is seen in Primary Care - it is known that Chronic pain is a presenting condition in 22% of primary care consultations 1 (indeed some authors put this much higher at 49%) this speaks

volume and current demand **patients with chronic pain consult their general practitioners five times more frequently than those without pain.**

(I would add that the British Pain Society, representing doctors and other health professionals, states that their survey found that “10 million in the UK suffer pain almost daily resulting in a major impact on their quality of life and more days off work” Scotland normally uses a figure of 700,000 in the community, few referred to our few pain clinics)

Unfortunately chronic pain is often under diagnosed now this is what has to **change** as so many patients spend god knows how many years not knowing what is wrong with them **with the focus of treatment only being the supposed causative factor –thus delays of treatment happen with subsequent dire consequences for the individual and enormous burdens for the NHS.** Hence so many people on benefits right now, if the doctors can't diagnose then patients are left stuck in agony unable to move on with their lives which does not just become a burden to the NHS but has also a huge affect on their family, as eventually they are flung into severe poverty with no vision of hope for themselves or their families, this also has a huge effect on mood, suicide, isolation, exclusion.

GP's if given the adequate training and prioritisation are perfectly placed to diagnosis and manage many of the chronic pain presentations that are seen – Maybe this could be redressed through the Universities etc while they are students, juniors etc as eventually this could work but not in the interim term **especially if given adequate resources such as physiotherapy and health trainers.** This sounds more like it although I would include a psychologist as there has to be more emphasis of treating all off the patient instead of one bit of them as this we see every day in life.

A never quite get why in the NHS they have so many ways of separating conditions when many go hand in hand.

“The new British Pain Society pathways which were complimented at the recent chronic pain SIGN meeting in Edinburgh are perfectly placed to give the correct patient centred pathways for management, starting within Primary Care,” Please see BMA letter, making it clear this can't be done without funding.

Welsh Government response

Wales not only has a residential service but this letter reveals Government tackles health boards. Result they claim is 87% compliance with a Pain Directive from Government on overall pain services. 87% compliance by 2011 to a 2008 Directive in three years while Scotland is, six years after the GRIPS report, still showing little or no sign of change. What a show up. So much for the Scottish excuse is that health boards are left to decide. Result here is that ten out of 14 Scottish boards don't give a budget for CP. In Wales, Government directs Boards. Why not here?

British Medical Association

I was a bit disappointed with short response but looks like the BMA won't waste time as no official body is tackling necessary funding. They say: **Any further transfer of work to primary care would have to be evidence based, be accompanied by appropriate resources and would need to be discussed/negotiated with the relevant professional organisation.** Once again there would have to be resources maybe a special team as they have for diabetes.

Action on Pain Charity response

“We believe that issues regarding the provision of pain management services in Scotland should be regularly debated and where relevant voted on in the Scottish Parliament. Not to do so would seriously underestimate the impact of chronic pain on the Scottish population which will only increase with an ageing population” It also insures accountability that elected MSP's fully understand the problems faced by their constituents and can add strength on a regular basis to redress and push for improvement .

“Much is spoken about moving more pain management services from secondary care into primary care. Indeed it has been mentioned that GPs are “perfectly placed” to provide such services yet the reality is somewhat different. It is widely recognised that the majority of GPs receive inadequate training in pain management during the pre-registration period with little incentive to further learn once qualified. The same can be applied to the nursing profession and allied health professions. This has led to the current seriously fragmented provision of pain management services within primary care across the U.K” This brings me back to an earlier response from Pain Association Scotland where I also mentioned that so much more work needs to be done in Universities etc so they can specifically learn about a major issue that will affect so many of their patients, specialist training is the key to preventative spend and like I said this will not change right now but could have a huge effect on budgets in the future.

“It could be argued that the SIGN guidelines may address this issue however like many similar guidelines in the past it is up to the individual GP as to how they apply them.” I have to say it again some doctors are set in their ways and don't want change this has to be redressed or there will be no way forward.

“What is critical is equality of service and access to that service. Should you live in Inverness or Alloa access to pain management services should be equitable which given the above circumstances is currently unachievable”

Thank you for raising this as the people who you would think should know better chose to ignore all of it, I made reference to this in my opening statement re redressing the inequalities of health and acts and laws surrounding it.

“Our position regarding providing a more social model of care than a medical one is simply this. Treatment for chronic pain is not just one of prescribing medication. Our vast experience shows that a holistic approach can pay handsome dividends by giving the person with pain the confidence to move forward with their life. Whether it is just putting somebody in touch with someone in a similar situation or pointing them in the direction of a social outlet, volunteering or equipment that may help them it is essential that you never forget that chronic pain impacts on people in different ways. Now I know some of this is provided by Pain Association Scotland and maybe some funding provided by Health & Social Care Alliance but it would be good to look at numbers to work out what MORE needs to be done.. Therefore service provision needs to reflect this which the medical model alone cannot hope to achieve. However by amalgamating the medical and social models we believe a very powerful asset would be developed therefore we commend this proposal.” I am convinced there are so many people out there that are not getting or using any of these services hence the problem.

“We now turn to the question of the establishment of a residential pain management centre for Scotland. It should be noted that Alex Neil, Health Secretary has publicly declared his intention to establish such a centre which we commend. We do however note that in his response on behalf of the Scottish Government, Mark O’Donnell, Deputy Director of the Planning & Quality Division, in a letter dated 31 January 2013 to the Public Petitions Committee appears to be attempting to mislead. He states that only a tiny minority of people in Scotland need to use such a facility with only 30 being sent to Bath with the clear implication that there is not an issue so such a centre is not needed in Scotland. We believe that this shows a worrying lack of insight so we would encourage the committee not to apply too much weight to his response.” I also found this concerning and raised much of same issues in my response to Scottish Government.

“The reality is that the residential centres in England and Wales can only handle so many residents each year being heavily oversubscribed and long waits before you can become admitted. It therefore follows that only a limited number can be admitted from Scotland in any one year hence the low numbers. Our experience shows that whilst it is correct that only a minority of people with chronic pain would benefit from residential care that minority is too big for current resources to handle.” I really have to agree with all of this part as I regularly speak to other people suffering from chronic pain who live near Bath and Wales but inform me that they can’t get access to the units. Some are even very resentful of Scottish Patients being put before them.

“What benefits does a residential centre bring? Please note Ian is referring to a long term residential service not the ordinary 2 to 3 weeks . How does it differ from the courses that the Pain Association of Scotland currently run? Let me say that I speak from **personal experience here and ask that the committee will take note of that experience as I spent a year in a residential rehabilitation**

centre after spending nine months in hospital following the incident that caused my injuries. Whilst you have the valuable formal sessions delivered by healthcare professionals and others during the day equally valuable is the time spent in the evenings with other residents. The chance to share experiences, talk openly and freely or in quiet confidence, to face up to and express your fears, to feed off each other, to overcome the worry of isolation and regain your confidence just cannot be replicated in a non-residential environment. The bond you build amongst each other is very special enabling you to move forward as well as establishing friendships that can be so helpful once you are discharged. It helped me get back on my feet and in the fifteen years from founding Action on Pain I have come across many people who have shared a similar experience continuing as I have to benefit from that time.” I found this so refreshing inspirational springs to mind and he has went on to use his own personal experience to help everyone else a wish the NHS could seriously do this not tap into small groups as and when required. Employ them to lead and change how things work this is the only way of changing the services making them patient led as I explained earlier in my response to Scottish Government. I'd add however that pain patients usually only need two or three weeks residential treatment, not a year,

“We have previously alluded to funding effective and accessible pain management services in Scotland that provide equal and early access to all that need them.” This is specifically important as any chronic pain conditions associated with nerve damage has to be done within 18 months or will not heal.

“Clearly the current fragmented service cannot be allowed to continue with the obvious need to develop and implement an effective replacement paramount. In order to achieve this there needs to be an open and honest appraisal of what is needed delivered within a timely manner. The recent Health Improvement Scotland report on pain services did in our opinion and that of many others do a disgraceful dis-service in the ability to achieve an effective service. Proved to be inaccurate and misleading had it been accepted on face value then the future of people with chronic pain in Scotland would have been badly compromised. That such a report was allowed to see the light of day causes Action on Pain serious doubt as to the integrity of those behind it in introducing an effective pain management service for Scotland. We therefore call for the whole process to be opened up to include greater Independent patient representation in any future decision making” Agree with everything in this part whole heartedly.

“Funding is an issue however it should be seen as a positive investment not just for the health economy but for the overall economy of the country. It is clear that the issue is going to get greater given the population mix so it is essential that people affected by chronic pain get early access to treatment in

whatever form is best for their individual needs be it in primary or secondary care. Early intervention can see a reduction in future GP appointments, a reduction in prescribing, less referrals to secondary care which all bring potential financial savings in the health economy. However if you expand this further if early intervention allows the person with chronic pain to stay in work then the need to go onto social or housing benefits is greatly reduced and the person continue to pay taxes all of which contributes to the overall economy of the country” Two words PREVENTATIVE SPEND.

“Funding the residential centre also has the potential to bring benefits beyond those already stated. Once established the centre has the potential to become a centre of excellence providing training opportunities for healthcare professionals and others who need to broaden their skills in order to deliver an effective service. Such a move would contribute to the running costs of the establishment.” A centre for excellence is a vision of hope not just for patients but also for the staff who are dedicated to improve this but being held back by either boards not awarding priority to their ideas or not funding the posts and resources needed for such a radical but well welcomed change.

“What we do not want to see is a continuation of the current “closed shop” secretive approach that is compromising the ability of people in Scotland to receive the treatment that they so richly need and deserve. We need honesty, trust and integrity to deliver a service that Scotland can be proud of. There has been far too much talking, far too many unproductive meetings, too much evasion and lack of openness, too much self-interest which continues to compromise the ability to move forward”. And this is where things really have to change the petitions committee have the opportunity to redress this **Please** grasp it with both hands.

From being involved with the cross party group, I have observed people clearly fighting for improvement and so frustrated as virtually nothing has really changed in the last 12 years. So I think that Ian is right things have to go further and I don't just mean in committees or Steering Groups etc but by including more patients, it's quite clear we also need people in the Scottish Government who understand and can also improve things but I must say HIS has to be investigated as I stated earlier.