

PROJECT  
REPORT

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A collaboration between  
GL11 Community Hub &  
NHS Gloucestershire ICS  
Living Well with Pain  
Programme

September 2023

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THIS CASE STUDY DESCRIBES HOW, WITHIN A SYSTEM-  
WIDE APPROACH, WE ARE USING THE PATIENT VOICE TO  
SHAPE SERVICES



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## Summary

1. The experience of chronic pain is complex and influenced by many factors including previous experience of pain, poverty, trauma, family and social support.
2. Medical treatments are of limited benefit to most people living with long term pain.
3. Empathic and validating relationships between people living with pain and healthcare professionals are key in supporting people to live well with pain.
4. Focus group sessions with people living with pain reveal important insights into the impact of pain on people's lives, how those with lived experience describe the impact of their pain on others, and how people experience healthcare and other support systems.
5. Social prescribers supporting people with pain describe challenges in supporting the needs of people living with pain.
6. Better communication between healthcare professionals and between people living with pain and healthcare professionals is identified as a need.
7. Collaboration between healthcare and community providers, particularly in provision of sources of peer support is valued by people living with pain.
8. Primary care teams have a good understanding of what is important to people living with pain but providing the time and support needed is challenging with current pressures.
9. The insights from people with lived experience are at the heart of developing a programme which helps support them.

## Introduction

### NHS Gloucestershire ICS Living Well with Pain Programme

The NHS Gloucestershire Working with People and Communities Strategy<sup>1</sup> states that: *We want to ensure that we involve people in a variety of different ways and will be open and transparent in our work. We want their involvement to be meaningful.* The activity, data, findings and recommendations presented in this Report are an example of this ambition being put into practice.

The NHS Gloucestershire Integrated Care Board (ICB) has brought together people to collectively provide high value, co-produced, integrated, evidence-based support and services to achieve the best quality of life for people with chronic pain. Our Pain Programme Group includes stakeholders from primary and secondary care, people with chronic pain, VCSE colleagues, mental health commissioners and providers, adult social care, and ICB partners leading on health inequalities, self-management and healthy communities, personalisation, social prescribing and creative health, transformation programme leaders, and patient engagement and experience teams.

"Good quality, empathic relationships with care providers, feeling validated and being partners in their care is more important to people living with pain than specific treatments."

### Project Background

There is an established recognition that there are numerous influences on the experience of persistent pain and associated disability. Many, if not most, of these influences lie outside the biomedical domain and include poverty, adverse childhood experiences, later life trauma, lack of educational support, family and social environment, previous experience of pain and expectations in relation to the continuing impact of the condition and what type of support might be helpful.

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<sup>1</sup> <https://www.nhsglos.nhs.uk/have-your-say/working-with-you/strategy-and-insight/>

Published literature shows that good quality, empathic relationships with care providers, feeling validated and being partners in their care is more important to people living with pain than specific treatments. Personalisation and place are key underpinning themes of our programme, and we understand the need to ask our own population what sort of support they would find most helpful in living well with pain.

Aligning expectations between clinicians and the people they support is key to developing useful therapeutic relationships. Our project aims to explore population perspectives on persistent pain and its impact to better inform individuals and organisations to provide support.

## GL11 Community Hub

GL11 Community Hub (GL11) are a Community Hub based in Cam, Gloucestershire. GL11's vision is

*A connected, kind and can-do community in GL11 area, achieved by:*

- 1. Creating a safe and supportive community space enabling friendship, bravery, learning and growth and*
- 2. Working with communities and partners to create solutions to achieve equal access and quality of services for everyone in Gloucestershire.*

GL11 have an established working relationship with the NHS and represent a balanced demographic in relation to deprivation (an important determinant of the experience of pain). [www.GL11.org.uk](http://www.GL11.org.uk)

# Description of The Project

## The Brief for GL11

We met with GL11 Community Hub to work in partnership to explore the lived experience of a group of people with chronic pain, and to discuss ideas about what support might be most helpful among members of the community. An important component of this work was to identify and support a group of individuals with lived experience of long-term pain who can both provide peer support and work with the NHS Gloucestershire ICB Living Well with Pain Programme to improve the health and well-being of people living with pain. We also set out to test the methodology of this engagement approach, to develop a model which could be adopted and adapted to gather the views of those with lived experience in other communities across the county.

## Methods

The first focus group participants were recruited from people that GL11 had an established relationship with. Subsequent workshops were advertised openly via social media and through social prescribers for the Stroud Locality. All participants were self-selecting.

## Focus Groups

GL11 held four face-to-face data gathering workshops and a further digitally enabled session via Zoom. One of the focus groups included social prescribing and other practitioners who support people with chronic pain. All groups were asked the same questions:

- Q1: How would you describe living with chronic pain?
- Q2: How does chronic pain impact on you?
- Q3: What support do you have to deal with chronic pain?
- Q4: What additional support would help you manage chronic pain?
- Q5: How do others respond to you having chronic pain?
- Q6: What else would you like to tell us / NHS about chronic pain that we haven't asked, that would help in this research?

The group of social prescribers were asked similarly themed questions. Detailed format of the focus group sessions can be found in Appendix 1

## Group Facilitators

NHS professionals did not take part in the sessions. The workshops were facilitated by two experienced facilitators from GL11. The role of the facilitators was:

1. To create a safe space where people can talk.
2. To agree a strong confidentiality contract – data would be non-attributable.
3. To explain the background and how the data will be used.
4. To run a structured data gathering process which posed six questions as outlined in Appendix 2.
5. To listen, clarify and document all comments.

## Results

### The Participants

(See Table 1)

1. All were local to GL11 postcode (Cam and Dursley).
2. GL11 interviewed four groups of people with chronic pain. In total, 20 people: 15 women and 5 men. One group was an existing Invisible Illness support group.
3. Ages ranged from 35 – 78, 6 were under 50. White. Mixed economic demographic.
4. Some had experience of different types of support groups – ME, Long Covid, chronic fatigue, invisible illness.
5. A fifth group of people who work with chronic pain sufferers were interviewed: three social prescribers and one person who ran art-based support groups specifically for chronic pain patients.

Gender	Age	Duration of CP	Location of Pain	Diagnosis? (Not asked- revealed in conversation)
Male	35	Since Childhood	All over	Fibromyalgia
Male	59	Since 2020	Lower back/Left Leg	Long Covid
Female	66	Since 2020	Back/Spine	Cancer Treatment
Female	60	10 Years +	Hip/Ankle/Knee/Shoulder	Brain Aneurysm
Male	65	2 years	Knees	?
Female	49	5 years	Back, leg + other	Horse Riding accident
Female	61	15 Years	Back	Inflammatory arthritis
Female	57	2.5/3 Years	Joints, Hip, Head	Long Covid
Male	70	27 Years	All over	Spinal Injury & Fibro
Female	45	All Life	Joints	Hypermobility Syndrome
Female	43	A Long Time	All Over	Long Covid / Fibromyalgia
Male	51	?	Feet X2	Diabetes
Male	75	30+ Years	Legs/Hip	Arthritis
Female	75	2 years	all over	?
Female	49	23+Years	All over	Fibromyalgia & chronic fatigue
Female	60	12 Years	Feet X2	Arthritis
Female	72	20 Years +	Back Spine Leg	Scoliosis
Female	74	7 Years	Spine	Spine Condition
Female	78	30 Years +	Back Hip Spine	Injury

**Table 1 Project lived experience participants.**

## Themes Arising from the Focus Groups

### **Lived Experience Participants**

Three themes emerged from the group sessions:

1. How chronic pain has impacted on peoples' lives.
2. How others respond to the people with chronic pain.
3. The peoples' experience of the health and community systems.

## How Chronic Pain Has Impacted on Peoples' Lives

### **1 Isolation**

All groups commented on feeling lonely, isolated, socially excluded due to incapacity, unheard and invisible, particularly if their pain was invisible. (See Appendix 2).

"I am used to only being seen in good moments - scared of being seen in bad ones."

### **2 Life Limiting**

All groups commented on feeling exhausted, restricted in what they can do in their day to day lives. Some said they were now unemployable due to their unreliability. Their lives had shrunk, they couldn't make social commitments and felt more alienated from the world they knew. (See Appendix 3).

"I got up at 4am to get here for 10am - that's what it takes to get mobile."

### **3 Mental Health / Feelings**

All groups reported a mixture of feelings that, over time, their condition will impact on their mental health. They reported feelings of anxiety, frustration, low self-worth, hopelessness, vulnerability, and depression. (See Appendix 4).

"I'm now some strange crying woman."

#### 4 Self Help

Some groups reported that they researched their conditions and had investigated some other self-help techniques. They spoke of having to initiate this as there was lack of signposting from health care professionals (see later comments on health systems). Many spoke of the power of being in a peer support group. They shared some of the self-help strategies they had tried but raised the issue of the financial costs of these.

More middle-class groups had more knowledge of and financial access to self-help strategies, whereas self-help strategies were mentioned less frequently in the working-class groups, probably due to lack of money and less access to self-help information. (See Appendix 5).

"I have to think of ways to be understood."

#### 5 Financial Concerns

More affluent people had some capacity to afford private health care and, in some groups, financial issues were raised less frequently. The working-class group spoke more frequently about financial constraints and how challenging it was to navigate the benefit system and needed information and help to do so. Some struggle to make ends meet as some cannot work. (See Appendix 6).

"People think I'm making it up."

### How Others Respond to People with Chronic Pain

#### 1 Lack of Understanding

There were many quotes on being neither understood nor believed by friends, family and health professionals. Some reported their families were supportive and that they needed support too. Some spoke of well-meaning people giving unhelpful advice and some felt patronised. They often experienced a lack of empathy.

"GP and whole NHS need to communicate."

There was a sense that some friends had given up involving them in social activities as they were unlikely to be able to attend. They said they would like to people to be more understanding and for people to be more educated in understanding chronic pain.

"Perpetual reassessment of everything - I have to find my own way round every problem."

Some said that peer support was the only place where they felt they were understood. (See Appendix 7).

"It's all self-navigation."

### Peoples' Experience of the Health and Community Systems

"Practical help with forms benefits etc is needed."

"Benefits are complex confusing to navigate."

#### 1 Communicating and Linking Between NHS Services

All groups thought that there needs to be better links between services. It was felt that GPs and specialists don't communicate with each other and that a more connected approach is needed. This is particularly the case when chronic conditions may require input from more than one specialist. Several spoke of needing more holistic treatment and requests to take the whole person into account, not just the current symptom being presented. This can lead to over prescribing of medicines which can result in a risk of unintended drug adverse effects. (See Appendix 8).

## 2 Dealing with GPs, Health Professionals & Wider NHS

People strongly requested that GPs and other professionals need to signpost to what other services, activities, support etc. might be available, rather than just prescribing.

There was some experience of GPs not listening, not understanding and not seeing the need for emotional support. There were requests to be seen as an individual and that people have different experiences of the same condition. They also would appreciate longer appointments to discuss multiple symptoms and have continuity with individual professionals and regular reviews. (See Appendix 9).

"Tell us what can health services do? I don't know if I expect too much?"

## 3 Medicines

There was a clear message that people don't want more medicines. Some take medicines to manage side effects of other drugs and GPs need to signpost strategies other than prescribing. (See Appendix 10).

"What is out there - aside from medication - we need to know."

"Everything is gauged towards emergency care - We need to live. Think prevention and living well".

"I trusted NHS years ago but have now given up, so I just get on with it alone now".

## 4 Peer Support

Every group spoke of the benefit of peer support and requested more opportunity for this. They spoke of their understanding of each other as they are 'all in the same boat'. One said the focus group was what has been missing for her i.e., talking to others with the same lived experience. (See Appendix 11)

While a lot of what was said was quite moving and sad to listen to, the group was energised and spoke openly. They said it had been an enjoyable experience and we suggest that this was due to the power of sharing experiences and being listened to by others who understood.

## 5 Request for Education About Chronic Pain and Its Management

Some expressed the need for understanding about what the NHS could offer, of what their expectation of 'normal and abnormal' should be with this condition and what they themselves could do to manage chronic pain. There were several comments about better understanding of chronic pain for carers, families, and the public. (See Appendix 12).

## Experience of Social Prescribers Working with People with Chronic Pain

We asked the same questions that were posed to those with chronic pain, to hear their perceptions and understanding of the lived experience of those they support. Their observations aligned with the experiences expressed by the people with chronic pain.

We also asked this focus group what they needed to enable them to provide better support. They requested the following:

1. Training and education on chronic pain - what to expect, how it manifests and how the brain responds.
2. Access to information related to;
  1. a pain directory on the services that are available.
  2. an 'idiot's guide' to chronic conditions including ME, Fibromyalgia.
  3. the services the NHS will and won't provide.

"I've given up on medication - I live with the pain."

"This is what is missing - talking to others with the same lived experience."



This group also raised the following concerns:

1. How do they support people when there doesn't seem to be many services that they can signpost people to?
2. GPs often refer people to social prescribers because they don't know what to do with them. Social prescribers feel they are expected to 'sort it out.' They said that GPs need to understand what social prescribers can and can't do.
3. They felt that their reputation was at stake with their clients. GPs may refer people because they don't know what to do. The social prescribers don't know either!
4. NHS is excellent in treating acute illnesses but less so in treating chronic conditions.

"Pain is invisible – it's hard to understand".

**Limitations**

This analysis is based on data from 24 individuals, from a limited rural, white, middle- and working-class demographic. This stage of the project did not include interviews with healthcare professionals.

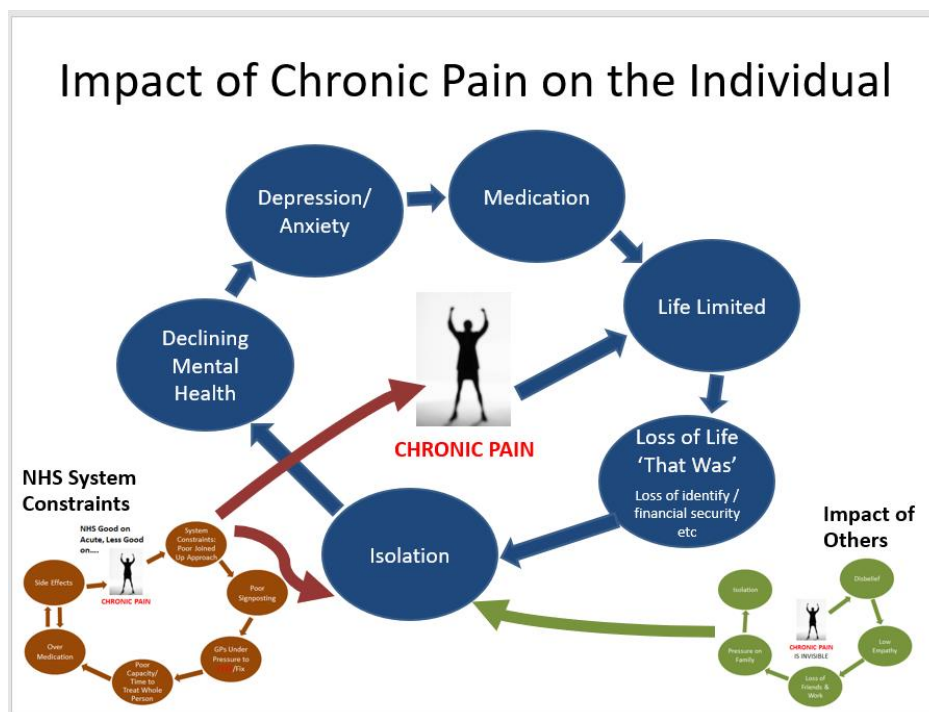
**Discussion**

The findings from this project concurred with other (larger) projects including Gordon et al 2016.

**Reflections on Cause and Effect**

From the data it would suggest that the impact of chronic pain is likely to result in a much more limited lifestyle. This can then cause feelings of loneliness and isolation as patients are no longer able to interact with friends, family, and work colleagues as they used to.

Isolation may be further aggravated when the response from the health system is fragmented or if some GPs are unable to respond in a supportive or helpful way. Over time, feelings of isolation and abandonment by friends and the health system could impact on their mental health, creating an even more limited life and possible dependence on additional medicines. (Figure 1)



**Figure 1: Impact of Chronic Pain: Cause and Effect Loops**

This poses the challenge of how to intervene in this vicious cycle of physical pain – limited life – isolation - mental ill health. If limited life and consequent isolation is at the core of the sufferer’s experience, there are several strategic options that NHS and the community may wish to consider as way of breaking out of this cycle.

“Peer support - others sharing same reality is really important”.

## Our Recommendations: Working in Partnership with Professionals, Patients, and the Community

Much was said in the focus groups about a more joined up approach and this requires working more collaboratively and this could be achieved in four ways:

Increased collaboration between doctors and specialists in their approaches to patients with chronic pain e.g.

1. GP to consultant
2. Consultant to consultant e.g., rheumatologist to neurologist
3. GP / consultant to other specialisms e.g., pain consultant / counsellors / social prescribers
4. Co-creating, developing and offering pain management strategies that give alternatives to medication and improve capacity to signpost to other less invasive approaches.
5. Developing a collaborative self-management approach. This would require a more holistic approach among all practitioners working with chronic pain and developing the relevant skills of working in partnership to do so. This approach would assist patients to co-create a personalised programme of pain management, with regular reviews, that would best work for them and their circumstances.
6. Developing partnering relationships with local communities to facilitate chronic pain peer support groups. These groups, if managed sensitively and empathically, enable people to share their experiences, ideas, and coping strategies. In so doing, they feel more understood and less alone. This can help create a more virtuous cycle and improve motivation, develop self-efficacy, build resilience, and enhance mental health as they navigate their lives, living with chronic pain. (See Appendix 13 on research on peer support groups)

## Further Observations

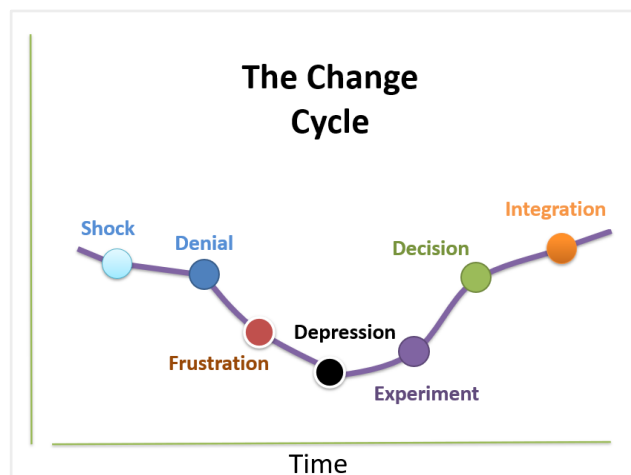
### ***Some People with Chronic Pain Do Not Identify as Living with Pain***

Whilst recruiting people for the workshops the team met several people who they perceived as having long term pain. When invited to attend, these individuals said that they did not feel they qualified as someone with long term pain. This cohort could be interesting to better understand their lived reality. Do we perceive them as having pain but in fact they don’t? Do they live with pain and manage their lives around it? Do they not identify as ‘someone with a chronic condition’?

### ***Duration Of Pain Symptoms and Impact of Poverty, Social Prescribing and Peer Support***

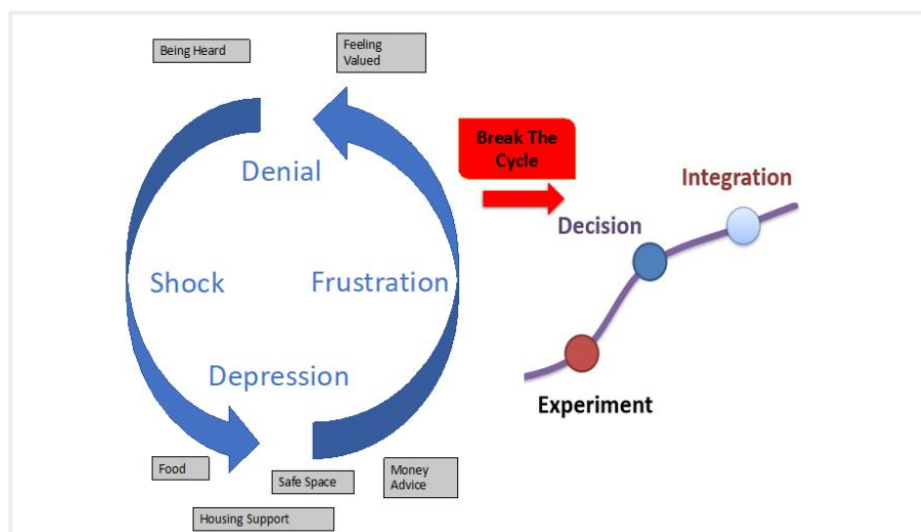
There was a marked difference in the people who had lived with their condition for several years and those who were relatively new to their situation. Those who had been living longer with pain had in many instances retreated from medication and formal professional support and seemed to have disengaged from statutory services. They had ‘found a way’ to live with the ‘new them’. Those new to the condition were searching for diagnosis and to ‘be fixed’.

It became apparent that people go through a change cycle and grief process (Kübler Ross 1973) when living with a chronic condition. This cycle could be helpful in how those wishing to support people living with pain approach those with a chronic condition. (Figure 2)



**Figure 2: The Change Cycle (Kubler Ross 1973)**

Those more recently diagnosed with chronic pain conditions, had more of an expectation of being ‘fixed’ by their health practitioner. This can hold them circling around in the ‘shock – denial – frustration – depression’ part of the change cycle, angry or frustrated that nothing seems to help or cure their condition. (Figure 3)



**Figure :3 Getting Stuck in the Change Cycle**

However, we also noticed some people who had had the condition for a longer time were angry and frustrated. We observed that those people mostly came from poorer backgrounds and were constrained by their financial and living circumstances. (See 1.5 Financial Concerns).

**Impact of Peer Support**

Initially we planned to separate the two cohorts but decided to work with mixed groups due to time constraints. Bringing both together was very powerful and was an exercise in peer support.

The offer of support such as peer groups must come at the correct point in a person's journey and is likely to be rejected if offered too early in the change cycle. This was echoed by the social prescribers we interviewed. (See Appendix 13 – benefits and challenges of peer support groups)

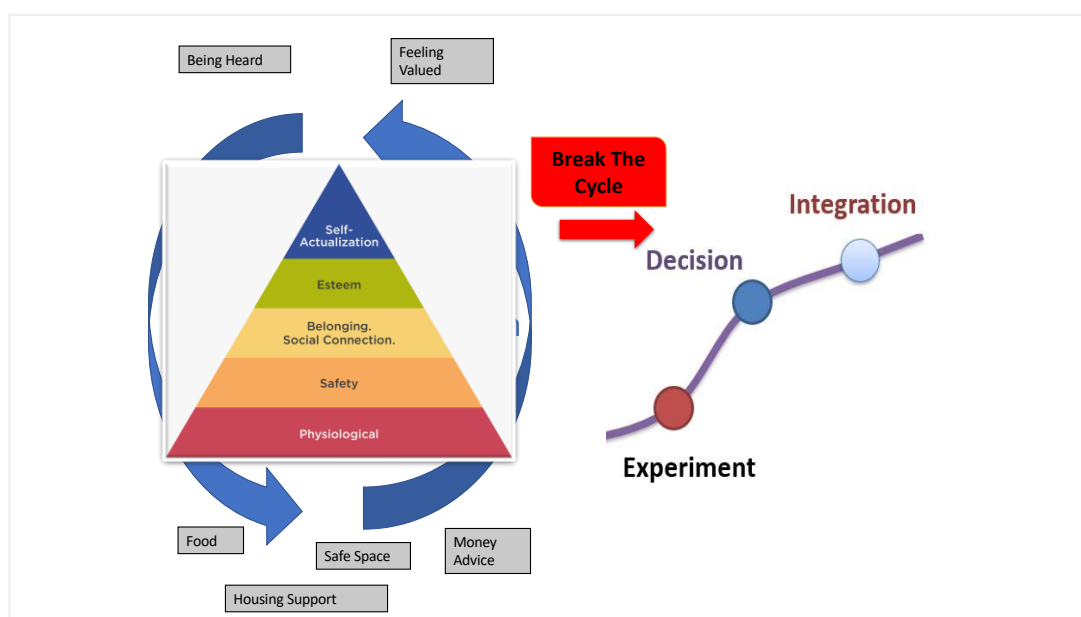
### ***Impact of Poverty on Social Prescribing***

Recent research by Dr Rochelle Burgess (Associate Professor, Institute of Global Health, UCL) into the effectiveness of social prescribing throws some light on why this is. (Rochelle, B 2023)

Social prescribing assists people to move through the change cycle. Dr Burgess' thesis is that people in different economic situations need different types of social prescriptions to assist them adapting to new circumstances.

More affluent people are more likely to feel secure in their day-to-day living conditions and circumstances. Their basic physiological and safety needs are met. They may also be able to afford complimentary self-help approaches that are not funded by NHS. Consequently, their isolation, mental health and wellbeing may be supported successfully by a social prescription of, say, an art group.

In contrast, poorer people living in damp conditions, struggling to make ends meet, with limited access to transport are less likely to be helped by the offer of an art group. Until their base line physiological and safety needs are addressed, they are more likely to stay longer in the early phases of change cycle of frustration, anger, and depression. (Figure 4)



***Figure 4: Meeting of Basic Needs and the Change Cycle***

For social prescribers, not only do they need to know about each client's mental and physical health challenges, but also what are their underlying economic and social circumstances? What are their base line needs that may require attention first? This could form the first part of their social prescription.

# Using What We Know to Change What We Do

## Sharing Findings with Healthcare Professionals

The clinical lead for the Living Well with Pain Programme and the team from GL11 used a Berkeley Vale PLT session to share findings from the focus groups. The practices at the PLT were those for whom the workshop participants were patients. We described the rationale for and conduct of the focus groups and asked the GPs and practice staff to share their thoughts about what was important to the people living with pain. They identified themes:

- Time to tell their story,
- Being believed,
- Understanding how pain impacted their lives,
- Being partners in their care.

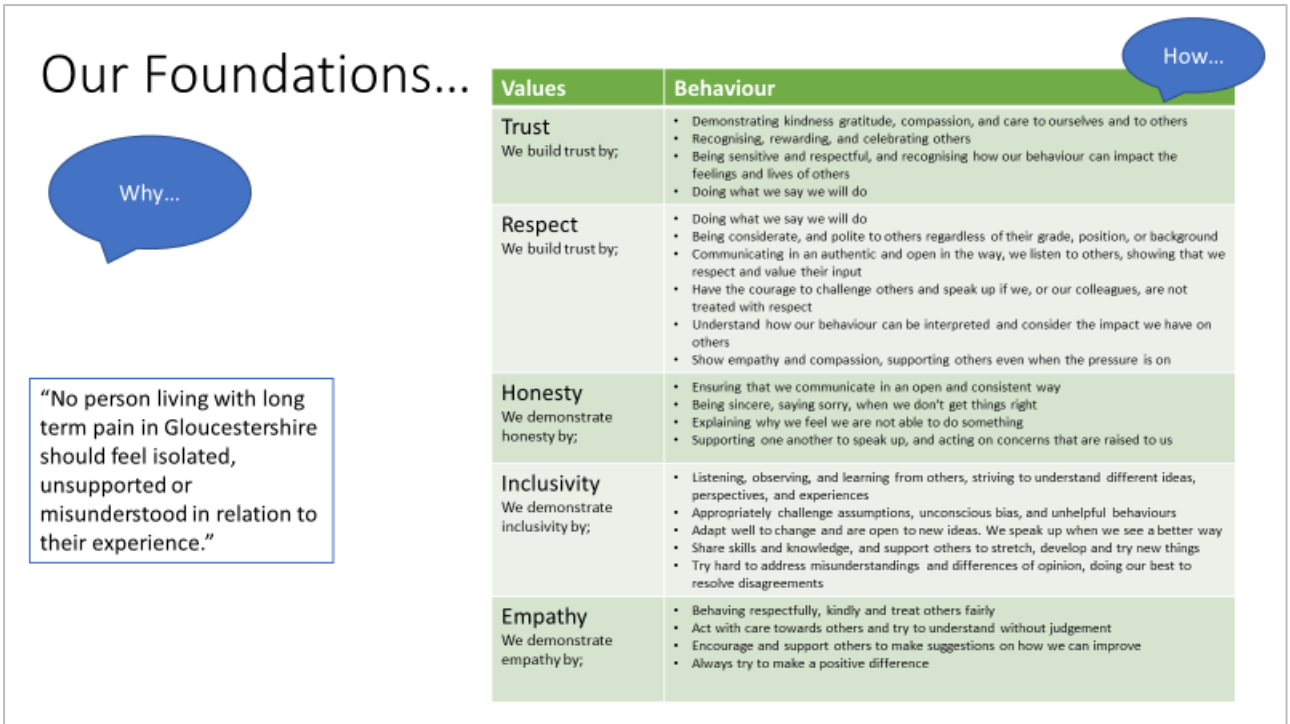
We demonstrated that primary care professionals understand what is important to the people they see living with pain but described challenges in building appropriate relationships in the time available to discussion. We discussed the importance of the wider primary care team, particularly social prescribing colleagues, in spending time with people with pain to support the holistic assessment needed to underpin the plan for support.

## Clinical Programme Group Workshops

A series of workshops were held by the Living Well with Pain Clinical Programme Group, alongside the GL11 insights project, to gain a broader understanding of how individuals felt they could better support individuals living with chronic pain. The stakeholder membership for these workshops included current health care providers from primary, secondary and community physical and mental health services, voluntary and community sector partners and commissioners. We used the initial findings of the GL11 insight project to assist with grounding our work on local lived experience, further building on the national context for taking a more holistic approach to support individuals.

We adopted an open space approach to the workshops to enable participants to share and gain ownership of an issue and come up with possible solutions. We developed a shared programme vision, shared values, and behaviours amongst the group of stakeholders. (Figure 5)

"I am dependant on chemicals and other people and adaptations, and on my family even young kids."



**Figure 5** *The Living Well with Pain Programme Vision and Values*

We agreed a programme approach based on three underlying principle which would be golden thread in all that we do (Figure 6).



**Figure 6:** *Living Well with Pain Programme: Undepinning Principles*

We then agreed on priorities workstreams for the programme, and we are in establishing workstreams for these (Figure 7).

# Workstream Planning

What...



- First meeting will be scheduled for ~6 weeks time TBC
- Workstreams will be fully supported by ICB Programme Team
  - Request for co-leaders for each workstream
  - Undertake detailed stakeholder mapping
  - understand the problem we are trying to solve within each workstream
  - May need more discovery work
  - Understand the interdependencies with other transformation programmes

***Figure 7: Living Well with Pain Workstreams***

## Peer Support

Gloucestershire has identified £60,000 for the development of peer support for people with long term conditions, which GL11 is working with the ICB to deliver over the next year.

The NHS Long Term Plan (2019) states that peer support is an essential element in supporting self-management and should be offered to everyone with a long-term condition (LTC). Targeted support for people with LTCs is also part of the Core 20 Plus 5 framework for action on Health Inequalities.

The VCSE have a key role to play in enabling people with long term conditions to connect and support each other. VCSE are closely connected to people in their community, have a holistic non medicalised lens, and the skills to work with people in an empathetic and human way. Local organisations can also add value in signposting people to other advice and services in their community that can support them.

The aim of this initiative is to work with the VCSE sector in Gloucestershire to:

- Understand the level of interest amongst VCSE organisations
- Identify the nature of investment needed in the sector to develop peer support (skills, staff, facilities etc.)
- To provide facilitation training and implementation support to enable delivery
- To provide seed funding for organisations to set up peer support.

## Final Reflections

VCSE partners have long been key in providing services for people with long term conditions in their local community. This project has shown the importance of inviting partners to join us in the strategic space and bring the voice of their local communities to discussions about supporting people to live well with illness. GL11 have unique and trusted relationships with their local community and this key collaboration brings the ideas of a population to whom we wouldn't usually have access to our work and allows local communities to directly influence and co-design services that meet their needs. This insights report has enabled us to test a new way of engaging with our community and strengthen working relationships between the NHS and the voluntary community and social enterprise sector. We aim to share the findings in the report via the Know your Patch Network to further build our understanding of what matters to people living at place, which may differ depending on population demographics.

This work will help us to ensure that we address the personalised care agenda to co-produce, develop and shape offers to support people living with chronic pain in the future.

## Further Reading

**Burgess R** The Spark 'Social Prescribing' BBC Radio 4 iplayer (28/3/2023)  
<https://www.bbc.co.uk/programmes/m001kh3h>

**NICE guideline 192** Chronic pain (primary and secondary) in the over 16s: assessment of all chronic pain and management of chronic primary pain NICE 2021 <https://www.nice.org.uk/guidance/ng193>

**Gordon K, Rice A, Allcock N et al** Barriers to self-management of chronic pain in primary care: a qualitative focus group study *Br J Gen Pract* 2017 Mar;67 (656):209-217 doi: 10.3399/bjgp17X688825 doi: 10.3399/bjgp17X688825.

**Kübler-Ross E** (1970). On death and dying. Collier Books/Macmillan Publishing Co.

**Upshur C, Bacigalupe G, Luckman R** They Don't Want Anything to Do with You: Patient Views of Primary Care Management of Chronic Pain *Pain Medicine* 2010; 11: 1791–1798

## Contributors to Report

### From GL11:

Audrey Harris  
Elaine Hynd  
Indigo Redfern

### From ICB:

Becky Parish  
Caitlin Lord  
Cathy Stannard  
Corinne Robinson  
Joy Lavender  
Lisa Gallagher  
Lucy Spelman



# Appendices

## Appendix 1: Design and Content of Focus Group

**Draft Design:** Data Gathering Chronic Pain Session 1 - Pilot

**Objectives Of Meeting:** To Find Out People's Lived Experience of Chronic Pain

Time		Flips	Equipment
9.45	<ul style="list-style-type: none"> <li>Arrive and coffee</li> <li>Confidential collecting base line data from participants (anonymised)</li> </ul>	Agenda for flip: <ul style="list-style-type: none"> <li>Living with chronic pain</li> <li>Impact on your life</li> <li>Support</li> <li>Other people's responses to CP</li> </ul> What else does NHS need to know	Name labels and pens
10.00	<b>Introduction</b> <ul style="list-style-type: none"> <li>Welcome / thank you for agreeing to come and contributing to this / who we are + roles including note taker.</li> <li>Background to project               <ul style="list-style-type: none"> <li>purpose of this project / what NHS wants to find out.</li> <li>this is first phase – gathering experiences to feed back to NHS.</li> <li>Pilot – we will ask for feedback at the end about what has worked and what we can do differently.</li> </ul> </li> <li>Introductions to each other:               <ul style="list-style-type: none"> <li>5 mins in pairs: name what has inspired you to come.</li> <li>Share in the group (headline thoughts -we will be sharing lots later)</li> </ul> </li> <li>Aim of this meeting</li> <li>Agenda for the meeting and how we will work (pairs / trios / share)</li> <li>Boundaries and confidentiality               <ul style="list-style-type: none"> <li>Data we gather is non-attributable.</li> <li>What is shared here stays in the room (safeguarding exception)</li> <li>This session is about you and your health – take care and if you feel you need a break – please let us know what you need</li> </ul> </li> </ul>		
10.20 10mins	<b>Q1:</b> How would you describe living with chronic pain. <ul style="list-style-type: none"> <li>Form pairs – someone you don't know.</li> <li>5 mins share.</li> <li>2 mins: write each idea on SEPARATE post-it-note.</li> <li>Post each idea on flipchart.</li> </ul> Gather round and have a look – what thoughts / observations do you have?	Flip: What words and phrases would you use to describe living with chronic pain? Write each thought on a separate post-it-note boldly	Felt pens Post-it note - 5 per person
10.30 15mins	<b>Q2:</b> How does chronic pain impact on you? <ul style="list-style-type: none"> <li>New pairs</li> <li>5 mins share / discuss.</li> <li>10 mins share with group as a pair.</li> </ul> facilitator collects on flip	Flip: How does chronic pain impact on you?	
10.45 25mins	<b>Q3:</b> What support do you have to deal with chronic pain? <b>Q4:</b> What additional support would help you manage chronic pain? <ul style="list-style-type: none"> <li>2 groups working on separate flipchart questions.</li> <li>5 mins: One group works on Q3, the other on Q4.</li> <li>Groups swap over.</li> <li>5 mins: Group adds to the second flipchart.</li> <li>Facilitate small groups.</li> </ul>	2 Flips on separate flip stands: <ul style="list-style-type: none"> <li>What support do you have to deal with chronic pain?</li> <li>What additional support would help you manage chronic pain?</li> </ul>	

	<ul style="list-style-type: none"> <li>5 mins: Groups return to original chart. What observations / thoughts do you have?</li> </ul>		
11.10 15mins	<p><b>Q5:</b> How do others respond to you having chronic pain?</p> <ul style="list-style-type: none"> <li>5 mins: new pairs</li> <li>Share thoughts for 5 mins.</li> </ul> <p>10 mins: Facilitator collects on flip – invites contributions</p>	Flip: How do others respond to you having chronic pain?	
11.25	<p><b>Q6:</b> What else would you like to tell us / NHS about chronic pain that we haven't asked, that would help in this research? We will collect this in the closing round.</p> <p>5 mins in pairs</p>	Flip: What else would you like to tell us / NHS about chronic pain that we haven't asked, that would help in this research?	
11.30	<p>Closing round:</p> <ul style="list-style-type: none"> <li>One thing you've enjoyed.</li> <li>What else do we need to know – we capture this</li> <li>Request for feedback</li> </ul> <p>Appreciation of your help, information, insights, and time</p>	Flip: What else would you like to tell us / NHS about chronic pain that we haven't asked, that would help in this research? For facilitator to fill in.	
11.45 close	<p>Request for feedback – in terms of the design of this session</p> <ul style="list-style-type: none"> <li>what worked</li> <li>what could be improved</li> </ul>	<p>2 flip on separate flip stands:</p> <ul style="list-style-type: none"> <li>what worked</li> <li>what could be improved</li> </ul>	Square post-its

## Appendix 2: Comments on Isolation

### **Event 1**

1. Isolating x2
2. Excluded
3. Not visible
4. No one sees the whole person
5. Exclude me - People assume you can't do something without even asking or trying to make concessions
6. Pain is invisible – it's hard to understand

### **Event 2**

1. Unseen
2. Lonely x2
3. Isolating
4. I can't do the social bit anymore
5. I am used to only being seen in good moments - scared of being seen in bad ones

### **Event 3**

1. Isolating
2. Lonely
3. Invisible
4. Alienating
5. My family are no longer mine
6. No one knows me
7. I am not heard
8. I smile and nod
9. Not listening to me and not responding to me
10. People not listening to me and not responding to me

### **Event 4**

1. People don't realise because nothing shows
2. Not understood
3. Isolation
4. Its invisible - I don't look disabled
5. I have no support (to deal with CP)

### **Event 5** (*social prescriber group*)

1. Isolates himself
2. Not wanting to go out
3. Some people don't come forward
4. Not talking to people
5. Withdrawn
6. Alone
7. Hides away
8. Internalise
9. Asking for help is hard
10. They give up looking for support if its long term
11. They need to know they are not alone and to be believed
12. They feel invisible

## Appendix 3: Comments on How Pain is Life Limiting

### **Event 1**

1. Uphill struggle
2. Prevents me doing everyday activities
3. Time stealer
4. Exhausting
5. Restricting
6. Adjust to the new normal
7. I can't do what I like to do anymore
8. What is my significance as a person now?
9. Limits what I can do
10. Go through such a lot to get to this point of acceptance
11. Learn to deal with getting older Vs you're too young for this
12. People like to plan things - I feel pressure to plan my life but I cannot
13. NOW is the only reality

### **Event 2**

1. Draining
2. Exhausting
3. Brain fog x 2
4. Variable- good minutes, bad days
5. Demotivation vs I just can't do it
6. Restricting
7. World shrinks
8. Unpredictable
9. No light at the end of the tunnel
10. Lost my life
11. Made me unemployable and unreliable
12. Can't commit to anything - work friends family
13. What you think you can do one day, you can't do the next
14. Changes depends on how you feel
15. Pain dictates mood
16. If I do anything physical I am slow and it hurts
17. No spontaneity
18. Managing fatigue is exhausting - What have I done to feel like this? So I know what to avoid next time
19. Planning everything is exhausting
20. Can't sleep due to pain levels - avoid going to bed
21. Insomnia
22. Waking up is hard - can't get out of bed
23. If I can't sleep the pain is worse , then I can't sleep cos pain is worse
24. I got up at 4am to get here for 10am - that's what it takes to get mobile.
25. Pain wakes me up
26. I can't keep up with the life I once had
27. Had to get new hobbies and new interests
28. Have to say no to invites

### **Event 3**

1. Exhausting
2. Debilitating

3. Never ending
4. No relief
5. I want.... body can't follow
6. Life changing
7. I am wanting to sleep all the time to get rid of the pain x2
8. I am now unreliable - I want to be reliable
9. Can't walk
10. Sleep most of the time
11. alienated from outside world and family
12. I am dependant on chemicals and other people and adaptaions, and on my family even young kids

**Event 4**

1. Sleeplessness x2
2. Exhausting x4
3. Painsomnia
4. Debilitating x2
5. Monotonous
6. Inconvenient
7. Feels like you can't do anything
8. Weak
9. Disabling x2
1. Not been able to work x2
2. Need aids and rails x2
3. Forgetfulness
4. Can't do what I need or want to do
5. Must think ahead- Can I do that?
6. Planning everything - These thoughts rule my life
7. I can only sit all day
8. Restrictions on where I can live - But I really don't want to move

**Event 5** (*social prescriber group*)

1. They see themselves as lazy
2. They compare what they can do to what they could do
3. Barriers
4. No end point
5. Can't get out of bed
6. Can't work
7. Self-care is too much
8. Smallest chore is too much
9. Need time to plan to do anything
10. Halt on normal life
11. Everything is an effort

## Appendix 4: How Pain Affects Mental Health/ Feelings

### **Event 1**

1. Sad
2. Shockingly hard
3. Anxiety and worry - mood changes
4. Challenging
5. Crushing
6. Frustrating

### **Event 2**

1. Embarrassing
2. Self-berating
3. Vulnerable
4. Frustrating
5. Depressing
6. Guilt
7. Affects my personality
8. Affects self-worth
9. Comorbidities - chronic pain and depression are linked
10. I need help with lessening anxiety
11. I need more emotional support

### **Event 3**

1. Hopeless x3
2. Alienating
3. Fear of sleep
4. Stuck in a circle
5. Frustrating
6. Devastating x2
7. Helpless
8. Deskillling
9. I know some issues are mental
10. Trying to be logical
11. Boxes in head - shut and open lid- Deal or not deal
12. Need help with lessening anxiety
13. Need more emotional support
14. I'm now some strange crying woman
15. Finding an emotional way of dealing with physical pain

### **Event 4**

1. Hell x2
2. Can alter mental awareness
3. Mind blowing
4. Never ending
5. Unrelenting
6. Unbearable
7. Fear of doctor

**Event 5** (*social prescriber group*)

1. Depression
2. Anger
3. Depressed
4. Not accepting
5. More accepting if they've had condition longer
6. Hard to let go of the old me
7. Hopelessness
8. Given up
9. Shame
10. Internalise everything
11. Loss of identity
12. Grief

## Appendix 5: Comments on Self Help

### **Event 1**

13. Constantly on Dr Google
14. Need to be proactive
15. Perpetual reassessment of everything - I have to find my own way round every problem
16. Constantly advocate for my needs
17. I have learnt to ask for help - My relationship has improved
18. Online info
19. Everything is self-initiated
20. Volunteering can help

### **Event 2**

1. Access to Private Health care - Including Phycologists - Essential
2. Physiotherapy to help breathing
3. Chronic fatigue clinic
4. Cold water clinic
5. Self-help googling/YouTube
6. art by prescription
7. self-started local community garden
8. blogging
9. breathing technique
10. Perrins technique
11. Low inflammation diet
12. Supplements to reduce inflammation
13. Chest physio

### **Event 3**

14. meditation sleep music
15. Private counselling
16. cold water swimming/dipping
17. meditation and guided relaxation
18. Mindfulness x 2
19. Heat and cold
20. Cold to reduce inflammation
21. Heat reduces muscle pain
22. Cold shower
23. Visualise the pain and switch it off, pain in leg switch off etc
24. Planning small achievable achievements
25. Tens machine
26. App- carmap
27. heated blanket
28. It's all self-navigation
29. Adapting routine and environment
30. Planning and pacing through the day/week
31. Little things to look forward to often

### **Event 4**

1. Posture and other exercises
2. Pacing - in my own way in my own time



3. Relaxation techniques

**Event 5** (*social prescriber group*)

1. They don't know where to go to get help

## Appendix 6: Financial Concerns

### **Event 1**

1. I need money for people to do things for me
2. Money spent - Private vs NHS
3. Extra spending
4. Just go private its quicker but that costs money
5. Practical help with forms benefits etc is needed

### **Event 2**

There were no comments on money

### **Event 3**

1. Husband working extra to support me
2. We bear the cost - treatment etc

### **Event 4**

1. Financially draining
2. Financially burdened - Houses gadgets treatments
3. Difficulty getting PIP- Questions don't apply to me?
4. Benefits are complex confusing to navigate
5. Tenancy Allowance
6. Private consultants - 10K operation. 1k injections
7. Had to pay privately for diagnosis
8. Pay for own follow up
9. Housing help needed
10. A carer with a carer allowance
11. More joined up benefit system one benefit not loads
12. No medicals for benefits - trust my GP
13. I worry about people who have no friends or benefit
14. Need for one benefit system
15. People should be paid enough - Carers etc
16. Benefit system needs sorting out

### **Event 5 (social prescriber group)**

There were no quotes on this

## Appendix 7: Comments on How Other People Respond to the Person with Pain

### **Event 1**

#### **Lack of Understanding**

1. Being heard here is holistic - not what I experience from NHS
2. People think I make it up
3. Oblivious to fact I'm in pain
4. Take a tablet and get on with it
5. Get dismissed
6. People think I'm making it up
7. Believe us
8. Pain to be believed and understood
9. Lack of understanding
10. Patronise me
11. Empathy is hard for people
12. I have to think of ways to be understood
13. It's not real

#### **What We'd Like**

14. Want to be acknowledged but when not heard I get stubborn
15. Leave me alone vs hear me but don't pity me. Contrary.
16. Hear my experience but don't define me by it
17. Recognise we are real
18. Don't tar everyone with same brush, see us as individuals
19. Not everyone has same experience even if they have same conditions
20. Difficult to fit into the 'normal world' more concessions needed
21. Support our families

### **Event 2**

#### **Lack of Understanding**

1. Not understood
2. Unheard
3. Lack of empathy
4. This is real
5. How are you? They don't really care when you answer so I can't be bothered to reply. I'm fine.
6. People forget - its invisible
7. You look well. I'm not!
8. Medics don't understand
9. I can't do what I used to - people don't understand
10. Sometimes I can sometimes I can't - you can see people's faces - they don't understand
11. Lack of empathy

#### **What We'd Like**

12. Understanding Husband and family - They could use support and info
13. Not all disabilities are visible - I wish people could understand that
14. More public understanding
15. Wear lanyard to be visible

#### **Friends and Family**

16. Some understanding friends
17. Old friends want the old you not the new you who can't do things
18. I don't get invited any more
19. Some people are lovely and include you and fit you in, adapt to you
20. Family can be lovely
21. Reality of seeing how you manage can be helpful for them to see
22. I am not making it up
23. My family's lives have changed as much as mine
24. I have new friends who understand

### **Event 3**

#### **Lack of Understanding**

1. Lack of understanding -Especially from medical people
2. No understanding
3. Not understood
4. Misunderstood
5. Need understanding
6. People try but don't understand, they can't
7. I feel like there has to be an outwards sign all the time - a limp etc
8. if I'm out with non-understanding friends - they say oh have a paracetamol but no understanding there at all
9. I have to prove it all the time
10. I'm invisible
11. No one looks at me
12. People don't want to hear same thing again
13. Oh aren't you looking well!
14. when are you going back to work...?
15. Oh you should be doing this... What you doing next?
16. Friends say - oh my body aches after a ten mile run.... Ohhhh F OFF!!!! Come back to me in ten year's time and tell me if you're still in pain from that run!

#### **Friends And Family Support**

1. I have to ask for help all the time
2. I have made new friends
3. Difficult for you and them
4. My family try
5. Difficult for family to continue to support me - I wince when people touch me
6. People withdraw from me, they avoid me in the street

#### **People Give Unhelpful Advice**

1. I'm in a wheelchair - lady put hand on my head and said I can heal you
2. Advice... have you tried.....
3. People offer solutions
4. Have you tried... Oh I read in the paper.....
5. It comes from a good place but very frustrating to hear
6. So many experts out there
7. People stop asking how I am
8. They say 'Oh are you better now?' Closed question - are you better now? I say yes
9. It's your responsibility to get better

#### **What We'd Like**

No data

#### **Event 4**

##### **Lack of Understanding**

1. I have to prove myself
2. It's invisible - I don't look disabled
3. People think I'm fine
4. People don't believe - there's anything wrong with you
5. People close to me - it's just white noise to them
6. Not recognised
7. She's only got a couple of years left what's the point of her
8. People don't listen any more
9. They don't care - just stare at you
10. I don't tell people - they don't want to know
11. Judgement - you're too big (is that my view? Or theirs)
12. Judgemental
13. With an outward sign ,people are nicer - stick etc

##### **Friends and Family**

I rely on my friend

People treat old/young differently

It's been better since Covid - people help more

##### **What We'd Like**

I had cancer ten years apart and things have changed - people talk about it now I hope this will happen with pain

Take it seriously

#### **Event 5 (Social Prescriber Group)**

##### **Lack of Understanding**

1. Not being believed
2. Looking for acceptance
3. They feel patronised
4. Empathy from others can be hard
5. More empathy needed
6. Patience from others is needed
7. Support group leaders need to understand the nature of different conditions
8. Need for belief and acceptance from GPs and society
9. Impatient
10. Irrational – not believed
11. Disbelief that it can't be fixed
12. Judged to be lazy
13. Pity
14. People don't know what to say
15. Have you tried – because people can't cope with what they are saying
16. Disbelief that it can't be fixed

##### **Friends and Family**

17. Caring is wearing on others
18. Spreads into family and friends

## Appendix 8: Communicating and Linking Between NHS Services

### **Event 1**

1. Better links between services
2. Communication between health authorities- esp. in different areas
3. GP and whole NHS need to communicate
4. Everything is piecemeal - join it up
5. Need for holistic support and care
6. Continuity of care

### **Event 2**

1. Different professions don't talk to each other - they need to
2. More joined up services
3. Joined up working
1. Different doctors need to talk to each other
2. A more joined-up approach
3. Holistic health care is needed - Everything is organised into systems - Rheumatology, Gynaecology etc they just look at one thing Leg head lung - you need to join us together and look at whole person, including mental health

### **Event 3**

4. Joined up thinking - 22 medications is a ridiculous place to get to – pharmacist questioned it and reduced it to 8
5. Team of specialist who look at me as a person and talk to each other
6. Holistic care
7. More holistic approach

### **Event 4**

1. More joined up services
2. Please join up everything

### **Event 5 (social prescriber group)**

1. GPs hand people to us because they don't know what to do with them and we are expected to sort it out - they need to understand what social prescribers do and can do
1. Need for consistency
2. One size does not fit all
3. NHS needs to understand people's limits

## Appendix 9: Dealing with GPs, Health Professionals & Wider NHS

### **Event 1**

4. GPs need to signpost
5. More signposting needed
6. GPs need to signpost other than to medicate.
7. GPs have no idea what's happening in the area
8. Working with the GPs I lost all hope. I had to find my way through other means
9. Everything is gauged towards emergency care - We need to live. Think prevention and living well
10. Longer GP appointments so we can discuss multiple things
11. People other than medical people know things - we need to see them too
12. I am given private physio but I never get an NHS review
13. Don't tar everyone with same brush - see us as individuals
14. Not everyone has same experience even if they have same conditions
15. Mental Health is as important as physical health

### **Event 2**

16. More Signposting - what else? Where else can I go?
17. Face to face and online appointments - it is not one size fits all
18. Signposting is getting better but we want more
19. I have to do a lot of self-support - please help with this
20. Some GPs listen - some are good. Some don't listen and are bad
21. Medics don't understand

### **Event 3**

1. GPs need evidence and use NICE guideline, which is fair enough, but need more open-mindedness
2. GPs no longer have normal conversations - they aren't allowed to recommend things like acupuncture as not evidenced based - That's not helpful
3. Need regular reviews
4. Six monthly review for chronic pain would be nice, rather than just live with it
5. Even if you just on a list for appointments you feel cared for rather than just left
6. Medics don't understand the need for emotional support
7. Lack of Understanding - especially from medical people
8. I get no NHS support
9. I have a brilliant pharmacist
10. If they don't know what to do with it, they shrug you off!
11. They've drawn a line through my name and written me off
12. NHS told me to google symptoms - But this leads to life threatening conditions mentioned- No support offered
13. Misinformation from NHS
14. Nonchalant NHS clinic - not present in our conversation
15. Long Covid clinic is shit

### **Event 4**

16. I need a clear diagnosis.
17. I trusted NHS years ago but have now given up so I just get on with it alone now
18. Need for Continuity - Regular appointments etc

19. Please can we see doctors - telephone consultations are not good enough.
20. More information - what can I do
21. Need continuity - Regular appointments etc

**Event 5** (*social prescriber group*)

1. Battling with clinical services
2. Consult with them don't tell them
3. They want to be diagnosed treated and fixed as you would be with a broken wrist
4. GPs to be honest when they don't know
5. Belief and acceptance from GP and society



## Appendix 10: Thoughts About Medicines

### **Event 1**

6. Right drug for right pain - Make the prescription fit
7. Solutions other than medication
8. I am given medication only - But that makes it worse
9. I take over the counter pain killers
10. GPs need to signpost other than to medicate

### **Event 2**

1. What is out there - aside from medication - we need to know
2. I take medication to manage other medication.

### **Event 3**

3. More layered approach not just more and more and more drugs
4. Joined up thinking - 22 medications is a ridiculous place to get to – pharmacist questioned it and reduced it to 8
1. They gave me medication straight away
2. They just give me medication - don't look into it

### **Event 4**

1. I've given up on medication – I live with the pain

### **Event 5** (*social prescriber group*)

No comments on medication

## Appendix 11: Need for and Benefit of Peer Support

### **Event 1**

1. Peer support - others sharing same reality is really important
2. This is what is missing -talking to others with the same lived experience

### **Event 2**

1. The Long covid support group is helpful
2. The online chronic pain group self-help course is helpful
3. Need for more local peer support groups

### **Event 3**

1. The ME support group
2. My peer support group is helpful
3. Mel Richard's Long covid support group
4. Peer support helps - we understand each other
5. Chronic fatigue group in Bristol - Peer support
6. Others who are in the same boat
7. GL11's long covid group
8. Peer support with Pain

### **Event 4**

1. More peer support
2. More emotional support
3. Access to more friendship groups

### **Event 5** (*social prescriber group*)

1. Peer support - can be difficult to get them to engage
2. Peer support would help
3. It would be nice to be with people who have similar (Quote from client)
4. Be with others who understand - friends who get it can not be understated

## Appendix 12: Comments on Education

### **Event 1**

1. Tell us what can health services do? I don't know if I expect too much?
2. What is normal what isn't. More education in the public is needed
3. Is this normal or not normal?
4. Normalise the ageing process
5. Educate people about CP

### **Event 2**

6. Raise awareness - carers and in the public
7. More information needs to be available
8. More advice on aids/equipment
9. Who is out there?

### **Event 3**

1. Educate people- public understanding
2. People only understand certain conditions

### **Event 4**

1. I need to know what I'm entitled to
2. Housing help
3. I need a firm clear diagnosis
4. More information - what can I do
5. More public understanding of chronic pain

### **Event 5 (Social Prescribers)**

1. Training on CP - what to expect how it manifests etc How brain responses
2. Pain directory – what services are available
3. Idiots guide to conditions – ME, chronic fatigue
4. What services will and won't do
5. Hard for us – we want to help but don't know what's on offer
6. GPs hand people to us because they don't know what to do with them and we are expected to sort it out - they need to understand what social prescribers do and can do
7. Our reputation is at stake - GPs refer to us because they don't know what to do but we don't know what to do either!

## Appendix 13: Peer Support Benefits and Challenges

Peer Support can be defined as the sharing of learning and knowledge between people with shared lived experience within a safe space.

Peer Support involves giving and receiving support and can take varying forms:

1. Virtual groups
2. Face to face groups
3. One to one conversations
4. Telephone calls

We recommend peer support to be offered by a trained facilitator or a lay person with lived experience themselves.

Much research has been conducted into peer support groups, particularly in the fields of mental health or support for long term conditions such as diabetes. Outlined below is a summary of some of that research and the benefits of peer support.

### ***The Benefits***

**MIND** (2015-17) conducted research into peer support for mental health (the *Side by Side project*). They found that for a peer support group to be successful, careful consideration should be given to the needs of each specific group in terms of the individuals, locality, culture etc. They found that positive changes occurred in individuals attending such groups in the areas of wellbeing, hope, connection and empowerment. They were found to rely less on friends and family and were less dependent on medical interventions.

**National Voices** published a summary of over 524 studies on peer support. The report suggests that peer support improves a person's life experience, behaviours and overall health outcomes. The report encompasses a multitude of different types of peer support ranging from one-to-one, virtual support to facilitated groups.

**NHS England's Five Year Forward View** references peer support as a 'slow burn, high impact' action that should be seen as 'essential' to the future of the NHS.

**Nesta's** report, *People Helping People*, is a summary of the positive impact of peer support showing that it can lead to improvements for people with long-term conditions in regard to wellbeing outcomes. This report highlighted a decrease in demand for health services.

### ***The Challenges***

During our research we heard of some of the challenges in terms of setting up peer support groups, particularly concerning people's hesitancy in joining. These included:

1. Perception of the groups being a 'moaning shop' – not wishing to join a group of people who are miserable
2. Fear of being vulnerable with people they don't know
3. Fearing it is pointless – they just want to be cured by the GP