

## 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)

**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 has been a long term ambition of mine and the X-Party Group on M.E. of which I was a member for a Decade. My only concern would be getting patients to a single location so there would therefore need to be back up at a local level. I am appalled at the lack of knowledge on ME and associated pain and therefore recommend Education for the medical community and medical students

**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?**

In the case of Option 2, my recommendation would include Professor Julia Newton at the Department of Ageing, in Newcastle - the only Biomedical ME Centre in the U.K. Unless experts in ME, and Researchers, could be included, then this option for me would be useless. Too many Health Professionals are advocating exercise and damaging patients health.

**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.**

We need to widen the scope of illness models. One size does not fit all. It could mean the difference between improving someone's quality of life and having severe damaging effects as has happened in ME. I have had chronic pain for 37 years but nothing prepared me for the illness which is M.E. which I have had for 24 years. It is a devastating and disabling illness. Education of professionals is paramount to the management of M.E. I am familiar with many aspects of chronic pain as a member and at some time a facilitator of a Pain Group.

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.

The journey would be difficult for some, especially bed bound patients. The most severely ill must be considered.

Travel costs should not be a deterrent since Mary Scanlon intimated at a group (ME) meeting, that the Health Service should foot the bill. Ring-fencing should therefore be a priority for all forms of Chronic Pain.

In 4th we have a Specialist ME Nurse. Expand on that within every HB area, and consider that for a specialist nurse in chronic pain of a peripatetic nature.

I liked the idea of upskilling local clinicians which is absolutely paramount to a good service.

What about a chronic pain symposium which could be podcast. Could we draw on the experience of other countries and their pain specialist experts and expertise?

**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)*

Appropriate training for medical students and medical staff SIGN Guidelines on different aspects of chronic pain to assess what is appropriate and what would harm the patient. "Do No Harm".

We should draw on the experience of the Homeopathic Hospital as cited in the Parliamentary Debate. They have awards.

Gairnhead Hospital has a cancer care unit which treats patients with complementary therapies and is very successful. Look at all models, especially those patients sensitive to pharmacology, I have seen enormous improvement with self management in patients, especially discuss that address other as they do. Introduce, NLP, Relaxation etc.

**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.**

I know a number of people who have attended Professor Julia Newton's clinic in Newcastle. Professor Newton is successfully doing research into M.E and is able to distinguish a number of sub-sets of this illness as well as identifying other conditions, including Metabolic Syndrome, MS, liver dysfunction etc. Correct diagnosis imperative.

This can only be good for the patient since there are symptoms of vasovagal syncope and Orthostatic Intolerance that can be dealt with for improved quality of life and wellbeing. with tilt-table testing. lets upskill our physicians!

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?

My GP was reluctant to refer me to Professor Julia Newton since she felt "we did not really know enough about ME!"

Let's refer us to the people who do and get them sorted - or at least a better quality of life.  
Basic human requirement.

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 am not conversant with chronic pain services. I saw a consultant 16 years ago and my GP has ~~not got any~~ no knowledge on how to treat the pains experienced by M.E. patients. The tendency is to pace one's life and manage as well as possible. But it is not a good way to proceed, with a very poor quality lifestyle. There is knowledge out there. Let's access it.

(End of questions. If you require more space to write answers, you may submit as many additional pages as you wish. If doing so, please clearly state the question numbers that your answers relate to.)

P.T.O

I was a Civil Servant in the Scottish Office for 23 years working to a number of senior Civil Servants at a high profile level. Described as an outstanding officer conversant with Civil Service procedures, nothing prepared me for the journey ahead when I developed ME.

The world of benefits, working and coping, was an absolute minefield and nightmare. Senior Officers in the Scottish Office said "This shouldn't be happening to anyone - least of all you". These officers were Under and Assistant Secretaries. I never acquired benefits.

I returned to work in a supported employment capacity as an Office Manager and Company Secretary. Others are not so lucky. This required extensive pacing and rest. My mission has remained to help others in such straitened circumstances. I was a member of the X-Party Group on ME for its duration. Currently, a member and some times facilitator of a Pain Management Group (ROSYTH). Development of Guidelines for GPs and Needs Assessment Study have showed little or no progress and have been devastatingly slow, after 10 years of commitment and hard work.

I also petitioned the Scottish Parliament on the lack of dental services which was very successful indeed. I would recommend the Glen Pavilion in Dumfries or the Carnegie Conference Centre for next meeting.  
on file