

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 X
- 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 individual who has experienced chronic pain for over 25 years since initially diagnosed with a long-term, chronic and incurable condition and I have since developed multiple conditions that have been complex to treat. I also have experience of caring for family members with severe pain issues due to chronic medical conditions. I was 6 weeks old when my Dad was diagnosed with a serious long-term condition that meant he suffered from severe pain, so I am aware of what it is like to grow up and live and support others with chronic pain issues. I am also a former health professional.

I am also a member of the organisation the Friend's of the Homoeopathic Hospital, a group & charity that supports the work of the NHS Centre of Integrative Care and the patient's, many of whom have pain issues and currently depend on the hospital to assist in their treatment & management of their condition.

Question 2: Please choose your preferred option (Chapter 2 provides details).

- Option 1 – a centre of excellence in a single location X
- 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.

A specialist service has been used successfully in Bath in Somerset and also in Wales to help treat people in other parts of the UK who experience chronic pain issues and require treatment.

A similar service and model of care to provide care for people living in Scotland is required to be developed that better meets the needs of the population and also prevents the need to travel long journey's to the South of England. This will also reduce the need for patient's to provide substantial upfront funds for travel costs to be able to access care.

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 & 3 are currently untested in delivering an appropriate model and level of service that will adequately support people with chronic pain issues. Scotland is a large country and has remote and rural areas that can make travelling and access to health facilities difficult. It is important to be innovative and try to find other ways that may assist in providing appropriate care. However a Specialist Centre is required initially as this would provide a hub where in the future other pioneering and innovative ways of reaching patients and treating them can be piloted in the development of improved services, this could be a hub for research that helps to improve future care.

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.

Specialist nurses in the management of chronic conditions have been invaluable in improving care and access to health facilities. A network of specialist pain management nurses would be invaluable in the management of improving care and supporting a specialist residential pain service.

Also other medical professionals such as physiotherapists require the need for specialist training in helping people to manage & deal with chronic pain.

Charities like the Pain Association who deliver group sessions and support require improved funding and support to provide more facilities in the community for people to attend before or following discharge from any specialist service. Also individual medical charities for people with long-term chronic conditions and illness whose members have pain issues require more support and funding to improve the information, care and support to their members who have to deal with pain issues.

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.

There are many barriers that can affect people accessing medical services including the location of the service and ease and cost of access by public transport. Costs and fares are better paid upfront so that if patients do not have enough funds to wait until these are reimbursed or else travel tickets can be provided in advance. Also the ability to have the option of an overnight stay if a person's medical condition means it is difficult for them to travel in the same day & have round trip home to access treatment. If a person sees multiple specialists in relation to their condition it is preferable if they can access them at the same time in the same hospital or clinic to save on multiple visits and allow a multi-disciplinary team approach to care.

The prior commitments of the patient can affect the ability to agree to access treatment offered whether that is caring commitments for children or older members of the family such as grand-parents or parents. Provision of appropriate respite and support is needed in these cases & identification of needs. People who are working also need an appropriate explanation that they can provide their employers so they know that treatment is necessary and will improve their employees' health condition and improve their ability to work efficiently.

Distance from friends and family can be an issue when accessing in-patient treatment so provision of facilities that assist people to keep in touch with family members & friends who provide support. Also the ability to have access to facilities where they can possibly stay nearby & visit or also take part in treatment support sessions & group work sessions or also allow access to a phone taking in-coming call and also a computer to allow email or skype contact with family and friends who are further away.

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 | X <input type="checkbox"/> |
| Supported one to one sessions to teach coping skills | X <input type="checkbox"/> |
| Group sessions | X <input type="checkbox"/> |
| Residential accommodation | X <input type="checkbox"/> |
| Opportunity for immediate carer/support provider to accompany patient | X <input type="checkbox"/> |
| Peer support | X <input type="checkbox"/> |
| Tailored exercise programme | X <input type="checkbox"/> |
| Medication assessment | X <input type="checkbox"/> |
| Other (please tell us in the comments box below) | X <input type="checkbox"/> |

Access to a variety of holistic and complementary care approaches is also important to provide people with a wide variety of tools to help them to self-manage their condition and to cope with their pain is essential in any model and service that help people in managing and treating their pain needs effectively. It is important it is not just a bio-medical model that is provided but that it also encompasses and utilises a wide variety of holistic care approaches.

I have personally found a variety of approaches important in helping me to deal with pain, to help with stress reduction and best manage my condition. Treatments such as acupuncture, massage, Indian head massage, aromatherapy, reflexology, cranial-sacral therapy, acupressure, electro-acupuncture, electro-stimulation therapy and chiropractic care, along with pacing, meditation and bio-feedback have all been useful in the management and treatment of my pain and underlying medical conditions. Had I not been initially referred to the NHS CofIC then I would not have had access to their treatment methods and the approaches that they have helped me to explore and develop to help me better manage my condition.

I have personally found the residential treatment at the NHS CofIC particularly useful in the treatment of my condition and I have had several residential day patient and in-patient admissions in the past when my health has required specialist hospital input. Also the ability to have access to peer support is also essential and valuable in this model of care.

I believe that any Scottish Model of care for a Specialist Pain Service should allow access to a similar model of care and illness and chronic disease treatment & management developed by the NHS CofIC providing individualised patient focused care with full multi-disciplinary team support and working in partnership, allowing access to peer support and also providing support to family members and carers.

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.

National funding is required for any service that may be provided wherever it may be located. A Pain Service is a true specialist, tertiary service providing a Scotland wide care and support. It is therefore important that centralised ring-fenced national funding is provided, as if one single Health Board Area is responsible for the management of the Service it may then affect care and access to the Service and any Centre in the future, depending on their own personal priorities. Services for chronic conditions often miss out on funding to acute service provision.

This is due to the experience & current situation with the access & care at the NHS Centre of Integrative Care (NHS CofIC) at the Glasgow Homoeopathic Hospital where several Health Boards have refused to allow referral to the NHS CofIC (the patient's attend the unit and the host Board cross-charge the referring Health Board). This has set up a post-code lottery for people living throughout Scotland depending on what Health Board area they live, and people are being denied care they have once relied on or wish now to be referred to.

It is important to take heed of what has been experienced by the NHS Centre of Integrative Care as now that several Health Board areas have denied access to their patient's to the hospital this has meant that numbers being referred to the unit have reduced. This has caused the Chief Executive of the Board responsible for the hospital to say that this has put care and continuation of services at the hospital in jeopardy. The only way to prevent this happening the future to other tertiary services and to give any service full autonomy then National, ring-fenced funding is required and I believe the best way to fund the Scottish Specialist Pain Service is by national funding.

The NHS CofIC would provide a suitable location of any pain service, so long as any service is fully integrated with current provision and care at the hospital and that the patients who currently use the service will continue to gain access to all facilities and also be able to access the input & care of the Specialist Scottish Pain Service. There is room at the NHS CofIC site for

expansion. There was always plans to develop further phases on the current hospital site including plans for a teaching & education centre and hydrotherapy pool. The hospital currently has the necessary multi-disciplinary approach to support care and rooms for group work facilities. Access to hotel beds if required are available at the nearby Pond Hotel. The hospital has good transport facilities and is accessible by car, bus and train, accessibility has been improved to the station for those who are disabled by recently installing a lift.

As I have attended the NHS Centre of Integrative Care at the Glasgow Homoeopathic Hospital for over 20 years I found that access to a variety of holistic and complementary approaches to care integrated in a unit that combines the bio-medical approach in unison with an integrative care model is important in the treatment and self-management of my condition. I have received this care as a residential in-patient, an out-patient and as a participant on the WEL (Well-being Enhanced Learning) Programme, an illness and chronic disease self-management course delivered at the hospital.

These approaches have helped me to better cope with my condition, which although at present with current medical understanding is currently incurable, this care helps me to improve the understanding & self-management of my condition. This enables me to be involved & employ a variety of approaches to assist the long-term management of my condition. It is a partnership approach to care where the multi-disciplinary team professionals along with the person and their family and carers are involved in the provision and management of the care methods utilised.

The staff at the NHS Centre of Integrative Care are extremely experienced in dealing with the care & management of people and their family members & carers with a variety of illness and long-term, chronic and degenerative life-long and life-limiting conditions. They are able to employ many tools to help in the management of a variety of conditions not just orthodox conventional treatments but also utilise various holistic approaches. At present they use low cost and no cost interventions to help improve the quality of life providing individualised patient-centred and focused care. They also already have substantial experience of treating individuals with chronic pain and the management of conditions where severe pain is an issue. Many patients have been referred to the hospital in the past due to having a medical condition where pain is an issue that they required medical input and support.

At present this approach employed by the NHS CofIC is mainly offered to people with a variety of complex conditions many of whom have been failed by conventional treatment & care. However the methods employed by the NHS CofIC has the potential to help even more people with a variety of illness & long-term chronic conditions if only they knew of its existence and those professionals caring for them were willing for them to be referred for treatment. There is scope for this model to be expanded to other areas and to allow ease of access to the many hundreds of thousands with long-term

conditions and chronic issues.

There is a need for a network of appropriately trained specialist pain management nurses both in the community and based in the local hospital and in the specialist residential pain centre. These nurses can identify and refer patients and also help assist in the management of patient's to help spread and reduce the workload. They can also help with access to services.

I used to work and live in Somerset and have travelled from Scotland on many occasions by car, train and coach. I have also been in hospital in Somerset requiring acute emergency care and this was a very difficult time as I was separated from family and friends and it is a difficult journey to also expect family members to undertake from Scotland and for me to make to try to return to Scotland recuperate. I believe that this is an unacceptably long journey to expect people in severe chronic pain to undertake, and also to ask family members to travel, as well as the costs that will be incurred. (My family lived in a shared cottage for family members in the grounds of the hospital).

A model of more appropriate care for Scotland is urgently required to be developed that better meets the population needs of Scotland and the estimated 800,000 sufferers who experience chronic pain. A Specialist Unit and 'centre of excellence' is the best way to provide this model that can be developed to then inform and provide relevant more local support, training, education and service provision that will better treat and manage the care of those affected by chronic pain issues. Other services can then be developed and piloted as necessary to assist with the provision and the development and further services with the aim to provide a gold standard model care.