

## 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 x
- 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 x
- 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 x
- 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.

I believe the quality of the individual's delivering this service is key to its success. A centre of excellence in a single location isn't a patient centric solution essentially; in the practical way of being away from 'home' but to enhance the quality of the service I believe it would be the best solution out of the three.

A centre would hopefully encourage funding for research and attract individuals of high calibre wishing to specialise in the study of chronic pain.

Highlanders expect to travel for general services due to the great distances between places in the highlands, so location is almost immaterial to the argument. I don't believe the patients attending the clinic would access the service via public transport due to extreme mobility problems but it may support the carers and family members wishing to visit their loved one.

**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?**

It is my belief that the quality of the service could be compromised or weakened if delivered by local chronic pain clinicians, if it is believed that a centre of excellence might attract a high calibre of individual, passionate and committed to delivering a first class service.

The idea of spreading their theories and ideas geographically might weaken the passion for successful outcomes or detract from the service.

The logistics of delivering the programme as an outreach service might detract from the quality of the service and place a strain on staff retention.

My father suffered from Motor Neurons disease and really benefited from a multi-disciplinary outreach service. The main difference is that he lived in London, the service was only offered in his immediate location, so there was a denser population in a smaller area to serve. This not practical for a highlands service but highly beneficial to the user.

**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.**

There are three levels of chronic pain service in the Scottish Service Model for Chronic pain. The creation of additional levels of chronic pain services suggest that the first two are ineffective for a small number of patients.

Could it change to one level with repeated referrals to **satellite units** in each health board area, linked to a central centre of excellence where all the research study is undertaken?

Initial visits to the service would be day patients, becoming residential in extreme cases. The satellite units would offer beds and facilities for residential patients. To overcome the projected low numbers of residential patients, group sessions could double up with day patients?

The outward view of the service to the patient is that the chronic pain service is a 'stand alone' educational service for best practice that is recognised as a valuable field for study.

This solution addresses patient psychology better and demonstrates a serious commitment to helping individuals improve their lives, closer to their homes.

**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.**

I have experience of residential treatment away from my family and home at

the Dingwall Rheumatology Unit. I agreed to the treatment because I felt I might better support myself with my condition.

**Isolation** – when you are ill you need your familiar support system more than ever (partner, children, neighbours, friends)

**A major strain on your partner** – your partner has to pick up home duties as well as running to visit you and all the emotional worry of a sick partner.

**Mobility issues** – we would assume the person has access to a car and someone to drive them. Taking public transport is out of the question when in chronic pain.

**Out of context** – altering mind sets away from the routine of home means what might be achieve in residential treatment may not be so easily carried over into home routines.

**Sleepless nights** – nurses check in on you throughout the night, I could never rest properly.

Based on my experience at Dingwall, I wouldn't access a residential service again.

**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)                      | x <input type="checkbox"/> |

**Diet** – undertake serious research into the correlation between diet and inflammation. Include re/education about foods, encourage food diaries. Allow patients to identify specific dietary requirements, foods they can tolerate and provide this diet in the residential centre.

**Support networks** – when returning home, how can the individual sustain learned good practice?

A social network of others in similar situation should be in place. Places to meet up or even online communities.

**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.**

N/A

**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?**

N/A

**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.**

Evidently, patients are more likely to turn to their community pharmacist for help in addressing chronic pain. This could suggest that either the patient feels that the doctor may dismiss the issue as trivial, they don't want to bother the doctor as they think they are not coping well or the pharmacist is the easiest way to access more effective pain killing drugs.

Satellite units linked to a centre of excellence might act as a beacon to support and educate patients in chronic pain.

Their presence might also address the stigma attached to accessing services like these in local communities.

The approach should be 'support and education', a self help model and not a 'treatment', where therapies are done to patients.