

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

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.

The document seems to assume that SIPMP should remain, as now, a last resort. I strongly disagree with this. Relatively early intervention is critical in many pain conditions, especially as it can be easier, cheaper (and of course, better for everyone) to prevent loss of function and/or psychological damage than remedy it. Similarly, over-reliance on medication is easier to prevent than resolve. I believe that low take-up of the current service is due to barriers, not lack of need in Scotland, and that earlier, more frequent, specialist interventions in chronic pain would significantly improve both outcomes and cost-efficiency. It is key that GPs are able to access/refer patients with chronic pain *as soon as* that pain exceeds their own expertise and/or treatment options. While the service as is, is clearly necessary, the delivery of specialist pain management should be more common and more used.

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?

This is *essential*. Travel is almost always itself a significant pain-trigger/experience, which not only prevents people accessing services, but also limits their benefit. The more that can be done locally, the better. As we have the technology for remote face-to-face consultations (and even group therapy) this should be used as often as possible. By definition, people accessing an SIPMP will already have been adequately physically assessed in other contexts. In many cases, they will not therefore need to see a specialist in person, but will need individualised, frequent advice and support. This can certainly be provided by video networking supported in

e.g. local hospitals and medical centres.

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?

This is also exceptionally important: the people who would benefit most from specialist interventions are often those with the most pain-based restrictions. Three hours is a reasonable maximum, and there need to be a variety of means of travel available, as people find different forms of transport more/less painful than others. Complexity of transport access should also be considered, both to any site and within it. Up-front and at-the-time reimbursement needs to be available for costs, as people with disabling pain are rarely financially secure. For residential treatment, it would be best to offer both on-site and independent accommodation to take account of co-morbidities and varying needs. Companions are entirely necessary, and should be very much encouraged, especially as their attendance will improve lay understanding of management techniques.

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

Yes x No

I think this is reasonable, but, as above, not inevitable. Earlier and more frequent use of such services is an investment in lower overall socio-economic and medical costs long-term. The NHS in Scotland should be encouraged to make much more use of specialist pain management, and the national service must be designed to accommodate this. The current situation is a disgrace!

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?

Patients should have the option of choosing less 'appropriate' treatments sooner, or waiting, having been given full information about the choice. For many people, the opportunity to interact with specialists and other people with chronic pain will be much more significant than whether those people are otherwise 'like them'. Chronic pain is so little understood by the public that such opportunities are priceless.

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

Yes No

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?

As part of the participant's costs. *Some* other person's understanding is crucial to the long-term success of such management programmes. This may often be a formal carer, but also often *not*. If a friend, partner or family member is best placed to psychologically support the patient, they should be equally encouraged to participate. Investment in this is investment in successful management and positive outcomes, which is the point of offering the service at all.

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?

Choice is key, to accommodate patients' specific needs. I believe it is important to offer some on-site accommodation, while acknowledging this may not be best for everyone. Equally, there should be a mix of free, subsidised and independent accommodation, all with consideration of not only distance, but travel complexity/options to site.

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?

Not currently, but they could do and need to (and yes, it did influence my choice). The type of service under consultation needs to be underpinned by – and help deliver – a much wider and deeper understanding of chronic pain throughout the Scottish NHS (including, e.g. rural clusters and pain rates). I do not believe this would be particularly difficult to achieve – many of the principles are simple, just not widely understood. There also needs to be an integrated mechanism for communicating about chronic pain, which acknowledges its multi-dimensionality. The McGill Index, for e.g. is a useful standard which now has various short-forms, and is far superior for chronic pain than simple measures of intensity, which are more relevant to acute pain. If this were used throughout the NHS, it would improve communication, monitoring and patient understanding. It is also much easier (being verbal) for GPs and patients to understand. Interventions do not have to be expensive to be effective! Feeling unable to communicate about pain, and/or have that pain acknowledged, is a major source of unnecessary distress, while confident communication can make the subject less fraught for GPs and other non-pain-specialists, while also reducing the regrettably common tendency to, in practice, rely on medication levels over self-report.

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?

Yes. All patients should have the option of receiving all levels of information – the principal benefit of SIPM is to help patients understand, and achieve a sense of control over, their pain. Information is essential, and understanding clinicians assumptions is particularly important in communicating and learning about pain.

Commissioning and Governance

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

It seems pretty clear (tens from hundreds of thousands of sufferers) that current low take-up is to do with barriers to access, not lack of need. Everything possible needs to be done, therefore, to ensure that such barriers are removed and equality of access is safeguarded.

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

If you wish to add any further comments regarding the issues raised in this consultation paper, please use the box below.

I suffer from disabling, severe chronic multi-dimensional, non-neuropathic pain, and have also been a carer for others with chronic pain. Improving the specialist intervention service alone is not enough: this needs to be integrated with services provided locally and remotely.