

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.

Creating a Centre of Excellence for Pain Management/Treatment would compliment the service that has been offered at the Homeopathic Hospital for many years.

1. The Centre for Integrated Care is already at the Glasgow Homeopathic Hospital.
2. It could enhance the service that they currently offer.
3. Health Board/Government funding continued to a known site.
4. Complimentation of services offered would benefit the patients
5. Already established access to Gartnavel's other outpatients clinics such as the eye clinic has been given to Scotlands rural and island community so this would not set a president. Therefore travel and stay arrangements well established in the hospital area.
6. There is also the established Cancer Centre at Gartnavel which again deal with rural areas outside of Glasgow
7. People in chronic pain do not use cancer services such as the Maggie Centre.

8. People with after effects of Cancer can suffer chronic pain but may not wish or emotionally unable to go back there for help therefore a multi-user chronic pain centre of excellence holding all that is offered from them and/or alternative therapies would be very beneficial.

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: even in the bigger cities this is not always available to people due to a variety of reasons even the simple thing of being aware that a service exists locally or limited times to attend offered. For employed patients this may have an impact on their employment attendance and can cause extra stress on top of their already pain stressed condition if they are going to two different clinics. Some employers may not recognise a non-clinician service as warranting time off work as most of these services are during the day. This can put the patient in a 22 catch situation and make depression even more liable.

Option 3: A roving centre would not reach all of Scotland and things like time, availability of transport especially in rural Scotland and there is also access to consider and weather conditions and communication breakdowns. I have great difficulty attending other mobile health unit and have to make alternative arrangements to attend at their headquarters instead.

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.

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

√

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)	√

I have had the experience of chronic pain for more than 20 years and the trials and tribulations of trying to get some medical practitioners to recognise that was the case and trying to get support and help in dealing with it.

Chronic pain assessment is a priority as not everyone has a condition with a neat label. Due to this a **one to one to teach coping skills** initially would be good then going on to **group sessions**. Chronic pain not only affects the patient but also the family surrounding them and each one can be very different. Some don't have family which brings in another set of circumstances.

Residential accommodation for some would also be good as pain during the night may require further identification of support as this can differ greatly from how patients cope with pain at those times.

Opportunity for carer/support provider to accommodate patient would be in the first instance essential: In the case of child or even young adult as the experience of stress increase in a new environment and talking about their pain can manifest in loss of pain control. This can also apply to adults and they may also not take in what is being said to them or remember instructions and become confused and withdrawn. It also avoids duplication and misunderstanding on the carer/supporters side. As stated before chronic pain does affect the people surrounding the patient as well as the patient. This has an impact back on to the patient to how effective the change is on their handling of the patient both physically and mentally regarding the patient. Some chronic pain has no visible criteria or appearance and belief that it is there can go a long way in achieving control over pain.

Tailored exercise program again ideal to individual requirements. It is well known that the body holds natural endorphins which help pain. Controlled exercise for the individual to activate these endorphins but do not worsen or stress other parts of the body would be great.

Peer Support: It is so easy to feel that as you are surrounded by pain that you are in this alone. A sense of humour can lift a deep depression from

forming. Depression can come upon you so quickly. A child might not want to keep talking to adults or non-chronic pain children so it can help to talk to other children who understand. They may get quicker to a smile and laugh for the child affected. It goes without saying that this situation also goes for adults too. This peer group would continue long after being assessed especially now with modern communication media.

Medication assessment and other: It would be obviously good to review the medication assessment but also as well as that looking at alternative medication or non- medication therapies and treatments going hand in hand with traditional.

Treatments or alternatives AND THEIR SUCESS may not have been thought or known about by the patients GP or even specialist hospital consultants who give up on their patients when no traditional methods work.

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.

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

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.

I have had a variety of experience in trying to control my chronic pain and symptoms. The early experiences were very bad where I felt I was banging

my head against a brick wall to even be recognised by my GP. You would think I had horns coming out of my head!

I worked along-side medical doctors and consultant who saw for their own eyes the symptoms manifest for short times in front of them. I was sent via one of them to a colleague who determined I also had multi allergies which was a majoring factor in my condition. With the advice of my medical colleagues I changed GP.

My new GP indeed was willing to listen and actively encouraged me to look into alternatives therapies that I could do myself while waiting for Rheumatology and Neurology appointments. (reiki and imagery via night time and weekend course)

Both consultants eventually once diagnosed that there was nothing further they could do – I was a number off their list as being dealt with. None referred me to chronic pain services. The Neurologist did admit that I was in severe chronic pain with peripheral neuropathy but to try a new medication not yet available in Scotland when it did become available. Outcome of that was it caused internal bleeding and if continued to use it I would have been dead in 3 months if not sooner.

The request to seek Homeopathic referral was put in place. I was treated holistically along-side the general medication that my GP and I had sourced that I could tolerated without too bad a reaction. By that time I had been in touch with a specialist nurse run clinic locally but was unable to attend all of them due to work and release from work. I now have moved out of the area due to my health problems.

I still attend the homeopathic hospital and in November will be trying different medication to hopefully stem both my conditions.

The above may seem irrelevant but in locating a centre for excellence it seems logical and cost effective to locate where some of the requirements are already in place.

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