

# **Future Provision of Specialist Residential Chronic Pain Management Services in Scotland**

## **Consultation Report**

**Scottish Government Response to Consultation Findings**

**April 2014**

## Ministerial Foreword



Chronic pain is very much a clinical priority for the Scottish Government and for NHS Scotland.

This report sets out our response to the Analysis of the Consultation Findings on the Future Provision of Specialist Residential Chronic Pain Management Services in Scotland, published on 23 January 2014.

The response to the consultation has exceeded our expectations and I would like to thank everyone - patients, carers, family members, healthcare professionals and organisations, who took the time to reply to the written consultation and to those who joined us at the stakeholder events. You have shared with us not only your comments, views and insights, but also your personal experiences and this is the true value in carrying out any consultation or engagement with our stakeholders.

**The consultation has shown overwhelming support for the development of a specialised residential chronic pain management service provided by a Centre of Excellence at a single location.**

The responses to the consultation have also provided us with a much clearer understanding of the difficulties that people living with chronic pain experience in their everyday lives. You have shared with us the things that are most important to you – knowledge, understanding, being listened to; the barriers you face in accessing services - getting the right information, knowing what is available and how to access services, travelling and costs.

Many of those who responded have suggested ways in which the new service will help to improve local service provision.

You have shown your support for all of the elements that will be included in the programme that the new service will provide and given us many exciting and innovative suggestions for how the service can be enhanced.

I am pleased to say that work is in progress to take forward the establishment of the new residential service.

The new **Scottish National Chronic Pain Management Programme** will be a nationally designated service commissioned by National Services Division of NHS National Services Scotland on behalf of the Scottish Government.

The service specification for this work has been developed taking account of the views expressed in this consultation. It sets out the aims and objectives of the new service and outlines the minimum range of healthcare competencies and skill level required, along with the range of facilities needed to provide the service. Once approved National Services Division will work with the host Board to develop a full detailed business plan.

### **The New Service for Scotland**

The specification advises that a **Scottish National Chronic Pain Management Programme** will be delivered through a psychological approach with an emphasis on living better with chronic pain.

The Scottish National Chronic Pain Management Programme will be available to all residents of Scotland who are assessed by the local chronic pain management service as likely to benefit from participation in the intensive residential programme of assessment.

Every effort is being made to ensure that the new service will be established as soon as possible and further announcements will be made at key points in the process including when the location of the service is confirmed following the important steps now being taken to ensure the new service is of the highest quality.

Whilst much progress has been made on improving chronic pain services I recognise that more still needs to be done. I look forward to continuing to work with our stakeholders to progress this important work.



**Michael Matheson MSP**  
**Minister for Public Health**

## **Executive Summary**

### **Overview**

This report responds to the findings of the consultation as set out in the independent report 'The Provision of Residential Chronic Pain Services in Scotland: Analysis of Consultation Responses' and sets out the Scottish Government's proposals for taking forward the development of these services.

Detailed analysis of the consultation was conducted independently and the results published on 23 January 2014. A full report is available on the Scottish Government website at <http://www.scotland.gov.uk/Publications/2014/01/7685>. In addition, a separate analysis summary has also been published - <http://www.scotland.gov.uk/Publications/2014/01/9795> - along with the consultation responses for which consent to publish had been given.

The consultation focused on people who may benefit from treatment provided by the establishment of a specialist residential service in Scotland. This type of service is designed to improve quality of life, enable patients to better manage their chronic pain and reduce their disability.

### **Responses**

A total of 228 responses were received to the consultation. Where respondents consented to publication of their response, these are available in full on the Scottish Government website at: <http://www.scotland.gov.uk/Publications/2013/11/9145/0> .

The aim of the consultation was to reach a wide audience and the range of responses received suggests that this has been achieved. It is also noteworthy that just under half of the responses received were from people directly affected by chronic pain, as the individual or a carer or family member. When adding to this the responses received from organisations representing people with chronic pain, we can be confident that the result of the consultation fully reflects the experiences and views for whom the service is for.

### **Preferred option**

A total of 89% of respondents selected a single option. Of those respondents who answered Question 2 (see Annex C, page 30), 75% indicated a preference solely for Option 1 (A centre of excellence in a single location).

Respondents noted a number of reasons for their preference including views that Option 1 offered the potential: for providing a high quality service; for bringing together an expert multidisciplinary team in one place (which would be easier to monitor, inspect and audit); for attracting and retaining staff; for promoting peer support; and offering the most sustainable solution.

In addition, it was considered that a centre of excellence has the potential to foster research and to develop clinical guidelines for use across Scotland to support further improvement in chronic pain services at a local level.

Following the publication of the Analysis of Consultation Responses, the Cabinet Secretary confirmed on 23 January 2014 that work will now progress to establish the service at a single location.

### **Barriers to service provision**

Most respondents identified travel and costs as the main barriers, in particular the need to pay for travel in advance. Many respondents also noted barriers to gaining access to services such as the reluctance of GPs and other health and social care staff to refer them, and the lack of recognition and understanding of pain levels and associated conditions.

The views submitted in this area have provided some particularly useful insights into how we can shape future improvements in service delivery and access to services.

### **Components of service provision**

Respondents provided a wide range of ideas and suggestions about the scope and content of the proposed service including pain assessment, the role of carers, follow-up arrangements, education and information, the needs of specific groups (such as deaf and deaf-blind people, veterans, children), and specific facilities (such as access to a gym or pool).

These ideas provide a useful steer on what respondents feel are priorities and will help to inform the future development of the work. All of the core elements identified have been endorsed by the findings of the consultation, and have been included as requirements for the new service.

### **Retention of access to current services in Bath or elsewhere**

A total of 205 respondents expressed a view at Question 7 (see Annex C, page 31), 48% of which agreed that existing referral arrangements (such as to the Bath Centre for Pain Services) should be retained for occasional use. Some of these respondents further qualified their answer by adding that this should only be in cases where this is the patient's wish or is most appropriate to their situation, or only in exceptional or emergency circumstances.

**The Scottish Government is absolutely clear that the Scottish National Chronic Pain Management Programme will be the primary service provider and the use of alternative providers would be considered only in very exceptional circumstances, based on clinical need, in consultation with the patient, family, carer, referring clinician and the national service.**

## **Next steps**

National Specialist and Screening Services Directorate (NSD) has a role on behalf of all NHS Boards in Scotland and the people of Scotland to commission specialist services as per need. This is taken forward following agreement by Scottish Government based on the recommendation of National Specialist Services Committee (NSSC) and the NHS Board Chief Executives group.

In line with the Cabinet Secretary's commitment that a specialist service would be provided in Scotland, the short life expert group, with full involvement of patients and service users, formed by NSSC developed a specification for a national specialist residential chronic pain management programme.

The resulting service specification was approved by NSSC at its meeting on 5 March 2014. NSD has subsequently written to all NHS Boards in Scotland inviting proposals from them, by 30 April 2014, to deliver the residential Chronic Pain Management Programme for Scotland. NSSC has identified a small group to work with NSD to assess the proposals and to make recommendation as to which NHS Board will be invited to host the programme.

NSSC expects to report to the Scottish Government in May 2014 to advise on the results of this exercise.

NSD will then work with the identified clinical team, local service management and the NHS Board to agree a Service Agreement which will ensure that the Scottish National Chronic Pain Management Programme will be provided in a safe, effective and person centred way, beginning as soon as possible.

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# Chapter 1: Introduction and background

## About this report

This report responds to the findings of the consultation as set out in the independent report 'The Provision of Residential Chronic Pain Services in Scotland: Analysis of Consultation Responses' and sets out the Scottish Government's proposals for taking forward the development of these services.

Chapter 2 of this report relates to our response to the main findings of the consultation with Chapter 3 setting out the planned next steps.

Detailed analysis of the consultation was conducted independently and the results published on 23 January 2014. A full report is available on the Scottish Government website at <http://www.scotland.gov.uk/Publications/2014/01/7685> . In addition, a separate analysis summary has also been published - <http://www.scotland.gov.uk/Publications/2014/01/9795> - along with the consultation responses for which consent to publish had been provided.

## Background to the Consultation

The consultation focused on those people who may benefit from treatment provided by the establishment of a specialist residential service in Scotland. This type of service is designed to improve quality of life, enable patients to better manage their chronic pain and reduce their disability.

This service is not currently available in Scotland. At present people for who it is considered may benefit from such a service are assessed and receive treatment outwith Scotland. Most commonly the service has been provided by the Bath Centre for Pain Services, at the Royal Hospital for Rheumatic Diseases.

In 2009 the National Chronic Pain Steering Group carried out a review of the provision of specialist pain management services and at that time concluded that there was insufficient evidence to support provision of such a service in Scotland. However, the group committed to review the position again in the future.

In keeping this commitment, National Specialist and Screening Services Directorate (NSD) of NHS National Services Scotland were asked to scope and assess options for the future provision of chronic pain services. An expert group was convened, comprising of professional providers of chronic pain services in Scotland, third sector organisations and patients. The group commenced work in March 2013.

During a debate in the Scottish Parliament on 29 May 2013, Mr Alex Neil, MSP, Cabinet Secretary for Health and Wellbeing pledged to establish the first specialist residential pain management service in Scotland. The Cabinet Secretary recognised that there were a number of ways in which a service in Scotland could be developed and acknowledged the importance of seeking a wide range of views to inform a decision on the most appropriate way to provide the service.

## About the consultation

A public consultation was held to seek views of patients, their families, carers, clinicians and other stakeholders. National Services Division agreed to provide a report of their scoping and assessment of the various options for providing the service, which could be used to form the basis of a consultation paper. A consultation paper was launched initially on 3 July 2013, however, early feedback indicated that the consultation document was technical in nature and not as accessible as we would have wished. The Cabinet Secretary took the decision to suspend the consultation in order that it could be re-drafted to ensure as wide a range of views as possible would be received. A small review group was formed, which included external and third sector representation, to consider the feedback and re-draft the consultation document. The consultation was re-launched and was open for comment from 2 September to 27 October 2013.

The consultation set out three potential options for the future provision of specialist residential services in Scotland:

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)

The consultation document included a Respondent Information Form and a consultation questionnaire, which explored 11 questions (the questions are provided at Annex C). In addition to seeking views on the options presented, the consultation questionnaire invited respondents to identify any other ideas and sought views on a range of issues including: barriers to services; components of a service; current service provision and personal experience of service use. Respondents also had the opportunity to comment on any aspect of chronic pain services in Scotland.

An electronic version of the questionnaire was available for download or in HTML format on the Scottish Government website, and hard copies and large print format versions of all documents were available on request. Information on the consultation and links to the documents were circulated via email to a wide stakeholder group (see Annex D).

To support the consultation, the Health and Social Care Alliance (The ALLIANCE) in conjunction with the Scottish Government organised a series of network events across Scotland. These events were widely publicised through the ALLIANCE and Scottish Government and were held in:

- Glasgow - 23 August 2013
- Inverness - 21 October 2013
- Dumfries - 23 October 2013
- Glenrothes - 24 October 2013

A total of 77 participants attended the stakeholder events. The comments from all of these events were summarised by the ALLIANCE and submitted to the Scottish Government as part of the ALLIANCE's consultation response.

We would like to thank the team at the ALLIANCE for their work and support in arranging and delivering these events.

## **Chapter 2: Summary and Conclusions**

In this chapter we will explore the main themes identified in the analysis report of the consultation findings and set out our response to the points raised. Our full response relating to the next steps in establishing the new service is discussed in Chapter 3. Due to the way in which people responded to the consultation, the analysis report grouped related questions under five main sub-headings. We have kept, where possible, the same format in order that this report can be followed alongside the analysis report.

### **The Consultation**

#### **Analysis of the data and presentation of the information**

The analysis of the responses was conducted independently as a Social Research project, in adherence with social research professional and ethical guidelines for undertaking research. Throughout both the analysis report and this report, where the term “respondent” is used, this refers to one response, even where this may represent the views of more than one contributor. Each of the stakeholder events was treated as a “response”.

While much of the information in the analysis report is qualitative, the presentation of the information involved both quantitative and qualitative material. In terms of quantitative information, this covered:

- The number and types of respondents
- The number and proportion of respondents who addressed each question
- The balance of views expressed in the tick boxes at the “closed” questions
- The overall patterns of views relating to the three options

Much of the focus of the analysis, however, was qualitative and the presentation of the material reflected this by highlighting the overall themes and the range and depth of views expressed. The analysis report uses qualitative terms such as “a very small number”; “a small number”; “several”; “many”; “a large number”; etc. to describe views expressed on particular themes.

### **Responses**

A total of 228 responses were received to the consultation. Where respondents consented to publication of their response, these are available in full on the Scottish Government website at: <http://www.scotland.gov.uk/Publications/2013/11/9145/0>.

## Respondent categories (Question 1)

Question 1 asked respondents to select from a list to describe the basis on which they were responding. As can be seen in the table below, the most common type of response was received from individuals who experience chronic pain, with 35% of responses in this category.

**Table 1. Respondents identified by category**

<b>Category</b>	<b>No.</b>	<b>%<sup>1</sup></b>
An individual who experiences chronic pain	79	35
Other stakeholder	43	19
A family member or carer of someone who experiences chronic pain	33	14
A health professional	30	13
An organisation representing people who experience chronic pain	18	8
Respondent selected more than one category	14	6
Undetermined	11	5
<b>Total</b>	<b>228</b>	<b>100</b>

Also common were responses from the other stakeholder category which included:

- Some NHS and health bodies
- Royal Colleges and professional organisations
- A variety of representative organisations
- An MSP
- A local authority
- A number who did not specify the nature of their involvement

## Conclusion

The aim of the consultation was to reach a wide audience and the range of responses received suggests that this has been achieved. It is also noteworthy that just under half of the responses received were from people directly affected by chronic pain, as the individual or a carer or family member. When adding to this the responses received from organisations representing people with chronic pain, we can be confident that the result of the consultation fully reflects the experiences and views for whom the service is for.

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<sup>1</sup> % of total respondents to the written consultation.

## Views of Options (Question 2)

### Preferred Option

Question 2 asked respondents to identify their preferred option from the three options presented in the consultation paper.

**The consultation indicated a clear preference for Option 1.**

A total of 89% of respondents selected a single option. Of those respondents who answered Question 2, 75% indicated a preference for Option 1 alone. Within each of the respondent categories a similar pattern of support for a centre of excellence emerged.

**Table 2: Preferred Option**

Preferred option	No.	% <sup>2</sup>
Option 1 – centre of excellence in single location	154	75
Option 2 -	28	14
Option 3 -	12	6
Options 1 & 2	4	2
Options 1,2 & 3	4	2
Options 1 & 3	1	<1
Options 2 & 3	1	<1
<b>Total</b>	<b>204</b>	<b>100</b>

Respondents noted a number of reasons for their preference including views that Option 1 offered the potential: for providing a high quality service; for bringing together an expert multidisciplinary team in one place (which would be easier to monitor, inspect and audit); for attracting and retaining staff; for promoting peer support; and offering the most sustainable solution. In addition, it was considered that a centre of excellence has the potential to foster research and to develop clinical guidelines for use across Scotland to support further improvement in chronic pain services at a local level.

Question 3 asked if there were any of the options that were disagreed with. Option 1 generated the fewest comments in this respect. Those who responded largely related to location and access, noting that there would still be issues associated with travelling distance and potential inaccessibility due to, for example, health or weather.

Additional concerns related to staffing and resources which may impact on local services and the development of waiting lists.

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<sup>2</sup> % of total respondents who ticked one of the options.

Question 4 asked for any other ideas not covered by options included in the consultation. Around a fifth of those who responded indicated the benefits of a combination of the options. A number of respondents ticked more than one option indicating broad support for the development of a centre of excellence, along with elements of service provision from the other options presented. This included the option to include, for example, telehealth solutions that would be of benefit particularly for those in remote and rural areas.

### **Location of Service**

Although no specific question was included in relation to the location of a service for Option 1, (or the other options) a number of respondents offered additional comments on this. In particular, a number of respondents to the consultation have suggested that the service could be located at the Centre for Integrative Care based in Glasgow. Additional comments in the consultation noted other specific and more general geographic locations with suggestions including:

- Southern General Hospital, Glasgow
- Astley Ainslie Hospital, Edinburgh
- St John's Hospital, Livingston
- Glasgow, Perth, Stirling and Dundee
- Central belt or at north/ south locations
- A location with good transport links

### **Conclusion**

Following the publication of the Analysis of Consultation Responses, the Cabinet Secretary confirmed on 23 January 2014 that work would now progress to establish the service at a single location.

With a clear preference indicated for Option 1, this section of the report does not cover the detail of views expressed and the range of comments made in relation to the other options presented in the consultation. However, there was clear support for some of the elements of the other options and these are considered in Chapter 3.

### **Barriers to Service Provision and Respondents' Experiences (Question 5)**

Question 5 asked respondents to identify any barriers to accessing a residential pain management service. Of the 74% of respondents to the written consultant who addressed the question, almost all identified barriers to service provision.

Most respondents identified travel and costs as the main barriers, in particular the need to pay for travel in advance. It was noted that arrangements for meeting costs differed by health board area and that clear guidance to help people understand how to claim expenses would be beneficial. It was also noted that difficulties in planning travel arrangements could be a barrier in itself. Parking facilities were also noted as a potential problem.

For some, existing carer responsibilities or childcare would be a barrier and it was suggested that social care or respite care be arranged to help resolve this. Employment and the need to take time off work were commented on, with the suggestion that information for employers could be helpful in addressing such issues.

### **Gaining Access to the Service**

Many noted gaining access to the service as a barrier in itself noting a number of reasons for this including:

- Reluctance of GPs and other health and social care staff to refer
- Lack of recognition of the level of pain or the condition
- Lack of knowledge and awareness of service options (by healthcare staff and patients)
- Lack of understanding of arrangements for referral and access to services

Comments were also made on the:

- General lack of accessibility of services
- Time taken for a diagnosis (and possible misdiagnosis)
- Length of waiting time
- Lack of availability of beds
- Sufficiency of numbers for provision
- The need for clear and well communicated referral arrangements

Attending the service itself and the added anxiety of attending an unfamiliar location were noted as barriers and it was suggested that providing a virtual tour of the facilities and an introduction to staff would help people familiarise themselves with the service prior to attending and reduce some of the anxiety.

### **Conclusion**

This information provides us with some very useful insights into how we can improve the delivery of services.

### **Travel and Costs**

Difficulties with travel and costs are not confined to accessing national services and are for many a consideration when accessing local services, especially for people living in remote and rural areas. There are existing arrangements to help people with travel costs, information on which is set out below.

The Patient Travel Scheme provides help with travel costs for those in receipt of certain Department of Work and Pension benefits, and also to those not in receipt of benefits, but otherwise assessed as being on low income by the NHS Business Services Authority.

The Scheme is administered by each Health Board individually but, in general, patients pay their travel fare upfront and, upon attending hospital, present their documents to reception in order to claim a refund. Claims can also be made up to three months after the date of travel, upon completion of a claim form. More information on the Scheme is available at:

<http://www.scotland.gov.uk/Resource/Doc/348077/0115949.pdf>

Health Boards also have the discretion to refund the cost of travel for patients that are not covered by the Patient Travel Scheme, but where travel is required to a distant hospital and is considered to be part of the cost of treatment.

In terms of the current residential programme at Bath, travel costs for those participating have in most cases been met by the referring Health Board, with accommodation costs included in the overall cost of the treatment.

Healthcare Improvement Scotland (HIS) recently launched the new Chronic Pain website which is a resource for quality assured information on chronic pain for patients, carers, family and healthcare professionals. A sub-group of the National Chronic Pain Steering Group has been tasked with maintaining the website, which includes pages for each of the NHS Boards. A request to add the guidance on the Patient Travel Scheme to the website has been sent to the group and individual boards have been asked to include local arrangements for travel costs on their individual pages.

Specific information for the new Scottish National Chronic Pain Management Programme will be added when available.

### **Accessing Chronic Pain Services**

The Scottish Government are committed to ensuring that people have access to high quality safe and effective services as close to home as possible, with ready access to specialised services when needed. In achieving our vision it is crucial that patients, health and social care professionals have knowledge of those services available locally and nationally, and how and when to access these.

Further information on local chronic pain services and on the current improvement programme at Annex A.

An additional resource for information about what support may be available in your local area is ALISS - A Local Information System for Scotland.

ALISS is a search engine which aims to make it easier to find local resources. More information is available on the website at: <http://www.aliss.org/>

### **Other barriers**

Employment was a key theme identified in the responses to the written consultation. Healthcare Improvement Scotland recently conducted a data collection exercise, the initial high level findings from this exercise highlight the high proportion of people living with chronic pain who are of working age and struggling to remain in work.

The Scottish Government recognises the link between work and health and the Health Works Strategy, published in 2009, sets out a range of actions to ensure that health is not a barrier to work. The Scottish Centre for Healthy Working Lives provides a valuable resource for employers and employees, and has led on the delivery of a number of the actions in the strategy. There is a clear opportunity both for the National service and local chronic pain services to link with the work of the centre to further support people to remain in work.

Of particular benefit for people living with chronic pain will be the national roll-out of the musculoskeletal (MSK) service redesign. An integral part of the re-designed pathway is the Musculoskeletal Advice and Triage service (MATs), which at first point of contact signposts people to a range of support including: self-management resources, physiotherapy services, employment advice and physical activity. Through the National Chronic Pain Steering Group we are ensuring that chronic pain services are linked with the MSK redesign as this rolls out across Scotland, there are already excellent examples of the benefits of aligning this work with chronic pain redesign, particularly in NHS Ayrshire and Arran.

### **Respite/social care**

We recognise that due to the length of the residential programme that for some people there will be additional practical difficulties that will act as a barrier, in particular where arrangements for childcare or respite care would need to be made. This is a prime example of why integration of health and social care is needed.

The Bill, which became the Public Bodies (Joint Working) (Scotland) Act on 1 April 2014, was introduced to Parliament on 28 May 2013 and passed by the Parliament on 25 February 2014. The Act sets out the legislative framework for integrating health and social care, which will support improvement of the quality and consistency of health and social care services in Scotland. An extensive period of engagement was carried out last year and we continue to work collaboratively with stakeholders through a range of working groups to develop regulations and guidance.

The Act will put in place arrangements for integrating adult health and social care, in order to improve outcomes for patients, service users, carers and their families and to enable Health Boards and local authorities to work together effectively to deliver quality, sustainable care services. This is expected to help facilitate a shift in spending towards community based services based on the needs of the population, ensuring an effective focus on reducing unplanned care and improving outcomes. This should also aid the provision of seamless care, through the joint commissioning of services.

The Act will tackle the challenge of ensuring a consistent provision of quality, sustainable care services for the increasing numbers of people in Scotland who need joined up, integrated support and care - particularly those living into older age and people with multiple, complex, long term conditions.

Integration authorities will be accountable for delivering new Health and Wellbeing outcomes. NHS Boards and local authorities will put in place integrated budgets, delegated to their local integration authority, to ensure better, more effective use of their total resources.

### **Previous experience (Questions 8 - 10)**

Questions 8 – 10 asked for views of those with previous experience of attending residential services. A small number indicated personal experience of using such a service, however, most identified that they had knowledge of others' use of the service through professional capacity, or as a peer. The specific services identified included: Bath; Abingdon Hospital; the Chronic Fatigue Syndrome clinical service in Newcastle; and a spinal unit. In commenting on the advantages/disadvantages of the experience, most of those who responded were generally supportive of this type of service.

Question 10 asked if the service had been offered and declined and the reasons for declining. A total of 27 respondents made comments on this question with almost half noting they had never been offered the service or had been refused access to it. Of the half that had been offered and declined, the main reasons given were that of location and distance. A very small number also noted reasons of:

- Costs (general and “upfront”)
- Time away from home and family
- Work commitments
- Health issues (e.g. medical commitments)
- Patients' perceptions of provision (e.g. fear; expectations; lack of readiness to engage)

### **Conclusion**

Respondents to the consultation generally supported the need for and saw advantages of specialist residential chronic pain management services. It is not unexpected that only a small percentage of the respondents had direct experience of this type of service given the numbers of referrals currently being made.

The reasons for declining a placement provide a helpful insight into the perceived barriers. These will be considered in the development of future service provision.

The establishment of the service in Scotland will help to address some of the identified barriers such as its distance from home. However, we recognise that the very nature of the service and why it works in terms of its length and intensity would be lost if the programme were to be shortened to address issues such as time off work / away from home and family.

## Components of Service Provision (Question 6)

Question 6 sought views on the suggested components to be included in the specialist programme, asking respondents to select from a list with the option to identify any additional components not listed.

**Table 3. Aspects of residential pain management services to be included**

Aspect of service	No.	% <sup>3</sup>
A chronic pain assessment	195	97
Supported one to one sessions to teach coping skills	182	91
Residential accommodation	183	91
Medication assessment	182	91
Tailored exercise programme	174	87
Group sessions	168	84
Opportunity for immediate carer / support provider to accompany patient	168	84
Peer support	157	78

These aspects were developed for the consultation by the NSD expert group, drawing upon an understanding of the service currently provided in Bath. The consultation indicated overwhelming support for the identified elements to be considered in the provision of the new service.

A total of 201 respondents addressed the question indicating strong support for all the elements of service provision identified in the consultation, with more than half selecting all of the elements.

In addition to suggestions on the ways in which the service elements could be designed, respondents also suggested other elements which could be included in the service, these covered for example:

- follow up with ideas of how this could be done including utilising email, telephone, web-based 'top ups', evaluations etc
- education and information for patients, carers and family members
- family therapy or psychology
- ongoing support via a helpline, DVDs or memory sticks
- access to education, employment and benefits support and advice
- general awareness raising
- support required for a range of specific groups

<sup>3</sup> % of those who addressed this question.

- facilities e.g. pool, hydrotherapy, gym, cooking facilities
- a research centre

## Conclusion

This provides a very useful steer on what respondents feel are priorities and will help to inform the future development of the work. All of the core elements identified by the expert group have been endorsed by the findings of the consultation and have been included as requirements for the new service.

Individual respondents provided a wide range of ideas and suggestions about the scope and content of the proposed service including about assessment, the role of carers, follow-up arrangements, education and information, the needs of specific groups (such as deaf and deafblind people, veterans, children), and specific facilities (such as access to a gym or pool). These ideas have been taken into account in developing the specification for the new service and will help shape the future design of the service and programme.

Further details on how we envisage ensuring that these views are addressed are set out under the discussion of the Scottish National Chronic Pain Management Programme in Chapter 3.

Some of the suggestions, whilst important in the overall care of people living with chronic pain, may not be considered for inclusion in the national service. This is, for example, the provision of interventions such as acupuncture, which we expect to have been considered locally as part of the initial care plan.

### Retention of access to the current service provided in Bath (or elsewhere in the UK) (Question 7)

Question 7 in the consultation sought views on the retention of the current service for occasional use.

Retain access to Bath	No.	% <sup>4</sup>
Yes	98	48
No	51	25
Don't know	56	27

A total of 205 respondents expressed a view at Question 7, 48% of which agreeing that the service should be retained either for occasional use as indicated by the question or further qualifying that:

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<sup>4</sup> % of those who addressed the question.

- Where this is the patients wish
- Is the most appropriate choice in a personalised approach
- If there is a particular specialist service or expertise that could not adequately be provided in Scotland (e.g. because of a small number of patients in a particular group)
- Only in exceptional circumstances
- In an emergency

Other comments noted that the retention of the current service would not be required once the Scottish service was established, or that it should be retained then reviewed or phased out, or retained while the volume of referrals is assessed. It was also suggested that professional links be maintained to support staff in the new service.

## **Conclusion**

In taking forward the development of the new service and considering any future use of the current provider or alternative providers, the comments made throughout the consultation are fully considered in the context in which they were given.

The Scottish Government is absolutely clear that the Scottish National Chronic Pain Management Programme will be the primary service provider and the use of alternative providers will be considered only in very exceptional circumstances, based on clinical need, in consultation with the patient, family, carer, referring clinician and the national service.

## **Other Issues Raised (Question 11)**

As part of the consultation we were keen to hear the views on any aspects of current chronic pain services across Scotland and also about the consultation process itself. This section of the analysis report covered the range of comments made in response to Question 11. Over half of the respondents to the written consultation made additional comments which covered a wide range of topics.

A large number of respondents made comments on the current context and nature of services. Many of the comments related to the nature of pain and its impact on individuals' lives.

Several respondents commented on the need for a residential service and the likely level of demand for such a service. It was commented that the likely level of demand is currently unclear, or that there are conflicting views on likely demand. This is reflected in the range of comments made, with some respondents noting that the level of demand has been underestimated and others noting that improving local service provision could reduce demand. It was also noted that the consultation should have included information on the level of demand and cost implications.

In addition, it was suggested that the consultation should have included a review of the evidence base comparing outcome data for the residential and outpatient approach to the delivery of specialist chronic pain services.

A number of questions and issues were raised for clarification relating to:

- the conditions that would be covered by the service
- the referral processes
- staffing
- provision in particular areas and to particular groups
- other aspects of the options presented in the consultation document
- funding and costs
- the evidence available

## **Conclusion**

### **Level of Demand**

The consultation document did not provide information on the likely level of demand as accurate information on likely level of service use is not available. Whilst numbers of current users is recorded, NHS Boards do not currently collect data on the numbers of those who are referred but do not attend/decline.

As identified by respondents, it is considered that with improved access to local services and improved awareness and management in primary care, the number of those requiring specialist treatment may decrease over time. On the other hand, improved awareness of the specialist service and the availability of the service in Scotland may result in an increase in the numbers of referrals.

In previous years the number of patients attending Bath has been within the range of 20 to 32 patients per year, with the highest attendance in 2010/11. However, current figures for 2013/14 show a marked decrease in referrals at 14 by 13 March 2014. Anticipation of the new Scottish service may have contributed to this decline.

Chronic Pain affects 800,000 people in Scotland with an estimated 223,000 experiencing severe chronic pain. We know that there is currently an unmet need for this service and based on current numbers of people seen in the secondary care setting and the rise in demand for these services being reported by boards we expect that the number of people who would access the service is higher than the current rate of referral. In commissioning the service, an estimate of likely level of demand has been assessed at around 100 patients per year. Further detail is provided in Chapter 3.

## **Current service provision**

Many respondents commented on the current provision of services, a number of whom highlighted problems in this area including: a view that the service is generally poor; services vary between different areas; and there are particular problems for those in remote and rural areas. It was suggested that there can be long waiting times for accurate diagnosis and treatment and that services may not have adequate staffing levels. Some also noted a reliance on pain medication, or difficulties accessing particular forms of treatment or support for specific conditions.

Some positive comments were also made. These related to the development of the residential service and the general work underway to improve services across Scotland.

Many comments were made on the way forward with recognition of the need for improvement of services at a local level to ensure access to effective pain services across Scotland for all those who need them, not only those who are worst affected.

The need for clear pathways was identified and other suggested developments included:

- the development of primary care services
- the provision of support to local practitioners
- a continuing focus on self care
- early access to appropriate advice
- reduced waiting times
- appropriate referrals
- ongoing development of children's pain services at a local level
- NHS Board implementation of the Scottish Service Model for Chronic Pain

It was suggested that there should be local pain teams and clinics in all areas and Managed Clinical Networks across Scotland, utilising telehealth solutions and including outreach or mobile services.

Other key themes identified included the need for education and training, with comments on specific groups for which training should be provided:

- Medical and other relevant students
- 'Frontline' primary care and ancillary staff
- GPs and local pain clinicians
- Physiotherapists
- Pharmacists
- General health and mental health staff
- Wider staff groups

Specific issues for training were also identified:

- The nature of chronic pain and different types of chronic pain

- Diagnosis of particular conditions
- Alternatives to pain killing drugs
- Treatments for chronic pain
- The nature of services available

Suggestions were also made on how training could be provided:

- Continuing Professional Development (CPD)
- Secondment or rotation from existing services to an intensive service
- Shadowing
- Clinical guidelines
- Sharing knowledge and experience on a national level
- Chronic pain symposium which could be podcast to the wider community

## **Conclusion**

Throughout the consultation both in the stakeholder events and in the written responses there was considerable discussion and reference to current local chronic pain service delivery. It is clear that there is uncertainty around which services are /should be available locally and about what a residential service aims to provide and how this fits within the overall provision of chronic pain services.

Comments were made at various sections in the analysis report. This section of the report aims to address these points.

Whilst some positive comments were made in the response to the consultation, most people who commented on current services were less positive about their experiences. This is disappointing and we recognise that whilst improvements are being made there more remains to be done.

The Scottish Government is committed to providing the highest quality services and wants people to be at the heart of the NHS in Scotland, to ensure that the services our NHS provides are truly person-centred.

It is essential that we listen to the lived experiences of patients and take action to address problems when they arise. This is, in many circumstances, best done locally with the appropriate NHS Board. Patients can raise concerns through the established NHS Complaints procedure or they may choose to share their experiences via Patient Opinion.

Completely independent of government and the NHS, Patient Opinion is a website where patients, their carers or family members can tell other people about their experiences of the NHS. NHS Boards are alerted to stories posted about services in their area and are encouraged by the Scottish Government to post responses saying what they have done in light of what patients have said. It aims to make it easier for people to give feedback and for NHS Boards to get those opinions to the people who need to see them and ultimately, to make services better.

This can be done on line at [www.patientopinion.org.uk](http://www.patientopinion.org.uk) or by telephone, the number is: 0800 122 31 35.

## **Patient Involvement**

The Charter of Patients' Rights and Responsibilities sets requirements for all NHS Boards to engage with patients, carers and families in decisions about services. All of the local chronic pain Service Improvement Groups and Managed Clinical Networks are required to have patient involvement/engagement.

We have also recognised this at a national level by strengthening the membership of the National Chronic Pain Steering Group to include direct patient membership to compliment the third sector membership.

## **Chronic Pain Services**

The Scottish Service Model for Chronic Pain (see Annex B) sets out the range of services that should be provided locally (levels 1-3) through to the more specialised interventions that may be provided regionally or nationally (level 4). The model sets out a tiered model of care in the approach to pain management covering the range of support available of which pharmacological management is one component:

Level 1 – Self management support in the community – advice and information about pain, including resources available from third sector providers/organisations.

Level 2 – Primary care support – treatment and management provided by a GP, pharmacist or Allied Health Professional (AHP).

Level 3 – Secondary care support – specialist treatment and management provided by a range of healthcare professionals in the hospital setting, delivered by multidisciplinary teams, including outpatient Pain Management Programmes.

Level 4 – Tertiary Care – highly specialised treatment and interventions, including Spinal Cord Stimulation (SCS), Intrathecal Drug Delivery, specialist residential Pain Management Programme.

Since the launch of the consultation the model has been refreshed and is included at Annex B of this report.

The routine assessment and management of chronic pain is a required competency of all healthcare professionals as well as being an important component of healthcare planning.

The Scottish Government is clear that the provision of the national specialist residential service in Scotland is not an alternative or substitute for the provision of the locally delivered chronic pain primary and secondary care services described in level 1-3 of the service model.

Assessment for and referral to the national service will be made by the secondary care team having followed a care pathway through level 1 – 3 services.

We recognise that there is much to be done but that with the range of activity underway and planned at local and national levels, change will start to be seen quickly and more patients will experience the highest quality of care.

**The Scottish Government is fully committed to the implementation of the Scottish Service Model for Chronic Pain and ensuring the provision of the full range of services it describes.**

More information on the work in progress to achieve this is provided in Annex A.

## Chapter 3: Scottish Government Response - Setting out what next

### Scottish National Chronic Pain Management Programme

National Specialist and Screening Services Directorate (NSD) has a role on behalf of all NHS Boards in Scotland and the people of Scotland, to commission specialist services. A specialist service will be commissioned where this has been agreed by Scottish Government based on the recommendation of National Specialist Services Committee (NSSC) and the NHS Board Chief Executives group.

In line with the Cabinet Secretary's commitment that a specialist service would be provided in Scotland a short life expert group, with full involvement of patients and service users, was formed by NSSC to develop a specification for a national specialist residential chronic pain management programme.

This group considered the findings of the responses to the public consultation published on 23 January 2014. Following the meeting of the expert group on 29 January 2014, the service specification was agreed and signed off, which includes reference to the referral pathway, the elements of the specialist programme to be offered, the accommodation needed to deliver the programme, and the support that will be required by individuals as follow up to their participation in the programme.

The service specification was approved by NSSC at its meeting on 5 March 2014. NSD has subsequently written to all NHS Boards in Scotland inviting proposals from them to deliver the residential Chronic Pain Management Programme for Scotland. NSSC has identified a small group to work with NSD to assess the proposals and to make recommendation as to which NHS Board will be invited to host the programme. NHS Boards are invited to submit proposals by 30 April 2014.

NSD will then work with the identified clinical team, local service management and the NHS Board to agree a Service Agreement which will ensure that the **Scottish National Chronic Pain Management Programme** will be provided in a safe, effective and person centred way.

NSSC will report to the Scottish Government in May 2014.

An announcement on the location of the service will be made following approval and notification of the decision on the preferred provider. We anticipate that an announcement will be made by the end of May 2014.

Every effort is being made to ensure that the development of the service is taken forward swiftly. Following the decision on the approved provider a number of actions will need to be taken before the service will be launched. These will include:

- Undertaking any appropriate Equality Impact Assessments/Business Regulatory Assessments.
- Recruitment of staff and undertaking of any required training.
- Carrying out any necessary capital works.
- Development of treatment programme.

## **Scottish National Chronic Pain Management Programme – Service Specification**

The Scottish programme will deliver an evidence based biopsychosocial approach, that will aim to replicate the current service provided by Bath. This means an approach which takes account of the complex interplay of biological, psychological, and social factors in the understanding of health and illness. The range of service elements which have been incorporated in the service specification of the new Scottish National Chronic Pain Management Programme are detailed below.

The programme will offer residential accommodation for those who wish to stay, however, it is not intended to offer an inpatient level of care, nor is it designed to offer specialist pain alleviating interventions (implantable devices, surgical resections, injections etc,) if these are required these will be arranged and/or delivered by through existing specialist or regional chronic pain management services.

The Scottish National Chronic Pain Management Programme will be available to all residents of Scotland who are assessed by the local chronic pain management service as likely to benefit from participation in the intensive residential programme of assessment and intervention which will be carried out over a 2-4 week period. It is expected that the patient's carer will also be directly involved at appropriate times. The programme is delivered through a mix of one to one and group activities with an emphasis on helping the individual with chronic pain to manage their condition more effectively.

Numbers of referrals have initially been estimated as 100 per year. However, the programme will be able to run on a monthly basis with up to 10 participants per programme.

Objectives of the programme are to:

- Offer a detailed biopsychosocial assessment which will include review of the referred diagnosis of chronic pain
- Promote the highest possible quality of life for patients with chronic pain
- Provide psychological and behavioural interventions that support patients (and their carers) to better manage their pain, enabling them to lead more normal lives with reduced disability
- Support clinicians and local care providers in managing their patients care
- Reduce recurrent inappropriate admissions and attendances to other health care services by promoting self-management
- Increase social and physical functioning, promoting return to work and maintaining productivity through employment
- Promote independence and wellbeing for patients through the provision of structured self-management support.

## Staff

The programme will be delivered by a core multidisciplinary group of key professionals (clinical and academic) who have a remit to lead and deliver the highest standard of patient care, research, audit output, teaching and training in the area of complex pain and pain-associated disability, within a dedicated environment. The multidisciplinary team will be skilled in and have specialist interest and experience of working with patients with chronic pain. The team will consist of (as a minimum):

- Clinical Psychology.
- Specialist nursing – pain management.
- Physiotherapy.
- Occupational therapy.
- Medical specialist in chronic pain management.

## Referral

Referrals to the **Scottish National Chronic Pain Management Programme** will be made through an existing local or regional specialist chronic pain service. In the majority of cases, as with the current service provision, referral to the programme will follow the patients participation in a local programme of chronic pain management but will be available to individuals who are unable to access local out-patient / day care because of issues of remote geography / difficult travel.

The National Chronic Pain Steering Group will help to ensure that awareness of service and the referral criteria are widely shared, alongside their existing work to increase awareness of local service provision and development of care pathways.

## Assessment

Following referral the team will undertake a range of specialist interdisciplinary and multidisciplinary assessments leading to the development of an agreed care plan including:

- Review of need for further investigations/pain interventions (may involve referral being returned to local/regional specialist team for action)
- Review of current pharmacological interventions
- Detailed biopsychosocial assessment
- Planning of appropriate psychological and behavioural interventions

All patients will be offered an initial specialist assessment to understand the individual needs of the referred patient and to explain the programme in detail. It is expected that the patient's family and / or carers will be involved in aspects of the assessment and offered the opportunity to participate in the actual programme itself. Patients can then consider whether or not they feel the programme is right for them and that they are able commit to it.

Following assessment it is anticipated that the 2-4 week residential chronic pain management programme will invite patients to join a group of 8-10 participants who

will be encouraged to offer peer support as well as benefitting from the expert inputs from the multidisciplinary team.

### **Needs of specific groups**

The current programme in Bath is able to offer tailored courses to match a range of needs for specific groups, for example individuals with similar experiences, situations or conditions. The consultation has suggested mixed views on the need for specific tailored courses, however, previous users of the service report that this can aid the peer support element of the programme and be of benefit in maintaining informal networks following attendance on the programme. The Scottish programme will aim to encourage peer support and where possible provide similar tailored provision however this will be largely dependent on referrals received. The main aim of the service is managing the effects of chronic pain and the impact of this on daily life, it will be available to all those assessed as likely to benefit from and appropriate for the programme, regardless of any underlying condition.

While the service specification developed primarily relates to a programme to be offered to adults, particular attention will be given to a number of specialist groups including children and young people and through transition to adult services. It is recognised that tailored courses for children and young people may be difficult to provide within reasonable timescales as the cohort of patients in this group is likely to be small.

The programme will need to meet the particular requirements for the range of groups identified as with any other service, in compliance with current Disability and Equality legislation.

### **Follow up and discharge**

Following the programme participants will in most cases be discharged home with an agreed self-care plan and offered appropriate support to develop their independence/independent living. This will include specific patient experience questionnaire to be completed at appropriate time periods following discharge.

### **Information**

The consultation highlighted the need for clear information and advice. This is important at all stages in the patient journey and is an integral part of the Scottish Service Model for Chronic Pain. The new Chronic Pain website provides a national resource of information. Many of the local Service Improvement Groups have identified this as a priority and the National Chronic Pain Steering Group are working with boards to encourage sharing of best practice in this area to ensure the provision of consistent quality assured information.

In further supporting this, the Scottish National Chronic Pain Management Programme team will be asked to develop clinical guidelines, in partnership with local/regional services. Clinical guidelines will help to deliver a consistent approach within and across all Pain Management Programme (PMP) teams in Scotland, whilst continuing

to support individual needs. When developed, these guidelines will be available to participants as part of the continuing support following attendance in the programme.

### **Accommodation**

The consultation outlined the requirements of both the clinical space required and the need for suitable residential accommodation. The service specification mirrors these requirements and adds the potential option for hydrotherapy where this may be available. The host board will need to identify residential accommodation near to but out with the clinical environment that will need to be available for patients and carer/partner/family who will be encouraged to accompany the participant.

### **Costs**

Boards will outline in their proposals to host the service indicative costs for providing the service. The successful NHS Board will, working with NSD, develop a full application for submission to the NSSC, to enable the service to be established as soon as possible.

A decision will be taken in discussion with the approved provider, as part of the Service Agreement, whether the existing arrangements for meeting travel costs will continue or whether these will be included in the financial arrangements of the new Scottish National Chronic Pain Management Programme.

### **Future Development**

A key theme from the response to the consultation was that although a Centre of Excellence is the preferred option – elements of the other options also had merit and could be considered in the design of a service delivered from a single location. In particular the use of telehealth solutions.

This view is acknowledged and supported by the Scottish Government and the Cabinet Secretary expressed this in his foreword to the consultation, stating that none of the options were mutually exclusive.

In providing high quality patient centred services we need to explore and provide innovative approaches to the delivery of our healthcare services. Respondents have not only identified this need but have also suggested ways in which this can be achieved.

The initial focus will be to establish the core service programme, however, as the service develops we would encourage partnership working with patients and communities to explore and test options to further enhance provision. The service will continue to evolve over time to incorporate new and emerging innovative approaches to ensure that the service will provide the most up to date care and treatment.

Further elements of the service will be introduced as the service establishes, for example web site, clinical guidance etc. Details of progress will be communicated with stakeholders and through public communication channels as appropriate.

## **Improvement Programme – Implementing the Scottish Service Model for Chronic Pain**

### **Our commitment**

We expect the implementation of the Scottish Service Model for Chronic Pain will lead to the improvements which we all want to see and provide consistent, equitable chronic pain services across Scotland. Scottish Ministers have given their commitment to accelerating progress on the chronic pain improvement programme of work.

The Scottish Government has supported the programme through a range mechanisms including: the provision of clinical leadership; funding to support our third sector partners; funding for the production of campaigns to raise awareness of support provided in the community setting by pharmacies and third sector; and pump prime funding over two years for the establishment of Service Improvements Groups/Managed Clinical Networks, which alone will amount to just over £1.3m.

### **Background**

The Improvement Programme has been supported by Healthcare Improvement Scotland since 2009. During this time, working with the National Lead Clinician for Chronic Pain, a number of key achievements have been made including:

- development of the Scottish Service Model for Chronic Pain
- establishment of the National Chronic Pain Steering Group
- commitment from all boards to implement the model
- establishment of Service Improvement Groups / Managed Clinical Networks in every Board
- publication of SIGN Guideline 136 on the management of chronic pain
- launch of new Scottish chronic pain website
- establishment of a support network for NHS Chronic Pain Service Improvement Groups, to promote sharing of experience and best practice
- national community pharmacy campaign in January-February 2013
- national data collection exercise.

### **The National Chronic Pain Steering Group**

The National Chronic Pain Steering Group has a remit to lead and oversee the improvement programme through the implementation of the Scottish Service Model for Chronic Pain. A number of sub-groups have been established to take forward work in specific areas:

- Research
- Learning & Development
- Children's Services
- Website & Editorial
- Self-management
- Primary Care

Most patients with chronic pain can be well managed in a community or local hospital setting by appropriately trained members of interdisciplinary local and specialist Pain Management Services.

Work has to date largely focused on developing chronic pain services in the secondary care setting. It is recognised, however, that ensuring early and appropriate management in the primary care/community setting is essential and will help to reduce both incidence of chronicity and inappropriate referrals to secondary care.

The recently published Scottish Intercollegiate Guidelines Network (SIGN) Guideline 136 on the management of chronic pain provides advice and recommendations on a range of interventions that may be considered within the primary care / community setting (such as supported self-management, physical therapies, exercise therapy, electrotherapy (e.g. TENS), acupuncture and pharmacological therapies).

The guideline also reviewed the evidence on the use of psychologically based interventions and recommends consideration of referral to a pain management programme, which can increase coping skills and improve quality of life. Outpatient Pain Management Programmes (PMPs) were established in six health board areas in 2013, a further two boards established PMPs in early 2014 and in three other boards have PMPs under development.

### **Current Activity**

There is a great deal of work underway at a local level in each health board area and we are already seeing many examples of good practice. For example: development of a new electronic referral template from GPs to the secondary care service to improve the referral process; a pilot to test electronic direct referral from GPs to the Pain Association Scotland; various education programmes for primary care staff and multidisciplinary team members; establishment of new Pain Management Programmes.

Access to relevant information throughout the patient journey is a key part of supporting people living with chronic pain. Many Boards are developing information locally and the National Steering Group will encourage the development of consistent information which can be added to the newly refreshed national website. This website brings together quality assured information and resources for patients and healthcare professionals. Each Board has a dedicated page on the website to provide information about the services in place locally.

A new support network for the service improvement groups has been established to ensure that the learning and experiences from these projects and other examples of good practice can be shared across Scotland. A national event for the newly established support network was held by Healthcare Improvement Scotland on 20 March 2014, and we expect to hold further national events in the future. A series of WebEx meetings have also been held on a range of specific topics, including service user engagement, data collection, children's services and the chronic pain website, which have been a useful way of sharing experience virtually.

The research sub-group are considering future data collection, following the recent exercise conducted by HIS and exploring new methods for capturing information at a primary care level.

### **Monitoring Progress**

The key concerns highlighted in the consultation are around access to services and waiting times for those services. Addressing these issues is a central part of the work going forward. Boards are actively working to reduce waiting times, particularly for Pain Psychology services, and we have seen significant reduction in these waits in a number of areas. Boards have also made progress in addressing staffing vacancies and a number of staff members (including a clinical nurse specialist, psychologists and a physiotherapist) have recently been recruited. The Scottish Government and the National Chronic Pain Steering Group will continue to monitor progress closely.

The results of the recent data collection exercise will be provided in a report by HIS, this will provide boards with an up to date baseline from which progress can be measured.

To help drive forward service improvements all Boards are required to include improvement aims for chronic pain services in their Local Delivery Plans for 2014. Progress will be monitored by the Scottish Government through the Annual Review process. In addition, regular updates are provided to the National Chronic Pain Steering Group.

### **New Support Arrangements**

HIS's specific role in the Improvement Programme concluded on 31 March 2014. New sustainable arrangements have now been put in place to ensure improvements are maintained and progressed. A new National Clinical lead and new Chair of the National Chronic Pain Steering Group have been appointed. In addition, a new National Co-ordinator has been appointed to provide support to the Steering Group as well as to local Service Improvement Groups/Managed Clinical Networks.

The key priorities for National Co-Ordinator and Clinical Lead will be working with the National Chronic Pain Steering Group and local service improvement leads network managers to:

- Embed new arrangements for monitoring to support the LDP process.
- Ensure the development of consistent referral criteria and care pathways and that these are shared and communicated widely through the support network and the national website.
- Work with SIGs/MCNs to encourage and support the management of chronic pain in the primary care community setting through the implementation of the SIGN Guideline 136.

The minutes of the meetings for the National Chronic Pain Steering Group along with progress updates will in future be published on the new national chronic pain website.

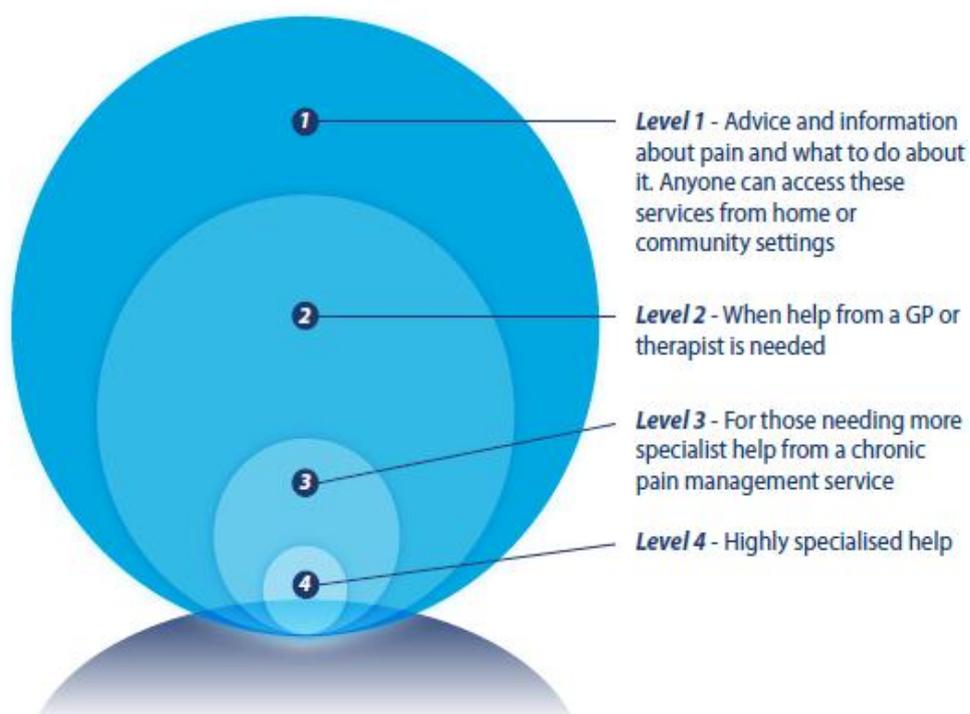
The Scottish Government is clear that equitable local chronic pain services should be in place across Scotland and through the work described above this will be achieved.

## The Scottish Service Model for Chronic Pain



### Chronic Pain Scotland Service Model

*Most people get back to normal after pain that might come on after an injury or operation or for no apparent reason. Sometimes the pain carries on for longer than 12 weeks despite medication or treatment – this is called chronic or persistent pain.*



*Information and guidance supporting all levels  
Visit [www.chronicpainscotland.org](http://www.chronicpainscotland.org)*

## Consultation Questions

The questions included 5 closed questions and 6 open questions, which encouraged respondents to provide further comment, as follows:

**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 healthcare professional
- d) An organisation representing people who experience chronic pain
- e) Other stakeholder

Comments

**Question 2: Please choose your preferred option**

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

Comments

**Question 3: Are there any of the options you disagree with?**

**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.**

**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.

**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)

Comments

**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?**

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

**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

**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

**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

**Consultation distribution list**

Members of the Cross-Party Group on Chronic Pain  
NHSScotland Board Chief Executives (territorial Boards and special Boards)  
NHSScotland Directors of Planning  
National Specialist and Screening Services Directorate (NSD)  
Healthcare Improvement Scotland (HIS)

Scottish MSPs, MPs and MEPs  
Scottish Local Authority Chief Executives  
Scottish Government Library  
Scottish Parliament Information Centre (SPICe)  
Convention of Scottish Local Authorities (CoSLA)

Action on Pain  
Age Concern and Help the Aged Scotland  
The ALLIANCE (formerly the Health and Social Care Alliance Scotland)  
Alzheimer's Scotland  
Ardmillan Hospice  
Arthritis Care  
Association of British Pharmaceutical Industry (ABPI) Scotland  
Association of Community Health Partnerships  
Association of Directors of Social Work  
Ayrshire Hospice  
Bethesda Hospice  
Black and Ethnic Minority Infrastructure Scotland (BEMIS)  
British Medical Association  
British Pain Society  
Capability Scotland  
Care Inspectorate  
Children and Young People's Health Support Group  
Citizens' Advice Scotland  
Coalition for Carers in Scotland  
Community Care Providers Scotland  
Community Food and Health Scotland  
Community Pharmacy Scotland  
Community Practitioner and Health Visitors Association  
Equality and Human Rights Commission (EHRC)  
Equality Network  
Equal Opportunities Commission  
Fibromyalgia Friends Scotland  
Haemophilia Society Scotland  
Headway  
Health Scotland  
Healthy Working Lives National Advisory & Advocacy Group  
Highland Hospice

Inclusion Scotland  
Leuchie House  
Marie Curie Cancer Care  
MS Society  
National Rheumatoid Arthritis Society  
Neurological Alliance Scotland  
North British Pain Association  
Pain Association Scotland  
Pain Concern  
Prince and Princess of Wales Hospice  
Revive MS Support  
Royal College of Anaesthetists Advisory Board for Scotland  
Royal College of General Practitioners, Scotland  
Royal College of Midwives, Scotland  
Royal College of Nursing, Scotland  
Royal College of Paediatrics and Child Health, Scotland  
Royal College of Physicians & Surgeons of Glasgow  
Royal College of Physicians, Edinburgh  
Royal College of Surgeons, Edinburgh  
Royal Pharmaceutical Society  
Save The Children  
Scottish Cancer Coalition  
Scottish Council of Voluntary Organisations (SCVO)  
Scottish Health Council  
Scottish Interfaith Council  
Scottish Partnership for Palliative Care  
Scottish Public Service Ombudsman  
Scottish Recovery Network  
Scottish Womens' Convention  
St Andrew's Hospice  
St Columba's Hospice  
Strathcarron Hospice  
Universities Scotland

Grunenthal  
Medtronic  
Napp  
Pfizer  
Reckitt Benckiser

This email distribution list was used on Monday, 2 September 2013 to advise stakeholders that the (revised) consultation had been re-launched. We have since continued to maintain and update this distribution list as additional interested groups and individuals have notified us that they wish to be kept up to date with future developments.



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