

## 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.

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

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

Option 2

Option 3

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

It needs to be highly specialized and offer all treatments as an inpatient in one centre to ensure a quality non- fragmented service. If the patient suffers from pain travel to different centres for treatments is difficult and detrimental for those with high levels of pain. It is best to receive intensive treatment

and have one journey.

My daughter has attended 4 different hospitals on many different occasions to consult with Physicians- Neurologists, Pain Specialists, Psychologists and Physiotherapists and has had to travel many times causing her great distress as travel increases her pain.

It would have been so much easier for her and more successful if she had been admitted to a Specialist Unit where the medical and nursing staff had knowledge of her condition. On one occasion when admitted to hospital she was 'boarded' in an inappropriate ward area where none of the staff had any education or knowledge of her condition – in fact no one I spoke with had heard of her illness.

The Pain team would visit very occasionally, including the pain nurse- no therapeutic relationship was ever established. My daughter became more and more frightened and distressed as her pain medications were given ad hoc and not as prescribed in a timely and routine manner due to lack of understanding.

**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.**

My daughter has asked many times to have a referral to the Centre at Bath. She has been told that "we offer the same (*in Scotland*) as Bath". However we know that that is not true as the centre at Bath offer a much more intensive, supportive and specialised inpatient service with an excellent success rate.

**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 x

Supported one to one sessions to teach coping skills x

Group sessions x

Residential accommodation x

- Opportunity for immediate carer/support provider to accompany patient x
- Peer support
- Tailored exercise programme x
- Medication assessment x
- Other (please tell us in the comments box below) x

Specialised medical treatments

**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 x

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

Yes  (please answer Question 9)

No x (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?**

Never offered in five years of suffering...and have frequently asked for a referral to a residential service in Bath.

**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.**

A centre of excellence in a single location is essential in Scotland. It will be cost effective, efficient and will help the high number people suffering from chronic unremitting pain gain a better quality of life including managing to help some people return to fulfilling employment.