Pain Medicines Patient Safety Programme Survey Feedback

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Date: 14.4.23

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1.0 Introduction

The Pain Medicines Patient Safety Programme is a 3-year programme co-ordinated by NHS Fife and Fife Health and Social Care Partnership.

The aim of the programme is to work with health professionals, patients, carers and the wider community to increase our understanding of the impact of pain in day-to-day life and improve the way patient pain is managed in hospitals, GP Practices and in the wider community.

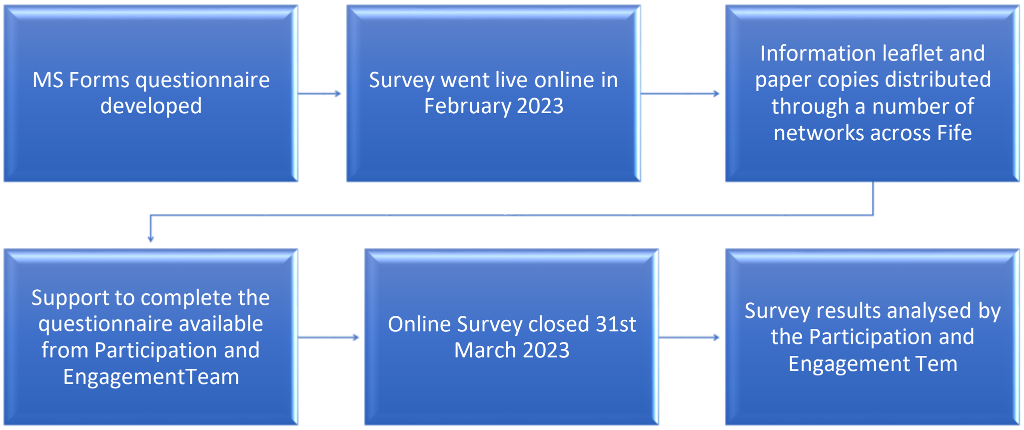
Patient and Carer Surveys were developed to capture the experiences of people living with long-term pain or caring for someone that does, and people across Fife were invited to share their experiences of managing pain and pain medicines by completing the survey.

The results of the survey will help to inform the current and future work in managing pain, prescribing pain medicines and improving the patient's experience.

The purpose of this report is to provide an overview of the results of the Patient Surveys and to inform the work of the programme which will help shape the Tests of Change and Projects for Year 2.

In Section 5 – Supported Self-Management – patients were asked to share their experiences of alternatives to pain medicines. This information forms part of the report but NHS Fife are not endorsing non-evidence based alternatives and cannot supply the range of methods used.

2.0 The Engagement Approach



The surveys were promoted online and via social media by NHS Fife, Fife Health and Social Care Partnership and Fife Carers Centre. Paper copies were available on request. Survey flyers with QR code to access surveys and paper copies with prepaid envelopes were also distributed by the Participation and Engagement Officer attending Pain Association Scotland Meetings, via all GP practices in Dunfermline,1 in South West Fife, 3 Community Pharmacies in the Dunfermline and Cowdenbeath cluster area and to patients attending Fife Pain management Service.

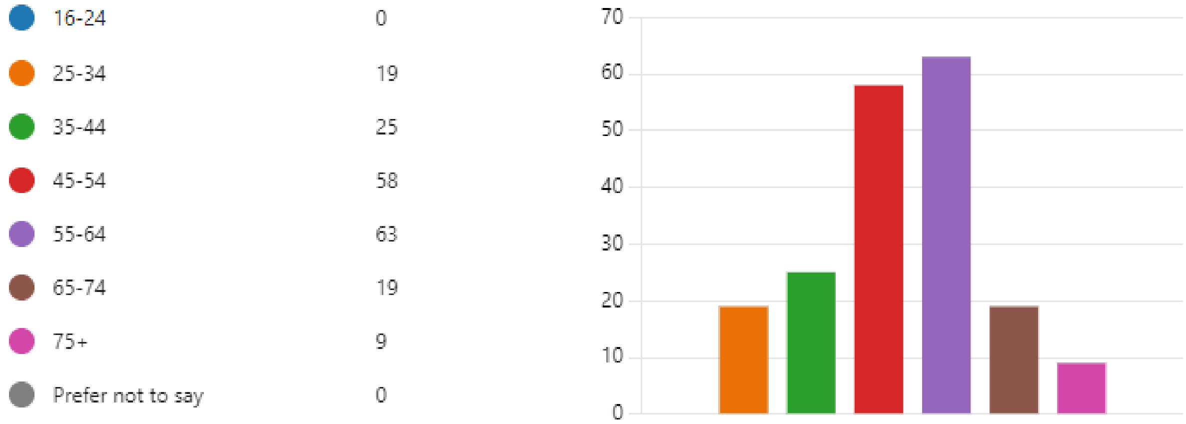
Fife Health and Social Care Partnership Participation & Engagement team have analysed the completed surveys and the findings are as follows:

3.0 Background Information

3.1 A total of 193 people completed the Patient survey for those with lived experience of chronic pain

Age

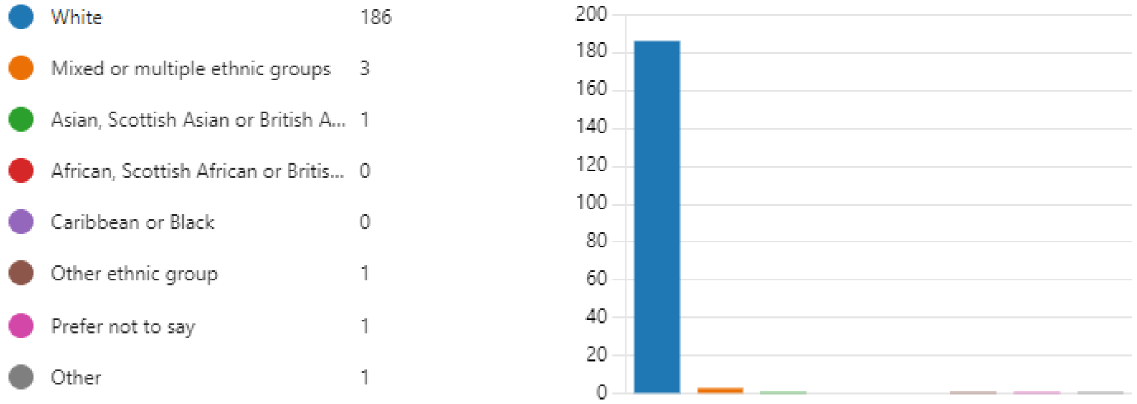
3.2 The majority of responses from the Patient Survey were from those in the 45-54 and 55-64 age groups – full information contained in the graph below:



● 16-24	0
● 25-34	19
● 35-44	25
● 45-54	58
● 55-64	63
● 65-74	19
● 75+	9
● Prefer not to say	0

Ethnic Background

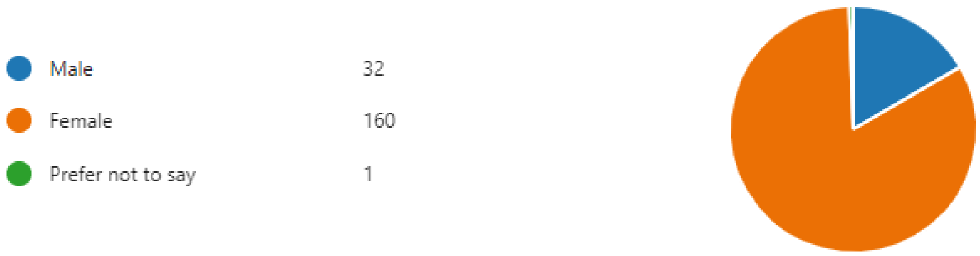
3.3 A total of 186 people who completed the Patient Survey were white – full information below:



● White	186
● Mixed or multiple ethnic groups	3
● Asian, Scottish Asian or British A...	1
● African, Scottish African or Britis...	0
● Caribbean or Black	0
● Other ethnic group	1
● Prefer not to say	1
● Other	1

Sex

3.4 160 people who completed the Patient Survey were Female and 32 were Male

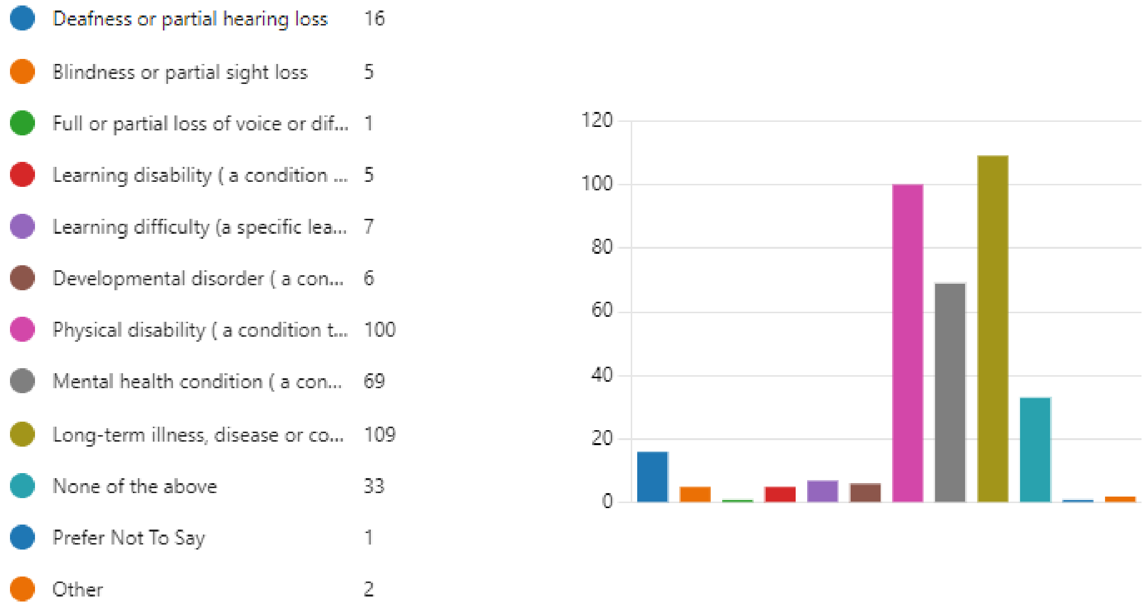


Trans History

3.5 191 people who completed the Patient Survey responded that they did not consider themselves to be trans or have a trans history. 1 person preferred not to say.

Other health conditions

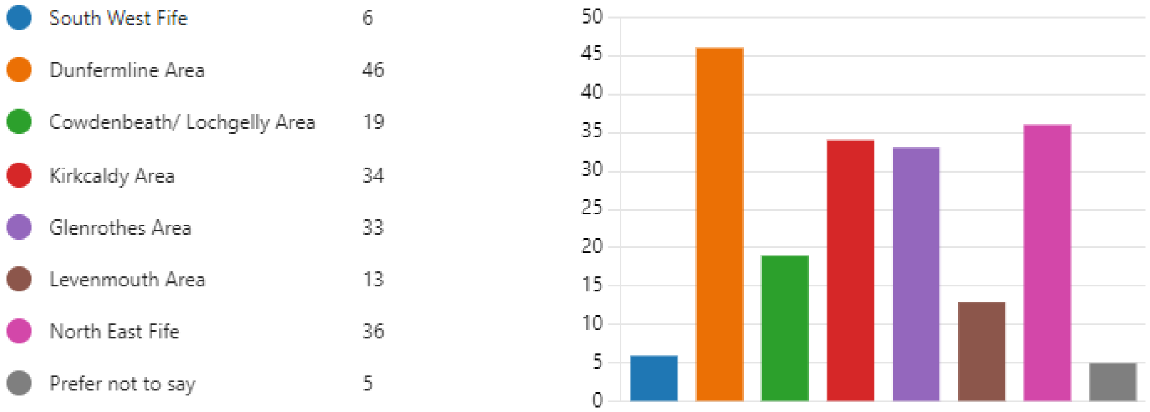
3.6 People were asked about their other health conditions and had the option to choose all that applied to them. 109 people indicated that they had a Long-term illness, disease, or condition, 100 people had a physical disability and 69 people had a mental health condition. Full details provided below:



Which part of Fife did respondents live in

3.7 The highest number of responses came from people who lived in Dunfermline with 46 responses and North East Fife with 36. The lowest number was from South West Fife with 6 responses.

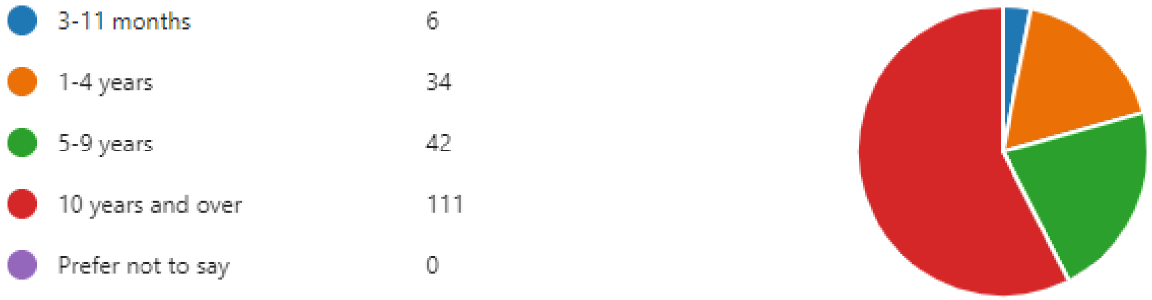
137 patients who responded provided postcodes.



4.0 Experience

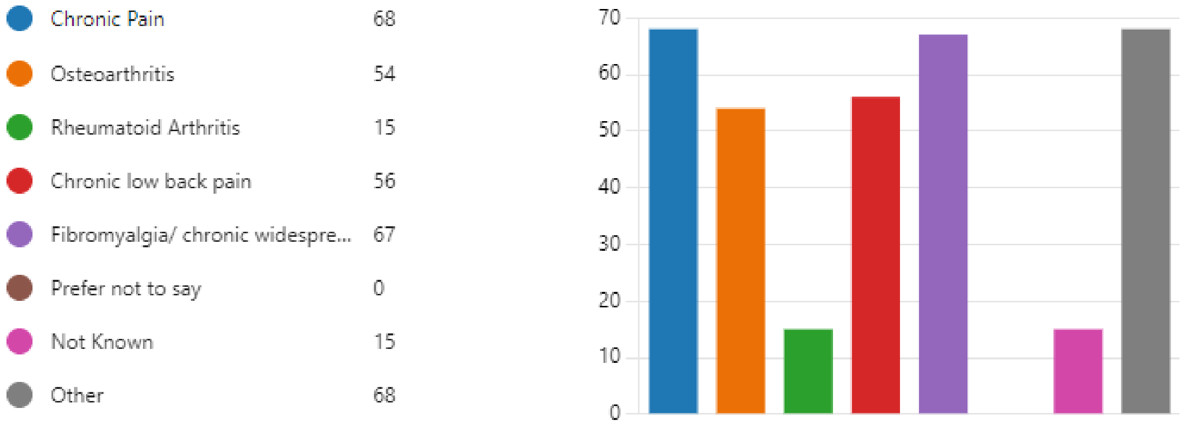
How long were people managing pain

4.1 Over half of the people who responded had been managing pain for more than 10 years with 42 people managing pain for 5-9 years. 6 people had been managing pain for 3-11 months.



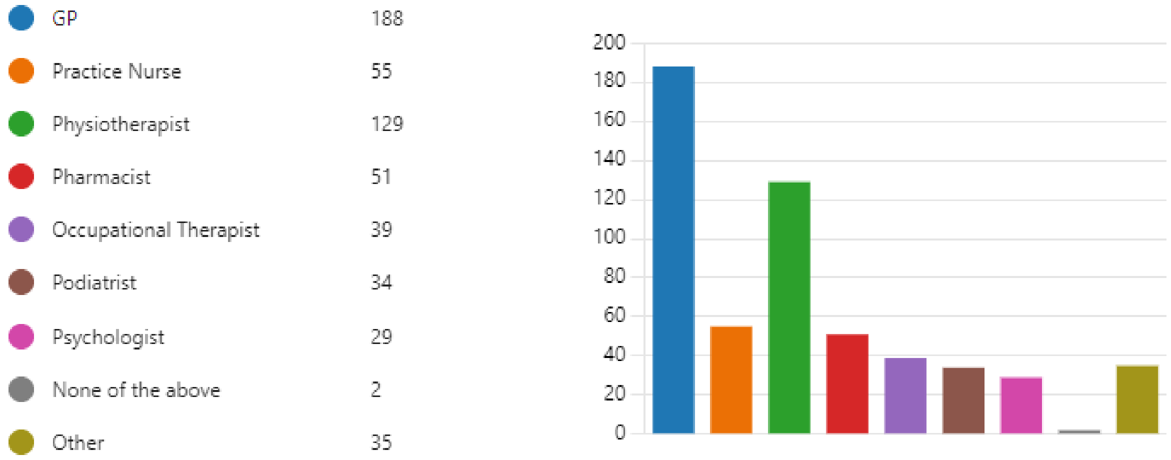
Diagnosis

4.2 68 people who responded had been diagnosed with Chronic Pain and 67 had Fibromyalgia with 68 people having a condition that was not listed. The conditions in the other section were wide ranging and included; trigeminal neuralgia, ankylosing spondylitis, endometriosis, migraine, neuropathy, hypermobility, Ehlers Danos Syndrome, raynauds disease, irritable bowel syndrome, ulcerative colitis, lupus and hip dysplasia.



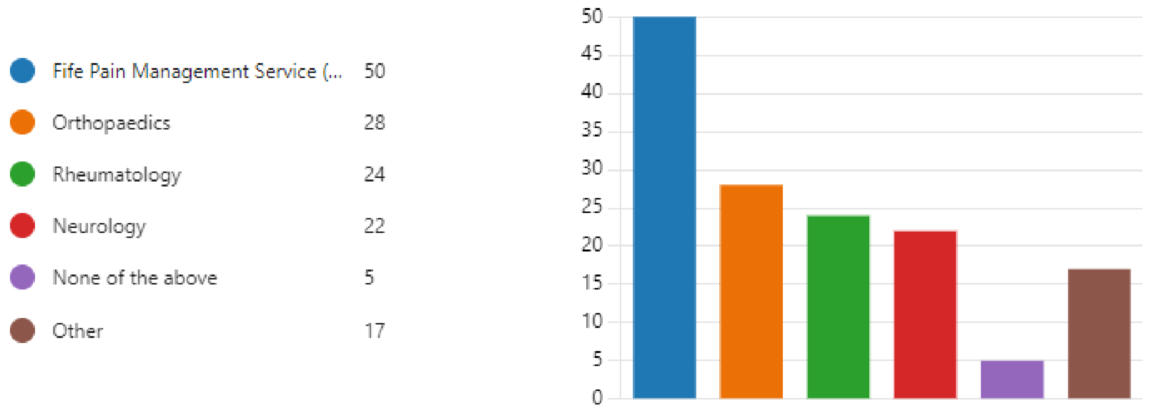
Which healthcare professionals had people seen

4.3 Nearly all the people who responded had been seen by their GP and over 60% had also seen a physiotherapist. 35 people had seen professionals who were not on the list including gynaecologist, chiropractor, dermatologist, rheumatologist and other specialist consultants. Full details below:



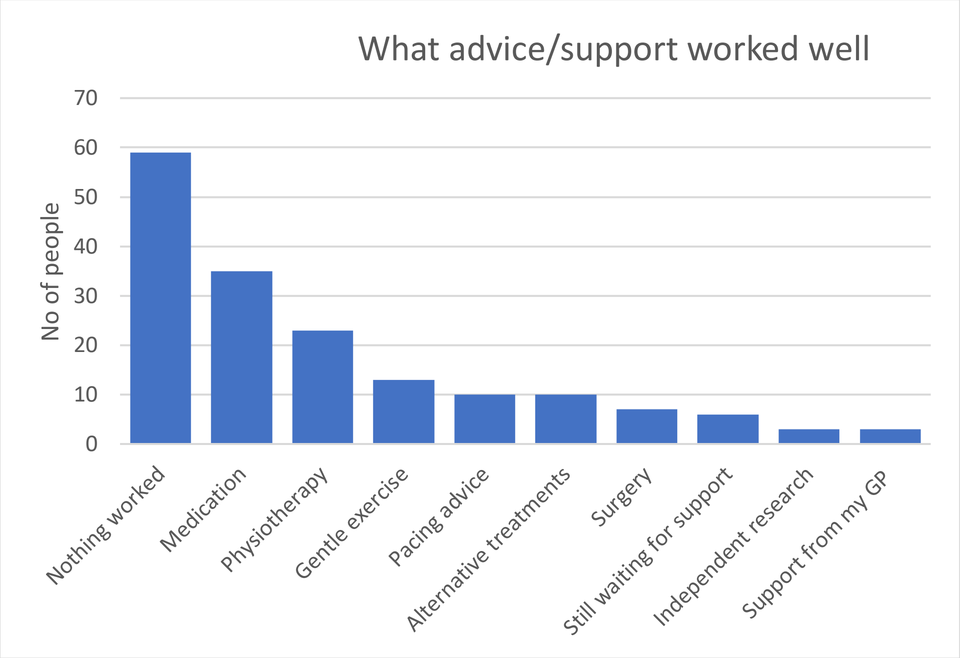
Referrals to Specialist Services in the hospital

4.4 More than half of the people had been referred to specialist services with the remainder who had not. 17 people had been referred to services which were not on the list including, gynaecology, urology, endocrinology and pain clinics in other areas. Further information on which services they had been referred to is included in the table below:



Which advice or support from healthcare professionals worked well

4.5 – Over a quarter of the people who completed survey said that nothing had worked well for them. 17% said that medication was helpful.



Comments included:

"None really, tried various medications with little success"

"Absolutely not had any support or advice. When fibromyalgia mentioned, can hear their eyes rolling across the room"

"Taking regular analgesia has some effect. Not had much in the way of advice apart from that"

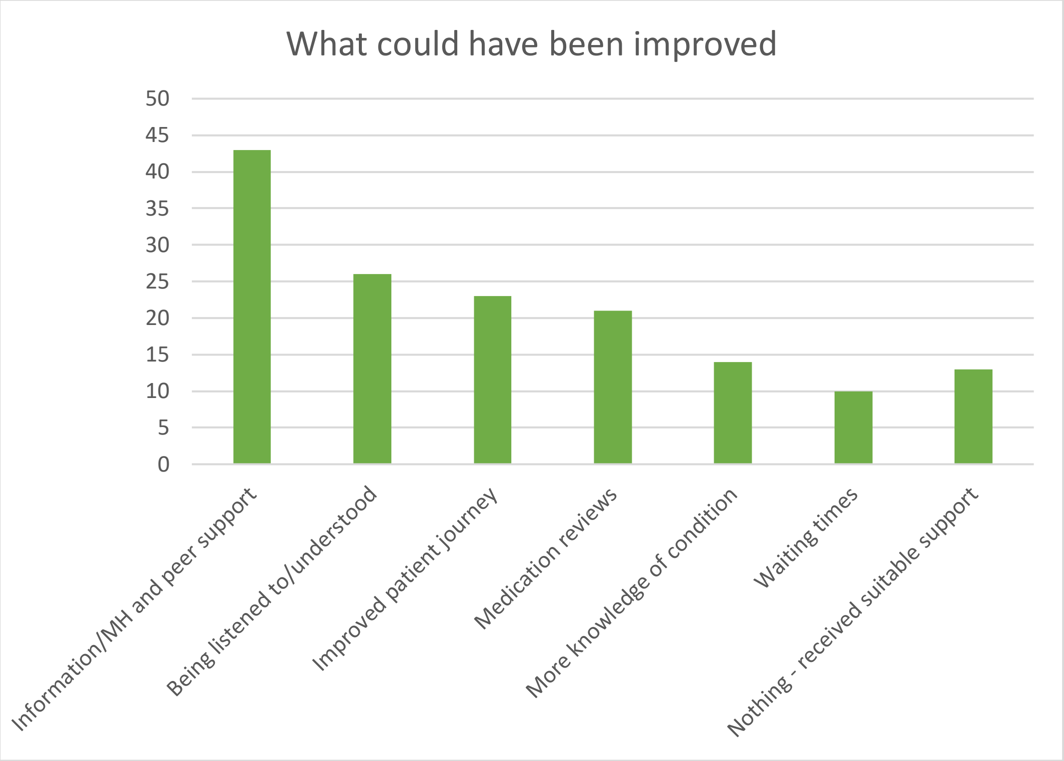
"Rituximab recently but many other drugs have been successful for some time but then ceased to work, e.g. Cimzia, Etanercept, Methotrexate, Sulphasalizine plus painkillers such as Co-Codamol. In addition steroid injections to help manage flares".

"General advice from pain management and other NHS physios.

"Hands-on treatments from physios in the past improved my functioning a lot, but the NHS seems unwilling or unable to provide that now- I now have to pay to access this from a private physio, along with massage therapy which is also very helpful."

What could have been improved about the advice or support from healthcare professionals

4.6 Almost a quarter of people felt that having additional information, particularly around peer support and mental health support would have helped. Over 12% did not feel that they had been listened to and understood.



"Don't put everything down to being overweight. It isn't always the reason. I lost weight and pain is exactly the same"

"A better understanding of fibromyalgia from all healthcare professionals and be empathetic towards the person. Also not to belittle the persons pain"

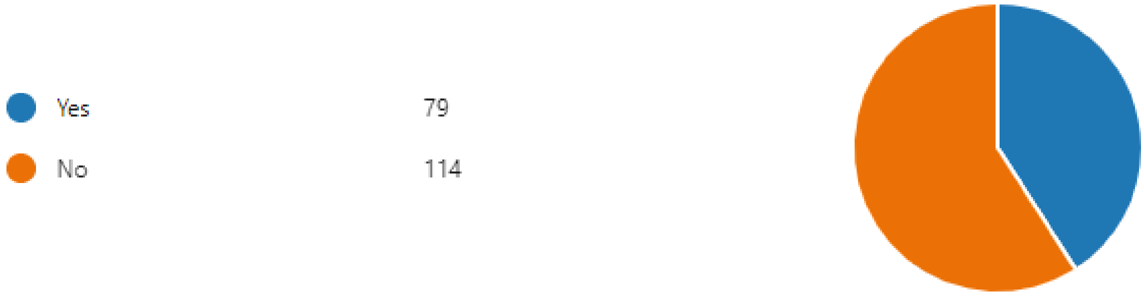
"Not everyone has the same symptoms or deals with it the same way"

"No follow up after medication prescribed. Simply on repeat prescription for months/years"

"I struggle with Fibromyalgia pain on an ongoing basis, experiencing frequent flare-ups and varying degrees of pain and life being quite impacted by the symptoms. I manage the condition with painkillers and trying alternative therapies on an ongoing basis. I've never been referred to Rheumatology or the Pain Management Service. I've had one physical examination prior to diagnosis and have had telephone consultations following on from this over the years. I feel advice and support is quite limited"

Paying privately for support to manage pain

4.7 79 people who completed the Patient Survey had paid privately for support to manage pain with 114 people answering that they had not paid for private support.



What services had been paid for privately to help pain

4.8 Approximately 16% of people paid privately for physiotherapy treatment with 10% paying for massages. Other privately purchased services included acupuncture, chiropractor and podiatry with single numbers of people paying for a range of other services including private scans, appointments with consultants and alternative therapies.

What makes pain worse

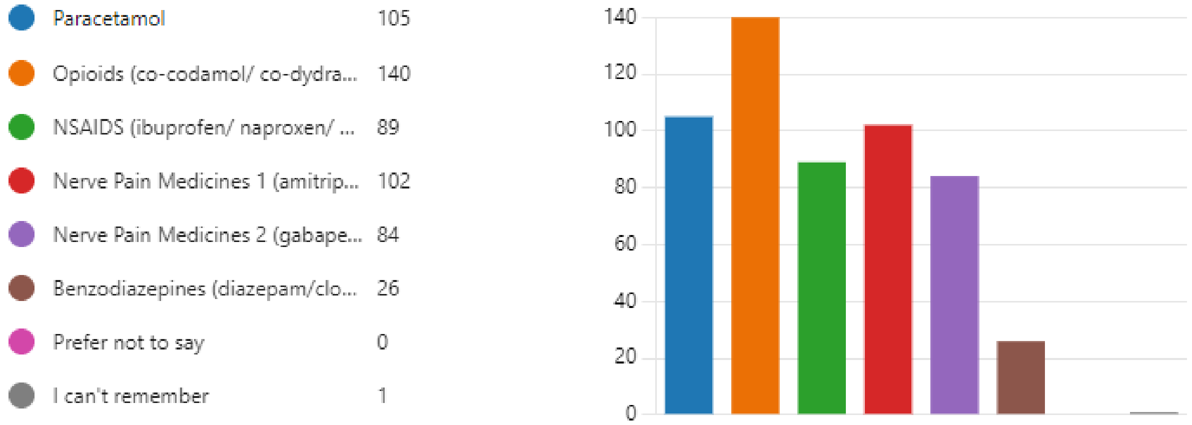
4.9 A quarter of people said that their pain was made worse by exercise with approximately 15% saying that stress, over exertion and cold weather made it worse. Other things that made it worse included remaining still for too long, lack of sleep, fatigue and lack of medication.

What helps pain

4.10 More than half of people said that their pain was helped by pain medicines with around a quarter of people feeling that heat and rest helped pain. 10% felt that exercise helped with lower numbers mentioning tens machine, moving around, sleep and CBD oil. 16 people responded that nothing helped their pain.

Prescribed Medications

4.11 178 people had been prescribed medicines to help with their pain with 15 people not having medicine prescribed.



Medication Reviews

4.12 43% of people had not had their medicines reviewed by a healthcare professional within the last 2 years with 23% reporting that a review had happened within the last 3 months. 44% of respondents who answered this question reported having had their medicines reviewed in the last 12 months.

Purchasing medicines, vitamins and supplements to help with pain

4.13 Over a third of people purchased a range of vitamins with approximately 10% buying over the counter medicines including paracetamol, ibuprofen and aspirin. People also bought CBD oil and gels/rubs with one person purchasing cannabis.

Borrowing pain medicines from family or friends

4.14 34 people had borrowed medicines with 144 people answering that they had not.

What has gone well with experience of pain medicines

4.15 – Approximately 20% of people said that nothing had gone well with their experience of pain medicines with 15% mentioning specific medications that had helped to ease pain. 10% of people said that their medicine eased the pain with lower numbers stating that it helped them for short periods and enabled them function or to sleep.

"The doctors seem content to prescribe so I am not in pain. They are accessible and can be ordered easily through the pharmacy. I appreciate prescriptions being free as it would be expensive to manage my pain otherwise".

"Over time I've been able to get just about the right level of pain medicines to help: I currently take paracetamol, dihydrocodeine. I can't take naproxen or diclofenac as it results in mouth ulcers. I take a triptan medication for migraines

They mostly take the edge off my pain and help me carry out every day tasks"

What has not gone well with experience of pain medicines

4.16 – A quarter of people mentioned the side effects of pain medicines and approximately 15% said that their medication did not work. 5% said that it only helped for a little while and single numbers of people mentioned that they had experienced a lack of follow up, support and that they had not felt listened to. 3 people were concerned about addiction.

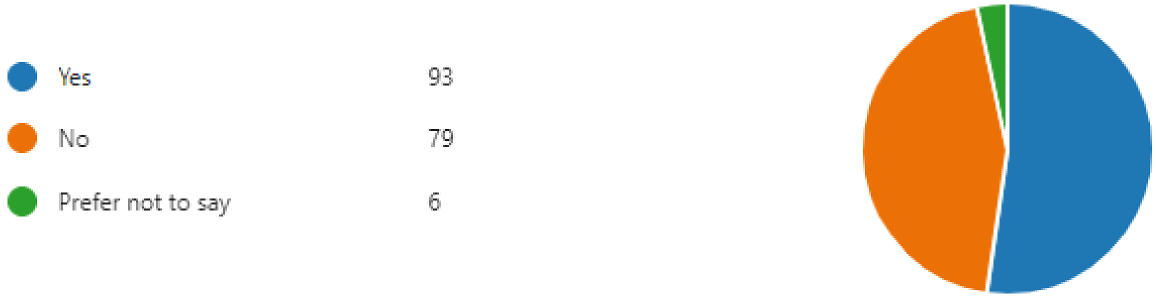
"Built up tolerance to pain medicines and they have little to no effect"

"Differing advice, not following up referral and not having regular review"

"Limited effectiveness for the type of pain I have, inability to maintain daily function when needing to take high dose opiates"

Information about pain medicines

4.17 93 people felt that they had been given enough information about pain medicines with 79 indicating that they had not. 6 people preferred not to say.



What could have been improved about the information given when medicines were prescribed

4.18 Around 20% of people felt that they would have liked more information on side effects with 12% feeling that better communication would have helped. Single numbers mentioned that they felt advice on using medication, more frequent reviews of medication and alternatives to medicines would have been helpful.

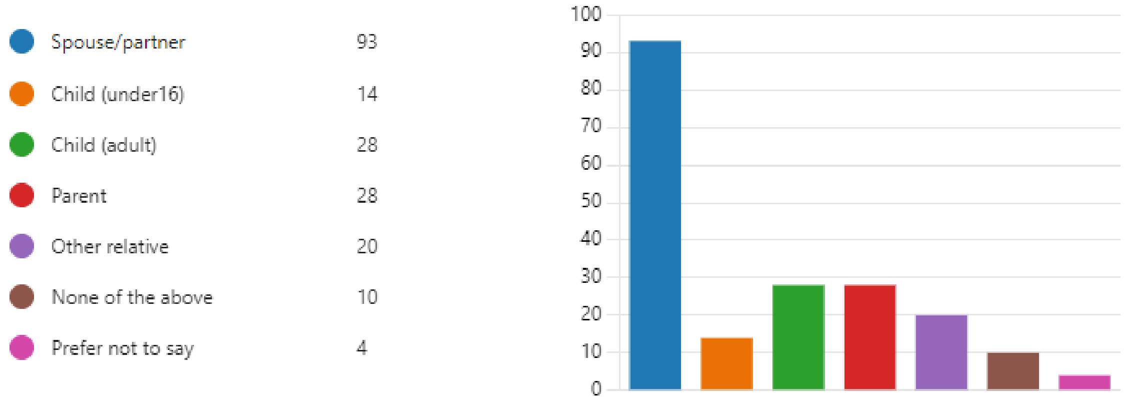
“brief explanation of what they were designed to achieve to know if they were actually doing that - the blurb that comes in packs can be overwhelming with so much info that by the time you've read it all, you've forgotten what it said at the start”

“More explanation on what the side effects are and what to expect”

“The dangers of long-term use should have been made known to me, and medical reviews have been few and far between (sometimes lapsing for years)”

Support from others with day-to-day tasks

4.19 More than half of the people relied on others to support with day-to-day tasks and almost a third of people did not. Most of the people who relied on support received this from a partner with others relying on parents and adult children. 14 people who responded were supported by a child under the age of 16.



5.0 Supported Self-Management

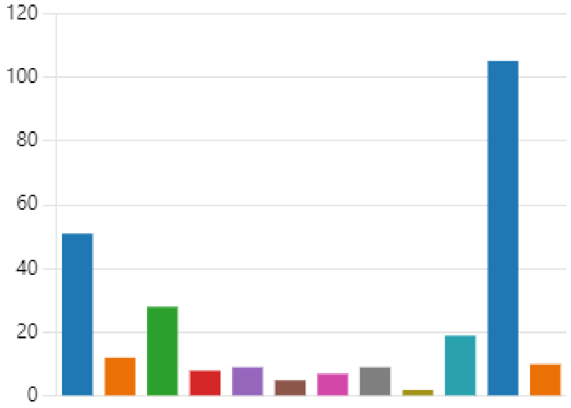
What do you understand about the term supported self-management

5.1 Over a third of people understood the term to be things that they could do for themselves while being supported by health professionals and another third did not know what the term meant. 10% understood it to mean that they had to fix themselves.

Which healthcare professionals spoke about supported self-management

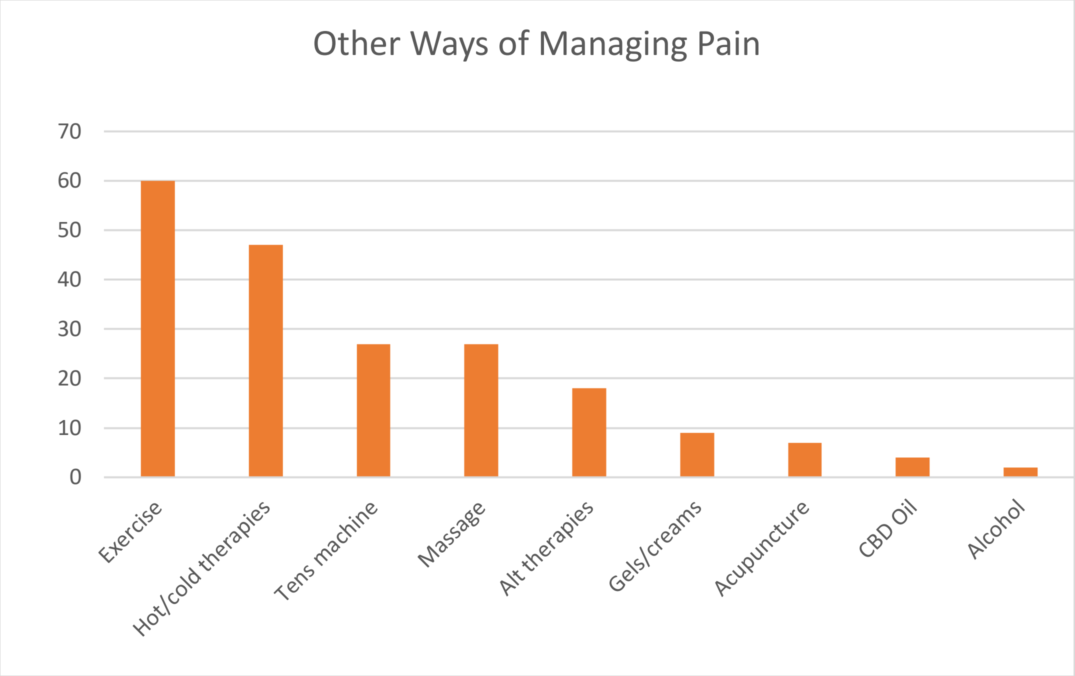
5.2 More than half of people who responded had not been spoken to by any of the professionals listed in relation to supported self-management. A quarter of people had been spoken to by their GP and others had discussed with a physiotherapist. Further details in the table below.

●	GP	51
●	Practice Nurse	12
●	Physiotherapist	28
●	Pharmacist	8
●	Occupational Therapist	9
●	Podiatrist	5
●	Psychologist	7
●	Specialist Service Consultant	9
●	Occupational Health	2
●	No one, I found out myself	19
●	None of the above	105
●	Other	10



Have you ever used any other ways to manage pain aside from pain medicines?

5.3 75% of the people who responded had used other ways to manage pain as outlined in the table below.

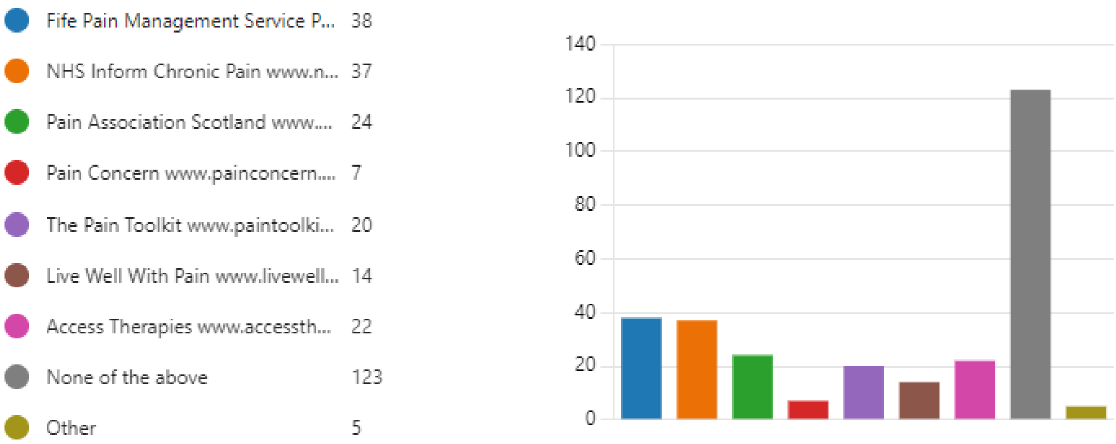


How did they help to manage pain

5.4 A quarter of people said that using other ways to manage their pain gave them some short term/limited relief. Around 10% felt that they didn't help at all, 7% felt that they reduced pain levels with another 7% saying that they distracted them from the pain. Single numbers of people mentioned that they improved mobility, reduced stiffness and helped with their mental health.

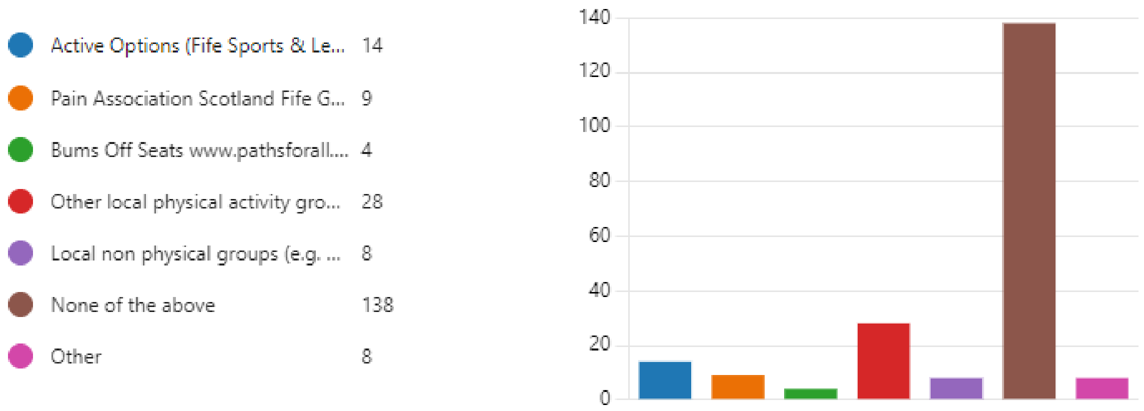
Website resources used to help manage pain

5.5 More than half of the people who responded had not used any of the listed website resources to help manage pain. Approximately 20% of people had used Fife Pain Management Service Pain Jigsaw. Full details in the table below



Other groups or services to help manage pain

5.6 Almost 60% of people had not used any of the listed services or groups. Approximately 15% of people had used local physical activity groups with others attending Active Options (Fife Sports and Leisure Trust).



Other comments about supported self-management

5.7 Comments:

“Despite having suffered with back pain for many years, the suggestion of attending a pain management clinic has only just been offered by my GP. I am currently awaiting a physio review and after that I will be referred to attend the pain management clinic. Given that acupuncture and manipulation have been helpful in managing my pain it would be fantastic if these could be offered through the NHS. Other boards in Scotland also offer free classes at local sports centres if a clinical benefit is identified and I think I could benefit from this by attending something like aqua aerobics (but I don't think Fife so this)”.

“Would be a good idea to give patients some information on self- management on diagnoses”.

“When you have a physical disability and physical activity worsens your pain being told repeatedly physical activity will help you get over it is not helpful. When you have a neurodivergent brain mindfulness isn’t always an option and when you suffer with personality disorders this again is an issue. Too many of these websites are aimed at people with the sole focus of pain but there are many comorbidities alongside pain that is not taken into account here”

“Pain clinic team are stand out 11/10 and have a real positive impact on quality of life. Everything is so connected and well ran through them it’s a pleasure to be supported by them”

6.0 Overall Experience

One thing that could have been done differently

6.1 Key themes with 17% of people highlighting that they wanted to be listened to with 10% feeling that better understanding of their pain condition would have helped. 10% of people would have liked more information and support to manage their condition and 6% mentioning having more effective medication. Small numbers of people felt that an earlier diagnosis and face to face appointments would have made a difference.

"Being listened to, understanding and taken seriously"

"A mandatory review with nurse/GP An overview of ladder of painkillers covering all options available"

"Health professionals need to listen to patients and not play Russian roulette with people's health and lives"

"Finding someone who believes the amount of pain I'm in and finding something that works"

"Better understanding of psychology/mental health from NHS staff in general- not just those in pain management"

What matters most about managing a long-term pain condition

6.2 A quarter of people stated that the most important thing was being able to function daily with 15% wanting to feel there was more understanding of their condition. 15% of people felt that having effective pain relief was the most important thing and 13% felt that quality of life mattered most. Single numbers of people wanted to feel that they had been believed and others wanted some pain free, comfortable spells.

"To allow me to continue to be as active as possible to help support my disabled wife and daughter"

"Getting the correct medications and advice from professionals"

"Access to the exact information to help yourself or supplement medication with exercise/movement and where to source it. I hated taking medication but it did help initially"

"Mental health support because you feel so guilty and a burden to your family. Being listened too, you know your body and what it's telling you"

"Understanding! Too much bias out there and thinking it's all in your head. Fibromyalgia is awful ! But I've learnt to manage it"

Comments, thoughts, and ideas

6.3 Comments:

"**To check up yearly on pain management and regular reviews of pain medication"**

"Maybe not make the person feel so alone when having this condition and actually help instead of saying well we have tried everything theres nothing life to try just take you opoids which make me like a zombie so again thats no way to life. Doctors are so easy to give up on people with long term pain conditions and also dont believe them when they say how much pain they are in. Doctors and other health professionals need update literature and have a degree of understanding of what its like to live day to day with this".

"I believe mentorship would help (positivity from historic sufferers)"

"I think it would be beneficial that when patients are in pain for over a set period of time, they should referred for pain management review. Every specialty or GP should be supporting patients to access the best possible advice and care"

"There has been no offer of (and, no, I haven't asked for) mental health support, despite my crying/upset in front of 3 different GPs. One of whom prescribed me codeine at one visit and Tramadol at another. Had I not been as strong a character as it seems I am, it's a worries me what I could potentially have done with all this dangerous meds !!! (And, yes, I tried to use them as pain relief but they made me feel worse in different ways..)"

"Further training for health care staff regarding fibromyalgia. Some still don't even believe it exists and this is very upsetting for patients"

"I want to feel seen, understood and believed when I talk about my pain.
Pain is one of the biggest barriers in my life, when I feel like I have to justify its existence to doctors I feel like I am not seen or understood".

It would be helpful if there was more information available about the pain management clinics.
Perhaps self-referral would be good as it seems to work well with podiatry

Sharing Stories

6.4 59 people indicated that they would like to share their stories

Lived Experience Group

6.5 62 people indicated that they would be interested in being part of a Lived Experience Group.

7.0 Additional Comments

The Pain Medicines Patient Safety Programme is aiming to increase understanding across patients and healthcare professionals who support them and improve the way pain is managed in our hospitals, GP Practices and in the wider community. The surveys were distributed to enable people living with long term pain conditions in Fife to share their experiences and help us understand what works for them and improve pain management.

8.0 Conclusion and Discussion Points

The response to the surveys highlighted that the pain population of Fife were keen to engage with the Pain Medicines Patient Safety Programme People and share their experiences. People responded from across Fife and we have gathered a lot of quality data which will inform the work of the Programme as it moves into Year 2 and Year 3.

The key themes that emerged are that most people living with long term pain have been managing pain for more than 10 years. Chronic Pain and Fibromyalgia were the most common conditions and nearly half of the people had not had a review of their medicines for over 2 years.

Most people who responded had been referred to specialist services with many of those referred to Fife Pain Management Service (FPMS).

Almost all of the people who responded had been prescribed pain medicine and over half of them felt that they had been given enough information about their medicines. Those who had not had enough information would have liked more frequent reviews, better communication and more information about side effects. To ensure safe and effective use of pain medicines guidance is that medicines should be reviewed regularly (at least annually). Despite current challenging times within the NHS post pandemic, 44 % had received review. Reviewing medication is not the sole responsibility of the GP, this can be carried out by other health professionals. In some instances, reviews may have happened but may not have been well enough communicated using the teach-back technique at the end of a consultation.

Two thirds of people living with long term pain conditions rely on support from family members with day-to-day tasks.

More than half of the people understood the term Supported Self-Management but the remainder did not understand this approach and had not been spoken to by any professionals. Many who did not know said that they would have liked more information about this. Many people had, however, tried alternative ways to manage pain.

Many people wanted to feel that they were being listened to and their pain condition was understood by health professionals. Being able to function and have a good quality of life was what mattered most.

9.0 Survey Limitations

The dissemination routes may have impacted on the geographic spread of patient responses with the greatest number of respondents being in the Dunfermline area where there was distribution and advertising via all GP practices. Reassuringly there is a wide spread of responses across Fife.

Again, distribution via Fife Pain Management Service (FPMS) may impact on answers to some questions compared to if distribution had only been via the general populace. FPMS is a specialist service with an ethos of supported self-management with support offered via a multidisciplinary team rehabilitative approach focusing on function and quality of life strategies whilst ensuring safe and effective use of medicines. Time has not allowed us to compare and contrast results from those that have attended FPMS and those that have not.

The survey ran for 6 weeks, a longer duration may have allowed more people who may have been unable to access the digital version to request hard copies before the closing date.

10.0 Next Steps

The information gathered from the Patient and Carer Surveys and the Patient and Carer Stories will inform the work going into Year 2 of the Programme. Currently opportunities around forming a Lived Experience Group and Peer Support are being explored.