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 x☐

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 x8☐
(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.

Cheaper as can up skill existing health providers in local locations so more access to the service.

It would be good to have a residential base which was the centre of excellence and then local outreaches which support what was learned at the centre for excellence or provide earlier intervention to help people who wouldn't be eligible for the centre for excellence

Would reduce waiting times and improve access

Can link into other local initiatives which support the programme offered by the pain clinicians e.g. arrangements with Glasgow Life over access to exercise, access to local community led services which support e.g. peer support, drop in for practice of e.g. meditation

Local services would help improve aftercare as there would be better connections between services which would support people maintain new behaviour changes etc.

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?

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.

Have a campaign to raise awareness of issues of pain and tips on self-management which could be displayed on screens in GP surgeries etc

Raise awareness of supports for chronic pain and how to access it, use a tier model as group accepted people have different degrees of chronic pain which has variations in how much it impacts on people's lives

Use Skype and other developments in IT to help improve access to specialists and consultants so don't always need to leave the house for treatment if pain is very bad

Telephone helpline for people suffering chronic pain

Improve access to complimentary therapies, people with chronic pain say reiki works, however, not part of NICE guidelines due to lack of evidence base, increase credibility of complimentary therapies, many third sector services could help increase access to this

Raise awareness of pain association and NHS information services

Improve access to hydrotherapy explore other ways this can be offered

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.

Cost of travel even when fare repaid how do you pay in first place

Fear of accessing the facility, what will happen, what will it be like, where is it, who are the people I would see, what are they going to do to me

Money is invested in this just now but what about in the future when more people may need it but there is less money to pay for it

Being too sore to travel to the facility, where is it, if going in a car how long would it take as sitting for long journeys could cause more pain

Don't know the service is there, depending on which health professional you see depends what you find out about what support is available

People facing multiple challenges and other commitments e.g. childcare, or, suffering a mental health problem e.g. anxiety in social situations, or, multiple health conditions multiple outpatient appointments having a conflict of appointments e.g. person waiting to get a residential place and then gets an appointment for another health appointment been also waiting for ages for which to attend

Anxiety about changes to other support and services person may worry if seen as more capable to manage pain then other supports maybe withdrawn

Waiting lists may be a barrier

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 7 votes ☐

Supported one to one sessions to teach coping skills 7 votes ☐

Group sessions 7 people agreed but one person felt groups where people have different experiences/duration of pain don't work as well as groups where everyone has similar experiences ☐

Residential accommodation 4 votes ☐

Opportunity for immediate carer/support provider to accompany patient 6 agreed however, was confusion people thought there was 24/7 nursing care didn't realise treatment was residential not inpatient ☐

Peer support 7 votes ☐

Tailored exercise programme 7 votes ☐

Medication assessment 7 votes ☐

Other (please tell us in the comments box below) ☐

Jacuzzi to use outside sessions Comfortable chairs with cushions and snuggle blankets for people to sit in Calm relaxing environment where people feel safe to try something new

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 x5 ☐ Nox2 ☐ Don't Know ☐

Question 8: Have you previously attended, or supported someone attending a residential service outside Scotland?

Yesx 1 ☐ (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.

They were finally diagnosed correctly and the proper treatment started as the facility they went to had experts in this area, the experience was really positive as finally someone got to the bottom of what was wrong and helped get the right treatment started

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 however, there was discussion about the anxiety someone may have not only attending a new service but actually moving to another area for some people their comfort zone for travel can be quite a small area due to anxiety and other underlying health and social issues

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.

A virtual tour of what to expect at the residential facility would help allay anxieties e.g. show surrounding area, have staff introduce themselves explain their role, demonstrate what is offered so people know what to expect maybe even have people who have used the facility share the

difference it made for them

Could there be residential facilities in communities where e.g. a house is used to run a programme so people can live there and get support

Even though people use services due to their health complaint there can still be white coat syndrome which means accessing a service in itself can cause anxiety, for this and for other services recognise the impact anxiety can have on people hearing what is being said (when people are anxious their mind can often be so overflowing with worries that people say yes they understand and get that but in reality they just want out of the situation, or they don't understand what was suggested but lack the confidence to ask it be explained, or person doesn't hear what is said as either it is something which is scary so its blocked out or they are preoccupied so their awareness of their surrounding and learning opportunities are affected, or the person doubts their ability to adopt e.g. a new behaviour

Have evidence of feedback to specialist, often see specialist they refer you onto someone else, does that person feedback to specialist do they know about on-going care what works what doesn't

Encourage GP's to get involved with ALISS and Links so they know what alternatives there are to painkillers so this isn't first option, yes tablets maybe needed but there should be more than take these tablets this is the way it is nothing else can be done, people need hope

Some people have no support, friends or family and this can make pain worse being lonely can increase pain, people need supported to still have a dream and a life

Raise awareness of diagnosing conditions so people get the right treatment they need sooner