Consultation response: the provision of specialist residential chronic pain services in Scotland

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.

Due to how debilitating travelling would be, it would mean resting for days or weeks lots more medication which would impair my thinking so would it difficult to take part in probably feel more self extra painkillers. My only worry is to choose option 2 however is that presently the pain clinicians doesn’t feel he can offer me anything so am hesitant to medications and he has discharged me after only seeing me twice. I therefore wouldn’t get referred to the service you speak of. I think it would be important for the local clinicians to learn from specialists that biological methods of treating pain are not the be all and end of all. One size (treatment) doesn’t fit all. I would hope for more complementary therapies to be offered + self management skills.
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 have concerns about Option 1 - where would it be? Would patient transport be provided? As I couldn't mentally function, or physically cope with public transport to somewhere I don't know, or to faraway distances. My cognitive ability is compromised with pain levels, fatigue set in. I would worry about there being no local follow on support if treatment was far away. The local clinics need to be retrained through updated support and alternative ways of addressing pain - not just medication. If patient transport was supplied then the stress would be taken out of travelling to distance so wouldn't be the bodily effects to deal with.

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.

Bringing in more complementary, non medication, focus of addressing pain - not just CBT through - more things like acupuncture, mindfulness training, hypnotherapy, bowen technique, osteopath, chiropractor, aromatherapy, massage, tai chi instruction (for health version not mainstream version)

The physio therapists, doctors, clinicians need to be made aware of the different types of pain there are such as fibromyalgia, chronic fatigue, etc. as they seem to say there's nothing they can do for you - it's not like arthritis or such where you can get injections etc. Being told to go away there is nothing to help you leads to self harming. Teaching people how to cope with self harm would be good too as the doctors + even mental health people we met, don't want to know.
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.

1. Upfront travel costs.
2. Wouldn't be able to cope with planning journey by public transport, would be stressing about missing connections etc. would be stressing about getting there on time - generally the whole process would be stressful. Panning about not being able to carry luggage by myself etc. Panning about falling asleep due to medication on the bus/train and going beyond your stop etc. Would need to be patient transport car driver someone else picks you up from your door and is responsible for getting you there on time.
3. People with anxiety, depression etc. Might exacerbate their levels of distress being away from home, family pets - maybe have no one to take care of them for 2-4 weeks etc.
4. GPs and local pain clinicians discounting that you are eligible due to the type of illness you have or the fact that you cannot tolerate medication - e.g. fibromyalgia - doesn't respond well to usual treatments and involves so many other systems of the body that a lot of the current people I deal with - discharge me from their care - pain clinic, physiotherapy - saying there's nothing we can do for you. GP shrugs shoulders - so would they even refer me?
5. The sheer exhaustion of the pain + exhaustion that would be the end result of travelling any distance to the place would mean recovery time would be few days before able to do any testing assessment.
6. Back to anxiety levels - for those of us who haunt slept away from home in over 20 yrs then there would be anxiety round not being able to sleep or not liking the food offered at meals etc. Would there be allowances made to provide medication for this purpose?
7. Would you be able to take hot water bottles etc - i have to use one throughout the day to ease pain.
8. Would you have to wait all day for there to be enough people to run the treatment course if it was Option 2?
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 - i.e. chronic fatigue sufferers - chronic movement, Tai Chi

Medication assessment

Other (please tell us in the comments box below)

Hydrotherapy sessions

Complimentary therapy treatments - holistic approach such as acupuncture, nutritionalists, allergy testing for foods substances that might be causing or exacerbating pain. Alexander Technique, Tai Chi for long-term pain sufferers - not the standard type of martial art Tai Chi. Qi gong. Hypnotherapy. Herbal or homeopathic prescribing. Prescribing of natural health supplements i.e. Melatonins - for sleep, 5HTP - for mood, pain, fatigue, sleep. Cannibis medicinal - for pain. Different psychological services than are available now. CBT doesn't work for everyone - but maybe a more pain specific tool to help improve our ways of coping mentally emotionally.

Self harm support - needs addressing that just now in GP or mental health. Mindfulness training. Follow on groups. Relaxation training. Creative expression to act as a distraction to pain. Counselling on the fact that there is no cure - so how to get to grips with accepting this is what your life is now and how best to self manage it.

It is hoped the local healthcare professionals would be brought up to speed on how to deal with long term chronic pain patients - as they only seem geared to acute pain treatments and people who can tolerate medication - anybody else with is turned away - this being physiotherapists, pain clinics, GPs, Mental Health Team.
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.
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?

N/A never been offered.
Don't believe I would ever get chance to get referred or offered a place as my GP didn't think it even worth referring me to local pain control clinic at the hospital due to me being unable to tolerate side effects of medication - I am on the lower minimum of pain relief just now that no way meets my requirements for pain relief but my GP doesn't want to offer stronger medication or medication for sleep as it may result in me getting addicted even although it is well documented in my notes that I do not abuse medication. After arguing he got a referral to pain clinic - I was then only seen for 2 apps than discharged saying they could offer me nothing. Is what now? Some with Mental Health issues can't tolerate other depressants. My GP has even said not to bother taking up the Chronic Pain service offered by pharmacy as she reckons it would lead to over-prescribing. So it is doubtful I would get referred as my conditions - fibromyalgia, chronic fatigue, post viral fatigue.

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.

Sorry for the state of the writing but it pains me to write, apologies if my answers aren't always relating to the question asked as I can go off on a tangent and not realise I'm not covering the question asked.

There definitely needs to be continuity of support locally once any intensive 2 week programme has been done - cause if the local healthcare crew are going to be up to speed you will default back to how you were without ongoing support. Local training is required especially for physios - as who only seem willing to treat acute cases. There needs to be acknowledgement that not everyone can tolerate medication that doesn't mean they should have the clear shut on them. GPs need to back up patients. When it comes to completing benefit forms - you have to pay for a supporting letter, just now and even then if nowhere tells the true extent of how your daily life is affected by pain - as they only see you for 8 mins at a visit. They don't realise the struggle and so may report that you can cope as with day to day activities - which ends up resulting in you losing your benefit. It is a bad enough having the Welfare system on your own with out a GP naming you may be able to work.

(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.)