Pain Medicines Patient Safety Programme Carer Survey Feedback

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1.0 Introduction

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

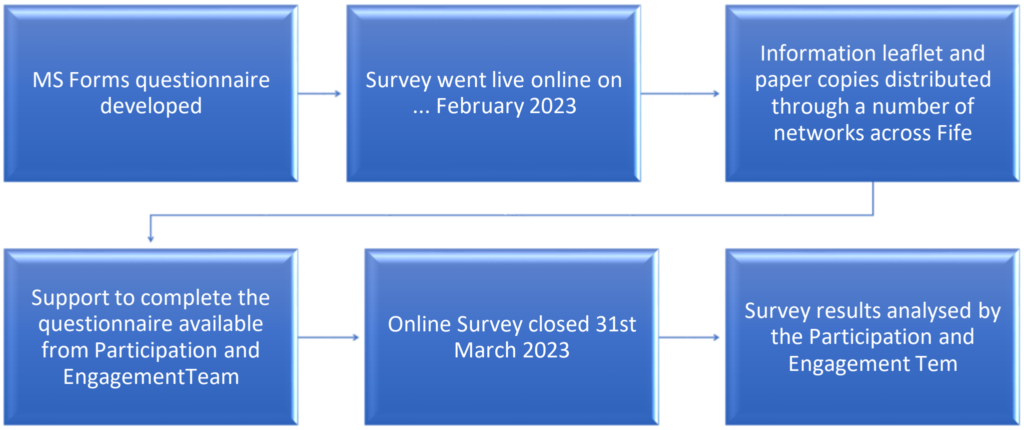
The aim of the programme is to work with health professionals, patients, carers and the wider community to increase our understanding of the impact of pain in day-to-day life and improve the way patient pain is managed in our hospitals, GP Practices and in the wider community.

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 Carer Surveys and to inform the work of the programme which will help shape the Tests of Change and Projects for Year 2

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.

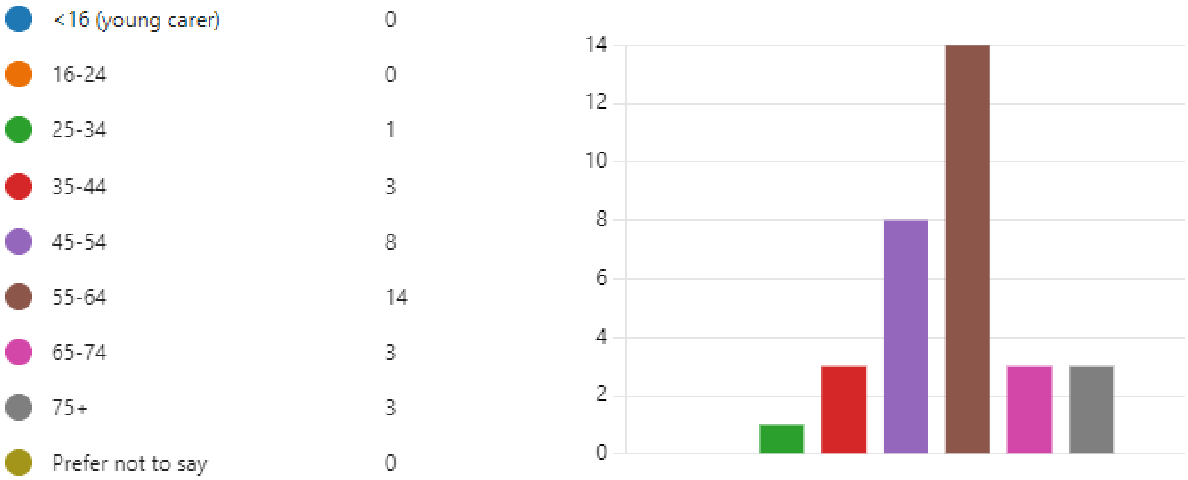
Fife Health and Social Care Partnership Team have analysed the completed surveys and the findings are as follows:

3.0 Background Information

3.1 A total of 32 people completed the Carer survey for those who are carers/relatives of people living with chronic pain.

Age

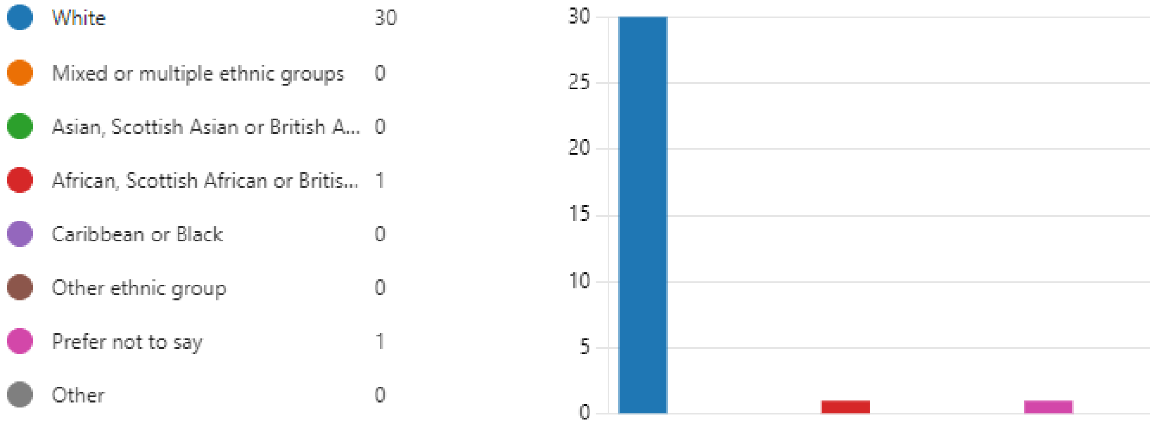
3.2 The majority of responses from the Carer Survey were from the 45-54 and 55-64 age groups:



<16 (young carer)	0
16-24	0
25-34	1
35-44	3
45-54	8
55-64	14
65-74	3
75+	3
Prefer not to say	0

Ethnic Background

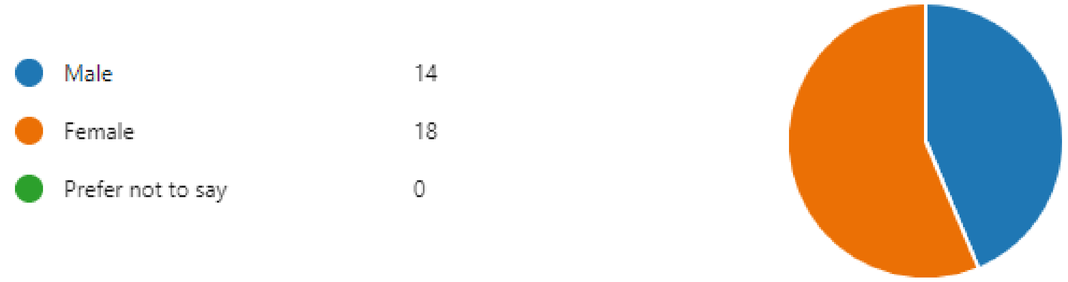
3.3 30 people who completed the Carers Survey were White, 1 person was African, Scottish African or British African and 1 preferred not to say



White	30
Mixed or multiple ethnic groups	0
Asian, Scottish Asian or British A...	0
African, Scottish African or Britis...	1
Caribbean or Black	0
Other ethnic group	0
Prefer not to say	1
Other	0

Sex

3.4 18 people who completed the Carers Survey were Female and 14 were Male.



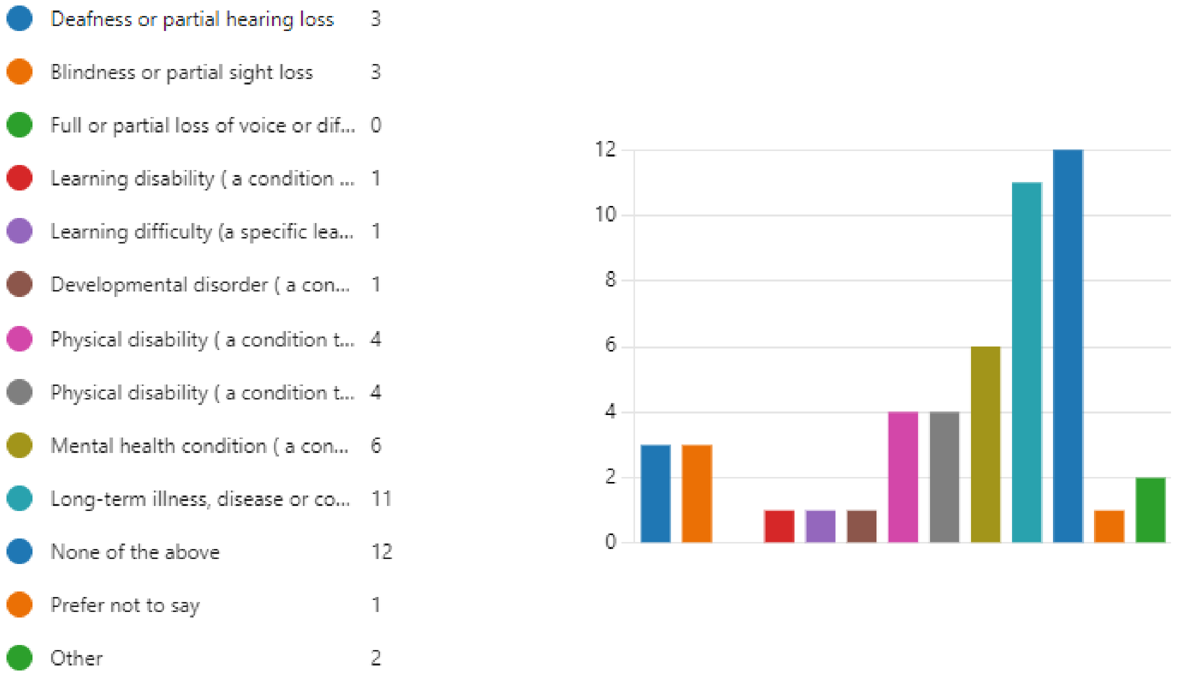
●	Male	14
●	Female	18
●	Prefer not to say	0

Trans History

3.5 None of the people who completed the Carers Survey considered themselves to be trans or to have a trans history.

Carers living with their own health conditions

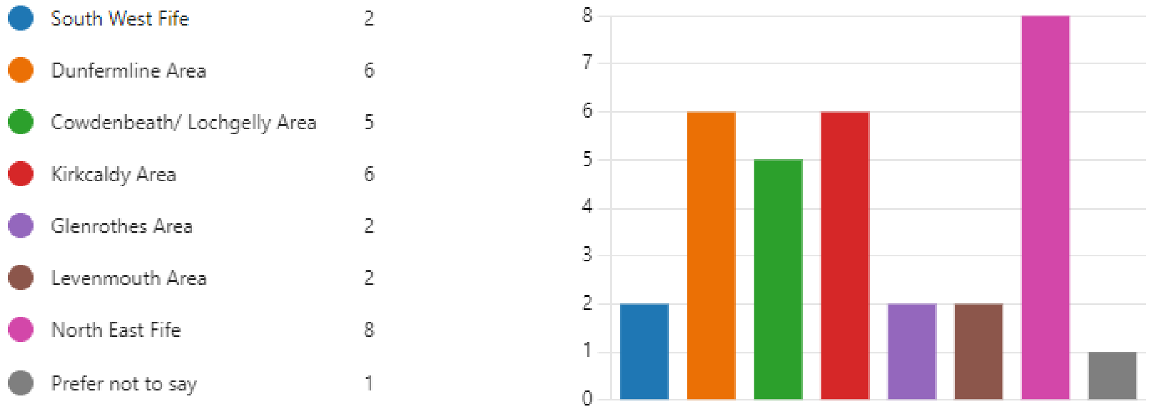
3.6 Carers were asked about their health conditions with 11 people indicating they themselves had a long-term illness and 6 people had a mental health condition.



●	Deafness or partial hearing loss	3
●	Blindness or partial sight loss	3
●	Full or partial loss of voice or dif...	0
●	Learning disability (a condition ...	1
●	Learning difficulty (a specific lea...	1
●	Developmental disorder (a con...	1
●	Physical disability (a condition t...	4
●	Physical disability (a condition t...	4
●	Mental health condition (a con...	6
●	Long-term illness, disease or co...	11
●	None of the above	12
●	Prefer not to say	1
●	Other	2

Which part of Fife did respondents live in

3.7 Responses were received from across Fife with the highest number from North East Fife.



22 Carer responses provided postcodes.

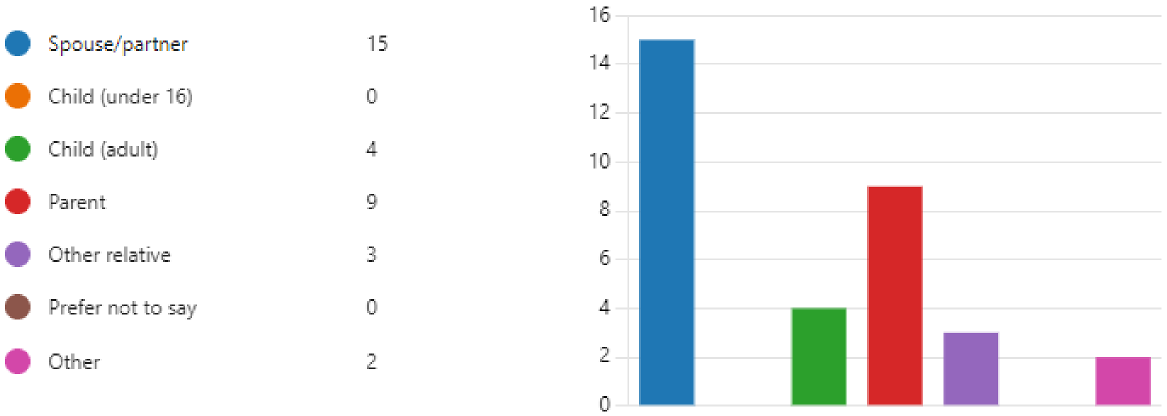
4.0 Experience

How long had the carer been supporting someone to manage pain

4.1 12 Carers had been supporting someone to manage their pain for more than 10 years

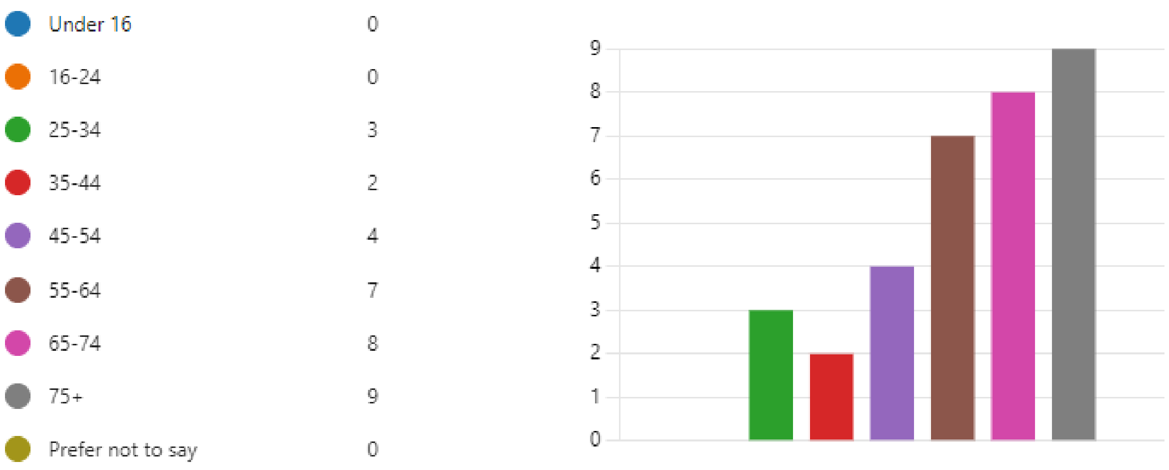
Nature of relationship to the person living with pain

4.2 More than half of the people who responded were caring for a spouse or partner with 9 people caring for an adult child



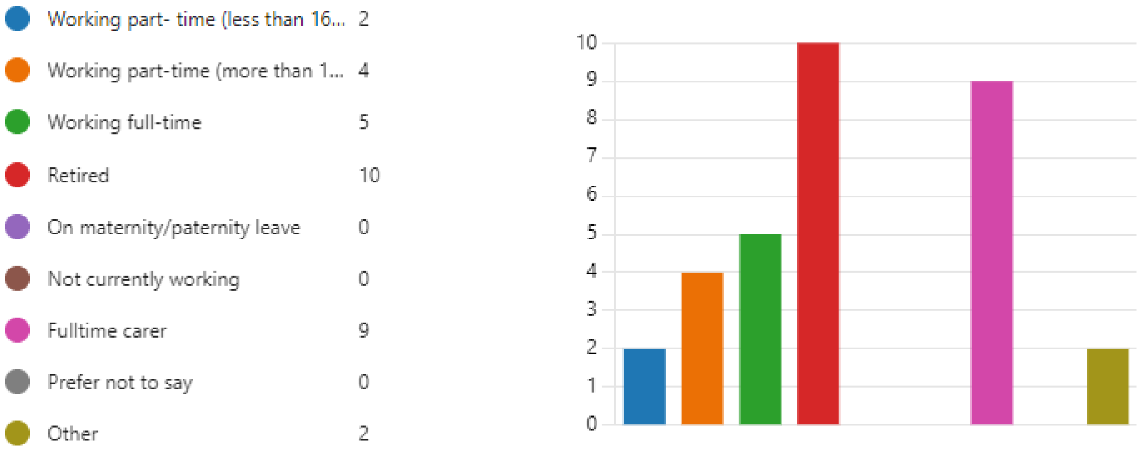
Age of the person being cared for

4.3 More than half of the people being cared for were over the age of 65



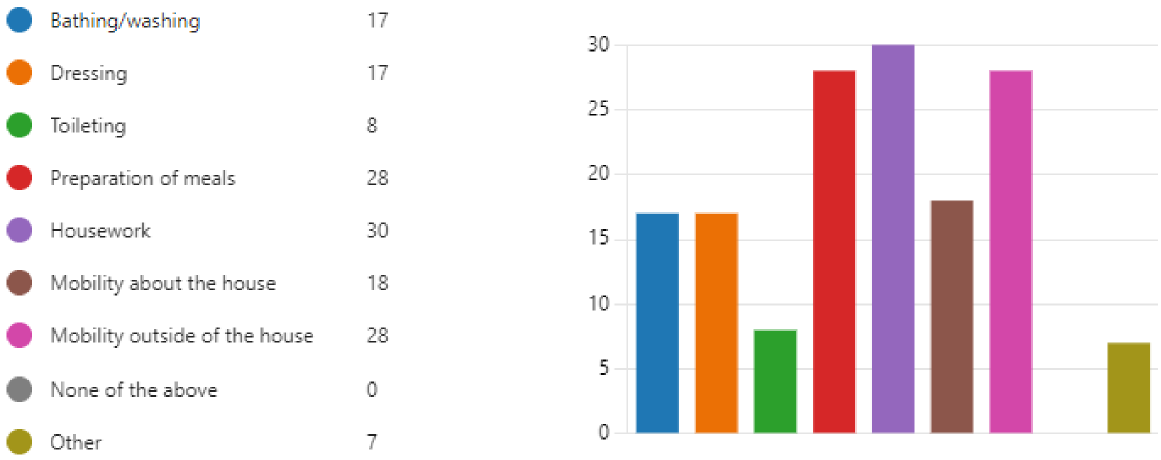
Employment Status of the Carer

4.4 10 people were retired with 9 people answering that they are full time Carers.



Activities of daily living requiring support

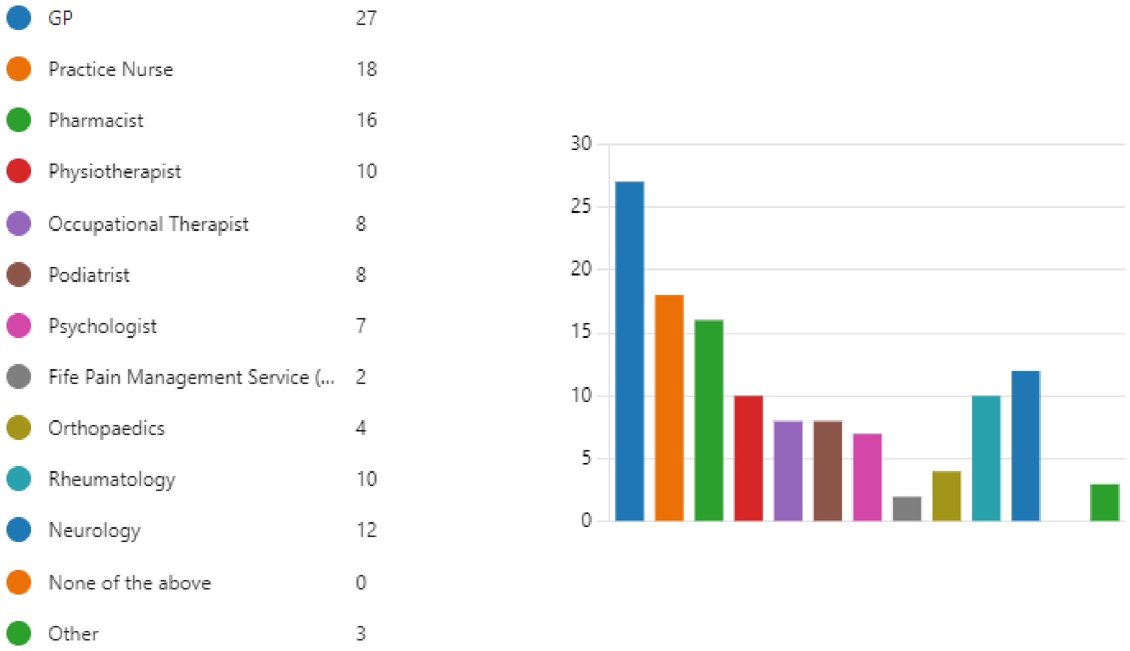
4.5 People reported a range of activities that required daily support. Almost all were supporting with domestic activities and more than half were assisting with mobility and personal care. Other support included emotional support and shopping.



Bathing/washing	17
Dressing	17
Toileting	8
Preparation of meals	28
Housework	30
Mobility about the house	18
Mobility outside of the house	28
None of the above	0
Other	7

Support with attending healthcare appointments

4.6 26 people attend all healthcare appointments with the person they care for, 4 attend some appointments and 2 people do not attend appointments. The range of appointments attended is outlined below.



GP	27
Practice Nurse	18
Pharmacist	16
Physiotherapist	10
Occupational Therapist	8
Podiatrist	8
Psychologist	7
Fife Pain Management Service (...	2
Orthopaedics	4
Rheumatology	10
Neurology	12
None of the above	0
Other	3

What does the cared for person find most challenging about managing pain from the Carer's perspective

4.7 7 people reported that the person they cared for found living with unmanaged levels of pain the most challenging thing. 5 people answered limited mobility and 5 mentioned that a lack of support and understanding was challenging. Full details below:

Comments included:

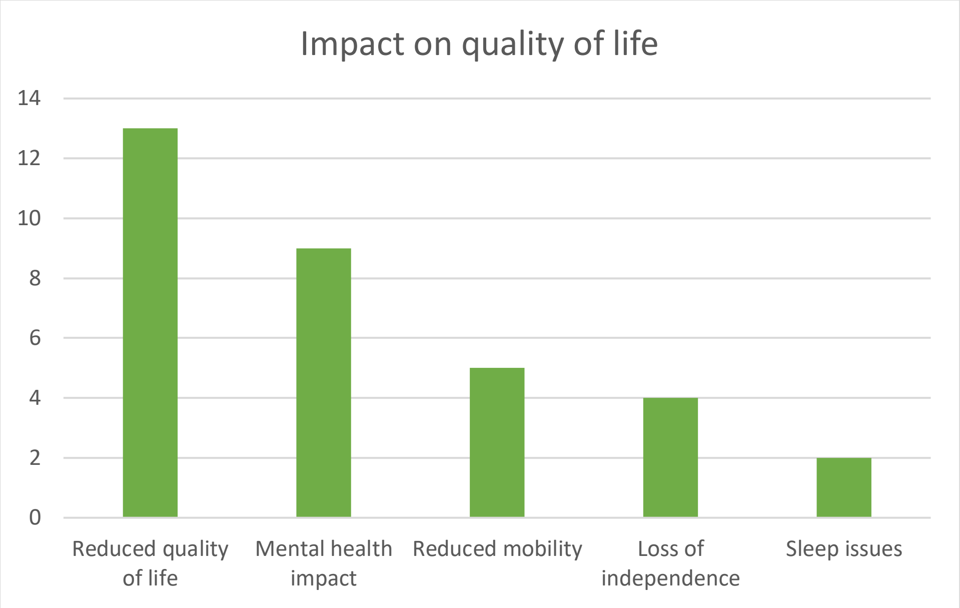
"On maximum dosage of pain relief but doesn't always keep pain under control. His condition makes mobility painful so he tries to move less even though that isn't good for him either. Wouldn't consider more powerful pain relief because he would be more 'out of it' than he is now"

"Getting the right medication and also trying to find something that will work"

"the endlessness of it, never any respite, no prospect of improvement plus NHS don't seem to have the capacity or resources to care for him"

What impact does pain have on the quality of life of the person who is cared for

4.8 40% of people described a poorer quality of life for the person they cared for with isolation, reduced social opportunities, loss of interest in hobbies and maintaining friendships all impacts of living with pain. 28% responded with comments around the mental health impact which ranged from feeling angry about life to feeling suicidal.



Comments included:

"Devastating. He rarely leaves the house now and needs to rest in the afternoons. He has flare ups which make everything worse. He has become more introverted and has lost self confidence. He suffers from depression - I took early retirement recently and that has helped".

"It has taken away his life".

"She has lost the majority of friends, due to cancelling at last minute. She has to sleep a lot and cannot exert herself too much. Often felt suicidal"

What impact does caring for someone managing pain have on their Carer

4.9 Half of the people who responded mentioned the emotional impact caring had on them. They reported finding it stressful seeing a loved one in pain, constantly worrying and feeling distressed. Almost a quarter found it physically tiring and others mentioned the impact on their own mental health and poorer quality of life with little time to themselves.

Comments included:

"My heart breaks for him and the life we should have now. We can't go out as a couple very often and holidays are extremely rare. Intimacy is a thing of the past".

"Can be upsetting seeing them in so much pain, feel unable to do much other than care, feeling alone, emotionally and physically drained at times"

"It is very difficult. I am ill myself and exhausted all the time. I'm not able to support him emotionally as well as I used to. I no longer see my friends, I've lost touch with most of them. I don't go out anywhere".

What helps carers provide support

4.10 A quarter of people felt that receiving support from family and friends helped them to continue in their caring role with almost a fifth saying that they did it because loved the person and it was their role to care. Others mentioned practical support and attending support groups helped them to manage. 2 people said that nothing helped or they did not have enough support.

Comments included:

“Friends, family and loving him. Trying to stay positive and focus on the pros rather than the cons. I am part of an AS support group on Facebook. On a practical level, applying for and receiving Adult Disability Payment (for him), Carer's Allowance (for me) and his blue badge. The extra money means we are not struggling financially after my early retirement and when I do need to take him out in the car, the blue badge means I'm not stressed about finding a space near to our destination”

“My own health & relative fitness at 84 years of age - motivation and a measure of practical skills as I undertake all manner of domestic and personal tasks in support of my wife”

“My wife has various aids wheelchair , gutter frame , panic alarm , wet room , shower chair , grab rails, bed rail closomat toilet with aerolet and perching stools”

“Nothing- it's very lonely”.

What is most challenging thing caring for someone managing pain

4.11 A quarter of people responded that the most challenging thing was feeling helpless when a loved one was suffering. Other challenging things mentioned included a lack of support and feeling they had to hide their own emotions. 3 people mentioned that the person they care for takes their frustration out on the Carer.

“To be there 24/7, and to see my wife in constant pain is very distressing”

“His constant pain is emotionally draining for us all”

“Most challenging is that she is still in. A lot of pain and I feel I just can't help her with the pain”

“The emotional side- that everything gets taken out on me”.

What would support Carers to help provide care

4.12 A quarter of people responded that they needed more support to help provide care, including things like respite from caring, the right care packages, financial help and aids/adaptations. 5 people felt that having the right pain relieving medication would help.

“GP or pain specialist who would actually prescribe medication with frequent review”.

“Someone to come out to see my mum such as gp ect not just giving her medication all the time and not even see her”.

“A wet room that he was promised from occupational therapy. And maybe another day centre day or a person in to see him for company”

“Currently been awarded a care package but due to lack of staff no carers available to help”

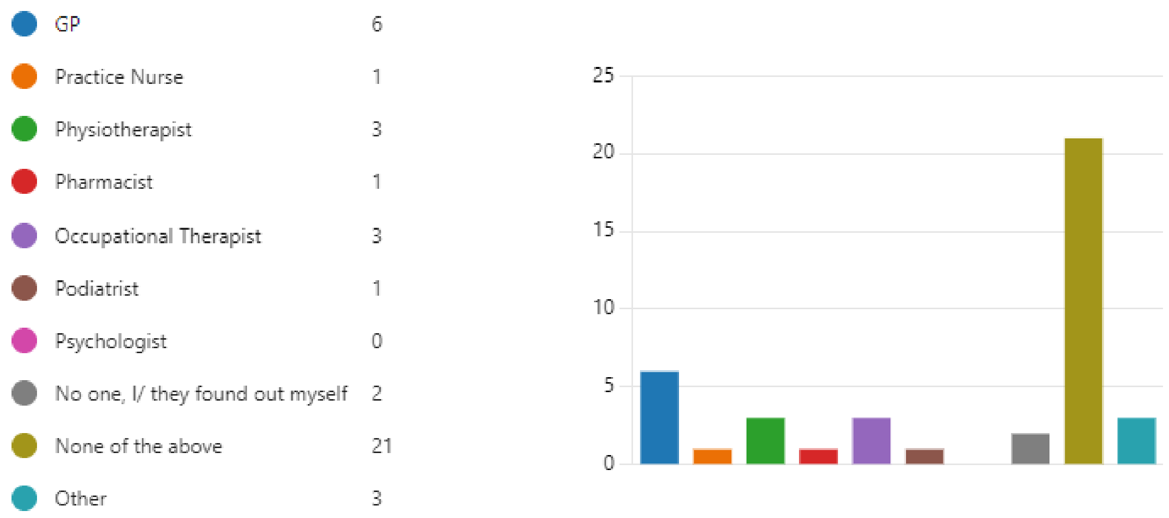
5.0 Supported Self-Management

What is understood by the term supported self-management

5.1 60% of the people who responded did not understand the term. Almost a third understood that it meant doing things to look after themselves with support from professionals.

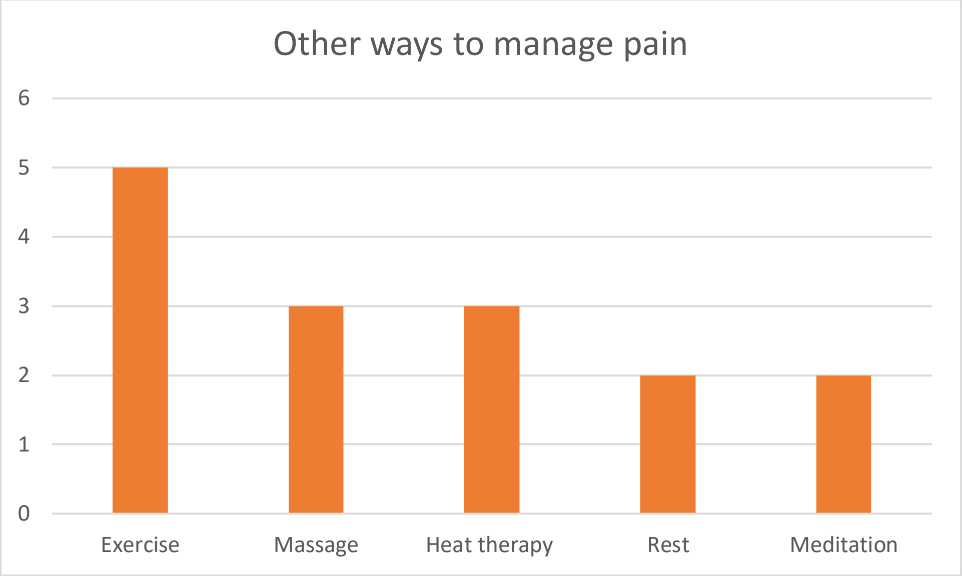
Which health care professionals spoke about supported self-management

5.2 21 people indicated that no-one on the list of professionals had spoken them or the person they care for about supported self-management. 3 people had spoken to social care staff or family. Full details below:



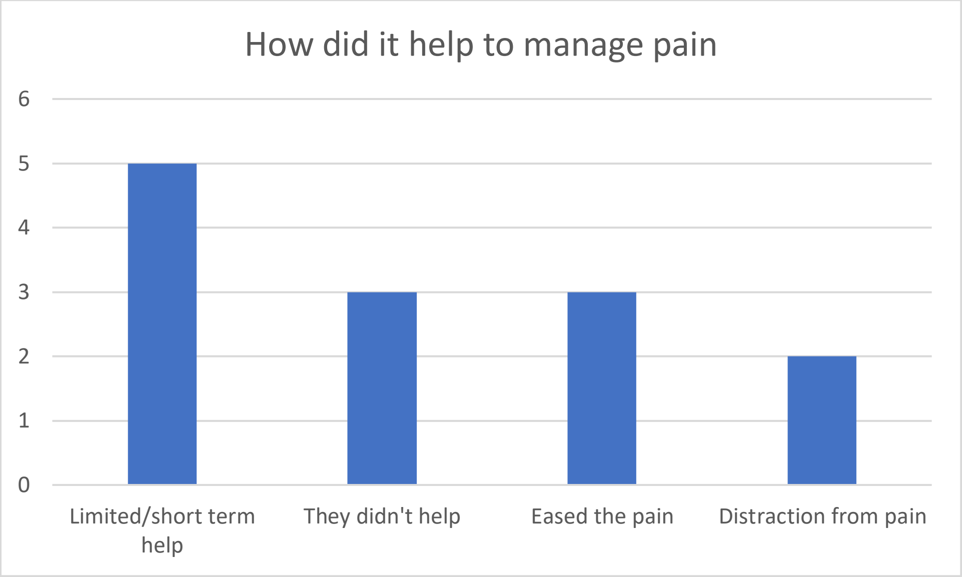
Has the person who is cared for ever used other ways to manage pain aside from pain medicines

5.3 16 people indicated that other ways to manage pain had been used with 16 people saying that they hadn't.



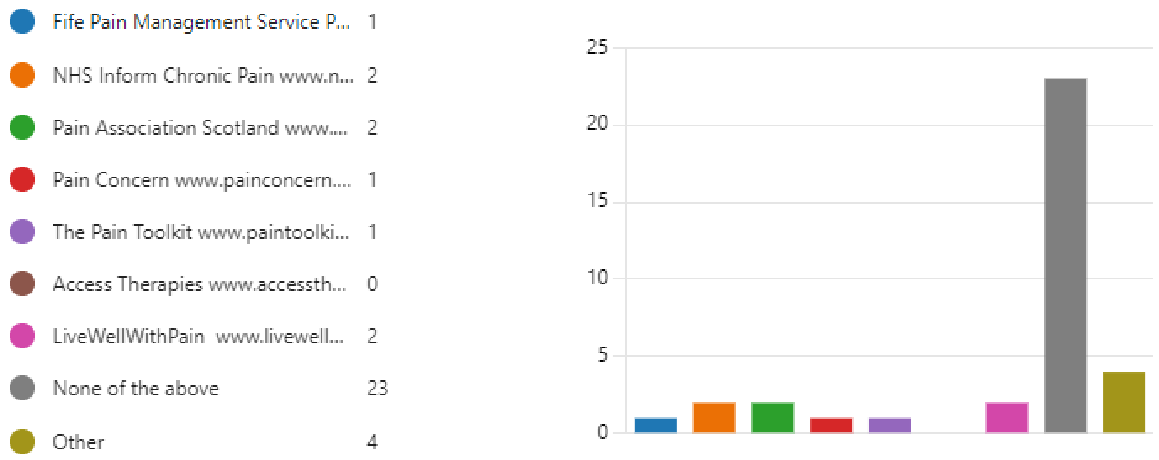
How did these ways help to manage pain

5.4 Information included in the table below



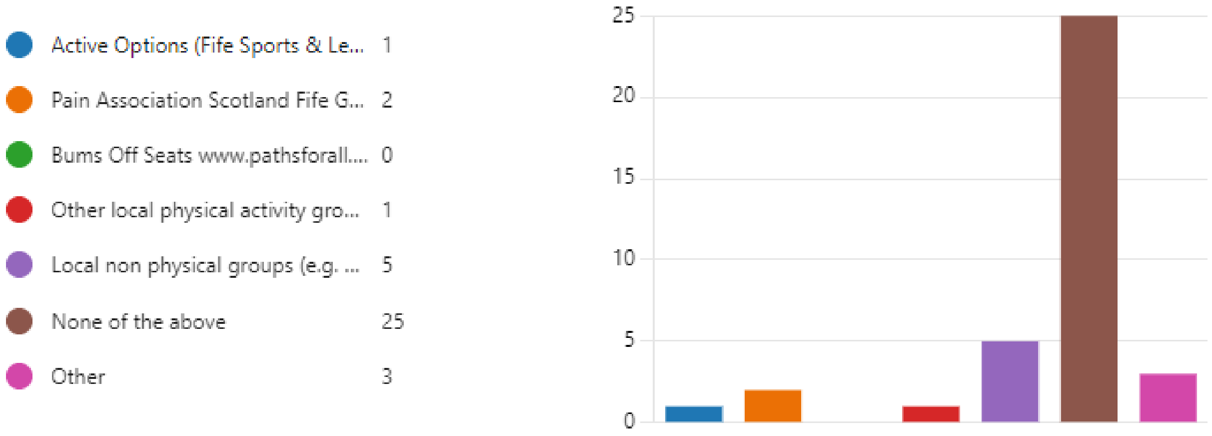
Have other website resources been used to help people living with pain

5.5 23 people reported that neither they nor the person they care for had used or accessed any of the listed websites. 4 people selected other but no other websites were listed in the responses. Low numbers of people selected some of the options listed



Which groups were attended by the cared for person to help manage pain

5.6 25 people reported that the person they care for had not attended any groups. 3 people selected other but did not mention other groups and a low number of people attended some of the groups listed.



Any other comments about supported self-management

5.7 Comments included:

"Being more active would be easier if he wasn't in so much pain all the time. He is never pain free and his default level of pain drains him completely, never mind when he has a flare up. I know painkillers can mask symptoms and that we need to feel pain to keep us safe, but surely there has to be a better middle ground?"

"I believe supported self management would have to be well funded and staffed adequately, with a robust communication network to be effective"

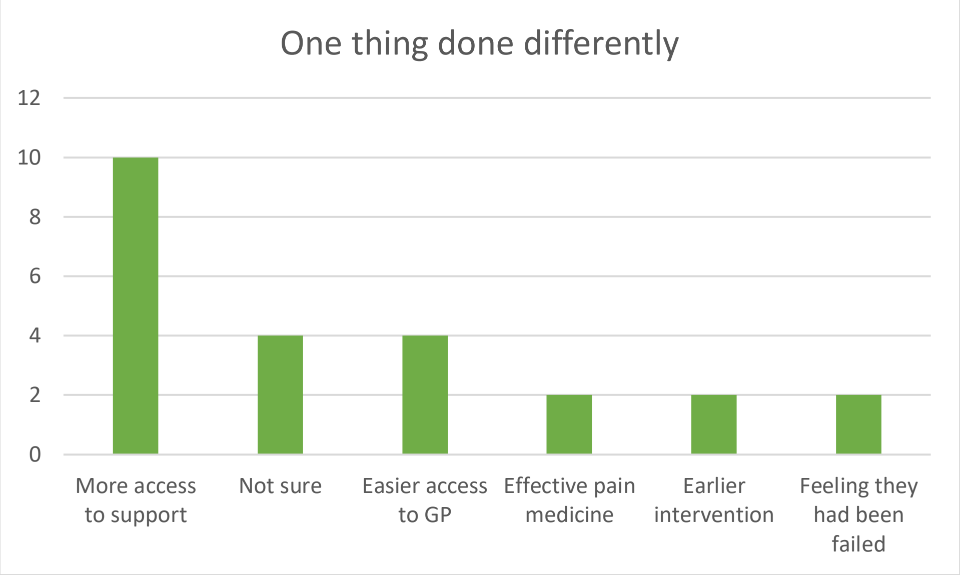
"My partner suffers from M.E. And groups don't take into account the requirements for someone with ME"

"Mum would never attend a group, and has little time for self management... Unless she came up with it herself"

6.0 Overall experience

One thing that could have been done differently regarding the healthcare support of the cared for person

6.1 Key themes with almost a third of people mentioning that they would have liked more access to support including information on pain management, mental health support and respite care.



Comments included

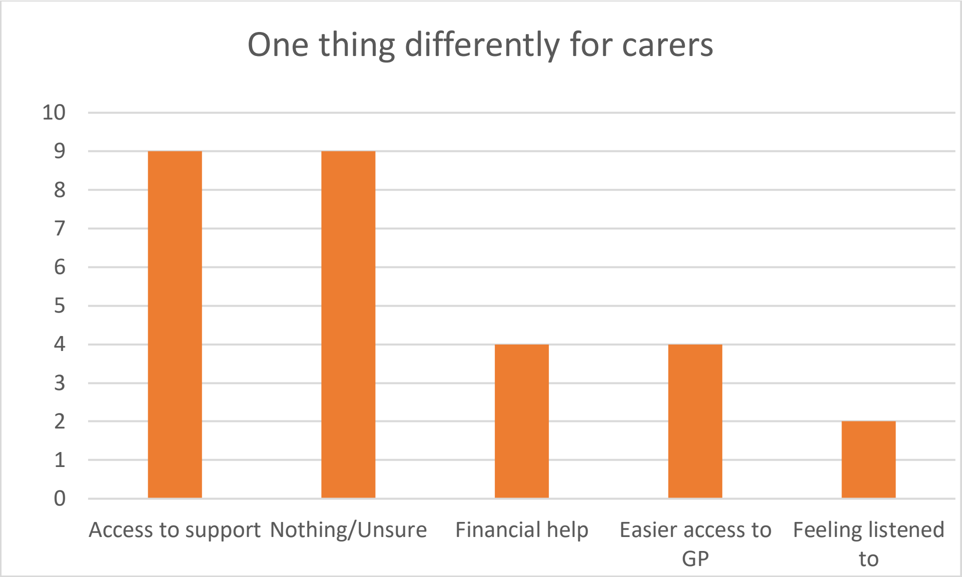
“Earlier information/guidance vis a vis what support services are "out there" in Fife and beyond e.g. I never knew of the existence of Fife Carers, Commercial Street, Kirkcaldy until summer 2021 - an excellent agency”

“Being aware of what support is available earlier”

“Treating the mental health stuff, actual support for childhood trauma and personality factors”

One thing that could have been done differently to support the Carer

6.2 Key themes with than a quarter of people would have liked more access to support including respite, equipment and information about other services available with more than a quarter saying that they were unsure or nothing could have been done differently.



Comments included:

"Extra daily support to give me a better quality of life"

"More input from GP to provide me a better understanding of the pain"

"Easy access to some short term respite whether that be for me or my wife".

What matters most as a carer supporting someone living with pain

6.3 Key themes with more than half of the people responded that what mattered most was being able to access support for the person they were caring for. 4 people mentioned that having a good quality of life for themselves mattered so that they could continue in their caring role.

Comments included:

"Being there and trying to keep his spirits up. For him - more effective treatment/management of his pain/condition"

"For my mum to have a better quality of life"

"Making sure their pain is managed and kept to a minimum as much as possible"

"Trying to keep a quality of life"

Any other comments, thoughts or ideas to share

6.4 Comments included:

"It would be good for people in the future if they were aware of what support is available"

"I do not presently have neither time nor inclination to "share" - I am living the nuts and bolts business of just coping and caring alone until any "cavalry" might come riding in form of Care Package or whatever"

"I know nhs is under an extreme amount of pressure and I greatly value all the work that staff put in. And how lucky we are to have an nhs."

Sharing stories

6.5 8 people responded that they were interested in sharing their story

Focus group for Carers

6.6 7 people responded that they were interested in being part of a focus group for carers of people with lived experience of pain

7.0 Additional Comments

The Pain Medicines Patient Safety Programme is aiming to increase understanding across patients, those who care for them 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 Carers were keen to engage with the Pain Medicines Patient Safety Programme 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 many carers have their own physical or mental health issues and have been caring for someone for more than 10 years. The majority support with domestic tasks and more than half provide assistance with mobility issues and personal care. Reduced quality of life was reported both for the Carer and for the person living with pain with limited social opportunities and mental health and emotional impacts for both.

What mattered most to Carers was having better access to the support services and information that they needed to improve quality of life for both them and the person they care for.

9.0 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/Focus Group and Peer Support are being explored.