

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)

St John's Patient Forum

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.

This will build on current local pain services and provide an additional level of support from a HUB and use of current and future telehealth developments.

It would provide a more equitable and accessible service if delivered locally, without the financial burden or challenges of travelling a distance. Support from family and friends is easier to manage locally rather than long distances.

Building up relationships locally with specialists is more likely to increase patient/carers confidence and better outcomes knowing that you can be referred back to the outpatient service and have knowledge of the team.

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?

3 would be difficult to manage, staff and resource and how would equity/access be assured geographically.

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.

Travelling arrangements, family/carer support or if they have no one to come with them. Uncertainty of knowing where you will stay and if facilities meet your needs/requirements and if the cost, costs of travel/lost of working time, carers or childcare expense, uncertainty of what will be involved and who will provide care and who you might meet. If additional support is required for language, disability or assistance dogs.

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)

Diet, alcohol and drugs, alternative therapies, CBT, anxiety/pain management, benefits/finance, information provision management, mobility assessment/treatment, mental health wellbeing

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.

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?

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.

A co-ordinated local chronic pain service would be much more valued and utilised if based in Scotland. The reduction in cost to the patient and their carers in terms of pain, deterioration in health as well as the reduced financial burden to the NHS would be a much better outcome for everyone

From this consultation exercise it is clear that there is a varied knowledge about the current chronic pain services within NHS Lothian and Scotland.