

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) x

I'm responding on behalf of the Scottish Independent Advocacy Alliance

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.

We don't have a preference

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?

n/a

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 feel that people experiencing chronic pain should have access to individual and collective independent advocacy. Independent advocacy can

help people access information, understand their options and make fully informed decisions, on an individual basis. On a collective level, groups of people experiencing chronic pain could get together to lobby and campaign around issues that are relevant to them at a local and national level. When people are experiencing chronic pain they may not be in a position to discuss and negotiate their care and treatment, an advocate would help them to communicate their needs and help them secure the services they require.

Many people who seek Independent Advocacy support do so because they believe they have no control over their lives, often they feel that their lives and circumstances are incomprehensible and unmanageable. Their options have been severely limited, they feel they have no choice over things even as fundamental as where, how or with whom they live.

The process of advocacy aims to restore control, supporting that person to consider their situation and possible options, helping to make sense of their world. Advocacy also will help them to speak up or speak up on their behalf, ensuring that their voice is heard and so gaining, or regaining, control over their own lives and circumstances. Gaining such control will contribute to lower stress levels which can lead to improved health.

Today's society tends to focus on problems, needs and deficiencies.

Services are often designed to fill gaps and fix problems. People become passive recipients of services; things are done to them rather than with them. They are disempowered by the very systems that are in place to support them.

The medical model of disability is seen by many as still prevalent today. It impacts on attitudes towards people who have disabilities, defining people in terms of illness or medical condition. This model promotes a view of someone with a disability as needing to be cured and/or cared for leaving control firmly in the hands of professionals. Choices for the individual may then be limited to the options provided and approved by those professionals.

In supporting individuals to consider their situation and find out about options and possible courses of action advocacy supports people to make informed choices while considering the possible outcomes of those choices.

Advocates work to ensure that the person's wishes and views are heard and taken fully into account either by supporting them to speak up or by speaking up on their behalf. Advocacy aims to empower those they work with, ensure that they are as fully involved as possible in any decisions made about them and help them take control over their lives and circumstances.

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.

n/a

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)

n/a

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 x

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.

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