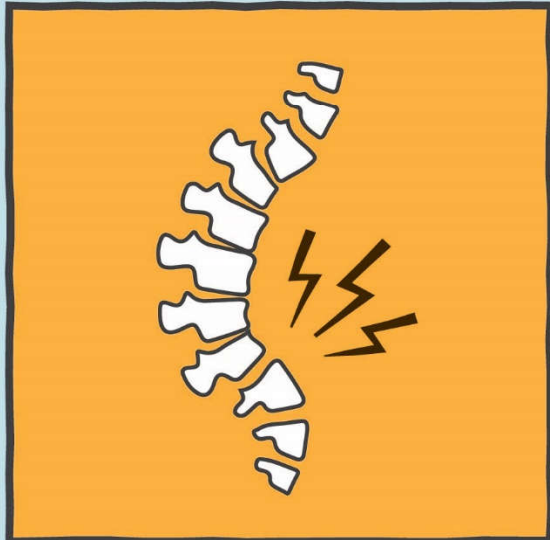
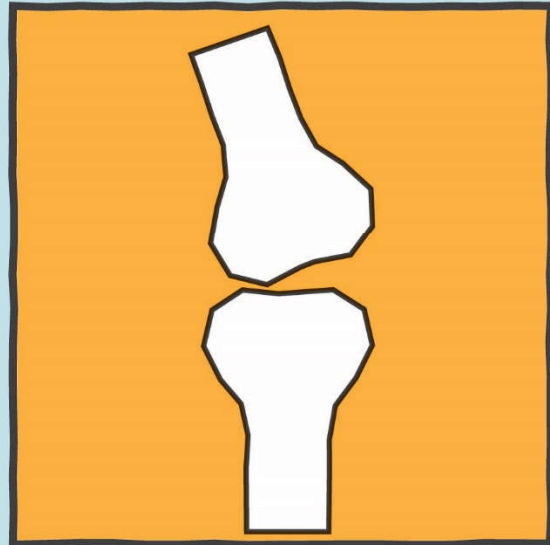


# Out of Pain

Breaking the cycle of physical pain  
and homelessness



**Groundswell**  
Out of homelessness

  
**Trust for London**  
Tackling poverty and inequality

## Groundswell

Groundswell is a registered charity, which exists to enable people experiencing homelessness to take more control of their lives, have a greater influence on services and have a full role in our community. Our vision is of an equal and inclusive society, where the solutions to homelessness come from the experiences of people who are homeless.

### Groundswell's Research: Insight and Action

**Generating insight:** We aim to uncover the issues faced by homeless people and crucially, develop achievable solutions. All of our projects are delivered by and collaboratively run by people who have experience of homelessness themselves as peer researchers. "Formal" researchers can struggle to overcome some people's mistrust of authority figures, whereas the empathy and shared connection of peer researchers can get the real picture. Often peers can be the only ones who can engage "hard to reach" homeless people.

**Participation:** We involve people affected by the issues in all stages of the research process ensuring that we are asking the best possible questions and that means the findings are really owned by participants.

**Solutions to homelessness:** Groundswell believes in using innovative facilitation to bring together many different views - from lived experience, from policy makers, from academics and from the front-line - to analyse our grassroots insight to generate new solutions.

## Acknowledgements

This research would not been possible without the hard work and dedication of the Peer Researchers who were involved throughout the project.

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We would also like to thank Pain UK and in particular their Chair, Antony Chuter for his guidance throughout the project.

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# Out of Pain: Breaking the Cycle of Physical Pain and Homelessness

## Executive Summary

Out of Pain is a research study into the extent, cause and impact of physical pain on people experiencing homelessness, which was conducted by Groundswell and led by peer researchers. The project is funded by Trust for London.

It was a co-produced, mixed methods exploration including: a literature review, seven focus groups (N39) and 222 one-to-one surveys. Data collection was carried out between October 2017 and February 2018 in temporary accommodation and day centres across London. Early findings were presented at an *Action Day* facilitated by Groundswell in June 2018 to a group of people working in homelessness and health, academics, peer researchers and others with experience of homelessness. This workshop was attended by 38 people who took part in group work to respond to findings and help generate recommendations.

The research supports the literature regarding the widespread impact of chronic pain on people experiencing homelessness<sup>i</sup>. Furthermore, the findings indicate that pain and chronic pain are also contributing to people becoming homeless in the first place and remaining in or returning to homelessness. The aim is for a more effective and accessible range of responses to be established regarding what works in relation to the treatment of pain amongst people experiencing homelessness. To understand the realities of living with chronic pain when homeless, comparisons between the general UK population, full survey population and a subset of survey participants in chronic pain are highlighted through the course of the report.

## Summary of findings

**Physical pain is widespread among people experiencing homelessness.**

- **62% reported to be currently experiencing physical pain when interviewed;** 47% experience physical pain on a daily basis and a further 9% experience physical pain every other day.
- **Chronic pain affected over half of all participants;** 53% reported experiencing chronic pain with many having had long term experiences of chronic pain; almost a quarter (24%) had been suffering from physical pain for 10 years or more.
- **Many of the medical conditions causing ongoing pain were higher than present in the general population.** The most common were: broken bones (39%), arthritis (23%), migraine (22%), pain after surgery (22%), sciatica (14%) and cluster headaches (12%).

Homelessness and traumatic life experiences drive and compound the effect of physical pain.

- **Violence, self-harm and accidents leading up to and since people had been homeless were at the root of some people's health issues, ongoing injuries and pain;** 26% had been a victim of violence, 21% had had accidents and 16% had self-harmed.
- **Rough sleeping places a severe burden on the body and is directly linked to pain;** 87% had aches and pains from sleeping rough, 90% had hurt their back from carrying a backpack and 87% agreed that injuries take longer to heal when sleeping out.
- **Poor availability of healthy food caused short and long-term health impacts on participants;** 62% of survey participants reported to have had stomach cramps because of a lack of food. Less than half (45%) of participants would claim they currently have a healthy diet.

Issues commonly associated with multiple excluded homelessness (MEH)<sup>ii</sup> and difficulties engaging with medical professionals are thwarting successful treatment of pain.

- **Drug, alcohol and mental health issues can make diagnosis and treatment difficult and over half of the cohort experienced both;** 63% had experienced mental health difficulties, 58% reported to have experienced substance misuse issues.
- **Prescription medication was commonly administered by health professionals as a response to pain but for many they wanted to explore other medical and non-medical options.** Amongst participants in chronic pain the most common medical response was prescription medication, although less than half (47%) in this group wanted to be treated in this way.
- **The type of medication and the way it is prescribed to homeless people is not meeting their needs.** Short prescriptions and difficulty in the ongoing management of medication was highlighted by some participants; 54% of participants said that their tolerance to pain medication had been affected by their drug use.
- **A third of participants (32%) were not happy with the care they received last time they saw a medical professional.**

In the vacuum of successful treatment, people turn to unorthodox measures to be able to deal with and manage pain.

- **Illicit substances and alcohol were widely used to manage physical pain;** 43% of participants had used drugs and/or alcohol to deal with pain.
- **Obtaining prescription medication without a prescription was common;** 25% had taken opioids, 2% steroids, 19% anti-inflammatories, 11% Pregabalin and 3% Fentanyl.
- **Use of emergency care to deal with pain issues was widespread.** Among those experiencing chronic pain, three quarters (74%) (Base=111) had been to A&E in the last year, nearly all (85%) (Base=111) because of their physical pain.

Chronic pain is having a severe impact on lives and contributes to people becoming homeless and remaining or returning to homelessness

- **Commonly, participants reported that pain issues had been a contributing factor to why they became homeless;** 39% of all participants felt that physical pain had contributed to them becoming homeless, 50% reported physical pain had caused trouble with personal relationships, 67% of those suffering from chronic pain said that physical pain made it difficult for them to hold down a job.
- **Physical pain contributes to poor mental health of many participants;** 69% said physical pain had been bad for their mental health. Three quarters (73%) of those that were in chronic pain felt they had mental health issues.
- **Chronic pain and interrelated disability caused an impact on the mobility of many participants.** Among participants in chronic pain three quarters (73%) reported that they had a disability, 32% had difficulties moving around the hostel due to mobility issues.
- **Chronic pain is causing many participants to be unable to do daily tasks that would allow them to live a more fulfilled life.**

## Out of Pain Recommendations

While there is huge variation in the lived experience of homelessness, there is a need to recognise that physical pain is a common and life limiting condition. The following recommendations have been developed as a result of the Groundswell Out of Pain *Action Day* with input from health and homelessness professionals, academics and people with experience of homelessness. Implicit in the delivery of these recommendations is the necessary funding and that the recommendations be delivered in a way that includes the voice of homeless people throughout the planning, delivery and evaluation of services and interventions.

### Homelessness services

The scale of chronic pain among people experiencing homelessness means that a response from homelessness services is needed to better meet needs. Creating a holistic, supportive environment informed by pain and wider health issues is a key component of this support.

- R1. Training.** Training for front line staff on the link between pain and homelessness is needed to understand the impact it has on the lives of people, how to support and access support.
- R2. Get busy.** Hostels and other homelessness services need more opportunities that encourage people to be active both physically and mentally for a range of abilities.
- R3. Pain management in homelessness services.** Specialist pain management support tailored to the needs of people experiencing homelessness is essential to provide people with pain management skills.
- R4. Diet.** Where food is provided by homelessness services, there needs to be more healthy options. Providing a varied diet to people who use services will have a positive impact on wellbeing.



## Healthcare providers

Chronic pain is a common and life limiting condition within the homeless community. More needs to be done to raise awareness of the issue among medical professionals and develop an understanding of how to support homeless patients to manage pain through a wider range of interventions.

- R5. Raising awareness.** General Practice surgeries need to better understand the link between homelessness and physical pain and what the possible referral pathways are for treatment beyond prescribing pain-relieving medicine. Existing examples of good practice within specialist homelessness GP services and pain specialists must be identified and shared widely.
- R6. Training for specialists.** There is a need for pain specialists to have a better understanding of homelessness and the often complex needs their patients may be dealing with and the impact this may have on their ability to engage in treatment.
- R7. Moving care into the community.** Local pain support and treatment, including physiotherapy and pain management, should be more readily available and accessible. Ideally, these services could be brought to day centres and hostels.
- R8. Appropriate prescriptions.** Short prescriptions need to be made to people only when a real risk to the person's safety is evident, not based on a judgement relating to a patient's status as homeless.
- R9. Complementary and alternative therapies.** The call from participants in this study for alternative and complimentary therapies to help manage pain represents a need for greater access to therapies through the NHS.

## Alcohol, drug and mental health services

The interrelated nature of physical pain, mental health issues and substance misuse in working with people experiencing homelessness has been a clear theme within the findings of this research.

- R10. Pain conscious support.** Time limited treatment within pain management, substance misuse and mental health services means that people are at real risk of returning to a cycle of neglecting health and living with pain. Chronic pain is an ongoing condition that can be a driver for substance misuse and mental health issues and services need to offer sustained support.
- R11. Pain and prescribing.** Provision of adequate pain medications to people experiencing homelessness, particularly for people with substance misuse issues, is key to supporting recovery and sustained wellbeing. Good practice in this area needs to be shared with prescribers.
- R12. Routes into pain management.** When services identify that chronic pain may be a driving factor behind substance misuse or mental health issues, it is vital that referrals are made into pain management services. We recommend creation of these pathways allowing a speedy and holistic response.

## Housing First

The most sure-fire way of preventing the trauma placed on the body as a result of homelessness and breaking a cycle of chronic pain and homelessness is to provide non-conditional and independent accommodation with high quality, holistic support that is intensive and open-ended.

- R13. Housing First.** We recommend the further roll out a housing first model across the UK.

## Introduction

Many homeless people are living lives where physical pain represents a daily reality. The link between inequality and experiences of physical pain are well established<sup>iii</sup>. For homeless people who face some of the most extreme social and economic exclusions in society, chronic pain is damaging physical and mental wellbeing and creating another obstacle for people to move away from homelessness and live more fulfilled and meaningful lives.

Existing research has clearly demonstrated a significant health inequality in the physical pain experienced by homeless people, much of this has come from international evidence. One recent study by Fisher et al. in the UK found 59% of those experiencing homelessness were in chronic pain, with an average duration of pain being over six years<sup>iv</sup>. There is a need to validate the findings of Fisher et al. in relation to pain prevalence. In addition, there is a need to establish the mechanisms by which pain can lead to homelessness and be caused by experience of homelessness. This study set out to explore the extent, causes and impact that physical pain is having on people experiencing homelessness.

Pain management programmes and other interventions have been shown to be highly effective treatments amongst the general population, however the challenges of care particularly around addiction issues and 'chaotic' lifestyles make treatment a significant challenge for people experiencing homelessness. By understanding how homelessness and physical pain interrelate we ultimately aim for a more effective and accessible range of responses to be established regarding what works in relation to treatment of pain amongst people experiencing homelessness.

**For a further review of academic and clinical literature please see the appendix.**

## About Groundswell

Groundswell is a registered charity, which exists to enable people experiencing homelessness to take more control of their lives, have a greater influence on services and have a full role in our community. Our vision is of an equal and inclusive society, where the solutions to homelessness come from the experiences of people who are homeless.

Since 1996 Groundswell have been supporting homeless people to be involved in delivering solutions to homelessness. This includes the Homeless Health Peer Advocacy (HHPA) service which supports homeless people to address their health needs and our Insight and Action Programme which uses peer research to uncover the issues faced by homeless people and crucially, develops achievable solutions. All of our projects are delivered by and collaboratively run by people who have experience of homelessness themselves.

Groundswell's HHPA service supports homeless people to access healthcare, delivered by Peer Advocates – volunteers who all have personal experience of homelessness. Peer support enables people to overcome the practical, personal, and systemic barriers, which can prevent homeless people from addressing their health needs. In the financial year 2017-2018 we delivered 2900 one-to-one engagements, and almost 700 Health Promotion sessions with people experiencing homelessness. We also deliver specialist peer health support projects focusing on women, Hepatitis C, mental health and hospital discharge.

As a result, Groundswell is uniquely placed to uncover new insight into the health inequalities faced by homeless people. Groundswell's peers have a deep understanding of the realities of homelessness and the barriers that prevent people experiencing homelessness from accessing the healthcare they need – both through their lived experience and through delivering this work. Groundswell's Insight and Action work was created in recognition of the uniqueness of this perspective and works with peers to capture this on an ongoing basis to have a genuine and unique grassroots insight into the realities of homelessness. The topic of physical pain was set as a topic to explore in-depth by Groundswell Peer Advocates through the regular focus groups and informal feedback sessions that take place through the delivery of the project. Previously we have employed this model to explore oral health and respiratory health among homeless people.

## Methodology

**Design.** Groundswell's research is co-produced. The area of exploration, chronic pain, was decided upon in collaboration with Groundswell Homeless Health Peer Advocates and then reviewed with homelessness and health professionals who concurred that it was an area thinly investigated in relation to homelessness in current literature. The Insight and Action model was designed through consulting clinical experts, academics, people experiencing homelessness and other key stakeholders and employs a mixed method approach that makes use of qualitative data through focus groups for which the data then informs a survey that gathers quantitative data. This made it possible to explore participant's understanding of chronic pain and related lifestyle and behaviours as well as getting a sense of the extent of experiences shared in the focus groups. In addition, we collected a series of case studies that illuminate the subject with the telling of personal stories of pain and homelessness, which captured the complexity of individual experience and illustrates how homelessness and pain interrelate. Informed consent was sought and received from all participants.

**Literature Review** A literature review of current learning around chronic pain, health inequality and homelessness was undertaken which shaped the key areas of exploration for the project. This involved discussion with academic partners to find appropriate literature as well as online searches of academic and clinical journals. While recent learning from UK settings was initially sought, gaps in literature meant that international literature and older sources were also explored to develop learning. The full literature review is available in the appendix.

**Focus Groups.** An employed Groundswell peer researcher facilitated a series of seven focus groups in homelessness hostels and day centres to gain in-depth insight into the experiences of service users relating to physical pain and wider health issues. Questions in the focus groups were deliberately broad allowing participants to discuss their perceptions, opinions and attitudes towards homelessness and healthcare services, as well as to highlight myths and misgivings that may be associated particularly with access to health services. Focus Groups were recorded and audio recordings were transcribed, thematically coded and analysed.

**Peer Researchers.** Opportunities to participate in the research were promoted in hostels and daycentres across London and among the Groundswell team. Following an information session on the project describing aims and roles, three new volunteers and five volunteers who had had previous involvement with Groundswell joined the Peer Research team. A two-day training was initially run that focused on the research processes and practical approaches to interviewing where learning took place through presentations, small group work and hands-on activities. The initial session created a framework for a survey schedule based on the findings from the Focus Groups. Three follow-up sessions were then run where the survey was further developed, tested and refined. A team of eight researchers delivered the fieldwork for this project.

**Survey.** In collaboration with researchers, a health audit survey was developed to understand the extent to which pain affected participants and the driving factors behind this. This also included a series of statements from the focus group transcripts to gauge the extent to which experiences were shared and opinions agreed with. Between October 2017 and February 2018 Researchers undertook data collection face-to-face with people who are currently homeless across London. This was delivered by peer researchers on a one-to-one basis using tablet computers.

**Validated Scales.** Measuring pain amongst people experiencing homelessness is challenging. One study suggests that commonly used validated scales are not widely understood by people experiencing homelessness and may produce poor quality data<sup>v</sup>. During the testing and refinement stage of the survey there was some difficulty with the use of the scales such as the 'Brief Pain Inventory (Short Form)'<sup>1</sup> and the 'Wong-Baker Faces Pain Rating Scale'<sup>2</sup> due to the wording of the questions. A decision was made to use part but not all of the 'Brief Pain Inventory (short form)', but some issues were still highlighted during the fieldwork particularly around the applicability of the questions for people experiencing homelessness when assessing impact on daily life. For example, when exploring how pain has interfered with 'sleep', which may be disturbed due to rough sleeping or 'relations with other people', when participants may already be isolated. It is particularly so with rating the impact of pain on 'enjoyment of life'; one participant summed the difficulty in responding to this question with the response, "Do I Look Like I am Enjoying my Life?!". For this reason the research explores some of the topics highlighted in this measure but does not include the full data.

**Analysis.** Survey responses were inputted into SPSS<sup>3</sup> data analysis software. Preliminary findings were fed back to peer researchers through workshops who directed the analysis of the data. This report was produced based on the study's findings.

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<sup>1</sup> The Brief Pain Inventory (BPI) rapidly assesses the severity of pain and its impact on functioning. The BPI has been translated into dozens of languages, and it is widely used in both research and clinical settings.

<sup>2</sup> This tool was originally created with children for children to help them communicate about their pain. Now the scale is used around the world with people ages 3 and older, facilitating communication and improving assessment so pain management can be addressed.

<sup>3</sup> SPSS (Statistical Package for the Social Sciences) is a software package used for statistical analysis.

**In total 269 people with experience of homelessness directly participated in this project.** This included seven focus groups involving 39 participants and 222 one-to-one survey interviews, which were conducted by eight peer researchers.

## **Participant profile**

Of the 222 survey participants who took part in this research, 77% identified as male, 19% identified as female and 1% identified as transgender. These figures are comparable to the rough sleeping population of London revealed through Combined Homelessness and Information Network (CHAIN)<sup>4</sup> figures (male 85%, female 15%, transgender 0%) with a slight increase of those who identify as female and transgender represented in this study.

Participants ranged in age between 20 and 75 with 58% of participants ranging between 36 and 55, similar to CHAIN figures (54%). However, this study also saw a slight increase in those aged over 55 represented at 16% (CHAIN 11%). Regarding place of birth this study found 60% of participants self-reported to be born in the UK in comparison to 47% in CHAIN figures.

Among those we spoke to, 67% felt they had current issues with their mental health, which compares to 47% identified by CHAIN as currently having a mental health support need. Similarly, 57% of participants reported having experience of substance misuse issues compared with 35% with a current drug use support need and 44% with a current alcohol use support need as identified by CHAIN. This latter finding can in part be explained by this study investigating lifetime prevalence compared to CHAIN who report on current prevalence. Although comparable data is not available from CHAIN reports, 52% of participants in the present study considered themselves to be living with a disability.

## **The Scale of the Issue**

### **Experiencing physical pain**

This study supports literature that indicates that physical pain is a widespread issue for people experiencing homelessness. Among participants in this study, 62% reported to be currently experiencing physical pain at the time of the survey: 47% told us that they experienced physical pain on a daily basis and a further 9% experience physical pain every other day. The link between inequality and experiences of physical pain are well established, for example, men and women in the lowest income households are more likely to report chronic pain (42%), compared to those in the highest quintile (27%)<sup>vi</sup>. In the case of people experiencing homelessness who are subject to some of the most extreme social and economic exclusions, there is evidence in this study that people experiencing homelessness are at a higher likelihood to be subjected to physical pain.

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<sup>4</sup> CHAIN is a multi-agency database recording information about people sleeping rough and the wider street population in London. The system, which is commissioned and funded by the Mayor of London and managed by St Mungo's, represents the UK's most detailed and comprehensive source of information about rough sleeping. Reports on CHAIN data are available on the Greater London Authority website: <https://data.london.gov.uk/dataset/chain-reports>

In clinical terms, physical pain can be described as “An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage”<sup>vii</sup>. Pain can be broadly seen as acute in nature where it lasts for less than three months and is related to soft tissue damage, or chronic when lasting for a longer period typically defined as over three months. The causes of physical pain are diverse but can be broadly understood to be either in regular episodes of acute pain or through long-term chronic pain where the causes may have been an injury or an illness but have resulted in a condition to be managed itself.

We aim to understand the drivers and impact of chronic pain within the homeless population. In this study we will refer to and examine a subset of the survey participants who are experiencing chronic pain to highlight how they compare to the wider homeless population. Significant differences between the full survey and chronic pain subset will be highlighted through the course of the report.

The issue with defining pain is that people experience physical pain in different ways, particularly differing in frequency and intensity. For those experiencing physical pain, the ways people may describe their pain are diverse and very personal. For some, physical pain can be ongoing and constant but for others it can come and go, sometimes daily, sometimes less frequently.

The range of ways that physical pain can be experienced in terms of frequency and severity makes it difficult to measure an individual’s own experience of pain. One person may have a sensory experience that is vastly different than that of another due to different factors driving that pain, or even their sensitivity to the sensation of pain itself<sup>viii</sup>. This participant explains their experience of pain:

*“Because you know even when you are in pain, it’s not constant. Its waves. I mean... my arthritis isn’t bad every day. It’s bad. [...] There are days I can walk without a walking stick, there are days I can make a cup of tea. But there are days when I can’t. And there are days when I can’t even get out of my bed.”* – Focus Group Participant

The personal nature of the way physical pain is felt and processed by people means that it is not uncommon for people to build a relationship to ‘their’ pain and describe it in such terms. Feeling that you are facing something that no one else can fully understand can be a lonely place. One participant explains his pain:

*“[What] other people feel [...they] are not going through the same thing. They sleep at night while you can’t sleep. You have to take medication after medication. He [My partner] has seen me sometimes, I can’t get off the bed. [My partner] Has to literally carry me when my back is really painful. And that is pain. Like he said you won’t to get over that. But I can’t. You know what I mean.”* – Focus Group Participant

**How would you describe your pain?**

**Extremely painful** Too much pain, I cant walk **Agonising** Can be excruciating depending on weather! **Dull** Dark pain **EXCRUCIATING** They are on fire  
 A constant dull ache in the background Like someone twisting my back **ACHE** I can't lay flat  
**Constantly IN PAIN** **THROBBING** **Agony** Getting really agitated  
 It makes me cry **Burning** Headaches stop me sleeping  
**Severe REALLY BAD unbearable** Hot needles in my skin ... **EXTREME** Very painful, especially in the cold  
 Like my bone is in a vice **Shooting** Horrible  
 Drags me down Complete Nightmare **SHARP & INTENSE!** gasping for death  
 I can't lay flat my back hurts **NIGHTMARE**  
 It's like when you shoot an arrow into wood  
**I CANT WALK** like a dagger in my shoulder  
 Spasms and pains in head from neck **Like a knife**  
**uncomfortable** Aches muscle cramps

Figure 1: Selected Responses from open ended survey question: 'How would you describe your pain?'

We asked survey participants who reported to be experiencing physical pain to describe their pain; responses ranged from short one-word descriptions to quite extensive accounts. The most common words that appeared in all responses were ‘ache’, ‘bad’, ‘shooting’, ‘sharp’ and ‘constant’. Some descriptions were particularly illustrative of the pain participants were facing:

*“Feels like someone has my leg in a vice and is turning it. Hot needles in my skin. Like my bone is in a vice.”*

*“A humming in your nervous system that won't go away. Linked to the ringing in my ears.”*

Another common theme was how participants’ descriptions related their pain to external factors such as the weather, a likely link to the way their bodies are exposed to the elements. For example:

*“Too much pain, can't walk, headaches stop me sleeping. Worse when cold”.*

*“Depends on the weather cold and damp puts pain in 9 to 10 region”.*

## Chronic Pain

Experience of chronic pain, typically defined as over three months experiencing physical pain, is a common and debilitating condition within the general population. Among participants in this study over half (53%) reported experiencing physical pain for three months or more, with many participants having experience of pain for significantly longer. For example, almost a quarter (24%) had been suffering from physical pain for 10 years or more.

*Table 1: Proportion of survey participants experiencing physical pain by length of time.*

Length of time experiencing physical pain anywhere in body	Percentage of participants (Cumulative)
More than 3 months	53%
Over 1 Years	48%
Over 2 years	42%
Over 5 Years	32%
Over 10 Years	24%

This figure is lower than Fisher et al.<sup>ix</sup> revealed in their research, which found 59% of those experiencing homelessness were in chronic pain with an average duration of pain being over six years. However, it is significantly higher than the figure for the wider UK population; The British Pain Society’s (2011) ‘Putting Pain on the Agenda’ report states one in eight people

(12.5%) live with chronic pain in the UK<sup>x</sup>. As the figure for the UK prevalence of chronic pain is difficult to calculate there are a range of figures often used, but against all comparators with the general population, the findings of this study reveal a disproportionately high prevalence among people experiencing homelessness. This is particularly stark when the age of this studies’ cohort, which is significantly lower than the general population, is taken into account. For example, a recent systematic review suggests that chronic pain affects



between one-third and one-half of the UK population, with the burden disproportionately felt by the elderly – up to 62% of people over 75 experience chronic pain<sup>xi</sup>.

All participants who identified they were in chronic pain reported that they were currently experiencing pain at the time of the interview. Three quarters (74%) said they experienced pain every day (Base 112) with the remainder reporting it was less often.

### **Who is in chronic pain?**

Experience of chronic pain is widespread across the research cohort. To understand who chronic pain is affecting we have compared the experiences and other characteristics of participants who reported to be in chronic pain to the wider survey participants.

A key consideration, and in line with existing research looking at the general population<sup>xii</sup>, is that female participants in this study were more likely to have experienced chronic pain; with a higher proportion of women (27%) in the chronic pain survey than in the total survey (20%). However, other demographic factors like age and ethnicity had less of an impact on whether participants experienced chronic pain. For example, similarly to all participants in the survey 63% were in the 36-55 age categories (Base 104). Further to this, how long participants had experienced homelessness and when their homelessness first began did not have a significant impact. Where in common with the full survey, respondents had often first become homeless when young, with 42% aged under 25 and 16% under 18 (Base = 111).

The great majority of participants who were experiencing chronic pain (90%) had slept rough at some stage in their lives, including 24% currently sleeping rough (Base 110). Over half (53%) had slept rough for two years or more in total, and a third (35%) for five years or more (Base 99).

In terms of the support needs of this group, participants who had chronic pain were significantly more likely to report to have physical disabilities (73% compared to 52% of all survey participants), and noticeably more likely to report to have physical health issues (83% compared to 68% of all survey participants). Participants in chronic pain were also more likely to report to have learning difficulties (30% compared to 23% of all survey participants). However, suffering chronic pain did not have a significant impact on likelihood of experiencing mental health issues. Participants who reported to be experiencing chronic pain, were no more likely to have substance misuse issues than the wider research population.

In many cases participants who are in chronic pain were more likely to have had adverse experiences in the past. For example, participants experiencing chronic pain were more likely to have been victims of domestic violence and marginally more likely to have been in social care. Chronic pain did not have a significant bearing on the likelihood of having slept rough or having had criminal justice issues.

Table 2: Proportion of all participants who have had adverse experiences compared to participants experiencing chronic pain.

Proportion of all participants who have had adverse experiences compared to participants experiencing chronic pain.				
Experience of Issue	All Participants		Participants in Chronic Pain	
Has been in social care	23%		25%	
Consider self to have a disability	52%		73%	
Domestic violence	25%		30%	
Learning Difficulties (e.g. Dyslexia)	23%		30%	
Mental Ill-health	62%	27% Admitted to Psychiatric Unit	64%	30% Admitted to Psychiatric Unit
Physical health difficulties	68%		83%	

## Locating Pain

This study asked participants to identify if they were currently experiencing pain, the location of this pain, duration the pain had been experienced for and the intensity of this pain. The most common place where pain was experienced among all survey participants was in the legs (25% of all survey participants) and the back (23% of all survey participants). For those that reported they were experiencing chronic pain, participants reported higher proportions of pain in different parts of the body and frequency of pain. The most common areas where chronic pain was experienced was in the back (45%), legs (45%), head (21%), arms (20%) and feet (19%). One participant explains where his pain affects him:

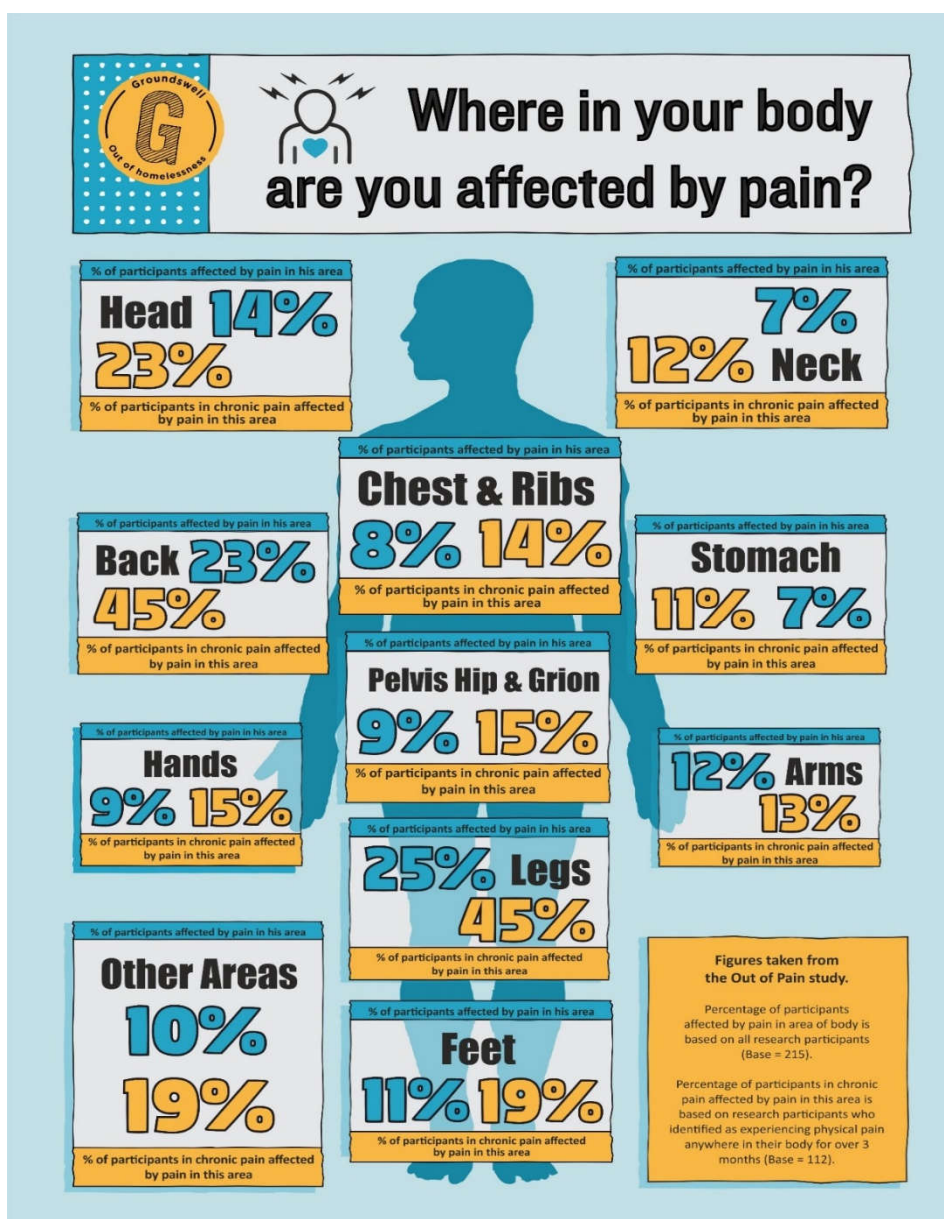
*“Most pain like I said, it really is my arm. And just like... It’s like it’s pulling strings sometimes. Like most of the time it’s like in a lock, you know what I mean. My back is actually locked. And that is some serious pain man.”* – Focus Group Participant.

For many participants pain was not localised to one area of their body but experienced across their body in multiple locations. One participant explains how physical pain affects him:

*“I mean I am in constant pain. My knees, my hands, my back. But the doctor has said to me where is the pain? And I say all over my body. Because there is not one part where there is not a pain.”* – Focus Group Participant.

Participants were asked to rate the level of their current pain experienced in the different parts of their bodies using a 1-10 scale. Two thirds of participants (67%) who reported to be experiencing chronic pain, reported that they were experiencing moderate to severe pain (5 or above) somewhere in their body which is likely to have significant impact on social activity. Again the prevalence of severe pain among research participants is significantly higher than within the general population where in between 10.4% and 14.3% of the population (around 8 million people) chronic pain is moderately or severely disabling based on Von Korff's chronic pain severity assessment tool <sup>xiii5</sup>.

Figure 2: Location of Pain in the body for proportion of participants.



<sup>5</sup> The Chronic Pain Grade Scale (CPGS) developed by Von Korff and colleagues is a validated, bidirectional tool that assesses the severity of chronic pain, based on its characteristics and the impact on a person's activities. The scale uses a severity score based on participants' subjective assessment of their: current pain; worst and average pain over previous six months; pain related disability and pain interference with social and work related activity. An algorithm divides respondents into: low disability, low intensity chronic pain (Grade I); low disability, high intensity chronic pain (Grade II); high disability, moderately limiting chronic pain (Grade III); and high disability, severely limiting chronic pain (Grade IV.)

## Identifying the Causes of Pain

### Case Study: The Hell of Homelessness and Pain

The following case study was written by a Groundswell peer researcher, who volunteered on this project and who joined Groundswell specifically because of her own experience of physical pain and homelessness. She is now in her mid-thirties and lives in stable accommodation. The case study is unedited.

*“The first time I became homeless I was only 16 and I slept rough for four years. I left home as a result of childhood abuse. As a young girl on the street I found it difficult. I was very naive and not at all streetwise. Sleeping rough was a terrifying experience – the complete lack of safety and never getting any proper sleep, because I was too frightened and too vulnerable. I remember those days as a lot of aimless wandering, walking for hours at night because I didn’t know what else to do. There was never any way to get comfortable, we’d get hosed down by street cleaners in the early morning. Imagine being woken up in your sleeping bag, being hosed down with freezing water. Every single day people would abuse me, just because of the situation I was in. I was spat on, insulted, pissed on and hurt countless times. I was also brutally sexually assaulted and badly beaten up. When I look back I’m not sure how I survived.*

*I found it very difficult to get any help. I remember getting told by an outreach worker that I “survived too well on the streets” and because I didn’t have “drug or alcohol problems, mental health problems, hadn’t been in prison, or in care and wasn’t pregnant, I wasn’t vulnerable enough” to be housed, not even in a hostel. Looking back, I can’t comprehend how any 16-year-old girl sleeping in a doorway is not vulnerable enough.*

*I was experiencing both chronic pain and chronic fatigue which was unbearable on the streets. A couple of times I tried to see a GP about back pain, but they always dismissed it without even examining me. I remember being so cold and the cold would make the pain.*

*Those four years were so traumatic and have left long-term physical and mental scars. Later when I was in my late twenties I unexpectedly saw the man who had assaulted me when I’d been on the streets before and it led to a kind of breakdown. I started to get really bad flashbacks, nightmares and started to re-live and re-play in my mind all those experiences from sleeping rough before. I had severe depression and PTSD, was self-harming as the only way to cope with my memories and ended up attempting suicide many times. I was also experiencing so much physical pain, but I didn’t know what was causing it and the pain was making my mental health a lot worse. I was diagnosed with M.E/Chronic Fatigue Syndrome. I was too unwell to work and found myself homeless for a second time. I spent another three years sleeping rough from the age of 27-30. The second time felt much harder as I was so unwell. I went to the Homeless Persons Unit many times but still wasn’t considered ‘vulnerable enough’ or in ‘priority need’. I ended up in A&E after a serious suicide attempt, spent a week on an acute medical ward and then was discharged straight back onto the street again. Some days I could hardly walk because my back hurt so much. Eventually I was sent for an MRI, which showed I had fractured my spine in early childhood most likely as a result of childhood abuse. I was told I needed surgery to try and slow down inevitable mobility loss as there was so much damage to my spine.*

*I ended up in supported housing and then got my own flat. I had back surgery a few years ago - multi-level spinal fusion of the lumbar spine with implants of metal rods and screws. However, I still continue to suffer from chronic pain. I've also been diagnosed with Osteoarthritis and Osteoporosis and have a lot of joint pain and my joints dislocate easily (especially in my hands).*

*Although I had a pre-existing back problem, I believe that the many years I spent homeless made my condition much worse. Sleeping rough on cold concrete pavements, not being able to get comfortable, and being so vulnerable to being attacked by others and the impossibility of getting help made it much worse than it needed to be. I doubt I would have ended up with Osteoarthritis/Osteoporosis at a young age if I hadn't have spent seven years (in different periods) on the street, I may have got those conditions later in life – but it feels like being homeless caused such a decline in both physical and mental health.*

*Since being housed there has been a huge difference in being able to access both physical and mental health services. I've also noticed a difference in how medical professionals treat me. As someone on the streets, I would be judged, and assumptions would be made about my life-style, I was often blamed for my situation. I had some awful experiences in A&E where I was treated so badly at the times I was most vulnerable and really needed help. There is something about being homeless which makes people see you with less compassion, less empathy and with a lot of blame. Once I was housed I was able to get treatment for pain conditions, I didn't have any treatment at all for chronic pain while I was on the street."*

As the case study illustrates, pain and homelessness interrelate in complex ways. Both the extreme physical stress, of rough sleeping in particular, and the material and discursive barriers people face in accessing treatment play out to prolong and exacerbate pain and prevent individuals from escaping homelessness.

### **Medical conditions causing pain**

Survey participants were asked to identify whether they had a diagnosed health condition that was causing them ongoing pain or discomfort. Across all participants there were high rates of diagnosed conditions, which in the case of many conditions were significantly higher than the rate in the general population even though the average age of participants was younger than the general population and many of the conditions were likely to be more prevalent in older age groups. The most commonly diagnosed health problems participants identified were: broken bones (39%), arthritis (23%), migraine (22%), pain after surgery (22%), sciatica (14%) and cluster headaches (12%). In many instances the conditions identified are long term and may have been lifelong. For example, one focus group participant explains the conditions that cause him physical pain:

*"Yeah what it is about physical disabilities, cerebral palsy which I was born with, from birth. And I do get pains, leg pains, a lot of leg pains. I can't walk long distance;, I have to rest every ten minutes. And I am used to what I have got and it's not curable."* – Focus Group Participant

However, in other cases participants identified conditions that had developed since they had been homeless. Some of these may be related to lifestyle factors, for example high rates of acute pancreatitis were highlighted, which has been demonstrated to have been linked to alcohol consumption. When compared to the rate of prevalence in the general population there was also a particularly high prevalence of cluster headaches, a rare form of primary headache with a population frequency of 0.1%.

Table 3: Proportion of participants affected by chronic conditions compared to the general population.

Condition	Proportion in UK General Population	Participants in this study
Amputation (Limb)	<1% <sup>xiv</sup>	1%
Arthritis (any type)	13% Osteoarthritis <sup>xv xvi</sup> <1% Rheumatoid arthritis <sup>xvii xviii</sup>	23%
Acute pancreatitis	<1% <sup>xix</sup>	4%
Broken bones	38% <sup>xx</sup> (Figure based on lifetime prevalence)	39% (Figure based on experience since first homeless).
Cluster headaches	<1% <sup>xxi</sup>	12%
Complex regional pain syndrome (CRPS)	<1% <sup>xxii</sup>	5%
Endometriosis (Rate based on Females only)	10% <sup>xxiii</sup>	5%
Fibromyalgia	4% <sup>xxiv</sup>	1%
Frozen shoulder	2-5% <sup>xxv</sup>	10%
Gout	2% <sup>xxvi</sup>	4%
Kidney Stones	5% <sup>xxvii</sup>	7%
Migraine	9% <sup>xxviii</sup>	23%
Muscular dystrophy	<1% <sup>xxix</sup> <1% <sup>xxx</sup>	4%
Pain after surgery	30% <sup>xxxi</sup>	18%
Slipped disc	1% <sup>xxxii</sup>	10%
Sickle cell disease	<1% <sup>xxxiii</sup>	1%
Sciatica	4-6% <sup>xxxiv</sup>	14%
Stomach ulcer	11% <sup>xxxv</sup>	10%
Ulcers on your skin	1% <sup>xxxvi</sup> *Leg Ulcers	4%

Sciatica was also a common ailment among participants, particularly in comparison to the rate of prevalence in the general population. One participant explains his experience:

*“Some days you can’t move. Some days it’s like so painful I am walking like a cripple, know what I mean. And, I get pain down my left leg, a nerve goes down my left leg. It’s called sciatica. That is part of the back pain. I think it’s a trapped nerve to be honest. Every now and again it’s re-trapped, it really, really gives me jip.”* – Focus Group Participant

Among participants experiencing chronic pain there were higher proportions of diagnosed health problems. The most common diagnosed conditions were: broken bones (48%), arthritis (39%), migraine (29%), pain after surgery (28%), sciatica (19%), cluster headaches (18%) and slipped disc (15%) (Base = 112). As might be expected, the proportions here are higher than in the overall survey participants.

The difficulty that people experiencing homelessness may face in engaging with healthcare services and in diagnosing physical pain conditions may mean that the diagnosis rates highlighted in this study could be lower than is actually present in the homeless population. This was a matter highlighted by some participants who in some cases had not been given a diagnosis for a condition they experienced.

*“Pain in your body, you’ve got pain in your body. Yeah is exactly what I have got. And I can’t – been to doctors, and the doctor sent me to the physiotherapist, because of pain in my legs and all that. When I am standing up. Doing some exercises and all that. But I am still getting the pain. And I have got swelling as well. And they can’t seem to find what the problem is. Because I just - I have just got this constant pain. And swelling as well. And it’s not going away.”* – Focus Group Participant

### **Traumatic events resulting in injury**

The reality of experiencing homelessness, whether on the street or in accommodation, is that you are vulnerable to acts of violence<sup>xxvii</sup>. A common topic in focus groups was around how violent attacks had occurred in people’s lives, which had resulted in ongoing health conditions. For example:

*“OK well basically my arm is shagged. Because I got stabbed in the arm two or three years ago. And I have been having pins and needles for about six months so I went to the doctor and he said – I showed him where the wound was. And he said oh well that is going to happen. Now how do I explain that some mornings my arm... I can move it. But it’s - and he turns around and goes oh well that is bound to happen because have got nerve damage. Now the doctor has admitted that. And I explained how I got injured and whatever. And he says that’s natural two years later, you’re going to feel some residual nerve damage from it.”* – Focus Group Participant

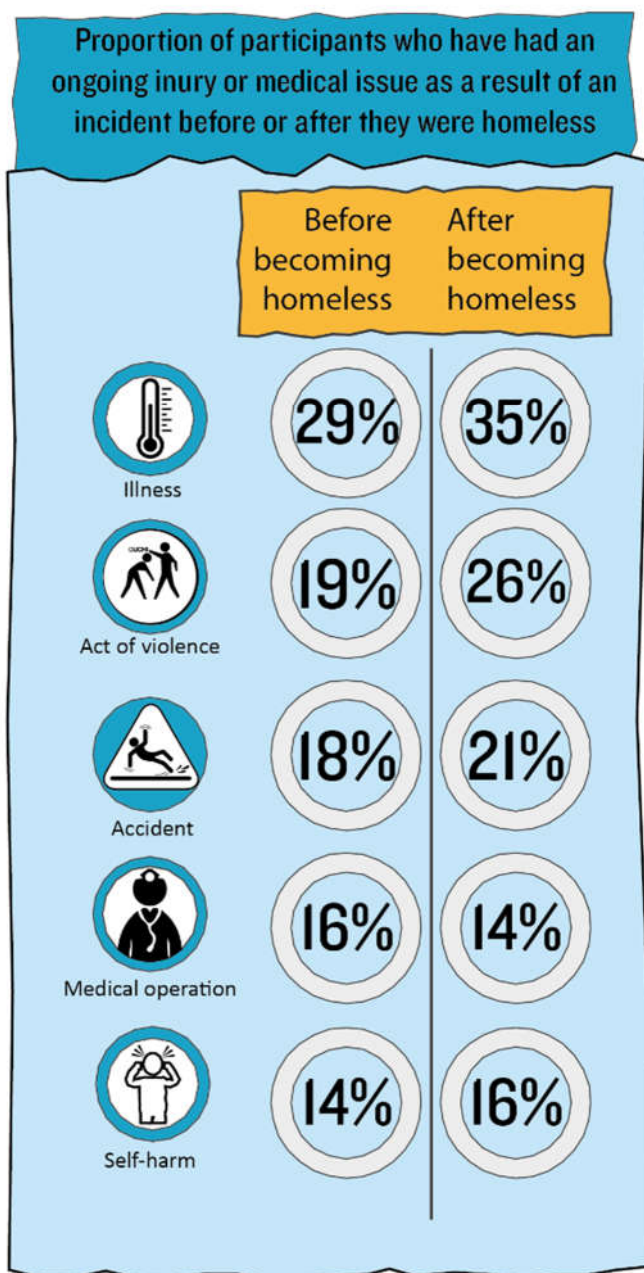


Figure 3: Proportion of participants who have had an ongoing injury or medical condition as a result of an incident before or after they were homeless.

Participants were asked whether they had been affected by an incident that resulted in an ongoing injury or health problems before and after they became homeless see figure 3.

Among participants in chronic pain, similarly to all participants, a fifth (21%) had been affected by health problems or an ongoing injury resulting from an accident before they became homeless. A quarter (27%) of participants had been affected by an accident since becoming homeless. A further quarter (23%) had been victims of violence before homelessness compared with a third (35%) since becoming homeless. 18% reported having self-harmed before they were homeless, and 20% since. 38% were affected by an illness before becoming homeless, with 44% affected since. A fifth (21%) had a medical operation before they were homeless and a similar proportion (20%) since (Base = 112).

### Diet

Access to food, particularly healthy and nourishing food can be difficult when experiencing any form of homelessness. Lack of funds to purchase foods and limited access to cooking facilities often perpetuates a poor diet, which can have significant impacts on health and wellbeing. This can have immediate implications for people who can feel the impact viscerally, for example, 62% of survey participants reported to have had stomach cramps because of a lack of food. Among participants who were experiencing chronic pain this figure was higher at 70% (Base = 105). One participant explains their experience:



*“Constantly sick [...] because you have no food, energy and nutrition in your body. The muscle cramps and pains obviously run in your body through not having anything in there to burn and digest. And to use as fuel. So your body seeks it out through muscles and your bones and that is painful.” – Focus Group Participant*

Food for people experiencing homelessness is available through day centres and soup runs, however participants felt this was often unhealthy. Less than half (45%) of participants would claim they had a healthy diet (Base = 207). For participants who reported that they were in chronic pain this was slightly higher with around half (49%) (Base = 110).

The long-term impact of a poor diet has also been demonstrated to be linked to conditions that can cause physical pain. For example a 2013 review into the effects of vitamin D on musculoskeletal health found adequate vitamin D status seems to be protective against musculoskeletal disorders including muscle weakness, falls, and fractures.<sup>xxxviii</sup> This is a factor that some participants in this study were very aware of. For example, this focus group participant reflects their view:

*“I don’t think people are aware of how big an effect not eating a healthy diet affects their body – the dry skin, the hair falling out, the eczema, the thin skin. So you don’t... associate it with eating poorly because you are homeless, you are not able to cook a meal and so on. So you don’t associate the two until you’re in a situation like this and the penny drops. But when you are actually out there on the street you don’t see that link, because all you are trying to do is survive that day, get through that day. [...] When you have got no money and you have got nothing and what have you – getting and drink of water is so hard. It’s so hard. So you are dehydrating. Your body slows down. You are not using the toilet properly. Your body’s functions don’t work properly.” – Focus Group Participant*

### **Physical pain and mental health**

Amongst all participants in this study 69% agreed that physical pain had been bad for their mental health (Base = 182). Among participants who identified being in chronic pain the figure was higher, 79% agreed that having physical pain had been bad for their mental health (Base = 104).

The links between chronic pain and poor mental wellbeing have been well established. One study showed that people experiencing chronic pain were more likely to have problems with anxiety or depression than those with no pain. The likelihood of reporting anxiety or depression increased markedly as the pain grade increased, however, the relationship between the two can be complex and self-perpetuating<sup>xxxix</sup>. Further to this, while chronic pain may be a driver for anxiety, anxiety can also cause individuals to be more sensitive to physical pain<sup>xl</sup>. This is because the regions of the brain that deal with the regulation of sensory processing pain when subject to anxiety can exacerbate experiences of pain<sup>xli</sup>. Within the homeless population where mental health issues are widespread and it has been demonstrated that chronic pain is a significant problem, the coexistence of the two issues can have a significant impact on activities of daily living.<sup>xlii</sup>

Sixty-nine per cent of the general survey population reported mental health issues (Base = 215), 56% had been diagnosed as having a mental health issue by a medical professional,

and 56% had been prescribed medication for a mental health condition (Base = 216). For those that identified as being in chronic pain, they were marginally more likely to experience issues with their mental health. Three quarters (73%) of those that were in chronic pain felt they had mental health issues, 59% said they had a diagnosed mental health condition and slightly more (61%) had been prescribed medication for a mental health condition (Base = 111).

*“Even if you’ve got physical pain without the emotional, once the tolerance is gone for the physical pain your emotional just explodes. That’s when you just go fucking mental. [...] You start having weird mental breakdowns, like crying and then next minute you are like pure angry version of Superman, you just want to take and hurt everyone. Because you want someone to try and feel or acknowledge something that is going on in your world.” – Focus Group Participant*

### **A marker of brain injury?**

In line with recent research around the prevalence of brain injuries among people experiencing homelessness<sup>xliii</sup>, there is evidence in this study that may indicate instances of this issue among participants in this study. Brain injury has been demonstrated to be more prevalent in the homeless population than the housed population and may be a causal factor in homelessness. The high rate of traumatic incidents among participants in this study, as well as the high incidence of migraines and cluster headaches, could be understood to be linked to this phenomenon. Post-traumatic headaches are one of the most common symptoms after brain injury, with 30% reporting they continue long after the injury occurred. However, the lack of a documented history will lead to misdiagnosis.

Difficulty in diagnosing brain injuries is a key issue as an estimated 75% of mild brain injuries may be unreported and unassessed by medical professionals<sup>xliiv</sup>. Such low rates in reporting can be attributed to unawareness of the injury due to no loss of consciousness or symptoms not materialising until days, weeks or months post-injury. A lack of insight produced by the injury itself may also occur. These symptoms can vary depending on the location or severity of the brain damage and can mirror other diagnoses leading to greater scope for a later misdiagnosis.

The lack of self-reporting and insight into potential difficulties caused by brain injury may lead to these only being recorded when homeless people gain access to services. One study found that 90% of participants had sustained their first traumatic brain injury before they were homeless<sup>xliv</sup>. Without a documented history of brain injury, healthcare professionals may then attribute these difficulties to other factors such as substance misuse or mental health problems such as depression.

## Pain and Homelessness

### Case Study: 'It's hard to keep yourself warm when you are on the streets.'

John is in his sixties and has recently moved into a bedsit after rough sleeping on and off for over 20 years. We met him at a day centre where he participated in the survey and then responded to an opportunity to participate in an interview. John has Chronic Obstructive Pulmonary Disease (COPD). COPD is an umbrella term used to describe progressive lung diseases including emphysema, chronic bronchitis, and refractory (non-reversible) asthma. This disease is characterized by increasing breathlessness.

*"When I was on the street there was not that security and that warmth that I get from my bedsit and having heating and all that. You might be in one area one day, another area another day, and this could throw you off kilter. It was very difficult to avail health clinics and professionals when needed, that's why it's very important to me because of the conditions that I have; I am conscious of continuous infections.*

*My experience [of pain] happens when I come down, crash down, with chest infections mainly. I have a lack of oxygen in the blood because I have COPD, asthma and all that which creates 'leadness' in the muscles like a limp feeling. What happens then is I find it very, very difficult to walk because I get very severe pains in the muscles in the legs. It's like a severe flu that normal people will receive, but you could say five times greater because of the COPD, which I suffer with two weeks a month. So half a year I suffer like this where I have severe pain.*

*Because I suffer with COPD I cannot take painkillers stronger than Anadin, because when you are suffering with such bad breathing and you take a strong painkiller it makes your breathing even lazier. If that happens you could actually go into a coma. I have nights where I don't sleep, and after a couple of days my energy to think and ability to think is not there because exhaustion comes into play as well. Day to day things like writing letters or keeping up with appointments I can't do through them periods. The pain you can sort of deal with, but it's the sleepiness and the mental fatigue that can become more painful because you get a stress with it. The stress of not being able to think straight, draw simple lines, things that I take for granted when I am thinking right in everyday life.*

*Lots of people that are homeless have more medical issues than people that are settled, because very often it's their medical conditions that make them homeless because it makes them unemployable. One can get poorly in life, just like that. It's not lost on me that if I wasn't smoking I probably wouldn't be getting the infections. As well as the fact that when I was born I was one of twins, three months premature, so my cardiovascular system was very weak and I didn't develop as strong as I should have.*

*I am just coming out of the last course of antibiotics so my strength has come back into my limbs again, and I hope I get two weeks plus pain free. But as day follows night I definitely will come across another chest infection inside two or three weeks and the pain will start again for another two weeks."*

## Journeys through pain and homelessness

The relationship between pain and homelessness is a complicated and interlinked phenomenon and cannot simply be explained as having a linear relationship. For example, 47% of survey participants who reported to be in chronic pain began to experience pain on a daily basis before they became homeless, and 38% identified that this was subsequent to them becoming homeless; 14% reported that they first began to experience physical pain in the same year they first experienced homelessness.

Among all participants in this study, 39% felt that physical pain had contributed to them becoming homeless (Base = 171). Among participants who were in chronic pain this increased to half (50%) of the cohort agreeing that physical pain had contributed to their becoming homeless (Base = 99). This correlates strongly with the number of people who were experiencing physical pain on a regular basis before they became homeless.

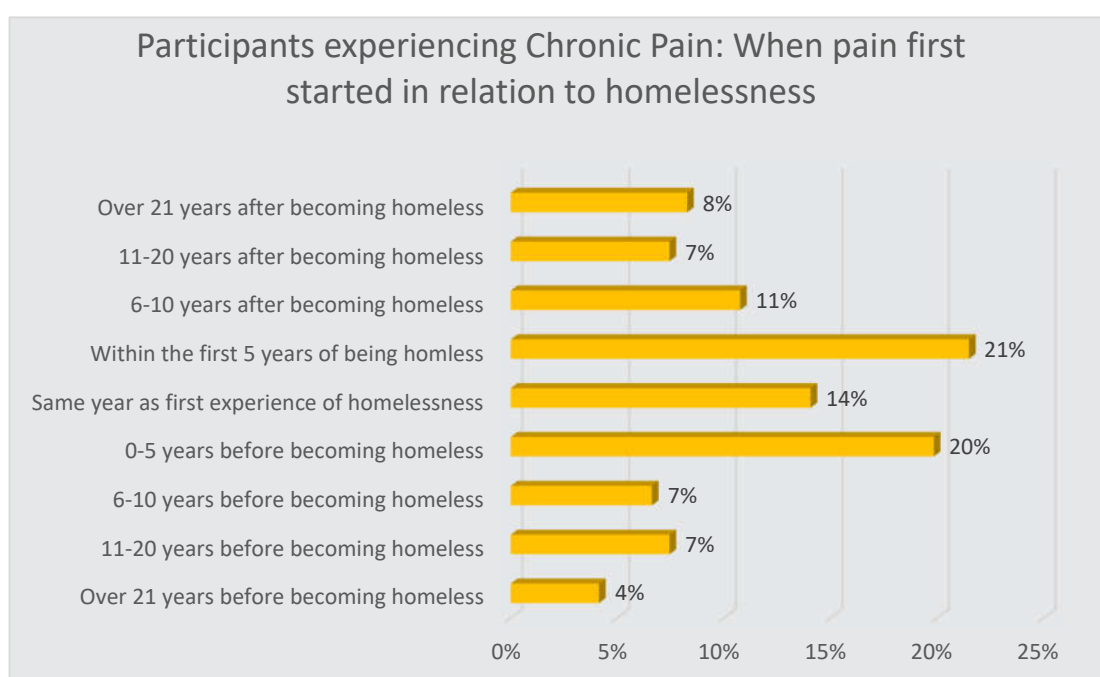


Figure 4: Participants experiencing chronic Pain: When pain first started in relation to first experience of homelessness

For 55% (Base = 111) of participants who reported to be in chronic pain, their experience of daily pain came within 5 years either side of their first experience of homelessness.

Job loss following pain and pain related disability is recognised as typical for those attending pain clinics, and financial loss is often an inevitable outcome of job loss. Forty-one per cent of people who attended pain clinics report that their pain has prevented them from working, and 13% have had to reduce their hours.<sup>xlvi</sup> The 2008 Chief Medical Officer report states that 25% of pain sufferers lose their jobs.<sup>xlvii</sup> With this in mind, it is perhaps unsurprising that only one respondent who reported to be in chronic pain had a full-time job and three people had part-time work.

Among participants who reported to have experienced chronic pain, 69% had difficulty maintaining a job because of their physical pain (Base = 103). Fifty-nine per cent agreed physical pain had caused trouble with personal relationships (Base 106), compared to 50% in the total survey population (Base = 178). Thirty per cent of survey participants who had used drugs said that pain had contributed to why they had first used drugs (Base = 129).

### **Rough sleeping and pain**

The great majority of survey participants agreed that sleeping rough had an impact on their physical health with survey participants reporting that rough sleeping and factors relating to that having caused a number of their pain problems. For example: 87% agreed that sleeping rough leads to aches and pains (Base = 196), 90% agreed that carrying a backpack or other items all day can hurt your back (Base = 196), 87% agreed that injuries take longer to heal when sleeping out (Base = 195) and 92% agreed that walking around during the day makes feet hurt (Base = 194). One focus group participant explains this:

*“Walking down the road with a 65 litre rucksack on your back every day for like eight years. It really does hurt.”* – Focus Group Participant

For participants who were experiencing chronic pain, there was a higher likelihood that homelessness had an impact on their physical condition. Ninety-five per cent agreed it caused them general aches and pains, particularly back pain from carrying their personal belongings around all day. Ninety-six per cent had painful feet from walking around all day. Ninety-two per cent agreed injuries took longer to heal while sleeping out (Base = 99). One participant explains how the physical and mental stress placed on her whilst sleeping on the streets meant she found it difficult to manage physical pain:

*“Yes, sleeping rough you know. Have to change from bus stop to bus top, sitting down all that, it gets to your legs. It gets to you head. You can’t sleep. Your brain is constantly stressed. The stress gets to you. And makes your brain like – not in a painful way – but it kind of shuts down. So your body sets down with it.”* – Focus Group Participant

Occupying your time can offer a distraction from physical pain, but the realities of homelessness mean that often, time is difficult to fill. For example, 66% of all participants agreed that boredom made it difficult to stop thinking about pain (Base = 177). Among those in chronic pain this figure was marginally higher with 70% agreeing boredom made it difficult to stop thinking about their physical pain (Base 104).

One participant reflected on the strains that sleeping rough places upon his body:

*“You don’t realise it’s happening. It’s like any kind of torture. It’s like sleep deprivation or starvation. Or stress positions. Any kind – because you are sitting there but you are forced. So it is a mild form of torture. But no one is actually physically doing it for you. But it’s the environment that is doing it. And then you’ve got the same thinking well I should be out of this. And therefore it is all piled on you, and you think for fucks sake I just want to get my head down and you can’t do nothing about it. So it is like a... It is basically torture.”* – Focus Group Participant

When an existing diagnosed condition is present, homelessness can further aggravate the condition. One participant explains his experience:

*“If you have already got an existing illness, being homeless makes it worse. Personally I have got like a lot going on. I have got arthritis through my spine and my hands what have you. And when I am out and it’s cold and damp, you can’t move. You can’t move. You haven’t got the will to move. So you become stiff, you become achy. And... It’s... I think your mental health suffers more than your physical health when you are out on the streets, I really do.”* – Focus Group Participant

### **Temporary accommodation and pain**

Living in temporary accommodation such as hostels was highlighted as aggravating and in some cases being a driving factor for causing pain. Fifty per cent of all survey participants agreed that their last hostel mattress had been comfortable, 44% disagreed (Base = 107). Simple factors like having a comfortable place to sit were highlighted as an issue in the focus groups, 38% of survey participants agreeing that they had nowhere to sit during the day in their accommodation (Base = 167). However, for those who are experiencing chronic pain in the environment of hostels these factors were more prevalent. For example, 61% did not believe that their mattress had been comfortable the last time they had been in a hostel (Base = 59), compared with 50% of the full survey, 40% agreed they had nowhere to sit in their hostel room (Base = 86).

Thirty-two per cent agreed that they had difficulties moving around the hostel due to mobility issues (Base = 169), this increased to nearly half (48%) for participants who were experiencing chronic pain (Base = 88). The hostel environment was also felt to have a negative impact on health, ability and self-care more generally. For example, one participant reflects on this:

*“I know right now, because I have not been looking after myself for the past few weeks, because I have been a bit depressed and things like that. I have not up to my... and its been noticed I am not up to... I am known to make actual efforts to... To really make an effort to do more, look after myself physically. But part of that is my confidence. I am surrounded by – no disrespect – people in the same scenario. So it’s not... so I am starting to [over talking] I am starting to slip. And I have noticed. Maybe just not having a few extra drink or beers or this, that and the other and it starts [unclear]. When actually I know... actually I am fit as hell and I should be. But if I am surrounded – like I said it’s the environment – if I am surrounded by this, it is so easy to fall into it. So yes, if...er... you know what they says, the adage ignorant is bliss. So if somebody is walking through... that guy who has got not a care in the world, scratches his leg, next day plaster, whatever, carries on with his life. For somebody in an environment that is really oppressive, that scratch is going to turn into a wound. Does that make sense in a description, an analogy of how it works? Because the environment is not allowing them... either spiritually or physically to heal.”* – Focus Group Participant

One participant who had recently moved in to accommodation explains how his pain has been ongoing and how his experience of physical pain has had an impact on his transition into accommodation:

*“I haven’t actually slept in my bed for like a month. From spending as long as I have, at least half of my life already being on the street. I forgot the feeling of comfortability. I would rather sit on a hard floor because that is what I find comfortable, instead of sitting on a sofa. Or laying on my bedroom floor, because I am so used to laying there, my muscles being all sore and contracted and tensed up and that. I am so used to that punched feeling in my arm, that when I lay on the bed or I try to get comfortable in the bed I just end up in more pain.” – Focus Group Participant*

## Managing Pain

### Case Study: Seeking the right treatment

Robert is in his fifties and was met by Groundswell Peer Researchers in a day centre in London where he volunteers. He was interviewed by a Groundswell Peer Researcher, which was audio recorded and transcribed. The Peer Researcher who conducted the interview wrote the following case study based on his responses to their questions.

*“I spent 35 years of my life sleeping rough. I worked most of the time and still slept rough because I was misdiagnosed as being claustrophobic when I was actually people phobic. For the many years I spent sleeping rough I already had conditions that were causing me problems. I had a motorcycle accident when I was 17 that left me in constant pain, and that has been with me now for most of my life and will be with me for the rest of my life.*

*Being uncomfortable is one thing, being uncomfortable in pain is completely different. I did go to accident and emergency on some occasions, but the problem with being on the streets is you can’t get access to proper medication because you aren’t registered anywhere and have no fixed abode. And because of problems people have with addiction, hospitals aren’t going to give morphine or opiates to a person who is sleeping rough; they don’t know why the person is going to use them or what they are going to use them for. So that’s another limitation in the way that a person can access pain management on the streets.*

*When I was on the streets I was lucky enough to be able to deal with pain in without medication but more with a positive attitude. When you are desperate on the streets, have nowhere to go, and everything is going round and round in your head, the mental attitude is probably the most difficult part for people to get their head around. You need to get yourself a plan of what you are going to do, or have people talk to and show you a path out of it, otherwise effectively you amplify the pain.*

*After I had the motorcycle accident the only person I saw was the family doctor and I just coped with it myself, but when it got too bad I ended up in hospital and got referred to a specialist in pain management. Twenty-two years ago there wasn’t a lot people could do other than give opioids – a massive amount of opioids – so I ended up on morphine for quite a long time. Then it progressed and I got to see more in-depth specialists that discovered the trapped nerves in my shoulder from the motorcycle accident. I saw a specialist in neurological pain who put me on to the Gabapentin because they said that a lot of my pain was coming from problems with the nervous system. A few years ago I finally went for an in-depth analysis of what my actual pain issues were and that’s when we discovered the correct combination of drugs: Gabapentin, co-codamol, and the drugs for my chest and the*

*fluoxetine for my nervous system and mental state. The correct medication, the correct diagnosis and the correct mental attitude, when it was all combined it was a perfect combination that allowed me to function as normally as possible.*

*I have lived a long impressive life, I have done an awful lot of things and it takes its toll. When, for the majority of your life, you don't have a warm bedroom and fixed place to relax – not just physically but mentally – then it is far more stressful on the body. You feel pain far more. I was lucky enough that when I was finally diagnosed with being people phobic, not claustrophobic, it allowed me to get access to a flat and allowed me to go back to a more mainstream life. I have a place where I can go back, where I have got my solitude, warmth and comfort, but I still deal with a lot of problems that are left over from those times. The pain management will be there for the rest of my life – I know that it is palliative – I do still feel the pain, I do experience it.”*

### **Access to Treatment**

Among all survey participants 91% reported to be registered with a GP (Base = 204). Of all participants 85% had been to a GP since becoming homeless (Base = 206); 77% had been to a GP about pain (Base = 176) and 29% had been to another medical professional about a pain issue (Base = 204).

Among those experiencing chronic pain there was a higher likelihood to seek medical treatment than those without chronic pain issues; they were likely to have marginally better rates of access and usage of primary medical care. The majority (93%) were currently registered with a GP (Base = 107) and 90% had been to a GP since becoming homeless (Base = 108). Of these, the same proportion (90%) had been to a GP about physical pain since they became homeless (Base = 97), while 37% had been to another medical professional because of their physical pain since becoming homeless (Base = 108). This indicates that two thirds of homeless people experiencing chronic pain are not accessing specialist care for pain issues.

*“You do find it very hard asking for help when you are out on the streets because... you are so used to the knock backs and the ‘no’s and the being ignored and the not being noticed. Or being shuttled off to someone else – it’s not my problem. You know? Go and speak to them and then you go to them and they send you somewhere else. When you get put into a situation like this, you have still got that mindset so you are very reluctant to reach out and say will you help me? Know what I mean? [...] I think being homeless is so destructive, so destructive.” – Focus Group Participant*

While participants were likely to be accessing primary medical services they are also using emergency care regularly, which may be an indicator that primary care is not meeting their needs. For example, 70% of all participants had been to an A&E in the last year (Base = 206), of these, 80% had been because of physical pain issues (Base = 145). Among those experiencing chronic pain, three quarters (74%) had been to A&E in the last year (Base = 108), nearly all (85%) because of their physical pain (Base = 80).



*“You kind of give up on yourself. You do. And you are waiting until things are extreme before you ask for help because you’re so used to being ignored and being seen as invisible. That it... you have to get to a breaking point before [you get help].” – Focus Group Participant*

In line with previous research<sup>xlviii</sup> poor compliance with medical services and poor treatment of underlying conditions are significant factors in poorer outcomes. In focus groups participants often reported how they had had difficulty communicating with medical professionals, particularly when they have short appointments, to discuss issues with their GP. People experiencing homelessness often face complex issues that limit their ability to engage with healthcare services, for example, among all participants in this study 63% had experienced mental health difficulties and 27% had been admitted to a psychiatric unit. Further to this 58% reported to have experienced substance misuse issues, 26% had been in residential treatment for these. There is a body of evidence that shows common connections between chronic pain, depression, panic disorder, PTSD and substance use. However, clinicians treating people experiencing homelessness may not be aware of this complex relationship, which can often mean that people’s pain issues go untreated<sup>xlix</sup>. Although it is not always clear whether physical pain or mental health are cause or effect, the need for a multidisciplinary approach to chronic pain management to address all areas related to chronic pain is needed<sup>l</sup>.

A key finding of the research is that while the use of prescription medication is widespread among participants who are facing chronic pain, less than half (47%) want to be treated in this way. While two thirds (65%) had been offered prescribed medication for dealing with their pain, access to other types of care like a pain management clinic, another specialist or complimentary therapies was highly in demand.

*Table 4: Type of treatment that participants experiencing chronic pain have received and what they would like to receive.*

Type of Treatment	% of participants in Chronic Pain given this treatment for Pain	% of participants in Chronic pain who want this type of treatment for Pain
Prescribed medication	65%	47%
Referred to a pain management clinic	23%	38%
Referred to another medical specialist	25%	37%
Referred to a physiotherapist	36%	30%
Offered 'alternative' or 'complimentary' therapies	19%	33%

The following is from an interaction in a focus group in a hostel in central London:

Participant: *“When you get into hostels, it becomes a lot easier to access like physiotherapy. And things like that. Because you have got an address to send a letter to.*

Researcher: *“Have you accessed physiotherapy?”*

Participant: *“Yes. My appointment is on Friday. But it’s – because I have an address to send to an appointment to. When you are out on the streets, you have got nowhere to get that appointment letter sent to. Most of us when we were out on the streets, we didn’t have a phone. Or if we did we didn’t have credit so we couldn’t be phoning up these places to be making appointments and things like that. So it is really hard accessing them kind of services when you’re on the streets. “*

### **Being believed and overcoming shame**

Overall, participants were positive about their most recent contact with a medical professional: 80% thought the medical professional had believed them (Base = 160), 75% said the medical professional had diagnosed the issue (Base = 162) and 79% had received treatment (Base = 161). Seventy-six per cent of participants reported they felt cared for, (Base = 162) and 68% were happy with the care they had received (Base = 201). However, this still means that a third (32%) are not satisfied with the treatment they receive and some focus group participants were particularly disgruntled by the care they had received:

*“I go to the doctor, yeah. I tell him listen. I lost two stones in three months and I am not eating at all. And he was like oh you are a good weight [unclear]. I am like listen, but to be honest, I will be eating like two toast the whole day. And I am like listen mate there is something wrong, because I am not eating at all. And he is like – I don’t believe he took me too serious. Because I was just feeling weak generally. I have got food in my room but I was just not eating at all. And the guy was like – I feel like he wasn’t really listening to what I was saying. He was judging me by how I physically looked and what I was actually claiming.” – Focus Group Participant*

A key variable in whether participants were satisfied with the healthcare they had received most recently was whether participants reported to have had current or previous substance misuse issues. One participant explains his experiences:

*“Once they find out if... Well there is so many things like being drug user or homeless – you always get second rate medical treatment. They just think you aren’t worth treating. They just try and get you out the door, see you later.” – Focus Group Participant*

A two-way process of misunderstanding and poor communication may be causing this difficulty in providing treatment that is seen as satisfactory by the patient. Chronic pain sufferers frequently experience shame regarding their condition which in turn prevents communication, seeking and accessing help<sup>li</sup>. Seventy-one per cent of participants in this study reported to feel ashamed of their situation, this was the same amongst participants experiencing chronic pain (Base = 110).

*“Of course. Well a lot of it is you are so embarrassed. I think that is pretty much the bottom line. It’s not a choice. We are actually bloody embarrassed about our situation. And I often find when you go to jobsworths, I often find that it’s like well this is your fault. This is your*

*fault! But I even turn around and say trust me, given a choice [I wouldn't be in this situation].” – Focus Group Participant*

The invisibility of chronic pain presents challenges to both the sufferer and professionals treating the condition. Patients reported difficulties communicating their discomfort, fearing they will be perceived as ‘self-indulgent’ or ‘weak’, or that they will not be believed. It may be the case that clinicians could be doubly blocked by a lack of understanding of physical pain and homelessness:

*“I don't think they do but they do. They know it but they don't understand it. It seems like any time people moan at them saying I am pain and I need help. They are like oh it's just another day kind of. You know they don't actually understand the amount of pain that somebody is in to go to them to say I am in pain, can you help me. They are just like oh here is a service, go and find it yourself.” – Focus Group Participants*

This is compounded further when psychological factors are involved. The sufferer may feel professionals interpret the pain as mental health related, or that they are malingering, which exacerbates the individual's anxieties about how they are perceived. Similarly, as chronic pain transgresses the categorical divisions between mind and body it challenges current medical understanding, and therefore professionals face difficulties in competence when treating the condition.

### **Pain relief medication**

Barriers to accessing medical services where people would traditionally be prescribed medication can mean that pain relief medication can be difficult to obtain. Similarly limited available funds can be a barrier to purchasing medication from a pharmacy.

*“Yeah I broke my toe before and that is why I have got a problem with my foot. I broke my toe and it mended in a dislocated position. And I was supposed to go to the doctors but being homeless I couldn't make an appointment. So then I couldn't get no pain relief from the doctors. So after that I had appointments, the next day I got recalled to jail and everything, because I couldn't walk to my appointments. And that is all because of my foot. Walking nonstop on top of it. And it snapped it again.” – Focus Group Participant*

Among those that identified as experiencing chronic pain, 61% were currently using prescribed medication to deal with physical pain (Base = 109). However, several focus group participants discussed how managing medication to make sure they have the most impact can be an ongoing issue:

*“They give you co-codamol and then they don't touch it. Basically don't work. [...] I haven't managed my pain in any way correctly. They haven't asked me... the doctor hasn't divulged that information whether I get a stronger drug or... they aren't opiate based, because I don't want opiate based.” – Focus Group Participant*

While access to prescribed medication is a clear issue for people experiencing homelessness, once access is achieved the way medication is prescribed can present difficulties. For example, in focus groups and one-to-one interviews short prescriptions were highlighted as a major issue which participants linked to their experiences of homelessness.

*“I was on my painkillers before I was homeless, so mine was a long-standing thing. But then when I became homeless they stopped giving me the three months’ supply and started giving me three days at a time. I get given quite a lot of painkillers. I have naproxen as a painkiller, I am on tramadol. And I get paracetamol. And when you are homeless they don’t like giving you a big supply. [...] So, you are constantly having to run backwards and forwards to get your prescriptions and what have you. And it’s a pain in the arse, it really is a pain in the arse.”* – Focus Group Participant

Experiencing homelessness also has a clear impact on the types of medication prescribed to people. We explored how participants had been prescribed medication before and since they have become homeless to understand what this impact might be. Among participants who reported to be in chronic pain, around half the cohort (54%) had been prescribed medication by a medical professional for physical pain before they became homeless (Base = 105). In the wider research population, 41% of all participants had been prescribed medication for pain before becoming homeless, which correlates with the proportion of people who identified that they had experienced pain on a daily basis before they became homeless (41%).

Among all participants before they became homeless, 41% had been prescribed medication for pain. Of the total sample, 31% had been prescribed opioids, 11% steroids, 28% anti-inflammatories, 4% pregabalin/gabapentin.

Of the 54% in the chronic pain cohort who had been prescribed medication for physical pain before they became homeless (Base = 105): 46% had been prescribed paracetamol, 38% opioids, 33% anti-inflammatories, 14% steroids and 6% pregabalin/gabapentin (Base = 112).

Responses from participants about the types of medication they have been prescribed before and after becoming homeless do not indicate that the types of medication available to them by prescription differ, particularly when controlling for participants who were not in chronic pain before they were homeless. For example, after they had become homeless, half (51%) of participants chronic pain had been prescribed paracetamol, the same proportion (51%) prescribed opioids, 38% anti-inflammatories, 13% steroids, 9% pregabalin and 3% fentanyl (Base 112).

However, while those who had access to pain medication before homelessness are unlikely to have the type of medication available to them changed, there is evidence that accessing new medication may be more difficult. One participant explains:

*“I think they are judging people, thinking they are just blagging the meds. Everyone that comes in the surgery, oh they are junkies they are just blagging meds. That’s what I always think.”* – Focus Group Participant

Respondents were asked whether they had ever purchased or obtained prescription medication that had not been prescribed by a medical professional to deal with pain since becoming homeless: 35% had taken paracetamol, 25% had taken opioids, 2% steroids, 19% anti-inflammatories, 11% pregabalin and 3% fentanyl (Base = 222).

Among those experiencing chronic pain, the amount of people who had purchased or obtained medication that had not been prescribed was higher: 36% had purchased paracetamol, 28% had purchased opioids, 21% anti-inflammatories, 14% pregabalin, 4% fentanyl and 3% steroids (Base = 112).

*“Yeah they put me on painkillers. It didn’t work. So I had to go out and buy some drugs for my pain. And it only worked a couple of hours and then you are back in pain. So what is the difference? I might as well just suffer in pain. Because it’s like... the pain I have got yeah, will not work. The painkillers will not work. The painkillers yeah... just not work for me. So I have to find different way of getting other drugs for my pain.” – Focus Group Participant*

Table 5: Types of medication used by participants experiencing chronic pain.

Type of Medication	Participants who identified they were in Chronic Pain		
	Prescribed before people became homeless	Prescribed medication since becoming homeless	Obtained without prescription since being homeless
Paracetamol	46%	51%	36%
Opioids (morphine, codeine, tramadol, oxycodone)	38%	51%	28%
Steroids used to treat pain associated with inflammation (triamcinolone)	14%	13%	3%
Anti-inflammatories (ibuprofen, diclofenac, naproxen, etoricoxib, and celecoxib.)	33%	38%	21%
Pregabalin /gabapentin	6%	9%	14%
Fentanyl	0%	3%	4%

### Effectiveness of Pain medication

Drug and alcohol use was a common topic of discussion around medication in relation to pain management and effectiveness of medication. While managing pain with medication can be a difficult balance to strike generally, having had a history of illicit drug use may further complicate this. The effectiveness of pain medication was an issue highlighted by participants particularly for those who have experience of using illegal drugs. Among all participants in the study, 54% said that their tolerance to pain medication had been affected

by their drug use (Base = 130) and increasing to 61% of participants with chronic pain. One participant explains:

*“It’s hard to say. It’s just... there is nothing that I could do to make it go away. Nothing. Doesn’t matter the amount of drugs. The kind of drugs. Nothing seem to take it away.” – Focus Group Participant*

## The Impact of Pain

### Case Study: My pain & my recovery

The following case study is from an interview with Janette who is in her late-thirties and now works in a support service for people who suffer with mental ill health.

*“My pain is linked to my past of self-neglect, I have old fractures and osteoporosis due to my long history of severe anorexia. It worsens if I’m doing too little or too much like carrying heavy things such as shopping. Uncomfortable beds or chairs or even chairs that look comfy, like car seats, make it worse. I have struggled to sleep in a bed, even when I had a home, because I had lots of negative associations with being vulnerable and feeling that I did not deserve comfort. My pain tends to flare up when I’m not looking after myself or if I stop doing the things I need to do, like yoga, to help manage my pain.*

*My pain flaring up is a trigger for relapse for me, particularly if I feel I am not coping well with my pain. Because my pain is directly linked to the ways I mistreated myself for years it triggers all those feelings of regret and shame very quickly. At times my physical pain has been a good distraction for my mental and emotional pain; I have previously self-inflicted pain in order to not feel the psychological pain or not to have the thoughts in my head that were so overwhelming and distressing*

*My pain has worsened in the last few months, waking me up at night and making sitting for any more than very short periods difficult. I had hoped this was linked to a bit of scoliosis I have had since birth – hence I have always had back pain – and a bit of arthritis I have in my lower spine after my hip surgery, but it turns out I have some new hairline fractures in my spine.*

*I have developed ulnar nerve palsy – pain along my ulnar nerve – that gets quite severe and again wakes me up. It has affected sensation and mobility in my right hand meaning I am even more clumsy. This is linked to liver damage and malnutrition, both of which I sustained through my anorexia. I am still having investigations as up to now hospital teams have not been able to find a remedy.*

*I feel medical services could have listened to me more. People make assumptions all the time and often do not listen to the person in front of them, they are more interested in reading what is on the paperwork they have – which may be wrong or out of date – and often the patient is the one left with the damage and distress that ensues. I have intense stories because of my history of self-harm, anxiety, panic attacks, and a diagnosis of personality disorder. When I present a doctor with a new pain, most recently my hip fracture and foot*

*fracture, I am told it is muscular and that my anxiety was making it worse. It took several trips to the GP and A&E, lots of distress, and my femur snapping at work, before they would even do an X-Ray (or MRI, as sometimes my osteoporotic fractures do not show up on X-Rays) and realise that I had been forced to walk around on a fracture for a week despite asking for medical assistance.*

*Sometimes I'm given the message that I just have to learn to live with the pain as it is and I am "lucky to be as recovered as I am so I can't ask for much more." This sometimes feels quite lacking in compassion, but I think it may be well-meaning people just trying to lower my expectations.*

*Distraction helps me to manage my pain, or using my recovery in a positive way like through my work. Although I can't afford it regularly at the moment, yoga, exercise and massage has also been helpful, so has having a health and wellbeing plan to do the things I need to do to stay well. What has helped the most though is people listening without judging, or people having hope for my future when I don't have any."*

### **Living with pain**

The implications of chronic pain on an individual's quality of life are well documented. Impaired quality of life secondary to pain may be expressed by depression (including increased suicide risk), anxiety, sleep disruption, appetite disturbance and weight loss, cognitive impairment and limitations in the performance of daily activities. These added burdens are expected to improve with effective pain management<sup>lii</sup>.

A person living with physical pain can have as poor quality of life similar, if not worse than, those with severe health conditions. For example, the impact of physical pain on quality of life has been compared to that of significant neurological diseases such as Parkinson's<sup>liii</sup>. Pain also has a dramatic impact on the sufferer's ability to function in society. Lower back pain is ranked highest out of 291 conditions studied by the Global Burden of Disease study, ranking number one for years lost to disability worldwide. Notably, four of the top 12 disabling conditions globally are persistent pain conditions (low-back and neck pain, migraine, arthritis, other musculoskeletal conditions).<sup>liv</sup>

Among all participants in this study, 54% considered that they had a disability (Base = 214) and 53% were in receipt of ESA/Disability benefits (Base = 222). Among participants who reported to be experiencing chronic pain they were more likely to consider they had a disability; three quarters (73%) of this chronic pain group reporting that they had a disability (Base = 112) compared with 54%. Two thirds (63%) were receiving ESA/Disability benefits.

One study focusing on individual's experience of chronic back pain found that loss emerged as a continuous thread throughout most participants' experiences. The term 'loss' is used in this context to refer to life events or changes that resulted in the participants being or feeling deprived of something they valued. As a result, most participants reported that their lives were socially and environmentally restricted<sup>lv</sup>. The 2008 Chief Medical Officer report states that 16% of sufferers feel their chronic pain is so bad that they sometimes want to die<sup>lvi</sup>. Chronic pain is also associated with increased risk of death independent of socio-

demographic factors.<sup>lvii</sup> In this study, participants particularly highlighted the impact of chronic pain on day-to-day living. One participant explains his experience:

*"[When you see a medical professional they ask...] Can you bend your leg like this, can you do this, can you touch your toes, what have you? But they don't say go and put the kettle on. Those are the things where we actually struggle, the actual physical things. Like holding a kettle – when my hands... I have got no feeling in these two fingers because I have got a trapped ulna. But when my arthritis... My thumbs lock up like this, my finger twists up like that. They just lock like that and I can't physically hold a cup for the kettle. And if I do how the hell am I supposed to transfer a pan full of boiling water with these hands that don't grip into a cup? How? I can't do it." – Research Participant*

## Dealing with Pain

Finding a strategy for managing pain is essential to being able to live a fulfilled life. However, this study has revealed that the strategies employed by people experiencing homelessness may be unsustainable or even detrimental to the health of the individual. Among all participants, 61% had seen a medical professional because of their pain, 49% had used over the counter medication and 48% had been to A&E. However, in a wide range of cases, participants had used alcohol or drugs as a tool to manage physical pain. Forty-three per cent of participants had use alcohol (Base = 222) as a way to manage pain. This participant explains:

*"So I [Use] ... brandy or something. And you just drink it and just afterwards just go to sleep after that. Dulls down the pain yeah. So forget about it and get a good sleep. I don't know whether... I don't think it is the right thing to do, for medication I don't think like that. But sometimes you know, [It's a] way of life. When I was living in [Location] it was an everyday theme, you know, kind of like there. And kind of go like... friends like they kind of needed it. It's for the pain, for the pain, for the pain. I understand yeah." – Focus Group Participant*

Also widespread was the use of illicit drugs to manage pain with 43% of all participants reporting to have used drugs to manage pain.

*"It feels as though everything is sort of hidden from you. You need to look it up yourself to find out. You know what I mean? It's... yeah basically. I mean I started heroin two years ago to manage pain. Just smoking it. I ain't used it now for nearly a year. But that ain't the way forward. I smoke a lot of weed to be honest with you, to help with the pain. That helps, that really does help. That's what I think I should be prescribed, you might laugh, it is possible, people do do it." – Focus Group Participant*

However, it was acknowledged by focus group participants that using illicit drugs as a pain management tool was not sustainable and meant that people often had to increase the dosage to be able to maintain its effectiveness in managing pain.

*"After about a year of smoking heroin, you've got to start injecting [...] when you take drugs to numb the pain and emotional pain. Even drinking as well, drinking a lot can sometimes get rid of pain. So I think when you are out on the streets it is easier to take something that can knock you out." – Focus Group Participant*



## A cycle of pain and homelessness

While pain can be a driving factor behind why people have become homeless, there is also a likelihood that the limits it can have on ability to live day-to-day means that it may be making it difficult for people to escape homelessness. The cycle of homelessness that is often led by untreated mental illness, addiction, and childhood trauma can spin a life out of control and chronic pain can further perpetuate this cycle. This cycle is not something that participants were unaware of. Some participants explained this in no unclear terms:

*“Alcohol is pain relief... having a broken jaw, because you were drunk and fell down a flight of stairs after you got in a fight. There is no cause and effect. It’s just pure effect.”* – Focus Group Participant

The psychological impact of being homeless and living with pain can cause people to ‘give up’ on their situation, which in turn can mean they do not address the social and health needs they face.

*“The way that drags you down and... when you are... Once your spirit has gone, when you feel like you are nothing, you don’t care. You don’t care about the pain in your in your legs and your feet or whatever. You don’t care. You don’t care that you have got no access to a shower and your feet are sore in your shoes. And your armpits are rubbing, and you are getting a boil because you have not had a shower. None of that... you don’t care about that because you give up on yourself.”* – Focus Group Participant

For some, moving on from homelessness is impacted by the poor health that is often cause, and frequently is, the effect of homelessness.

*“But it comes back to haunt you. In old age. That is the point. And if you are homeless and you don’t have that comfortable surroundings for yourself, those come back and it’s going to exacerbate over and over again. We are talking compound interest on your health. So everything is going to be compounded. So one little scratch turns into an open wound, and then later on it becomes your leg that’s amputated. And then later on it’s your life it’s compounded.”* – Focus Group Participant

## Conclusion

This study has revealed the widespread and life-limiting nature of physical pain among people experiencing homelessness, in many cases chronic in nature. Almost two thirds of participants in this study were experiencing physical pain when they participated in this study and over half had issues with physical pain that could be defined as chronic. Driving this issue is the high rates of diagnosed medical conditions such as arthritis and cluster headaches that are disproportionately affecting homeless people compared to the general population. There is also significant evidence that the daily trauma of homelessness and the vulnerability it places on the body has a causal relationship to physical pain and is compounding the effect of chronic conditions.

While participants in this study reported having some access to medical care, the suitability of this care for managing chronic pain can be questioned based on the evidence. The type of

response that participants reported to be receiving to their pain issues are not meeting their needs. Therefore many people have taken measures that may be further damaging their health in order to manage their pain such as the use of alcohol or illicit drugs or obtaining medication that has not been prescribed for them.

Chronic pain is having a severe impact on the lives of homeless people. In many cases, living with physical pain was credited by participants as contributing to their homelessness. For a significant number of participants it was providing a barrier to escaping homelessness. Better access and improved models of healthcare responding to the needs of homeless people living with chronic pain is likely to not only improve their quality of life but could also lead to homeless people escaping social exclusion. As a result, people experiencing homelessness and living with pain would be able to reintegrate in society for their individual benefit, and for the benefit of society more generally.

## Appendix I: Literature Review

### General poor health across the homelessness population

People with experience of homelessness are known to have significantly worse health outcomes than the general population and higher rates of mortality.<sup>lviii</sup> One recent UK study has shown that almost all long-term physical health problems are more prevalent in the homeless population than in the general public.<sup>lix</sup> Using information supplied by over 2,500 people, the study showed that 35% had been to A&E over the past six months and 26% admitted to hospital in the past six months. Aside from the human cost, the cost to the NHS for secondary care has been estimated as 8 times that of the general population.<sup>lx</sup>

### Chronic pain across the general population

Pain has been defined as “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”<sup>lxi</sup>. Experience of chronic pain, usually defined as over three months experiencing pain, is a common and debilitating condition within the general population. Chronic pain is an individualised experience with multiple causes, set of causes, or manner of causation of a disease or condition<sup>lxii</sup>. It can cause unexpectedly prolonged suffering when, for example, an initial injury evolves into a complex disease state. A transient ankle sprain may turn into a complex regional pain syndrome lasting for months to years; or a week-long episode of shingles may cause post-herpetic neuralgia with disabling pain for months or years<sup>lxiii</sup>. Moreover, chronic pain can be an accompanying symptom of largely irreversible underlying disease, such as degenerative arthritis (osteoarthritis), spinal stenosis, or compression fracture resulting from osteoporosis in older people. Chronic pain can also be a primary complaint of clinical conditions such as fibromyalgia and trigeminal neuralgia, for which neither the aetiology nor mechanism is currently well understood.

The British Pain Society’s (2011) ‘Putting Pain on the Agenda’ report states one in eight people (12.5%) live with chronic pain in the UK.<sup>lxiv</sup> A recent systematic review suggests that chronic pain affects between one-third and one-half of the population of the UK with the burden disproportionately felt by the elderly – up to 62% of over 75s experience chronic pain<sup>lxv</sup>. In between 10.4% and 14.3% of the population (around 8 million people) chronic pain is moderately or severely disabling based on Von Korff’s chronic pain severity assessment tool.<sup>lxvixvii</sup>

A report from the pain summit 2011 highlights that understanding what allows people living in pain to remain in employment is vital. Of the approximately 27 million people in employment, 26% have a health condition or a disability. Of those who are inactive (approximately 9 million) 48 % have a condition or disability.<sup>lxviii</sup>

Persistent pain affects around one in seven of the UK population i.e. 13%. This equates to about five million adults in the UK. Generally, pain becomes more prevalent as the population ages, although the prevalence of pain in those under 40 years of age is about 17%.<sup>lxix</sup>

### Implications of chronic pain for individuals

The implications of chronic pain on an individual’s quality of life are well documented. Impaired quality of life secondary to pain may be expressed by depression (including

increased suicide risk), anxiety, sleep disruption, appetite disturbance and weight loss, cognitive impairment, and limitations in the performance of daily activities. These added burdens are expected to improve with effective pain management.<sup>lxx</sup>

A person living with physical pain can have as poor quality of life similar, if not worse than those with severe health conditions. For example, the impact on quality of life has been compared to that of significant neurological diseases such as Parkinson's.<sup>lxxi</sup> Pain also has a dramatic impact on sufferer's ability to function in society. Low back pain is ranked highest out of 291 conditions studied by the Global Burden of Disease study, ranking number one for years lost to disability worldwide. In fact four of the top 12 disabling conditions globally are persistent pain conditions (low-back and neck pain, migraine, arthritis, other musculoskeletal conditions).<sup>lxxii</sup>

The links between chronic pain and poor mental wellbeing have been well established. One study showed that people experiencing chronic pain were more likely to have problems with anxiety or depression than those with no pain, and the likelihood of reporting anxiety or depression increased markedly as the pain grade increased. Although it is not clear what comes first, a recommendation is made for a multidisciplinary approach to chronic pain management, which addresses all of the areas related to chronic pain.<sup>lxxiii</sup>

One personal account of pain describes the experience of chronic pain: *'together with the pain, depending on the severity, goes the depression, because I do find it's a very depressing illness. When you've got something, you're constantly feeling, knowing, that it's always going to be with you... I think pain can make you feel lonely because you feel that you're the only one who is suffering and can cope with it, and that is a lonely experience.'*<sup>lxxiv</sup>

One study, focusing on individual's experience of chronic back pain found that loss emerged as a continuous thread throughout most participants' experiences. The term 'loss' is used in this context to refer to life events or changes that resulted in the participants being or feeling deprived of something they valued. 'Lost activities' included walking, going to the theatre, out for a meal, driving or travelling more than a short distance by car or public transport, playing with children/grandchildren and going on holiday. As a result, most participants reported that their lives were socially and environmentally restricted.<sup>lxxv</sup> The 2008 Chief Medical Officer report states that 16% of sufferers feel their chronic pain is so bad that they sometimes want to die.<sup>lxxvi</sup> Chronic pain is also associated with increased risk of death independent of socio-demographic factors.<sup>lxxvii</sup>

Job loss, following pain and pain related disability, is recognised as typical for those attending pain clinics and financial loss is often an inevitable outcome of job loss. Forty-one per cent of people who attended pain clinics report that their pain has prevented them from working, and 13% have had to reduce their hours.<sup>lxxviii</sup> The 2008 Chief Medical Officer report states that 25% of pain sufferers lose their jobs.<sup>lxxix</sup>

The National Pain Audit Third Report highlights that although pain has a major impact on work there is little research on how health services can best help people in pain return to work or retain work.

### Barriers to treating chronic pain

Chronic pain sufferers' frequently experience difficulties communicating their condition, which in turn prevents them from seeking help. Jackson's (2005) ethnological research found the invisibility of chronic pain presents challenges to both the sufferer and professionals treating the condition. Patients reported difficulties expressing their discomfort, fearing they will be perceived as 'self-indulgent' or 'weak', or that they will not be believed. This is compounded further when psychological factors are involved as the sufferer may feel professionals interpret the pain as the result of mental illness, or that they are malingering, which exacerbates the individual's anxieties about how they are perceived and perpetuates feelings of shame. Similarly, as chronic pain transgresses the categorical divisions between mind and body it challenges medical understanding, and therefore professionals face challenges in competence when treating the condition. Whereas pain is seen as a symptom rather than a disease, chronic pain has lost this function and has become the problem itself. Interventions that focus on 'managing' pain, rather than curing it, assign less responsibility to health professionals who work to 'co-manage' the problem with the patient. Repositioning themselves from the role of 'healer' to one of 'manager' can be viewed as a response to the threat to knowledge chronic pain produces, which is then internalised by chronic pain sufferers as having a condition that cannot be cured but rather controlled. This role leaves the patient bearing more responsibility to manage the pain themselves and cooperate in a process which they feel to be a 'lost cause'.<sup>lxxx</sup>

According to Waddell (1992), "the medical system encourages passivity, chronicity, and powerlessness".<sup>lxxxi</sup> This is supported by Walker, Holloway & Sofaer's (1990) research<sup>lxxxii</sup> in which chronic pain patients reported feeling 'lost in the system'. The 'system' was described as 'the medical, social security and legal systems designed to treat or support those who are ill or disabled, [but] effectively rendered participants powerless, helpless and angry'. Participants all described long periods spent waiting for referrals, investigations, appointments, surgery, further opinions and the pain clinic and none of the participants were satisfied with the medical process, listing a catalogue of poor communication and poor understanding. This 'system' was experienced by participants as a dehumanising process in which they did not feel they were treated as an entire person but rather, as one participant stated, 'bits and pieces'. Similarly, Kleinman (1998) found "biomedical and behavioural approaches often fail to take account of the social world of pain patients, resulting in their dehumanisation".<sup>lxxxiii</sup> The challenge of treating chronic pain patients and the challenges to receiving satisfactory treatment demoralises both the professional and patient, encouraging mistrust and fractious relationships.

### Implications of chronic pain for public health services

The implications of these issues for health services are significant. Sixty-six per cent of people attending A&E seeking help with pain had more than three visits to a healthcare professional in the preceding six months.<sup>lxxxiv</sup> However, it is also recognised that appropriate treatment can make a significant difference. Attending specialist pain services improves quality of life (in total, 56% of providers reported post-treatment improvement in EQ5D-3L score, and 76% reported improvement specifically in pain-related quality of life).<sup>lxxxv</sup>

The prevalence rates of pain are expected to rise as populations are continually ageing. One study estimates that by 2035, one quarter of the population in the European Union will be 65 or older—thereby increasing the public health impact of pain.<sup>lxxxvi</sup>

### Chronic pain and health inequality

Chronic pain is also well established as a strong example of the health inequalities faced across the population. Men and women in the lowest income households are more likely to report chronic pain (42%), compared to those in the highest quintile (27%).<sup>lxxxvii</sup> However, considering those with experience of homelessness this inequality is far more extreme.

A recent observational study into the nature and prevalence of chronic pain in people experiencing homelessness in the UK found that 59.3% of those experiencing homelessness were in chronic pain with an average duration of pain being over 6 years.<sup>lxxxviii</sup> This study, which used face to face interviews to users of homelessness services, found that the prevalence of chronic pain in people experiencing homelessness appears to be substantially higher than the general population, to be poorly controlled, and adversely affects general activity, walking and sleeping. In addition, the pain is often poorly managed with treatment less effective than that experienced across the general population. The author's hypothesis that poor compliance with medical services and poor treatment of underlying conditions are significant factors in poorer outcomes. In addition, they cite existing Canadian research<sup>lxxxix</sup> indicating that Doctors are reluctant to prescribe opiate based painkillers to those with histories of substance misuse and steroid based anti-inflammatory medications to those with histories of alcohol abuse. Research in the US has confirmed that this is a problem for treatment management.<sup>xc</sup>

Recent US phenomenological research has found that those experiencing homelessness are less likely to seek help regarding their health needs, with one study stating 'being ignored by society, or in healthcare settings, does discourage health-seeking behaviour'.<sup>xcii</sup> These findings are supported by Rae & Rees (2015) qualitative study investigating the perceptions of homeless people regarding their healthcare needs and experiences of receiving healthcare in London.<sup>xciii</sup> Rae & Rees highlighted the theme of 'priority' as key to understanding health seeking and health provision with interviewees feeling they were not perceived as a priority, or treated equally, to domiciled patients by healthcare providers. Interviewees also stated the experience of homelessness and limited resources had altered the importance they once attached to their own health and wellbeing and immediate concerns such as food or money were prioritised. As a result participants would invariably only seek-help with their health when reaching 'crisis point'. However, previous negative experiences such as being refused GP registration, forced relocation away from services, or poor hospital discharge had resulted in loss of trust and deterred engagement with healthcare providers. Negative interactions can in part be understood by healthcare professionals mainly interacting with those experiencing homelessness only once a condition has progressed to a later stage and is, therefore, more complex to treat. In turn this increases the likelihood of poorer outcomes for both the patient and the healthcare provider. Conversely, positive experiences with healthcare professionals, namely good communication, feeling listened to and understood, resulted in positive perceptions of healthcare provision. These findings highlight the importance of healthcare providers to better understand the patient's 'social world', to 'resocialise their understanding of who becomes sick and why, and who has access to healthcare and why'.<sup>xciv</sup>

Measuring pain amongst people experiencing homelessness is challenging. One study suggests that commonly used validated scales are not widely understood by people experiencing homelessness and may produce poor quality data.<sup>xcv</sup>

However, Fisher et al. were not able to confirm the causal relationship between homelessness and pain suggesting that it is likely to be both a cause and effect of homelessness.

Hwang et al.'s Canadian research also corroborates findings suggesting high levels of chronic pain and high intensity of pain, with over one third of participants classified in the IV pain grade (Von Korff) indicating disability resulting from pain. In addition, Hwang et al. found that only half of Dr's surveyed were treating their patients pain and that of those who were, 77% found challenges in treating pain especially around appropriate medications for those with addiction issues. Other international work has found similar high levels of pain amongst those experiencing homelessness. Doran et al. found that 79% of homeless and unstably housed women in San Francisco experienced limitations to their daily activities due to pain.<sup>xcvi</sup> Landefeld et al. found that in older American homeless people almost half reported chronic pain which was associated with a diagnosis of arthritis, PTSD and histories of personal abuse.<sup>xcvii</sup>

Whilst research has clearly demonstrated a significant health inequality in the pain experienced by homeless people, much of this has come from international evidence and the UK context is different. There is a significant need to validate the findings of Fisher et al. in relation to pain prevalence. In addition, there is a need to establish the mechanisms by which pain can lead to homelessness and be caused by experience of homelessness. There is also a very significant need to establish what works in relation to treatment of pain amongst people experiencing homelessness. Pain management has been shown to be highly effective amongst the general population, however these gains do not appear to be being experienced by those who are homeless. Addiction issues and "chaotic" lifestyles do make treatment a significant challenge. However, peer research has the potential to establish ways of working with this client group, which can work for them. Some evidence suggests that use of pictures in pain management messages can be effective in particular for groups who may struggle with English and literacy. The study highlights the involvement of the patient in the construction and evaluation of pictures is vital.<sup>xcviii</sup> Further exploration is necessary into the best means of communicating with people experiencing chronic pain and homelessness.

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