

## 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)

NHS National Services Scotland, through its National Services Division (NSD), provides the secretariat and support for the working group formed to advise on the provision of Residential Specialist Chronic Pain Management Services in Scotland. NSD currently manages the funding and access to residential Chronic Pain Management services in England through the national risk management arrangements on behalf of NHS 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 expectation is that local and regional services will be offering appropriate care to the vast majority of people who require help with the management of chronic pain. The numbers of people who will require access to the level of intervention that is proposed will be offered it in a specialist setting (with access to residential care) and should be relatively small. Patients, their family, carers and specialist staff will benefit if the care is provided in a single Scottish centre.

This centre can then develop the expertise and be able to monitor its activity and outcomes in a robust manner and in (hopefully a very short) time can demonstrate its excellence. The working group recognised that even with an

increase in referrals to a centre sited in Scotland there will still only be a less than full time caseload. It is therefore important that the Scottish specialist centre for chronic pain management is co-located, or at least the staff also co-employed, within a local or regional centre offering chronic pain management to a local population. It would be hoped that the model of care offered would allow clinical staff from other areas in Scotland to be part of the therapeutic team involved in an individual person's care.

As stated in the consultation paper, attendance at the specialist centre is intended to offer the individual with chronic pain advice techniques and the confidence to maximise their own independence and coping skills. Also to allow their family and carers to understand what is possible. All that is offered within the specialist centre will need to be reinforced within the local care services. Attendance at the specialist centre must be seen as part of a continuing care journey not an end point in itself.

The working group was sympathetic to the concept of the specialist service travelling around Scotland; this certainly would fit more closely with the 20:20 vision for delivery of healthcare in Scotland. However the concern is that the specialist staff would be spending too much time focussed on the logistics of delivering the programme in different settings rather than working with the patient group on helping with their chronic pain management.

It was also recognised that if the clinic were to move around the country it might help boost local clinical practice but on balance the evidence suggests that local services (in many areas) still have some development work to achieve and it would be unhelpful to distract from that need by an occasional visit to deliver the national programme.

On balance development of a single specialist centre for delivery of highly specialised care for chronic pain, with a residential facility in near proximity, is the preferred option.

**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 3: A specialist team of staff expected to deliver care at a distant (temporary) site is not thought to be workable. Whilst not formally tested the group recognised that the impact on the staff involved would be too great. There are a number of services delivered by staff who travel and even being away from home base for one or two nights is known to be disruptive. For the specialist programme to be effective the patients will wish to gain a relationship with the specialist staff over the 10-14 day programme and this is not thought to be practical if we wish to retain and build resilience into the specialist team in Scotland.

**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.**

It is hoped/expected that local staff, who have been involved in making the referral and who should be involved in support care when the individual returns to their own locality, should play some role in the specialist care delivered in the specialist centre. This will foster good relationships between staff and their patients and should also allow opportunities for strengthening relationship between the national team and local centres.

There should be a tele-health/specialist Multi Disciplinary Team maintained to discuss prospective referrals, to give advice on options for pre-work by the patient and family prior to admission; as well as to allow follow-up over a longer time to ensure that the Specialist centre understands whether the interventions offered have made a difference.

There is some evidence that patients can form a supportive self care network and consideration should be given to providing clinical input to a web based medical network established for those individuals who wish to use this.

**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 centre should be located in a setting that has effective public transport links although most patients will begin their journey through the specialist centre with severe limitations to independent travel.

**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 checked="" 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"/>            |

See ideas in box 5

**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.**

No comment

**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.**

The need for a continuing focus on self care, early access to appropriate advice on pain management whether from voluntary sector or primary care, along with delivery of high quality local chronic pain services must be recognised. The setting up of a specialist national centre should be seen as an incentive rather than an alternative. The proposed care pathway to access the national centre will review whether appropriate local care has been offered and whether such care will be available following attendance. The national service should not be seen as a substitute for local care provision.

Consideration could be given to including other chronic conditions which require a holistic approach to 'daily living', e.g. ME and chronic rheumatic disease.