The Scottish Government
Riaghaltas na h-Alba

The Provision of Specialist Residential Chronic Pain Services in Scotland: Analysis of Consultation Responses

Health and Social Care

social research

THE PROVISION OF SPECIALIST RESIDENTIAL CHRONIC PAIN SERVICES IN SCOTLAND

ANALYSIS OF CONSULTATION RESPONSES

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2014

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EXECUTIVE SUMMARY

This report presents the findings of a Scottish Government consultation on "The Provision of Specialist Residential Chronic Pain Services in Scotland". The written consultation took place between 2nd September 2013 and 27th October 2013. Additionally, four stakeholder meetings were held. The consultation document described three options:

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).

A total of 228 submissions were received to the written consultation and 77 participants took part in four events (including people experiencing chronic pain and other stakeholders). Respondents to the written consultation, by self-selected category, were as follows:

Respondent Category	**No.**	**%**
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
Total	228	

Overall views of the options

There was a clear preference overall for Option 1 – a Centre of Excellence in a single location. Among those who ticked a box in the written consultation to indicate their preference, the findings were as follows:

Option ticked	**Number**	**%**
1	154	75
2	28	14
3	12	6
1,2	4	2
1,2,3	4	2
1,3	1	<1
2,3	1	<1
Total	**204**	

Over two thirds of respondents in each of the categories (see table above) expressed a preference for Option 1 suggesting broad support for this.

A small proportion of respondents to the written consultation (5%) ticked more than one option. Participants in all of the stakeholder meetings also favoured a mix of elements, and some other respondents referred to the benefits of including aspects of other options (whether or not they expressed support for a specific option). Over a fifth of all respondents to the written consultation made some comments to suggest the need for, or value of, including elements of more than one of the options.

A small number of respondents suggested other alternatives (see Section 2 of the main report), or suggested that none of the options would be beneficial, or stated that they did not support the need for a residential service.

Perceived benefits of Option 1 related to: the overall high quality of the service and nature of provision; opportunities for staff development and recruitment; ease of delivery and management; the range of provision that could be made; and the positive impact on meeting service users' needs. There were also seen to be benefits in provision being closer to home and addressing some existing travel and access issues, as well as the option being tried and tested, and supported by evidence. Several respondents also identified benefits relating to cost-effectiveness and opportunities for attracting funding.

The most common benefits of the other options (identified by much smaller numbers of respondents than with Option 1) related to the opportunity to offer a service close to home and the lack of need to travel, as well as (with Option 2), the opportunity to use existing knowledge and develop local skills.

A low proportion of respondents expressed concerns with Option 1, but the most common related to travel issues and the single location. Common concerns with the other options focused on delivery and management issues such as their practicality, feasibility and sustainability. There were also concerns about the nature and types of provision possible, and the potential for a lower quality service. Other concerns included the impact on service users through perceived fragmentation, long waiting times, isolation and access difficulties, as well as concerns about staffing difficulties, cost-effectiveness, and the lack of experience and evidence for these options.

Among those who expressed disagreement with one or more of the Options, around 65% identified Option 3 (including both those identifying Option 3 alone and in conjunction with another option). Similarly, around half (51%) identified that they disagreed with Option 2. A smaller proportion (around 10%) identified that they disagreed with Option 1.

Barriers

Barriers to accessing a residential pain management service were seen to include:

- Costs.
- Location and distance.
- Transport and travel issues.
- Family commitments and access to personal support.
- Gaining access to the service.
- Education and employment commitments.

- Physical and mental health issues and personal perceptions of provision.
- The nature of the treatment and the environment.
- Limited funding or staff support for provision.
- Issues for specific groups.

Components of service provision

In terms of aspects of residential pain management services which respondents considered should be included in a Scottish service, the proportions of respondents who ticked boxes to support the inclusion of each of those suggested were as follows:

Aspect of service	No.	%[1]
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 carer / support provider to accompany patient	168	84
Peer support	157	78

Additional suggestions for components of Scottish service provision were:

- Particular types of treatment and therapies.
- Follow-up and review.
- Information, advice and other support to patients, carers and family members.
- Services to meet the needs of specific groups.
- Particular facilities.
- Provision in other settings.
- Planning.
- Social opportunities.
- Research.

Nearly half (48%) of those who expressed a view about the retention of the option of a referral to Bath believed that access should be retained.

Other issues

Many additional comments were made in the consultation about issues such as:

- The current context and nature of services (e.g. the nature of chronic pain; the likely level of demand or need for provision; problems with, and positive aspects of current service provision).
- The consultation itself (e.g. the consultation overall; the processes; questions and issues for clarification; and the role and nature of respondents).

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[1] % of the 201 who addressed this question

- The way forward (e.g. strategic issues; pattern of provision; staff education and training; location of a Centre of Excellence; the timing of developments; funding and resources; and the evidence base).

Overview

The consultation identified three options. Of these, there was a clear preference for Option 1 (a Centre of Excellence in a single location), in some cases in conjunction with another option. A significant number of benefits, as well as a few disadvantages, were suggested for Option 1. Most respondents supported the provision of a wide range of services in such a Centre of Excellence. Option 3 (an outreach or roving service), however, was identified most often by respondents as one they disagreed with. Nearly half of those who expressed a view suggested that access to the residential service at Bath should be retained either on the same basis as at present, or in a modified form.

Respondents identified a wide range of barriers to accessing a residential pain management service, including cost, location, logistical and personal issues.

SECTION 1: THE CONSULTATION

1.1 This report presents the findings of a written consultation carried out by the Scottish Government on “The Provision of Specialist Residential Chronic Pain Services in Scotland”. The consultation took place between 2nd September 2013 and 27th October 2013.

Background to the consultation

1.2 The Scottish Government recognised chronic pain as a condition in its own right in 2009. There have been a number of developments in Scotland in recent years to develop services to meet the needs of people living with its impact. There is now a Scottish Service Model for Chronic Pain[2], and service improvement groups are also being established to implement the model and help to develop chronic pain services locally.

1.3 As part of improving provision, the Cabinet Secretary for Health and Wellbeing has pledged to establish a specialist residential chronic pain service in Scotland. Such provision is currently made at the Royal National Hospital for Rheumatic Diseases in Bath, where people can receive specialist treatment on a residential basis over 2-4 weeks. It is recognised, however, that this location creates a wide range of practical and other difficulties for both patients and those who support them.

1.4 The Scottish Government recognised that there are a number of ways in which a specialist residential chronic pain service could be delivered in Scotland. A consultation was undertaken to enable the widest possible range of stakeholders to consider the options for such a service, and to identify their views of the way forward.

1.5 These views are summarised in this report, and will be considered in making a decision about the most appropriate model for a specialist residential chronic pain service in Scotland in the future.

The consultation process

1.6 The consultation document identified three options for the delivery of specialist residential chronic pain services in Scotland (described further in Section 2). The options presented were:

- 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).

1.7 Respondents were also invited to identify any other ideas. The consultation explored 11 questions, not only about participants’ views of the options, but also about issues such as: barriers to services; components of a service; and personal experiences of service use. Respondents also had the opportunity to make any other

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[2] http://www.knowledge.scot.nhs.uk/pain/scottish-service-model.aspx

comments about the issues in the consultation paper, or current chronic pain services in Scotland.

1.8 Written responses to the consultation were invited, along with the completion of a Respondent Information Form (RIF). A full list of the questions is provided at Annex 1.

1.9 Additionally, the Health and Social Care Alliance Scotland (referred to as the ALLIANCE) organised four stakeholder meetings to discuss the issues raised by the consultation. These were written up by the ALLIANCE and provided to the Scottish Government. These findings have also been included in the analysis and summary.

Submissions and respondents

1.10 A total of 228 submissions were received to the written consultation. Question 1 asked respondents to self-select from a number of pre-determined categories to describe the basis upon which they were responding. These are set out in Table 1 (below).

Table 1. Respondents by self-selected category

Respondent Category	**No.**	**%**[3]
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
Total	228	

1.11 As can be seen from the table, the most common category of respondent was individuals (35%). Also common were responses from other stakeholders (19%). This category included, for example: some NHS and health bodies; Royal Colleges and professional associations; a variety of representative organisations; an MSP; a local authority; and a number of respondents who did not specify the nature of their involvement. Responses were also received from a number of family members or carers of people experiencing chronic pain (14%); health professionals (13%); and organisations representing people experiencing chronic pain (8%).

1.12 As respondents were able to self-select, there was some cross over in the use of categories, particularly “health professional” and “other stakeholder”. Respondents on behalf of NHS bodies (13) used three different categories[4].

1.13 A total of 14 respondents (6%) selected more than one category, generally “individual” and “organisation”. In 11 cases, no category could be determined (e.g.

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[3] % of total respondents to the written consultation.

[4] “a health professional”, “an organisation representing people who experience chronic pain” and “other stakeholder”.

where the respondent had not completed the question, or had not used the form). A list of respondents is given at Annex 2.

1.14 Most of the respondents (215) either used the “new” [5] online form for their response, or substantially followed the sequence of the questions. A small number of responses (9) were submitted using a previous version of the response form or in a letter which did not address any of the questions directly (4). Responses were submitted in both hard copy and electronic formats.

1.15 A total of 77 participants attended the stakeholder events, which were held in:

- Glasgow (23rd August, 2013).
- Inverness (21st October, 2013).
- Dumfries (23rd October, 2013).
- Glenrothes (24th October, 2013).

Analysis of the data and presentation of the information

1.16 The analysis of the data involved a number of stages, as follows:

- An Access database was designed to include the data relating to each of the questions.
- Information was input verbatim, both from the written responses and from the summarised feedback from the ALLIANCE’s stakeholder events.
- Responses to the closed questions were analysed and the quantitative findings prepared.
- A series of Word documents was generated for the qualitative material, containing all of the responses to each of the open questions.
- Key themes and sub-themes were identified for each question, and detailed comments organised into a series of issue-based documents.
- The findings were summarised and the report prepared.

1.17 While much of the information in the report is qualitative, the presentation of the information involves both quantitative and qualitative material. In terms of quantitative information, this covers:

- 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.

1.18 Some aspects of identifying the patterns of views of the options (beyond the information in the tick box question) required subjective judgement. As such, the findings cannot be considered to represent an “exact” number but rather a general indication of the pattern of responses.

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[5] A prior version of the consultation was launched in July 2013 but redrafted and reissued following feedback to the Scottish Government.

1.19 Much of the focus of the analysis, however, was qualitative and the presentation of the material reflects this by highlighting the overall themes and the range and depth of views expressed. The 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.

1.20 It would be inappropriate to attempt to quantify respondents’ detailed views further. Among the reasons for this are that:

- Some points were made at different questions, or overlapped more than one theme and judgement was required to allocate some points to questions.
- Some responses were submitted on behalf of organisations and / or represented the views of a number of respondents.
- The stakeholder events did not involve a “count” of views.
- The focus of the detailed questions was on the identification of views and suggestions to inform the way forward, rather than on any “weighing” of responses.

1.21 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”.

1.22 The wording used to make a point sometimes follows the wording of a response closely. This ensures that a respondent’s point is reflected (even though it is not presented as a “quote”). Where a respondent requested that their material should remain confidential, the source of views presented has not been identified.

1.23 This report clearly cannot present all of the detailed individual points made by every respondent, nor can it provide a compendium of the material. It does, however, summarise the themes and issues raised, and the full text of the responses can be viewed on the Scottish Government website.

1.24 The remainder of the report presents the findings. The sections do not follow the sequencing of questions, but group together those covering related issues, as follows:

- Section 2 covers the findings relating to the three options in the consultation document, and other ideas (Questions 2, 3 and 4).
- Section 3 covers the findings on barriers to services and respondents’ experiences of residential services (Questions 5, 8, 9 and 10).
- Section 4 covers the findings on the questions relating to components of service provision (Questions 6 and 7).
- Section 5 covers any other issues raised in the consultation.

SECTION 2: VIEWS OF OPTIONS

2.1 This section outlines the three options set out in the consultation paper then presents respondents’ views of these options, as well as other ideas.

The options

2.2 The Scottish Government identified three options for the provision of specialist residential chronic pain services in Scotland. These are summarised below.

Option 1 – A Centre of Excellence in a single location

2.3 This option would involve the development of a national treatment and residential service in a single location, with a range of staff specialising in chronic pain. Local residential accommodation would be offered to those patients who wish to stay. This type of residential service would be similar to those provided in: Bath Centre for Pain Services; Pain and Fatigue Management Centre at Bronllys, Wales; and the INPUT pain management unit at Guys and St Thomas’s, London.

Option 2 – A service delivered by local chronic pain clinicians supported by other clinical advisors in another part of the country

2.4 This option would involve local skilled chronic pain teams providing the service, with remote support from other experienced staff from a central point or hub. A patient could have a consultation and assessment in their local area, but involve other clinical advisors using technology. The clinical advisor would work with and support the local team, who would provide the treatment on a day to day basis over a 2-4 week period. Local residential accommodation would be offered to patients who wish to stay. This would be similar to service models used for other chronic health conditions which need a very specialised service and access to additional advice.

Option 3 – A service delivered in different locations by a team of chronic pain specialists (an outreach or roving service)

2.5 This option would involve the service being provided by a specialist chronic pain team who would go to different parts of the country. The team would be organised and managed by one NHS Board and travel to other health board areas to carry out assessment clinics. They would then work with and support local teams to deliver the treatment daily over a 2-4 week period. Local residential accommodation would be offered to those patients who wish to stay. This model has not yet been tested in Scotland, as other services provided on an outreach basis tend to have only outpatient or day case appointments, and do not have residential accommodation.

Views of the options

2.6 Questions 2 and 3 sought respondents’ views of the options presented. For reference, the questions are set out below:

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 below.

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

If yes, please tell us which one(s) in the comments box, and why?

2.7 The findings are considered together in determining the overall pattern of views.

Overall views

2.8 Almost all of the written respondents (89%) ticked a box at Question 2 to indicate their preferred option. A small number (11%) either:

- Completed the previous response form (which did not offer these choices).
- Did not tick a box but made comments (a few of whom stated that they did not have a preferred option or were unable to select one).
- Did not address this question directly.

2.9 Respondents' overall preferences were also explored in the stakeholder meetings.

2.10 Of those who ticked a box at Question 2, around 85% made additional comments. Relevant comments were also made in all of the stakeholder events and by a small number of other respondents who did not tick a box.

2.11 Table 2 (below) sets out the preferred options of those who ticked boxes:

Table 2. Preferred option

Option ticked	Number	%
1	154	75
2	28	14
3	12	6
1,2	4	2
1,2,3	4	2
1,3	1	<1
2,3	1	<1
Total	**204**	

2.12 There was a clear preference overall for Option 1. Among those who answered Question 2 in the written consultation, three quarters (75%) ticked a preference for Option 1, while much smaller numbers[6] expressed a preference for the other options. Only 14% ticked Option 2 and 6% Option 3. A small proportion (5%) ticked more than one option, suggesting a preference for a combination of options, or “either / or” between different options.

2.13 Over two thirds of respondents in each of the categories (see table above) expressed a preference for Option 1 suggesting broad support for this.

2.14 These overall preferences were also reflected in responses to Question 3 (relating to options respondents disagreed with). Just over half of written respondents (54%) addressed this question. Most identified an option (or, in some cases, options) they disagreed with. Most also made additional comments relating to their views.

2.15 Overall, around 65% of those who addressed this question identified that they disagreed with Option 3 (including both those identifying Option 3 alone and in conjunction with another option). Similarly, around half (51%) identified that they disagreed with Option 2. A smaller proportion (around 10%) identified that they disagreed with Option 1.

2.16 Some respondents (while expressing a preference for a specific option) also suggested that elements of the other options would be beneficial. In addition, a small number of respondents who did not tick any box at Question 2 expressed a preference for a combination of options. Overall, over a fifth of respondents to the written consultation identified benefits of some combination of the options. Participants in each of the stakeholder meetings also favoured a mix of elements of the options, generally suggesting a combination of a Centre of Excellence at a single location, alongside local provision.

2.17 Questions 2 and 3 also explored respondents’ reasons for their overall views, and most made additional comments. These issues were also addressed at the stakeholder meetings. Views given at Question 2 tended to focus largely (although not only) on the perceived benefits of the particular option the respondent supported. Conversely, views at Question 3 tended to focus largely on concerns about options they did not support.

2.18 There were, however, some areas of overlap in the issues arising at each of the questions, and these comments are considered together. Some perceived benefits and drawbacks of particular options were also highlighted in response to other questions, and these have also been incorporated below.

Views of Option 1

2.19 Where respondents made additional comments at Question 2, the most common (by almost three quarters of these respondents) were about benefits of Option 1.

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[6] Proportions here relate to those who ticked one of the options.

2.20 A low proportion of respondents (around 10%) expressed disagreement with Option 1 at Question 3, and some concerns were highlighted by a similar proportion. The most common concerns related to location and access issues.

Option 1 – benefits

2.21 A frequent theme in terms of the benefits of Option 1 was the perceived high quality of the service with Option 1. Some respondents identified an overall need for this approach, or stressed its general benefits (e.g. in terms of being seen to provide the best service; being the most “sensible” or “practical” option; or presenting fewer challenges than the other options). It was also argued that the adoption of Option 1 would help provide priority for, and a focus upon the management of chronic pain.

2.22 Another frequent theme related to the overall nature of provision. Several respondents made comments on the opportunity for the development of excellence (e.g. a “world class” or “flagship” service), the opportunity for recognition and the development of leadership in chronic pain management in Scotland.

2.23 A number of comments focused on the perceived value of having a team of expert, well-trained trained staff located together in one setting, with concentrated expertise and a breadth of knowledge. Related to this, it was argued that there would be sufficient patients to develop and maintain this expertise and sufficient staff for a Centre to operate at all times. It was also suggested that Option 1 would enable all necessary facilities to be made available and provide a permanent base.

2.24 Staff issues were also a common theme. Many comments were made about the opportunity for staff development and learning. It was suggested, for example, that a Centre could offer training, learning and support to a range of staff (including the opportunity to learn from patients). It was also suggested that it could provide a learning “hub”, and enable shared knowledge, information, experience and best practice. Benefits in terms of attracting and retaining staff were also identified. It was suggested that specialists with existing expertise would be attracted to a Centre of Excellence.

2.25 In terms of the theme of management and delivery issues, it was suggested that this option would be most likely to deliver the service required, as well as being easier to manage and implement, and more sustainable. Benefits were also highlighted in terms of Option 1 being easier to monitor, inspect, audit and report upon. Some noted that it could also help support the development of local services.

2.26 Benefits were identified in relation to multi-disciplinary working (e.g. to meet complex needs), the delivery of integrative care, and the provision of a joined-up, rather than a fragmented service. It was also suggested that Option 1 would facilitate good communication, good links and effective patient follow-up.

2.27 Comments on types of provision were also common. It was suggested that Option 1 could offer a range of support and treatment. Comments were made on opportunities for specific kinds of provision, particularly peer support (which, it was suggested, may not be possible in the other options) but also traditional and complementary approaches and opportunities to try mobility resources. It was also suggested that there would be opportunities for research, development and innovation.

2.28 An additional theme was the positive impact on service users. There was a general view that this option would be beneficial to patients and carers in terms of meeting their overall needs and providing support. It was seen to provide a “rounded” service in one centre focusing on chronic pain care, as well as working with patients for a period of time.

2.29 It was also suggested that this option would have a positive impact on:

- The availability of equitable provision.
- Continuity of care.
- Access to information.
- Patient confidence.
- Reduced waiting lists elsewhere.
- Support to carers.

2.30 At a more specific level, it was also argued that Option 1 could best meet the needs of specific groups (e.g. minority groups; people in rural areas; and paediatric patients).

2.31 Location and access issues were also identified frequently among the benefits of Option 1, particularly in terms of a Scottish service being closer to home and addressing some of the current travel and access barriers both for patients and visitors (discussed further in Section 3). It was also argued that a single trip would be preferable to frequent journeys for treatment.

2.32 The view that Option 1 builds on both experience and evidence was also common. Many commented that Option 1 has been “tried and tested” as a method for treating those with chronic pain and the related issues. It was suggested that it is supported by the current evidence base (e.g. from specialist pain services elsewhere in the UK, from other services addressing specific conditions and from some respondents’ own experiences).

2.33 It was suggested that Option 1 would be cost-effective (e.g. by delivering economies of scale and removing duplication) and offer value for money. A view was expressed that a Centre was the most likely option to be fully funded, and that it would encourage external funding (e.g. for research). One respondent argued that it would be beneficial to put resources into a Scottish service.

Option 1 – issues and concerns

2.34 A low proportion of respondents expressed disagreement with Option 1 at Question 3, and / or raised issues and concerns. The most common concerns (although from a small number of respondents) were about location and access issues, particularly the need to travel (and related barriers such as distance, transport links, health, and weather issues). Concern was also expressed about the potential inaccessibility of a single location to some service users.

2.35 A few respondents expressed concerns about their perceptions of the likely overall quality of the service or expressed a preference for another option. A few also expressed concerns relating to specific aspects of the service, particularly the residential focus. It was suggested that: this would not be most patient-centred; it would be an artificial environment; it would be short term; and it would be contrary to other aspects of the overall policy direction.

2.36 One respondent suggested that there had been no attempt to assess the extent to which needs could be met by strengthening local services. A concern was also expressed by a further respondent about a potentially negative impact on local services.

2.37 Staffing concerns were also raised by a few respondents. These related to three main areas: recruitment (e.g. a potential shortage of highly trained clinicians and the potential to detract from current services); the impact on local clinicians who feel they cannot provide the treatment; and the impact on skills (e.g. with no “upskilling” of local staff and the potential for skills to be lost).

2.38 A very small number of respondents raised concerns relating to delivery and management issues, including: the practicality and sustainability of the option; and the implications for clinical responsibility and clinical governance.

2.39 A few concerns were raised about the implications of Option 1 for aspects of provision such as self-management, follow-up and maintenance. Similarly, some concerns were raised about the implications of this option for service users’ experiences, such as patient-centred care. The potential for both a lack of equitable access for patients and for the development of waiting lists was also noted. It was also suggested that this option would not meet the needs of all patients with chronic pain.

2.40 A very small number of respondents raised concerns about experience and evidence (e.g. whether there would be sufficient referral numbers to justify a new service; and the view that the model has been superseded in other parts of the world due to a perception of inefficiency, and ability to address only small numbers).

2.41 A very small number also raised concerns relating to funding and costs (e.g. high set up costs; higher costs than sending patients to Bath; follow-up costs; and the implications for resources to local services).

Views of Option 2

2.42 A small proportion of respondents identified benefits of Option 2 (around 13% of those who made additional comments at Question 2). A large number raised concerns (around half of those who addressed Question 3).

Option 2 – benefits

2.43 The most common perceived benefits of Option 2 related to location and access. It was suggested that Option 2 offered a service close to home (which, it was argued, accords with the Scottish Chronic Pain Service Model). It was also suggested that it would reduce the need to travel (viewed as important given the travel barriers for people experiencing chronic pain). It was argued that such a service would be more accessible and would promote greater equity of access, and deliver a good quality local pain services in all areas. The ability to consult with experienced and specialist clinicians (particularly in the early stages) was also considered beneficial.

2.44 Some respondents identified staffing benefits with Option 2. It was argued, for example, that there would be an increase in local skills. It was also argued that there would be benefits in terms of promoting local employment and removing the need for additional recruitment. It was suggested that Option 2 would lead to better staff retention.

2.45 A small number of respondents identified benefits in terms of the potential overall quality of the service with Option 2. It was suggested that this would offer the opportunity to build on and improve existing pain services, with additional support from the “hub”. One respondent argued that it would be the most effective, comprehensive and sustainable option and that it could bring about an intervention which could be a national standard. It was also suggested that developing local clinicians’ skills would support the Scottish Government’s pain agenda.

2.46 A small number also identified benefits in terms of both delivery and management. It was suggested that Option 2 would:

- Be quick to set up.
- Be more practical than a “roving” service.
- Enable a collaborative and flexible approach.
- Enable the development of local services.
- Support links to other local services and initiatives.

2.47 A small number identified opportunities for particular types of provision, including the use of telehealth, and the provision of follow-up and maintenance of support.

2.48 Benefits in terms of the impact on service users were identified by small numbers including:

- Providing a tailored approach to meeting patients’ needs (e.g. by drawing on the skill set of several health boards and meeting the needs of people in rural communities).
- Being more responsive to demand.
- Increasing confidence.
- Enabling support from friends and family.
- Providing consistency.
- Minimising waiting times.

2.49 A very small number of other benefits of Option 2 were identified. These included that it would be cost-effective through using existing expertise, and offer investment opportunities through demonstrating the lack of equity.

2.50 It was also suggested that there was a lack of evidence of the level of need for Option 1.

Option 2 – issues and concerns

2.51 Common areas of concern related to delivery and management issues, particularly the practicality, feasibility and sustainability of this option. Views were expressed that it: would not work; could lead to duplication of arrangements already in place for supervision; or would take an unacceptable length of time to set up. It was also suggested that the option would require inter-regional working (which would need dedicated resources).

2.52 A further common area of concern related to types of provision. Issues were raised about the lack of opportunity for face to face provision by specialist staff, with some offering the view that chronic pain consultations need to be undertaken in person. Some specific concerns were expressed about telehealth (with phone or video links) as a means of support. These included not only the lack of face to face contact, but other issues such as:

- Lack of clinician time.
- Lack of access to appropriate technology in some areas and for some patients.
- Lack of peer support to make this successful.

2.53 Several respondents raised concerns about the perceived overall quality of the service. Comments included views that Option 2 could dilute the benefits of a Centre of Excellence and that it would replicate current provision (or at least not add value). It was also suggested that it would compromise the ability to deliver continuity and quality of treatment.

2.54 Several also raised concerns about the impact of Option 2 on service users' experiences. It was suggested that treatment would be fragmented, disjointed and "piecemeal". It was also suggested that there could be lengthy waiting times relating to the level of demand and the need to accumulate sufficient patients. It was also suggested that provision to patients in different areas could be inequitable and that some patients may not be referred to the service.

2.55 A small number of concerns were also raised with location and access (e.g. inequality of access; multiple journeys). It was also argued that patients may feel isolated, and that attendance at different clinics may cause travel difficulties or impact on employment.

2.56 A small number of comments focused on concerns about funding and costs. These included concerns about the overall cost, or cost-effectiveness of Option 2, and the need for additional funding. The cost of training was mentioned specifically in this context. It was also suggested that funding for this option may be vulnerable and at risk of being limited, reduced or withdrawn.

2.57 Small numbers of additional concerns were expressed about the overall nature of the service in Option 2. These included a suggestion that it may not be possible to develop and provide the necessary expertise and specialist skills through this option. It was also suggested that the option would not provide the time period needed to work with patients and that it may dilute or undermine the residential element of the service.

2.58 It was suggested that the service would not be staffed by specialists or that suitable accommodation and facilities may not be available. At a practical level, it was also noted that it would be difficult for a remote expert to assess difficulties during a programme and give reliable guidance to a local team.

2.59 A very small number of staffing concerns were raised relating to difficulties in recruitment, and the availability of staff with the specialisms required. Potential variation in local expertise was also noted. A few respondents also raised concerns relating to experiences of similar types of provision (e.g. personal negative experiences of local assessment).

2.60 The lack of evidence for the effectiveness of this option was also suggested.

Views of Option 3

2.61 A small number of respondents identified benefits of Option 3 (around 6% of those who made additional comments at Question 2). Option 3 attracted the highest number of comments on issues and concerns (around 60% of those who addressed Question 3).

Option 3 – benefits

2.62 As with Option 2, the most common benefit identified (albeit by only a small number) related to location and access issues, particularly the local nature of provision and the lack of need to travel.

2.63 A very small number of positive comments were made about the overall perceived quality of the service, or respondents' general preference for the development of local services. A few respondents also highlighted delivery and management benefits, such as the development of a team approach and provision by local staff.

2.64 A few mentioned opportunities for particular types or means of provision (e.g. tailored provision and sustained peer support). A few also identified a positive impact on service users' experiences (e.g. through providing access to specialist provision for particular groups; and avoiding financial and emotional costs).

Option 3 – issues and concerns

2.65 Delivery and management issues were a common area of concern with Option 3, particularly suggestions that this would not be practical, workable, viable or sustainable. As with Option 2, it was suggested that this option would require inter-regional working (which would need dedicated resources, and may be difficult for members of different teams being brought together on an ad hoc basis). It was also argued that the option would take an unacceptable length of time to set up and that co-ordination and management would be challenging.

2.66 Staffing concerns were also common in relation to Option 3, particularly the perceived difficulties of recruiting and retaining staff. It was argued that the requirements of the staff role would create difficulties, including the level of specialism required. It was also noted that there is a current shortage of qualified and experienced chronic pain professionals in parts of Scotland.

2.67 At a practical level, it was suggested that the geography of Scotland and the nature of the service would require clinicians to be away from home for long periods, which would be unattractive to them. A concern was also expressed about the impact on local services of the involvement of “mobile” staff.

2.68 Amongst the concerns about the impact of this option on service users’ experiences were that it could lead to variation, inconsistency and fragmentation of provision. It was also suggested that it would lack a stable clinical base and could lead to isolation for patients and have disadvantages for patient-centred care. It was further argued that there could be lengthy waiting times. A number of reasons were offered for this concern, including small numbers and the need to accumulate a viable number of patients in an area, or as a result of the delivery team working elsewhere in Scotland. It was also suggested that fewer patients may benefit from such a service.

2.69 Several respondents raised concerns about experience and evidence, particularly what they saw as the untried and untested nature of the service. One respondent suggested that this option would need to be piloted before any future investment was made.

2.70 Other concerns identified by several respondents related to the overall perceived quality of the service. It was suggested, for example, that:

- The benefits of a Centre of Excellence would be lost or diluted.
- Provision could be “hit or miss”.
- The logistics of delivery might detract from the quality.
- There would be a lack of added value.
- The level and standard of provision would not be sufficiently high.

2.71 Concerns about funding and costs were also raised by several respondents. It was suggested that this option could be expensive as a result of specialists travelling to different locations. One respondent suggested there could be a need for incentives. It was also argued that this option could lead to a lack of investment in local pain services. There were also concerns about funding vulnerability.

2.72 Concerns were also raised about location and access issues including:

- Geographical variations in the provision of services.
- Access difficulties for staff attending specific areas (e.g. rural areas).
- The need for some patients still to have to travel and require accommodation.
- The travel time and distances involved in some areas.

2.73 Concerns about the overall nature of the service were also raised. It was suggested that Option 3 would not enable the necessary expertise to be developed. It was suggested that some areas would not have sufficient facilities. It was also suggested that there could be variation in the availability of appropriate accommodation.

2.74 As with Option 2, it was suggested that the residential concept could be diluted or undermined, and that the accommodation may not be staffed or supported by chronic pain specialists.

2.75 In terms of particular types or means of provision, it was suggested that there could be difficulties in providing group work and peer support with this option, as well as follow-up. It was also suggested that the option would not provide a sufficient time period for effective work.

Other options

2.76 Question 4 asked respondents to identify other ideas they may have. For reference, the question is set out below:

> 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.

2.77 Over a third of respondents addressed this question (39%), and suggestions were also made in the stakeholder meetings. Among respondents to the written consultation, however, the most common theme was not the identification of alternative options, but the identification of particular aspects of service provision, or the means of taking this forward. These are discussed in Sections 4 and 5.

2.78 A small number of respondents did, however, suggest other options at Question 4, although the most common suggestion was some form of combination of Options 1 to 3 (as set out in Question 2). As noted earlier, a small number of respondents had also identified their support for a combination of options by ticking more than one box at Question 2. Some respondents in all of the stakeholder meetings also expressed support for a mix of elements of the options presented.

2.79 Additionally, some respondents made reference elsewhere in their responses to the need for (or benefits of) the inclusion of aspects of other options as part of the development of provision in Scotland (whether or not they expressed support for a specific option).

2.80 Although it is impossible to provide a definitive number (given the nature of the data), the material suggests that over a fifth of all respondents made some comments suggesting the need for, or value of, the inclusion of elements of more than one of the options in the service provided in Scotland.

Combination of options

2.81 Where respondents suggested a particular combination of options, the most common was Options 1 and 2, or elements of all three. Some comments focused generally on the need for a combination of a specialist Centre of Excellence at one location, alongside, for example:

- Support for the improvement and development of high quality local pain services (and links to, or integration with such provision).

- The use of telehealth options (although, as noted, there were also some concerns with this).
- Outreach work (including, for example, domiciliary care and peripatetic work).

2.82 Some respondents suggested the potential to develop additional elements of provision at a later stage, including expanding to other areas and / or types of provision following the development of a Centre of Excellence.

2.83 It was also argued that it should be made clear that the establishment of a Centre of Excellence or specialist service should not be an alternative to, or at the expense of the continuing development of local pain services and that all regions should have appropriate provision in place.

2.84 Comments on the perceived benefits of a combination of options included overcoming perceived problems or gaps with a specific option in isolation, or providing a response to a perceived lack of evidence to support a specific option. The importance of good local services (and access to specialist input in some form at this level) was also identified as a benefit. Further benefits were seen to be the opportunity to provide the best service and choice for patients (given the variation in individual needs) and better health. It was also argued that this approach would align with wider Scottish Government objectives.

2.85 Suggestions were also made about the potential roles of a Centre of Excellence and local services. In relation to a Centre of Excellence, these included:

- Dealing with complex needs.
- Acting as a “hub” for service provision, learning and research.
- Providing specialist expertise and intensive treatment.
- Providing training and advice.

2.86 Suggestions about the role of local provision included that it could:

- Offer early intervention and assessment.
- Identify issues.
- Work locally with patients (including those with less complex needs).
- Provide regular local specialist clinics.
- Provide patient follow-up.

2.87 It was suggested that local services could meet the needs of those who did not, or could not attend a Centre of Excellence, and that they could generally complement the support provided at a Centre.

Alternative approaches

2.88 A small number of respondents suggested other alternatives, suggested that none of the options would be beneficial, or indicated that they did not support the need for a residential service.

2.89 Specific alternative suggestions included the development of satellite units in each health board area, offering beds and facilities for residential patients, and linked to a Centre of Excellence. It was suggested that this solution would demonstrate a commitment to helping individuals improve their lives closer to home. A further suggestion was the development of more than one Centre.

2.90 One respondent suggested a partnership with other regions or nations (e.g. Northern Ireland, Wales or Northern England), arguing that this could perhaps address perceived issues relating to the high costs and relatively small number of patients in the establishment of a facility in Scotland.

2.91 A few respondents suggested targeting resources elsewhere, such as:

- Improving the current inconsistency in funding of pain services.
- Investing at community / primary care level and providing multidisciplinary non-resident pain management in patients’ local environments.

2.92 It was suggested that multidisciplinary non-resident local services could help tailor approaches to individual circumstances and daily life, as well as providing the option of regular follow-up, support and refreshment of pain management skills. It was also argued that this model was being used successfully elsewhere.

2.93 A few argued that the long term care of sufferers should be improved. Suggestions included stopping treating chronic pain as an acute illness, and improving integration with other organisations to support chronic pain patients for the longer term.

Other comments and suggestions

2.94 As well as providing respondents’ overall views of the options presented, many respondents made additional comments or suggestions in their responses to Questions 2-4. Most of these focused upon aspects of a Scottish service they considered necessary (either in relation to a specific option or overall), or the means of taking the provision of specialist residential chronic pain services in Scotland forward.

2.95 Comments were also made on a small number of other issues, including: the nature of current provision; questions or issues for clarity; or comments on the consultation itself. All of these issues are discussed more fully in Sections 4 and 5.

SECTION 3: BARRIERS TO SERVICE PROVISION AND RESPONDENTS' EXPERIENCES

3.1 This section presents the findings on barriers to service provision and respondents' experiences of residential services (covering Questions 5 and 8-10 in the consultation document).

Barriers to accessing a residential pain management service

3.2 Question 5 asked respondents to identify any barriers to accessing a residential pain management service. For reference, the question was:

> 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.

Overall views of barriers

3.3 Around three quarters of respondents to the written consultation (74%) addressed this question directly, and almost all identified barriers. Barriers were also identified in the stakeholder meetings, and at other points in stakeholders' responses.

3.4 In addition to identifying barriers, around a third of these respondents (and some participants in the stakeholder meetings) also made comments about ways to overcome the barriers. Some argued generally that the barriers could be overcome, or that people in chronic pain would view relief from pain as the priority, and would address barriers in order to access treatment.

3.5 Similarly, several respondents qualified their response by suggesting that there were few (or no) barriers for people experiencing chronic pain, or that the benefits of getting intensive treatment and dealing with the pain would outweigh any barriers. Some suggested generally that there would be fewer barriers with the provision of residential chronic pain services in Scotland.

3.6 Respondents provided a large amount of information about the nature of barriers and ways to address these, and these are detailed below.

Costs

3.7 The barriers identified most frequently related to costs. Financial issues (for the patient and family or other support providers) were noted as presenting a general barrier for many. Many of the comments relating to costs focused specifically on the cost of travel and the lack of provision of "upfront costs". It was argued that expenses are high, and patients have to wait for reimbursement. One respondent stated that there are different arrangements for this in different health board areas.

3.8 Comments were also made about other specific costs, such as:

- Visits.
- Accommodation and subsistence.
- Lost working time.
- Carer expenses.
- Childcare expenses.

3.9 Comments were also made about the financial circumstances of some people who experience chronic pain (e.g. low income, receiving benefits, in debt or poverty). These were seen to exacerbate financial barriers. One respondent also suggested that home insurance (e.g. when the house is empty) can be an issue for people experiencing poverty.

3.10 A few comments were also made on the cost of provision to the government, and the cost of residential provision.

3.11 Comments were made frequently about the need to address barriers relating to costs. Suggestions included the provision of general financial support to meet costs (for patients and carers), as well as the provision of help with benefits. It was also argued that travel costs should be met and upfront costs paid (or reimbursed promptly). A suggestion from the stakeholder meetings was for clear guidance about financial support, and to ensure that people understand how to claim expenses.

3.12 A few respondents suggested potential means of delivering a subsidy to service users. It was suggested in one of the stakeholder meetings that there may be a future role for Third Sector organisations to support people who are struggling to cover upfront costs. It was also suggested that costs to service users would be less with Scottish-based provision.

3.13 In terms of the costs of service provision overall, it was suggested that it would be important to consider the long term savings and efficiency of provision (e.g. return to work, and savings from a single location).

Location and distance

3.14 Location and distance were also among the barriers identified most commonly. Among these, most comments focused on issues such as the distance of provision from a service user’s family, home environment or work, and the implications of distance for travel time.

3.15 A link between travelling time and the likelihood of visits was identified. It was argued that the distance from a service user’s home environment may also be challenging, and may impact on the success of the work carried out and the opportunity for follow-up.

3.16 Suggestions about addressing barriers relating to location and distance were also common. These included the view that provision in Scotland would lessen these (by, for example, having shorter travelling distances compared to travelling to England). While some respondents argued that a degree of travel would be required wherever services were located, it was also noted that there are existing transport links in Scotland.

3.17 Some respondents also argued that people in remote and rural areas are used to travelling to access services. A further view expressed was that having a single location would reduce or remove the need for repeated trips. Some respondents, however, stated that distance would still be significant for some service users (e.g. people in remote or rural areas), or may remain a problem for some.

3.18 Other suggestions to address location and distance barriers included having an accessible location with good transport links (and parking) and an established pain management programme. It was also suggested that the provision of additional centres and local support (including outreach) could help. Additionally, some specific suggestions about the location of the Scottish service were made at various points in respondents' material. These are considered further in Section 5.

Other transport and travel issues

3.19 More general transport and travel barriers were also highlighted. Some respondents mentioned general travel difficulties for people experiencing chronic pain. Most comments, however, focused particularly on some patients' lack of fitness to travel and the pain experienced during travel.

3.20 Other issues raised included the lack of access to, or availability of suitable transport (including physically accessible transport) or a lack of access to support with transport. A few respondents highlighted difficulties of planning transport to a service location (and the additional stress of this). One respondent argued that the number of stages in a journey, or the mode of transport available may be more of a barrier than the distance. Comments were also made about the potential impact of the weather and the difficulties of parking in some healthcare environments.

3.21 Many respondents made suggestions about ways to address these barriers. It was suggested that patient transport, community transport and other supported travel options should be available, in addition to meeting travel costs, considering the location of a service and providing local services.

3.22 It was also suggested that some patients would need rest time to recover from the journey before participating in treatment. The view was also expressed that the service in Bath should remain an option for some patients who may find this easier to access.

Family commitments and access to personal support

3.23 A further common theme was the identification of barriers relating to family commitments and access to personal support. While some respondents highlighted general family and home commitments (for patients and carers), most of the comments focused on more specific issues.

3.24 Several respondents mentioned childcare and other caring responsibilities (e.g. caring for elderly or disabled people or for pets). Barriers were also identified in terms of the amount of time away from family and home, and the consequent lack of access to personal and social support and care (practical and emotional). A few comments were also made about barriers relating to other support required (e.g. language and communication; assistance dogs; and particular equipment).

3.25 A number of suggestions were made about ways of addressing these barriers. For example, it was suggested that social care and respite support could be provided to assist with caring responsibilities. It was also argued that there should be opportunities for family members to stay, for carers / support providers to attend, and for carers' needs to be met. One respondent suggested that there should be access to a phone taking incoming calls, and a computer (for Skype and email contact). Additionally, it was suggested that equipment and other practical needs should be considered and met.

3.26 It was also argued that, for some patients, provision in Scotland would make it easier for friends and relatives to visit, or for someone to accompany them.

Gaining access to the service

3.27 Many respondents mentioned barriers to gaining access to the service. Several made comments on difficulties in getting a referral, such as:

- 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.

3.28 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.

3.29 A few respondents made suggestions about addressing such barriers. These included having: early diagnosis; prior support (e.g. group sessions or access to a specialist); clear and well-communicated referral arrangements; and adequate staff. It was also suggested that there should be equal access to the service, and education and awareness raising for those making referrals.

Education and employment issues

3.30 Education and employment issues were also highlighted as barriers by many respondents. Some cited general commitments, while others highlighted more specific issues. It was suggested, for example, that it may be difficult to get time off (for the patient and family members). Some respondents suggested that there could be problems such as loss of earnings or even loss of a job. Others noted a potentially negative impact on promotion prospects, or an impact on holiday entitlement (or the need to use annual leave to attend).

3.31 One respondent stated that children and young people may miss schooling and exams.

3.32 A few respondents made suggestions about ways of addressing education and employment barriers. These included the provision of support by employers and the provision of information and support to employers. One respondent suggested that access to a dedicated disability team helping people in work may be necessary. It was also suggested that services should meet the needs of children and young people (and this is discussed further at 4.57).

Physical and mental health issues and personal perceptions of provision

3.33 A further common barrier related to physical and mental health issues and personal perceptions of provision. As noted previously, the nature of pain was seen to present some travel barriers. It was also suggested that personal attitudes to pain may be a barrier. It was suggested at one stakeholder meeting, for example, that people may “underplay” their level of pain.

3.34 There were also seen to be barriers from the effects of specific issues or conditions (e.g. severe fatigue; complex nursing care needs; multiple health conditions; neurological conditions; and mental health problems). A few respondents stated that age could impact on accessing a service.

3.35 Additionally, several respondents mentioned patients’ perceptions of provision which may create barriers, such as:

- Expectations of the service.
- Previous negative experiences.
- Uncertainty and anxiety.
- Perceived stigma of being “sent away”.
- Concerns about a lack of anonymity.

3.36 In terms of addressing these barriers, it was argued that local provision could provide an option for many patients. It was also suggested that there should be education and awareness raising about the services available. One respondent suggested that a virtual tour of what to expect at a residential facility would help address some anxieties.

3.37 Some wider points about information and awareness raising as part of the way forward are considered further in Sections 4 and 5.

Aspects of the type of provision available

3.38 Aspects of the nature of service provision available were seen by several respondents as a barrier. These included the types of treatment and therapies available. Potential barriers were seen to include, for example, over “medicalisation” and use of medication, or a lack of access to some forms of treatment or input to meet patients’ needs.

3.39 Additionally, it was suggested that the duration of the treatment term could be a barrier, as could potential difficulties posed by a long period of continuing consultations. It was argued that the environment and facilities available could present potential barriers. There were also seen to be barriers relating to local services (e.g. the potential for polarisation of skills; the absence of appropriate pain services; and a lack of development of such services).

3.40 One respondent suggested that a residential pain management programme may hinder the implementation of the Scottish Service Model. They stated that it may be interpreted that patients' needs were seen to be being met.

3.41 A few suggestions were made about ways to address barriers relating to the nature of provision available. These focused on the provision of specific types of treatment and therapies (discussed further in Section 4) or access to particular facilities or means of provision. These included:

- A nurse-run residential in-patient unit.
- Appropriate residential facilities to meet a range of needs.
- The opportunity to return home.
- Multidisciplinary provision.
- Local support and provision.
- Flexibility in provision.
- The use of telemedicine and outreach.

3.42 It was also suggested that there should be research into chronic pain in the context of developing information systems for long term conditions monitoring.

Barriers for specific groups

3.43 A small number of respondents identified barriers for specific groups.

3.44 Among the groups identified were people in rural areas, particularly in terms of travelling distance, but also the existence of poverty in such areas.

3.45 Issues were also raised for children and young people. For example, one respondent stated that, for paediatric patients, the issue of timing would be important in terms of whether to treat them in holiday or school time (with the issue of the impact on education raised above). It was also suggested in one of the stakeholder meetings that self-management courses provided by the voluntary sector are often not open to children and young people.

3.46 Potential communication (and hence access to services) barriers were identified for deaf people; ethnic minority service users; and people with learning disabilities. There were also seen to be barriers for some people with specific conditions and co-morbid difficulties.

3.47 Suggestions focused on ensuring services meet the needs of these groups, and these are covered in Section 4.

The level of support for provision

3.48 A few respondents highlighted barriers relating to the level of support for provision. These included barriers relating to how the provision would be funded, whether there would be sufficient funding provided and whether there would be ongoing funding. It was also suggested that job security for staff could be a barrier, as could staff attitudes (e.g. unsupportive medical staff).

3.49 Some general suggestions about funding and resource issues were made at various points in respondents' material, and are considered further in Section 5.

Respondents' experiences of residential services

3.50 Questions 8-10 asked about respondents' experiences of residential services outside Scotland. For reference, the questions are set out below:

> 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.
>
> 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?

Previous use of services

3.51 A total of 23 respondents (10%) to the written consultation indicated that they had previously attended, or supported someone attending a residential service outside Scotland. Most also provided details of the advantages and disadvantages of this. A total of 27 respondents made comments at Question 9 (including a few who did not address Question 8).

3.52 Although a small number stated that they had personal experience of these facilities, most identified that they had knowledge of others' use of the facilities (e.g. through working with them in a professional capacity, or knowing them as a peer). A very small number had been involved as staff in such a facility. In a few cases, the nature of contact was unclear.

3.53 A few respondents gave their reasons for use of the facilities, and these included a lack of services locally and a need to access specialist provision. One respondent stated that local clinicians had sought peer support from clinicians based in Bath.

3.54 Several respondents identified the particular facilities they had attended or had supported someone to attend. These included: Bath; Abingdon Hospital; the Chronic Fatigue Syndrome clinical service in Newcastle; and a spinal unit.

Advantages

3.55 Among advantages of attending these facilities, some respondents highlighted the overall effectiveness of the provision by stating that it had worked well, or that the facility (in this case Bath) was recognised as a centre of good practice. Other general comments included that the patient had had a positive experience, or that there had been a positive impact upon them (e.g. enabling them to manage their pain). One respondent provided personal details of beneficial changes that had been made to their day to day life through attendance at Bath.

3.56 Some of the advantages related to the particular nature of provision available and the support received. A few mentioned the importance of the correct diagnosis having been made, and appropriate treatment having been started (which, in turn was identified as being able to improve functional impairment and quality of life).

3.57 Some aspects of the overall approach adopted were also highlighted as positive, such as:

- An empathetic service.
- Recognition of the problem.
- Honesty and realism.
- Support tailored to the individual needs of the patient.
- A positive environment.
- A consistent message from the pain management team.

3.58 Several comments were made about the benefits of having had access to a specific service. These included general comments about accessing a pain management service, or a service not currently available in Scotland. Comments on more specific issues highlighted the provision of intensive help and support over a greater number of hours, and the residential nature of the provision. A few respondents noted, however, that people with mobility issues would not be able to travel to a programme on a regular basis.

3.59 The opportunity for peer contact and group work support was also highlighted as beneficial. One respondent, for example, stated that they had been able to have contact with people the same age, facing similar issues. The inclusion of, and provision of support to other family members was also highlighted. A few respondents identified the constant availability of healthcare staff, or provision of follow-up telephone contact.

Disadvantages

3.60 The disadvantages highlighted most commonly related to aspects of the nature of provision available, particularly the lack of long term support. For example, a few respondents cited the lack of local support and maintenance, or stressed the need for ongoing support to maintain and sustain the benefits and enable progress to continue.

3.61 One respondent stated that the need to assess patients prior to being sent to Bath, reassess them after the programme, and provide follow-up has implications for resource management and clinical governance. It was also argued that provision of support locally requires joint working between health and a range of services.

3.62 A few respondents stated that transition from a remote specialist centre to home had been poor, with examples of limited communication between the specialist facility and services in the home area.

3.63 A few respondents cited disadvantages in the residential nature of the provision. These including the short duration of the residential programme and the costs. One respondent mentioned a concern about disjointed provision, without adequate communication between the health professionals involved in care. One suggested that patients reported that the demands of the (rehabilitation) programme had been too great, and suggested problems with a “one size fits all” approach.

3.64 Several respondents identified disadvantages relating to distance and travel. These included the general distance from home and support, as well as the length and inconvenience of the journey. A few respondents identified specific problems in travelling from a particular remote area to a service in England. One stated that the need to travel for assessment and follow-up appointments was a disadvantage. It was also argued that some patients who would be suitable for the service are unable to travel. Issues were also raised relating to the costs (and upfront costs) of this.

3.65 A few identified disadvantages relating to gaining access to the service. These included:

- A perceived reluctance to make a referral.
- Difficulties in identifying placements to suit individuals’ choice.
- Lengthy waiting time to confirm a patient’s acceptance, and a period of uncertainty.

3.66 A few respondents highlighted disadvantages relating to the overall experience (e.g. lack of a positive outcome) or costs and resources (e.g. different funding arrangements in different areas; and a view that this provision was not the best use of resources).

Reasons for declining

3.67 A total of 27 respondents to the written consultation (12%) made comments at Question 10 relating to having been offered but declined a residential service outside Scotland, and the reasons for this. Of these, just under half gave their reasons for having declined such an offer.

3.68 Although few detailed comments were made, the reasons related primarily to the location and distance of the service. The main issue raised was that it had been too far to travel, particularly for people experiencing chronic pain.

3.69 Very small numbers of respondents identified other reasons for declining such a service. These were consistent with some of the barriers identified earlier. Those mentioned included:

- 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).

3.70 Almost half of the respondents who addressed this question stated that they had never been offered such a service, or had been refused this. Additional comments suggested a perceived reluctance by GPs to refer patients (e.g. following a specific request); and a lack of knowledge of such services.

Other comments

3.71 A small number of respondents made other comments at each of these questions about aspects of a service they considered necessary, or the means of taking provision forward. These issues are addressed in Sections 4 and 5.

SECTION 4: COMPONENTS OF SERVICE PROVISION

4.1 This section presents the findings on the questions relating to components of service provision (covering Questions 6 and 7 in the consultation document).

Overall views of aspects of a service for inclusion

4.2 Question 6 contained a closed question which asked respondents to select (using tick boxes) from a list of aspects of residential pain management services which they considered should be included in a Scottish service. For reference, the question is set out below:

> 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)

4.3 A total of 201 respondents to the written consultation (88%) addressed the tick box element of Question 6. Of these, the percentages indicating the need for particular elements of provision were as follows:

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

Aspect of service	No.	%[7]
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

4.4 As can be seen from the table, there was strong support for each element of provision to be included in a Scottish service. More than half of the respondents who addressed the question ticked all of the boxes.

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[7] % of the 201 who addressed this question.

4.5 Respondents also had the opportunity to make additional suggestions. More than half of written respondents (52%), and most stakeholder meetings made comments on aspects of provision for inclusion in a service in Scotland. Relevant comments were also made at other points in responses, and are included below. Most of the comments focused on additional suggestions, although many made further comments on those in the list provided.

4.6 Some respondents made comments on other issues. A few stated, for example, that they agreed with the elements of services suggested in the document, or that there was a general need for more provision. One commented on the potential cost. A very small number expressed disagreement with the overall residential nature of the proposed service. One stated that all of the elements mentioned should be part of non-residential provision wherever possible.

4.7 Some respondents made additional comments about aspects of current service provision, the consultation or the way forward, and these are considered in Section 5.

Additional comments on the elements of provision listed at Question 6

4.8 Just over a third of the additional comments on issues for inclusion focused on the elements of provision in the list at Question 6.

A chronic pain assessment

4.9 As seen in Table 3, almost all respondents who addressed this question believed that “a chronic pain assessment” should be included in a Scottish service.

4.10 Additional comments focused largely on the general need for this, or the nature of provision. It was suggested that this should include:

- A functional assessment.
- A full 24 hour assessment.
- A mobility assessment.
- A general holistic assessment to consider the impact of the pain on the person’s life and family.

4.11 One respondent stated that, as part of the initial chronic pain assessment, there should be a targeted information session to manage patient expectations.

4.12 A very small number of respondents raised issues about the inclusion of a chronic pain assessment. One suggested, for example, that a chronic pain assessment would be largely uninformative when patients reach this stage. A very small number stated that it was needed before sending patients to a centre.

Supported one to one sessions

4.13 Table 3 also shows a high level of support for “supported one to one sessions” with 91% of those who addressed the question being in favour of their inclusion.

4.14 Very few additional comments were made, but it was suggested that these sessions could be carried out prior to group sessions. One respondent stated that some aspects of discussion must take place away from carers (i.e. one to one) and another stated that there should be an opportunity for patients and carers to take part (individually or together), in group work and individual sessions.

Residential accommodation

4.15 The inclusion of "residential accommodation" was also supported by a very large proportion of those who addressed Question 6. This was one of the most common elements of provision on which additional comments were made, and most of these focused on the nature of provision.

4.16 These included comments on the general need for residential provision in Scotland. Suggestions were also made about the type of accommodation that could be used (e.g. a nearby hotel; bed and breakfast; self-catering flats). One respondent suggested that there could perhaps be a pricing agreement with a local hotel to obtain good rates for patients' accommodation.

4.17 It was also suggested that the accommodation should be fully accessible to disabled people, with appropriate facilities (including IT), and one respondent argued that it should be in a non-clinical environment.

4.18 Other aspects of accommodation suggested were that it should be:

- Short term.
- Close to the point of service delivery.
- Private (although with opportunities for group activities).
- Available to carers and family members.
- Available over the weekend.

4.19 One respondent stated that there should be a mix of types of accommodation.

4.20 A very small number of respondents stated that they did not support the need for a residential service.

Medication assessment

4.21 Table 3 indicates a high level of support for the inclusion of a "medication assessment" (91% of those who addressed Question 6).

4.22 Few additional comments were made about this, but these included the general need for provision. Specific suggestions included that recommendation should only be made after consultation and in collaboration with a patient's usual GP. It was also suggested that alternative medication, or non-medication therapies should be considered alongside "traditional". One respondent suggested that a medication assessment could be done using video conferencing.

Tailored exercise programme

4.23 Although there was a high level of support for the inclusion of a "tailored exercise programme" (87% of those who addressed Question 6), few additional comments were made.

4.24 One respondent identified advantages of this in terms of meeting individual requirements and helping pain.

4.25 A few suggested that there could be drawbacks or difficulties, such as that exercise, done wrongly, could be harmful, or that some conditions may be worsened by exercise classes. It was also suggested that some patients did not appreciate such sessions.

4.26 One respondent suggested that the title should be amended to “tailored gentle movement” and another that a programme would need to be fully consensual and take account of the nature of particular conditions. A further suggestion was that consideration should be given to non-repetitive exercises and breathing / relaxing techniques. One respondent stated that a tailored exercise programme could be delivered locally.

Group sessions

4.27 There was a high level of support for the inclusion of “group sessions” (84% of those who addressed Question 6) and several respondents made additional comments on this element of provision.

4.28 Benefits of group sessions were seen to include: enabling individuals to share coping methods; supporting people to manage their chronic pain effectively; and helping individuals realise they are not alone.

4.29 Drawbacks were seen to relate to: personal preferences; variation in individual needs; and potential problems with group dynamics or establishing groups.

4.30 Most of the comments, however, related to suggestions about the nature of group sessions. These included suggestions about particular types of groups (e.g. self-management and self-help; specific courses or approaches) and groups in particular settings (including local provision; accommodation group work therapy). It was also suggested that group work should follow one to one work.

4.31 Further comments included that there should be more information about group provision and that groups should be properly supported and funded. One respondent stated that peer support (such as that provided by the Third Sector) in setting up such groups could be given to those with relevant expertise to run them. Another suggested linking in to services already offered.

Opportunity for immediate carer / support provider to accompany patient

4.32 There was a high level of support for the inclusion of the “opportunity for immediate carer / support provider to accompany patient” (84%). This was one of the most common elements of provision on which additional comments were made.

4.33 In this case, comments tended to focus on general expressions of agreement with this, or the perceived benefits. These were seen to include, for example:

- Enabling the patient to have support to travel.

- Providing an opportunity for the carer / support provider to develop a better understanding of chronic pain, how this is managed, and the nature of support provided to the patient.

4.34 One respondent argued that providing the opportunity for the immediate carer / support provider to accompany a patient would avoid duplication and misunderstanding on the part of the carer / supporter.

4.35 One of the stakeholder meetings suggested that professionals need to see how the individual goes about their daily life and how they interact with their carer. It was also stated that reintegrating back to home life with the carer is easier if the carer is involved in the whole process. Comments were also made about the importance of the carer's role (including in longer term self-management) and the need to recognise this.

4.36 A small number of respondents identified drawbacks of providing the opportunity for the immediate carer / support provider to accompany the patient. The main focus of these comments was on the perceived importance of enabling the patient to cope with less support. It was argued that self-management and peer support may be inhibited for some patients when accompanied by a carer.

4.37 A small number of suggestions were made on the nature of this provision. These included some suggested caveats, such as that the carer / support provider should only accompany the patient in some cases, by exception, or where the patient cannot carry out their day to day functioning without them.

4.38 Comments were also made on their potential role, for example, as supporting the patient or, in the view of one respondent, only if they are not involved in the patient's programme, but are given separate information and support.

Peer support

4.39 As with other elements of provision, there was a high level of support for the inclusion of "peer support" in a Scottish service (from over three quarters of those who addressed Question 6). Several respondents made additional comments, and most focused on the benefits of this.

4.40 The value of other patients' experience and peer-led approaches was identified. A very small number of comments were made about the drawbacks of peer support, particularly the problems of poorly facilitated support.

4.41 A few suggestions were made about the nature of provision. For example, one respondent stated that peer support was best provided on a generic basis to people experiencing pain. One suggested that peer support could continue long after being assessed, using communication media. Another suggested linking in to existing peer support being offered.

Further issues for inclusion

4.42 Almost two thirds of the comments on issues for inclusion in a Scottish service focused on the identification of additional aspects of provision (further to those listed at Question 6).

Treatment and therapies

4.43 The inclusion of particular types of treatment and therapies was one of the most common additional suggestions. Among those identified, several respondents argued that complementary approaches should be included (with a wide range of specific suggestions). It was also stated at one of the stakeholder meetings that there should be access to research-based integrative care.

4.44 It was also suggested that there should be access to specialised medical treatments and medication advice, and that community pharmacies could provide support. It was also argued that there should be access to physiotherapy and occupational therapy input.

4.45 Nutritional information, education and research were also highlighted for inclusion. Other suggestions were for access to: lifestyle advice; alcohol and drug support; and mental health and psychological support (e.g. CBT; anxiety and pain management; self-harm support; counselling; and some specific programmes).

Follow-up and review

4.46 The provision of some longer term input (including monitoring; follow-up assessment and review; and follow-up support) were also suggested frequently. A number of comments focused on the general need for this following completion of a programme.

4.47 Some means of follow-up were also suggested, such as the use of:

- Email.
- Telephone.
- Internet and web-based “top-ups”.
- Ongoing sessions.
- A review appointment at the end of treatment.
- General continuing treatment and support for the patient and family.
- A residential weekend.
- Peer groups.

4.48 One stakeholder meeting identified a need for support mechanisms in an individual’s local area, and another that there should be an annual recall for a “refresher” session.

Information, advice and other support to patients, carers and family members

4.49 Several respondents suggested a need for other forms of support to patients, carers and family members. A common issue raised was the perceived need for education and information for carers and family members. Some suggested means of undertaking this included:

- Specific sessions for this purpose.
- Family therapy or psychology sessions.
- Support and information services for carers and family members.
- Improved communications with the full family unit.

4.50 It was suggested that information should cover issues such as:

- Pain management.
- How to help patients.
- Financial issues.
- Accessing carer support services.

4.51 The need for information and support to patients themselves was also highlighted. This included information about, and signposting to services in their local communities (including, for example, Third Sector self-management training and peer support, and complementary health interventions).

4.52 The need for advocacy support was also identified, including a strong collective voice at a national and local level, and individual advocacy on a local and wider scale. Details were given of the nature and benefits of independent advocacy and the potential role of this in relation to those experiencing chronic pain.

4.53 It was also suggested that education and employment support and advice could be provided to patients. This included advice and support to return to work, and employability support (e.g. through links to appropriate services). One respondent argued that teaching and learning experiences suitable to a child’s needs should be provided during treatment, particularly for those in the midst of exams.

4.54 A further area of advice and support seen to be required for patients related to finance and benefits. One respondent also suggested that there should be specialised and tailor-made assistance and advice with mobility and comfort aids, as well as access to a resource list, or resource lending.

4.55 It was suggested that there should be wider awareness raising about chronic pain, for patients, families and the wider community. One respondent suggested a campaign to raise awareness of pain and that tips on self-management could be displayed in GP surgeries and other settings.

4.56 It was argued that there could be specific education to employers about chronic pain management in the workplace and means of meeting the needs of employees who experience chronic pain. The perceived need for staff education and training is discussed in Section 5.

Services to meet the needs of specific groups

4.57 Comments on the need for a service in Scotland to address the needs of specific groups were also common. Suggestions included, for example:

- People in remote and rural areas, with:
  - Appropriate means of addressing access issues.
  - Services meeting their needs.
- Deaf and deafblind people, with:
  - Full access to appropriate professional registered language and communication support.
  - Accessible residential accommodation and equipment for those who cannot hear.
  - The involvement of service users in service design and planning.
- Children and young people, with:
  - Specialist children’s services.
  - Recognition and consideration of the specific requirements of this group (with suggestions about how to do this).
  - A children’s rights impact assessment.
  - Appropriate teaching and learning causing minimal disruption to education.
  - Access to self-management groups.
  - Telehealth support accessible to all age groups
  - Acceptable waiting times for adolescent programmes.
- Disabled people, with:
  - A service that is accessible to disabled people.
  - The needs of disabled carers and family members addressed.
  - The specific needs of children and young people with learning disabilities taken into account.
- People with palliative care needs, with:
  - Fast decisions and implementation of care.
  - Guidelines to ensure collaborative working.
  - Access to new medicines and fast appeals.
  - An integrated approach, with effective protocols, procedures and technology.
- Military veterans, with the remit of the new service to include treatment of those returning from active duty.
- People in care homes or using care at home, with the identification of this group among those who could potentially use a Scottish service.
- People historically under-recognised or excluded from provision, with a need to address this, and a lack of clarity of how this will be done.
- People with specific conditions (e.g. ME-CFS; post-polio syndrome; chronic rheumatic disease), with an appropriate range of specific specialist staff involved in provision.

Particular facilities

4.58 A small number of respondents highlighted a need for particular facilities. Suggestions included that these should generally be pleasant and comfortable, and with “healing space” or “breathing space”. Specific facilities suggested included:

- Telehealth and videoconferencing facilities.
- A research centre (with comments on how this could be implemented).
- A trauma unit.
- A gym.
- A pool.
- Cooking facilities.
- A jacuzzi.

4.59 One respondent argued that there should be access to a particular piece of equipment. The need for the facilities to be accessible was also identified.

Provision in other settings

4.60 A small number of respondents made comments about the need to include provision in a variety of settings other than a residential centre or hospital. Suggestions included activities in the local community (e.g. eating out, shopping, gym, cinema) and weekends home.

4.61 It was also argued that there should be domiciliary provision, and provision to people in care homes. One respondent suggested the use of houses in communities to run residential programmes. The inclusion of local outreach work (including to clinicians) and the use of local clinics, as well as linking to other local support were also identified.

4.62 Some specific means of providing support in other settings were also suggested. For example, some respondents commented on the use of telehealth. It was suggested that this could have the potential for greater use and would, for example: enable contact with patients and health professionals remotely; improve access to specialists and consultants; and provide advice to local pain services. It was also suggested that work such as screening, links to support groups, and work to maintain progress could be carried out in this way.

4.63 Some respondents, however, expressed reservations about the use of telehealth (and related means of delivery) as noted in Section 2.

4.64 The use of social networking was also suggested as a means of providing support to individuals. Other suggestions included the use of a helpline and DVDs or memory sticks. It was also argued that Bath could be retained as an option.

Planning

4.65 A few respondents made comments about the need to include planning as an element of a Scottish service. One stated, for example, that care planning is an essential part of health care delivery in social care settings. It was also argued that there should be an appointment schedule developed after the first consultation, and one respondent suggested “goal setting” and “pacing”.

4.66 It was also suggested that systematic evaluation (pre-, mid- and post-programme) should be undertaken, to identify the effectiveness of the treatment.

Social opportunities

4.67 A few respondents suggested that social opportunities should be included as part of the provision. Specific suggestions included evening social events and the development of support networks between people using a service or in a similar situation (e.g. through online communities, a dedicated website or meeting places).

Research

4.68 Some respondents suggested that a Scottish service should include research (and, as noted, it was suggested that there should be a chronic pain research centre).

4.69 As well as the general need to engage with research, a few suggestions were made about the nature of research which could be undertaken. These included, for example:

- Comprehensive monitoring of outcomes.
- Identification of best practice.
- Research relating to new therapies and techniques (including non-pharmacological interventions).

4.70 It was suggested that this could increase effectiveness of treatments, reduce costs and inform service development at all levels.

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

4.71 Question 7 asked respondents about retention of access to the service in Bath (or elsewhere in the UK). For reference, the question is set out below:

> 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?

4.72 A total of 205 respondents to the written consultation (90%) expressed a view about the retention of the option of such a referral. Of these, as set out in Table 4 below, nearly half believed that access should be retained. Around a quarter indicated that the option should not be available, and a similar proportion that they did not know.

Table 4: Views of retention of access to the current service provided in Bath (or elsewhere in the UK)

Retain access to Bath	No.	%[8]
Yes	98	48
No	51	25
Don't know	56	27

4.73 Although no space was provided to make additional comments, 19 respondents made comments on perceived benefits and drawbacks of this.

4.74 Among the perceived benefits were the ability to meet the needs of specific individuals or groups (given the variation in individual needs). Comments included that the current service in Bath could be used, for example:

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

4.75 One respondent stated that some patients (e.g. children and those with Chronic Regional Pain Syndrome) would be disadvantaged without the retention of reasonably easy access to Bath. Another stated more generally that Bath provides a good model, while a further respondent argued that maintaining professional links and support between staff in Scotland and Bath would be valuable. One respondent stated that the Bath option should be retained because the funding for a local resource may be limited.

4.76 Comments on perceived drawbacks focused largely on the view that this would be unnecessary with a Scottish service. One respondent argued that the retention of Bath could detract from the NHS developing the new service in Scotland, and stated that it should not be used to tackle problems that should be addressed in Scotland.

4.77 A few respondents expressed the general view that Bath should be retained in the first instance, then reviewed or phased out. A few argued specifically that it should be retained while a Scottish service becomes established and gains experience, or until the volume of referrals is assessed. It was suggested that this would provide the opportunity to share expertise, and for a Scottish service to concentrate on basic pain management in the first instance.

Other comments

4.78 Comments were also made at these questions about the nature of current provision, the consultation itself and other aspects of taking the service forward. These issues are discussed in the final section.

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[8] % of the 205 who addressed the question.

SECTION 5: OTHER ISSUES RAISED

5.1 Question 11 gave respondents the opportunity to add any further comments. For reference, the question is set out below:

> 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.

5.2 Over half of respondents to the written consultation (55%) made additional comments here. Some provided additional information outwith the specific questions, and relevant comments were made by participants in all of the stakeholder meetings.

5.3 Some of these further comments related to issues explored at previous questions. These have been presented at the relevant points to avoid duplication. Similarly, some comments made at other questions were more relevant here, and are included below.

The current context and nature of services

5.4 A large number of respondents made comments on the current context and the nature of services.

The nature of chronic pain

5.5 Several respondents commented on the nature of chronic pain. Some, for example, focused on defining this, while others identified the impact of chronic pain on their lives. Among specific issues raised were the nature of chronic pain as a long term condition in its own right, and its association with many other long term conditions.

5.6 In terms of the impact of chronic pain, it was indicated that it is debilitating and life-limiting, as well as causing distress, discomfort and a reduction in individuals' quality of life. Examples were provided of respondents' personal experiences, or those of family members. Comments were also made about the difference that can be made to patients when their pain is addressed effectively.

5.7 Comments were also made on the widespread nature of chronic pain and its prevalence among children and adults. The importance of addressing the needs of individuals affected was also raised. A few respondents stated specifically that they welcomed the introduction of a specialist residential chronic pain service in Scotland.

The likely level of demand or need for provision

5.8 Several respondents made comments on the demand for a service in Scotland. Some of these focused on the general need for such provision, to address the issues identified above. Others made comments on the estimated demand. Comments were varied, and included the view that the likely demand for such a service is currently unclear, or that there are conflicting views of this.

5.9 A few respondents stated that there is currently a relatively small number of patients from Scotland who travel to Bath. It was also suggested in one of the stakeholder meetings that improving level 1 and 2 services could reduce the number of people requiring to use a level 3 service.

5.10 Some respondents expressed the view that the level of demand may be higher than expected, or that the number of patients that would be referred to a service in Scotland had been underestimated. It was argued that there may be more demand than indicated by the usage of Bath, and that the number attending Bath is a small proportion of those in Scotland who would be likely to benefit from a specialist residential programme.

Problems with current service provision

5.11 Many respondents (including participants in stakeholder meetings) made comments on current provision, a number of which focused on highlighting problems.

5.12 Some of these related to current service provision overall, and included the view that this is generally poor. It was also suggested that there is disparity of chronic pain services between different areas, with patchy provision, fragmentation and variability in the range of services and resources offered. A few respondents commented on specific problems for those in remote and rural areas.

5.13 Respondents also suggested that there can be a lack of understanding of chronic pain and the services available on the part of some GPs (and others, including the wider public), and a lack of referral (as noted at 3.27).

5.14 It was also argued that there can be long waiting times for accurate diagnosis and treatment, and that chronic pain may be treated as an acute, rather than a chronic illness. It was also suggested that services may not have adequate staffing levels and can be bureaucratic. One respondent expressed concern about competing agendas, with the patient being forgotten.

5.15 Problems were also highlighted with specific aspects of current provision. For example, some respondents identified limitations of the service in Bath (including some barriers identified in paragraphs 3.60 - 3.66). A few respondents cited problems with services in particular areas, or types of services (such as pain clinics and specific courses or groups).

5.16 Comments were also made on the use of medication (e.g. the reliance on pain killing drugs) and on difficulties in accessing particular forms of treatment, or support for specific conditions.

Positive aspects of current provision, progress and developments

5.17 Although fewer comments were made on positive aspects of current provision, several respondents identified these. A number, for example, made reference to the value of the service provided by the Centre for Integrative Care at the Glasgow Homeopathic Hospital in the Gartnavel complex. Comments included details of the nature and means of provision, examples of the beneficial impact, and concerns about the future of the provision. Positive comments were also made about the service in Bath, and other specific facilities, staff and treatments.

5.18 A few respondents made positive comments about overall developments. Some of these focused on the development of specialist residential chronic pain services in Scotland, the improvement of existing day services, and general work to improve chronic pain services across Scotland.

The consultation

5.19 Many respondents (including the stakeholder events) made comments on the consultation itself.

The consultation overall

5.20 In terms of the consultation overall, some respondents generally welcomed or supported this. Comments were also made on who should be included in the consultation; and the timing of this (with the hope expressed that it would not take too long).

5.21 One respondent stated that, while the focus of the consultation was on residential services, it is important to bear in mind those for whom the specialised services are unlikely to be relevant or available. Another stated that there was some cynicism that the decision about the way forward would reflect what was best for healthcare professionals, rather than people affected by chronic pain.

5.22 It was suggested at one of the stakeholder meetings that the Scottish Government should consider a follow-up meeting after the consultation to discuss future plans and maintain engagement in relation to the development and design of the service.

The consultation processes

5.23 Some comments were made on the written consultation. These included comments on the nature of the material provided and the means of responding (e.g. individual difficulties with this).

5.24 Comments were also made about the issues covered in the consultation document, and some perceived gaps in this. For example, a few respondents stated that there were no details of the cost implications of the options, the funding arrangements, nor the likely level of use. One respondent stated that the document did not provide a business case to demonstrate that a change from the status quo would provide value for money, and it was suggested that the status quo should have been included as an option.

5.25 Other issues raised included that the document did not include:

- A review of the evidence base comparing outcome data for the residential and outpatient approach to the delivery of specialist chronic pain services.
- Mention of the physical inpatient facilities and supervision needed in time periods outwith the programme.

- Details of whether the service was only for adult patients, and the arrangements for adolescents and children.

5.26 Comments relating to the stakeholder meetings focused largely on describing the nature and purpose of these (i.e. to help clarify views as part of the consultation on the development of specialist intensive chronic pain service in Scotland). A few suggestions were made about the location of such meetings in the future. One respondent provided positive feedback about the nature of the sessions.

Questions and issues for clarification

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

- The conditions that would be covered by the service.
- The referral processes.
- Staffing.
- Provision in particular areas and to specific groups.
- Other aspects of the options presented in the consultation document.
- Funding and costs.
- The evidence available.

The role and nature of respondents

5.28 Many respondents made comments about their own role and the nature of their interest in chronic pain, or the type of work they (or their organisation) was involved in. Information was also provided about:

- Those whose views were represented by a particular response.
- The nature of the response (and any limitations to the material).
- How the response was developed.
- How to contact the respondent.

5.29 One respondent endorsed a response from one of their member organisations.

The way forward

5.30 Many comments were made about the way forward in the development and delivery of specialist residential chronic pain services in Scotland.

Strategic and overall issues

5.31 A common theme was the identification of strategic and overall issues, including the principles and overall approach to service provision seen to be required.

5.32 Some of the principles identified related to the approach to patients. These included, for example the need to:

- Take a patient-centred approach.

- Treat them with dignity and respect.
- Recognise and address their chronic pain.
- Take a positive attitude to chronic pain.
- Treat them as individuals.
- Provide appropriate (and age-appropriate) care.
- Identify the way forward.

5.33 The importance of user involvement in the development and implementation of the service at all stages was also highlighted (including the involvement of specific groups of service users, such as deaf people and children and young people).

5.34 Some of the principles identified related to the approach to chronic pain, and these included, for example, that the service should:

- Provide support and education and encourage self-management.
- Treat chronic pain as a chronic illness.
- Take a more “social” and less “biological” approach.
- Provide a relaxed environment.

5.35 Some principles were highlighted relating to the overall approach to service provision, and suggestions included that it should involve provision that is:

- Integrated.
- Streamlined.
- Holistic.
- Based on early intervention.
- Flexible.

5.36 Some principles related to the wider context for the service, including that it should:

- Give the issue priority.
- Take a “grassroots” approach (with more support for levels one and two).
- Be evidence-based.

5.37 One respondent stated that service development should be part of an overall strategy for pain management, and another that there should be a vision for growth and development. It was also suggested that the service should be developed in line with the Scottish Service Model for Chronic Pain and that this should be implemented in each NHS board.

The overall organisation and pattern of provision

5.38 Many comments were made on the overall organisation of the service and pattern of provision. Among these, a common theme was the need for improvement and development of local services (as discussed in Section 2). It was argued that there would be a continuing need for local chronic pain service provision, whatever the option adopted. It was stated that, for some patients, local services would be their only access to treatment and support, and should be protected.

5.39 It was also stated that it is important that there is access to effective pain services across Scotland for all of those who need them, not only those who are worst affected. A few respondents argued, in this context, that there should be clear pathways for individuals.

5.40 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.

5.41 It was also suggested that there should be local pain teams and clinics in all areas and Managed Clinical Networks across Scotland. Additional suggestions included that service provision should include other elements, such as telehealth and outreach or mobile provision. A few respondents suggested that additional services could be developed and piloted at later stages, as required.

5.42 Suggestions were also made about the involvement of particular organisations and types of staff in the delivery of the service. Some of these reflected suggestions made in Section 4 about the types of treatment and therapies that should be provided. Other suggestions reflected the perceived need for the development of services overall. These included, for example:

- The involvement of condition-specific specialists.
- Specialist pain management nurses.
- Local clinicians including the primary care team and local secondary care pain service.
- Existing chronic pain service staff.

5.43 One respondent stated that there should be a lead clinician to deal with patients after discharge. Another argued that there should be a named professional to co-ordinate a person's care. A few respondents stated that there may be a role for a National Co-ordinator, to ensure that patient choice is respected within chronic pain services.

5.44 A further element of the overall organisation of provision was the perceived need for a specialist service to develop links to other services. Among those suggested were links to other clinicians and local services. It was also argued that there should be links to university departments (such as medical schools and health schools). One respondent suggested links to international higher education institutions.

5.45 It was argued in one stakeholder meeting that there should be links to existing specialist services such as: palliative care services generally; the Children's Hospice

Association Scotland (CHAS); and Marie Curie Cancer Care. One respondent suggested a “collegiate” approach to assessment.

5.46 Other suggested links included with:

- Other Third Sector organisations (e.g. the Pain Association and individual medical charities).
- Vocational rehabilitation, employment services and adult education.
- Other local statutory organisations.
- Other services in the community more generally.
- Bath (e.g. for staff training, learning from the model, and using resources).

5.47 One respondent suggested a central database of allied healthcare professionals who have been properly trained in chronic pain and are contracted to make domiciliary visits.

5.48 Some respondents stressed the multidisciplinary nature of chronic pain service provision and the need for a stable and cohesive multidisciplinary team. It was also argued that the staff team should be self-motivated, high calibre and experienced.

5.49 Suggestions were also made relating to some management and practical issues. One respondent, for example, argued that the service needs to be provided nationally, in order to ensure equity of provision. This issue was also raised in relation to funding. One of the stakeholder meeting participants argued that the service needs to operate without area influence.

5.50 Some respondents argued that there is a need for multidisciplinary management and / or joint working. One stated that there should be a strong medical lead. The importance of communication and feedback were also identified. One respondent argued that there would be a need for more accurate reporting of patients’ responses to treatment from a residential service to professionals providing continuing care.

5.51 Additional specific suggestions about management and practical issues included:

- The establishment and effective operation of Managed Clinical Networks (MCNs) and Service Improvement Groups (SIGs).
- The establishment of an integrated mechanism for communicating about chronic pain, acknowledging the multi-dimensional nature of this.

5.52 It was also suggested that there should be clear and consistent criteria for use of the service, and clarity about specific aspects of the service (e.g. carer attendance). One respondent argued that there should be clear protocols for all aspects of provision prior to the start of any programme.

Staff education and training

5.53 A further common issue was the perceived need for staff education and training. Some respondents mentioned specific groups for which training should be provided. Suggestions included:

- 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.

5.54 Some respondents suggested specific issues for training, such as:

- 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.

5.55 Other suggestions included that training should be part of the remit of a Centre of Excellence, and that it could create a revenue stream. One respondent argued that training delivery should involve those providing specialist health services (e.g. palliative and end of life care). A few suggested that patients should be involved in the provision of education to healthcare staff.

5.56 Suggestions were also made about the means of provision of education and training. These included, for example, the use of:

- Continuing Professional Development (CPD).
- Secondment or rotation from existing services to an intensive service.
- Shadowing.
- Clinical guidelines (although one respondent noted that guidelines may not be read by a busy GP).

5.57 It was suggested in one of the stakeholder meetings that the Patient Opinion website is a good way to inform services of good and bad experiences. It was also suggested that best practice should be collected and disseminated.

5.58 Some additional suggestions were made about wider awareness raising. One respondent argued that there is a need to share knowledge and experience on a national level. Another suggested using the experience of other countries. A further respondent stated that it would be useful to undertake education and awareness raising with employers, teachers and the wider public, to develop greater understanding and support for people experiencing chronic pain.

5.59 It was also suggested in one of the stakeholder meetings that there could be a Chronic Pain Symposium, podcast to the wider community.

Location of the service

5.60 A number of comments were made about the possible location of a Centre of Excellence. Some of these were general comments about the overall type of location. Other respondents mentioned a specific hospital or facility. Comments on the type of location included that it should have good transport links (including to remote areas), parking and be accessible to all areas.

5.61 Some respondents suggested a particular city or geographical area, with suggestions including: Glasgow; Perth; Stirling; Dundee; generally in the central belt; or at north and south locations.

5.62 In terms of the identification of a specific hospital or facility, several respondents suggested establishing a Centre of Excellence at the Centre for Integrative Care (in the Glasgow Homeopathic Hospital). Other suggestions included: the Southern General Hospital in Glasgow; the Astley Ainslie Hospital in Edinburgh; and St John’s Hospital in Livingston.

5.63 One respondent argued generally that a Centre should be co-located, or the staff co-employed within a local or regional centre offering pain management to the local population.

History and timing

5.64 Several respondents made comments on the history and timing of service development. Some argued that there has been lengthy debate and discussion involving a number of groups and meetings. A few respondents were critical of the nature of the previous process, or expressed concern at the length of time taken. A few highlighted the current opportunity and recent progress, or expressed a hope for a positive outcome and the overall improvement of services.

5.65 Some respondents argued that there is a need to finalise the details of the service, and to implement it as soon as possible. One stated that there is a need for strong leadership to take this forward.

Funding and resource issues

5.66 Comments were also made about funding and resources. For example, some highlighted the general requirement for funding provision as an essential element of the way forward. A few stated that there is a need for dedicated funding, and it was argued in one of the stakeholder meetings and by other respondents that there should be guaranteed ring-fenced funding.

5.67 One respondent argued that national ring-fenced funding is important to avoid possible inequity of care and access to the service. Another argued that national funding is needed to ensure stability and continuity of care (and to avoid threat of closure by a local health board). It was also stated that funding arrangements should be equitable.

5.68 It was argued that there should be funding and investment to support training, recruitment and development of staff. A few respondents commented on the need for facilities and staff resources to match the quality of the provision in Bath. One respondent argued that staff need dedicated roles, protected time and support to provide intensive services.

5.69 One respondent argued that the cost savings of not sending patients to Bath should be added to the chronic pain treatment budget in Scotland. Another proposed a basis for charging to NHS Boards (on a cost-per-case basis).

5.70 One respondent stated that relevant charities providing services and support also require improved funding to provide more facilities in the community.

Evidence base

5.71 Some additional suggestions were made about the evidence base for service provision, and the perceived importance of this.

5.72 In terms of the use of current material, for example, one respondent suggested a particular report[9] which could be applied to the development of a chronic pain service in Scotland. It was also suggested that international research findings and the experience of existing services could inform service development.

5.73 A few respondents suggested that research should be carried out to inform the development of the service, with suggestions including research:

- To examine the relative efficacy of the different potential approaches to service provision or relative value for money.
- To analyse evidence from other areas of healthcare on the use of specialist centres and the impact on local services and workforce migration.

5.74 One respondent stated that the outcome of the new Service Improvement Groups should be awaited, to assess the impacts or improvements they propose, prior to decision making. Another argued that the work of these groups may influence future assessment of ongoing need for residential pain programmes and how they could be delivered.

5.75 A few respondents questioned the current basis of the proposals, or the difficulty of decision making in the absence of data about the specific level of need. One stated that the decision should be made in the best interests of those affected by chronic pain, using figures independently audited and verified and available to public scrutiny.

5.76 It was also argued that there is a need to measure the effectiveness (including cost-effectiveness) of the service. It was suggested that there should be evaluation, monitoring and review of provision (including the medium to long term impact on patients and the wider socio-economic and full service impacts). One respondent stated that they would welcome Government feedback on how a specialist Scottish chronic pain service would be evaluated.

5.77 Specific suggestions relating to developing the evidence base included:

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[9] Referred to by the respondent as the ScotPHN report of September 2011 on the Health Care Needs Assessment for people living with ME-CFS.

- A scoping exercise to discuss key components of, and problems with current programmes in England.
- A standard, real-time, patient-related quantitative and qualitative tool.
- A chronic pain coding, with figures to be made available regularly.
- A UK national network to share and learn from outcome experiences.
- A review of waiting times and referrals.
- Ongoing measurement of the model against pre-determined, clear and measurable objectives (e.g. annual review of the model and outcomes).

5.78 One respondent argued that, if the system established does not get results which are similar to, or better than current leaders in this area, it should be possible to revert to the current system.

Overview

5.79 The consultation identified three options. Of these, there was a clear preference for Option 1 (a Centre of Excellence in a single location), in some cases in conjunction with another option. A significant number of benefits, as well as a few disadvantages, were suggested for Option 1. Most respondents supported the provision of a wide range of services in such a Centre of Excellence.

5.80 Option 3 , however, was identified most often by respondents as one they disagreed with. Nearly half of those who expressed a view suggested that access to the residential service at Bath should be retained either on the same basis as at present, or in a modified form.

5.81 Respondents identified a wide range of barriers to accessing a residential pain management service, including cost, location, logistical and personal issues.

ANNEX 1: THE CONSULTATION QUESTIONS

Question 1: We would like to know in what context you are responding. Please choose one of the following:

I am responding as:

a) an individual who experiences chronic pain ☐

b) a family member or carer of someone who experiences chronic pain ☐

c) a health professional ☐

d) an organisation representing people who experience chronic pain ☐

e) other stakeholder (please tell us in the comments box below) ☐

Comments

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

Option 1 – a Centre of Excellence in a single location ☐

Option 2 – a service delivered by local chronic pain clinicians (supported by other clinical advisors in another part of the country) ☐

Option 3 – a service delivered in different locations (by a team of chronic pain specialists – an outreach or roving service) ☐

Please tell us why this is your preferred option in the comments box below. The factors listed in Chapter 2 of the consultation paper may help you.

Comments

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

(If No, move straight to Question 4.)

If yes, please tell us which one(s) in the comments box, and why?

Comments

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.

Comments

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.

Comments

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?

Yes ☐ No ☐ Don’t Know ☐

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

Yes ☐ (please answer Question 9)

No ☐ (please move straight to Question 10)

Question 9: If you have attended, or supported someone attending a residential service outside Scotland, please tell us about any advantages and disadvantages of the experience.

Comments

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

Annex 2: THE RESPONDENTS

The respondents were as follows:

ABPI SPIG
Action on Pain
Agnes Leggat
Aileen Herd
Alan Brown
Alison Gray
Alison Green
Anne Kilpatrick
Anne Murray
Annie Matthews
Annie Pryce
Arthritis Care Scotland
Blair H Smith
Breast Cancer Care
Brian McAlorum
Brian Prentice
British Acupuncture Council
British Pain Society
Care Inspectorate
Carers Scotland
Carol Carter
Catherine Kerr
Catherine Lawson
Chartered Society of Physiotherapy Scotland
Children in Scotland
Christine Martin
College of Occupational Therapists
Community Pharmacy Scotland
Cope
Cope Stakeholders
Cronic Pain, NHS Forth Valley
Dana Green
David Weeks
Dorothy Grace Elder
Dr Iain Stewart Foulds
Duncan Hope
Elizabeth Dowling
Elizabeth Henderson
Elizabeth MacMillan
Erin McGuigan#2
Ewan Wallace
Faculty of Pain Medicine of the Royal College of Anaesthetists

Fife Integrated Pain Management Service
Fiona Burns
Fiona Kolanski
Fiona Laverty
Fiona Robinson
Fraser Bell
Friends of the Glasgow Homeopathic Hospital
Gabriel Blass
George Welsh
Gillian Bayne
Greater Glasgow and Clyde Managed Clinical Network for Chronic Pain
Health and Social Care Alliance
Heather Goodare
Helen Blacklock
Helen Holland
Helen McCluskey
Helen Smith
Helen Smith
Ian Bayne
Ian Buchanan
Ian Yogan
Intlife
Irene Logan
Isobel Jamieson
Jackson Carlaw MSP
Jacquelyn Wilson
James McEwen
Jane Chalmers
Jane O'Brien
Jane Williamson
Janette Walker
Jennifer Ahmad
Jill Hoggan
Julie McAnulty
Kate Dawson
Kathleen Robertson
Katrina Livingston
Kay Ritchie
Kevin Grant
Kris Murray Browne
Lawrence Daly
Leuchie House Short Break Care
Linda McBride
Lorna Leslie
Maire Whitehead
Malcolm Macleod

March Trust
Mariana Palinkash
Marie Curie Cancer Care
Mariette Lobo
Marilyn Hazlett
Marion Preston
Martijn Steultjens
Martin Dunbar
Martin Tighe
Mary Craig
Mary Hornsby
MSA Trust
Muscle and Movement Company
Nadine McBay
National (UK)Osteoporosis Society
Neil Ingall
Neil Sloan
NHS Ayrshire and Arran
NHS Centre For Integrative Care
NHS Dumfries & Galloway (including Chronic Pain SIG)
NHS Lanarkshire Corporate Management Team
NHS Lanarkshire, Chronic Pain Service
NHS Lothian
NHS National Services
NHS Orkney
NHS Tayside
Pain Association Scotland
Pain Concern
Pamela Smith
Paul Smith
Peter Greenstock
Peter McCarron
Phil Lacoux
Physiotherapy Pain Association North
Rebecca Harris
Roberta Gray
Rosemary Clarke
Rosemary Sutherland
Royal College of Nursing Scotland
Royal College of Physicians and Surgeons of Glasgow
Scottish Ambulance Service
Scottish Ass. Of Neurosciences
Scottish Board of the Royal College of Anaesthetists
Scottish Council on Deafness
Scottish Ind. Advocacy Alliance
Sharon Cranwell

Sheila Griffin
SMASAC
South Lanarkshire Council
St. John’s Hospital Patient Forum
Susan Archibald
The Neurological Alliance of Scotland
The Scottish ME-CFS Collaborative
Thomas Smith
Thomasina Whitehall
Transverse Myletis Group Scotland
Veronica Daly
Zoe Palmer

In addition, 19 respondents requested confidentiality, and a further 62 respondents requested that their names be withheld.

Social Research series
ISSN 2045-6964
ISBN 978-1-78412-203-4
web only publication

www.scotland.gov.uk/socialresearch

APS Group Scotland
DPPAS22173 (01/14)

GOVERNMENT SOCIAL RESEARCH
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