

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)

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.

It seems like the most sensible option but it would be good if the centre of excellence also catered for other chronic pain patients too. For example outpatient groups or talks by the specialist team using their expertise for chronic pain patients who don't fit the criteria for the residential group.

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?

I am not sure any of the options are the right way forward for chronic pain services in Scotland. Although I'm sure residential pain management courses are beneficial, it seems like a lot of money to treat a very small percentage of sufferers. I am very much on the side of pain management having benefited from 2 courses (8years apart) myself but it is not a quick fix & ongoing support essential for success & that is what we desperately to

improve. We need to stop treating chronic pain as an acute illness & improve the long term care of chronic pain sufferers. The vast majority of patients are not attending or being reviewed by any doctors but their GP giving them painkillers.

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.

We have to improve knowledge of chronic pain from GPs & healthcare workers right up to hospital clinics. At the moment treatment varies greatly & is very dependent on who you see & the tenacity of the patient.

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.

The main barrier would be people's perception. They may not want to stay in or near hospitals & be away from family with possibly no visitors. The upfront travel costs could cause a problem to some patients.

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

I think the peer support & group sessions are almost as important as coping skills but I would worry about what happens when they return home. What

ongoing support would there be?

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?

In the 18 years I have had chronic pain I have met many chronic pain sufferers & been involved in pain clinics, pain management courses & monthly groups I have not met anyone who went or was offered a residential course.

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.

As I already mentioned I am concerned about improving the overall treatment of chronic pain & I'm not sure this proposal would improve Scotland's chronic pain service, certainly not without other major changes . At the moment care is very patchy in Scotland: GPs don't always know what is available for chronic pain – not knowing or referring patients to hospital clinics, pain management groups or self-management monthly groups. Patients are sent to pain clinics but then referred back to their GP for their GP to monitor their condition even though many GPs by their own admission have no expertise in chronic pain. Everytime you may need the help of hospital treatment with a flare up, for example, you need to be referred again & put on the waiting list. It is not treated as a chronic illness but as several acutes which is wrong. It needs to be treated as a chronic illness & the focus being on keeping suffers well instead of just treating the flare ups when they come.

Educating healthcare staff is essential, I have been on 2 pain management courses in the last 18 years – both of which I had to find out about myself & ask to be referred. The second course has been more successful because it offered follow up monthly self-management groups which I am still attending over 5 years later.