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 Board and local Chronic Pain Service Improvement Group (SIG), which includes health professionals

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.

Option 1 preferred - reasons:

- tested model
- builds expertise through 'centre of excellence'
- best model for peer support
- the model most likely to deliver on all the factors listed at end of Chapter 2
- for patients in rural and remote areas (such as much of D&G), travel involved in Option 1 may not be much more than for Options 2 & 3.
- a limited number of Boards have the local capacity (in terms of resources, staffing, facilities & expertise) to deliver Option 2 even with support from elsewhere.
- because of the small population size of Dumfries & Galloway (~150k), it is expected that fewer than 10 patients per year would meet the criteria for the level 4 service (extrapolating from the

Bronllys Pain Management Centre, Wales). According to the Bath Centre, this is lower than the optimal number for running group sessions - both in terms of patient benefit and efficiency. Thus Options 2 and 3, if delivered in D&G, would not provide optimal benefit for patients at level 4. However with Option 1 such low numbers could join larger groups through referral to a single centre, and thus benefit optimally.

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?

Option 3

- Option 3 is not appropriate for most Boards as, by definition, there will be very small numbers of local patients who meet the criteria for the specialist (level 4) outreach residential pain service (e.g. <10 pa for D&G - see response above).
- Option 3 would be a very wasteful way of using the very valuable level 4 team of specialists in chronic pain, which in turn would mean that fewer patients would benefit from the service.
- As mentioned in the consultation report, it is very unlikely that staff would wish to spend so much time away from their base to deliver the 'roving' residential service, and so it is doubtful that Option 3 would be deliverable.

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.

As well as supporting Option 1, we support designing any new service to include the facility for telemedicine/ teleclinics - both for provision of expert advice to local chronic pain services and, where clinically appropriate, linking with patients/ families remotely - to support the long term aim of promoting self management of chronic pain.
This approach could:

- reduce the referral of patients to the specialist service by enhancing the knowledge & skills of the local service
- enable certain patients who feel unable to travel, even to a Scottish centre, to access specialist services/ expertise (e.g. through Skype)
- support discharge planning and 're-integration' of the patient to their local community - including links with their carers, family and local support networks.

Any residential service, whether delivered by a central, regional or local option, by definition removes a person from their home environment. Because of this, the chosen model needs to recognise and address certain potential issues such as:

- removal of people from their communities, sources and networks of support
- a "proclamation" of them being ill /different/ dislocated from all these sources, which could make re-integration necessary.

It is therefore very important that the specialist service communicates well with the local services, both primary and secondary care, to ensure benefits for the patient are sustained long term.

In addition to telemedicine, we recommend that the specialist service provides patients with a range of options for continued peer support following discharge, to fit the patients' preferences, such as social networking, chat rooms, etc.

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.

Many patients find travelling, especially long distances, very difficult due to pain. (However travel is more likely to be tolerated if to a residential service, when rest can be accommodated, than if needing repeated journeys to/from a non-residential service.)

In addition to discomfort of travel, related barriers can include - distance from home, cost of travel (even if can be reclaimed, up-front costs), out of reach of normal local/ family support circle.

Patients may have specific conditions that require consideration in residential accommodation (e.g. medical comorbidities /disabilities) for which there are adaptations at home.

Patient uncertainty and anxiety around the specialist service. (Good patient information needed.)

A past barrier resulted from there not being full understanding across all local Boards of the referral and funding arrangements for the Bath specialist services, which may account for some of the disparity in referral rates across Scotland. Therefore there must be clear and well-communicated referral arrangements, including criteria, for the future specialist service.

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)	☒

Self management ethos & skills

- The most important aspect of any chronic pain service is helping people to self manage. (It is felt this was under-played within the consultation document.)
- this includes acceptance that chronic pain cannot be 'cured' - but quality of life can be improved & disability reduced. (ref patient leaflet from Bronllys service, Wales)

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 ☐

(Unless in exceptional circumstances, when referral would need approval & funding from the local NHS Board, going through the exceptional referral process.)

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.

Advantage - residential component of the service, as patient could not manage daily travel to the alternative Scottish level 3 option.
Disadvantage - cost of travel to/from Bath

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?

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.

<u>Primary Care</u>
It is important to recognise the key role of primary care in supporting the patient long term to self manage their chronic pain, following discharge from the specialist residential service. Therefore the specialist residential service must have effective clinical communication links to the patient's primary care team, as well as the local secondary care pain service.

<u>Carers</u>
There is need for clarity regarding carer attendance within the residential service. Some patients do NOT wish their carer/ partner to accompany them. However for some patients it is important that their carer does travel & stay with them, especially when requiring help with activities of daily living.
As the main aim of the service is to enable the patient to self manage following discharge, for some this may only be achieved with the full involvement of their carer. Alternatively it may be that there is over-dependency.

<u>Location of Option 1 centre</u>
A Central Belt location would be nearest to the majority of the Scottish population. It is difficult to be specific about a preferred location - as different people have different preferences depending on their mode of transport. Rather - the approach should be that, whatever site is chosen, transport should then be optimised around each patient's needs.