

Consultation response

Question 1: We would like to know in what context you are responding. Please choose one of the following:

I am responding as:

- a) an individual who experiences chronic pain
- b) a family member or carer of someone who experiences chronic pain
- c) a health professional
- d) an organisation representing people who experience chronic pain
- e) other stakeholder (please tell us in the comments box below)

I founded the Scottish Parliament's Cross Party Group on Chronic Pain in 2001, when I was an MSP, after pain sufferers in Glasgow's East End approached at a parliamentary surgery. Public response was overwhelming – a record 130,000 posts to the Parliament from people pleading for help and against these marathon journeys to England. The “pain campaign” is therefore a truly public inspired one backed by many newspapers. It was even put on the video of the first 1,000 days of the Parliament as a Parliamentary “achievement”. But I was angry that too little was done subsequently and that's why I continued, with the original patients, campaigning in the ten years since leaving Holyrood. Real progress is being made now with the health secretary and the whole Parliament in unanimous agreement. Chronic pain is the single biggest overlooked health issue – and we face a fresh avalanche of need as the population ages.

Question 2: Please choose your preferred option (Chapter 2 provides details).

- Option 1 – a centre of excellence in a single location
- Option 2 – a service delivered by local chronic pain clinicians (supported by other clinical advisors in another part of the country)
- Option 3 – a service delivered in different locations (by a team of chronic pain specialists – an outreach or roving service)

Please tell us why this is your preferred option in the comments box below. The factors listed in Chapter 2 of the consultation paper may help you.

Creating one Centre of Excellence should be inspirational for the whole chronic pain situation and day services in Scotland; a great opportunity to have a hub, training staff and monitoring patient and staff experiences. Having researched the matter over many years, I am convinced that only Option 1 would work: start with one centre of excellence, later extend. We're

starting from zero – no residential service in Scotland, with people in pain sent as far as Bath for treatment. Day services are scant and short staffed – so as we haven't got that right over decades, how can we diversify staffing, funding and organisation at the start of residential?

Wherever it is located in Scotland, the distances won't equal arduous journeys to Somerset, twice (assessment then treatment). Wales has one residential pain centre, at Powys, and they are a hub for outreach.

A Scottish centre is a wonderful opportunity and does not require any new build, just creative use of some existing facilities.

Question 3: Are there any of the options you disagree with? (If No, move straight to Question 4.) YES.

If yes, please tell us which one(s) in the comments box, and why?

I disagree with both of the other options, unfortunately as I normally support local services but don't think either option is feasible presently. In fact, could dilute the residential concept and risk it disappearing into the long grass, which has happened too often on chronic pain issues. Moreover, "Remote control" of treatment by distant clinicians may not be very welcome to some local health professionals - and patients prefer to deal personally with a team. As for a "roving service" –this is untested, not known to be viable, as the Consultation documents admit - and it would be hard to attract and keep staff and organise staff being away from home for 2 – 4 weeks.

It's possible in future that parts of both these options could happen through one centre of excellence – but let's first get a firm base as a launch pad, , please.

Question 4: If you have other ideas that have not been covered, please tell us about these in the comments box below. You may want to include the advantages and disadvantages of each.

Comments (box expands with text input - there is no word limit)

Question 5: What do you think the barriers are to accessing a residential pain management service? (For example, distance away from family, work or family commitments, upfront travel costs.)

Please list as many as you wish in the comments box below and include any others that are important to you.

This question does not seem to have been put to patients sent as far as Bath for years! So while the factors mentioned count, they do not have the same impact within Scotland and must be put in perspective.

Some within the NHS here have, for many years, been agreeable to sending patients at the most complex/severe pain levels on 800-1,000 mile

return journeys to Somerset – twice for most. There is no comparison between that, which many would call an outrage, and any service within Scotland in distance and personal links. As the Consultation points out, there will be some degree of travel for most, wherever services are. There are regular air links within Scotland from the Islands, especially to Glasgow. And, for instance, 2.5 hours direct train from Aberdeen does not equate with 10 hours to Bath and train changes. Nor does it compare with a patient being sent one time from Shetland to Bath when there are direct flights Shetland/Glasgow. Anywhere in Scotland, some patients are more likely to have some friends and relatives as visitors - apart from someone accompanying them more easily, so less loneliness. At Bath, weekends and most nights are free, ditto Wales but in Wales some patients can go home at weekends, a boost to emotions. Few from Scotland at Bath will have visitors at weekends or evenings, another humane reason for a Scottish service.

Comments (box expands with text input - there is no word limit)

Question 6: Please choose from the list below which aspects of residential pain management services should be included in a Scottish service.

(choose as many as apply)

- | | |
|-----------------------------------------------------------------------|------------------------------|
| A chronic pain assessment | yes <input type="checkbox"/> |
| Supported one to one sessions to teach coping skills | yes <input type="checkbox"/> |
| Group sessions | yes <input type="checkbox"/> |
| Residential accommodation | yes <input type="checkbox"/> |
| Opportunity for immediate carer/support provider to accompany patient | yes <input type="checkbox"/> |
| Peer support | yes <input type="checkbox"/> |
| Tailored exercise programme | yes <input type="checkbox"/> |
| Medication assessment | yes <input type="checkbox"/> |
| Other (please tell us in the comments box below) | <input type="checkbox"/> |

I'm mindful that some patients do not appreciate group sessions or tailored exercise programmes as much as other services in a tick box situation but may be persuaded by staff in situ if staff believe they'll benefit. Comments (box expands with text input - there is no word limit)

Question 7: Irrespective of the final service model selected, should access to the current service provided in Bath (or elsewhere in the UK) be retained for occasional use?

Yes No Don't Know I believe retention could be an easy cop out if there are some in the NHS hierarchy who resist organising something new in Scotland or don't feel up to the task and continue using Bath on more than an "occasional" basis.

Our health workers certainly are up to the task with high skills and I hope that the failure of many years to create Scottish residential services is not down to a "Scottish cringe" attitude in NHS leadership. There's certainly been no Welsh cringe as they've long had their own residential service.

Some in the Scottish establishment have accepted sending patients on those arduous journeys, despite knowing that the small numbers sent don't reflect Scottish need – some refuse to go because they can't tolerate the huge journeys or upfront travel costs. So, effectively, the poor in pain have been cut off from help. The Scottish NHS has long paid around £10,000 per patient to English services, compared with the cost to the Welsh NHS of £5,000 per patient, because no-one has set up a Scottish residential facility. That promise has come through Scottish Government and Parliamentary action, listening to campaigners for patients. Cross border referrals are supposed to be for comparatively rare ailments But chronic pain is one of the most common conditions and it's against Human Rights to treat common conditions at great distances.

The Bath hospital deserves respect for their work – and is not to blame but using Bath to tackle problems which should be addressed in Scotland is not the answer.

Our health professionals just need the resources, staff and, most of all, strong, enthusiastic leadership.

Question 8: Have you previously attended, or supported someone attending a residential service outside Scotland?

Yes (please answer Question 9)

No (please move straight to Question 10)

Question 9: If you have attended, or supported someone attending a residential service outside Scotland, please tell us about any advantages and disadvantages of the experience.

Comments (box expands with text input - there is no word limit)

Question 10: If you, or someone close to you, has been offered but declined a residential service outside Scotland what were the reasons for this?

A friend who suffers severely was offered this but had to decline: length of journeys. Regarded such journeys as extra torture for pain sufferers which could harm good help given.

Question 11: If you wish to add any further comments on issues raised in the consultation paper or current chronic pain services in Scotland, please use the comments box below.

This Consultation is most welcome because it addresses practical need: the long overdue creation of a residential pain service. And there is a separate promise by the health secretary to improve day services and hold Boards to account.

Before this, progress in improving chronic pain services has been alarmingly slow on any major issue over the last few years. These practical moves were urged by Parliamentarians, volunteers from the Cross Party Group on chronic pain, and agreed and promoted by Mr Neil, the cabinet secretary for health.

Otherwise, a maze of bureaucratic control over chronic pain has emerged in the last few years which, so far, has not produced radical results visible to patients.

Chronic pain seems taken over by a growing empire of committees, a huge Steering Group, various Govt bodies, a quango, many meetings, talking shops, conference attendance, managed clinical networks in places where it's lack of staff which is the glaring issue. All at public expense – but the public needs to see results.

Whatever the above might achieve in a very long run, must be offset against the amount of time Scotland's overstretched pain professionals have to spend away from patients attending such meetings.

There is secretiveness also –official bodies meet behind closed doors, their membership is hand picked behind scenes with no open public recruitment and little public accountability. Nor is there proper accountability in the vague replies given to MSPs asking Parliamentary questions on chronic pain. An Update Report on pain management services last year was strongly attacked at Holyrood and in the media as it excluded key facts on staff and patient numbers in day clinics, the fact that 10 out of 14 health boards reported giving no specific funding for treatment, and other “bad news” which had been submitted by Boards but omitted from the report. This was dealt with by an investigation by the Public Petitions Committee. An outstanding factor was that this Report by Healthcare Improvement Scotland, over which they later admitted its deficiencies, had been approved by the Steering Group. So a lack of questioning voices within the bureaucracy surrounding chronic pain may be the problem. HIS has promised to improve on this. We'll see.

While rock bottom services in resources were being presented in rosy terms, in Greater Glasgow and Clyde, waiting lists for an appointment with a pain psychologist reached 72 – 82 weeks by August 2012. This was reported to the Steering Group. But even the health secretary was not informed, as he confirmed on April 30 2013. These waiting lists were reduced after he was told (by the cross party group).
(See debate, chronic pain, May 29, Scottish Parliament)

Ministers, Parliamentarians and the public need to know of specific shortages. The aura of secretiveness has grown in the last 2 – 3 years and is preposterous considering pain is a normal, devolved subject. Strong leadership is needed to cut to the chase. There should be no delay in starting residential services at last.

Comments (box expands with text input - there is no word limit)