

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)

Pain Concern is a UK-wide charity who represents and provides support for people across the country living with chronic pain.

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.

Given the framework of this consultation, Pain Concern supports the establishment of a centre for excellence within Scotland. We recognise the need of people living with chronic pain to have access to professionals with specialised skills and this could be achieved through a centre of excellence.

The access this would provide patients to wide-ranging and specialist services would certainly have a positive impact on patient rehabilitation. The capacity of a centre to provide training to other pain-management specialists could also contribute towards a more synthesised approach to care.

However, this support is offered with some reluctance because of concerns regarding how financing such a development could affect local services. If the cost of establishing the centre resulted in any budgetary constraints on primary care services, it would prove counter-productive. Most of our service-users tell us that they would like early management of their pain,

support in staying at work, and assistance in remaining active in their respective communities. There is evidence that early management of acute pain can help prevent chronic pain and minimise downstream disability.

Creating a specialist service would thus require additional funding to prevent disrupting the development of primary care patient services.

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?

Options 2 and 3 on their own do not appear to us as viable models, both in terms of practicality and financing. Regarding option 2, local clinicians may not have had the opportunity to develop the requisite skills to address the complex needs of certain patients. Patients suffering from complex neurological problems would lose out in this regard.

Option 3 raises the issue of recruitment for such a role. Specialists who are willing to travel around the country and stay away from home for long periods of time are few and far between. If recruitment is achieved, how can one guarantee that this service will be effective for patients when it is untested? How long would patients need to wait before being seen? How will this affect their condition?

When one considers these issues of recruitment and efficacy alongside the financial costs involved in funding travel/accommodation, it becomes clear that Option 3 is not supportable.

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.

Given the small number of patients that this centre would likely serve in the Scottish context, there are significant issues to consider surrounding the development of critical mass in patient numbers. The needs of young adolescents and other specialist groups should be at the heart of decision-making and the consideration of national boundaries should not influence meeting the needs of these and other specialist groups who need access to peer support as well as tertiary care. If run in Scotland, waiting times for adolescent programmes should be acceptable, otherwise these patients should continue to attend the Bath centre or a similar service elsewhere.

Pain Concern supports the consideration of collaborating with other regions in the UK if such a centre were set up. Given the high costs associated with the setting up of such a facility, and the relatively small number of patients from Scotland that may attend it (currently around 30 a year), perhaps a partnership with other regions/nations such as Northern Ireland, Wales or

Northern England could be achieved.

Ultimately, any alternative arrangement made should not have any detrimental impact on patients.

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.

Pain Concern is keen to note that any centre, be it in Scotland, Bath or elsewhere, will involve travel for its patients. A centre in Scotland could feasibly be more difficult to travel to if patients are expected to travel by car, coach or rail. For those living with chronic pain flying to a centre, e.g. Bath, may be seen as a less daunting trip than having to experience the discomfort of a 3 or more hour drive or train trip to Edinburgh, for example. This would need to be addressed in terms of travel arrangements for patients.

In more extreme cases, travel is not just a discomfort for patients, rather an impossibility. We support the view of the Neurological Alliance of Scotland who posit that for many people with neurological conditions, pain assessment could and should be done at home rather than during a residential stay.

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 checked="" type="checkbox"/> |

In agreement with the Neurological Alliance, where there are complex patient needs, we stress the need for assessment before sending patients to a centre.

Relating to the unchecked “opportunity for immediate carer/support provider to accompany patient”, we believe that wherever possible, it can benefit patients to personally equip themselves with the tools to manage their own pain and develop peer-support networks; something which may be inhibited where a carer accompanies the patient.

It can also often be unnecessary for patients, but this is certainly not the case for patients with complex neurological issues. This highlights that some services are not applicable to certain patients, demonstrating the need to not merely roll out services generically.

Another suggestion we wish to put forward is to make available some form of family therapy. The management of pain needs to be holistic, encompassing not just the individual, but significant others too. For example, the impact pain has on children where parents have complex needs can be greater, and this needs to be included when planning their care.

The above leads us to support Martin Dunbar’s view that a possible approach incorporating option 1 and elements of option 3 could give the best results of holistic care.

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.

Pain Concern supports the continued collaboration with the Bath Centre for Pain Services, especially where this relates to the rehabilitation of young people and others with special needs.

Patient testimonials suggest that young people, in particular, benefit from being surrounded by their peers. Given the small number that the proposed Scottish centre might serve, the likelihood of there being multiple young patients is low. If Scottish young people are required to attend a centre in Scotland, there is the distinct possibility that their management will suffer as a result of losing the aforementioned peer-based support and/or experiencing long waiting times.

Overall, we welcome the effort to improve chronic pain services in Scotland. However, these efforts must consider that we are aiming for progress, not lateral movement. Lateral movement will be the outcome if a centre of excellence comes at the expense of essential local services and primary care based chronic pain management.