

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 a carer... although i get no carers financial assistance, as my son awaits a DLA appeal which is taking several months, but have been caring for my son on a daily basis

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.

Although travel for the client can be an issue, i would hope a blend of a centre with outreach support would be possible, with the majority of cases seen at a centre would keep professional hours at a majority of working at a patient hands on level rather than a majority of hours used up by travel, a fully equipped medical specialist centre could also be a resource/training/awareness for gps & other consultants,a&e staff, nurses, the DLA!!! & offer related support groups, 24hr hotline, and professionals as i feel there is no support for the family of someone with chronic pain..... the culmative stress is immense,however it is ultimately immediate family that helps with the majority of the everyday issues. A specialised centre with dedicated specialist staff, could also offer thorough medical investigations/assessments, alternative therapies, relaxation, hydrotherapy pool, acupuncture,.... tailor made or mobility resources to try out.... (I have spent a fortune on comfort/mobility aids for my son as nothing had been offered to him.. ."nhs doesn't provide that any more")

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?

Travelling to another part of the country, would prohibit people from that resource, however i would take my son anywhere if it was to help, however cost and loss of my wages through time off would be a factor as he would need to be accompanied by me, but is a sacrifice id gladly make, rail/bus or patient ambulance would be an extremely painful option for my son, my car with comfort seating options by trial and error is his only method of transport or he would be housebound.

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.

Alternatives to addictive pain medications should be tried irrespective of cost as this would surely outweigh the long term cost,
Full medical assessment as a priority, has every option/investigation been done to diagnose the full cause of the pain, if not access to other regions to alleviate waiting lists and wait time for chronic pain sufferers, to minimise further complications & heightened pain issues,
Cost of local fitness gym resources with a carer if necessary, with medically advised tailor made gym programmes that are monitored, so speed up health and well being, & less of a drain on nhs resources, use of gym equipment classes pool, sauna, massage etc..... would also hopefully reduce costs of addictive pain medication, many of which cause adverse side effects that lead to other medical issues including mental health.....
most gyms are maintained to a high standard & i imagine are regulated in some way with certified personal trainers that would be on hand if there were immediate issues, but recommended training programmes could be set out by nhs specialised staff ie- physio/OT/orthopaedic??..... also local gyms are open for long hours and the client is more likely to do the exercise as they could do it on their low pain parts of the day, rather than missing physio appointments etc due to high pain

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.

We never knew it existed, referral to the ONLY pain specialist in highland was in march, a 5minute useless phone call in july, not physically seen by a pain specialist until September and still awaiting pain injections due in November!!!..... mean while my sons medication for pain increases as his body gets so used to it its ineffective, but been told from the initial referral,

“addictions to medications is a common issue”..... this scares us, why are non addictive drugs not tried???... surely much healthier and cost effective in the long run.

My sons case has had a lot of negative issues and poor & extremely slow support even after diagnosis, resulting in seeking private opinions/tests to speed up the process of diagnosing his condition which have proved invaluable, , however i am concerned that nhs consultants have taken umbridge to this as he still is on long waiting lists & i do feel 24hr chronic pain with severely reduced mobility should be treated as a priority.....

backlogged waiting lists are so long locally i feel he should be offered consultations elsewhere, as the slow process has had a detrimental affect to his pain, health & mobility causing the need for more specialists to be involved,

Unfortunately there is huge waiting lists that are backlogged & understaffing in nhs highland, a rapidly expanding area that does not seem to value financial input into healthcare.

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)

Specialised realistic tailor made assistance/advice with mobility/comfort aids, a resource list or resource lending place, somewhere to try out cushions & comfort /help/aids in particular, 2 small mobility shops locally have very little & limited items that they just want to SELL to you, help & tips with care at home/work/uni/college.... assistance with DLA/ carers allowance/benefits/finances..... as my son still does not receive DLA, he is currently awaiting a DLA appeal hearing which has taken months, advice/training for immediate family/carers as to how best they can help physically and emotionally with day to day living and care,

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?

Have never been offered, did not know such a facility existed

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 extremely disappointed at the slow referall time & investigation of my sons illness,... recognition of his pain by professionals has certainly been an issue to his detriment, this has been a huge strain on us all, I find the excuse of waiting lists, staffing & poor communication a cruel uncaring excuse,... also an alarmingly poor response/support from the local a&e/nhs 24 when attended for assistance on occassions even though told he was diagnosed with chronic pain..... possibly an area where specialised training/awareness/compassion is definitely required. The option of out of region referral ie the service at bath should be kept open as whatever funding is granted for a local resource might be limited, so lets not close the doors to options. We have researched the usefulness of an upright mri scanner & have had feedback from consultants/professionals that yes indeed it does give a totally different picture & useful information as opposed to horizontal mri's & could be of value in my sons so presumably in others also,... why are these not easily accessible in Scotland as in England?... surely the search for a cause/diagnosis/cure is more cost effective than lifelong pain treatment?... i strongly feel that there should not be blocks to investigating chronic pain & its causes, & patients should not

be written off with a “your stuck with it” attitude without reasonable thorough investigation as a matter of priority, & to be referred out of region if waiting lists locally are long, the 12 & 18 week waiting list guidelines are disgracefully long especially for people trying to live with chronic pain, as to be told your 20 year old son is written off to a life of “he may never work again”, “apply for DLA”, “try home management”... whatever that is?.. & to wait months for suitable pain relief due to waiting lists, is desperately heartbreaking to see him struggle courageously for a bit of normal quality of life every day, so yes a local collaborative specialist centre resource with outreach facilities will undoubtedly reduce waiting lists elsewhere on the NHS & will heighten awareness across the board and help people gain relieve from suffering a whole lot quicker,.... is that not what the NHS is meant to do?