Gathering Views Report on Chronic Pain

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Section 1: Executive summary

1.1 The Scottish Government has developed a Framework for Pain Management Service Delivery – Implementation Plan in partnership with people with chronic pain[1], clinical, research, third sector communities and other key stakeholders.

1.2 Healthcare Improvement Scotland - Community Engagement was commissioned to undertake a Gathering Views exercise in May 2022 to support the ongoing development and implementation of the Framework by gathering information from people in Scotland living with chronic pain. It is intended that the recommendations from this exercise will be used to inform future delivery of the Framework, as well as provide an evidence base for improvement opportunities for local pain services across Scotland.

1.3 The Gathering Views exercise was undertaken during August and September 2022 in all 14 territorial NHS board areas in Scotland with individual interviews taking place via phone calls, video calls or in face-to-face settings. The work involved gathering lived experience from individuals living with chronic pain by asking questions about the care and support they had experienced through health and social care services and local support groups. This report sets out a range of themes that matter most to the people we spoke to regarding their care.

1.4 A total of 92 people across Scotland took part in this exercise over a five week period. Interviews were organised through engagement offices using links through local contacts, NHS services and third sector organisations. A mix of participants from all demographics were sought including those in areas of multi-deprivation, the seldom heard and people who have not previously spoken about their chronic pain. Representation was achieved from all the territorial health boards reflecting a mix of urban, rural and island community views which were captured.

1.5 Based on findings from this Gathering Views exercise, the report outlines five main themes:

- Staff understanding and attitudes
- Access to Support Services
- Different types of support
- Self-management
- Patient feedback

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[1] Chronic pain is defined as pain that persists or recurs for longer than three months. Chronic pain is a common condition and estimates suggest it affects between one third and a half of adults in the UK. In Scotland it is estimated that 5% report severe chronic pain, which impacts their daily activities and quality of life (Draft Framework for Pain Management Service Delivery).

The themes cut across the four aims of the Framework which are:

- Person-centred care
- Access to care
- Safe, effective support to live well with chronic pain, and
- Improving services and care.

A summary of the recommendations are as follows with further detail around the recommendations provided in Section 5:

Recommendation 1

Development of national training and guidance for staff to support the diagnosis, treatment and support of chronic pain, including self-management.

Recommendation 2

Support the development of a training and resource package for people with chronic pain and the people around them and make this widely available.

Recommendation 3

Consider the provision of further support and what can be made more widely available to people with chronic pain, such as nutritional advice, exercise, creative activities or alternative therapies.

Recommendation 4

Proactively promote the importance of patient feedback and ensure that feedback processes are fit for purpose and widely available.

Recommendation 5

Improve circulation of information and awareness around support that is available that does not require a formal diagnosis of chronic pain.

Recommendation 6

Consider the impact of chronic pain on patients’ journeys and what can be put in place to support individuals to access care.

Recommendation 7

Consider the findings in this report to ensure that the Framework for pain management service delivery addresses, and certainly does not exacerbate, health inequalities and barriers which may be more prominent among certain groups of the population.

Section 2: Background

2.1 The purpose of Healthcare Improvement Scotland is to enable the people of Scotland to experience the best quality of health and social care. Healthcare Improvement Scotland – Community Engagement is committed to supporting the engagement of people and communities in the development of health and social care services.

In May 2022, the Scottish Government commissioned Healthcare Improvement Scotland – Community Engagement to undertake a Gathering Views exercise. This was to support the ongoing development of the Draft Framework for Pain Management Service Delivery, to ensure the priorities of people with chronic pain, especially as they relate to local contexts, are appropriately reflected as the Framework is implemented.

2.2 **The Framework for Pain Management Service Delivery – Vision and Aims**

The Scottish Government's 2020 Programme for Government included creation of a new Framework to assist those living with chronic pain. In 2021, the Draft Framework for Pain Management Service Delivery was developed and following public consultation, the final Framework for Pain Management – Implementation Plan was published in July 2022. These findings contribute to the ongoing development and implantation of the Framework and subsequent relevant pieces of work.

Scottish Government's shared vision is to ensure timely access to effective, safe and person-centred care that improves the quality of life and wellbeing of people living with chronic pain in Scotland.

Chronic pain affects between one-third and one-half of the population of the UK, corresponding to just under 28 million adults, based on data from the best available published studies, and this figure is likely to increase further in line with an ageing population[2]. It can affect all ages and all parts of the body, and 5% of people in Scotland report severe chronic pain which impacts their daily activities and quality of life[3]. The Framework for Pain Management Service Delivery - Implementation Plan focuses on the needs of adults living with chronic pain, which is defined as persistent or recurrent pain lasting longer than three months.

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[2] Fayaz A, Croft P, Langford RM, Donaldson LJ, Jones GT. Prevalence of chronic pain in the UK: a systematic review and meta-analysis of population studies. BMJ Open. 2016 Jun 20;6(6):e010364. doi: 10.1136/bmjopen-2015-010364. PMID: 27324708; PMCID: PMC4932255.

[3] Smith BH, Elliott AM, Chambers WA, Smith WC, Hannaford PC, Penny K. The impact of chronic pain in the community. Fam Pract. 2001 Jun;18(3):292-9. doi: 10.1093/fampra/18.3.292. PMID: 11356737.

The aims of the Framework are:

- Person-centred care
- Access to care
- Safe, effective support to live well with chronic pain, and
- Improving services and care.

The Framework is intended to support improvements in healthcare for everyone, ensuring that people in Scotland have a clear understanding of what chronic pain is, what matters to people living with chronic pain and how their needs can best be met.

Section 3: Approach

3.1 Healthcare Improvement Scotland – Community Engagement has developed an approach called Gathering Views[4]. This aims to gather lived experience views on specific subject areas to inform the development of policy and services.

3.2 Gathering Views exercises are not undertaken as formal research, nor as formal public consultation. The engagement is intended to supplement work undertaken by Scottish Government or other commissioners, consider new or different ideas and make recommendations based on the findings.

3.3 The Scottish Government produced a national EQIA and Fairer Scotland Duty Summary Draft Framework for Pain Management Service Delivery - Annex A: Draft Equality Impact Assessment and Fairer Scotland Duty to assess potential impacts for people from each of the protected characteristics, socio-economic factors and remote and rural settings.

3.4 While some lived experience engagement activities had already been delivered at the national level throughout development of the Framework, there was a need to hear from local communities which more fully represented the diversity of chronic pain and its impact in Scotland. Due to the sensitive topic of this exercise, it was decided that a qualitative approach using individual interviews would be the most meaningful method of engagement. We were keen to engage with people who represented a number of areas and had potentially not had their voices heard[5]. We spoke with all the people identified throughout the five week engagement period.

3.5 The question set (Appendix 1) was developed to help us to understand people's views, insights and experiences with living with chronic pain and accessing services. Ten questions, some with supplementary questions, were asked. Questions to establish key demographics, such as age and sex, and chronic pain impact were added to the question set, as well as asking individuals for their postcode which would allow us to link in with existing data based on the Scottish Index of Multiple Deprivation (SIMD)[6] and Urban Rural Classification.

3.6 An information sheet was provided for the participants as well as a consent form to take part in the work and all participants provided written or verbal consent in

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[4] There are several examples of our previous Gathering Views exercises available on our website www.hisengage.scot where this report has also been published.

[5] People that represented these areas were: seldom heard, areas of deprivation, the male population, those in remote and rural areas, and those whose voices have not been heard previously on chronic pain.

[6] The Scottish Index of Multiple Deprivation (2020) can be found here https://www.gov.scot/collections/scottish-index-of-multiple-deprivation-2020/ and the Scottish Government 6-fold Urban Rural Classification (2016) can be found here https://www.gov.scot/publications/scottish-government-urban-rural-classification-2016/pages/2/

advance of the interview (Appendix 2).

3.7 Equalities monitoring questions, in the form of an online survey were shared with the participants, either before or during the discussion (Appendix 4), which they could also complete via email or paper copy, achieving a 68% response rate.

3.8 Recruitment methods were agreed based on the scope and aims of this work. We carried out 92 individual interviews over a five week period, collecting extensive and in-depth responses. Following a qualitative approach and according to the objectives of this work, the aim was to collect rich and meaningful feedback from a wide range of people, for example people in areas of deprivation or those who have not previously spoken about their chronic pain, rather than focusing on the number of participants. Carrying out 92 interviews provided both insight into the national picture around chronic pain and people's experiences of it and allowed sub-group analysis to highlight particular examples or challenges that people with specific characteristics face, for example linked with age or sex.

The Gathering Views exercise obtained feedback through discussions with individuals, via phone, video call and face-to-face.

3.9 The questions covered the following areas:

- Local Chronic Pain Support
    - What types of support participants access
    - Benefits and barriers that participants experience
    - What matters most to participants

- Feeding Back to Services
    - Participants' experiences of providing feedback
    - Benefits and barriers experienced by participants
    - What matters most to participants

3.10 The interviews were challenging at times for both participants and interviewers due to the sensitive topic and the significant impact chronic pain has on people's lives. It is important to recognise this as it could have an impact on the responses and findings.

3.11 The themes that emerged from the questions we asked can be found in the feedback and recommendations section of this report as well as recommendations which were identified during the analysis process. Where appropriate, we have used anonymised quotes from people who participated in the Gathering Views exercise to illustrate what we have heard. Quotes are not accompanied by any identifiable characteristic, such as location, but are attributed to a sub-group, for example; older participants or those located in remote rural areas, when appropriate.

3.12 The analysis process focused on a qualitative approach and took place in two stages. At the first stage, all participant responses were themed and categorised, identifying a number of key and overarching themes discussed in this report.

At a second stage, sub-group analysis was conducted aiming to highlight specific themes, barriers or support needed by particular sub-groups of the participant sample and around key demographics. This was based on the following key demographic characteristics which were asked at the start of the interviews (See Appendix 1). To note, equalities monitoring information was not considered for this, as it was collected separately, anonymously and for monitoring rather than analysis purposes.

Sex: responses were analysed based on two sub-groups, where respondents had said their sex is male (35 participants) and where they had said their sex is female (53 participants). The responses of the three respondents who said they preferred not to answer this question were not included in this sub-group analysis but are included in the overall analysis and findings. This question is aligned with the approach followed by the 2022 Scotland Census question set, supporting a self-identification position[7]. To note, 3% of respondents considered themselves to be a trans person or have a trans history based on responses to the equalities monitoring questions. However, due to the limitations in the scope of this work, trans status was not an aspect that was focused on in sub-group analysis.

Age: responses were analysed focusing on two sub-groups, the younger participants, up to and including 35 years old (9 participants) and the older participants that are 66+ years old (27 participants). Responses of participants that are between 36-65 years old were not included in this sub-group analysis but are included in the overall analysis and findings.

Ethnicity: the sub-group analysed for this were all participants who had said their ethnicity is any category that was not White British/Irish (12 participants). The responses from participants who said their ethnicity is White British/Irish were not included in this sub-group analysis but are included in the overall analysis and findings.

Rurality: analysis was based on three sub-groups: i) remote rural areas (14 participants), ii) accessible rural areas (7 participants), and iii) large urban areas (21 participants). Responses from participants whose postcodes fell in the remaining categories of the 6-fold Urban Rural Classification were not included in this sub-group analysis but are included in the overall analysis and findings.

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[7] Information on the 2022 Scottish Census question set can be found at the following link: https://www.scotlandscensus.gov.uk/documents/sex-question-recommendation-report/html/

Deprivation: sub-group analysis for this focused on the responses of participants whose postcodes are within SIMD1 areas (10 participants) but are included in the overall analysis and findings.

Disability: while specific sub-group analysis around disability was not conducted, some participants highlighted particular barriers linked to their disabilities. They are also highlighted in the report.

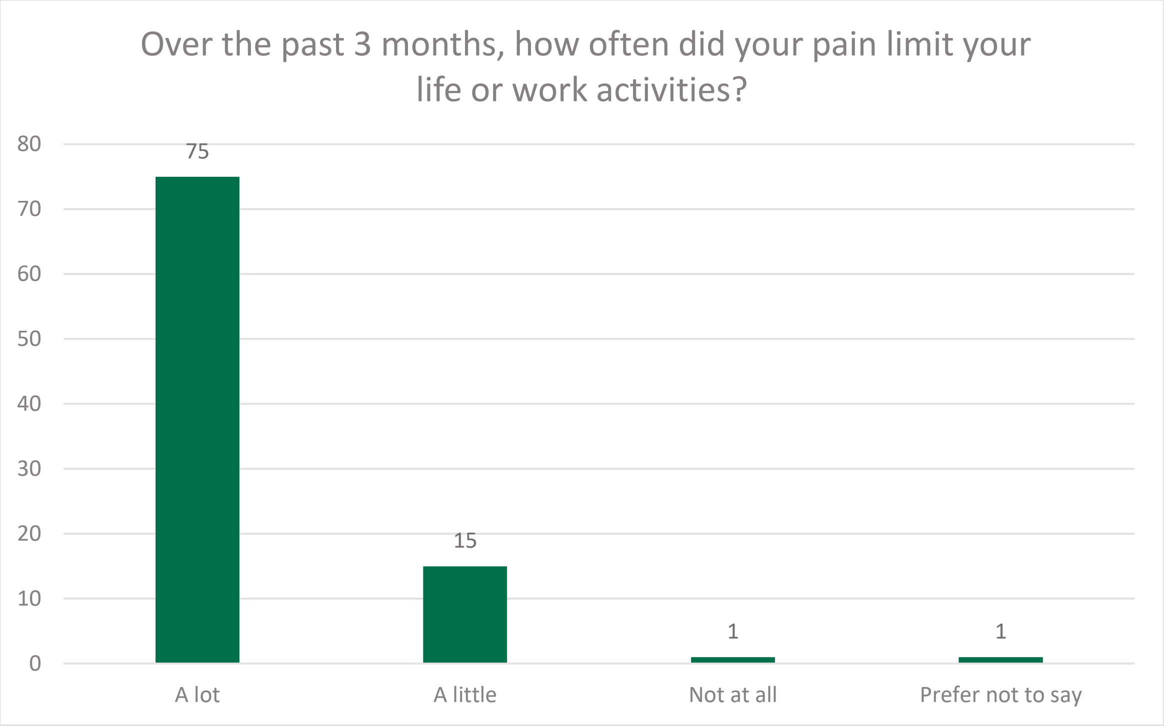
Sub-group analysis findings are included throughout the report alongside the main key findings. Where findings are enriched by further detail or examples coming from sub-group analysis, they are accompanied by the visuals above.

Section 4: Feedback

4.1 Having interviewed 92 participants, a significant amount of feedback was received through this Gathering Views exercise. The quotes that appear throughout the report are from people who took part.

4.2 All participants confirmed in advance that they have chronic pain. When interviewing someone's carer, they confirmed that the person they care for has chronic pain.

The impact of chronic pain varied between participants. For 82% of participants, chronic pain limits their life or work activities a lot, and for 16% a little. Only 1 person said that their chronic pain does not limit their activities. This is important to consider when reading through this report, as the majority of participants are significantly impacted by their chronic pain. This is a higher percentage than what may be expected across the Scottish population, where it is estimated that 5% report severe chronic pain which impacts their daily activities and quality of life[8]. Furthermore, we recognise that this information is about self-assessed pain and on the day of the interview specifically. We acknowledge that this may have influenced the participants' responses and experiences.



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[8] Smith BH, Elliott AM, Chambers WA, Smith WC, Hannaford PC, Penny K. The impact of chronic pain in the community. Fam Pract. 2001 Jun;18(3):292-9. doi: 10.1093/fampra/18.3.292. PMID: 11356737.

Participants provided a wealth of feedback including ideas and suggestions for improvements. Throughout the feedback, the following key themes emerged:

- Staff understanding and attitudes
- Access to Support Services
- Different types of support
- Self-management
- Patient feedback

Staff understanding and attitudes

An understanding of what it's like to live with chronic pain

Most participants felt that there was a lack of knowledge and understanding around chronic pain and how it impacts people on a day-to-day basis. This relates to NHS staff but also includes carers, support workers, the patient's family and friends.

One person thought that a lack of comprehension around chronic pain from clinicians can cause patient's faith and interest in the service to decline. Participants felt that if NHS staff had better knowledge and awareness of the impact chronic pain has on patients, it might improve the service they provide and the patients would benefit from this. An example was having knowledge of available support services in the local area which would enable professionals to proactively signpost patients to a tailored support service.

Participants noted that it is important for practitioners to understand what services are working well for users and which are not as this could help identify funding needs for areas that are underachieving. Participants thought a better understanding of chronic pain would enable better promotion of services available and allow early intervention with treatments. Some participants thought it would encourage professionals to be more flexible when prescribing, particularly around support beyond medication, including alternative therapies.

Participants also thought that employers being aware and acknowledging chronic pain would promote support and compassion in the workplace to allow people to continue working. Although some people have had to leave their jobs due to lack of employer support, others said their employers were able to offer adjustments and wellbeing support to assist with chronic pain management.

It was very important to participants that clinicians understand the impact of chronic pain on their lives.

A younger participant noted that living with chronic pain is incredibly hard for young people as it gets in the way of making relationships, working and going to university or training. An older participant characteristically said,

"Chronic pain may not kill you, but it takes your life away."

One participant from a minority ethnic background, highlighted that chronic pain can be a barrier to working and attending English language classes which holds them back from further integrating into their community.

Several participants felt it was important to remember the impact that chronic pain has on the person’s family and friends, as they often are required to provide support.

The importance of being believed and not being judged

A number of participants spoke about how important it is that staff are non-judgmental, kind and treat patients with dignity, fairness and respect. Staff need to show empathy and acknowledge what it’s like to live with chronic pain and some participants feel there is a need for more staff training around chronic pain so that staff have a better knowledge and appreciation of its impact on people’s lives, improving the support they can provide.

There was also a strong feeling from some participants that they are not listened to or believed by healthcare professionals when talking about their pain, leading to the feeling that they have been patronised and disrespected.

Some female participants discussed how they feel that chronic pain in women is not taken seriously, as women’s health issues are still a taboo area and there is lack of understanding for both the conditions themselves (e.g. endometriosis, menopause, hypermobility during and after pregnancy) and their link with chronic pain. One participant, for example, recounted how her chronic pain was dismissed as being hormonal. On the other hand, some male participants also highlighted that it is difficult to be believed as a man, meaning that they may be less confident and inclined to become involved in groups and seek support.

Younger participants have also found it difficult to be believed and understood, saying that clinicians judge without listening and assume that the pain can’t be that bad due to their age.

A participant who has learning difficulties recounted how clinicians have asked them if they are imagining the pain, not believing that their pain was a real issue.

Being believed was also important to participants from minority ethnic backgrounds, explaining that they want to be valued no matter where they come from, but have felt they are being treated with less dignity due to their nationality, often evident in their name, feeling that they need to prove they are not “trying to abuse the system”.

A holistic and person-centred approach to care

A holistic approach to care was important to participants, as highlighted by the quote below. One person thought that no one had a holistic view of them or understood what they were going through both mentally and physically, and it was thought that services are reactive rather than proactive.

“A holistic approach would allow a wider understanding to my life and how my pain affects me and my family. I want to have the ability to stay active and be part of a community."

Within this holistic approach, it is also important for people to be seen as an individual, recognising that everyone has their own individual experience, circumstances and support needs. For example, some participants suggested having an individualised care plan with a range of support available, as further discussed later in this report. Participants noted that decisions on care should be made in partnership and by sharing experiences. While person-centred care would require multidisciplinary support, participants thought that sharing their experiences would provide a platform for a more joined up approach to care. Participants appreciated being asked ‘what matters to you?’ during this Gathering Views exercise with many saying they had never been asked that question before but would wish to be asked this by others who provide them with care and support.

“If they don’t know and you don’t take the time to explain, then how will it change?”

However, participants also understand that due to current pressures on staff, achieving a person-centred care approach can be challenging.

“It is a 15 minute appointment and they are under pressure - to get you in, to get a history and get you out to see the next person. I find the whole process quite impersonal. I don’t think it is very patient-centred.”

Person-centredness should also consider people’s key characteristics, as different people will need different support.

For example, some of the older participants mentioned that they can be hesitant to complain and tend to hold back about their chronic pain, especially if, for example, they are perceived as “just the old person going off”, often seeing pain as part of the ageing process.

Some male participants also mentioned feeling this way and holding back about their chronic pain, meaning that they may need a bit more support to engage with services. For example, some male participants suggested the development of leaflets around chronic pain in men, to frame chronic pain in a way that is more likely to resonate with them. Both men and women highlighted the need for more support groups and opportunities for involvement specifically for men and women respectively, or with a focus on specific conditions, for example endometriosis.

Representation can also be important.

Some participants from minority ethnic backgrounds described feeling like they are the only one from their culture sitting there and that clinicians don't appear to understand how different cultures may experience and manage chronic pain differently, with some cultures, for example, being less likely to seek out support.

Some younger participants said that they don't know many others in their age category with similar experiences, for example being under 40 years old and still working, meaning that they feel like the odd one out.

Access to support services

Getting access to support

Participants' responses around the process of getting access to support highlighted some positive but also negative experiences. Some participants were able to access services through their GP and referrals relatively easily. For some, support was easy to access with few barriers and participants spoke of support being arranged for them through their GP or upon discharge from hospital, without having to do anything themselves. Some participants spoke of repeat prescriptions now being available online which makes access to pain medication easier. One participant told us about resources they received from the health service to prepare them for hospital visits, including a list of services and contact numbers which they found to be helpful.

On the other hand, some participants stressed the lack of NHS support and services, leading to difficulty in accessing support. Many participants said that they do not feel appropriately supported by services in their local area and highlighted issues around communication and lack of follow-up. Many participants told us of the difficulty in accessing services, such as getting a GP appointment and referrals on to further support, often feeling forgotten about or rushed by their GP. They also said they find it difficult to get help from the GP unless it's an emergency and recognised that the demand for support was stretched, meaning that there were often long waiting times for referrals. Some felt that their GP did not know enough about local support groups.

Participants in remote and accessible rural areas also noted this and highlighted the need to improve local staff's knowledge about available support, especially in cases where temporary locum GPs replace long-standing services.

Some participants were happy to take a proactive approach in sourcing information for themselves, but others were less so and were unsure as to how to do that, saying that there is a lack of advice and direction on where to get information and support. One participant also spoke about their struggle to find out about services due to the small amount of information available in waiting rooms, which they described as anxious places and not an easy first point of contact.

An example of the disparity in people's experiences is access to local NHS pain clinics. Many of the participants referred to local NHS pain clinics and told us how valuable these are, including the access to a multi-disciplinary team. However, some participants were unaware of their existence or were only aware due to word of mouth from other people with chronic pain, rather than being told about them or referred to by their GP. Participants highlighted that they would like wider access to local pain clinics and to be referred to these by their GP.

Equitable access to support

Independently of people's own experiences, participants highlighted the importance of equitable access to support. It is important to participants that services, support and information should be accessible to all and not determined by a person's age, mobility, ability to pay, or where they live.

However, participants' responses often highlighted disparities in the support they can access.

Participants in remote rural areas and accessible rural areas noted particular barriers, meaning they can't access support that they are advised to when others are able to. Some services are simply not available locally and when they are available further afield, service agreements need to be in place, which is not always the case. For example, one participant in a remote rural area recounted how they obtained a referral but this was declined due to a lack of service agreement between local services and the service provider required. Some participants specifically noted the need to be supported to access services centrally when needed, for example in Glasgow or Edinburgh.

Further support groups and activities in remote and accessible rural areas can also be limited, for example; access to the gym, swimming, walking groups or mental health groups. Depending on how the groups are set up, there can be further barriers. For example, when groups that cater across islands organise in person activities, people who are located on a different island can find it difficult to join.

However, it is important to note that a participant in an accessible rural area highlighted that the support they are now getting from a small local group is much better than at their previous group in a large urban area as they felt that they were not taken seriously there.

In both remote and accessible rural areas, a lack of specialist staff and knowledge was also noted, leading to delays in diagnosis and not being able to access support. Some participants in remote rural areas discussed how difficult it can be when services discontinue or move, for example when a GP retires who has been providing support throughout their lives and knows their medical history. These participants came to rely on the relationships they had developed over time with clinicians in the area, making it difficult to get support from temporary locum GPs where they know there will be no continuity nor local knowledge.

The rurality of participants’ locations was not the only factor, however.

Participants in areas with higher deprivation often mentioned significant barriers to accessing support from their GP, for example due to GPs merging and multiplying the number of patients they support. They also mentioned being aware of support available in other locations that is not available in their area, such as a “hub” where people can get peer support when struggling and access other activities that helps with their mental health.

Financial barriers were also present for a participant who has disabilities, who explained that they feel they are expected to pay for support due to receiving a disability allowance, rather than access it for free.

Transport issues

Transport and travel can be a significant barrier to accessing services, especially due to the nature of chronic pain and its impact on mobility, and this was highlighted by many participants. People told us that using public transport can be difficult due to the unpredictability of chronic pain and participants who don’t drive or have mobility issues said that accessing support and patient transport was not easy. Some highlighted the issue of having to pay privately for transport.

In remote rural areas, transport was an even more important barrier to participants, as they are often expected to travel out with their local area to access support, for example see a clinician or have tests done, and public transport can be limited or poor in these areas. For example, a participant in a remote rural area explained how they had been referred to have an MRI on the mainland, but due to communication issues the appointment was cancelled even though they had travelled to the city and they then had to wait for a further two months for the appointment to be rescheduled.

Weather issues also can play into this, meaning that participants could be away from home for long periods of time, exacerbating their chronic pain.

This is also the case for some patients in remote rural areas that access support at a national level, for example in London, who are expected to travel frequently and are not connected in with local services and support. A participant in a remote rural area suggested that, due to transport being such a challenge in the area, there should be staff that are able to go to people's homes and check on them if they are not able to attend appointments.

Language barriers

Effective communication was highlighted as an important factor for clinicians to understand the participants' needs.

Some participants, especially those from minority ethnic backgrounds, highlighted the significant impact that language difficulties are having on their access to support and care. They explained how language difficulties make them feel less confident in their communication with clinicians, recognising that this is a problem for both themselves and the clinicians. Some have tried using Google translate to help express themselves and discuss their chronic pain and what they need, but this hasn't been helpful as it compromised their rapport and communication with the clinician. They highlighted the need to have translated materials and a translator to ensure that they understand all information and can communicate their needs effectively. Due to these difficulties, they also prefer face-to-face communication rather than written communication or via phone, as it allows them to see facial expressions and body language.

Older participants also noted that they prefer face-to-face communication as many can be hard of hearing.

The importance of joined up care

Many participants feel that chronic pain services are not joined up, with some participants suggesting that services are not aligned, are difficult to navigate and should work more closely together. Many also spoke about the importance of consistent care, for example clinicians knowing one's medical history, with people finding it anxiety-provoking and stressful when they must often repeat their story and situation to different people within varying services.

Some female participants explained their concerns about how chronic pain may link to other aspects of their health, for example fertility and menopause.

A further challenge for the connection between services can be a difference in location. For example, some participants in remote rural areas described communication issues between local services and those on the mainland, while they were referred to one location for tests and another location for follow-up treatment.

Early diagnosis and intervention for chronic pain

Early diagnosis and intervention is important to participants. Many participants recounted their long journeys towards obtaining a diagnosis, this taking over 10 years for some. Due to waiting so long without being able to access support, some found that further health problems arose around their chronic pain, making intervention, when it finally came, harder to manage.

Access to online and offline resources

Many found the move towards a digital-first approach during the COVID-19 pandemic helpful, as many groups and support services, such as Near Me, are now carried out online. Many participants mentioned using online support to find out information, self-educate and get peer support, for example. Participants said that having information about chronic pain support available through NHS websites, including NHS Inform, made life easier.

This was particularly frequent among younger participants, who highlighted the benefits of support through digital means. They highlighted the benefits of using digital tools, and especially social media, for peer support, sharing information, discussions and self-education. One of the older participants also pointed out that online support can be more accessible for those who are immunocompromised or less mobile and able to travel.

Although several participants preferred digital support, others however, highlighted limitations and barriers to access.

Some older participants noted that they don’t have access to the internet or digital devices, and that they are not confident in using them.

This highlights that both online and digital, and offline, more “traditional” resources need to be available for all.

Different types of support

Medication

Participants expressed a range of views about using painkillers to manage chronic pain. Many told us that their GP has supported them to get medication and that medication is the only form of support they receive, stating they would be in worse pain without their regular medications. Some manage their day-to-day pain through using medicines such as paracetamol and opioids and highlighted how important having access to medication is for them.

On the other hand, some participants told us about painkillers hindering their ability to carry out daily tasks, such as driving, but explained that they were not aware of what other pain management support could help them. It is important to participants that information on medication is clear and tailored to the individual's experience, with some saying they believe that medication is a short-term fix and not a long-term solution. Some participants who take medication were concerned because if they stop taking it, they begin to feel withdrawal symptoms, so they don't feel they have a choice in whether they take medication or not. Some also discussed their struggle in taking pain medication when in recovery from addiction. Some participants mentioned that prescription medicines need to be reviewed regularly and there should be access to pain injections if needed.

A variety of support

As many participants highlighted, support around chronic pain needs to move beyond just medication and towards including a wide range of support, depending on people's preferences and needs. Participants explained to us that their current pain management support ranged from NHS services to alternative therapies and self-management techniques. Many participants said their GP has referred them to other NHS services, such as podiatry, physiotherapy and psychology. Many participants referred to local NHS pain clinics and told us how valuable these are.

"The quality of the pain clinic staff, they really are just outstanding. The skills they have at keeping us all on track is wonderful."

But while there seems to be some access to support beyond just medication for some, many participants said they would like to be able to access additional support and treatments through the NHS, whether treatments not currently available or just increased access to those that are available. For example, participants discussed wider access to physiotherapy, massage, exercise or creative activities and ultrasound treatments. Participants highlighted how a range of support and activities can be helpful in managing their chronic pain, including emotional support and nutritional advice. Acupuncture and spiritual care were also highlighted as beneficial for managing chronic pain, as well as having the opportunity to see a chiropractor or osteopath. Some told us about managing their pain through methods such as relaxation and breathing techniques. Other participants explained how practical support can be important, such as help to obtain a Blue Badge and support from their employer to have a better work/life balance. In this context, it is important for participants to know about local support services or activities that may be helpful to them and that they have access to them.

Mental health support

Mental health support was particularly important to the participants, so is highlighted here separately. Participants explained how mental health support would help their day-to-day life. Several participants explained that accessing services and support for their chronic pain can have a negative impact on their mental health. People with anxiety, for example, can find it hard to explain their pain and often have difficulty in attending support groups. Participants discussed the complexity of chronic pain, with one describing sharing their medical history as very difficult and personal. For this reason, some felt it is important to receive support to attend services or groups when living with mental health issues and chronic pain.

Furthermore, people with chronic pain often experience feelings of loneliness, relying on family members, friends and informal carers for support. Many participants discussed the value in peer support, social connections and personal networks for managing their pain, telling us that having chronic pain can be isolating and having a network of people experiencing similar issues helps them to feel less alone. Many participants also spoke of the importance of wellbeing support they access through charities and their employers and some spoke of the benefit of attending different activity groups or online group sessions, such as on drawing, painting and writing poetry. Participants described some of the groups as being part of a community and stated that hearing other people's experiences is helpful. For some, the social aspect of groups is a good distraction from the pain.

For example, a male participant said:

"What has been good for me is coming to the Men's Shed. It's a distraction from feeling pain and gets me out of the house. I come every day."

While people spoke about these networks as an important way of finding out information, many were frustrated, however, that information on support and services isn't more widely available from the clinicians in the first place.

"Sometimes it's knowing others are going through the same thing and being willing to share your experience with each other."

But while participants explained that mental health support would help their day-to-day life, many felt that there is a lack of support and improvement in this area and a significant need for further resources.

"The significant issue I found with managing chronic pain was not pain management oddly enough, it was the lack of psychological support, on a local basis."

Self-Management

Being empowered and supported to self-manage chronic pain

Having more control and being empowered to look after their own health is something that many participants spoke of as being important to them, for example being able to self-refer instead of always having to go through their GP. One person said that what matters to them is to be happy and to be able to look after themselves at home, which can be hard, and some noted that adaptations to help people live independently at home should be considered. Some, for example, have paid for private treatments and purchased equipment themselves when the NHS couldn’t help, which causes financial implications.

“I purchased a lot of equipment to try and help with the pain.”

While self-managing their pain however, participants also discussed how this is often supported by family, friends or informal carers.

For example, older participants highlighted their reliance on others for transport and accompaniment to appointments, limiting what support they can access.

Patient education and knowledge

Participants highlighted the importance of education to be able to manage their own health. Some wanted to understand more about their condition(s) and future treatment plans, as this would support their understanding around treatments and help reduce anxiety. One person said that they had not had the diagnosis fully explained to them, with others stating that professionals need to understand the importance of talking things through clearly with patients. Participants said that an understanding of self-management tools would improve their daily life, with many wanting to better understand what is available to help them with managing their chronic pain. Some requested more widely available resources on self-management of chronic pain and coping strategies and having access to self-management talks and programs provided through the NHS and third sector. Although no examples were given, some participants mentioned that they had indeed turned to self-management tools during long waiting times.

Patient feedback

Many participants had not provided feedback for services they had accessed, with the majority telling us that they were unaware that they could do this or that they had not been asked for it. Only 34 participants out of the 92 (37%) had shared their experiences and views with service providers.

Different ways of providing feedback

There was a good mix of responses to the many mechanisms across Scotland for providing feedback. Some of those who have found ways in which to share their experiences and views, have done so through local NHS board patient surveys, whilst others used the complaint service, sit on forums or attend board meetings. Some have informal chats or follow-up appointments with their GPs and consultants where they can provide their thoughts and comments.

While recognising that these are not always known or available to all, participants' responses included the following further mechanisms:

- GP and Patient Participation Groups,
- pharmacists,
- consultants,
- local council,
- national groups such as CCUK (Crohn's and Colitis UK),
- research projects and consultations directly from the local Health Board,
- service providers directly,
- using the local NHS website,
- local MPs/MSPs,
- NHS Networks, Pain Clinics/Groups and Community/Third Sector Groups,
- the NHS complaints procedure,
- social media, and
- colleagues working in the NHS.

Experiences of providing feedback and responses to feedback

Some participants had positive experiences after talking with staff and found that they were keen to listen.

"When I went to the pain services – they were keen to hear feedback."

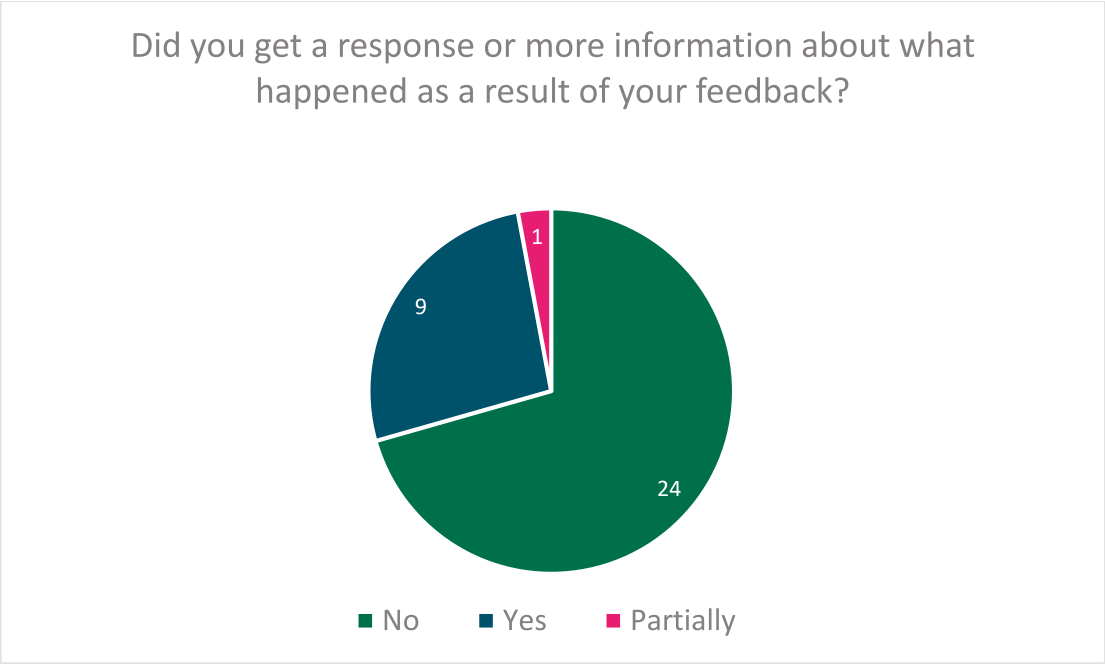
In fact, some participants suggested that there should be different platforms made available to provide feedback, as it was thought that many people would be confident enough to speak up about their experiences if they had the platforms to do so.

Other participants, however, found sharing their experiences less positive, feeling that they have not being listened to or understood, leaving them sad and frustrated.

Several participants felt that the language barrier was often an issue when providing feedback and found there was a distinct lack of translated materials available, linking in with the language barriers and needs discussed above.

One person was reluctant to talk to a local service in a small area where anonymity might be compromised, which they thought could in turn have an impact on the care they receive.

Some reported that, although they had taken the time to give feedback, they received no response to this or that the responses they received were not helpful. Indeed, of the 34 participants who had shared their experiences with their service provider, only nine received a response as highlighted in the chart below.



Participants were left angry, disillusioned, disheartened and frustrated when they received no response to their feedback, while some had been told that they would be contacted, but never were. Nine people did receive a response and were satisfied with responses from their GPs and local health board.

Benefits of providing feedback

Participants highlighted that there would be better outcomes for patients if professionals provided responses to feedback and that it would also be beneficial for the service provider. For example, this could help implement a Pain Management Framework that is easy to navigate and clearly sets out the routes for early intervention and support available for people. One participant felt that if everyone shares their individual experiences, a national picture of chronic pain services would be clearer.

There were also many participants who spoke about the importance of feeding back to help make a difference to the lives of others and sharing experiences and knowledge to help others was highlighted many times throughout the survey.

For example, a younger participant said:

"I'd like the experience of care to be better for young people - it's really hard to be taken seriously and to be believed when you say you have pain when you are young. Especially when it's chronic and when there's no easily identified cause and no underlying issues."

Although many participants spoke about the current systems and service planning and delivery, others also spoke about the importance of professionals learning from patient experiences in order to help with the provision of different types of support, as well as understanding specific challenges, for example around transportation or how to support people with learning disabilities.

Improvements to current processes of feeding back

When considering how to improve current methods of sharing experiences with service providers, several participants felt that a more proactive approach to collecting feedback from people would be beneficial. One participant noted that there should be space to build a relationship with their healthcare professional in order to feel comfortable sharing their experiences rather than it just being part of a process. Several participants also felt that the ways that people provide feedback could be made more accessible. One participant noted that information about being able to share thoughts and comments is not readily available and could be provided through GP surgeries. Several participants felt that providing views and suggestions online via an app or survey would be a good method. One participant also said that they would provide feedback if there were links on social media that were promoted rather than having to seek out an official website to do so. Several participants said that they would want more support to engage in the feedback process. One participant noted that it would be advantageous to have a carer or advocate to attend meetings with them in order to do this. And another participant said:

"Could have an anonymous survey online that people can fill in rather than speaking to someone face-to-face."

Varying methods of engagement

The diversity within the participant sample of this work highlighted the range of needs that need to be met to allow all people across Scotland to engage effectively.

Participants want to give feedback in a safe space, for example in a specific location such as a local group that they attend to support them, in order to have peer support present which makes the person feel comfortable. They also noted the importance of building relationships with clinicians in order to feel safe about sharing their views. Some participants are happy to contribute in any way, however others have very specific preferences and needs. Some prefer to be in a face-to-face setting for confidentiality reasons and due to the personal sensitivity of the topic, whereas other people want to feed back as part of a group, creating more of a discussion and providing peer support, feeling they would get more benefit out of it. Some see the most benefit from meeting face-to-face setting, as online communication is not as accessible to them. Others, however, want to give feedback only online because it's more flexible and anonymous.

Younger participants highlighted how social media should be used more for engagement.

Participants with mobility issues want the option to engage from their home in order to avoid needing to travel.

Participants with language barriers or learning difficulties want to be supported to share experiences, potentially by being accompanied by a translator or carer respectively.

Section 5: Conclusions and recommendations

This section of the report brings together the main conclusions drawn from the findings of this Gathering Views exercise and outlines recommendations. The findings are not ranked in order, they are numbered for ease of reference. -

5.1 Staff understanding and attitudes

It is clear from the findings that people who suffer with chronic pain believe there is a limited understanding of what it is like to live with the condition across all areas of health and social care across Scotland. Participants also highlighted the importance of being believed and not being judged, and that they would like to see a holistic and person-centred approach to their care, making it clear that different people have different needs, preferences and experiences.

5.2 Access to support services

It was apparent from the findings that the availability and range of local NHS support services varies across Scotland, as did the participants' experiences of support. Participants highlighted challenges in getting access to support, for example obtaining a diagnosis or finding information. They also noted the need for equitable access to support, independently of age, sex, location and background. Further particular barriers that were discussed were transport issues and language barriers. Participants also highlighted the importance of joined up care and early diagnosis and intervention. The need to provide access both to online and offline resources and support was noted as well.

5.3 Different types of support

Participants discussed access to medication, which for some was very important. However, many also discussed the need to move beyond just offering medication and needing to have access to a variety of support, whether further clinical support by physiotherapists, for example, or peer support, alternative therapies and exercise or creative activities. The importance of access to mental health support was also discussed.

5.4 Self-management

Participants discussed how they need to be empowered and supported to self-manage their chronic pain, which has become more prominent due to their experience of limited or lacking support. As part of this, they highlighted the need for help to further develop their understanding and knowledge around chronic pain and how to manage this.

5.5 Patient feedback

It is apparent from the findings that most participants had not been asked to provide feedback or discuss their experience and views with services. Furthermore, from the small number who had been asked to do so, most had not heard back around what came of their feedback, which left them feeling negative about their experience, angry and disillusioned. Participants highlighted the importance of providing different ways to feedback and varying methods of engagement, as different people are more likely to engage in different ways. They also discussed an array of perceived benefits that patient feedback can have on services, as well as potential improvements to current feedback processes. Specific challenges were also noted, such as access and language barriers.

Recommendations

The recommendations below are for Scottish Government to take forward, working where appropriate with NHS Scotland and partner organisations. The recommendations cut across the four aims of the Framework for pain management service delivery:

- Person-centred care
- Access to care
- Safe, effective support to live well with chronic pain, and
- Improving services and care.

Recommendation 1

Development of national training and guidance for staff to support the diagnosis, treatment and support of chronic pain. This could be developed with the support from charities, third sector organisations who provide advice and support for people living with chronic pain, as well as specialist nurses and clinicians. People living with chronic pain and their families/carers must also be involved to bring real life experience to the guidance. This would aim to:

- Improve staff knowledge and understanding around chronic pain, its links to other conditions and its impact on people’s lives and the people around them, as well as how this differs between individuals and groups, for example younger or older people, people from minority ethnic backgrounds, people with addictions, etc. Also improve understanding and clarity around different experiences and pathways to support for chronic pain, including self-management, highlighting that not all chronic pain is, or needs to be, formally diagnosed, but is equally valid.
- Support a holistic and person-centred approach to chronic pain care that acknowledges, recognises and validates people’s experiences of chronic pain. This should also highlight impacts on other aspects of people’s lives, as well as

how people's experiences and needs differ. Support shared decision-making and effective discussions around chronic pain, asking "what matters to you" and discussing the patient's preferences, for example around medication.

- Empower and support patients to understand their chronic pain journey, their treatment plans and engage in shared decision-making, including information around what support does not require a formal diagnosis of chronic pain, for those who may not go down the formal diagnosis route or those in the process of obtaining one. This should also include support that may be more general, but can be helpful to people with chronic pain, such as general wellbeing or mental health support, explaining why this is relevant.
- Train staff in effective approaches towards people with chronic pain, for example deep listening, adopting a non-judgmental and kind, respectful approach, and providing validation of their experiences and care needs.
- Inform staff on what further support and activities may be helpful to patients, such as exercise, creative activities, or alternative therapies.
- Provide a list of local and national resources and support to proactively signpost patients to. This should include resources and support around mental health and self-management, including contacts where helpful. These should be available in accessible and translated formats. Signposting to support should include resources that are freely available or require payment, making this clear, and there should be a mix of digital/online and in person/offline resources. This information should also make clear what support patients can access without having a formal diagnosis.
- Provide information on supporting people to access services, e.g. through access to a translator.
- Reinforce the importance of asking patients for feedback and providing opportunities for them to do so, as well as the need to respond to people's feedback and let them know whether and how it was actioned.

Recommendation 2

Support the development of a training and resource package for people with chronic pain and the people around them and make this widely available. This would aim to:

- Increase understanding and knowledge around chronic pain and its impact on people's lives, including links with other conditions and characteristics, the impact of medication and the different pathways to support.
- Approach people holistically but using a person-centred approach, recognising that people's needs and experiences are different. This should also recognise that not all people with chronic pain have, or need, a formal diagnosis of chronic pain and individuals will follow different pathways to support, but despite this their pain, needs and experiences are valid.
- Empower and support patients to understand their chronic pain journey, their treatment plans and engage in shared decision-making, including information

around what support does not require a formal diagnosis of chronic pain, for those who may not go down the formal diagnosis route or those in the process of obtaining one. This should also include support that may be more general, but can be helpful to people with chronic pain, such as general wellbeing or mental health support, explaining why this is relevant.

- Include signposting to further local and national resources. This should include resources and support around mental health and self-management, as well as other types of support that might be helpful, such as exercise, creative activities or alternative therapies. This should include resources that are freely available or require payment, making this clear to users. The information should be clear, available in accessible and translated formats and cater for different groups, for example towards men or women, younger and older people etc. This should be available digitally but also through "offline" routes and should signpost to a mix of digital/online and in person/offline support and resources.
- Reinforce the importance of providing feedback to services and the benefits this can have.

Recommendation 3

Consider the provision of further support and what can be made more widely available to people with chronic pain, such as nutritional advice, exercise, creative activities or alternative therapies.

Recommendation 4

Proactively promote the importance of patient feedback and ensure that feedback processes are fit for purpose and widely available. This should include providing a range of feedback opportunities and using different tools, digital/online and offline. This process should be clear, accessible and ensure that people's feedback is responded to.

Recommendation 5

Improve circulation of information and awareness around support that is available that does not require a formal diagnosis of chronic pain. This is to empower individuals who don't have a formal diagnosis of chronic pain, or are in the process of obtaining one, to access support, especially in the context of the significant challenge around waiting times. This will also involve making clearer and more explicit what wider support, for example general wellbeing or mental health support, may also be useful for people with chronic pain specifically.

Recommendation 6

Consider the impact of chronic pain on patients' journeys and what can be put in place to support individuals to access care, for example addressing transport needs, language barriers, local limitations, financial implications and personal preferences. This could include face to face communication, providing a translator, travel support or adaptations to allow people to live independently.

Recommendation 7

Consider the findings in this report to ensure that the Framework for Pain Management Service Delivery addresses, and certainly does not exacerbate, health inequalities and barriers which may be more prominent among certain groups of the population. These findings should also inform and enrich the EQIA developed by Scottish Government as part of the Framework development, and be taken forward in EQIAs for the subsequent pieces of work, by health providers for example. Finally, these findings should also be considered when developing the training and resource packages in recommendations 1 and 2, to ensure that the different needs of groups and individuals are met, for example regarding access, language, cultural aspects, and representation.

Section 6: Next steps and acknowledgements

6.1 We welcomed the opportunity to engage with the groups identified in the national EQIA and previous discovery work. We have worked to fill some of the evidence gaps and hope Scottish Government considers the recommendations in order to work towards meeting the needs of as many people as possible as it implements the Framework for Pain Management Service Delivery. While some recommendations are mentioned in specific reference to one characteristic group, they may also be relevant for others in the general population.

6.2 This report has been shared with the Scottish Government. The findings will be used to help inform an evidence base, with a view to the improvement of the Framework.

6.3 Healthcare Improvement Scotland - Community Engagement will liaise with the Scottish Government to provide feedback to participants about how the views expressed in this report have been used.

6.4 We will use the learning and experience of this exercise including the equalities monitoring information within our work to inform future methods of Gathering Views.

6.5 Healthcare Improvement Scotland - Community Engagement thanks everyone who took part and shared their experiences, thoughts, insights, comments and suggestions. We are very grateful to the organisations who supported us to link with groups and individuals and for the time they gave us to discuss the issues covered in this report.

Appendices

Appendix 1 – The questions used in the Gathering Views exercise

Key Demographics

What is your sex?

Which age group do you belong to?

What is your ethnicity?

Deprivation and Rurality

- What is your postcode?

Chronic Pain Severity

- Would you say you have chronic pain?
- Over the past 3 months, how often did your pain limit your life or work activities?

Local Chronic Pain Support

1. Do you receive any support from **local** health services, community groups or charities to help with your pain management? (Local services would be in your local authority or health board area and include GP as well as NHS pain clinics and community groups).

If yes,

a. what are these?

i) How did you find out about these? (GP, Internet, social media etc.)
ii) Was it easy to find out about these services or were their barriers, if barriers what were these?

iii) Was it easy to receive the support they offered? Why was this?

iv) Does the support help you with your pain management, if so, how?

If no, why is this?

2. Is there anything that could be made easier for looking for chronic pain support in your local area?

3. Is there any other kind of support for chronic pain that you think should be available in your local area that would improve your day-to-day life?

4. What matters to you most about the care and support you receive for chronic pain from your local services?

Feeding back to services – personal experience

5. i) Have you ever given feedback about your chronic pain care to the NHS, a community group or other service?

If yes,

> i) How did you know, or find out, how to share your feedback about your chronic pain care?
>
> ii) Did you get a response or more information about what happened as a result of your feedback?
>
> iii) If yes was it useful feedback?

Feeding back to services – general

6. What do you think might be the benefits of sharing your experience of your care for your chronic pain?

7. What benefit would local health professionals gain from you sharing your experience of living with chronic pain?

8. Is there anything that stops you or could be made easier to share your experience or feedback about health services or other support you have used for your chronic pain?

9. What would matter to you most about you being involved in the design of new local chronic pain services or changing existing local chronic pain services?

10. How would you like to be involved in sharing your experiences to improve local chronic pain services, if at all? We're thinking about how best you can participate in discussions about improving local services, so e.g. face-to-face meetings, telephone interviews, online surveys etc.?

Appendix 2 – Materials circulated to participants before the Gathering Views discussions

Healthcare Improvement Scotland | Community Engagement

Gathering Views Consent form

Chronic Pain

By ticking the options below you are giving your consent to take part in a Gathering Views discussion between 15th August 2022 – 16th September 2022.

1 I have read and understood the information sheet ☐

2 I have been able to ask questions about the project and am happy with the answers. ☐

3 I understand that I can choose whether or not I will take part in this discussion and that I can choose not to answer any question or stop taking part at any time, without having to give a reason. ☐

4 I agree for what I say to be used in reports and publications about this work, but that my name will not be used. I give permission for Healthcare Improvement Scotland to hold relevant personal data about me and I understand that my comments are anonymous and confidential. ☐

5 I agree to take part in this project. ☐

Name ____________________

Signature ____________________

Date ____________________

Healthcare Improvement Scotland | Community Engagement

Framework for Pain Management Service Delivery - Gathering Views of People with Lived Experience of Chronic Pain

Background

In July 2022, the Scottish Government published the Framework for Pain Management Service Delivery Implementation Plan which was developed in partnership with people who have chronic pain, clinical staff, researchers, third sector communities, and other key stakeholders.

Throughout the development of the Framework, a number of lived experience engagement activities have already been delivered at a national level but now there is a need to hear from local communities, which more fully represent the diversity of chronic pain and its impact in Scotland.

Definition of chronic pain (Draft Framework for Pain Management Service Delivery)

Chronic pain is pain that persists or recurs for longer than three months. Chronic pain is a common condition and estimates suggest it affects between one third and a half of adults in the UK. In Scotland it is estimated that 5% report severe chronic pain, which impacts their daily activities and quality of life.

Gathering the views of people affected by chronic pain

Healthcare Improvement Scotland (HIS) has been asked to conduct a Gathering Views exercise to ensure the priorities of people with chronic pain, especially as they relate to local contexts, are appropriately reflected as the Framework is implemented.

We will be inviting people living with chronic pain, and carers of people living with chronic pain, to share with us any local opportunities for improvement as well as the key issues and barriers that you face**.** This will help inform national and local approaches to the implementation of the Framework and increase the chances of successfully delivering meaningful improvement in how local pain services are provided.

It is intended that recommendations from this exercise will be used to inform future delivery and resourcing of the Framework, as well as provide an evidence base for improvement opportunities for local pain services across Scotland.

We want to speak to a range of people who may have different experiences or opinions in managing and living with chronic pain. We want to make sure we have a good range of people in terms of age, gender, ethnicity, and where people live, as well as some people who may have a long-term health condition. Your views are as important to us as everyone else's, so we want to speak with *you.*

People in a similar position in the future will benefit from you sharing your opinion.

The conversation

You will be invited to an individual discussion with an engagement officer from Healthcare Improvement Scotland. The conversation can be face-to-face, over the telephone or through an online platform such as Zoom or MS Teams. We will ask you some questions about your experiences of living with your chronic pain. We can share the planned questions with you beforehand if you prefer, please just let us know.

During the conversation, we will be taking notes. Your responses will be analysed and captured in a report, which will be shared with the Scottish Government. Quotes may be used to illustrate the main things that we've talked about. Quotes used will not contain the individual's name or job title, however, they will be associated with a particular group. Text may be edited to enable use in a variety of formats.

Do I need to take part?

Taking part is completely voluntary but we hope you will take the time to do so. This is a way of working with members of the public to help inform decisions about how care is provided – it really will make a difference to how we aim to deliver health and social care services in Scotland.

Even if you decide to take part, you can change your mind at any time without giving a reason. When talking about your experiences or when thinking about the interview afterwards, please tell us if you do not want us to include certain information.

Equalities Monitoring

Equalities monitoring information is being captured, including data relating to sex, sexual orientation, disability, age, religion and ethnic group. Providing this information is entirely optional. This information is to ensure we gather feedback from people from a range of backgrounds and contexts.

Data Protection

Healthcare Improvement Scotland comply with the Data Protection Act 2018 and GDPR 2018 when handling your personal information.

Any personal information about you will be treated as private and confidential and any identifying information you provide will be made anonymous in any published reports. Your information will only be used in this Gathering Views exercise and the resulting report. Your details will not be used for general marketing activities, nor shared with anyone outside Healthcare Improvement Scotland unless we have your permission or are required to do so by law. All personal information, written notes and related information, including this consent form, will be stored safely and in compliance with the Data Protection Act 2018. If you wish to see a copy of the notes taken during the discussion, please submit a sharing request to his.informationgovernance@nhs.scot. Please note that these notes will not be shared with you as a matter of course.

This discussion may be held over an online platform. Although we do not plan to gather personal information from participants, if you register to take part you must be aware that some companies transfer data to servers based in the USA and that any personal information you choose to share will be transferred to a country that does not provide the same data protection safeguards as the UK and EU.

For our full privacy policy, please go to www.hisengage.scot/privacy.

For more information about how we process your personal data, or if you have a concern, contact our Data Protection Officer at his.informationgovernance@nhs.scot. Alternatively, you have the right to complain to the ICO https://ico.org.uk/concerns/.

Get in touch

If you have any questions, please get in touch with your local Healthcare Improvement Scotland – Community Engagement office:

Name:

Email:

Phone:

Or you can contact Lisa McCartney, Area Manager (Community Engagement – North East Region), Healthcare Improvement Scotland by telephone 07823 447855 or by email lisa.mccartney1@nhs.scot.

Appendix 3 – Deprivation and rurality information

This information highlights the range of participants in this Gathering Views exercise in terms of deprivation and rurality classification. This is based on participants' postcodes, requested during the first part of the interviews.

Deprivation

Participants were from areas across the deprivation quintiles, as defined by the Scottish Index of multiple deprivation (2020), with SIMD 1 being areas with highest deprivation and 5 being areas with the least deprivation[9].

SIMD Quintile	No of respondents	% of respondents
1	10	11%
2	15	16%
3	27	29%
4	19	21%
5	18	20%
Preferred not to answer	3	3%
Total	**92**	**100%**

As explained by Scottish Government, the Scottish Index of Multiple Deprivation is a relative measure of deprivation across 6,976 small areas and is the Scottish Government's standard approach to identify areas of multiple deprivation in Scotland. If an area is identified as 'deprived', this can relate to people having a low income, but it can also mean fewer resources or opportunities. SIMD looks at the extent to which an area is deprived across seven domains: income, employment, education, health, access to services, crime and housing. It is important to note that SIMD is an area-based measure of relative deprivation: not every person in a highly deprived area will themselves be experiencing high levels of deprivation.

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[9] The Scottish Index of Multiple Deprivation is a relative measure of deprivation across 6,976 small areas (called data zones) in Scotland. If an area is identified as 'deprived', this can relate to people having a low income but it can also mean fewer resources or opportunities. SIMD looks at the extent to which an area is deprived across seven domains: income, employment, education, health, access to services, crime and housing. SIMD is an area-based measure of relative deprivation: not every person in a highly deprived area will themselves be experiencing high levels of deprivation. Scottish Index of Multiple Deprivation 2020 found at https://www.gov.scot/collections/scottish-index-of-multiple-deprivation-2020/

Rurality

We recruited participants from across the spectrum of Urban Rural Classification in Scotland, though there was a higher percentage from rural areas. Participant numbers are categorised below according to the Scottish Government 6-fold Urban Rural Classification (2016).

Urban Rural Classification	No of respondents	% of respondents
Large Urban Areas	14	15%
Other Urban Areas	4	4%
Accessible Small Towns	27	29%
Remote Small Towns	14	15%
Accessible Rural	21	23%
Remote Rural	7	8%
Preferred not to answer	5	6%
Total	**92**	**100%**

Appendix 4 – Equalities monitoring data

Gathering Views equalities monitoring results

Response rate

Equalities monitoring questions, in the form of an online survey, were shared with the participants, either before or during the discussion. We also offered alternative ways to provide this information, via email or through a paper copy.

We received completed monitoring information for 63% of all participants who took part in this Gathering Views exercise.

Characteristics of respondents

Out of the 58 participants who completed a monitoring form:

- 53% were female and 45% were male and 2 preferred not to say.
- 3% considered themselves to be a trans person or have a trans history.
- 2% of respondents were aged 16-25. 3% were 26-35 while 36-45 were 10%. A further 29% were aged 46-55, 24% were aged 56-65 and 31% were 66+.
- No respondents had experience of being in care.
- 56% considered themselves as disabled people, 38% said they were not and 7% preferred not to say.
- 5% used British Sign Language.
- 32% were unpaid carers.
- 93% were heterosexual/straight, with 3% identifying as bi/bisexual, 2% gay/lesbian and another 2% preferring not to say.
- A majority (36%) had no religion, while 48% were Christian, 5% were Pagan, 3% Muslim, 5% followed another denomination and 2% preferred not to say.
- The majority (84%) had a white Scottish or British Ethnicity, while 2% each were White Irish. A further 2% were African, African Scottish or African British, 2% Chinese, Chinese Scottish or British, 2% had a mixed ethnic group and 9% were other ethnicities.
- 25% reported a current experience of socio-economic disadvantage, while 65% did not and 9% preferred not to say.

Messages

- The 63% response rate for the equalities monitoring was a separate data collection to the key demographic questions which were asked to determine age, sex, ethnicity, rurality at the beginning of the exercise.
- The form was provided to all participants electronically either during or following their participation. In some cases, the offices helped people to fill out the online form, i.e. asking the equalities monitoring questions over the phone and filling in the form on their behalf.

Appendix 4(i) - Equalities Monitoring form

About this Equalities Monitoring form

We are capturing equalities monitoring information, including data relating to sex, sexual orientation, disability, age, religion and ethnic group to ensure we gather feedback from people from a range of backgrounds and contexts. We want to understand how representative the people we talk to are.

You are not required to answer any questions you do not wish to answer. The information you provide is not linked to your name or any other personal details and will be kept anonymous.

1. What is your sex?
   - ☐ Female
   - ☐ Male
   - ☐ Prefer not to say
2. Do you consider yourself to be a trans person or have a trans history?

   Trans is an umbrella term to describe people whose gender does not correspond with the sex they were registered at birth
   - ☐ Yes
   - ☐ No
   - ☐ Prefer not to say

   If you answered yes, please tell us your preferred terms - e.g. non-binary, trans man, trans woman (optional).

3. Which age group do you belong to?
   - ☐ Under 16
   - ☐ 16-25
   - ☐ 26-35
   - ☐ 36-45
   - ☐ 46-55
   - ☐ 56-65
   - ☐ 66 and over
   - ☐ Prefer not to say

4. If you are under the age of 26, please can you tell us whether you have ever had any experience of being in care? This can include foster care/supported care, kinship care, residential care, looked after at home (supervision order).
   - ☐ Yes, I have had experience of being in care
   - ☐ No, I have not had experience of being in care
   - ☐ Prefer not to say

☐ Not applicable

5. Do you consider yourself to be disabled?

(The Equality Act 2010 defines a disability as a physical or mental impairment that has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities. Substantial means the effect is more than minor or trivial and long-term means the condition has lasted or is likely to last 12 months or more)

☐ Yes
☐ No
☐ Prefer not to say

If yes, please include any more information you are happy to share:

6. Can you use British Sign Language (BSL)?

☐ Yes
☐ No
☐ Prefer not to say

7. Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical/mental ill-health/disability; or
- problems related to old age?

☐ Yes
☐ No
☐ Prefer not to say

8. Which of the following best describes your sexual orientation?

☐ Bi/Bisexual
☐ Gay/Lesbian
☐ Heterosexual/straight
☐ Prefer not to say
☐ Something else. Please write in:

9. How would you describe your religion, religious denomination or belief?

☐ Buddhist
☐ Christian - Church of Scotland

- ☐ Christian - Roman Catholic
- ☐ Christian - another denomination
- ☐ Hindu
- ☐ Jewish
- ☐ Muslim
- ☐ Sikh
- ☐ Pagan
- ☐ None
- ☐ Prefer not to say
- ☐ Other, please write in:

10. What is your ethnicity?
    - ☐ African, African Scottish or African British
    - ☐ Arab, Arab Scottish or Arab British
    - ☐ Bangladeshi, Bangladeshi Scottish or Bangladeshi British
    - ☐ Black, Black Scottish, Black British
    - ☐ Caribbean, Caribbean Scottish or Caribbean British
    - ☐ Chinese, Chinese Scottish or Chinese British
    - ☐ Indian, Indian Scottish or Indian British
    - ☐ Mixed or multiple ethnic groups
    - ☐ Pakistani, Pakistani Scottish or Pakistani British
    - ☐ Roma
    - ☐ Showman/Showwoman
    - ☐ White Gypsy/Traveller
    - ☐ White Irish
    - ☐ White British
    - ☐ White Polish
    - ☐ White Scottish
    - ☐ Prefer not to say
    - ☐ Other, please write in:

11. Do you usually have enough money each month to pay bills, buy the food, clothing and essentials you need and participate in your community?
    - ☐ Yes
    - ☐ No
    - ☐ Prefer not to say

12. Please use this space to tell us anything else you would like us to know about how you identify in relation to any of the above questions.

You can read and download this document from our website.
We are happy to consider requests for other languages or formats.
Please contact our Equality and Diversity Advisor on 0141 225 6999
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