

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)

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

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.

A centre of excellence based in a single location will offer many advantages for patients living in Scotland who struggle with chronic pain. Given the level of expertise within Scotland, it is unfortunate that these patients currently have to make a long, potentially uncomfortable, and expensive journey to England. Although the numbers of referrals to the specialist service in Bath are currently quite small, this does not necessarily reflect the large reported numbers of people in Scotland experiencing chronic pain; it seems entirely possible that a national service for Scotland could receive a significantly higher referral load, based on a more accurate reflection of need. However, it is entirely necessary to acknowledge, respect, and build upon the successful model currently available in England.

Any Multi Disciplinary Team (MDT) delivering a specialist programme within a designated centre of excellence in Scotland will require an expert knowledge and understanding of: managing multimorbidity; chronic pain mechanisms; preferred modes of treatment; and will need to be consistent in their delivery of the most appropriate, and where possible, evidence-based therapeutic approaches.

In an increasingly patient-centred national health service, it is essential to consider novel and emerging approaches to the management of long term conditions. Integrative Medicine embodies such an approach and offers fertile ground for development and integration of a service such as the residential pain management programme.

There is a growing body of evidence for integrative interventions such as Mindfulness-based therapies, self-efficacy and self-management strategies, and wellness enhancement, which all build self-awareness and inner resource development skills. These approaches can be a very effective addition to the more traditional model of pain management interventions, such as physical rehabilitation and skilled psychological support.

Another significant consideration is that of the fragmentary impact of traumatic life experience, particularly in the early years of development. This has been shown to have a major detrimental impact on a person's ability to manage and recover from a variety of health issues, including chronic pain. Skilled intervention in the field of trauma therapy, such as that currently incorporated within the practice of Integrative Medicine, would facilitate a holistic and inclusive means of rehabilitation in this high morbidity client group. The importance of the therapeutic relationship in supporting the rediscovery of the person's inner strengths and abilities is central to this approach.

Integrative Medicine draws from best practice and evidence, but adds a wider holistic and individualised dimension to the patient journey. Therapeutic relationships with skilled clinicians allow patients to consistently feel supported and heard, whilst coached through integrative interventions, such as those described above. The ethos of this approach is to enable a person to rediscover or rebuild their own inner resilience, strength, and creativity, in order to engage with effective self-care and self-management. It is an inherently individualised, person-centred, and whole-person approach. Evidence from interpersonal neurobiology, empirical research into compassion and empathy forms much of the bedrock of this approach.

Current research indicates that the activation of a person's self-care abilities can trigger lifestyle changes e.g. healthy nutritional and exercise choices, as well as attitudinal shifts supportive of successful long term outcomes and the ability to 'cope'. This approach is a solid foundation on which to build a more structured specialist service for those with chronic pain.

In Scotland, the Integrative Medicine approach offered at the NHS CIC already successfully delivers, as a centre for excellence, comparable services for people with CFS/ME, as well as routinely catering for high morbidity client groups with a wide range of other long term health conditions.

It will be essential to develop a seamless service pathway and ensure clear communication between referrers and the specialist team. This is potentially more achievable from one Centre of Excellence, where established communication pathways would also ensure consistency of follow up and support, for patient and primary referral source alike. The development of expert-patient and peer support groups will be explored and developed, with this becoming more practical as patient flow through the specialist service increases.

A designated specialist service should also have a role in supporting the ongoing training and skill enhancement within the Pain MCN.

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

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 2 would create extra demand on local teams and possibly create inequalities of service between regions. Option 3, a peripatetic team, would possibly have issues of recruitment and staff retention due to the mobility required to deliver the service. There would also be variations in suitable accommodation between regions.

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.

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

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.

Travelling to a specialist centre will always be an issue for those with chronic health conditions, and any designated service should be close to road, rail and airport links. Acceptable travel time and distance will vary from person to person, depending on their level of pain, disability, and functional status.

It should be noted that, it is conceivable those travelling from the more remote areas of Scotland may still find a journey to a National Centre difficult. However, a National Service for Scotland is likely to considerably reduce the distance between patients and their friends and families; it will be important to enable, as far as possible, for the person's carers to be allowed to accompany them during their visit to the Centre, perhaps even to participate in the programme themselves.

Indeed, there is empirical evidence that the involvement of carers in a patient self-management initiative significantly improves therapeutic adherence, with resulting improved outcomes. This should be taken into consideration; particularly with respect to an individual's ability to cope if the programme is residential in nature, with a clear recognition that age and the patients level of disability are important factors in the equation.

A variety of cost-efficient accommodation options should be explored, ranging from hotel, B&B, self catering accommodation, or purpose built accommodation on site. The service in Bath, provides ward-based care for those with higher levels of disability. The balance between this model and the residential approach would need to be assessed and discussed in the consideration of a model fitting the needs for the people of Scotland.

Equal access should be ensured, with no person meeting the entry criteria for the programme being excluded due to individual financial restrictions.

Patients often comment on the isolation created by their health difficulties and loss of confidence is often a result of the struggle to cope with pain issues. A designated service for Scotland can have a significant benefit in terms of improved accessibility, with face to face peer support; importantly allowing also for continuity in care. A national service is likely to grow and develop over time to include expert patient support groups and buddy systems. This fits perfectly with the ethos of Integrative Medicine.

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

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 | x |
| Group sessions | x |
| Residential accommodation | x |
| Opportunity for immediate carer/support provider to accompany patient | x |
| Peer support | x |

| | |
|--|---|
| Tailored exercise programme | x |
| Medication assessment | x |
| Other (please tell us in the comments box below) | x |

There should be a seamless continuity of care and bidirectional communication between the patient's local care providers and the specialist service. A named health professional, within the specialist service, who co-ordinates the person's care, and with whom they have a therapeutic relationship, will be central to the approach and linked to outcomes for the self management model.

Accommodation should have the appropriate range of facilities as outlined in the consultation document.

As well as these essential rehabilitation facilities, a consideration of the wider environment will be necessary. It is recognised that recovery is enhanced within an environment of tranquillity and peacefulness, with the therapeutic use of green space being a 'hot topic' in public health research circles. A well chosen environment can facilitate the opportunity for self-reflection and learning, by creating a 'breathing space' for those whose health difficulties have become overwhelming.

The key ingredients of: a skilled specialist clinical and rehabilitation team, with compassionate coaching and therapeutic engagement for patients, set in a soothing environment is, in our opinion, the ideal to strive towards for a National Centre for Excellence.

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 x

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

Yes x (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.

Our perspective is a result of our role within the NHS Centre for Integrative Care, where patients in this category are sometimes referred.

Although we are aware of the positive outcomes reported by the specialist service in Bath, we have been involved in ongoing rehabilitation and support for patients who unfortunately have not had such a positive outcome with respect to their experience of the service. These patients generally reported that the challenges of the rehabilitation programme were too demanding and not appropriately pitched for their level of capability. Although the Bath model is appropriately non-medical, there were often issues around the residential nature of the service which may benefit from review and discussion within any proposed Scottish service.

Patients have also reported a feeling of isolation, based on the perceived ‘distance from home’, lack of follow-up, and break down in the communication chain between the Bath service and their local care providers.

Our impression is that a ‘one size fits all approach’ is not universally successful. Using an integrative, collaborative and individualised patient needs assessment, and paying particular attention to baseline state, level of resilience, and ‘readiness for change’, is a critical factor in creating an integrative and mutually collaborative rehabilitation programme within a healing environment.

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.

This response indicates the potential for enhancing the provision of pain services in Scotland, by the addition of an Integrative Medicine approach.

It is important to highlight that discussion and streamlining of care pathways will be required, in order to ensure the integrity of the Integrative approach. Such a service will be unique in the blending of evidenced expertise from the current approaches utilised in Bath, with the emerging sciences of enablement through supported self-management coaching within Integrative Medicine.

This will be an exciting, innovative blend of services, designed to improve and enrich the care currently provided for patients in Scotland. The NHS Centre for Integrative Care will ensure that a high quality service, worthy of National Status is consistently available for the people of Scotland.

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