

## 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:

d) an organisation representing people who experience chronic pain X

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**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.

Patients in Scotland could potentially benefit from the establishment of a centre of excellence. To be effective and to justify the investment of resources, this should be fully integrated with local Tier 1 and 2 services and care pathways for the wide range of patients experiencing chronic pain. It should be equipped to provide clinical specialist (including condition-specific) input beyond that already available or readily deliverable at local level and part of its function should explicitly be to monitor national patient outcomes, engage with research developments and to collate and disseminate best practice.

Clinical expertise, capacity for national monitoring of outcomes, sharing of best practice and supporting service improvement are the key factors that make this the most attractive option. We also strongly support the intention to make this a centre capable of providing flexible, person-centred services and of making full use of technology to connect with patients and local health professionals remotely where appropriate. As part of an integrated patient care package.

Patients with ME-CFS make up a substantial proportion of those experiencing long term chronic pain. We would therefore expect the centre to include a specialist with good and up-to-date knowledge of this condition.

In particular, we know from patient and carer feedback that this group requires informed specialist inputs on pain medication – including appropriate doses – due to sensitivities and reactions characteristic of ME that are not associated with other common pain causing conditions.

People with ME-CFS also commonly experience a strong, prolonged exacerbation of symptoms following exercise (described as PEM – Post Exertional Malaise in the literature).

It has long been reported by patients and now widely recognised by proponents of Graded exercise and activity therapies for people with ME-CFS that rehabilitative exercise has to be approached cautiously with this group, starting from a very low base-line and proceeding gradually and flexibly. Again, advice about exercise that may be appropriate for other groups of patient experiencing chronic pain symptoms will not necessarily be suitable for people with ME-CFS and may cause more harm than good.

It is important that the model chosen does not over-emphasise intensity of delivery, as this would be likely to make the service inaccessible to those with most need, many of whom will need domiciliary delivery. For patients with ME-CFS, many of those who would be mobile enough to travel to a residential facility, would be unable to sustain participation in an intensely-delivered treatment programme.

In future, those able to mainly self-manage, but who could have previously required referral to Bath due to shortcomings in local service delivery, may be catered for at tier 2 service level. If suitable services at this level are not available, in some circumstances they may also be better catered for by regional or area outreach services.

There will be a period of development of chronic pain services at all levels before ongoing future requirements become clearer. However, tier 3 services will always be presented with the most difficult cases. Focusing on providing expert inputs to the treatment and care of these patients will provide a more reliable model for viable service provision than one which requires patients with substantial restrictions to their mobility and/or capacity to sustain activity (including sitting upright and social interaction) to travel to intense, generic residential courses.

To retain lasting benefits from attendance at a residential service, a greater degree of accurate reporting of patient's responses to the treatments offered needs to be provided to the professionals providing continuing care, compared to the current norms of reporting between service tiers and providers.

**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 on its own would be unlikely to deliver satisfactory results, particularly in the short term. Even a virtual centre of excellence would have difficulty developing in the circumstances of a roving service.

**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 not currently clear how need from amongst patient groups which have been historically under-recognised and poorly catered for will be better met through the development of this service. Yet, such a step would justify the substantial investment entailed in developing the service.

The need for domiciliary visits for assessment and development of individual treatment has to be central to tier 3 service development.

**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 wording of this question appears to assume a level of mobility which would preclude those patients with the most need / least capacity.

We are concerned that the model of service proposed is underpinned by an assumption that the needs of the majority of patients with chronic pain will best be met by providing them with generic exercise and behavioural therapies. While we recognise that these type of therapies and support have their place and may be helpful (if properly applied) to a proportion of patients, it is our experience that such therapies will be minor adjuncts to medication and aids in many cases.

It is important to note that such therapies are already available in some health board areas to patients with chronic pain. If this is all that is to be substantially provided by the new service, the value of providing them within a national residential centre is unclear. For many patients, current, pressing additional needs would not be met and the service offered would not justify the trip.

Many patients who need this level of treatment will need financial support to be able to access the service. Any – even short-term – gap in remuneration of expenses could be a substantial barrier to accessing treatment.

It is also worth noting when considering location, that the distance of any stage of a journey may be less of a barrier than the number of stages in a journey or the mode of transport available. Patients with ME-CFS will typically need rest time to recover from such a journey before being able to usefully participate in treatment.

A significant proportion of patients would need or wish to be accompanied by a carer to attend the centre. It is important that the needs of carers are fully catered for by the service and, ideally, carers (and close family members who may not necessarily see themselves as 'carers') should be explicitly welcomed and actively included in the services provided as key people in providing ongoing support to the

patient.

**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
Supported one to one sessions to teach coping skills	
Group sessions	
Residential accommodation	X
Opportunity for immediate carer/support provider to accompany patient	X
Peer support	
Tailored exercise programme	
Medication assessment	X
Other (please tell us in the comments box below)	X

Patients requiring tier 3 services will generally need a high level of assessment (including technical investigations where necessary).

All of the services listed could potentially be helpful to some – though not all – patients. They are not all best suited to delivery at tier 3 level and there will be differences (as described above) in suitability for different patients. It is important that all services delivered are informed by specialist, up-to-date, condition-specific knowledge and tailored to meet individual needs and priorities.

There also needs to be comprehensive monitoring of outcomes (including patient perspectives) – taking in the whole, integrated patient care pathway – and a cycle of learning and service development at all levels based on those outcomes.

Expectations of what can be achieved within the confines of a short, intensive programme need to be realistic, and based on medium to long term outcomes evidence.

**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?**

Don't Know X

**Question 8: Have you previously attended, or supported someone attending a residential service outside Scotland?**

Yes (please answer Question 9)

No X (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.**

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**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?**

not applicable

**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.**

References to attendance at the residential course at Bath appear to indicate weighting towards ability to participate in certain forms of treatment, with little indication of other aspects of treatment being adequately delivered. This raises the concern that currently unmet needs, including those of many of the most severely affected, will continue to be neglected by services at all levels.

It remains unclear from the information provided whether this service is intended for all potential presentations of unresponsive chronic pain, or is aimed more at meeting the needs of specific patient groups.

Design of tier 3 services has to be focussed on meeting the greatest needs of individual patients, whatever their diagnosis or co-morbidities. Service development should not focus on providing specific types of services because they are cheaper or easier to deliver than those that will better meet actual patient needs. Cost effectiveness needs to be considered from the perspective of wider, medium to long term impacts on a patient (and their families' life), wider socio-economic impacts and full service impacts at all levels of service and across health and social care divisions.

While there are many challenges in establishing this type of national service, this is also an important opportunity to put into practice admirable national commitments to the core principles of integrated, patient-centred care.