Consultation response

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) ×

NHS Lanarkshire, Chronic Pain Service

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.

Out of the options suggested, the Chronic Pain Service's consensus was that Option 2 reflects the most effective, comprehensive, sustainable and cost effective response. Reasons being:

- It would result in a consistency of service delivery across health boards, removing any 'post code lottery'.
- It would facilitate an optimised intervention that could be provided as the national standard
- It would lead to investment opportunities. Existing resource allocation across health boards would have to be determined, demonstrating the lack of equity in service provision, enabling individual health boards to develop pain management teams reflective of their population. This may help increase staff numbers in NHSL and widen the variety of professions involved eg. recruiting an occupational therapist
- There would be an increase in the local skill set, through facilitated consultancy and/or first hand experience (participating in the delivery of the Residential PMP). This knowledge and skill set could then be cascaded down to Level 1 & 2 practitioners, according to the structure of individual pain services
- Waiting lists/time would be minimised as this option would be able to

balance demand and capacity best

- This option (a nMCN) has demonstrated improved quality in other services. Being able to consult with other experienced clinicians is always advantageous, especially in the early stages of establishing a service.
- There would be linking and networking with other services/health boards, resulting in the associated sharing of skill, expertise and best practice
- This option would utilise the existing expertise and knowledge base- there would not be the need to recruit additional highly specialist practitioners. For NHSL this would involve adapting an existing PMP, rather than establishing one from scratch. In other words, it would be the most cost effective- using what already exists, more creatively.
- Option 2 would also be the quickest to set up, for NHSL, as it would draw on the expertise of the existing pain management professionals.
- Option 2 provides a flexible response- such a regional model would be able to draw on the skill set and staff resources of several health boards (the clinical advisors) to tailor a residential PMP to patient's needs and referral demand eg. running a SIPMP for adolescents or a SIPMP for a common condition
- It would be better geographically- there will always be travelling involved but this residential PMP option could be delivered closer to patient's homes
- The provision Telehealth would be helpful for clinicians in more remote locations
- This option would promote and consolidate established pain services
- Option 2 is probably the most sustainable, as it provides professional development to the existing pain clinicians, which is more likely to lead to their retention. The regional residential PMP would also be a continually active, evolving and dynamic service, reflecting best current practice. It would be responsive to referral demand, unlike option1, which runs the risk of losing momentum if the residential PMP is not run regularly

There are negatives associated with option 2:

- Any Residential PMP will be very resource intensive and will require long term funding for additional pain management staff of all professions
- Generally, health boards lack trained and skilled staff in pain management. Whilst NHSL has the highly skilled clinicians to run the Residential PMP there is no alternative staffing available to carry out the day to day operation of the pain service, when those specialist clinicians are running the residential PMP. This would result, effectively, in the existing pain management service 'shutting down' for the duration of the residential PMP (and its associated assessment/admin). There may not be the pool of interested staff available in NHS Scotland to fill this gap.
- Setting up 14 separate Residential PMPs in 14 Health boards, with 14 pain management teams is extremely resource heavy. However, this would be beneficial, in the long term, for the delivery of pain services to the Scottish population
- Long waiting times due to infrequent residential PMPs- we may only offer 1 residential PMP per year (perhaps less). Based on current experience there isn't the volume of patients to warrant running one more regularly. We would have to rely on referrals increasing (with the resulting increase on an already stretched service) to justify the existence of such a specific service.
- The demand may not be there- currently, across the 14 health boards, only 2 or 3 refer to Bath (mainly due to an absence of their own level 2 PMP).
- There isn't a suitable clinic/physio gym/residential accommodation complex in NHSL (or most likely, many of the other health boards)

- Within Scotland, an informal nMCN is already in place- pain clinicians already have close links with each other. Formalising this would add little to what already exists. It is doubtful whether NHSL pain management staff would benefit, significantly, from being able to consult with another clinician. The provision of this set up would benefit health boards with no existing (or patchy) pain services.
- One of the main criteria for patients referred to the Residential PMP is an inability to travel to the Level 2 PMP- not clinical complexity. Those complex patients are already being seen in the NHSL pain management service. The clinicians running NHSLs PMP already receive formal supervision from other clinicians. A named supervisory clinician on an nMCN or an advisory team would only duplicate the supervision arrangements already in place (and which have to stay in place as part of the NHSLs clinician's conditions of practice). Using telehealth would have little or no benefit for NHSLs clinican's practice.

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?

NHSLs Chronic Pain Service feel that a specialist residential PMP is not the most patient and condition centred treatment and should only be explored in the absence of investment and development at a community based/primary care level, in which each health board could establish pain management teams capable of providing long term management at a more local level. The common criticism to all 3 residential options is that it is contrary to the nature of chronic pain and the purpose behind its management- a specialist residential service is, afterall, an artificial situation that removes an individual from their home environment, where they would best placed to generalise and apply pain management skills, for the long term.
Also, all PMPs aim to address patient's avoidance of activity and enable them to become more physically active by including a structured exercise component, supported by psychological input. It would be very hard to achieve the strength and fitness gains over the short period of time available in a residential programme. This is particularly true in chronic pain, as activity levels are limited due to pain levels. Such exercise gains require a longer length of input than available through a residential PMP. It is implicit in a residential PMP that patients will continue to be motivated to exercise independently, without therapeutic and peer support. Clinical experience suggests that this carry over and maintenance is very hard to achieve and this would consequently reduce the efficacy and outcomes of any residential PMP.

However, considering that a residential PMP is being proposed we would disagree with options 1 and 3 for the following reasons:
Option 1

- There would be high funding required initially, with associated high set up costs.
- Recruiting may be problematic as a number of full time, very experienced clinicians would be required and there are few highly trained clinicians in Scotland at present. Recruiting from the existing pool of clinicians would then detract from current pain management services, which are already

struggling to meet demand.

- Determining one convenient, central location for the building would be difficult- for those in more rural locations going to a main city in Scotland is not much different to attending Bath, in terms of travelling. From the opposite perspective, there would be considerable travelling problems involved in attending a rural location. There would be little equity of access across Scotland. Transport links, geography and terrain and the inclement Scottish weather would present particular challenges.
- There would be no 'skilling up' of local staff- NHSL staff would have little or nothing to gain from establishing a national unit- there would be no local skill development. Additionally, resources may get directed towards the national unit resulting in an actual skill loss to existing PMP services.
- It has been our experience that patients attending the Bath programme require follow up, reassessment and input with NHSL pain management services. This arrangement would not change with a national unit, meaning NHS Scotland paying twice for the same type of therapeutic input. Given that there would have been a missed opportunity with developing NHSL staff skills, the burden of treatment would fall back onto the existing pain service. In addition to this duplication in input and lack of continuity in individual treatment, there would also be implications for clinical responsibility and clinical governance.
- The provision of one residential unit may result in less equitable access to pain management for the full spectrum of NHSL patients. It is unclear whether the residential PMP would be willing or practically able to offer an intervention for patients with co-morbid problems (eg. psychiatric disorders, developmental disorders, neurological conditions etc). Experience suggests that these patients are best managed locally, utilising existing services and community resources to deliver pain management interventions in a consultancy model. If funding is diverted from NHSL towards a national unit, this model of consultancy working would be even less likely due to lack of investment in future training and in developing a network of pain educated community based staff.
- One national unit would develop waiting lists quickly- this is particularly an issue with Scotland. Travelling, in Scotland is problematic due to it's rural environment. An inability to travel regularly to a local PMP would be one of the criteria for referral to the national unit and Scotland has more travelling challenges than England. Therefore, the national unit would need to accommodate more of those unable to travel easily.
- The specialist unit may be perceived as a 'fixing unit' by those patients attending and those referring. This is contrary to the ethos of pain management that emphasises self-help and increasing self-sufficiency for long term.
- There may not be sufficient referral numbers to justify a new service being established. Currently only 30 patients/year are sent to Bath. However, it is unclear whether the provision of a national service would subsequently increase referral rates.
- NHSL would not benefit from having a residential PMP, out with the health board. We currently send few or no patients to Bath. In order to send an equitable number of NHSL patients to a residential PMP, we would need to increase the volume of patients being assessed and be less selective in the service's eligibility criteria. With present capacity, this would not be feasible or purposeful. Only the health boards, with no existing PMP would benefit.
- It may be financially more expensive to send someone to a centralised Scottish Unit than down to Bath

Option 3- Many of the criticisms above apply to this option. However, specific issues are:

- Lack of available appropriate accommodation in every health board. The residential PMP would have to include a large group room, with a gym and accommodation in close proximity.
- Low referral numbers- it is doubtful that many of the health boards would have sufficient referrals (unless there was no PMP already running in that health board). The consequence would be long waiting times in each health board.
- Retention of clinicians- this would be a very unattractive role and practically unworkable. This is partly due to Scotland's geography (ie. the Highlands and islands are a long way from the central belt- clinicians would be away from home for long periods of time).
- May be a lack of investment in local pain services. There may not be the perception that specialist, skilled clinicians are required.
- There would be a problematic lack of ability to follow up patients, to provide ongoing long term input, monitoring and care- practically, how will these patients be reviewed etc.
- Conversely, each health board would have to establish their own pain management team, to provide follow up once these patients have participated in their brief, intensive input. This would be a duplication in provision, with the obvious consequences for funding and clinical time.

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.

If there was the option for designing a pain service that aimed to be patient centred, condition specific, sustainable and cost effective, it would not be a residential pain management programme. We feel this is a reactive, short term, 'quick fix' solution to a long term issue.
The aim in helping people with chronic pain is- teaching them evidence based pain management approaches; tailoring those approaches to an individual's particular circumstances; helping them apply and adapt the strategies in their day to day life and then dealing with the obstacles to them moving forward with their lives, creatively and in a model specific manner. It involves working systemically, with patient's families, their employers etc. It would also involve a different model of care (to the brief residential input being proposed), in which patients could have the option of regular follow up, support and a 'refreshing' of pain management skills. This type of model is being used, successfully, in other countries (eg. Australia and Sweden) and other parts of the UK (eg. Birmingham). A residential programme would be a retrogressive, not progressive step in the management of chronic pain for Scotland.

All the patients who currently attend NHSL's PMP are in severe amounts of pain and often have additional psychological difficulties (eg. depression, anxiety). Anecdotally, they have fedback that one of the useful aspects of

the PMP is having to actually attend for the treatment. It imposes a structure to their day and week; it forces family members to change, in order to accommodate them; it provides a 'hands on' opportunity to implement the pain management strategies taught on the programme and promotes self efficacy, as the patient learns they can actually cope and deal with setbacks. Many of these benefits would be missing from a residential PMP, which by it's nature is a brief, intense, isolated, artificial environment.

Investment should be made at community based/primary care level, to facilitate the delivery of pain management in patient's local environment by a network of trained multidisciplinary staff. There should be greater integration with other statutory (eg. social work) and voluntary sector (eg. vocational rehab, active health) organisations in order to support these patients for the long term.

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.

Travelling time
Time away from family
Other responsibilities- eg. caring commitments, child care
Lack of ability to pace the intervention- by it's nature it is brief and intense input. As a patient, if you are having a pain flare up that week/fortnight you are not going to be able to optimise the level of input you receive.
Work commitments
It is unclear what the exclusion criteria for a residential PMP would be. Patients with co-morbid difficulties may find that these act as barriers to them accessing a residential PMP. Such co-morbid difficulties may be addiction problems, psychiatric disorders, learning disabilities, neurological/neuropsychological problems and those with recent contact with the Criminal Justice System.

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) ×

Occupational Therapy input- eg. home adaptations; vocational rehab etc.
Long term review and follow up
Mental health support
Linking with local statutory/voluntary organisations

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.

Advantages: Bath is recognised as a centre of good practice and innovation
Disadvantages: It is still necessary to assess patients prior to being sent to Bath and then re-assess those patients following their completion of the programme, with the resulting implications for resource management and clinical governance. The patients are usually discharged back into the local pain service's care and require follow up treatment. The residential programme does not promote the integration of pain management skills in the patient's own environment- often this is work that the local pain team has to complete. As a result there is often duplication of input. There is a lack of consistency of care- with a lot of clinicians involved in the same patient's treatment. Patients can experience flare-ups for the duration of the programme, meaning they gain less from attending. The short duration of the residential PMP prevents patients from experiencing the strength and fitness gains that those attending a community based PMP do.

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 (box expands with text input - there is no word limit)

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.

As outlined in the responses above, we would urge the Executive to re-think the proposed strategy for provision of care for chronic pain patients. A residential programme is not an economical, condition specific, clinically effective or sustainable intervention for a long term condition. By its very nature, a long term condition requires a different model of working. A residential programme would represent a missed opportunity for developing appropriate pain management interventions for the population of Scotland. Any health board with an existing pain service will, most likely, not benefit from the provision of a residential PMP and may in fact find their service suffers detrimentally, as funding and resources are re-directed. A residential PMP should only be a treatment option for those unable to travel and for those health boards with no pain service provision. However, this suggests the need to invest at a community/primary care level to provide flexible, local, patient centred interventions rather than establishing one national unit that patients would still have to travel to.