About the ALLIANCE

The ALLIANCE’s vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

Introduction

Chronic pain is a long term condition in its own right, as well as being associated with many other long term conditions. Healthcare Improvement Scotland (HIS)\(^1\) describe chronic pain as “continuous, long-term pain lasting more than 12 weeks or pain persisting after the time that healing would have been expected to occur after trauma or injury.” The recent Scottish Intercollegiate Guidelines Network (SIGN) draft guidelines points to evidence that as many as 18% of the population may be affected by moderate to severe pain at some point in their lives.

The ALLIANCE welcomes the Scottish Government’s consultation paper on a specialist intensive chronic pain service and the Government’s ongoing efforts to

improve chronic pain services across Scotland. A specialist intensive service is part of a wider suite of services to support people who experience chronic pain across Scotland and efforts placed on specialist services should consider how they can have an impact on the provision of local services.

The ALLIANCE is concerned that Healthcare Improvement Scotland\(^2\) report that “pain is not consistently managed across the whole health and social care system at present… In some areas, there is a well-defined chronic pain service that can specify funding and staffing for chronic pain. In other boards, staffing and resources are shared across services that support a range of conditions.”

The ALLIANCE would express particular concern about the disparity in the range of services and resources to tackle chronic pain available in different parts of Scotland. We are concerned that this has had the knock on effect of creating a significant variability of provision across Scotland which may have a negative impact in ensuring the best possible treatment for chronic pain in each area.

The ALLIANCE would encourage the Scottish Government to consider a role for national co-ordinator to ensure patient choice is respected within chronic pain services. The ALLIANCE believes that such a national post would allow for a co-ordinated voice for people who use chronic pain support and services, as well as the third sector. Such a resource could potentially be housed, and provided by, the ALLIANCE.

**Consultation Questions**

**Q1: We would like to know in what context you are responding.**

The ALLIANCE is responding as an organisation that represents people who experience chronic pain. In drawing together our response we consulted widely with our members and other stakeholders through chronic pain networking events attended by the Scottish Government in Glasgow (23 August 2013), Inverness (21 October 2013), Dumfries (23 October 2013) and Glenrothes (24 October 2013). Notes of these meetings can be found as appendices to this response.

**Q2: Please choose your preferred option (Chapter 2 provides details).**

Option 1 – a centre of excellence in a single location would be our preferred option, however the Scottish Government should consider the benefits of adopting aspects of all three approaches. Our consultation sessions have highlighted that there was a clear preference for a single, residential centre of excellence, but while a residential

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\(^2\) The ALLIANCE is a company limited by guarantee. Registered in Scotland No.307731 Charity number SC037475.
service in Scotland would be of great value, there needs to be a particular emphasis placed on improving local support mechanisms. The creation of a centre of excellence should allow for outreach and telehealth options as well as a particular focus on improving practice in local areas.

An easily accessible location for any specialist service will be critical. If a centre of excellence is created, this would need to be located close to good transport links and easily accessible to most of the population. Delegates at various events suggested that Glasgow, Dundee or Perth would be good options.

It was also expressed clearly that whichever option was chosen, people who experience chronic pain did not want chronic pain services to be a “top down” approach from the Scottish Government. People who experience chronic pain should be involved in the decision making process at all stages.

To support this development, the ALLIANCE believes that people who experience chronic pain would benefit from the creation of a national co-ordinator post, whose role is to ensure that patient choice is respected. It is clear that such a role is needed on a local and a national scale to support patients to raise concerns, influence service design, campaign, network and provide mutual support. Such a role could be housed within the ALLIANCE.

Q3: Are there any of the options you disagree with?

The ALLIANCE would question the financial viability of Option 3 – a service delivered in different locations by an outreach or roving service, as transporting a team of specialists across the country on a regular basis may be costly.

Q5: 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.)

At present, people who require specialist intensive treatment for chronic pain access this through the Royal National Hospital for Rheumatic Diseases in Bath, Somerset. The ALLIANCE is concerned that this level of travel may further exacerbate the impact of chronic pain for people travelling across the country and welcome’s the Scottish Government’s commitment to providing a local solution for people who use this service.

Individuals accessing the service currently cover the upfront costs of travel and then receive this back in arrears from their local health board (however, there are different arrangements depending on the health board area in which you live). People who are
disabled and/or living with long term conditions are already far more likely to be living in poverty, experiencing debt and be unemployed or in low paid, less secure employment. As such, they are likely to be put off from attending such a service and during consultation sessions we were given anecdotal evidence that this was stopping some people from attending the service in Bath. The ALLIANCE believes that the Scottish Government should consider working with third sector organisations to find a solution to this issue.

**Q6: Please choose from the list below which aspects of residential pain management services should be included in a Scottish service.**

- Peer support
- Group sessions

Group sessions, and peer support in particular, play a critical role in supporting people to understand how to manage their chronic pain effectively. Delegates at our events said that this kind of support was best when provided through peer support, on a generic basis to people experiencing pain, rather than focusing on individual long term conditions.

- Residential accommodation
- Opportunity for immediate carer/support provider to accompany the patient

The option for family carers to be involved in assisting them to participate in the programme is critical to ensuring that ongoing support and understanding the impact of chronic pain on the individual's everyday life and the support they have from a carer. It is important to many people that their carer understands how best to manage the pain, alongside the individual.

Other aspects a residential pain management service should include:

- A focus on supporting self management

Self management is a critical element of taking a holistic approach to the treatment of, and management of, chronic pain. Any intensive chronic pain service must be focussed on giving self management tips and advice for the longer term use of people who experience chronic pain and their families.

- Training for clinicians
- Telehealth options
- Links with universities and innovations in the treatment of chronic pain
The creation of a national co-ordinator post to ensure that patient choice is respected. It is clear that such a role is needed on a local and a national scale to support patients to raise concerns, influence service design, campaign, network and provide mutual support. Such a role could be housed within the ALLIANCE.

The ALLIANCE

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has nearly 400 members including large, national support providers as well as small, local volunteer-led groups and people who are disabled, living with long term conditions or providing unpaid care. Many NHS Boards are associate members and many health and social care professionals are Professional Associates. Commercial organisations may also become Corporate Associates.

For more information

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Appendix 1

Health and Social Care Alliance Scotland
Notes of chronic pain networking event, Glasgow, 23 August 2013

At present, people who live in Scotland, but who require a specialist, intensive chronic pain service, travel to Bath in South West England to receive a programme of care from the Royal Hospital for Rheumatic Diseases.

During a Scottish Parliament debate on chronic pain services, the Cabinet Secretary for Health and Wellbeing, Alex Neil MSP, committed to holding a consultation with stakeholders to find out the best way of introducing a specialist service in Scotland.

On 23 August 2013, the ALLIANCE hosted a networking meeting for people who experience chronic pain and other stakeholders in order to help clarify views on the development of such a service. The aim of the event was to discuss the Scottish Government’s consultation on a specialist intensive chronic pain management service.

Key points from the discussion

On the whole, participants felt that there were merits across the various options present in the consultation paper. However, all participants saw Option 1 as a starting point with other ideas being added in.

Delegates felt that this should encompass the following key elements:

- A residential option to avoid travel to Bath for those who wished it
- The option for family carers to be involved in assisting them to participate in the programme
- A central belt location, with good accessibility. This could potentially happen in an existing premises
- A greater emphasis on telehealthcare
- An emphasis on links with local services and improving knowledge of chronic pain across the country
- Ring-fenced funding

Any new specialist service should consider domiciliary care approaches as well as residential. Delegates were keen to stress that self management and coping

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mechanisms “for when you come home” are an important part of managing and taking control of chronic pain.

More should be done to support self-management groups and encourage education. A strong collective voice that meets individual’s needs at a national and a local level is required. This could potentially be met by access to independent advocacy.

Accommodation group work therapy is something that already happens across Scotland, but needs to be built on. Delegates suggested that this could be the next stage of the Scottish Government’s thinking in this area.

It was also expressed clearly that people did not want this to be a “top down” approach. People who experience chronic pain should be involved in the decision making process at all stages.

Notes from participants

What should the service be?

- There should be an option 4 – aspects of all options. 1, 2 & 3 are required to improve the service.
- All 3 options are required in order to provide the services that is needed
- Southern General is being rebuilt. Why not build a specialist residential centre for chronic pain
- We need a residential centre but also need improvement in local services
- Consensus – option 1 – need a specialist residential centre Scotland.
- Option 1 plus outreach
- One centre, residential where required

Where should it be?

Delegates expressed a range of views, including:

- Must be in the most easily accessible place to most of the population, e.g. Perth
- Jubilee Hospital? Unit could be built there and they have accommodation already
- Homeopathic unit in Gartnavel Hospital – could that be used
- Location of residential building should be in the central belt due to easy access, excellent physician skills
- Additional place to have a meeting would be at NHS Centre of Integrative Care at the Glasgow Homeopathic Hospital as majority of patients with long term chronic pain issues
• If it is to be located at the NHS Centre of Integrative Care then it needs to be fully integrated service i.e. not two separate teams of staff.
• NHS Centre of Integrative Care has all facilities needed already in place – OT, physiotherapy, group work rooms and room for expansion. Phase 2 was to include hydrotherapy unit. Pond Hotel for additional rooms.
• Central location with peripatetic service hand in hand.
• Residential option central belt. Former premises. Family accommodation and Centre of Excellence, telehealth is an important tool for Self Management. Video conferencing. Make it attractive to professionals. University links. Option 1 is the only viable option
• Rural and urban may need more outreach/transport etc

How it should be delivered

• Centre of excellence
• Any service dealing with pain should be fully holistic – not medicalised.
• Take in grassroots learning and requirements and valuable learning. Pre-education is required for all healthcare professionals and doctors. Holistic review.
• Patients input required at level 3
• It should start bottom up (from the patient) to the top level (Doctor). Not from the top people down to the people with chronic pain
• Patients must be brought in to discussions right from day 1 and through all meetings as it all starts from us on pain problems. It’s up to us patients to get this up/running successfully
• Living with chronic pain requires initial assessment/ongoing treatment as required. “Patient” may not be healed
• Chronic pain is neglected and needs a holistic approach – specifically to education
• Guaranteed ring fenced funding
• Who is going to be in overall charge? It needs to operate without area influence. Its own finance.
• Train medical students in the discipline of chronic pain. Need full time dedicated pain specialists
• Regular reviews because people develop other chronic illnesses
• Possible role for national co-ordinator to ensure patient choice is respected
• Better to upskill local services
• Services should be tailored to the needs of the individual
• Early diagnosis, self-help and support groups
• Peer Support. Reviews in Medication. Review Patients. Getting the right people from a range of specialisms
• As a service user I find being with other service users is less lonely than being with professionals
• Being with people who understand you helps
• Access to complementary therapies as well as research based integrative care

Future consultation events

• Potential meeting places:
  o Aberdeen/Inverness (North)
  o Stirling (Central)
  o Fife (East Coast) or Edinburgh
  o Dumfries and Galloway (Borders)

Advocacy

• Individual advocacy is needed on a local and wider scale
• Independent advocacy
• Advocacy. Local people designing services
• Collective advocacy – so that people can get together to influence service design and delivery, campaign, network and provide mutual support
• Access to independent advocacy for everyone with chronic pain
• Local people should be involved in the design and delivery of services
• Specialist advocacy in the model of a national co-ordinator role to ensure the patient voice is respected

Other issues raised by delegates

• Better to have local pain clinics and immediate access. We have hundreds of members who can’t get access
• People don’t know how to be referred to pain services and GPs don’t either
• The service for integrated health is available at the Homeopathic Hospital which is being under used because of a lack of knowledge
• “People self support groups” are up and running in Paisley and Drumchapel. More are required around Scotland
• More groups other locations need information to send out about meetings, discussions at Parliament etc.
• GPs lack education about chronic pain and don’t know where to send sufferers
• Concern about time it is taking and about what happens in the interim – i.e. a lack of services, ongoing treatment, education of specialists, information, holistic approach, need specialist medical input
• Who will refer folk to this service?
• Should the service model be renamed to patient model?
• How is phantom pain going to be treated (for service personnel i.e. army)
• Patients have a habit of underplaying their pain. Saying three instead of six or more.
• Does each health board have a clinician in pain?
• How are patients assessed to reach referral levels?
• Widen the scope of illness model. Community Health Partnership inviting patients to input
• Chronic Pain Symposium - podcast it to the wider community
• Is there a clear definition of chronic pain?
• Properly funded ongoing self help groups
Appendix 2

Health and Social Care Alliance Scotland
Notes of chronic pain networking event, Spectrum Centre, Inverness, 21 October 2013

At present, people who live in Scotland, but who require a specialist, intensive chronic pain service, travel to Bath in South West England to receive a programme of care from the Royal Hospital for Rheumatic Diseases.

During a Scottish Parliament debate on chronic pain services, the Cabinet Secretary for Health and Wellbeing, Alex Neil MSP, committed to holding a consultation with stakeholders to find out the best way of introducing a specialist service in Scotland.

In October 2013, the ALLIANCE held a series of networking meetings for people who experience chronic pain and other stakeholders in order to help clarify views on the development of such a service. The aim of the event was to discuss the Scottish Government’s consultation on a specialist intensive chronic pain management service.

Throughout the consultation period, which ran from 2 September 2013 to 27 October 2013, each of these events were promoted and marketed by both the ALLIANCE and the Scottish Government. For example:

- Circulated to the Scottish Government’s distribution list which includes all MSPs, all health boards, all local authorities and a range of stakeholder groups and individuals
- Through the ALLIANCE’s network of 400 members across Scotland via the ALLIANCE’s website, weekly members bulletin and targeted emails to nominated contacts and policy officers
- The membership of the Scottish Parliament’s Cross Party Group on chronic pain
- To local members of Pain Concern and the Pain Association Scotland
- To individuals who had been in attendance at a previous networking event in Glasgow on 23 August 2013
- The events were also promoted on the consultation page on the Scottish Government’s website
- Promoted through ALLIANCE social networks
- In Voluntary Action Scotland and Voluntary Health Scotland members bulletins
- An ALLIANCE press release was sent to local news outlets

http://scottish.parliament.uk/parliamentarybusiness/28862.aspx?r=8176

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Key points from the discussion

- There are very few people in the Highland area who will currently be travelling to Bath. However, it is much easier for people to get to Glasgow than to Inverness. This could mean an extra overnight stay for people who experience chronic pain.
- If a single service is set up, from a Highland perspective it is almost immaterial where this is located as people will almost always have to travel anyway.
- Transport links will need to be good for a specialist centre to be truly patient focused.
- An element of choice should be available for people to make up their own minds about what is best for them. This should allow for a very local service but also for the option to travel. Cross boundary flow between boards will be necessary.

- Travelling from Inverness can be very expensive and the process, where an individual pays the cost and then claims it back could be a barrier to people accessing the service, whether that is in Scotland or further afield. It is important that people understand how they claim this money back.

- There is some concern, particularly where courses are provided in local areas, that you might be known to others on courses. Some people will turn down courses if they are concerned they might know others attending the course.
- Some people are happier to travel to different areas to attend courses where they won't be known. However, this is different to travelling to one national, specialist centre - the benefits of this might be lost.

- People shouldn't have to travel to assessments. Reduce the amount of travel for people as far as possible as this can exacerbate the pain they experience.
- Delegates felt that a mix of the options may be best. For example, the assessment of whether someone needs to attend a specialist centre should still happen at a local level but then refer people on to a specialist residential centre.

- Some people were unaware of the Bath centre. There was some concern expressed that GPs and consultants were not making people aware that this was an option for people who experience the most intense chronic pain. Some delegates felt that Level 1 and Level 2 were not currently being offered to people and so Level 3 was unlikely to be.
- GPs are often dismiss chronic pain as being part of another condition e.g. MS and only treat the underlying condition. As a result the chronic pain element does not get adequate treatment. GP require more knowledge of the options.
- Improving Levels 1 and 2 could diminish the number of people needing to use the Level 3 service.
• However, it is difficult to make a decision between these options without the costs of each services - and the implications of this - outlined in the consultation paper

• Lots of people only get access to Level 1 support by self referring to voluntary organisations such as Arthritis Care or the Pain Association

• Peer support plays a vital role in this. Self management courses have worked in Highlands and Islands when they are run by people who have long term conditions. This provides a different style of learning and people don't feel they are being talked down to

• Courses are often better with a mixture of different people - not condition specific

• People experiencing chronic pain spend more time in their community pharmacies than in GPs practices and pharmacies are an untapped resource for supporting people who experience chronic pain

• More should be done to support the promotion of self management in community pharmacies. Campaigns should be backed by education and training for pharmacists

• Option 3 outlined in the consultation paper seems a little unrealistic when you consider the numbers of people using the service.

• The expense of sending a team of specialists across Scotland would be huge in comparison to bringing people to specialists

• It's possible that only a specialist centre could offer all of the following due to economies of scale. They may not be viable in any other model:
  
  o Support for local services
  o Education
  o Training
  o Links to universities and innovative approaches
  o Industry
  o Appropriate accommodation

• The Rheumatology Clinic in Dingwall has been offering support similar to what is being proposed for around 20 years. This is not about being "done to" but learning and supporting self management. More about education and not treatment
Health and Social Care Alliance Scotland
Notes of chronic pain networking event, Cairndale Hotel, Dumfries, 23 October 2013

At present, people who live in Scotland, but who require a specialist, intensive chronic pain service, travel to Bath in South West England to receive a programme of care from the Royal Hospital for Rheumatic Diseases.

During a Scottish Parliament debate on chronic pain services\(^5\), the Cabinet Secretary for Health and Wellbeing, Alex Neil MSP, committed to holding a consultation with stakeholders to find out the best way of introducing a specialist service in Scotland.

In October 2013, the ALLIANCE held a series of networking meetings for people who experience chronic pain and other stakeholders in order to help clarify views on the development of such a service. The aim of the event was to discuss the Scottish Government’s consultation on a specialist intensive chronic pain management service.

Throughout the consultation period, which ran from 2 September 2013 to 27 October 2013, each of these events were promoted and marketed by both the ALLIANCE and the Scottish Government. For example:

- Circulated to the Scottish Government’s distribution list which includes all MSPs, all health boards, all local authorities and a range of stakeholder groups and individuals
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- The membership of the Scottish Parliament’s Cross Party Group on chronic pain
- To local members of Pain Concern and the Pain Association Scotland
- To individuals who had been in attendance at a previous networking event in Glasgow on 23 August 2013
- The events were also promoted on the consultation page on the Scottish Government’s website.
- Promoted through ALLIANCE social networks
- In Voluntary Action Scotland and Voluntary Health Scotland members bulletins

Key points from the discussion

- There was general support for either option one or two. Delegates saw the benefits of having a national specialist service for chronic pain.

- A single centre would need to be located as closely as possible to the best transport links in Scotland
- "It's not where we put the service, it is how we get people to the service"
- Would need to accommodate people flying in from the Islands as well as having good transport links. The Glasgow area could be ideal for this.
- There would still be a significant amount of travel for some people no matter where you have the centre
- If it is established within a pre-existing health environment, parking can be very difficult. This may mean that people need to walk further than is possible.
- Proper disability access is required

- A patient delegate told the group that they never travelled more than around 14 miles at any one time and thus travelling to Glasgow or Edinburgh would be out of the question and could even make travelling with their own Board area problematic. Travelling presents a major barrier for people who experience chronic pain as it can be physically too much for some people
- Access is paramount and a well thought out transport service is required. Community transport options could be built into this development

- A specialist centre could highlight and lead to support for a significant level of unmet need across Scotland.
- However, there is no pre-existing data on the number of people turning down the service in Bath

- After support is a critical element. How can we provide the support mechanism in an individual's own local area after they have left the specialist service?
- Patients are the experts on their own long term condition

- Local support should have a telehealth link to a specialist centre
- Close relationships should be developed between immediate, local professionals and specialists in any national service. Access to expert resource would be very helpful to local clinicians
- If it is too much of a barrier for people to attend then a flexible telehealth facility - with Skype communication options - will be very important to people

- The service should allow for a family member/ carer to accompany and stay with the patient during the programme where the patient chooses this.
It's helpful if your immediate carer understands the support you've received
The learning process is not just for the person who experiences pain but also for the carer and it can be difficult to explain if the carer is not there.
Professionals need to see how the individual goes about their normal daily life - how they do things and interact with their carer, to understand the impact of chronic pain on their life.
Reintegrating back into home life with the carer is much easier if the carer is involved in the whole process and it would be useful to encourage support for carers.

Wales has its own specialist service - which Scotland could learn a lot from. The service provides residential support but also acts as a hub for outreach services throughout Wales.

A new specialist service would need to have a focus on self management.
This is not included in the list of services on Page 16 of the consultation document but it is very important.
We should be clear that specialist services are not about a "cure" - more about coping strategies and help to live with chronic pain - and GPs need more education about this – as this is often not explained to the patient until very late in their care journey.
A specialist treatment should set self management in place - and it should be a one off - people should not be referred on numerous occasions.

It's good to share your experiences with people who experience chronic pain - though not necessarily because they have the same condition. The difficulty is when you are on your own and some people don't understand.
Many people feel isolated so getting together with people who experience chronic pain can be a good source of support.
Should encourage social networking between people using a service when they leave. Can be a good source of peer support – the service could include links to secure social networks through a dedicated web site.

The Centre for Integrative Care can provide the time to spend with a GP and discuss the holistic issues affecting someone's chronic pain.
We need to take a more social approach (and a less biological approach) to the treatment of chronic pain in the future.
Appendix 4

Health and Social Care Alliance Scotland
Notes of chronic pain networking event, Rothes Halls, Kingdom Centre, Glenrothes, 24 October 2013

At present, people who live in Scotland, but who require a specialist, intensive chronic pain service, travel to Bath in South West England to receive a programme of care from the Royal Hospital for Rheumatic Diseases.

During a Scottish Parliament debate on chronic pain services⁶, the Cabinet Secretary for Health and Wellbeing, Alex Neil MSP, committed to holding a consultation with stakeholders to find out the best way of introducing a specialist service in Scotland.

In October 2013, the ALLIANCE held a series of networking meetings for people who experience chronic pain and other stakeholders in order to help clarify views on the development of such a service. The aim of the event was to discuss the Scottish Government’s consultation on a specialist intensive chronic pain management service.

Throughout the consultation period, which ran from 2 September 2013 to 27 October 2013, each of these events were promoted and marketed by both the ALLIANCE and the Scottish Government. For example:

- Circulation to the Scottish Government’s consultation distribution list which includes all MSPs, health boards, local authorities and a range of stakeholder groups and individuals
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- The events were also promoted on the consultation page on the Scottish Government’s website.
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⁶ http://scottish.parliament.uk/parliamentarybusiness/28862.aspx?r=8176

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Key points from the discussion

- Most delegates advocated the adoption of a mixture of the options (with a particular emphasis placed on Options 1 and 2)
- A specialist service would be best placed in somewhere with good transport options. Delegates felt that Perth, Stirling and Dundee were good options
- Accommodation must be available over the weekend, not just between Monday and Friday
- Travel should be included no matter of the individual's income. Clear guidance should be available from the outset regarding the provision of financial support for travel.

- It is difficult to say which option is best when we don't know the number of people who will be involved
- There needs to be a clear eligibility criteria that is consistently applied by consultants across Scotland for referring people to Level 3 services

- Some concern was expressed that a single centre would see the same travel issues. While it wouldn't be as far, people would still need to travel long distances in some instances
- Ambulance/patient transport service should be available for patients unable to reasonably use public transport

- It is essential that specialist services facilitate children's services as well as services for adults
- Self management courses provided by voluntary sector are often not open to children and young people and this should be addressed

- Too often people go to their GP numerous times with no solution found and they are told "sorry there is nothing we can do for you"
- There is a lack of continuity across the service. Your Doctor needs to understand how the system works
- Need to ensure GPs and consultants are aware that Bath is an option now
- Education needs to improve - right from university level
- A grassroots approach is required, including more support for levels one and two
- The Patient Opinion website is a good way to let services know about good and bad experiences. Boards must respond to comments.

- After attending a four week programme people should be recalled to follow-up on a yearly basis for a refresher session
- People do not get adequate ongoing support when they are at home
• Family carers should be included in the service. It's important that they know the issues.
• The learning at a specialist centre can set people who experience pain and their carers in good stead for the future management of their pain.
• There is lots of existing knowledge available that we can draw on.
• Much can be learnt from the CHAS and Marie Curie cancer specialist services that already operate across Scotland - the specialist service should link with these services to provide ongoing education on chronic pain to complement these services they provide.
• A co-ordinated approach is needed, particularly in reference to advocating on behalf of people who use chronic pain services. There is a role for the ALLIANCE in providing this.
• There may be a future role for third sector organisations to provide support to people who are struggling to cover the upfront costs of their travel before they are reimbursed.
• The Scottish Government should consider setting up a follow up meeting after the consultation period ends.
• This will enable people who have come along to these events to hear more about the Scottish Government's plans for the future and to ensure that those who have shown an interest remain engaged in the development/design of the service.