

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.

We circulated this document to the 1471 people on our mailing list(189 in Scotland) as well as advertising it on our website for five weeks in order to obtain the most detailed and relevant response possible. We circulated it to our complete mailing list in order to reach out to Scots living outside of Scotland who have relatives/friends back home who are affected by chronic pain. In total we have received 293 responses of which 103 originated from Scotland –the highest response we have had to such a request in nearly sixteen years.

The results are as follows;

Option 1	231
Option 2	38
Option 3	24

The overwhelming majority for Option 1 clearly reflects the obvious logic of establishing a centre of excellence in a single location which would easily offer the best option for people affected by chronic pain. A common thread

in the responses was Options 2/3 presented a real danger of services being fragmented as well as being of varying standards. They would be no better than what is available now and indeed offered the potential to further destabilise pain services in Scotland. Almost without exception respondents thought that establishing a central location was a “no brainer” as it would offer the very best of services on a consistent basis giving people affected by chronic pain who needed specialist support a real and sustainable service within Scotland. Additionally several pointed out that within the NHS specialist regional trauma units have been established bringing all the expertise under one roof which makes sense both in medical and financial terms. Equally important is the fact that it is easier to monitor the quality and effectiveness of service provision when under one roof. There was a strong belief that examples such as this only strengthened the case for Option 1

A clear strand emerged from the responses of being able to work in a group environment during the day but equally away from the formal sessions where you build bonds with each other and share experiences that offer the potential to move forward. Only Option 1 would permit this to occur further devaluing the case for Options 2/3. Action on Pain believes that it would be a serious mistake to ignore such an opportunity.

The majority of respondents did not see any problem travelling across Scotland to a central location with a strong feeling that it would be easier for relatives/family etc to keep in contact. In stark contrast there was little if any support for continuing the service in Bath with many questioning the logic behind establishing this in the first place.

Across all the responses a common thread emerged. Would the needs of people affected by chronic pain be the over-riding priority and if not why not? We detected an understandable stream of cynicism within the responses that the decision would be made on what was best for healthcare professionals rather than people affected by chronic pain. Several had noted the commitment made by the Health Secretary being really concerned that attempts were being made to dilute that commitment by people with “self-interest “at heart. It is fair to say that Action on Pain does have some sympathy for these concerns. It would be tragic if such an opportunity is compromised in this way.

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 2/3 offer no benefit whatsoever to people affected by chronic pain. In our opinion not only is the business case compromised but also the ability to deliver continuity and quality of treatment.

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.

Action on Pain would suggest that a centre of excellence offers further benefits than that offered to people affected by chronic pain. We firmly believe that such a centre offers an unrivalled opportunity to provide a high level of training to healthcare professionals in order to equip them with a better understanding of how to effectively manage people affected by chronic pain. This would also create a revenue stream which would contribute to the overall running costs of the centre

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.

Clearly up-front travel costs are an issue especially for those on low income or benefits. Feedback we have had suggests very little objection to travelling to a central location in Scotland provided that the treatment they get when they get there is good. The feedback also suggested that the majority of people would find ways to deal with any potential family issues and that a central location would almost certainly ease these issues.

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

Advice on how to get back into work-either paid or voluntary
Social events in the evening

Patient experience-bringing in people who have learnt to manage their pain and are happy to share their experiences

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.

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?

Could not afford the up-front costs and worried about travelling that distance

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.

Action on Pain was established in 1998 to provide support and advice for people affected by chronic pain. Since then we have become the major UK general pain charity with a reputation for being “down to earth” and “in touch”. We are entirely run by volunteers all of whom either have chronic pain or have a family member affected by it.

We are totally independent neither seeking or receiving funding from central or local government which enables us to provide an open and honest view without the fear of funding being removed.

Our approach to this consultation has been to ensure that as many people as possible get the opportunity to make their views known in order that the right decision is made. We would respectfully point out that although we are based in England our coverage extends across the whole of the UK and beyond with frequent contact with Scottish people enabling us to provide an

entirely credible opinion based on the views of our respondents which we trust will be given due weight. We note that although Action on Pain featured notice of the consultation on our website one of the Scottish based pain charities failed to do so which surprised us.

In conclusion based on the evidence we have provided it is clear that Option 1 is the obvious choice. We would like to think that the decision is made in an open and transparent way using figures that have been independently audited and verified being available to public scrutiny. Above all the decision must be made in the best interests of people affected by chronic pain rather than any “self-interest” within the healthcare or government system.