

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)

The Neurological Alliance of Scotland is a forum of not-for-profit organisations and groups representing many thousands of people affected by neurological conditions in Scotland

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.

The Neurological Alliance of Scotland recognises the importance of establishing a specialist centre which could provide depth and breadth of clinical expertise, engage with research developments and provide training and support to locally based health professionals. Whilst we support a national centre we believe that it is crucial that such a centre is properly integrated with locally based pain assessment and management services if it is to assist local development and improvement which is needed. A centre of excellence should not be at the expense of investment in locally provided services which may be more accessible and appropriate for many people with neurological conditions.

We recognise that a specialist centre allows for the development of expertise, experience and competency that would not be easily achievable with options 2 and 3. However due to the nature of many neurological conditions, people affected by chronic pain will also have a range of other

complex needs which would mean ongoing pain management must be well supported locally and linked in with the multidisciplinary team providing ongoing care. We are aware that pain management services for people with neurological conditions are not routinely available and even where there is provision, there can be significant waiting lists. The nature of complex degenerative neurological disorders would mean that referral to a national centre on a residential basis is not always appropriate or possible. It is important therefore that local pain services are resourced to be able to provide pain assessment and management to those unable to attend a specialist centre.

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?

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

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.

Any services provided, whether national, regional or locally based would require input from condition specific specialists if providing care to people with neurological conditions. It is important that people with a long term neurological condition have care and support delivered by staff who understand neurological disability and the management of complex problems associated with neurological conditions. Whilst a national centre would not necessarily have specialist neuroscience staff it would be important that clinicians within a specialist centre have links with condition specific specialists who can provide input where necessary.

We also believe that as well a residential service, domiciliary care approaches should also be considered. For example, for many people with neurological conditions, pain assessment could be done at home rather than during a residential stay.

We believe it is imperative that patients and carers are involved in the development of a specialist service and that such a service should be holistic. The involvement of patients at all levels will be crucial in ensuring that the service is responsive to the needs of those living with chronic pain.

Data and audit will be crucial and part of the function of such a centre should be to monitor outcomes and collate and disseminate best practice.

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.

Cognitive issues –people with a neurological condition may have some level of impairment in cognitive function which may be a barrier to them accessing such a service. It will be important to ensure the services provided account for the needs of those with cognitive impairment.

Mobility issues – many people with neurological conditions have reduced mobility and require assistance with personal care. Often people with a neurological condition will require night time care. A residential service would need to have the capacity to support those with restricted mobility.

Communication difficulties – some people with a neurological condition may have communication difficulties. It will be important to ensure that these are understood and accounted for and that any written information is communication accessible.

Finance – many people would need financial support to access such a service.

Carers/Family members –many people with neurological conditions would require the support of a carer/family member if they were to access a residential service. It would be crucial to ensure that carers are able to attend with the person and that their needs are also accounted for.

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)

As an organisation representing a range of different neurological conditions we can see the value in all aspects listed. However different elements would not apply to all. Some conditions would benefit from certain aspects more than others and even within conditions there will be differences in suitability for different people depending for example, on levels of cognitive impairment and mobility. It will be important to ensure that pain management services are responsive to individual needs.

We strongly support the opportunity for carers/family members to accompany the patient. Carers/family members of people with neurological conditions may often provide personal care such as getting someone dressed, turning them in their sleep, helping them to the toilet, helping them move about or administering medication. It is important that carers are seen as partners in the ongoing care and support of the person with a neurological condition and have access to the information they need. Self management techniques are an important part of ongoing chronic pain management and carers will be vital in supporting those people with complex needs due to their neurological condition, to self manage pain once they are back at home.

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.

The Neurological Alliance of Scotland welcomes the commitment to improve chronic pain management services for people living with chronic pain in Scotland. We are unclear as to the demand for a specialist residential services but believe this is a useful model to develop expertise and share best practice provided it is not at the expense of local services.

Young people with neurological conditions want to access services that are age appropriate and tailored to their needs. For groups such as this where numbers are likely to be extremely small, referral to the current service in Bath may continue to be most appropriate.