

## 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)

I am responding as an individual with 10 years experience of being on the Cross Party Group on ME and as someone who has attended a pain group for 8 years. This group has an extra curricular meeting in which I set up workshops with presentations and subjects relevant to coping with chronic pain such as life coaching, CABx, Pharmacology, physiotherapy etc and also to assist individuals to understand their chronic pain and manage it more effectively.

**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.

Specialist services are needed with a strong medical lead. This should exist within the context of wider networks which encompass other clinical disciplines and services. Above all, service users need services that have positive attitudes to chronic pain and where appropriate appraisal can be made for each individual and ongoing monitoring of condition progression. This should, however, be accompanied by supportive care in the community along with primary and community care.

Patients may feel marginalised and isolated if their GP refuses to make a referral to a Residential Centre. We need a patient centred approach with:–

- Immediate investigations leading to prompt diagnosis.
- Treatment congruent with the disease process, which may differ from

patient to patient.

- Appropriate referrals to consultants from a range of specialisms
- Reduced waiting times for out-patient appointments.
- Responsiveness to International research findings (a recent study in Holland found infection in low back pain, effectively treated with antibiotics).

**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?**

I would consider this option to be unworkable for the reasons given, ie staff having to be away from home for weeks at a time. It would need huge incentives and in a cash strapped NHS that looks improbable.

**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.**

Setting up Managed Clinical Networks across Scotland to provide a broad range of medical and therapeutic inputs. On a National level, making sure there is a sharing of knowledge and experience to allow crossover arrangements and to allow for the development of a more focussed approach in researching and evaluating treatment interventions.

Access to a centre such as the one at Gartnavel set up by Cancer Support Scotland which has just been awarded funding. Based on a complementary therapy approach, this centre offers an excellent Holistic service, particularly for people who are drug sensitive.

**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.**

One of the main barriers occurs at Primary Care level where GPs are allocated around 5 minutes for a consultation and do not regularly review patients or their medication. GPs approach such consultations with a view to prescribing only, often not anticipating the need for further disciplines to be involved, possibly on grounds of cost, and are therefore reluctant to refer elsewhere. But I do perceive a strong case for action at primary care level, if GPs are properly trained in chronic pain.

Diagnosis can take an extraordinary length of time because of the need to meet certain criteria before proper investigations such as scans and MRIs are commissioned, quite often causing additional distress, pain and expense to patients who look elsewhere for help in the complementary

fields, often helped with acupuncture but at great expense. Early diagnosis and support is paramount and the need to develop effective clinical standards for services.

An epidemiological study with routine reporting of chronic pain within the context of developing information systems for long term conditions monitoring under the Quality and Outcomes Framework (QOF) is needed.

A service which supports research work should be reviewed by the Chief Scientist's Office and a strategy developed. Consideration could be given to developing a centre for research excellence and dissemination.

**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)                      | √ |

Enhanced funding for local pain management support groups which provide a valuable service to people with long term chronic conditions. Peer support such as that provided by the Third Sector in setting up such groups to individuals/groups who have the relevant expertise to run such groups – the Expert Patient. Patients with optimistic explanatory styles and long experience of dealing with chronic pain are of immense benefit to newly diagnosed patients with chronic pain. We need to look at the wider picture and what happens to patients when they have exhausted the medical channels and are in need of additional support.

**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  I have no experience of this facility and do not know of anyone who has so do not feel in a position to comment.

**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.**

I am aware of patients who have attended Professor Julia Newton's CFS Clinical Service in Newcastle. Their experience has been positive with definitive diagnoses and treatment which can improve functional impairment and quality of life. There is a real reluctance for doctors to refer people there though, possibly again on grounds of cost. I would hope that the consultation exercise will look at the amount of research which has been done in this area and the possibility of including this in a Centre of Excellence. This would require a number of disciplines such as Consultants in Infectious Disease, Immunology, Neurology, Physiology, cardiology among others. But this will depend on making it attractive enough for these clinicians as it is in other chronic illnesses such as heart disease, stroke, diabetes and cancer.

**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?**

I applied for a consultation at Newcastle but was refused by the GP

**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.**

I have observed that there is a resistance for referral to secondary care despite the need for regular assessment of long term conditions. Chronic pain is sidelined with little in the way of support mechanisms as experienced in Diabetes, Stroke, Heart Disease and Cancer.

What might be useful in the context of chronic pain services, is examination of the ScotPHN Report on the Health Care Needs Assessment for people living with ME-CFS of September 2011. Much of which is contained in it is applicable to the development of a chronic pain service where the groundwork has been done. It just requires a bit of joined up thinking along with the GRIPS report.

A SIGN Guideline, while it would be helpful, may not be read by a busy

General Practitioner. This was my recent experience with the Good Practice Guide on ME/CFS when my GP asked me what had come out of the Cross Party Group on ME. When I mentioned the guide he delivered a blank stare and said he didn't know about that! This took years to come to fruition and it is doubtful if general practitioners know about it, let alone read it.

The main thing is to get the patient out of a no-man's land sort of grief about losing a life of physical ability to a different life of different possibilities as smoothly as possible.

It would also be helpful to have a central database of allied health care professionals who have been properly trained in chronic pain and are contracted to make domiciliary visits. Start in the University Medical Schools.