

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)

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

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.

Improved local services should be the first priority, bring each areas service up to an acceptable level able to provide a service which can demonstrate change - most areas simply need to change how they deliver there service in some cases without increased staffing levels. If we already have the level of skills to deliver Intensive Pain Management Programmes surely these should be being delivered **now** and the waiting times and lists reduced to reflect this. It has also been demonstrated in the past that patients with chronic pain do not respond well to a tele-health model.

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

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

Option 1 The fundamental concern remains that the premise for this model starts from the most specialist end of the spectrum and assumes that all

those who have attended the residential service in Wales are referred appropriately. There is no obvious attempt to assess the extent to which these people's problems could be addressed by a more general strengthening of local services. This model has been superseded in other parts of the world owing to its inefficiency in both time and cost and can only address a very small number of the population. This option is further compounded if the model goes down the road of disease specific, age or other individual criteria to access the course. **Chronic Pain** is the issue across the board and people benefit from being together with their chronic pain not their condition. Even if 100 people went to Bath every year it would still cost less than a dedicated centre. How will the centre be staffed? as there is already a shortage of healthcare professionals working within this field and withdrawing local staff to man a dedicated centre or roving service will only further increase local waiting times which the same professionals are currently not managing. We feel strongly that by substantially improving local services might well reduce significantly the numbers requiring residential services. It also does not address how the maintenance of skills would be addressed. We all know that if skills are not maintained then they will very quickly be lost.

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.

Option 1 Sounds like a nice idea until hopefully those involved consider the real associated costs, criteria and issues of developing such a service. Although the document states "there are patients in Scotland suitable for this level of treatment" there is no attempt within the document to quantify the numbers; nor is it clear what warranty there is for the assertion that "a Scottish service is likely to grow in the future". Therefore how can the planning of such a service be put on a sound basis? Additionally there is nothing in the document which gives an indication that there is an element of the proposed service that is unique to a residential service. Option 2 If local services were improved people wouldn't need to travel or have to address related issues. What is not clear is what further input would "local skilled chronic pain teams" require, and who are they "other experienced staff" who would provide that input? Option 3 Realistically this is a non-event, staffing for a start would be an issue. We remember when one PMP was being established because there was no staff parking, it didn't happen - never mind the people being away from home for weeks on end. And what impact would that have on other local services to establish a dedicated mobile staff unit. The concern for both options 2 & 3 is the option of the voluntary nature of the residential element of the service, which surely undermines the whole concept of a residential service. Surely it makes sound sense to await the outcome of the new SIGs to assess what impacts/improvements they propose/implement before such decisions are made.

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.

For the biggest percentage of patients they simply want a vastly improved local service.

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
- Supported one to one sessions to teach coping skills
- Group sessions
- Residential accommodation
- Opportunity for immediate carer/support provider to accompany patient
- Peer support
- Tailored exercise programme
- Medication assessment
- Other (please tell us in the comments box below)

If it's going to happen then patients would want the lot - stand by for the cost

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

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.

As an organisation we have supported people on their return from Bath. There has been a mixed response to their personal experience but they all agreed that they required the on-going training and support provided by this organisation to sustain any benefit experienced.

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?

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

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.

Further to previous comments - Questions :

- Option 2 - How many such services would be required across Scotland ?
- How many patients could be referred at any given time?
- Can you clarify what are the other tested “similar service models exist for other chronic health conditions” mentioned at the top of page 10?
- The document states that “care will need to be taken that the availability of the new service does not result in a lack of investment by NHS Boards to improve their local service”. How can this be guaranteed when we have already been told that the Scottish Government “can’t tell” Health Boards what to do regarding expenditure?
- Document also says there is supported evidence that positive outcomes are achieved through Bath – where is the evidence for the maintenance of the outcomes?
- There is no mention of a cost/benefit analysis which should surely be done before any final decisions can be made
- What additional provision will there be for those in remote and rural areas? They will still be required to travel from the Highlands and Islands