

CONSULTATION QUESTIONS

Preferred Option

Question 1: Which is your preferred option?

- Option 1 – Designated specialist service model
- Option 2 – Development of a national Managed Clinical Network
- Option 3 – Participation in a national Multi-Disciplinary Team
- Option 4 – Development of a Regional approach

We would like to better understand the reason why you have chosen this option. The following questions aim to provide you the opportunity to provide further information in support of your choice.

Question 2: Do you consider that your preferred option will offer superior clinical outcomes?

Yes No

Question 3: Do you consider that your preferred option will offer increased cost effectiveness?

Yes No

Question 4: Do you consider that your preferred option is the best model in achieving a service which is deliverable?

Yes No

Question 5. Do you feel that your preferred option will offer most benefit to the wider delivery of chronic pain management services in Scotland, for example the opportunity to develop skills?

Yes No

If you have answered No to any of the questions above, please provide your reasons in the box below.

Comments are also welcomed here if you feel that any of the other options (please state which) would meet the needs described at Questions 2 through 5.

Comments *So far the needs of Scottish patients have been met by one UK service in Bath. It would be best to offer one Scottish service initially, until demand is measured and skills honed. Later it*

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might be appropriate to offer a regional service, but not before more specialist expertise is gained.

Question 6: Are there any other options which you feel should be considered that have not been included in the options presented?

Yes No

Question 7: Are there any other elements which should be included in a SIPMP which have not been identified in the current model?

Yes No

If you have answered Yes to Question 6 and/or 7 – please provide further information in the box below.

Comments *The specialist services listed do not include acupuncture, which I have found of great benefit.*
Equity of Access

A key aim of developing services is to ensure that there is equity of access across Scotland. Information at pages 11-12 of the consultation paper provides explanation of some of the points to consider. A full Equality Impact Assessment (for further information, please see Chapter 5 of the consultation paper) will be carried out on the preferred option identified through this consultation. To help inform this assessment, the following questions aim to seek views in this area.

Question 8: What are your views on using tele-health facilities to access / consult with specialist pain clinics?

Comments *Probably not very helpful, as therapy depends largely on individual requirements and one-to-one empathy.*

Question 9: What consideration should be given to potential travelling time / distance / costs? For example, how far/long would it be reasonable for someone to travel to access a SIPMP?

Comments *Ideally, half a day, though I was prepared to travel for a day to access the Baha clinic.*

Question 10: Is it reasonable that participants wait longer to access SIPMPs if delivered in Scotland because of smaller numbers of referrals?

Yes No

Comments *We really do need our own Scottish centre.*

Question 11: What would be an acceptable time to wait to ensure that a participant joins the most appropriate SIPMP, for example one that is age or condition specific?

Comments *About 6 months would be reasonable*

Question 12: Should the current service provided in Bath be retained to ensure availability of patient choice?

Yes No *Also, Bath provides a good model and yardstick.*

Question 13: Should participants of SIPMPs be offered the opportunity for their immediate carer/support provider to join the programme?

Yes No

If you have answered Yes to Question 13, please provide further information in the box below. How do you feel the costs should be met – for example, through the NHS as part of the participants clinical costs, or through carer funding?

Comments *Some patients will be disabled and unable to travel without a helper/carer. NHS should fund.*

Question 14: If residential accommodation is required to participate in an SIPMP, this would be considered by the Equality Impact Assessment. As part of this assessment, are there any points you would specifically wish to be considered, for example distance from the point of delivery, cost, type of accommodation?

Comments *Accommodation need not be luxurious (e.g. modest hotel, bnb) but must be accessible for disabled people.*
Local Skills, Resources and Capacity

Question 15: Options 2-4 provide three different models for the delivery of services at a local level. Do you feel that local teams have the skills, resource and capacity to deliver SIPMPs for Scotland locally?

Yes No

If you have answered No to Question 15, please provide additional comments in the box below. For example, did this influence the choice of your preferred option?

Comments *The very specialized cohort of skills required are unlikely to be found in the average local setting at the moment. Later perhaps local teams could be developed.*

Provision of Information

Question 16: What level of information should be provided to a potential participant? For example, should participants of SIPMPs receive copies of the clinical guidelines used by clinicians?

Comments Yes, but avoid medical jargon.

(Happy to help with a Plain Language Summary)

Commissioning and Governance

Question 17: Are there any other safeguards that should be included in any other commissioning agreement, for example, travel costs?

Comments Definitely travel costs should be provided where people are on benefits. Also care's costs.

Business Impact Regulatory Assessment

Published with this consultation is a partial Business Impact Regulatory Assessment (BRIA) – for further information, please see Chapter 6 of the consultation paper. Once the preferred option is known, further consideration will be given as to the necessity (or not) of completing a full BRIA.

Question 18: In terms of potential impact of the models described in this consultation, are there any comments you would wish to be considered in terms of impact on any organisation that may be affected? This could include public sector, private sector or voluntary organisations.

Comments Private/voluntary sector counselling organisations should be included in consultations: at the moment they fill the gap. If you wish to add any further comments regarding the issues raised in this consultation paper, please use the box below.

Comments

This is a really good initiative. I had to go all the way to Bath to access the clinics initiated by Radiotherapy Action Group Exposure (RAGE) and Cancer Relief Macmillan for women suffering progressive damage from radiotherapy. For years all we had was peer support. Now the long-term problems are at least recognized, and clinical support is offered. A similar service in Scotland is long overdue. But it needs a special kind of empathy to make it work, and this should not be diluted. This is why I think it should be set up centrally to start with, until appropriate experience is gained. Then local centres could follow. Scotland could go one better by integrating complementary approaches, e.g. acupuncture, massage, counselling, ^{409/11} into the programme. This might prove to be cost-effective.

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2 September 2013

Mr Alex Neil MSP
Cabinet Secretary for Health and Wellbeing

cc. Alan Burns, The Scottish Government Clinical Priorities Team

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Dear Mr Neil

I have pleasure in enclosing my personal response to your consultation document on the provision of specialist intensive chronic pain management services. Although the South Edinburgh Health Forum, which I co-chair, often responds to such consultations as a group, on this occasion two of us volunteered to send in personal responses, owing to the particular nature of our own experience.

My experience of such services has been particularly relevant, because I have actually visited the clinic in Bath that has pioneered the treatments you outline in your document. At the time I was suffering persistent low-level pain from fibrosis in the breast and armpit resulting from progressive radiotherapy damage. The clinics in Bath had been set up following campaigning from Radiotherapy Action Group Exposure in collaboration with Macmillan Cancer Support. There I experienced a genuinely empathic service, tailored to individual needs. It was particularly helpful to have an oncologist actually acknowledge the cause of the problem (unlike my own oncologist in Guildford 20-odd years ago). Peer support was also of great value. However, it was a long journey!

The only thing missing from your document is acknowledgement that complementary therapies can actually help. I myself have gained great benefit from acupuncture, administered by a local Chinese practitioner. Other techniques such as yoga may also be of benefit. I should add that I am able to fund my acupuncture, helped also in the past by a grant from Macmillan, but many people would not be able to do so. Genuine integration of healthcare should mean, in my view, the integration of well-researched complementary approaches as well as the blending of health and social care.

In this connection I must also mention my great disappointment that NHS Lothian has withdrawn funding from homoeopathic services provided by medical practitioners. This seems to me to be unwise, and very unlikely to be cost-effective, as many of the patients who benefit from homoeopathy have long-term conditions for which mainstream medicine fails to provide relief. I myself have certainly benefited from consultations with a homoeopathic practitioner to whom I was referred on the NHS by my GP.

Yours sincerely



Heather Goodare
(consumer reviewer for the Cochrane Collaboration)