

An analysis of the views of
people living with chronic
pain across Scotland



My Path, My Life, My Right to Live Well



November 2021

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Chronic pain in Scotland

What do we mean when we think of chronic pain?

Chronic pain is considered to refer to pain persisting for more than 12 weeks despite medication or treatment. It often occurs alongside, or as part of long term conditions, such as arthritis and fibromyalgia.

Chronic pain has a considerable impact on the quality of life for many people in Scotland. Approximately 800,000 people¹ across Scotland are affected by chronic pain to varying degrees and it can result in significant impact on the daily lives of both those directly affected and those close to them. The scale of the challenge in improving care is therefore significant.

ALLIANCE involvement in the chronic pain agenda

It is recognised that successful progress in improving care will require the collective efforts and engagement from a wide range of stakeholders including the third sector and, most importantly, people with lived experience of chronic pain.

The ALLIANCE believe a person centered approach is necessary to understand the challenges of day-to-day life including access to a range of services where appropriate, both specialist and primary care led; issues of self management, drug dependency and social prescribing to ensure policy, interventions and services reflect the needs of individuals and their families.

This is especially relevant because “medicines remain the most common therapeutic intervention available to clinicians despite the fact that the burden of harm relating to medicines is well reported.” (AIEPC, 2017). In fact, the NHS spent £1.68 billion on medicines in Scotland in 2015/16, nearly 14% of its total budget. Whilst there are several information and knowledge-based initiatives surrounding self management, the use of pain medication and even alternatives such

as social prescribing, this approach will help set priorities, identify issues and outline solutions which might not occur to or be valued by those who are not experts by experience.

The ALLIANCE, as the national third sector strategic intermediary, has strong expertise in engaging people of lived experience in policy and practice development across health and social care in Scotland, and is well placed to develop and host this work. The ALLIANCE has a long term interest in chronic pain and particularly in understanding how it affects the day to day lives of those who have to live with it. We especially want to ensure a strong voice for those who live with chronic pain to ensure that services and policy are developed WITH and not FOR those who live with pain.

In considering this, we want to understand what steps can be taken to ensure equal access to chronic pain services across Scotland. To this end the ALLIANCE has developed a network of stakeholders including those with lived experience to ensure that services and policy are informed by those who have personal experience of chronic pain.

¹ [Chronic pain \(healthcareimprovementscotland.org\)](http://healthcareimprovementscotland.org)

People at the Centre report for Mobilisation Recovery Group (2021)

As part of the Mobilisation Recovery Group, the ALLIANCE was asked by the Scottish Government to conduct a programme of engagement to ensure that there was a person-centred focus from the outside of remobilisation during and following the COVID-19 pandemic. In the ALLIANCE's final report, the specific impact of the pandemic on people living with chronic pain was repeatedly highlighted. Amongst the issues that those who spoke to us raised, were:

- the lack of access to basic services,
- categorisation of chronic pain support as 'non-essential',
- being passed repeatedly between services without receiving support,
- and the postponement or suspension of care.

In order to better understand these issues and to extend the range and reach of lived experience into the communities of Scotland, the Scottish Government asked the ALLIANCE to conduct a survey that would be used to inform their ongoing work on chronic pain policy.

This report captures what we heard from those who responded.

How we undertook the survey and analysis

Over a three week period ending on the 17 September 2021, the ALLIANCE promoted an online survey which sought to understand and capture the challenges that those living with chronic pain were experiencing.

In order to complete the survey, participants had to live in Scotland and either personally experience chronic pain or care for someone who experienced chronic pain.

In this context the experiences of 462 people who currently access services for chronic pain were captured, to inform the Scottish Government's national consultation on the draft Framework for Chronic Pain Service Delivery.

Although 475 people clicked onto the survey, the total number of people who fully completed the survey was 462 as there were three initial filter questions which if answered "no" would mean they were not eligible to complete the survey and so were directed to the end of the survey at that point. These questions were: "I have read and understood the Privacy Statement", "Do you, or the person you care for, live in Scotland?" and "Are you, or the person you care for, troubled by pain or discomfort?".

Additionally, not all 462 participants answered every question as some questions were optional to answer given the sensitive nature of the question e.g. age and how many years respondents had been living with pain. The final question which asked for any additional comments was also an optional question. Throughout this report some participant details have been changed slightly to preserve anonymity, while maintaining the most important information. Where changes have been made to quotations those alterations are indicated via square brackets (e.g. "My advocate, [Name], was great"). For the purpose of analysis, this was coded in the Statistical Package for the Social Sciences (SPSS) as missing data. The data reflects a qualitative as opposed to a representative approach.

The ALLIANCE is grateful to the University of the West of Scotland (UWS) for their work in supporting analysis of the data which was interrogated using the SPSS.

Demographic information

Gender

Overall, by far the majority of respondents were female: 394 female (85% of respondents), 58 male (13% of respondents), 1 transgender man (0.2% of respondents) and 1 non-binary individual (0.2% of respondents) participated in the survey (see Chart 1). A further 8 people (2% of respondents) preferred not to disclose their gender.

Chart 1: Respondents' gender



Age

All participants were asked to share their age. Of those who chose to answer the question, the age ranges of participants varied from 15 years old to 85 years old. As Table 1 shows, most respondents fell into the 45-54 year old category but there was a reasonable response across all age categories.

Table 1: Numbers and percentages of respondents in each age band

Age brackets	Number of participants	Percentages
Under 25 years old	19	4%
25-34 years old	29	6%
35-44 years old	77	17%
45-54 years old	161	35%
55-64 years old	128	28%
65 years old or older	45	10%
Total	459	100%

Ethnicity

In relation to ethnic origin, 444 survey respondents identified as white, eight people described themselves as “mixed or multiple ethnic groups”, two people identified as “Asian – Indian, Pakistani, Bangladeshi, Chinese or other Asian background”, two people identified as “African, Caribbean or any other Black/African/Caribbean background” and one person stated that they were part of an “other ethnic group”. A further 5 people chose not to specify their ethnicity.

Therefore on the basis of completed information, the overall spread of respondents is slightly less ethnically diverse than is typical for Scotland, with only 12 respondents who described themselves as Black, Asian, or from mixed, multiple or minority ethnic groups (3% of participants).

Health Board area

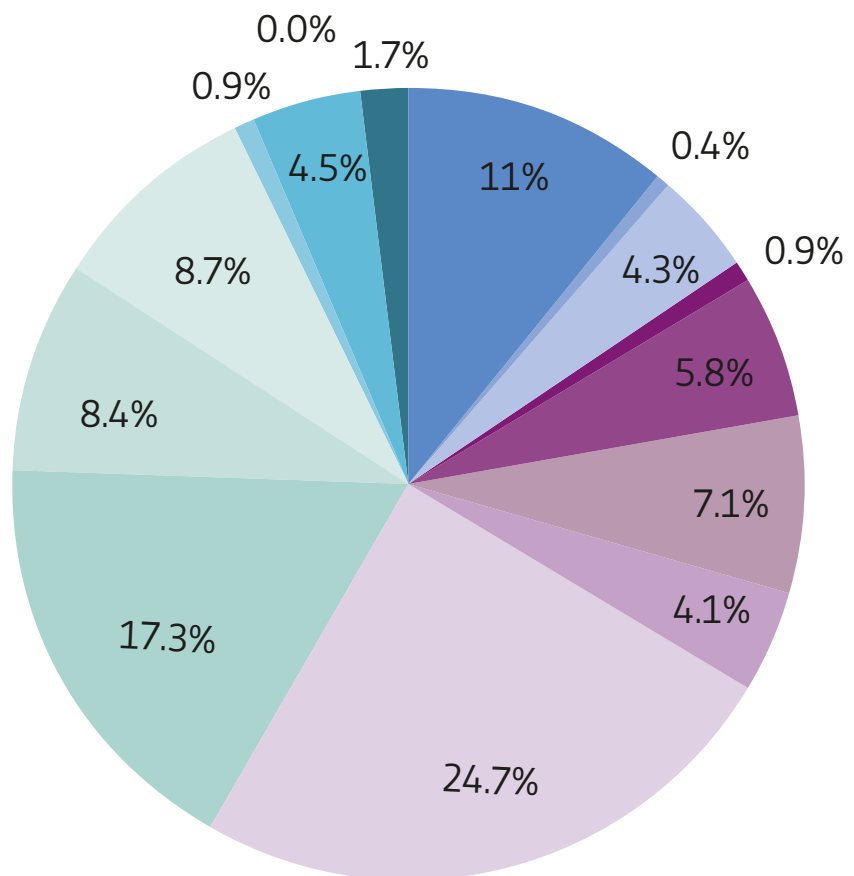
It was encouraging to note that survey responses covered all Health Board areas ensuring a reasonable cross section of urban and rural perspectives.

114 survey respondents (25%) lived in NHS Greater Glasgow and Clyde, 80 (17%) lived in the NHS Highland area, 51 (11%) lived in NHS Ayrshire and Arran, 40 (9%) lived in NHS Lothian, 39 (8%) lived in NHS Lanarkshire, 33 (7%) lived in NHS Forth Valley, 27 (6%) lived in NHS Fife, 21 (5%) lived in NHS Tayside, 20 (4%) lived in NHS Dumfries and Galloway, 19 (4%) lived in NHS Grampian, 4 (1%) lived in NHS Orkney and in NHS Western Isles, and two people lived in the NHS Borders area. A further 8 people (2%) selected “prefer not to say” (see Chart 2).

Chart 2: Which Health Board area do you/they live in?

Survey respondents' Health Board area

- NHS Ayrshire and Arran
- NHS Borders
- NHS Dumfries and Galloway
- NHS Western Isles
- NHS Fife
- NHS Forth Valley
- NHS Grampian
- NHS Greater Glasgow and Clyde
- NHS Highland
- NHS Lanarkshire
- NHS Lothian
- NHS Orkney
- NHS Shetland
- NHS Tayside



Living with more than one long term condition

Client group long term physical health condition

Survey respondents self-identified as living with a range of chronic pain conditions, with the majority reporting that they live with multiple long-term conditions. 355 participants (76.8%) said that they have another long-term physical health condition (see Chart 3).

Chart 3: **Client group/disability/long term condition**

Other than what you have described, do you/they have another long term physical health condition?

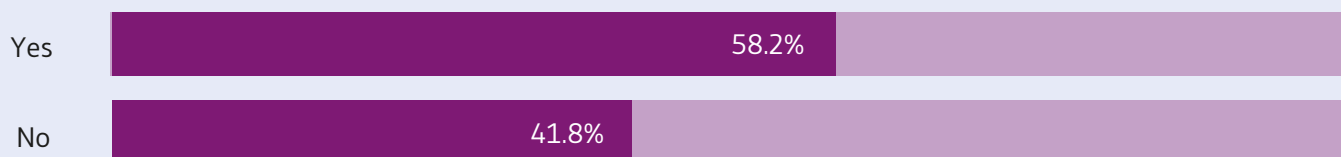


Client group long term mental health condition

Survey respondents self-identified as living with a range of chronic pain conditions, with the majority reporting that they are experiencing longer term mental health difficulties: 269 participants (58%) experienced long term mental health difficulties lasting 12 months or more (see Chart 4). This paints a picture of a strong link between those experiencing chronic pain and mental ill health.

Chart 4: **Client group long term mental health condition**

Are you/they experiencing any longer term difficulties in relation to mental health that is expected to last 12 months or more?

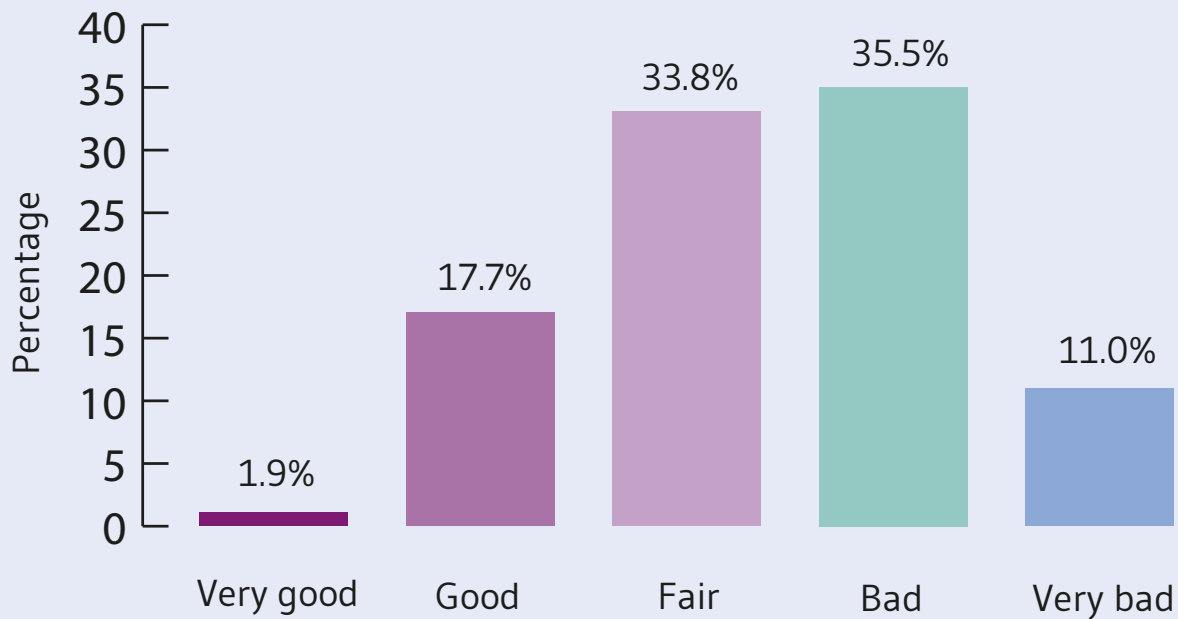


General health

As Chart 5 shows, 164 survey respondents (35%) rated their general health as bad, 156 (34%) rated their health as fair, 82 or only 18% rated their health as good, 51 (11%) rated their health as very bad and only 9 survey respondents (2%) rated their general health as very good.

Chart 5: **Respondents' general health**

How is your/their health in general?
Would you say it is:



Experiences of chronic pain

As mentioned previously the definition of chronic pain is people who have lived with pain for more than 12 weeks. Although there was no filter on this question so people could answer and still continue if they lived with pain for less than 12 weeks. All respondents who answered, self identified as having lived with pain for over three months.

Survey respondents were also asked to specify how long they have been living with pain. The vast majority of respondents (97%) said they had been living with pain for more than 12 months. 13 (3%) of respondents said they had been living with pain for 3-12 months.

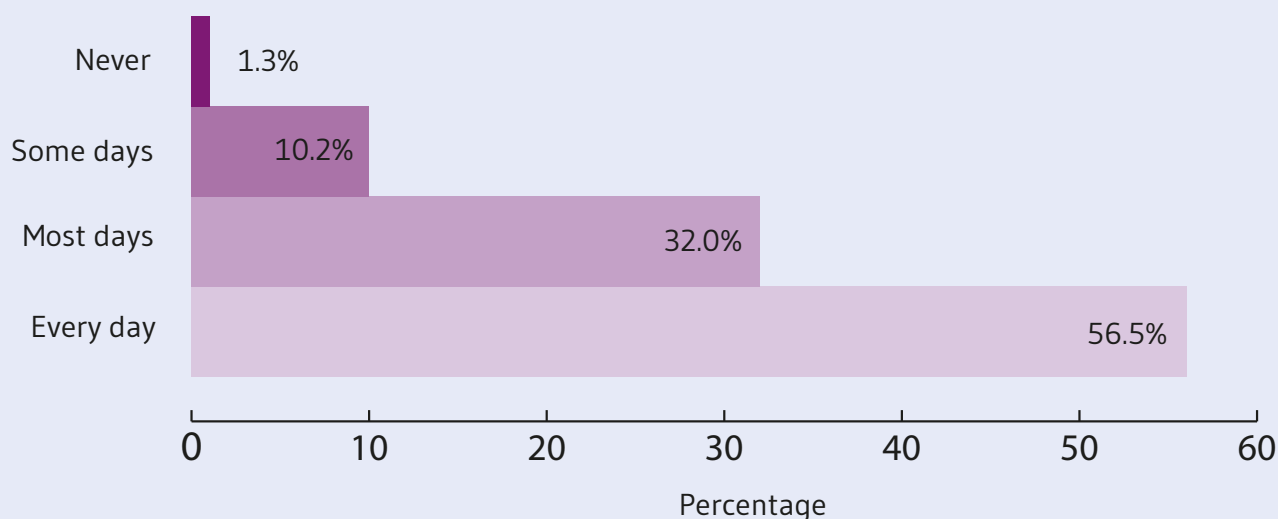
The range of years living with pain varied between respondents from 1 year to 56 years. The average years living with pain for participants was 13 years.

Impact of pain

Survey respondents were asked how often pain limited their life or work activities over the past 3 months. As Chart 6 shows, 261 (56%) of respondents said that pain limited their life or work activities every day, 148 (32%) said that pain limited their life or work activities most days, 47 (10%) of respondents said that pain limited their life or work activities some days and 6 (1%) of respondents said that pain never limited their life or work activities over the past 3 months.

Respondents who said that their pain limited their life or work activities every day or most days were categorised as having high impact pain (89%) and respondents who said that their pain limited their life or work activities some days or never were categorised as having low impact pain (11%).

Chart 6: Over the past 3 months how often has pain limited your/their life or work activities?



Pain management

A majority of respondents (79%) reported that they were currently being prescribed medication to help manage their pain while 95 respondents (21%) reported that they weren't currently being prescribed medication to help manage their pain.

Support accessed

Respondents were asked which resources they had used to get support in managing their pain.

By far the majority of respondents (89%) had used a GP to get support in managing their pain, 307 respondents (66%) had used a physiotherapist to get support in managing their pain, 244 respondents (53%) had used specialist pain services at a hospital to get support in managing their pain, nearly half of respondents. 224 (48%) had used NHS or charity information about managing pain including online resources to get support in managing their pain, 131 respondents

(28%) had used a chemist or pharmacist to get support in managing their pain, 128 respondents (28%) had used a nurse or other health worker at a GP surgery or Health Centre to get support in managing their pain, 126 respondents (27%) had used an osteopath, chiropractor or acupuncturist to get support in managing their pain, 96 respondents (21%) had used a homeopath or other alternative medicine professional to get support in managing their pain, 80 respondents (17%) used a psychologist to get support in managing their pain and 10 respondents (2%) used a residential pain service where they have stayed away from home to get support in managing their pain.

7 respondents (2%) said that they didn't use any of the above-mentioned resources to get support in managing their pain and 67 respondents (15%) said that they used other resources to get support in managing their pain.

Clearly most respondents were therefore in contact with GP or specialist pain management services.

Table 2: **Have you/they used any of the following resources to get support in managing pain?**

Answer choice	Response percent	Response total
1 NHS or charity information about managing pain including online resources	48.5%	224
2 GP	89.0%	411
3 Nurse or other health worker at GP surgery/Health Centre	27.7%	128
4 Physiotherapist	66.5%	307
5 Chemist or pharmacist	28.4%	131
6 Specialist pain services at a hospital such as a doctor, nurse or physiotherapist	52.8%	244
7 Residential pain service where you/they have stayed away from home	2.2%	10
8 Psychologist	17.3%	80
9 Osteopath, chiropractor or acupuncturist	27.3%	126
10 Homeopath or other alternative medicine professional	20.8%	96
11 None of these	1.5%	7
12 Other (please specify):	14.5%	67
	answered	462
	skipped	13

Other resources used for support in managing pain

Question 9 asked respondents to specify which other resources they had used in getting support to manage their pain. 66 respondents specified

what other resources they had used in getting support to manage their pain. The responses can be categorised as follows:

Wide range of resources

A small number of respondents mentioned a very wide range of resources that they had used in managing their pain, not all successfully. This possibly reflects a measure of anxiety in trying to find something that works to manage their pain:

“Peer support and access to physical, creative and mindfulness activities at a local centre for people with long term conditions”

“Alternative therapies, acupuncture, hydrotherapy, meditation and mindfulness, neurologist, heat and cold therapy, home aids, OT”

“Many other treatments to self-manage eg devices to lie on, Epsom salt baths, traction positioning, numerous medications (to no avail), etc.”

“Pain clinic, Pain Concern meetings, stress control classes, relaxation, reiki, yoga”

Massage and relaxation techniques

Massage was the most popular alternative treatment with 13 respondents mentioning that they had used this. A range of other relaxation techniques were also mentioned, such as reiki, meditation, flotation tank, acupuncture, hydrotherapy and 4 respondents mentioned mindfulness:

“Massage therapist / reiki / flotation tank / limbic reflexology and ordinary reflexology / meditation etc”

Medication

Some mentioned using prescription medications or supplements, with 4 respondents stating that they took cannabis:

“Regular cortisone injections”

“I use some supplements”

“Cbd oil and caps”

“I eventually had to give up on all the above and became a private cannabis patient”

Specialist treatment and surgery

Some had been referred for specialist treatment, for example to a psychiatrist, neurosurgeon rheumatologist and orthotics, while others had had surgery:

“Surgery for endometriosis”

“Implantation of a sacral nerve stimulator”

Groups

A few respondents had found it useful to attend meetings with third sector groups such as Pain Association Scotland:

“Access to physical, creative and mindfulness activities at a local centre for people with long term conditions”

“Pain Association Scotland monthly meetings”

Private

A number mentioned that they had gone privately for treatment:

“Acupuncturist was taken up privately and paid for by myself - I wouldn’t expect the NHS to pay for this”

“I eventually had to give up on all the above and became a private cannabis patient”

“Private mental health services and private physio!”

Digital

Some respondents mentioned digital support that they had used, which included social media such as Facebook, apps and physio podcasts.

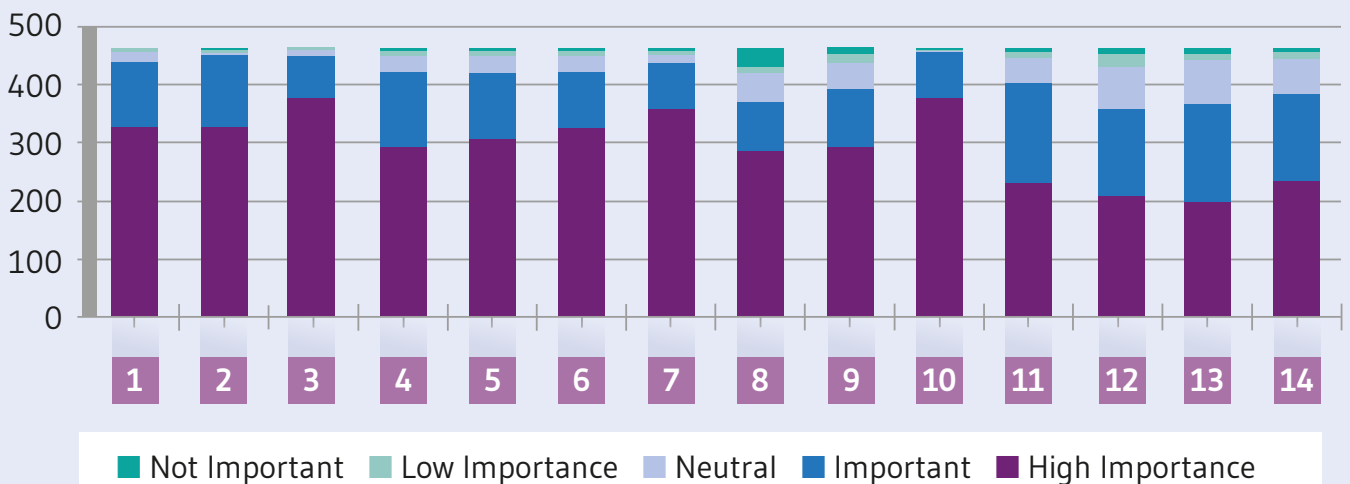
Other treatments mentioned included oxygen therapy, tens machine and occupational therapy.

What Matters to You?

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance do they place on more public information about what chronic pain is, its impact on people in Scotland and how to access support.

Chart 7: **What Matters to You?**

- | | |
|----------------------------------|-----------------------------|
| 1 Information on chronic pain | 8 Employment support |
| 2 Pain management options | 9 Welfare and benefits |
| 3 Pain management closer to home | 10 Treatment available |
| 4 Waiting times | 11 Information sources |
| 5 Understanding medication | 12 Using digital technology |
| 6 Being physically active | 13 Feedback opportunities |
| 7 Mental health and wellbeing | 14 Research participation |



1 More public information about what chronic pain is, its impact on people in Scotland and how to access support

As Chart 7 shows, a majority of respondents placed importance on more information about what chronic pain is, its impact on people in Scotland and how to access support. 16 respondents (4%) were neutral or placed low importance on more public information about what chronic pain is, its impact on people in Scotland and how to access support.

2 Support and information to learn about different options that may help you manage your pain

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on support and information to learn about different options that may help them manage their pain. As Chart 7 shows, a majority of respondents (82%) placed high importance on support and information to learn about different options that may help them manage their pain, 71 respondents (15%) rated support and information to learn about different options that may help them manage their pain as important, 6 respondents (1%) were neutral on support and information to learn about different options that may help them manage their pain, 4 respondents (1%) placed low importance on support and information to learn about different options that may help them manage their pain and 1 respondent rated support and information to learn about different options that may help them manage their pain as not important.

3 Information about what services and health and care teams are available locally and how they might help you to manage your pain closer to home

Respondents were asked to think about how chronic pain impacts their day-to-day life and what



importance they place on information about what services and health and care teams are available locally and how they might help to manage their pain closer to home. As Chart 7 shows, a majority of respondents (82%) placed high importance on information about what services and health and care teams are available locally and how they might help to manage their pain closer to home: 72 respondents (16%) rated information about what services and health and care teams are available locally and how they might help to manage their pain closer to home as important; 10 respondents (2%) were neutral on information about what services and health and care teams are available locally and how they might help to manage their pain closer to home, and 3 respondents (1%) placed low importance on information about what services and health and care teams are available locally and how they might help to manage their pain closer to home.

4 Information about waiting times for services in your area and support available while you are waiting for your appointment

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on information about waiting times for services in their area and support available while they are waiting for their appointment. As Chart 7 shows, a majority of respondents (63%) placed high importance on information about waiting times for services in

their area and support available while they are waiting for their appointment: 129 respondents (28%) rated information about waiting times for services in their area and support available while they are waiting for their appointment as important, 29 respondents (6%) were neutral on information about waiting times for services in their area and support available while they are waiting for their appointment, 8 respondents (2%) placed low importance on information about waiting times for services in their area and support available while they are waiting for their appointment and 3 respondents (1%) rated information about waiting times for services in their area and support available while they are waiting for their appointment as not important. Survey results therefore demonstrate overwhelmingly that waiting times in local area is a key part of what matters to people with chronic pain.

5 Access to support to help you understand and manage medication you are taking for your pain

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on access to support to help them understand and manage the medication

they are taking for their pain. As Chart 7 shows, a majority of respondents (66%) placed high importance on access to support to help them understand and manage the medication they are taking for their pain, 112 respondents (24%) rated access to support to help them understand and manage medication they are taking for their pain as important, 33 respondents (7%) were neutral on access to support to help them understand and manage medication they are taking for their pain, 5 respondents (1%) placed low importance on access to support to help them understand and manage medication they are taking for their pain and 5 respondents (1%) also rated access to support to help them understand and manage medication they are taking for their pain as not important.

6 Access to support to help you keep physically active and carry out day to day tasks

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance do they place on access to support to help them keep physically active and carry out day to day tasks. As Chart 7 shows, a majority of respondents (71%) placed high importance on access to support to help them keep physically active and carry out day to day tasks: 95



respondents (21%) rated access to support to help them keep physically active and carry out day to day tasks as important, 28 respondents (6%) were neutral on access to support to help them keep physically active and carry out day to day tasks, 8 respondents (2%) placed low importance on access to support to help them keep physically active and carry out day to day tasks and 4 respondents (1%) rated access to support to help them keep physically active and carry out day to day tasks as not important.



7 Access to support to help you manage the impact of your pain on your mental health and wellbeing

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on access to support to help them manage the impact of their pain on their mental health and wellbeing. As Chart 7 shows, a majority of respondents (78%) placed high importance on access to support to help them manage the impact of their pain on their mental health and wellbeing, 77 respondents (17%) rated access to support to help them manage the impact of their pain on their mental health and wellbeing as important, 15 respondents (3%) were neutral on access to support to help them manage the impact of their pain on their mental health and wellbeing, 6 respondents (1%) placed low importance on access to support to help them manage the impact of their pain on their mental health and wellbeing and 4 respondents (1%) rated access to support to help them manage the impact of their pain on their mental health and wellbeing as not important.

8 Access to employment support when pain is preventing you from being, or remaining in work

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on access to employment support when pain is preventing them from being, or remaining in work. As Chart 7 shows, a majority of respondents (62%) placed high importance on access to employment support when pain is preventing them from being, or remaining in work, 83 respondents (18%) rated access to employment support when pain is preventing them from being, or remaining in work as important, 53 respondents (11%) were neutral on access to employment support when pain is preventing them from being, or remaining in work, 9 respondents (2%) placed low importance on access to employment support when pain is preventing them from being, or remaining in work and 30 respondents (6%) rated access to employment support when pain is preventing them from being, or remaining in work as not important.

9 Access to information about welfare and benefits you may be eligible for

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on access to information about welfare and benefits they may be eligible for. As Chart 7 shows, a majority of respondents (64%) placed high importance on access to information about welfare and benefits they may be eligible for, 100 respondents (22%) rated access to information about welfare and benefits they may be eligible for as important, 45 respondents (10%) were neutral on access to information about welfare and benefits they may be eligible for, 14 respondents (3%) placed low importance on access to information about welfare and benefits they may be eligible for and 9 respondents (2%) rated access to information about welfare and benefits they may be eligible for as not important.

10 Information about the different types of treatment available for chronic pain and when they are used

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on information about the different types of treatment available for chronic pain and when they are used. As Chart 7 shows, a majority of respondents (82%) placed high importance on information about the different types of treatment available for chronic pain and when they are used, 78 respondents (17%) rated information about the different types of treatment available for chronic pain and when they are used as important, 3 respondents (1%) were neutral on information about the different types of treatment available for chronic pain and when they are used, 1 respondent placed low importance on information about the different types of treatment available for chronic pain and when they are used and 2 respondents rated information about the different types of treatment available for chronic pain and when they are used as not important.

11 Information about charities and other groups nationally and in your area that offer support to manage chronic pain

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on information about charities and other groups nationally and in their area that offer support to manage chronic pain. As Chart 7 shows, half of respondents (50%) placed high importance on information about charities and other groups nationally and in their area that offer support to manage chronic pain, 172 respondents (37%) rated information about charities and other groups nationally and in their area that offer support to manage chronic pain as important, 44 respondents (10%) were neutral on information about charities and other groups nationally and in their area that offer support to manage chronic pain, 9 respondents (2%) placed low importance on information about charities and

other groups nationally and in their area that offer support to manage chronic pain and 6 respondents (1%) rated information about charities and other groups nationally and in their area that offer support to manage chronic pain as not important.

12 Being able to use digital technology to get advice or see your doctor about your pain

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on being able to use digital technology to get advice or see their doctor about their pain. As Chart 7 shows, less than half of respondents (45%) placed high importance on being able to use digital technology to get advice or see their doctor about their pain, 150 respondents (32%) rated being able to use digital technology to get advice or see their doctor about their pain as important, 74 respondents (16%) were neutral on being able to use digital technology to get advice or see their doctor about their pain, 21 respondents (5%) placed low importance on being able to use digital technology to get advice or see their doctor about their pain and 9 respondents (2%) rated being able to use digital technology to get advice or see their doctor about their pain as not important. This reflects feedback from other work completed by the ALLIANCE which suggested that for certain conditions involving for example mental health or where it is important to have physical examination, digital may not be the first preferred option of those who experience long term conditions and a flexible approach is necessary.



13 Opportunities to share your experiences and feedback to improve your local services

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on opportunities to share their experiences and feedback to improve their local services. As Chart 7 shows, less than half of respondents (43%) placed high importance on opportunities to share their experiences and feedback to improve their local services, 171 respondents (37%) rated opportunities to share their experiences and feedback to improve their local services as important, 77 respondents (17%) were neutral on opportunities to share their experiences and feedback to improve their local services, 8 respondents (2%) placed low importance on opportunities to share their experiences and feedback to improve their local services and 9 respondents (2%) rated opportunities to share their experiences and feedback to improve their local services as not important.

14 Opportunities to engage with and participate in research into chronic pain

Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on opportunities to engage with and participate in research into chronic pain. As Chart 7 shows, about half of respondents (51%) placed high importance on opportunities to engage with and participate in research into chronic pain, 151 respondents (33%) rated opportunities to engage with and participate in research into chronic pain as important, 59 respondents (13%) were neutral on opportunities to engage with and participate in research into chronic pain, 12 respondents (3%) placed low importance on opportunities to engage with and participate in research into chronic pain and 6 respondents (1%) rated opportunities to engage with and participate in research into chronic pain as not important.



Summary of what matters to those who experience chronic pain

Therefore, from the available choices, as Chart 7 shows, what matters most to the majority of respondents (82%) is: support and information to learn about different options that may help them manage their pain, information about the different types of treatment available for chronic pain and when they are used and information about what services and health and care teams are available locally and how they might help them to manage their pain closer to home.

Also, from the available choices, as Chart 7 shows, what doesn't matter to some of the respondents is: access to employment support when pain is preventing them from being, or remaining in work (6%), access to information about welfare and benefits they may be eligible for (2%), being able to use digital technology to get advice or see their doctor about their pain (2%) and opportunities to share their experiences and feedback to improve their local services (2%).

Personal experiences of chronic pain and what people told us

Experiences of chronic pain

Question 18 asked respondents whether they had any additional comments to make about their experiences of chronic pain. 62 participants responded to this question and the majority were negative responses. However open questions of this kind tend to invite more negative responses and 413 of the 475 respondents did not feel strongly enough to answer this question.

Issues raised by those who responded were be grouped into following themes.

Support

Support was a common theme, with several participants mentioning their feelings of lack of care and support given to chronic pain patients:

"The support I have received has been non existent"

"I strongly believe there needs to be significant improvement in care and support for people living with chronic conditions and chronic pain."

"I get no help or support despite asking for help"

However, there were some more positive comments about support:

"I have long experience of the difficulty of accessing pain management support but also now have long term benefit of regular pain management treatment via the team at the Victoria Hospital Glasgow....."

"Support from local Pain Clinic arranged by my GP and run by a pharmacist has been invaluable. I believe this has stopped me from feeling depressed through isolation"

Lack of understanding

The issue of lack of understanding of pain by practitioners was raised by a number of respondents with several feeling that GPs and others should have more understanding of chronic pain:

"GPs need more training and understanding of rarer conditions such as EDS"

"Lack of resources for chronic conditions and a lack of knowledge surrounding these conditions"

Information

Patients also mentioned the need that they felt themselves for more information about treatments for chronic pain:

"More information about treatments different types of pain"

"Advice on alternatives rather than just handing out meds"

"Understanding what chronic pain is"

Process

There was a feeling that the whole system for dealing with patients with chronic pain was inadequate, with delays to treatment, lack of access to treatment for specialist pain:

"The process of being 'seen' in the NHSO service was deeply traumatic"

"Delays were extensive and when I was eventually seen, I was dismissed as being almost responsible for the pain, by 'not managing stress' well"

Some had given up on getting help within the system:

"Given up on getting help with pain"

Access

Access to services was identified as a problem:

"I feel like we need better access to specialist pain services as a whole especially for those with undiagnosed conditions"

"Better access to specialist pain services"

"I have MS and very difficult to access neurologist or a MS nurse not seen them in years as was told there was nothing they could do for me"

"I feel that not having access to my usual GP/consultants due to covid extremely detrimental to my health"

Even where there was access to a service, it was not always regarded as suitable:

"I had access to the pain clinic in Glasgow before I had a diagnosis. It was not appropriate methods of management for my condition"

Continuity of care

Continuity of care was identified as a problem by some with some saying that they saw a different doctor every time:

"Please improve continuity of care"

"Please improve continuity of care, and invest in other online pain management programs as this will empower people with chronic pain to help to feel in control of their own pain in their own time"

"The receptionist just puts you in to see a different doctor every time so it is frustrating to cope with this situation as well as coping with chronic pain"

Communication

Communication was seen as a major problem:

"The whole system is lacking proper communication when it comes to trying to arrange appointments...."

"Lack of communication from hospital to GP following diagnosis. (No letters several months later)"

Dismissive attitude

Once they were seen several participants mentioned that their GP had a rather dismissive attitude to them:

"Especially as a young person. I was often dismissed and each thing was treated separately"

"They also need to start believing what female patients tell them and not dismiss everything as 'anxiety'"

Quality of life

Several mentioned the impact of chronic pain on their quality of life, with some very distressing feelings expressed:

"My quality of life is just so sad"

"All I am looking for is some form of quality of life"

"I often feel so depressed and feel that my quality of life is so poor that I really don't want to be here any longer"

"Most days I just feel that I have no decent quality of life and often feel I don't want to be here any more because I can't bear the prospect of spending the remainder of my life in chronic pain, which will only get worse in time"

Economic impact

The economic impact of having chronic pain was also mentioned:

"Chronic pain always causes a decrease in finances. On top of that people like me have to pay to get help"

Patient satisfaction

There were some patients who were satisfied with the service provided. One had already benefited from an online service "Peace by Piece" during Lockdown:

"I was able to access this service and the team members were always professional and friendly which made me extremely grateful for their service during this tough time"

Suggestions for improvement

Respondents did have some suggestions about how to improve things:

"It would be useful if linked up services were provided to deal with all the aspects of chronic pain conditions and co morbidities that exist within particular conditions"

A couple of participants were in favour of digital support for dealing with pain:

"Invest in other online pain management programs as this will empower people with chronic pain to help to feel in control of their own pain in their own time"

"I hope that the future of pain services sees the huge benefit of online services, its crucial for people like me who get exhausted just getting myself washed dressed and fed"

Pain impact

The question ‘How often has pain limited your/ their life or work activities?’ was regrouped into low pain impact and high pain impact with “never” and “some days” regrouped as “low impact” and “most days” and “every day” coded as “high impact”, where low impact meant that pain had a low impact in limiting participants’ life or work activities and high impact meant that pain had a high impact in limiting participants’ life or work activities.

The data was examined to consider how often pain has limited life or work activities in relation to age, gender, years living in pain, whether medicine is currently prescribed, health in general, whether the participant has another long term physical health condition, and mental health. The results are summarised in Table 3 below, which shows that being currently prescribed medication, health in general, having another long term physical or mental health condition all had an impact in limiting participants’ life or work activities.

Table 3: Significance of links between variables and impact of pain on life and work activities

Variable	Significant
Medicine prescribed	Yes
Health in general	Yes
Another long term physical health condition	Yes
Mental health	Yes
Age	No
Gender	No
Health Board Area	No
Ethnic Group	No
Pain duration	No

Impact of whether medication is being prescribed and pain limiting activities

Table 4 below shows the number of participants in the high and low impact categories broken down by whether or not participants are currently being prescribed medication to help manage their pain.

The results of the analyses reflect that the number of respondents in the high impact

category who were prescribed medication (82%) was much higher than respondents in the low impact category (60.4%). This suggests that pain limits participants’ life or work activities more for those who have been prescribed medication than for those who haven’t.

Table 4: Whether medication is being prescribed and pain limiting activities

	Impact of pain on life or work activities		Significant
	Low impact	High impact	Total
Is medication currently being prescribed for pain			
Yes	32	335	367
No	21	74	95
Total	53	409	462

Health in general and pain limiting activities

Table 5 below shows the number of participants in the high and low impact categories broken down by participants ratings of their general health.

The results of the analyses reflect that respondents who have a higher pain impact are

6.5 times more likely to rate their general health as fair (34%) and 64.8 times more likely to rate their health as bad (40%) and respondents who have a lower pain impact are more likely to rate their general health as very good (8%).

Table 5: Health in general and pain limiting activities

	Impact of pain on life or work activities		Significant
	Low impact	High impact	Total
Health in General			
Very Good	4	5	9
Good	30	52	82
Fair	17	139	156
Bad	2	162	164
Very Bad	0	51	51
Total	53	409	462

Having another long term physical health condition and pain limiting activities

Table 6 shows the number of respondents in high and low impact categories broken down by whether or not participants experienced any another long term physical health condition.

The results of the analyses reflect that the proportion of those in the high impact category

who have another long term physical health condition (79%) was higher than in the low impact category (60.4%). This suggests that participants who have another long term physical health condition are more limited in their life or work activities than for those who don't.

Table 6: Having another long term physical health condition and pain limiting activities

	Impact of pain on life or work activities		Significant
	Low impact	High impact	Total
Having another long term physical health condition			
Yes	32	323	355
No	21	86	107
Total	53	409	462

Experience of long term mental health difficulties and pain limiting activities

Table 7 shows the numbers in low and high impact categories broken down by whether or not participants experienced any long term mental health difficulties.

The results of the analyses reflect that the proportion of those in the high impact category

who experience long term mental health difficulties (61.6%) was much higher than in the low impact category (32.1%). This suggests that participants who experience long term mental health difficulties are more limited in their life or work activities than those who don't experience mental health difficulties.

Table 7: Experience of long term mental health difficulties and pain limiting activities

	Impact of pain on life or work activities		Significant
	Low impact	High impact	Total
Participants experiencing any long term mental health difficulties			
Yes	17	252	269
No	36	157	193
Total	53	409	462

Impact of age on pain limiting life or work activities

A correlation was carried out on the relationship between age and pain limiting life or work activities. This was not significant meaning that the amount that pain limited life or work activities was not related to the respondent's age.

Impact of Health Board area on pain limiting life or work activities

In investigating relationship between pain, work and Health Board area, there was no significant evidence that the amount that pain limited life or work activities did not vary by respondents Health Board area.

The link between the different resources used for managing pain and their impact on limiting life or work activities

Table 8 summarises which resources had a statistically significant influence on the impact of pain on limiting life or work activities. These were GP, nurse or other health worker at GP surgery/Health Centre, physiotherapist, specialist pain services at a hospital such as a doctor, nurse or

physiotherapist. Therefore, respondents who have a higher pain impact are more likely to have used these services than respondents who have a lower pain impact.

Table 8: Resources used to get support in managing pain and their impact on limiting life or work activities

Resources used to get support in managing pain	Significant
NHS or charity information about managing pain including online resources	No
GP	Yes
Nurse or other health worker at GP surgery/Health Centre	Yes
Physiotherapist	Yes
Chemist or pharmacist	No
Specialist pain services at a hospital such as a doctor, nurse or physiotherapist	Yes
Residential pain service where you/they have stayed away from home	No
Psychologist	No
Osteopath, chiropractor or acupuncturist	No
Homeopath or other alternative medicine professional	No
None of these	No
Other services	No

The results of the analyses, as shown in Table 9, reflect that respondents who have a higher pain impact (92%) are more likely to have been seen by

a GP to get support in managing their pain than respondents with a lower pain impact (66%).

Table 9: Participants seen by a GP to get support in managing their pain and pain limiting activities

	Impact of pain on life or work activities		Significant
	Low impact	High impact	Total
Participants seen by a GP to get support in managing their pain			
Yes	35	376	411
No	18	33	51
Total	53	409	462

The link between respondents seeing a nurse or other health worker at a GP surgery/Health Centre to get support in managing their pain and the impact that pain has had on limiting their life or work activities, is shown in Table 10. It reflects that respondents who have a higher pain impact

(30%) are more likely to have been seen by a nurse or other health worker at a GP surgery/Health Centre to get support in managing their pain than respondents with a lower pain impact (8%).

Table 10: Participants seen by a nurse or other health worker at a GP surgery/Health Centre to get support in managing their pain and pain limiting activities

	Impact of pain on life or work activities		Significant
	Low impact	High impact	Total
Participants seen by a nurse or other health worker at a GP surgery/Health Centre to get support in managing their pain			
Yes	4	124	128
No	49	285	334
Total	53	409	462

In examining the link between respondents seeing a physiotherapist to get support in managing their pain and the impact that pain has had on limiting their life or work activities, the results of the analyses, as shown in Table 11, reflect

that respondents who have a higher pain impact (68%) are more likely to have been seen by a physiotherapist to get support in managing their pain than respondents with a lower pain impact (53%).

Table 11: Participants seen by a physiotherapist to get support in managing their pain and pain limiting activities

	Impact of pain on life or work activities		Significant
	Low impact	High impact	Total
Participants seen by a physiotherapist to get support in managing their pain			
Yes	28	279	307
No	25	130	155
Total	53	409	462

In examining the link between respondents using specialist pain services at a hospital such as a doctor, nurse or physiotherapist to get support in managing their pain and the impact that pain has had on limiting their life or work activities, the results of the analyses, as shown in Table

12, reflect that respondents who have a higher pain impact (55%) are more likely to have used specialist pain services at a hospital such as a doctor, nurse or physiotherapists to get support in managing their pain than respondents with a lower pain impact (34%).

Table 12: Participants using specialist pain services at a hospital such as a doctor, nurse or physiotherapist to get support in managing their pain

	Impact of pain on life or work activities		Significant
	Low impact	High impact	Total
Participants using specialist pain services at a hospital such as a doctor, nurse or physiotherapist to get support in managing their pain			
Yes	18	226	244
No	35	183	218
Total	53	409	462

Prescribed medication

Respondents who are not currently being prescribed medication by a doctor to help manage their pain are more likely to not have used NHS or charity information about managing pain including online resources; a GP; a nurse or other health worker at GP surgery/Health Centre or a specialist pain service at a hospital such as a doctor, nurse or physiotherapist to get support in managing their pain than respondents who are currently being prescribed medication by a doctor to help manage their pain. Also, respondents who are not currently being prescribed medication by a doctor to help manage their pain are more likely to have not used any of the listed resources to get

support in managing their pain than respondents who are currently being prescribed medication by a doctor to help manage their pain.

The other listed resources were not significant, meaning that there was no difference between respondents that are currently being prescribed medication by a doctor to help manage their pain and respondents that are not currently being prescribed medication by a doctor to help manage their pain in their likelihood of using these resources to get support in managing their pain.

Table 13: Resources used to get support in managing pain and whether respondents were currently being prescribed medication by a doctor to help manage their pain

Resources used to get support in managing pain	Significant
NHS or charity information about managing pain including online resources	Yes
GP	Yes
Nurse or other health worker at GP surgery/Health Centre	Yes
Physiotherapist	No
Chemist or pharmacist	No
Specialist pain services at a hospital such as a doctor, nurse or physiotherapist	Yes
Residential pain service where you/they have stayed away from home	No
Psychologist	No
Osteopath, chiropractor or acupuncturist	No
Homeopath or other alternative medicine professional	No
None of these	Yes
Other services	No

In examining the link between respondents using NHS or charity information about managing pain including online resources to get support in managing their pain and whether respondents were currently being prescribed medication by a doctor to help manage their pain, the results are presented in Table 14. It reflects that respondents who are not being prescribed

medication by a doctor to help manage their pain (64%) are more likely to not use NHS or charity information about managing pain including online resources to get support in managing their pain than respondents who are being prescribed medication by a doctor to help manage their pain (48%).

Table 14: Participants used NHS or charity information about managing pain including online resources to get support in managing their pain and whether respondents were currently being prescribed medication by a doctor to help manage their pain

	Whether respondents were currently being prescribed medication by a doctor to help manage their pain		Significant
	Yes	No	Total
Participants used NHS or charity information about managing pain including online resources to get support in managing their pain			
Yes	190	34	224
No	177	61	238
Total	367	95	462

In examining the link between respondents seeing a GP to get support in managing their pain and whether respondents were currently being prescribed medication by a doctor to help manage their pain, reflect that respondents who are not being prescribed medication by a doctor

to help manage their pain (23%) are 3.5 times more likely to not see a GP to get support in managing their pain than respondents who are being prescribed medication by a doctor to help manage their pain (8%).

Table 15: Participants seen by a GP to get support in managing their pain and whether respondents were currently being prescribed medication by a doctor to help manage their pain

	Whether respondents were currently being prescribed medication by a doctor to help manage their pain		Significant
	Yes	No	Total
Participants seen by a GP to get support in managing their pain			
Yes	338	73	411
No	29	22	51
Total	367	95	462

The results of the analyses, as shown in Table 16, reflect that respondents who are not being prescribed medication by a doctor to help manage their pain (81%) are more likely to not see a nurse or other health worker at a GP surgery/Health

Centre to get support in managing their pain than respondents who are being prescribed medication by a doctor to help manage their pain (70%).

Table 16: Participants seen by a nurse or other health worker at a GP surgery/Health Centre to get support in managing their pain and whether respondents were currently being prescribed medication by a doctor to help manage their pain

	Whether respondents were currently being prescribed medication by a doctor to help manage their pain		Significant
	Yes	No	Total
Participants seen by a nurse or other health worker at a GP surgery/Health Centre to get support in managing their pain			
Yes	110	18	128
No	257	77	334
Total	367	95	462

In examining the link between respondents using specialist pain services at a hospital such as a doctor, nurse or physiotherapist to get support in managing their pain and whether respondents were currently being prescribed medication by a doctor to help manage their pain. Table 17 demonstrates that the results of the analyses, reflect that respondents who are not

being prescribed medication by a doctor to help manage their pain (59%) are more likely to not use specialist pain services at a hospital such as a doctor, nurse or physiotherapist to get support in managing their pain than respondents who are being prescribed medication by a doctor to help manage their pain (44%).

Table 17: Participants used specialist pain services at a hospital such as a doctor, nurse or physiotherapist to get support in managing their pain and whether respondents were currently being prescribed medication by a doctor to help manage their pain

	Whether respondents were currently being prescribed medication by a doctor to help manage their pain		Significant
	Yes	No	Total
Participants used specialist pain services at a hospital such as a doctor, nurse or physiotherapist to get support in managing their pain			
Yes	205	39	244
No	162	56	218
Total	367	95	462

In examining the link between respondents using none of the listed resources to get support in managing their pain and whether respondents were currently being prescribed medication by a doctor to help manage their pain, the results of the analyses, as shown in Table 18, reflect that respondents who are not being prescribed medication by a doctor to help manage their

pain (4%) are more likely to have used none of the listed resources/services to get support in managing their pain than respondents who are being prescribed medication by a doctor to help manage their pain (1%).

Table 18: Participants used none of the listed resources/services and whether respondents were currently being prescribed medication by a doctor to help manage their pain

Participants used none of the listed resources/services to get support in managing their pain	Whether respondents were currently being prescribed medication by a doctor to help manage their pain		Significant
	Yes	No	Total
Yes	3	4	7
No	364	91	455
Total	367	95	462

Duration of pain

The duration of pain was examined in relation to age, gender identity, whether medicine is currently prescribed, health in general, whether they have another long term physical health condition and mental health. Table 19

summarises these results, showing that age and whether respondents had another long term physical health condition were significant. It was determined that those of older age had a correlation with longer duration of pain.

Table 19: Relationship between pain duration and variables of interest

Variable	Significant
Age	Yes
Another long term physical health condition	Yes
Gender	No
Medicine currently prescribed	No
Health in general	No
Mental health	No

Impact of another long term physical health condition on duration of pain

As shown in Table 20, those who had another long term health condition had been living with pain for longer (14 years on average) compared

with those who did not have other health difficulties (10 years on average).

Table 20: Number of years living with pain and whether respondents have another long term physical health condition

	Do you have another long term physical health condition	Number of Respondents	Mean Number of Years Living with Pain
How many years living with pain	Yes	348	14.39
	No	99	10.04

Summary

It is clear from the results of this survey that chronic pain has a huge impact on the lives of those who experience it, that access to services and support makes a difference to living with chronic pain in a manageable way and that information particularly around waiting times in local areas is important to people in understanding how to plan and manage their lives.

The survey also shows that many people with chronic pain also live with other physical conditions and also experience mental ill health. Service planning needs to take into

consideration a holistic approach which meets individual needs.

For many of those who responded, chronic pain is something that they have lived with for years and therefore a planned programmed approach which addresses individual needs is paramount.

Appendix 1 further information

Recent Scottish Government Policies and Framework

[Scottish Service Model for Chronic Pain \(2014\)](#)

[Scottish National Residential Pain Management Programme \(2015\)](#)

[Quality Prescribing for Chronic Pain: A Guide for Improvement \(2018\)](#)

[Management of Chronic Pain in Children and Young People \(2018\)](#)

Chronic Pain [Report](#) and [Survey](#) (2019 and 2020)

[Framework for Recovery of NHS Pain Management Services \(2020\)](#)

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

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