The Painful Truth: 2,500 people who live with chronic pain tell their story
February 2014
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A Patient’s story

One man describes how long-term pain has changed his life and talks about his struggle to access support services for people in pain...

“My life has completely changed; I am not the same person anymore”

“My whole life involved being active, sports and being on the go. Now it is not. I have had to change my role in the family, within friendships, as a husband, as a father and a worker. My identity and confidence have vanished. I hardly go out (not through choice), and have very little support outside my home and church. My pain goes everywhere with me, and mainly controls my days. My routine revolves around pain. My medication could be harming my long-term health or life expectancy, however, without it I scream constantly.

I have to hunt for help and seek out the 'next step' on my pain journey as the information is NOT freely available..... There is no pain services 'network' available (professional or voluntary) and there needs to be. My psychologist tries to help, however, pain, immobility and depression is now my life.... and that is an awful, awful place to be in; especially without correct guidance, help and support from services that is required (not being passed here and there).

The sad thing is that many people working in the services you manage to hunt down really do want to help.... but even they cannot answer questions such as "who would I talk to about alternative pain management therapies?" or "who can I speak to about X procedure?"
Dear Reader,

During the course of our work within the Patient and Client Council we have the privilege of meeting and working alongside many remarkable people. In the past few years individuals who experience chronic pain have engaged with us in the Patient and Client Council to tell us about their experience of living with chronic pain, the challenges they face and their interactions with health and social care.

This project arose because chronic pain sufferers were passionate about the need to have their story told. No study of this kind has ever been undertaken in Northern Ireland. The 2,500 patient stories summarised in this report highlight the need for a coordinated well-resourced approach to delivery of care and treatment.

I would like to thank all the participants who participated in this study and who talked candidly about living with pain and their experience of health and social care services. Their input has provided valuable information which will inform work towards the development of services to address the needs of people living with long-term pain. The Patient and Client Council will strive to ensure that the voices captured in this report influence decision makers in 2014 and beyond.

Maeve Hully

Chief Executive of the Patient and Client Council
The response to this project has been remarkable; more than 2,500 people with long-term pain took time to describe how pain affects their lives, to offer their views on the treatment and care they receive, and to suggest how pain services might improve in the future.

In total 2,525 people contributed to the study; 2,459 people completed a detailed questionnaire, 61 people participated in focus group discussions, and 5 people chose to talk about their experiences of long-term pain in a one-to-one interview.

In this report, the voices of those who suffer from long-term pain are strongest when they describe the impact of pain on their life. People describe the challenges and frustrations of dealing with chronic pain on a daily basis and give personal accounts of the effect of pain on their life.

As well as providing a detailed reflection of what it is like to live with pain on a daily basis, this report addresses a number of key findings in the following areas: – diagnosis, waiting for pain services, long-term support, treatment, and future services.

**Getting a diagnosis**

Getting a diagnosis is very important to people with chronic pain; a diagnosis can help people begin to understand, treat, manage, and accept pain as a long-term condition. Just over half of all questionnaire respondents waited more than a year for a diagnosis, 29% waited in excess of 3 years.

It is clear from the findings of this report that many people with chronic pain feel that they are left to wait, frustrated and in pain, for too long. Waiting for a diagnosis is just the beginning; people also experience lengthy waits for other services such as; referral appointments, tests and scans, pain relief treatments, access to a pain clinic, self-management programmes and physiotherapy.

**Information, treatment and care**

Lack of effective treatment is an issue for many sufferers of long-term pain. Just under a fifth of all questionnaire respondents, (18%), said that the treatment they had received so far had not worked well for them or that they had been offered little or no support.

People believe that more time and resources should go into helping people with chronic pain find effective treatment and techniques to help them manage their pain. There is also some concern that some GPs and other health professionals are too quick to medicate, rather than looking at alternative ways to treat patients.
Alternative therapies are popular among people with chronic pain, but they are rarely provided by the health service and are expensive to pay for privately.

Long-term pain requires long-term support, however many people feel that they are not receiving the on-going support they need to achieve a better quality of life.

People with long-term pain want more help to enable them to manage their own condition. Throughout this study people said that, after initial diagnosis, they were given very little new information or practical advice on treatment or pain management; 68% of questionnaire respondents were not given any written information on their condition and 63% were not given any information or support with self-management of pain. Access to specialist pain management services such as the pain clinic is also thought to be difficult.

Lack of support leaves many feeling let down by the people who are supposed to help them to manage their condition effectively. About 800 questionnaire respondents feel that they do not receive good support from GPs and other health professionals. Some people struggle with apparent lack of understanding and empathy from their GP; in some cases it was said that the GP did not take time to listen, while others felt the GP was dismissive and unwilling to recognise the severity of their pain. It was suggested that some health professionals do not have sufficient knowledge, experience, or understanding of chronic pain to enable them to treat the condition or support the patient.

**How chronic pain affects people’s lives**

For most people who took part in our study, the impact of chronic pain is wide-ranging and does not just affect one aspect of their life. Long-term pain impacted on the majority of people’s ability to work (70%), home life (80%) and ability to take part in leisure activities (83%).

**Future services**

The findings of this report reveal that experience of long-term pain is unique to the individual and what works well for one person might not work well for another. However, it is clear from the findings of this report that in the future people with long-term pain would like to see a holistic, co-ordinated service that provides on-going medical, physical, and emotional support to people with long-term pain, which is delivered by compassionate health professionals who understand pain. As one person with long-term pain describes it, a service which ‘listens, takes action and cares’.
### Recommendations

In light of the key issues identified in this study, the following recommendations are made, along with the key organisation who should action any necessary changes.

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Lead responsibility</th>
<th>Report section reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Getting a diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Long-term pain should be recognised as a condition in its own right by all HSC organisations who deliver care.</td>
<td>Trusts</td>
<td>5.1.1, 5.1.2, 5.3.2</td>
</tr>
<tr>
<td>2. Training and/or information leaflets aimed at GPs and front line health care professionals should be developed. The aim of these resources should be to increase awareness and inform health care staff on what long-term pain is and its effects on those who have it.</td>
<td>HSCB, PHA</td>
<td>5.1.1, 5.1.2</td>
</tr>
<tr>
<td>3. Information resources developed for healthcare staff should be directly informed by and content/user tested with those people who live with long-term pain and/or their carers and relatives.</td>
<td>HSCB, PHA</td>
<td>5.1.1, 5.1.2</td>
</tr>
<tr>
<td><strong>Information, treatment and care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. A Strategic Framework for Pain Services should be developed. The framework should prioritise local primary care led multi-disciplinary teams and be supported by community pharmacy.</td>
<td>DHSSPS</td>
<td>5.2.1, 5.2.2, 5.2.4</td>
</tr>
<tr>
<td>5. Long-term pain management approaches need to be embedded into Integrated Care Partnerships so that those with chronic pain benefit from the delivery of responsive, innovative and multi-disciplinary health care in the future.</td>
<td>HSCB, Trusts</td>
<td>5.1.1, 5.2.1, 5.2.2, 5.2.3, 5.2.4</td>
</tr>
<tr>
<td>6. Service models based on local population needs should be in place across Northern Ireland.</td>
<td>DHSSPS, HSCB, LCGs</td>
<td>5.1.1, 5.2.1, 5.2.2, 5.2.3, 5.2.4</td>
</tr>
<tr>
<td>7. Patients should be offered a range of pain management care and support programmes including supported self-management.</td>
<td>HSCB, Trusts</td>
<td>5.2.4, 5.3.1, 5.4.2, 5.4.3</td>
</tr>
<tr>
<td>8. The role of mainstream alternative therapies should be reviewed specifically for support and help for those people living with long-term pain.</td>
<td>HSCB, Trusts</td>
<td>5.2.4, 5.4.2</td>
</tr>
</tbody>
</table>
### How chronic pain affects people’s lives

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Lead responsibility</th>
<th>Report section reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>9.</strong> An integrated Northern Ireland cross-departmental strategy to manage chronic pain is needed to allow people to manage their pain and to empower them to lead full and active lives.</td>
<td>Cross-departmental</td>
<td>5.3.1</td>
</tr>
<tr>
<td><strong>10.</strong> Information resources for patients, clients, carers and their relatives affected by long-term pain should be developed to help people understand, make decisions about and cope with long-term pain.</td>
<td>PHA</td>
<td>5.3.1, 5.3.2, 5.3.3</td>
</tr>
</tbody>
</table>
1.0 Introduction

Chronic or long-term pain is a feature of many people’s lives in Northern Ireland. Chronic (long-term pain) is commonly defined as pain which lasts for 3 months or more.¹ The Pain Alliance of Northern Ireland (PANI) estimates that 1 in 5 people (about 400,000 people) experience long-term pain which for many is a constant feature of their everyday lives.

Long-term pain is caused by a range of conditions. These include arthritis, fibromyalgia, multiple sclerosis, diabetes, musculoskeletal problems or endometriosis. This is not an exclusive list. Indeed the 2,500 participants of this study cite over 40 diagnoses as contributing to their pain (a list of these is included in Appendix 1). The voices of these people are seldom heard and people tell us that they feel very isolated. It is timely to collect their views and experiences with a view to raising awareness of the challenges facing people and to inform and shape future health and social care policy and service delivery in Northern Ireland.

While studies have taken place in the UK and the Republic of Ireland and in other European countries, we are not aware of any study having been undertaken in Northern Ireland, especially on such a large scale. The decision to undertake this study was largely as a result of people approaching the Patient and Client Council to tell their story and to seek support in raising awareness of their experience of existing services. The need for such work was emphasised in the Pain Summit held in May 2012 at which the Patient and Client Council listened to people’s experiences. The Patient and Client Council subsequently developed a project led by service users with input from medical consultants, nursing specialists and pharmaceutical professionals.

1.1 Aim of the Study

This present study aims to capture people’s experience of services provided for the treatment and support of those living with long-term (chronic) pain. In addition, we want to capture the personal impact that pain has had on people’s lives in order to understand better what support is required. In this report we summarise the background to policy in the UK. We also examine the literature about the epidemiology of pain and finally, but most importantly, we will report findings and

¹ Long-term (chronic) pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” by IASP (International Association for the Study of Pain). There is no internationally agreed timescale for defining long-term pain. The timescale used by many clinicians is three months (a pragmatic approach enabling them to address the needs of patients), but many studies on pain have used various definitions such as three months and six months to define long-term pain.
patients’ stories with a view to informing future policy and strategy regarding appropriate health and social care services in Northern Ireland.
2.0 Background

2.1 Prevalence of Pain

The number of people experiencing pain cannot be precisely quantified although research has repeatedly shown that pain is a major health issue. Researchers have tended to examine the prevalence of pain in one of two ways. The focus is usually on a specific condition (e.g. Multiple Sclerosis or cancer) or a defined group of people (e.g. older people with arthritis or living in nursing homes). Even within these populations, different studies have arrived at different levels of the prevalence of pain.

One of the largest studies was undertaken by Breivik et al (2006). In a study spanning 15 European countries and Israel, the researchers concluded that:

“on average one in five adult Europeans suffer from chronic pain”

(Breivik et al 2006: 309)

This study had over 46,000 respondents. There were variations from country to country, with the UK and Ireland both found to have a prevalence rate of 13%. Breivik et al defined chronic pain as having existed for 6 months, experienced in the past month and experienced at least twice a week, and having moderate intensity. Breivik et al however also state that the prevalence of pain in the population may be even higher as the methodology they used (a telephone survey) tends to exclude older people, people in nursing homes and people in lower socio-economic groups.

All of these groups would have high prevalence levels of pain. This assumption is borne out by data from a number of sources. Fox et al (1999) and Thomas et al (2004) have both detailed the greater occurrence of pain in older adults, while the English Health Survey (2011) notes a high prevalence of pain in England, which is at its highest in the lowest socio-economic group. People in this group were also more likely to experience pain which limited their day-to-day activities.

Perhaps the most significant finding of the survey was the impact of pain on general wellbeing. As the English Health Survey notes:

“One of the most striking findings ...is the relationship between chronic pain and mental health and well-being. Being in chronic pain was associated with poorer mental well-being, lower levels of happiness and higher prevalence of anxiety/depression”. (English Health Survey: 9)
In Northern Ireland, the prevalence of pain is estimated to be around 19%. It is useful, at this point, to compare this finding with a study carried out in the Republic of Ireland. The PRIME study identified a prevalence of 19% within the general population (Raferty et al, 2011).

There are a number of resources which indicate the prevalence of pain or at least certain types of pain in Northern Ireland. Back pain was detailed by the Health and Wellbeing Survey in Northern Ireland in 2001. This survey indicated that 41% of patients had consulted their GP about back pain and 20% of adults stated that they experienced severe back pain in the last year. This compares with the 2005/06 study which showed that 33% of men and 38% of women had been to their doctor with back pain while 14% of men and 18% of women said that they had experienced severe back pain in the past year. The latest census (2011) found that 10% of people who responded had “long-term pain or discomfort”. In this instance, “long-term” is defined as “a condition which has lasted or is expected to last at least 12 months”.

Hospital admissions due to pain have almost trebled in the past 12 years (see Figure 1) and referrals to pain consultants have increased by 270%.

Figure 1: Hospital activity for pain management in Northern Ireland, 1999/00 – 2010/11

The figure of 19% prevalence of chronic pain comes from an extension to the Pain in Europe survey. When the preliminary study was published (2003-4) Northern Ireland was the only part of the UK not included. The researchers received further funding to extend the study to Northern Ireland and the results were available in 2005. Their results were subsequently presented to The British Pain Society and to the Chronic Pain Policy Coalition.
2.2 Strategic Context

There is currently no co-ordinated approach or strategy for management of long-term pain in Northern Ireland. Management of long-term (chronic) pain has long been recognised as having economic and healthcare implications. As early as 1994, the Scottish office published a report which stated that:

‘Chronic pain management is probably one of the most challenging problems in medicine today. Its origins, assessment and treatment are complex. Chronic pain is a debilitating condition. Its prevalence is known to be widespread and it is a major claim on health care resources and the national economy’ (Currie, 1994:3).

It is only relatively recently, however, that developing a strategy to address the needs of those living with long-term pain has become a priority for national governments. Scotland and Wales have published policy documents addressing care pathways and coordinated services for the treatment of pain. In 2008 (in Getting to GRIPS with Chronic Pain in Scotland) the Scottish government recognised that there had been previous reports on pain and acknowledged people’s frustration that in spite of the evidence little had been done. As one of the actions arising from this document, the Scottish government explicitly stated that it would designate pain as a long-term chronic condition rather than a symptom associated with other disease or illness and pledged to act in putting appropriate services in place. Scotland has since established a Chronic Pain Steering Group with a designated clinical lead. A Research Strategy has been put in place, a cross party group established in the Scottish Parliament and an online resource for people experiencing chronic pain has been made available.

Similar developments were also taking place in Wales. The NHS in Wales published “Designed for People with Chronic Conditions: Service Development and Commissioning Directives Chronic Non-Malignant Pain” in 2008 which sought to put in place more co-ordinated services and more services in primary care and in the community. Wales has also established pathways for the treatment of pain which are published as part of the NHS Map of Medicine initiative which provides information on care pathways. Recently the Welsh Assembly published a strategy for commissioning and planning pain services for people with arthritis and musculoskeletal problems.

In England, the Chief Medical Officer devoted a separate chapter on pain in his Annual Report for 2008 (published in 2009), thus indicating that pain had become a significant public health issue. A Pain Summit was held in England in 2011. This was followed by a number of workshops which made a series of recommendations. After further consultation, a final report, Putting Pain on the Agenda (2012) was produced which set out 4 key recommendations. A working group for each of the four recommendations has been established to take the work on pain forward.
In Northern Ireland in May 2012 the Patient and Client Council in partnership with PANI held a Pain Summit (as indicated above). Work continues to address the need for improved services for people with long-term pain. In addition, the Director of Public Health, in her Annual Report (2012), which had a specific focus on older people, cited research that looked at the practice in pain management, recognising the complexity of pain in older people. A strategy for long-term pain is not yet in place although commissioning priorities for pain management are detailed in the Local Commissioning Plan 2013/2014. There is recognition that pain management needs to be improved in relation to older people in nursing homes who are receiving palliative care, while one specific measure for Trusts is to “support the implementation of a Musculoskeletal / Pain pathway by March 2014”.

In the Republic of Ireland the need for a pain strategy has also been promoted, primarily through research carried out in the Prime Study (Raftery et al, 2011) which details the prevalence of pain in ROI as well as its impact on people’s lives.

2.3 Pain Management Services in Northern Ireland

Pain management services are provided by consultant led or nurse led clinics. Pain clinics are generally held in hospitals, but are not necessarily local services. In addition, pain clinics do not offer the same service across Northern Ireland as some may be for the purpose of acupuncture treatment while others will be injection-based to alleviate pain or based on surgical interventions.

Pain services in Northern Ireland have developed locally meaning that there is a variation in the type of services provided across health and social care Trust areas. For example, the Ulster Hospital provides services for the South Eastern Health and Social Care Trust (SEHSCT) – clinics are held every day from Monday to Friday at the Ulster Hospital and there is a clinic one morning per week in Bangor and one morning per week in Newtownards. In the Western Health and Social Care Trust (WHSCT) area, pain clinics are available in Tyrone County Hospital and Altnagelvin, but not at all in the South West at present. Other Trusts provide services through their network of hospitals. A list of clinic location and services is given in Appendix 2.
3.0 Study Design

3.1 How was this study developed

The Patient and Client Council developed this study in response to issues raised by the public about a lack of awareness and knowledge about pain both generally and by health and social care professionals. From the very start of the project, service users have been involved in developing the project. A steering group was set up with people experiencing long-term pain, a consultant in pain management and representatives from pharmacy. The group focused on which groups and areas to target as well as the tools used in the study.

We sought ethical approval for this study from the Office of Research Ethics Committees Northern Ireland (ORECNI), however no formal approval was required as it was deemed to be audit and not research.

Working closely with service users, discussions initially took place as to how data could be collected for study. We concentrated on creating a questionnaire which could be completed by respondents with support available if necessary. However, while it was recognised that valuable data could be collected using this method, it was agreed that a qualitative dimension to the project would provide further in-depth information. A mixed methods approach was therefore adopted. This has been a developing methodology which has the benefit of providing a range of data which reinforce and support findings from different approaches. It can also help offset to some degree the limitations of both qualitative and quantitative methodologies.

The questionnaire was developed over time, based on people’s experience and a number of ways to make it as easy as possible to take part in the survey and share their views were organised. Both printed copies of the questionnaire for people to complete themselves and an online version of the questionnaire were made available. Posters advertising the study were displayed across Northern Ireland. A Quick Response (QR) code\(^3\) was placed on posters providing a link to further information about the project online. In addition, the QR code was placed on the front of printed questionnaires to allow respondents to quickly access an online version of the survey.

To further explore the experiences of those with long-term chronic pain, a focus group approach was developed. Focus groups were conducted by experienced group facilitators from the Patient and Client Council. Whilst not originally planned, due to the level of interest in the study a number of one-to-one interviews were

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\(^3\) A QR code is a type of barcode containing information which can be read by some digital devices such as a mobile phone or tablets. In this study, the QR codes were used to include a website link to information about our study and to allow easy navigation to an online version of our questionnaire.
organised to ensure that anyone who wished take part in the study had an opportunity to do so. A total of 5 people asked to be interviewed.

The summary outline below provides an overview of the final study design developed by the Patient and Client Council following initial discussions with services users and working with the project steering group.

**Figure 2. Summary outline - Overview of key stages in final study design**

**Stage 1 – Study design**
- Project steering group focussing on tools used in the study and targeting of participants;
- Involvement of service users on how data could be collected and key issues for investigation;
- Development of questionnaire and focus group topic guides.

**Stage 2 – Fieldwork**
- Online and paper questionnaire;
- Key issues from comments / stories captured feeding into focus group discussions.

**Stage 3 – Analysis and reporting**
- Coding and analysis of survey data;
- Thematic analysis of findings from focus group discussions, one to one interviews and case studies;
- Reporting of main findings and themes emerging from data collection.

**Questionnaire**
- Focus groups with people who live with long-term pain;
- Small number of one-to-one interviews and case studies.

**Focus groups**
3.2 Data Collection

The Patient and Client Council took a broad-based, practical approach to recruiting participants for this study. A comprehensive communication and distribution plan was implemented to extend the reach of our survey. We worked closely with health professionals such as GPs, physiotherapists and Community Pharmacy as well as voluntary organisations supporting people with pain – these included Arthritis Care, MS Society, Fibromyalgia Support Groups and ex-services groups\(^4\). Our Personal and Public Involvement (PPI) officers also talked to people attending Pain Clinics across Northern Ireland. Most people completed the questionnaire themselves although at pain clinics, PPI officers gave assistance when requested.

Focus groups were held across Northern Ireland and specifically targeted people experiencing long-term pain. They included local Arthritis Care and Fibromyalgia Support Groups. This was very much an opportunistic process as it meant that groups could be quickly set up and general advertising for participants did not have to take place. This was important given the limited timescale and resources available to recruit these groups.

3.3 Reporting

The data collected and presented in this report represents the views of over 2,500 people in Northern Ireland who live with long-term pain. The study has been designed to elicit detailed experiences of people who told us about living with chronic pain. The main findings of this report are therefore provided to enhance the knowledge and understanding of chronic pain in Northern Ireland, from the viewpoint of those who felt that they wished to have their voices heard and to tell their story.

Individual figures and tables presented in this report may not present the total number of respondents who took part in the survey component of this study due to respondent non-response to individual questions and/or question routing implemented in the questionnaire itself.

Percentages presented in this report may not add to 100% due to rounding.

Given the nature of the group discussions it has not been possible to assign numbers, percentages or weightings to quantify the numbers of people who raised specific issues. However, as a general guide the following definitions will give the reader an indication of the frequency of occurrence during group discussions:

\(^4\) See Appendix 4 & 6 for a full list of groups and organisations who supported this study.
<table>
<thead>
<tr>
<th>When we say:</th>
<th>We mean:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- “few”</td>
<td>= 10% of the people or less;</td>
</tr>
<tr>
<td>- “some”</td>
<td>= 11 to 25% of the people;</td>
</tr>
<tr>
<td>- “many”</td>
<td>= 26% to 50% of the people;</td>
</tr>
<tr>
<td>- “the majority”</td>
<td>= 51% to 75% of the people; and,</td>
</tr>
<tr>
<td>- “most”</td>
<td>= 76% + of the people</td>
</tr>
</tbody>
</table>

3.4 Limitations of this Study

Despite an extensive communication and outreach plan, it is possible that some groups may be under-represented. This may include people who are housebound, those who live in nursing homes or those in lower socio-economic groups.

Questionnaires were distributed widely in order to ensure that we reached a wide variety of people who experience chronic pain. Type of pain was not specified and therefore people’s experiences may vary as a result of their diverse medical conditions.

The definition of long-term pain was included on the first page of the questionnaire and also the poster used to advertise the study. This meant that people opting to complete the questionnaire felt that they met the specified criteria set out on the questionnaire. It was not possible to verify that everyone who completed a questionnaire met the required criteria.
4.0 The People

A Patient’s experience of living with chronic pain

“I have lived with chronic pain for 20 years now. There needs to be more time and treatment for pain. Doctors should take pain, especially chronic pain, more seriously. More research, more understanding, and maybe some public education to educate the general public on how this silent complaint is so debilitating. Thanks for listening... ”

A total of 2,525 people contributed to this project by providing their views and experiences of the treatment, care and personal impact of long-term pain.

2,459 people completed a questionnaire about long-term pain. The majority of respondents were female (64%, 1,572 people), and just over half fell into the 40 to 64 years age range (54%, 1,325 people) - see Table 1.

**Table 1. Achieved sample by demographic group**

<table>
<thead>
<tr>
<th>Group</th>
<th>%</th>
<th>Total (n)</th>
</tr>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>28%</td>
<td>681</td>
</tr>
<tr>
<td>Female</td>
<td>64%</td>
<td>1572</td>
</tr>
<tr>
<td>Not provided</td>
<td>8%</td>
<td>206</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 25</td>
<td>2%</td>
<td>39</td>
</tr>
<tr>
<td>25-39</td>
<td>13%</td>
<td>310</td>
</tr>
<tr>
<td>40-54</td>
<td>31%</td>
<td>760</td>
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<td>55-64</td>
<td>23%</td>
<td>565</td>
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<td>65-74</td>
<td>16%</td>
<td>391</td>
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<tr>
<td>75-84</td>
<td>7%</td>
<td>170</td>
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<tr>
<td>85+</td>
<td>2%</td>
<td>43</td>
</tr>
<tr>
<td>Not provided</td>
<td>7%</td>
<td>181</td>
</tr>
<tr>
<td><strong>Trust Area</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Belfast</td>
<td>11%</td>
<td>273</td>
</tr>
<tr>
<td>Northern</td>
<td>19%</td>
<td>461</td>
</tr>
<tr>
<td>Southern</td>
<td>17%</td>
<td>425</td>
</tr>
<tr>
<td>South Eastern</td>
<td>20%</td>
<td>488</td>
</tr>
<tr>
<td>Western</td>
<td>19%</td>
<td>455</td>
</tr>
<tr>
<td>Not provided</td>
<td>15%</td>
<td>357</td>
</tr>
</tbody>
</table>
Most respondents (93%) were people directly experiencing long-term pain, 7% of questionnaires were completed with the help of a carer on behalf of the individual experiencing pain. People identified the location of their pain, often indicating more than one area of the body or simply stating that their pain was ‘everywhere’ (29% of all respondents noted that they experienced their pain ‘everywhere’). Respondents’ answers in relation to where in the body they physically experienced their pain are provided in **Figure 3**.

**Figure 3: Where people experienced pain**

<table>
<thead>
<tr>
<th>Area of Pain</th>
<th>Percentage of Respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Back</td>
<td>44%</td>
</tr>
<tr>
<td>Legs/Feet</td>
<td>22%</td>
</tr>
<tr>
<td>Hip/Groin</td>
<td>8%</td>
</tr>
<tr>
<td>Arms/Hands</td>
<td>5%</td>
</tr>
<tr>
<td>Head</td>
<td>3%</td>
</tr>
<tr>
<td>Chest/Body</td>
<td>3%</td>
</tr>
<tr>
<td>Everywhere</td>
<td>29%</td>
</tr>
</tbody>
</table>

*Question asked: Where is your pain?  Base: 2459 (Multiple response, based on all respondents)*

In a final, free text section to the questionnaire, respondents were able to comment freely on their experiences. Some people with long-term pain took this opportunity to tell their story in detail. In addition, 5 people wanted to talk about their experiences of long-term pain and called the office to request a one-to-one interview with a Patient and Client Council staff member.

Finally, 61 people took part in 10 focus groups held across Northern Ireland to talk about the issues surrounding long-term pain in more detail. Participants discussed a range of topics including diagnosis, treatment, services, and the impact of pain on everyday life.
5.0 Findings

The following section outlines the findings from this study.

5.1 Getting a Diagnosis

It is evident from the findings of this study that getting a diagnosis is very important to people with chronic pain, so that they can try to begin to understand, manage and accept their pain.

5.1.1 Waiting for a Diagnosis

As Figure 4 below indicates, waiting time for a diagnosis can vary greatly. Just over half of all questionnaire respondents (865 people or 52%) said they waited more than a year for a diagnosis; of which, 23% (384 people) waited a period of 1 to 3 years and 29% (481 people) waited over 3 years. Approximately a third of people were diagnosed within 1 to 12 months (577 people or 34%), and about 6% of people (97 people) received an immediate diagnosis. A small number of respondents (49 people or 3%) said they were still waiting for a diagnosis.

Figure 4: How long did it take to get a diagnosis?

This varied waiting time for diagnosis was also reflected in focus group discussions. A few people who had to wait a long time for a diagnosis described how difficult and frustrating it was to repeatedly have to explain how they felt to different health
professionals. This explanation resulted in a lack of understanding or even doubt from the health care profession. In more than one case, individuals said they waited over 30 years for a diagnosis. In some instances, people felt that it had taken so long to receive a diagnosis and appropriate treatment that their medical condition had deteriorated and irreparable damage had been done. For those people who were still trying to get a diagnosis, the process was described as ‘stressful’, anxious’, and ‘soul-destroying’.

“I have had an overall negative experience with my pain with regard to diagnosis and treatment. Over ten years I have seen a multitude of doctors and medical workers, had an array of different tests and procedures carried out, and have been admitted into hospital approximately once every three months. It has been strenuous on me as an individual but also on my family. I had to get a second opinion (only with the help of my daughter’s articulation) and only then was I correctly diagnosed”

“Living with long-term pain is easier when the correct diagnosis is given. For too many years I struggled … Proper diagnosis would save the NHS a lot of money”

“It affects your mental health because you don’t know what is really causing the pain. It does scare me as I fear for the future, until I know what is wrong with me I will not settle”

5.1.2 Support with Diagnosis

Support from GPs and other health professionals is clearly of utmost importance to people with chronic pain - both support in getting an actual diagnosis in the first place and emotional support on receiving a diagnosis. However, some people said they did not receive the necessary support from their GP or consultant; they felt let down and frustrated. A few people decided to pay for a private consultation in the hope of getting a timely and accurate diagnosis as they felt this was not possible through the health service.

“What always puzzled me, when I was first realising I was with constant pain, was that the GP looked at me like I was from a different planet, like it never happened to anyone else before, like I was a mystery...”

“It has been a lengthy and anxious time with very little help from GPs. I feel I have been overlooked and it has taken far too long to be diagnosed”

“Due to the complicated nature of my symptoms I received little support from my GP. All routes of referral to the local hospital were met with disinterest and dismissive attitudes. It took a series of private consultations to provide me access to the appropriate clinician who could diagnose and manage my condition”
While the majority of questionnaire respondents said they were satisfied with the initial response they received from their GP, a sizeable minority (623 people or 38%) indicated that they were not happy with their GP’s response.

As Figure 5 below shows the most common type of action taken by the GP on this initial visit was to write the patient a prescription, (1,559 people or 63%), followed by to refer the patient to another service, (1,284 people or 52%). The three most common responses stated under ‘Other’ were; ‘nothing’ (81 people), ‘tests’ or ‘x-ray’ (73 people), and ‘advice’ (50 people). Please note that some respondents gave more than one answer to this question; Figure 5 reflects the percentage of questionnaire respondents who were offered each action by their GP.

**Figure 5: What action did your GP take when you first saw them about your pain?**

![Bar chart showing the percentage of respondents for different actions taken by GPs.]

- **Offered a prescription**: 63%
- **Made a referral**: 52%
- **Provided with a leaflet**: 4%
- **Other**: 14%

**Question asked:** What action did your GP take when you first saw them about your pain?  
**Base:** 2459 (Multiple response)

Amongst the focus groups on long-term pain were three Fibromyalgia groups, one ME (myalgic encephalomyelitis) group, and one Arthritis group. Members of these groups spoke about particularly difficult experiences of diagnosis. Many described how they had waited years for a diagnosis, during which time they found it difficult to get support from their GP or referrals to other services. It was suggested that there is reluctance amongst some GPs to diagnose arthritis, rather a tendency to put pain down to age or ‘wear and tear’ which prevents people from receiving the appropriate advice and treatment.

Many focus group participants with Fibromyalgia or ME felt there was a lack of knowledge or understanding of these conditions among health professionals, who
are sometimes even reluctant to acknowledge or recognise both as serious conditions. Again this can result in long delays in diagnosis, treatment and support in managing pain. Both these points were also raised across the questionnaires.

“They thought my ME was depression; I was asked ‘why not admit you have depression?’ – they thought it was all in my head”

“I was sent for lots of X-Rays, but was told all the time “you’re getting older, its wear and tear, wear and tear, wear and tear”, until it got beyond wear and tear”

40% of questionnaire respondents said that their GP had made a referral to another service on their behalf. The most common services people were referred to are shown in Figure 6 below.

**Figure 6: What services were you referred to by your GP?**

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist / consultant</td>
<td>38%</td>
</tr>
<tr>
<td>Pain Clinic</td>
<td>18%</td>
</tr>
<tr>
<td>Scan</td>
<td>16%</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>16%</td>
</tr>
<tr>
<td>Emergency Room</td>
<td>12%</td>
</tr>
</tbody>
</table>

Question asked: If your GP made a referral, what service(s) were you referred to?  
Base: 1216 (Only respondents that indicated their GP made a referral)

Almost two thirds of people (1069 or 62%) who were referred to other services by the GP said they received a diagnosis at their referral appointment. Most people were to some degree satisfied with the diagnosis that was made (948 people or 89%); of those, 72% were either ‘satisfied’ or ‘very satisfied’ and 17% were ‘quite satisfied’. The remaining 10% (105 people) indicated that they were ‘not satisfied’ with the diagnosis they received. From comments made in both focus group discussions and on questionnaires, many people were just relieved to finally get some sort of diagnosis or ‘label’ for their pain.
“I cried when I got diagnosed, I was so relieved. People don’t understand as you look well, it is an invisible illness”

58% of questionnaire respondents (805 people) said they were referred to other medical departments or specialist services following this initial referral appointment. Of those respondents who indicated how many times they were referred to a different department, the most common response was 1 or 2 different departments (394 people or 55%). However, it is worth noting that almost a quarter of people (167 or 24%) said they were referred to at least 4 different medical departments or specialist services following their initial referral appointment (see Figure 7 below).

**Figure 7: How many times were you referred to a different medical department / specialty?**

![Bar chart showing referral frequency](chart)

<table>
<thead>
<tr>
<th>No. of times</th>
<th>Percentage of respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td>30%</td>
</tr>
<tr>
<td>Twice</td>
<td>25%</td>
</tr>
<tr>
<td>Three times</td>
<td>21%</td>
</tr>
<tr>
<td>Four times</td>
<td>12%</td>
</tr>
<tr>
<td>Five times or more</td>
<td>12%</td>
</tr>
</tbody>
</table>

**Question asked:** How many times were you referred to a different medical department/specialty?
**Base:** 707 (Only respondents who were referred to other medical departments)

In a final, open-ended section on the questionnaire that allowed people the opportunity to comment freely on any aspect of their care, one of the most common issues raised was the amount of time people were left waiting while in pain before they were given any support. For many people this began with waiting for a diagnosis, or for the necessary support in order to get a diagnosis.

When questionnaire respondents who were referred by their GP to another service were asked how long they waited for an appointment after the referral, the majority of people (707 or 56%) responded 1 to 6 months. A fifth of people (249 or 20%) were
seen instantly or in less than a week and 12% (158 people) waited more than 6 months for their referral appointment (see Figure 8 below).

While some people are clearly attended to very promptly, it is not difficult to see how those people who are referred to multiple medical departments or specialist services can often wait months or even years before they receive a diagnosis for their pain.

**Figure 8: How long did you wait for an appointment after the referral?**

For many people waiting in pain for a diagnosis was just the beginning. This was followed by long waits for appointments with specialists, tests and scans, pain relief treatments, referrals to the pain clinic, physiotherapy, pain management programmes. It is evident that many people with chronic pain feel that they are left to wait, frustrated and in pain, for too long.

“**When in extreme or moderate pain one needs an early referral and urgent appointment. The waiting while in pain is the most difficult to deal with. Not weeks or months or days of waiting if at all possible as this can affect the ability of others to work in the family**”
5.2 Information, Treatment and Care

5.2.1 Treatment and Medication

Just over three quarters of all questionnaire respondents (1,718 or 76%) said that they were given treatment to help manage their pain. As Figure 9 below indicates, the majority of people said they were given painkillers to help manage their pain (1,032 people or 66%), with injections and physiotherapy the next two most common responses (12% and 11% respectively). In addition to the options listed in Figure 9, a small number of people said that they had been offered equipment or mobility aids, alternative therapies, or anti-depressants.

Figure 9: What options were given to you to manage your pain?

Across questionnaire and focus group discussions, two key issues about treatment for chronic pain emerged. Firstly, some people commented on the lack of effective treatment for chronic pain. This comment was often linked to the lack of support they feel they receive from health and social care services. It was suggested that once the GP or consultant tried medication, and perhaps referred the patient to a physiotherapist or a psychologist, there was little else they could do to treat the pain. Some people were frustrated by this “there’s nothing we can do” attitude. They felt that GPs and other health professionals should spend more time working with their patients to find more effective treatments or ways to manage their condition. A few people said they felt ‘abandoned’ or ‘given up on’ by their doctors.
“As a sufferer of long-term pain you feel as though you have hit a wall when it comes to treatment if you have tried all the medication and the treatment without success. Then you feel as though you get palmed off when you see your GP”

“In parts the care has been awesome … but I just think at this stage they’ve just said ‘that’s you on the scrapheap sunshine’. I don’t feel there’s any urgency to get me back”

For a few people, hope of finding an effective treatment or ‘miracle cure’ had long gone and pain was accepted as part of everyday life; they spoke about how difficult it was to come to this realisation and to accept that no further help was forthcoming.

“My diagnosis is ‘I have to learn to live with it’, was the hardest thing I have been told, not that ‘sorry we cannot help’ but just ‘live with it’”

“My diagnosis is ‘I have to learn to live with it’, was the hardest thing I have been told, not that ‘sorry we cannot help’ but just ‘live with it’”

“The second issue was on the subject of alternative therapies. Only 13 questionnaire respondents specified that they were given the option of alternative therapies to help them to manage their pain. Alternative therapies and treatments such as acupuncture, hydrotherapy, massage, meditation, reflexology, tai chi and chiropractic are popular among people with chronic pain; however these treatments can be expensive to pay for privately and are rarely provided by the health service.

“A lot of us end up paying for these treatments ourselves because we know they help us, but we have to fund them ourselves. A lot of us are on benefits so we’re low income and it can be quite a juggling affair”

In stark contrast, the vast majority of questionnaire respondents (2,114 people or 93%), as well as most focus group participants, said that they take medication for their pain. However, as Figure 10 below shows, when asked how effective this medication was almost a fifth of people (395 people or 19%) said “not effective”. A further three quarters of people (1,538 people or 74%) described their medication as only “somewhat effective” and (146 people or 7%) described their medication as very effective.
Figure 10: How effective or non-effective is this medication?

![Bar chart showing effectiveness of medication.
74% said somewhat effective, 7% said very effective, 19% said not effective.]

Question asked: How effective or non-effective is this medication?
Base: 2079 (Only respondents who indicated that they are on medication for their pain)

Just over 45% of respondents (890 people) said that their medication is reviewed at least once a year; but as Figure 11 indicates, a fifth of people (295) do not receive an annual review of their medication. 74% of people (1,215) said that the GP reviews their medication. It is worth noting that many people added that they have to initiate or ask the GP for this review, it is not automatically offered by the GP at regular intervals. Almost a fifth of people (312 or 19%) noted that the consultant reviews their medication and a small number of people said the nurse, the pain clinic, or the individual themselves undertakes this review.
Throughout the study, questionnaire respondents and focus group participants raised a number of concerns on the subject of medication for long-term pain.

The first relates to medication and side-effects. As the findings of the questionnaire reveal, many people with chronic pain take strong medication and pain relief on a daily basis. They are worried about the side-effects and long-term impact of medication on their body; many described the side-effects they experience, such as fatigue, poor memory, upset stomach, hallucinations, mood swings, and the impact this has on their daily life. For some, the side-effects of the medication were almost more difficult to manage than the pain the medication was supposed to treat.

“I feel that whilst I have every faith in my GP, my condition has not received any real relief. I have been fed strong drugs and morphine patches. They helped I thought, as the pain diminished, but the interference with my moods and brain activity nearly ruined my marriage after nearly 30 years. I had to wean myself off as many as I could until I got to a level of pain I could handle AND have my brain function at nearly normal as possible levels”

Some people raised their concern that GPs, and other health professionals, are too quick to hand out medication and are not interested in looking at alternative ways to treat or support patients to manage their pain. A few people described how they had gradually come off or reduced large quantities of medication and now try to self-manage their pain through coping mechanisms and alternative therapies.
“They’re only treating the symptoms and quieting you down kind of. It’s almost like drugging; well it is drugging you really. Whereas if some of the alternative therapies such as reflexology, aromatherapy, massage or hydrotherapy were available on the NHS, then people wouldn’t have to take so many painkillers. But they’re expensive…”

“I want to beg the health service to think again about all the prescribed drugs – they don’t always work and there are other treatments to explore, teach people more and stop making them reliant on drugs”

5.2.2 Information, Advice and Pain Management Support

Just over two thirds of questionnaire respondents (1,549 or 68%) said that they were not given any written information about their condition. Half of all focus group participants agreed that they were given little information or advice on their condition from the GP or other health professionals. Furthermore, as Figure 12 below indicates, a similar number of people (1,420 or 63%) said that they were not given any information or support on self-management of their pain.

**Figure 12: Were you given any written information about your condition / information or support on how to manage your own pain?**

<table>
<thead>
<tr>
<th>Question asked: Were you given any written information about your condition / were you given information or support on how to manage your own pain?</th>
<th>Base: 2266</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were you given any written information about your condition?</td>
<td>Yes 32% No 68%</td>
</tr>
<tr>
<td>Were you given information or support on how to manage your own pain?</td>
<td>Yes 37% No 63%</td>
</tr>
</tbody>
</table>

It is clear from comments made in both questionnaires and focus groups that many people with long-term pain feel that they are not receiving the necessary support to help them to manage their own pain. People repeatedly said that, after initial
diagnosis, they were given very little new information or practical advice on treatment or pain management, and were generally left to manage their own condition.

“I feel I am left to find answers myself. I am employed and live a busy, hard working life. Pain is constant and extreme. However, life goes on. It would be better with medical support to reduce pain”

“I feel I have been deserted and left on my own to deal with this disease and pain. There are no services to help me live like this. I live in hell and the health care trust doesn’t care”

Many people felt they were failed by the people who were supposed to help them to manage their condition effectively. As the GP is often the first point of contact for someone experiencing pain and also the main health care provider for those suffering chronic pain over a long period of time, comments about lack of support, information, and advice were often made directly in relation to GP services.

Experience seems to vary as to how supportive GPs are in helping people manage their pain in the long-term. GP services was one of the most common themes of the final free text section on the questionnaire, and about three quarters of people who commented on this subject described a poor experience. Half of those comments were from people who feel they no longer receive any real help from their GP in treating or managing chronic pain. People said they felt ‘ignored’, ‘given up on’, ‘forgotten’. GPs were seen to be disinterested, complacent, or offering only the most basic treatment or support. Some people said their GP did not monitor their condition or review medication and seemed reluctant to act when pressed by the patient to progress their treatment, such as refer them to a consultant, pain clinic or for other therapies.

“I do feel closer monitoring or rather some monitoring at all (!) of my condition by GP, district nursing team etc. might have been useful over the years. I /my family had to research the latest pain relief/treatments etc. ourselves and then ask my GP for them. At times it felt like we just had to get on with it with little support”

“I would welcome information about any advance or breakthrough in pain treatment. I would like my GP to be proactive here … a register of chronic pain patients informing us of current help in this area would be useful”

It was suggested that some GPs do not have the sufficient knowledge, experience, or understanding of chronic pain to enable them to treat the condition or support the patient. Some people struggle with apparent lack of understanding and empathy from their GP; in some cases it was said that the GP did not take time to listen, while others felt the GP was dismissive and unwilling to recognise the severity of their pain.
“Over the years I’d go to the doctor with a specific pain or symptom and would go away with a prescription - but never felt anyone understood the whole picture or listened to my whole story - they always made me feel I was moaning about trivial things. When I feel at my worst - the last place I feel like going is the doctors”

It is evident from findings that many of the people with chronic pain who contributed to this study accept they have a long-term condition and have to learn to manage and live with their pain. However, it is also evident they are not given the long-term support from health and social care services in order to help them manage their pain effectively and achieve a better quality of life.

5.2.3 Pain Clinic

Almost half of all questionnaire respondents said that they had attended a pain clinic (1,138 people or 49%). The treatment that people received at the pain clinic varied.

As Figure 13 below shows, the most common type of treatment people received at the pain clinic was an injection, 600 people or 40%, followed by a referral to pain management, 343 people or 23%. Under ‘Other’ the most frequent responses were medication or pain relief patches (138 people), physiotherapy/acupuncture (58 people), or simply ‘nothing’ (44 people). A total of 423 people (43%) said that they had since been discharged from the pain clinic, indicating that they had received an episode of care or treatment at the clinic rather than on-going care.

**Figure 13: What treatment did you receive at the pain clinic?**

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Percentage of Respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referred to pain management</td>
<td>23%</td>
</tr>
<tr>
<td>Referred to clinical psychologist</td>
<td>8%</td>
</tr>
<tr>
<td>Was given injections</td>
<td>40%</td>
</tr>
<tr>
<td>Other</td>
<td>29%</td>
</tr>
</tbody>
</table>

Question asked: What treatment did you receive at the pain clinic?
Base: 1497 (only respondents who indicated that they attended a pain clinic)

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5 See introduction page 6
A few people commented further on their experiences of pain clinics. Access was one of the biggest issues raised. Some people suggested that the pain clinic can be difficult to access as GPs appear to be reluctant to make a referral. Even after a referral, access can be difficult; individuals said that after one appointment they did not hear from the pain clinic again, they received no follow-up or review from the pain consultant, or that the pain clinic they attended closed or the pain consultant retired and they were not referred elsewhere. One person said that they actually received an appointment at a pain clinic and on attending discovered that it was no longer running.

“I was sent to a pain clinic which had not operated for years and which I waited on for one year. A doctor did come down and apologise for the clinic no longer in existence”

“Now I have help to manage my pain with my consultant and pain clinic but it was years before I even knew such a service existed and only got referred to it because I asked to be”

“I thought pain clinics were where people like me were referred to. If correct how come pain clinic hasn’t called my name yet? I know I was referred but??”

Some people said they did not benefit from attending the pain clinic. The main two reasons for this response were; the pain consultant could not treat their condition, or the pain consultant was dismissive or doubtful that the patient was experiencing any pain at all. A few people said they had to travel considerable distances to attend a pain clinic which they found challenging both physically and financially.

“I went to the pain clinic which was sometimes very upsetting when some doctors were telling me that I didn’t have pain. They don’t understand we can all learn, we can all read. To understand you have to live in a house with pain. You can have a loving family but be very lonely. I have had pain for 38 years”

While a few people did comment on their positive experiences of attending a pain clinic, it is clear from the findings that the pain clinic is often viewed as nothing more than a treatment centre for pain relief injections. It was suggested that a pain clinic should offer a more holistic service, able to diagnose, give information and advice, and support with long-term pain management.

5.2.4 What works and what does not work for patients?

Questionnaire respondents were asked to rate the way health and social care services have responded to their needs between the time their symptoms started and receiving treatment.
As Figure 14 below shows, 67% of people said the response from health and social care services was ‘average’, ‘very good’ or ‘excellent’; of which, 23% (526 people) indicated ‘very good’ and 7% (158 people) indicated ‘excellent’. However, the remaining third of respondents described the response from services as ‘poor’ (430 people or 19%) or ‘very poor’ (306 people or 14%).

**Figure 14: How would you rate the way health and social care services have responded to your needs?**

![Percentage of respondents (%)](chart_image)

**Question asked:** Between the time symptoms started and receiving treatment, how would you rate the way health and social care services have responded to your needs?

Base: 2248

In order to find out more, questionnaire respondents were asked what worked well for them in the treatment and support they received, and what did not work so well.

It is interesting to note that the three most common responses on the ‘what works’ and ‘what does not work’ lists are the same, medication, support, and physiotherapy. This indicates the importance of these three areas of care for people with long-term pain, and that each individual’s experience of ‘what works’ or ‘what doesn’t work’ for them can be very different.

It is also worth noting that just under a fifth of all respondents (approximately 18%) said that none of the treatment they had tried so far had worked well for them or that they had been offered no or very little support for their chronic pain from health and social care services.
What Works for You?

People with chronic pain told us what worked well for them in terms of treatment and support. The top eight responses, each mentioned by at least 50 people, are listed in order of the frequency with which they were said. The figure in brackets on the more detailed list represents approximately how many people gave this response.

1. Medication and pain relief
2. Support from GPs and other health professionals
3. Physiotherapy
4. Alternative therapies or treatments
5. Pain clinic
6. Surgery
7. Support groups, family support, charity organisations
8. Self-management

1. Medication and pain relief (800 people)

People named a wide-range of medication they take which works well for them. Many people said that pain relief medication, in the form of tablets, injections, patches, and gels, does help ease their pain each day. However, it should be noted that many people qualified this response with comments on the temporary nature of some pain relief, unpleasant side-effects of medication, and concerns about the effect of taking so much medication over a long-term period.

“The pain medication totally changed my life”

“The combination of prescription drugs. The understanding of my GP with regular reviews of my medication and adjustments to help ease the pain”

2. Support from GPs and other health professionals (460 people)

Many people said that the support they received from health professionals has worked well for them - support with diagnosis, listening to and understanding the individual, and acknowledging their pain. The majority of people said that this support, understanding, and advice came from their GP. Some people said they only received this level of support when they were referred to a consultant or specialist who understood their condition and could offer appropriate treatment.
“The advantage of an excellent and caring GP - readily affordable and easy to discuss and help, always listens”

“GP’s physical support (medicine) emotional support (longer appointments and listening) and mental support (anti-depressants, listening and helping me learn meditation)”

“Having someone who listened to me and acknowledged I needed support and offered me alternatives. To know that your "hidden" condition is a fact with on-going pain and your abilities are limited as a consequence - I will try in spite of my condition is my motto”

3. Physiotherapy (200 people)

Physiotherapy helped many people with chronic pain conditions. However, it should be noted that some people said they were only offered a very short course of physiotherapy through health and social care services, and not everyone could afford to continue their physiotherapy privately.

“Physio - finally someone who has more than 5 minutes to work out what to do. Useful practical information at last after 1 year of being offered drugs”

“I sought out a physiotherapist who specialised in my condition. Whilst under her care I did well managing my pain. However due to NHS cutbacks this ended, I have never been able to manage as well”

4. Alternative therapies or treatments (180 people)

Alternative therapies work well for many people with chronic pain. Acupuncture was the most frequently mentioned treatment. Also popular were hydrotherapy, chiropractic, yoga or Pilates, massage, heat treatment, and exercise classes. A small number of people said reflexology, aromatherapy, and osteopathy helped them. Again, many people said they had to pay privately for these therapies.

“Acupuncture, massage, reflexology, chiropractor, hydrotherapy. (I pay for these treatments) Anti-depressants, muscle relaxants, pain medication. All help to ease symptoms but do not cure”
5. Pain clinic (100 people)

Some people said the pain management advice and the treatment they received at the pain clinic (especially injections) really worked well for them.

“The pain clinic was the first time I felt listened to, after 8 years of being told the pain was not real”

“The pain specialist nurse at the pain clinic was a great help - review your medication. She listens and is there and explains why”

6. Surgery (80 people)

Surgery was an important part of some people’s treatment for pain.

“Seeing an orthopaedic surgeon who was willing to perform surgery to help, my GP who saw me weekly sometimes and got first-hand what I was suffering”

7. Support groups, family support, charity organisations (80 people)

For some people, support outside health and social care services made a positive difference; such as support groups where they can talk to peers who understand what they are going through; advice, information, and support from charity organisations who specialise in their condition; and the support of family and friends.

“Most of the support I have received has been from the fibromyalgia support group and not from our local health service. Acupuncture and massage has helped me but I have to fund this myself and can’t afford it on a regular basis”

8. Self-management (60 people)

People who found that conventional medication did not work well for them and those who said they received very little support from health and social care services talked about the many ways in which they had learned to ‘self-manage’ their pain including; relaxation techniques, pacing exercises, changing diet, self-hypnosis, using hobbies or word puzzles as a distraction, learning about their own condition, mindfulness, meditation, determination, and adopting a positive attitude.
“NLP [neuro-linguistic programming], CBT (cognitive behavioural therapy), mindfulness meditation, pain management (pacing, medication, exercise) and an extremely positive outlook”

“I have taught myself to focus on things beyond my pain such as mental arithmetic, word games, word patterns”

What Does Not Work for You?

People with chronic pain told us what did not work well for them in terms of treatment and support. The top six responses, each mentioned by at least 50 people, are listed in order of the frequency with which they were said.

1. Medication and pain relief
2. Support from GPs and other health professionals
3. Physiotherapy
4. Waiting time
5. Lack of action, treatment plans, or advice on self-management
6. Getting a diagnosis

1. Medication and pain relief (600 people)

Many people said that their medication did not work well for them. The most common explanations given for why medication was not thought to work well were; unpleasant side-effects, pain relief is short-term or minimal, too many drugs on a daily basis, and too much trial and error before finding the right medication. A notable number of people said that pain relief injections they received, often through the pain clinic, were either ineffective or only provided very temporary relief.

Side effects of medication - catch 22 situation - take medication that is so strong you can’t do anything or take less medication and still remain in pain”

“ Took two years to make GPs understand that the usual pain medication (paracetamol / ibuprofen / codeine and diclofenac) were 100% ineffective”
2. Support from GPs and other health professionals (380 people)

Many people said they were unhappy with the support they received from their GP, or in a smaller number of cases their consultant. The most common reason given for this response was that GPs and other health professionals lacked understanding, they did not take time to listen, and were not interested in the patient. Some people said health professionals could be dismissive of their symptoms and reluctant or unwilling to acknowledge or believe they were in pain. Other reasons given were; GPs are too quick to medicate rather than looking at root cause or alternative treatments, GPs are reluctant to make a referral to other services, health professionals lack knowledge of their condition, and there is poor co-ordination between different services.

“My GP continually tried to dismiss the pain I was in, even after years. They told me it was normal, that I just had to get on with it and learn to live with it. They never listened to what I was saying and always wanted to go with the least difficult option”

“The total lack of interest by many consultants, making me doubt myself and driving me close to a mental breakdown”

“GP had no idea what to do and you feel like you are passed around separate departments and no-one takes responsibility- most never listen to the patient and I knew what was wrong or at least where the pain was coming from at the start but no-one listened to me- also there is no joined up thinking. Each department works in isolation and rarely does anyone call you back for a review- the whole process is depressing, frustrating and infuriating”

3. Physiotherapy (230 people)

Some people felt that physiotherapy did not work well for them. The main two explanations given for this response were; the physiotherapist was reluctant to treat them properly due to their condition, or they were in more pain after receiving physiotherapy.

“Physio has left me depressed as I can’t do many of the exercises because of my pain. I was asked did I understand that I’d never be better!! That this would never go away!”
4. Waiting time (150 people)

Waiting while in pain for various services or treatments, such as referral appointments, physiotherapy, pain clinic, follow-up or review appointments, treatments, and surgery, was an extremely frustrating experience for people.

“The waiting time is awful - chronic pain is not life threatening so therefore I believe I am not seen as urgent. To make people in such severe pain wait years is inhuman”

“Nothing done - other than waiting, waiting, waiting for an expert to examine my condition”

5. Lack of action, treatment plans, or advice on self-management (100 people)

Some people were disappointed at the lack of advice and information they received from their GP and other health care professionals on how to manage their symptoms on a day to day basis (such as diet, exercise, relaxation techniques). A few people noted the complete lack of any treatment plan or interest on behalf of their GP in helping their patient control pain. This lack of action and ‘nothing can be done’ attitude of some GPs and health professionals was frustrating for people.

“No treatment plan given i.e. what I might expect from the service, information given on what medication might alleviate my pain and whether they could prescribe and if not where I might get help from - possibly my GP?”

“No one doctor took responsibility for managing / contacting / assisting me with how I was coping with my condition - it has been left up to me to manage pain and contact my GP when required”

6. Getting a diagnosis (80 people)

The diagnosis process did not work well for some people. Waiting for such a long time for an accurate diagnosis, and consequently for the appropriate treatment and support, can in some cases lead to a deterioration in health and irreparable damage. A few people continue to wait for a diagnosis and explanation for their pain.

“Doctors examining me then referring me on to another consultant without getting to the root of the cause. Six years being passed back and forward to doctors without any diagnosis”
5.3 How Chronic Pain affects people’s lives

5.3.1 Impact on Everyday Life

This section returned the largest response of the study, as people gave personal accounts of the affect pain has on their life and described the challenges and frustrations of dealing with chronic pain on a daily basis.

On the questionnaire, many people took the opportunity to provide additional information in the final, open-ended section in relation to any further feedback on the impact of chronic pain on people’s lives and those of their family. It is striking that, previously in the questionnaire, people were asked directly to describe how long-term pain had made an impact on their life and yet they took this opportunity to comment even further, reflective of the strong, emotional response on this subject. This question also generated the most discussion and debate within the focus groups.

The majority of people who responded to the questionnaire said that long-term pain affects three of the most central areas of their everyday life; home, work, and leisure.

Figure 15: How long-term pain has affected respondents

<table>
<thead>
<tr>
<th>Areas that long-term pain has affected</th>
<th>Percentage of Respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability to Work</td>
<td>70%</td>
</tr>
<tr>
<td>Home Life</td>
<td>80%</td>
</tr>
<tr>
<td>Leisure Activities</td>
<td>83%</td>
</tr>
</tbody>
</table>

Question asked: Has long-term pain affected the following: your ability to work, your home life, your participation in leisure activities?
Base: 2459 (Multiple response)
For most people, the impact of chronic pain is wide-ranging; it does not just affect one aspect of their life. Often one effect of pain can trigger or aggravate another and people can feel trapped in a vicious circle. For example, pain can affect a person’s ability to work, which can result in financial worries, stress, the loss of their main social outlet, and poor mental health. Chronic pain can prevent people from taking part in their favourite hobby or sporting activity, which can leave them feeling housebound, isolated, and can affect their friendships and involvement in family life.

Throughout this study, people gave very detailed, honest, and often emotional, descriptions of the impact of long-term pain on their life. Their response has been grouped into the following five categories:

A. Daily Life with Pain
B. Limitations on Lifestyle
C. Quality of Life
D. Identity
E. Relationships and Family

A Daily Life with Pain

“It has caused me to struggle with everything on a daily basis”

Many people said that pain affects every aspect of their daily life. Pain often dictates what they can or cannot do and is the dominant influence on their day-to-day life.

“It is miserable being in pain and it makes every day a challenge in doing what is normal to everyone else. I have to live my life around my pain rather than managing my pain to fit in with my life”

“My long-term pain changes from day to day. This has resulted in my inability to continue with full time employment. It impacts on every aspect of my daily life - social, work, rest and play. It makes me feel inadequate in many aspects of my life. I wish I had a magic wand to go back to my old self”

As Figure 15 above shows, 80% of questionnaire respondents said that pain has affected their home life. With chronic pain, the most basic daily tasks and activities that most people take for granted can become a struggle. Many people said that their pain makes household tasks such as cleaning, cooking, shopping and gardening more difficult or even impossible. Some people need help with personal care such as washing, bathing, and dressing each day.
“I can no longer do activities I used to do. I don’t shop - my husband has to do this now, I cannot do housework very easily due to pain so my husband tends to do everything. I have difficulties socialising because I am too tired and will often go to bed early at around 8pm. I do work, but I am lucky that I have an understanding and helpful employer, however I can only do work that involves sitting so my career opportunities are very limited. I haven’t been on holiday for over 5 years as the effort and additional pain would be too much. I can’t garden without a lot of help and support. I can’t get in and out the shower by myself, it takes a long time to get dressed and ready for work in the morning if my husband is not there to get clothes out ready for me. I very often will go without a shower or wash for several days if I am not working. I can’t walk the dog. I can’t carry things because I use crutches. I don’t cook a meal because I can’t stand for long at the cooker. I have lost friends. I have difficulty holding my arm above my head to dry my hair or put it up. I need help to take some items of clothes off. It has had a huge impact on my life and there is probably more than what I have written here”

B Limitations on Lifestyle

“The main impact is that pain has affected the choices I can make in my life”

Chronic pain can restrict people’s lives and place limits on their lifestyle. People described their frustrations at not being able to do the things they would like to do, or the things that they used to enjoy. Some people felt that they were ‘missing out’ on life, or unable to ‘live life to the full’.

“Having suffered fibromyalgia for almost 5 years and a mum to 3 young children, each day is a challenge. The pain leaves me restricted to what I can do or participate in. I have very little energy and chronic fatigue. All this results in depression and anxiety which has a huge impact on my life also”

“It has affected the choices I can make in my life. On occasions I am limited in the decisions I make as I simply cannot do everything I want to - even little simple things are difficult. I cannot always manage to get money from my purse, and have to ask for help carrying trays in coffee shops or pouring out a kettle of hot water. I try not to give in, or lie low due to the pain and still manage a full-time job. However I often need to explain to my child that my hands do not work properly so I cannot plait her hair, or open a jar or do an activity. I often feel tired, if I have had pain through the night and have had to give up hobbies such as sewing. Even holding a book can be difficult and yet to look at me I appear to be a healthy forty-two year old woman”
Work Life

The findings of the questionnaire show that 70% of people feel that long-term pain has affected their ability to work; an issue also reflected in focus group discussions.

More than 300 questionnaire respondents described the impact of pain on their work life. About two thirds of these had lost their job or had to retire early as a result of their condition, which often had a consequent effect on other aspects of their life such as personal identity, social life, relationships, or finances. The remainder said that pain impacts on their ability to work properly; people said they struggled at work, had to reduce their hours, or missed a lot of work due to illness.

The financial impact of unemployment or reduced hours was evident in many of these comments; particularly those who said they had were not eligible for disability support despite having a long-term condition which prevented them from working.

“"I’m not fit to work anymore and have had to give up my job as I was a brickie. This has put a big strain on my marriage because it’s not easy living on one wage and I’m only getting 70 odd pounds a week in incapacity benefit. Sitting at home has played around a bit with my head and things are not always good. I have little to no social life, as I can’t play football anymore and can't afford to go out much anyway”

“"It’s very hard for a man to sit back and watch other people do his work, and I know that I am in bad form and I worry that my bad temper and frustration is pushing people away. I’m aware that my condition will never go away but with the right care I can learn to deal with the pain. It does affect your mood and this needs to be addressed too. More understanding is needed at the first point of contact. More support with benefits and a crossover of services between health and welfare is a must because for those who have to beg for sickness benefit when living with all this pain just adds to the stress of it all”"

Social Life

When asked how pain had made an impact on their life, perhaps the most common response was that it limited social life; be that socialising with friends and family, taking part in sports or physical activities, or enjoying a favourite hobby or pastime. 83% of questionnaire respondents said that pain affected their ability to participate in leisure activities, and more than 500 people commented further on the subject.

Pain, poor mobility, and fatigue can have a huge impact on social life; socialising with friends, going out for a meal or for a drink, going to the cinema or theatre, shopping, outings, holidays, taking part in family activities. Some people described how their condition makes them feel withdrawn, lacking in confidence, distracted and disinterested, which can make socialising very difficult. Others said that they were unable to make or stick to social plans because they did not know if their pain would
prevent them from going out. Some friendships had broken down as a result of this unreliability or ‘always saying no’.

“Was registered nurse but cannot carry out nursing duties anymore. I can no longer complete hobbies such as running, cycling and canoe. Walking any distance causes a lot of pain so I meet up and socialise less with friends and family. Being in constant pain keeps my mood low, it’s all I ever seem to talk about - people have mentioned this to me”

“I can’t do things I used to enjoy like dancing, even wearing heels now - I ache. It’s affecting most of my day to day life. My house isn’t as clean as it was which gets me down. My friends have given up as I never am able to go out”

Many people said they had to give up fit and active lives because of pain. People talked about how difficult it was to give up the physical activities they had once enjoyed, such as running, dancing, swimming, cycling, going to the gym, and walking. For many, giving up on sports such as golf, football, cricket, bowls, and badminton, was a loss in terms of social life as much as physical activity. Hobbies like gardening, playing music, sewing, knitting, and even reading, were also affected by pain, fatigue, and limited mobility.

“I am 51 years of age and I am in constant pain. It affects my whole life. I was always very sporty, played rugby, a good golfer and always very active. Now I cannot walk any distance, cannot play golf, cannot sleep at night with the pain and it has affected my marriage an awful lot. I am on that much medication and anti-depressants”

“I am mostly bedbound, the medication I take is affecting my heart, I cannot work anymore, play music which has been my passion since the age of 6, had to give up on my college degree. I cannot look after my son or do any activities with him that we used to do. I have no social life and extremely limited interaction with anyone. Constant pain and its intensity make it hard to function along and lack of help and understanding from the medical profession is horrible as all I want is my life back!”

It is clear from many of the comments made that loss of social life and inability to exercise or participate in hobbies and leisure activities can have a huge impact on mental health, and can leave people feeling isolated and depressed. A few people said they had gained a lot of weight through inactivity and this had added to their pain, low mood and lack of confidence.
“I have become very depressed, I feel isolated and very much dropped out of society. Pain is not understood”

“My continuous pain has made life unbearable. I live in total isolation - lost all my contacts. Since I am unable to work I receive just a fraction of my previous income, just enough to survive but not to live. Life doesn’t seem to make any sense anymore. Day passes after day, week after week and there is nothing to look forward to”

C Quality of Life

“Quite simply, my long-term pain has robbed me of my joy of living”

As long-term pain can affect every aspect of life – home, work, and social – it can leave the individual feeling that their quality of life is poor. Many people commented on how their quality or enjoyment of life has been greatly limited by pain, with some people going as far as to say that their life had been ‘ruined’ or ‘destroyed’ by pain.

“Destroyed!! Lost job. Lost wife. Lost confidence. Lost friends. Lost leisure”

“I went from a very active working mum to having to leave work and give up exercise and stay at home. After a very short time I also went on anti-depressants which I am still taking. My quality of life has gone to zero”

“I feel I don’t have a life anymore. I am just existing”

People described how pain affects quality of life both physically and emotionally.

Physical Health

People described how the physical impact of long-term pain can reduce their quality of life; most commonly poor mobility, lack of sleep or disrupted sleep patterns, fatigue, difficulty sitting or standing in one place for long periods, and poor concentration. Figure 16 overleaf reflects just one of these aspects, but it indicates how commonly the physical effects of pain can impact on people’s quality of life. Almost three quarters of all questionnaire respondents (1,678 people or 73%) disagreed with the statement ‘long-term pain has not disturbed my sleep pattern’.
Side-effects from medication such as tiredness, lethargy, confusion, poor memory, lack of focus, disinterest, and stomach complaints, also affect some people’s day to day life. For many, the physical effects of pain and medication prevent them from participating fully in home or work life, which can in turn affect their mood and emotional wellbeing.

“I’ve been told that it’s part of the illness [rheumatoid arthritis]. I will get worn down, fatigue and tiredness. It’s a vicious circle. The more stressed you are, the more tired you are, the worse your pain is and the pain causes stress so it just goes round and round and round in a never ending circle and you do get very down”

“Every day from the moment I wake up, after yet another interrupted sleep night, there is a fleeting moment between opening my eyes and before becoming properly awake when I think and pray that everything will be back to normal and free from pain, then instantaneously my dream dissolves and I feel that cringing thud followed by a thousand jags searing up my legs for yet another damned day. I can’t stand and comfortably have a conversation with someone before the pain drives me to distraction. I can’t sit for long before I have to get up. I can’t hear or listen to what people are saying because my mind is totally absorbed by the pain. I used to read quite a lot but I can’t even do that anymore because if I even get to the bottom of a page I stop and ask myself ‘what have I just read?’ The one quality of life that I believe I have is actually being alive and being able to hope that tomorrow will be better. I know that many people no longer have that luxury and that annoys me whenever I start to whinge about how I feel”
Emotional Wellbeing

It is clear from findings that the emotional or mental impact of long-term pain is equally widespread. As Figure 17 below reveals, the majority of people (1,996 people or 88%) who completed a questionnaire said that long-term pain has had a negative impact on their mood.

**Figure 17: Long-term pain has had a negative impact on my mood**

Hundreds of people commented further on this issue. In fact, in the final, open-end section to the questionnaire, the mental and emotional impact of long-term pain was the single most common issue about which people wanted to write more. In both questionnaires and focus groups people described how they battled with depression, mood swings, irritability, anger, stress, anxiety, emotion or weepiness, feelings of worthlessness and low self-esteem. A small but notable number of people said they had considered or attempted suicide in the past because of pain. A few people suggested that there was not enough psychological support offered to people with chronic pain.

“It has ruined my life. It has resulted in loss of self-confidence and low self-esteem. I had to stop work 14 years early. I am 57 with the body of a 97 year old. It has affected my will to live”
“You don’t want to let people know how depressed the constant pain leaves you. How sometimes you wonder how futile life is. How your social life and friends disappear as you are too sore or drugged to go out”

“It has made me insecure in my life especially in my relationship with my boyfriend. It has nearly destroyed my relationship with my family/friends and boyfriend due to the strains the pain had put on me physically and mentally. I had to quit university because my pain got too much for me to handle. I also attempted to take my own life due to the long-term pain and how it affected me mentally and physically and because the health system just did not take me seriously and did not help me enough and I had no one to speak to who understood what I was going through. I just thought that I was a burden on everybody and that no-one could help me so at the time I just thought I would make everybody’s lives easier by ending mine and to be honest I just was screaming out for help and attention and for people to realise what the chronic pain was doing to my life”

D  Identity

“I am not the same person as before I had pain”

Developing a chronic pain condition was said to be life-changing, as pain prevented the person from participating in the activities they used to enjoy or living the kind of life they used to live. Many people said they struggled with the lack of independence that came with their condition, and found it difficult to accept that they often depended on others for help with basic daily tasks. This loss of independence had a subsequent impact on personal identity and feelings of inadequacy in some people.

“Long-term pain has stripped me of my identity - it controlled me, it affected every area of my life, my dignity, my emotional wellbeing, my memory, my capability, relationships”

“It has completely changed my life, and me as a person, I can no longer do anything without being in pain. It has affected how my husband and children see me as a wife and mother. I feel less of a person, and need their help with everyday life”

Some people said they no longer recognised the person they used to be, before they developed long-term pain. A few people described how pain had aged them prematurely and robbed them of their youth.
“Living and trying to cope with this pain has impacted every aspect of my life and completely changed my identity - in how I viewed myself but also in how others viewed me”

“I don’t even recognise the person that I am now, I was once a keep fit fanatic and career driven woman involved with lots of charities too now I can’t even shower independently”

E Relationships and Family

“It separates you from everything - you feel a burden on everyone around you”

The wider impact of pain on family and personal relationships was a common concern expressed by the people with chronic pain who contributed to this study. People are worried about their condition, the way it restricts their lifestyle and affects their mental and emotional wellbeing, impacts on their close family, friends and the relationships they share.

Many people described how their pain affects family relationships, as everyone in the household is affected by their condition. Some people said they felt ‘guilty’ because pain stopped them from participating fully in family life and yet they depended a lot on their relatives for care and support. Parents and grandparents said they were missing out on life with their children or grandchildren because it was sometimes difficult to lift them, play with them, or even give them a hug. A few people said that their condition negatively affected their relationship with their spouse or partner, and a small number of people said pain had contributed to the breakdown of their marriage or long-term relationship.

“It’s hard on the whole lot of them. It’s hard on the wife and boys ... they are under a lot of pressure, they watch me like a hawk ... they are there to pick up the pieces”

“I have to dig deep daily to cope with being a husband, dad, grandfather, brother friend etc. as you need a good memory to remember who you used to be and how you always acted day to day ... I am lucky I have a wife who is my best friend and carer and a supportive family, others have nobody.”

“My relationship has ended. I have few friends left. I look 20 years older than I am. I feel down all the time and have no will power anymore”

“It has stripped me of everything, especially my children’s life”
5.3.2 Acceptance of Pain by Others

“The pain may be invisible, but I am not”

More than 200 people who completed the questionnaire commented on the ‘invisibility’ of pain. This was also a common theme of focus group discussions. It is evident from the findings of this study that many people consider pain to be a ‘hidden illness’.

In the majority of cases, this comment was made in reference to the attitude of health professionals. Almost a fifth of all questionnaire respondents (18% or 420 people) feel that healthcare staff did not acknowledge their symptoms. Further commenting on this issue, people said that GPs and other health professionals were reluctant to acknowledge their pain or to treat them seriously. Some felt they were treated with suspicion, as though they were lying about their condition in order to get medication, access to disability benefits, or even sympathy. Those who said they were not believed clearly felt let down, defeated and alone, particularly as the delay in acknowledging symptoms caused a delay in receiving appropriate treatment.

“The MOST traumatic part of my story is the fact no-one believed me. I worked as a nurse, no-one supported me or gave me any help even though I asked for it. This included medical staff, nursing colleagues and line managers. I lost my job which broke my heart and took me years to come to terms with. I could write a book!”

“My GP’s first response was ‘we all get aches and pains’. I knew it was going to be an uphill battle…”

“It takes so long for the care professionals to first believe the patient, second to make a diagnosis, third to prescribe accurate medication for the pain and fourth to appear to understand the effect of pain on the patient”

While most people said they receive good support from family and close friends, there are some who feel that family, friends, and colleagues struggle to understand their condition because they are not dealing with a visible illness. The most difficult thing to hear was said to be, ‘you look so well’, when inside you are suffering the effects of chronic pain. A few people suggested that the wider public, and even family and friends, can make assumptions that people who complain about chronic pain are really just ‘lazy’, ‘attention seeking’, or that it is ‘all in your head’.
“People say to you, ‘you look really well’, when inside you’re dying”

“It is invisible [Fibromyalgia] people have less sympathy, less understanding. They say “just pull yourself together”, it is more complicated than that”

“I am only in my 20s but pain has robbed me of my youth and I act like a very old woman. I have lost friends because they cannot understand something which they cannot see. For 9 years I was told it was all in my head which had an emotional impact on my life. I had to sacrifice activities and interests just to be able to save enough energy to do day-to-day tasks and to continue in my education. People treat you differently when you look "normal" on the outside and many assume there is nothing wrong with you and that you are making it up for attention”

This sense of questioning or suspicion is frustrating for people who suffer from pain, and such a lack of understanding can be very isolating. It was suggested that there should be more research, understanding, and education within the medical profession and more awareness and education of chronic pain and conditions associated with chronic pain within the wider community.

5.3.3 Personal Acceptance of Long-Term Pain

Despite the limitations on lifestyle, the reduced quality of life both physically and mentally, and the reluctance of some health professionals and others to acknowledge the condition, a few people took this opportunity to describe how they had personally come to terms with their long-term pain. This usually involved finding ways to manage the condition, learning their boundaries and limitations, trying to stay positive, and generally learning to live with pain.

“It is just a part of my life now; I just get up and get on with it”

“It restricted and controlled me - now I control it”

“It’s nearly like a bereavement for people … you just have to accept it and get on with your life”

However, there were some people who said they still struggle to come to terms with long-term pain, especially as there is no foreseeable end to it, no ‘miracle cure’. A few people spoke about their fears for the future, worried that they would not receive the necessary support if their mobility deteriorated or if they lost their job as their condition advanced. It was suggested that people should be offered more help to come to terms with chronic pain and to accept the impact that it has on daily living.
“You just think to yourself, ‘is this it, am I going to just spend every day for the rest of my life in pain?’ Because you know there isn’t anything that can cure it, you’re not going to heal, not going to get better. I find that hard to deal with”

“Once diagnosed, medication was given, but the hardest part that I experienced was coming to terms with the condition. I felt that it was left up to me to find ways of coping with daily tasks and adjusting to situations.”

5.4 Future Services

People were asked what kind of treatment, care, or support would improve their life and to suggest what they would like to see from future services. Many were at a loss to suggest anything at all that might improve their condition or daily life with pain. Some people added that only ‘a cure’, ‘a miracle’ or ‘a new body’ would help.

The suggestions that people with chronic pain did make as to treatment or support that would improve their life, now and in the future, fall into three main categories, identified clearly by one person with long-term pain as “Listen – Action – Care”.

5.4.1 “Listen”

“Compassion, understanding, patience and time”

The most important aspect of future services for many people with chronic pain would be greater understanding and compassion from health professionals who have time and interest to listen to the patient and to try to understand how pain affects their daily life.

“Less rushed, more empathy and understanding of the limits chronic pain can have on your life and better use of a variety of applications/methodologies for pain management”

“Doctor usually refers to my pain as wear and tear. They don’t seem to understand the effect pain has on my life nor my inability to take anti-inflammatory drugs. Don’t have time to talk to me or discuss any alternatives”

Some people said that their life would improve if they received more recognition or acknowledgement of their pain from health professionals, as they felt that they were not believed, offered respect, or taken seriously when accessing services. As one person put it, in the future they would like to see “chronic pain deemed a valid medical condition”. A few people suggested that more public awareness or education around chronic pain might aid understanding and make pain more visible.
“To be taken seriously and believed, I just want help to live as full and effective life as is possible, I did not ask for my health problems but I have them and must find a way to exist in spite of them”

“I feel for me being accepted, heard and acknowledged as suffering from pain. A bit of empathy and human respect. Being seen by someone who deals with my symptoms and understands them would help. I haven’t had good experiences with many of the doctors I have seen. If you’re not demanding or forward they won’t bother”

“At the moment I feel that my dignity has been trampled. I don’t see my GP unless I really have to because every time I leave I feel that another bit of my self-respect has been chipped away. I want to be able to present the problem and feel that it is being taken seriously instead of dreading every appointment and having to push for everything that I need. At the minute my life feels like survival of the fittest”

5.4.2 “Action”

“Supportive care and a plan of action which will reduce pain or help me cope”

In the future, people want a faster service. Many with chronic pain said that access to services is much too slow; people would like to wait shorter periods of time for appointments, referrals, diagnosis, and treatment. Some added that they would appreciate being kept informed as to why they were waiting so long, rather than constantly chasing appointments themselves. People want more regular reviews of their condition, medication, treatment and support needs. Appointments should be planned very clearly in advance and not subject to delays or cancellations.

“A service that cares enough to invest in caring for long-term patients rather than dumping them out and leaving them to fend for themselves without any help. Not everyone has a family to assist them or support them and at present the system just leaves people with no follow up what so ever”

“Quicker response to diagnosis. Quicker referrals to consultants. Quicker agreement to carry out MRI scans or CT scans. One visit per month with GP that is not rushed to discuss on-going health”

“It would help if I felt my case was being reviewed and followed up. At the moment I have to ask for everything and if I hadn’t asked myself, I would probably not even be on the waiting list for the pain management programme. I always have to chase results e.g. of scans etc. - if I didn’t I would probably never get them. There should be some sort of support service available. At the moment there appears to be none and living with pain is very lonely and isolating. The rest of the world moves on and goes to work etc. while I stay at home alone”
People want easier access to services and treatments for chronic pain. Access to regular, long-term physiotherapy, rather than the short, one-off sessions that are currently available, was most frequently mentioned. Second on the list was better access to diagnostic tests and consultations with specialists in order to get a diagnosis that might aid understanding and allow for appropriate treatment. Other services which people said they would like improved access to were, in order of frequency, home care services, surgery, occupational therapy, pain clinic, counselling services, support groups, and dietician for diet and weight loss advice.

Many people suggested that alternative therapies can help people with chronic pain and should be more widely available through the health service, especially as people with long-term pain are often on low income and can struggle to pay privately for these services. The alternative therapies or treatments most commonly mentioned were, acupuncture, hydrotherapy, massage, exercise classes, chiropractic, reflexology, relaxation or meditation, pilates or yoga, and heat therapy.

Some people talked about the difficulties they face getting access to services and treatments on occasions when their pain flares up or becomes acute. It was suggested that a direct line of access or self-referral system for already existing patients with long-term pain would enable people to get medical intervention and support from services when they need it, rather than go through the GP, start referral process, and face months of waiting in pain each time they go through a bad period.

| “Ease of access to any treatment for my condition, i.e. all services in one spot with specific staff from consultant to physio to occupational health. And one point of contact” |
| “I don’t know but perhaps some form of psychological help in the form of counselling, hypnosis or meditation might help even if it just supports me emotionally to cope better. Are other alternative therapies a beneficial treatment, something like acupuncture or reflexology? I have not been able to or invited to talk to someone who could advise on such things. Maybe they would not help but it would be nice to know” |
| “Access to the resources I need to manage my own condition would be a huge bonus. Physiotherapy would help. I used to pay for private physiotherapy but cannot afford it as I cannot work full time anymore” |

Some people said they would like health professionals, particularly GPs and consultants, to be more proactive in diagnosing and treating their condition. They want to see more action; full investigations into the cause of pain, more timely intervention, diagnostic tests, appropriate referrals, and exploration of all possible treatment routes rather than just telling the patient “there is nothing we can do”. People want more options with their treatment beyond medication, and for health professionals to be more open to new or alternative treatments.
It was suggested that with more professional development among health care professionals, new research, and up-to-date thinking on chronic pain, treatment, and pain management techniques, support and treatment options for people with chronic pain might expand in the future.

Finally, almost one in six questionnaire respondents said that more effective pain relief or more appropriate and effective medication, with fewer debilitating side-effects, would help to improve their life.

“Would just wish that I could find someone who specialised in actual chronic pain who showed a genuine interest in my condition and was willing to put me on treatment and monitor and give me a sense of security”

“The health service needs specialists who understand skeletal problems and who have the time and interest to understand what a patient is going through. I would love a proper diagnosis in the health service and some serious consideration of treatment options and maintenance of my health despite this constant pain”

“I want the health care trust to understand that just diagnosing someone and leaving them with a pile of pain killers for the remainder of their lives is no way to live. I was offered no support or alternative therapies. I know that the hospitals don’t want to offer alternative holistic therapies as they say they have no official proof that they work, but for a chronic pain sufferer like myself when all other avenues of medical help has failed, it should absolutely be offered. Living with chronic pain and mountains of painkillers is not ‘living’, its ‘surviving’”

“If there were new treatments, please consider us long suffering souls”

5.4.3 “Care”

“Support, help, advice and understanding”

Many people with chronic pain said that their life would improve if they had more support from health and social care services, or if they could be assured that they will receive on-going support in the future. The clear message is that long-term pain is a condition which requires long-term support. People want a level of support which will help them to live as full a life as possible, with dignity and understanding. For some, this extends to financial support, as chronic pain can often affect employment.
A few people said that they would benefit from more specialist support for their particular condition, and hoped that in the future Northern Ireland might have a regional specialist for their condition.

“Understanding me as a person and providing help and support when needed to help me continue in my role as a wife, mother and my job”

“More on-going, up-dated, researched, reviewed information; knowledge; treatment; medication; care and support at regular reviewed appointments. Regular therapy sessions; advice and guidance relating, if appropriate, on diet, lifestyle and exercise; regular professional specialised local support groups with professional specialised trained personnel”

“All round support - physical, medical and emotional. Health professionals to work closely together on an all-round care plan i.e. pain clinic, psychiatrist and physical disabilities team”

Many people said they would benefit from some form of pain management plan tailored to the individual, which sets out a way forward in how to live and deal with pain on a daily basis and offers advice on the treatment, medication, and services available. Information and advice is essential for people with long-term pain; people said they wanted more practical advice on pain management, clear explanations about what is happening to them and why, information on available treatments and services, and more understanding and knowledge of their condition so that they can help themselves as much as possible.

“Supportive care and a plan of action which will either help reduce pain or help me to cope with it”

“Someone to make the pain manageable, practical support both physically and emotionally, to be treated like an intelligent person who is not lying or exaggerating her condition”

For some, a future service for people with chronic pain would provide more holistic care; a care package or pathway for people with chronic pain conditions, which would provide co-ordinated, integrated, multidisciplinary care, bringing together physical, mental and social support and treating the whole person and the condition rather than treating various symptoms or parts of the problem. Suggestions included a single point of contact in the form of a ‘pain specialist’ or a one-stop service for chronic pain conditions such as a ‘pain centre’. 
“A true multidisciplinary approach - physiotherapist, occupational therapist, pain relief clinic, emotional support, patient support group, complementary therapy, information booklets. Many things - as well as a single yearly 10 minute outpatient review appointment”

“Honesty, clarity, simplicity, more time at appointments, a 'network' of services (official and voluntary; physical and mental health) that communicates, are synchronised, multi-faceted and provide a combined 'holistic' approach”

“One room, a specialist team working for people like me, and when you enter the hospital you look for the sign which has been missing ‘Chronic Pain Dept.’ this way”

5.5 Living with Pain... Stories

Pain can be a life-changing experience. In the stories detailed below, people tell us about their day-to-day struggle with pain and their attempts to live as normal a life as possible. These stories illustrate that, with chronic pain, the ordinary things of life can become difficult, if not impossible. Each story is told in the individual’s own words and they are grouped into a number of themes.

1. The impact of pain on relationships, family life, and intimacy

These two stories illustrate the difficulties people face when pain has become a major issue in their lives – they find that pain not only affects them physically, but can have a negative impact on their relationships with those closest to them.

A woman gives an emotional account of how long-term pain has affected her close relationships and family life...

“Maybe the minister should come for a day and live with me, let him look into my husband’s eyes and see what I’m missing”

"It's been 10+ years that I have had this pain and it's not going away. If I had money I would pay for new hips, but I don't. It kills me to think that when I'm 60 they will replace my hips and that I knew if they did it now I could run around with my grandchild and dance with my husband...what I miss the most, dancing around with
my handsome husband... now I have to make do with watching him dance with friends. On a good week I might get half a spin round the floor with him, but I really suffer the next day.

My [husband] told me one evening after whiskeys that he missed me, it was very hard for him to say that and I worry about him because he doesn't talk about it, but it is the fun we used to have together that we both miss. No more on the beach, no more walks on the hills with the ramblers. And no more passion, I love my husband very much and I cry at night because I miss the closeness we had and I miss the sex. Days when I'm in lots of pain I know I'm hard to live with, and god only knows why he hasn't left me. Maybe one of these days he will, who knows.

I watch every day as my hands change and think ‘is this the next step, are my hands going to start to curl in?’ I see nanas with their grandchildren and wish I could chase mine down the park. But to be honest I would settle at this stage just to be able to stand up and hold him in my arms. I really hope you can do something.”

A woman talks about how pain altered her life completely; affecting relationships with family and friends and forcing her to leave a job she loved…

“When I first got sick I was a nurse, which I truly loved and was busy planning my wedding and having lots of fun with my friends and family”

“Following a routine appendectomy I noticed pain some weeks later. At first my GP at the time was patient. However after going to her following one of my outpatient appointments, she told me to get on with things that I was lucky it wasn't cancer. (I think I am a pretty grounded person who tries to put a brave face on things and get on, however I now find it hard to say when I'm not coping with the pain).

In time the medication changed me; it left me having no real interest in much and wasn't doing much for the pain. I lost some of my friends as I found it very hard to arrange things and keep to it. At this stage I had left nursing as I hated ringing in sick the whole time and letting the ward down and having to go to see those in
charge because of my sick leave. I just handed in my notice with no advice which I truly regret. I have had surgery twice, and take medicine which I would much prefer not to.

I have a truly amazing husband, we have suffered financially, physically [sex life] and emotional turmoil due to this pain. I have two beautiful girls but at times I cannot do all the things I want to do with them and very often have to disappoint them. We rely very much on family support when I’m in really bad form as I cannot drive due to pain and medication. We moved house and took girls out of school to be a little closer to them. I can be very irritable and agitated when in pain.

Constant headaches and feeling sick. Mobility, not only walking but lying, sitting can all be very difficult. Day to day life is difficult between pain and at times isolation. I can’t wear certain clothes and at time even the waist band on my underpants drives the pain crazy. I have a wee part time job which I never take for granted and love every day that I am fit to work, but at min[ute] off sick with the pain again.”

2. Learning to cope with pain

People living with pain have to make adjustments to their everyday lives. One of the biggest challenges, perhaps, is coming to terms with the fact that pain is going to be part of their lives for a long time. These two stories describe how two women came to terms with living in pain.

"Acceptance is a huge part in dealing with pain"

“I first took pain when I was 19 I am now 36. At the start I really did think it was in my head or that it would go away. Only once in that time spell did I find life very difficult and found it hard to stay strong, but due to family support I learnt to cope. It’s strange at the minute; I am off sick after a very good spell of very little pain. You
forget when your pain is manageable to cope with, how tough and bad things are when you are in a lot of pain and nothing you do or take can do much for it.

I have pain every single day, and I mean every second, but mostly I can manage. I love to walk and truly do think that some form of exercise is good for you, but at the minute I totally appreciate this is not the case for everybody or to do every day. Normal day-to-day things such as lifting the kettle or jar of milk, sitting to have your dinner, all causes pain. I can’t stand noise when I’m in bad form, which is strange as I work in a primary school. You go to bed sore and get up sore or sorer some mornings (note I say ‘get up’ because not every night can you sleep or get comfortable with the pain). I believe I am a strong, fun person to be around and always try to think positively (at minute very hard) and I would love to be fit to give some sort of support to those like me.

I have had to change my life totally because of pain, it makes you appreciate there is more than money out there, that your health is your wealth. In some ways our life when pain is manageable is probably better than some of my friends as they all work full time and longer to afford their houses, cars and holidays and that would have been me but because of the pain we had to learn to cut back and I am at home every day when the [children] come home from school. I attend a pain specialist down south which, apart from waiting times, is a lot more positive experience than the one I had here at home but that was a number of years ago.”

A woman details her experience of pain, the sexual abuse which caused her pain, and the importance of mental and emotional support in learning to cope…

“I get angry and frustrated with myself as I remember how I used to be and what I am now”

“I have been diagnosed with Degenerative Disc Disease, Fibromyalgia and Raynaud’s. My tailbone is cracked, my spine is curved and have lost a disc at the lumbar part of the spine. I have discs which are twisted and sitting on nerve ends. I
am in pain 24/7, and when spasms occur, I am left paralysed from the neck downwards, my whole system, nerves, muscles, joints are affected and in pain. When I come out of this, my whole system is affected with more pain on top of what I call normal pain.

Everything has slowed down; walking and doing simple jobs take forever. I found this hard to cope with and I am learning with the help of CMP (Condition Management Programme) to deal with it at a different level. I have a very young child too, so I have to be careful of what I can and cannot do when it comes to playtime.

My injuries came due to rapes; I have been raped 3 times by the one person, the last one ended in violence and beatings. He kicked me with steel toe boots, practically jumped on my back. I do have mental depression as at the time I didn't deal with it. I was also raped and abused by an uncle when I was 11 years old - with both of these incidents coming to a head after my [child] was born, I had a mental breakdown.

I have been fortunate with the counselling I am offered both by doctors and counsellors. I am in on-going therapy. I am grateful and thankful to the Social Care System who have offered whatever help they could. I have tried everything I have been asked to do and it is still on-going. I really don't know what I would do without them and I have encouraged others who are in a similar position to seek the help I have gratefully been offered. Thank you for taking the time to read this. Take care.”

3. **The importance of a health care service that listens, cares and takes action on pain**

It is clear from the findings of this study that people experiencing pain look for and value support from their health care professionals. In these stories, respondents tell how individuals can make a difference. Being listened to and being believed makes a difference to people even when their pain is very severe and medicine may not be effective. Finding health professionals who worked with them rather than against them helped and supported two of these respondents in their struggle with pain.
This man’s experience highlights the importance of a health service that listens, cares, and takes timely and effective action to diagnose and treat pain…

“I could write a book about my whole journey”

"Initially I injured my back at work. The pain was awful… I finished my night duty and phoned the GP surgery, I had to be assertive to get an appointment which I don't like and caused me more distress at a period in time were that was the last thing I needed (and I appreciate the role of a GP receptionist). I saw the GP and got strong painkillers and then he said come back in a few days. I did return in a few days and to be honest I was no better, the pain wasn't going away and I was concerned about what had happened. I was normal active and fit and now I was confined to my bed around the clock. This wasn't me. The GP give me more medications which helped a bit. I asked the GP for an x-ray which I got done and got a referral to physio.

That was ok but by this stage I started to get paresthesia in my leg and other body areas and this was very alarming. I could hardly sleep with the pain and I was exhausted. I asked the 2nd GP I saw could I get something to help me sleep or get me into a better sleep pattern. The GP didn't approach it well at all. I was warned that I could become a drug addict, when all I was looking for was something mild to help get me over to sleep because of my pain. I was fighting to try and improve myself and I had put a lot of faith and trust into that GP who really was abrupt, insensitive and hurtful. To be honest I was hugely disappointed in someone who I thought knew me and would help me, when in fact they did the complete opposite.

My condition deteriorated to the stage where it affected my continence which was embarrassing to talk about at such a young age. It affected my ability to go out, but also made me realise that my condition was unstable. I contacted a 3rd GP who was brilliant. I remember it was my birthday as well. They sent me straight to A&E and said that I should get an MRI scan urgently. I went to A&E, and the nursing staff were fantastic they couldn't have been nicer to me. I explained to the Doctor who examined me the whole story etc. and that my GP felt I should get an MRI scan. The A&E Doctor said they felt it wasn't necessary and that dribbling was "normal" for me at my stage in life and it was probably a slipped disc and nothing to worry about.
Another disinterested physician who to be honest was unrealistic, sharp, rude, inattentive and never offered anything stronger for pain or not ordering scans as an outpatient etc. To be honest I was disgusted with the way I was spoken to.

So a week later I returned to my GP (I was off work at least 4 weeks at this point in time) and met a GP who I have seen ever since. It was this GP who was the light at the end of the tunnel. This GP listened, was caring, honest, empathetic, UNDERSTOOD how this was affecting my whole life, recognised I wanted to get better, recognised the correct regime of drugs I needed to be on, ordered my MRI scan, referred me to ICATS team and ensured I got outstanding physiotherapy.

From my initial injury to today it has been over 2 years. I attended my physiotherapist for over a year and, like my GP, the physiotherapist was outstanding and a CREDIT to the Health Service. From an initial poor experience I got 2 healthcare professionals who were just outstanding and turned my whole experience around. If only all the other healthcare professionals were like [them]. Whilst there are problems that might not always get resolved, they offered long-term solutions and management strategies. I can say that there is some amazing work that gets done in the NHS and it never gets highlighted enough in respect to this topic.”

A man tries to describe his lifelong experience of extreme pain...

“The pain of all of this is beyond a normal person’s thinking”

"My pain is described as bad as terminal cancer, Arachnoiditis, which is extremely rare. My condition was hid from me until I got an MRI, I can no longer trust anyone. This has ruined my life. Now I am awaiting two more operations and sometimes I pray that I don’t make it...

At school the pain I had was bad and no one would believe me, not even the teachers. And because I could not do PE I got caned. I was really aggressive and disruptive in class, I did not want to be like this. I then left and started working … but
I still had incredible pain and went to the doctors and hospital many, many times and they just sent me home again and said that there was nothing wrong with me. In 1983 I was admitted to Musgrave Park Hospital and was there for 5 weeks and they found out that I have something in my back that should not be there. The consultant said to me, ‘we thought you were having us on because you looked so well’, they said back pain is hard to prove and some people want to claim compensation. I felt great after this because I was finally being believed.

I was transferred to neurosurgery and had an operation at the RVH and they found out I had spina bifida. I went back to work and was fine for 5 years and then the pain returned. This year I found out I have adhesive inflammation arachnoiditis. The pain is horrendous and has changed me completely. It is a very rare condition, even the clothes on your skin feels wet and your whole back feels as if you are on fire, it’s like permanent sciatica only worse. I cannot sleep.

I try to be polite but can get really cheeky and aggressive because of the pain. I cannot escape the horrendous pain. The neurosurgeon says go home and rest, I am not being given sufficient pain relief. The pain clinic say I am hard to treat. No one understands how it affects me; it is a complex disease and I find it hard to catheterise. I am on my own and I am isolated. For many other reasons no wonder people want to commit suicide, I now have started to hate people the world is rotten.

One man calls for greater education and understanding of the conditions that cause chronic pain…

“I took to the internet to find a proper diagnosis of my condition as the health care system was failing me”

"I first started getting bad headaches in my teens. I was lucky enough that migraine medication was able to stop the associated pain. During my twenty's the pain became more severe and no medication offered by GPs was having a positive effect on the pain. I also noticed that I was experiencing my headaches every two years around February and lasting anything from 3-6 months. It was in my early 30s and
during one of my cycles ... I discovered CH.com and read many of the testimonials and I knew straight away that this was the condition that I was suffering from [Cluster Headaches]. I took this new information to my doctor but he continued to treat me as a migraine patient. I put a post on Ch.com about my experiences and all of the replies advised me to get a young doctor as they are more willing to work and learn with you. I moved doctors and my life has changed dramatically for the better as my new doc is working with me rather than against me to better my condition.

On the 4-6-13 I was experiencing a really bad attack. It began at 1.30am and lasted for approx. 6 hrs. My wife rang the out of hours service to see if a doctor could visit and offer me some relief from this very bad attack that I was experiencing. My wife gave all my details to the nurse, quite clearly stating my condition and that an imigran injection or something similar would only work. A GP arrived after 45 mins and offered me two paracetamol … When in a full level 10 cluster attack you cannot sit still as you have to pace the room as you bite down on a cushion so your children who are asleep upstairs don't hear their father scream and cry with the associated pain. My wife asked the doctor did he not speak to the nurse about my condition and his reply was ‘but these paracetamol should do the trick, they’re very strong’. My wife kindly asked the elderly gentleman to leave our house. My experience over my life time with elderly GPs both in Ireland and England unfortunately has not been a very positive one. I continue to suffer from cluster headaches and I’m currently in cycle at the moment. I hope by filling in this survey that I raise awareness of the condition and the pain associated with it.”

4. **HSC and pain - lack of support, waiting in pain, too quick to medicate and paying privately for pain services**

Some people in this study commented in detail about the Health and Social Care system. While there were individuals who did their best to help the people, in these stories, the actual system of being referred and getting appointments seems to be uncoordinated. This led to people having to wait for weeks or months in a lot of pain and living with the fear that their condition was deteriorating while they waited. These two respondents recount their story.
An arthritis patient talks about waiting in pain and the cost of paying privately for treatment and services…

“Where to start! The 'system' is a shambles”

“Once diagnosed - I now receive a yearly review appointment with my consultant rheumatologist. This review appointment is consistently pushed back by months in order to facilitate 'new' patient appointments. This means my arthritic pain gets worse, and I have to wait longer to be seen. Then when I am seen and told I need a 'joint injection', I am put on a waiting list for this injection which can be anything up to 9 months away - all the time the pain is getting worse. It is madness.

BUT - if I contact a private clinic (where my consultant also works) - I can be seen and given the injection usually within 1 week for the cost of approximately £260 per injection. I have used my savings to attend these private clinics as a) it reduces my pain, b) improves my mobility and daily life, c) enables me to continue/go back to work. I feel it is scandalous that in total I may have to wait 18 months (review appointment waiting time plus injection clinic waiting time) when the same consultant (who is superb by the way) is working 2 miles up the road from the hospital and can be seen within 7 days.

There is also a zero multidisciplinary team approach to care. Medication is king it would appear and all other aspects of 'holistic' care are non-existent. Of course they are actually available - should you wish to pay for them. Keep taking the tablets and don't call us, we will call you seems to be the motto. Sorry if I seem a little disgruntled, but over the last 10 years I have spent a small fortune from my savings (via private appointments mentioned above) trying to keep myself as mobile, healthy and in employment. As they say in Northern Ireland - you do get a little 'fed up' at times. A genuine thank you for taking the time to compile this survey”

A person with long-term pain and mental health problems has met with apathy within the healthcare system, but experienced good community support services…
“Living with pain every day has worn me down. Sometimes I wonder is it worth going on. I am 61”

"I am overweight but always led an active life, I have mental health problems and under the care of a psychiatric nurse. I have developed arthritis in my lower back and also I have been told I need new hip and knee joints. It took a long time to diagnose what was wrong with me. I eventually paid for private health care diagnosis, which carried out MRI scans and were able to provide an accurate diagnosis very quickly. The NHS was unable to do this in over 2 years.

I encountered a lot of apathy within the NHS system, especially from GPs. The easy thing to do was diagnose me pain killers. I take a lot of pain killers every day, but they have little effect. I am increasingly less mobile which is affecting my weight problem. I spend a lot of time on my own in the house. I cannot go shopping easily as unless I park outside the shop I can’t easily walk to it. I get very down and depressed.

I have very good support services in the community. They are angels. I slept in a chair for over a year just to get some respite from pain. In over 2 years I did not get a full night’s sleep. Community services have now got me a proper bed and I get a night’s sleep. This has been through the care of individuals not of the NHS system, where I'm just a number. My brother and some friends look out for me and my community housing association have been very good."

5. Pain as life-changing; reality of everyday life with pain

People’s circumstances and lifestyles change as a result of long-term pain as seen in these two stories. In the first story a retired nurse talks of the financial consequences of having to give up work and deal with the complexities of the benefits system. In the second story, a young man speaks of the embarrassment of having to use a walking aid – his injury has also affected his ability to earn a living.
A retired nurse details the stark reality of everyday life with chronic pain and the financial consequences of a debilitating long-term condition...

“This is my life; me and my pain exist together”

"I have spent 1000s of pounds trying to find some relief from pain and continue to work (chiropractor/physiotherapy). As an ex-nurse, on reflection, some treatment most likely doing more harm than good. 7 years ago I was diagnosed with fibromyalgia - mention that word to most professionals is like using a swear word. When still working for many years I wished I could go to sleep and never waken up again, although I was not suicidal.

I could write reams about how pain affects every aspect of my life - but look at any chronic pain website or read any book - it has all been said before. It affects: sleep - bathroom visits are frequent - difficulty bathing/showering - shopping - cooking - social life - visiting family and friends - sitting on different chairs - sleeping on a different mattress - using a different pillow - all triggers off pain, discomfort and sciatica. I used to love walking, that’s now restricted and no pleasure as every step is painful. It causes memory problems and lack of concentration.

I had to give up work in 2005 aged 55 - before retiring, I had to attend counselling. I knew that I wasn’t fit to continue working as a nurse due to poor eyesight due to nystagmus. I couldn’t be re-deployed to a switchboard position even travelling to work, by the time I arrived I was ready to go to bed at 5pm and 8 am seemed a very long time away. I worried what we would live on. Thankfully I have survived; the benefit system is a nightmare. I receive a little and live on less than £10,000 p/a. Seems unfair after giving my life to a job I loved and to others for 40 years.

Especially in the last 8 years I have learned to accept and live with chronic pain (most of the time). There are many things I could say but my neck and shoulder is hurting and I am tired writing."
A young person with chronic pain talks about how it affects every aspect of their life; work, leisure, and, above all, mood...

“The biggest impact is my mood. No one seems to understand how severe the pain can get”

“I count myself as a young person who was very sporty and fit. I have always had on-going issues with my back pain since I was 18 but always fought through it. My pain threshold is high and have found over the years obstructed my diagnosis. Then Sept 2012 my back and legs gave in. I couldn’t walk or move with the crippling pain. I was bed ridden for a few months. I don’t remember much because of high doses and injections of medication.

My work has been affected (self-employed). My mood and memory, my adventurous sporty side has been laid to rest, any distance without my walking aid (which at my age I find embarrassing). The medication I am on now leaves me in a ‘drunk state’ but at least it helps me to get on with my life. This impact - when you have a life it takes such a drastic change and I have gone from a non-believer in taking tablets to a long-term user. Even the simple tasks in life, housework, driving, and even dressing myself became an issue...

I finally found the right GP that listens, got me on the right medication, although with healthcare money cuts I have now been refused diclofenac sodium disp. 500mg and asked to try naproxen. I have tried it but it doesn’t help when the pain is bad….This will probably be another NHS fight but here goes…”
6.0 Conclusions

Pain is a major issue for many people in Northern Ireland. It is not a visible illness and the extent of suffering for those who live with long-term pain is not always clear to others. However, participants in this study noted that living with pain can affect every aspect of their daily lives from lifestyle, relationships and identity through to general quality of life.

Through the experiences of patient stories we collected in this study, people have told us about their experience from initial diagnosis through to treatment, support and what it feels like to live with long-term pain.

Getting a diagnosis

The findings of this study show that getting a diagnosis is very important to people with long-term pain so that they can try to begin to understand, manage and accept their pain.

Some of the people who talked to us said that their life would improve if they received more recognition or acknowledgement of their pain from health professionals as they felt they were not believed, offered respect or taken seriously when accessing services.

Some participants who took part in our focus groups noted that they felt let down or frustrated by the support they received from their GP or consultant during their diagnosis. Furthermore, getting a final diagnosis can often prove difficult, with over half of respondents who took part in our survey waiting more than 12 months. Diagnosis also meant that, for many respondents, referrals to a series of different services and healthcare professionals were also required which contributed to long waits. People who are referred to multiple medical departments or specialist services can often wait months or even years before they receive a diagnosis for their pain.

As a consequence of long waits for a diagnosis, a few people talked about how they had decided to pay privately using their own savings so that they could get timely and accurate diagnosis as they did not feel that they could get this through their own Health and Social Care service.

For many people, waiting in pain for a diagnosis was just the beginning. People talked about long waits for appointments to see specialists, for tests and scans, referrals to pain clinics, physiotherapy and pain management programmes.

Feedback within focus groups found that many people with long-term pain felt that they are left to wait, frustrated and in pain for too long.
Information, treatment and care

Issues with treatment were raised by many people that we talked to. Medication to control pain was acknowledged as often necessary, however some respondents noted that it was the only treatment available to them and it was mentioned by some that conventional medication did not always work for them.

Treatments such as physiotherapy were felt to have helped many people in our study. Alternative therapies such as acupuncture, hydrotherapy and massage were also felt to help some. However, few respondents (<1%, n=13) in our survey specified that they were given the option of alternative therapies to help them manage their pain.

Many people with long-term pain feel that they are not receiving the necessary support to help them manage their pain. A sizeable minority (38%) of respondents indicated that they were not happy with the initial response they received from their GP when they first saw them. There was also variability in experiences of GPs and other healthcare staff. Many experiences were positive, but respondents in this study also indicated that they had negative experiences such as GP and other health professionals’ lack of understanding and disinterest.

How chronic pain affects people’s lives

Long-term pain impacted on the majority of peoples’ ability to work (70%), home life (80%) and ability to take part in leisure activities (83%).

There was a recognition from some people we talked to that they needed to learn about and self-manage their condition.

Participants in this study were clear about what they wanted in terms of future services. These were summarised by one person with long-term pain into the following three categories-

1. Listen – “Compassion, understanding, patience and time”;
2. Action – “Supportive care and a plan of action which will reduce pain or help me cope”; and
3. Care – “Support, help and advice”.

71
This report has outlined the experiences of over 2,500 people who live with long-term pain across Northern Ireland. Table 2 provides an outline of recommendations on how long-term pain could be treated in relation to (1) getting a diagnosis, (2) information, treatment and care and (3) how chronic pain affects people’s lives. These are provided by key organisation who should action any necessary changes.

Table 2. Summary of key findings and recommendations

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Lead responsibility</th>
<th>Report section reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Getting a diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Long-term pain should be recognised as a condition in its own right by all HSC organisations who deliver care.</td>
<td>Trusts</td>
<td>5.1.1, 5.1.2, 5.3.2</td>
</tr>
<tr>
<td>2. Training and/or information leaflets aimed at GPs and front line health care professionals should be developed. The aim of these resources should be to increase awareness and inform health care staff on what long-term pain is and its effects on those who have it.</td>
<td>HSCB, PHA</td>
<td>5.1.1, 5.1.2</td>
</tr>
<tr>
<td>3. Information resources developed for healthcare staff should be directly informed by and content/user tested with those people who live with long-term pain and/or their carers and relatives.</td>
<td>HSCB, PHA</td>
<td>5.1.1, 5.1.2</td>
</tr>
<tr>
<td><strong>Information, treatment and care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. A Strategic Framework for Pain Services should be developed. The framework should prioritise local primary care led multi-disciplinary teams and be supported by community pharmacy.</td>
<td>DHSSPS</td>
<td>5.2.1, 5.2.2, 5.2.4</td>
</tr>
<tr>
<td>5. Long-term pain management approaches need to be embedded into Integrated Care Partnerships so that those with chronic pain benefit from the delivery of responsive, innovative and multi-disciplinary health care in the future.</td>
<td>HSCB, Trusts</td>
<td>5.1.1, 5.2.1, 5.2.2, 5.2.3, 5.2.4</td>
</tr>
<tr>
<td>6. Service models based on local population needs should be in place across Northern Ireland.</td>
<td>DHSSPS, HSCB, LCGs</td>
<td>5.1.1, 5.2.1, 5.2.2, 5.2.3, 5.2.4</td>
</tr>
</tbody>
</table>
7. Patients should be offered a range of pain management care and support programmes including supported self-management.  
HSCB, Trusts, 5.2.4, 5.3.1, 5.4.2, 5.4.3

8. The role of mainstream alternative therapies should be reviewed specifically for support and help for those people living with long-term pain.  
HSCB, Trusts, 5.2.4, 5.4.2

### How chronic pain affects people’s lives

9. An integrated Northern Ireland cross-departmental strategy to manage chronic pain is needed to allow people to manage their pain and to empower them to lead full and active lives.  
Cross-departmental, 5.3.1

10. Information resources for patients, clients, carers and their relatives affected by long-term pain should be developed to help people understand, make decisions about and cope with long-term pain.  
PHA, 5.3.1, 5.3.2, 5.3.3

### Next steps

As part of this study, a range of views and experiences were collected from the 2,500 people who took part in this study. Further analysis and reporting of the data collected during this study will be undertaken by the Patient and Client Council and used to further increase our understanding of the patterns, trends and particular issues for different respondent groups such as by age, gender and by condition type.

The Patient and Client Council throughout this project developed links with people who experience long-term pain, Health and Social Care staff who work to help people with long-term pain and groups and organisations who work with, and represent the views of those who experience long-term pain in their lives. To monitor progress achieved in implementing recommendations, the Patient and Client Council will continue to talk and listen to people who were involved in this project to ensure that changes are made to help improve the lives of those who experience chronic pain.
Bibliography and References


British Pain Society, FAQs, accessed online 27 August 2013: http://www.britishpainsociety.org/media_faq.htm


DHSSPS, Northern Ireland Hospital Statistics: Outpatient Activity, various years, available online: http://www.dhsspsni.gov.uk/index/stats_research/hospital-stats/inpatients/hospital-stats-previous.htm


Dr Foster and The Pain Society, Adult Chronic Pain Management Services in the UK, 2003


The Pain Toolkit, available online: http://www.paintoolkit.org (last accessed 20 September 2013)


### APPENDIX 1

#### List of Diagnoses Causing Pain (as noted by respondents)

<table>
<thead>
<tr>
<th>Condition by group type</th>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MUSCULOSKELETAL CONDITIONS</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Arthritis (not otherwise specified)</td>
</tr>
<tr>
<td></td>
<td>Avascular necrosis</td>
</tr>
<tr>
<td></td>
<td>Back Pain</td>
</tr>
<tr>
<td></td>
<td>Cauda Equina Syndrome</td>
</tr>
<tr>
<td></td>
<td>Cervical Spondylosis</td>
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<tr>
<td></td>
<td>Charcot’s Foot</td>
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<tr>
<td></td>
<td>Costochondritis</td>
</tr>
<tr>
<td></td>
<td>Diffuse Idiopathic Skeletal Hyperostosis (DISH)</td>
</tr>
<tr>
<td></td>
<td>Frozen Shoulder</td>
</tr>
<tr>
<td></td>
<td>Gout</td>
</tr>
<tr>
<td></td>
<td>Hypermobility Syndrome</td>
</tr>
<tr>
<td></td>
<td>Musculoskeletal and nerve damage</td>
</tr>
<tr>
<td></td>
<td>Osteoarthritis</td>
</tr>
<tr>
<td></td>
<td>Osteoporosis</td>
</tr>
<tr>
<td></td>
<td>Plantar fasciitis</td>
</tr>
<tr>
<td></td>
<td>Sciatica</td>
</tr>
<tr>
<td></td>
<td>Wear and tear</td>
</tr>
<tr>
<td><strong>RHEUMATOLOGICAL CONDITIONS</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ankylosing spondylitis</td>
</tr>
<tr>
<td></td>
<td>Churg Strauss Vasculitis</td>
</tr>
<tr>
<td></td>
<td>Ehlers Danlos syndrome</td>
</tr>
<tr>
<td></td>
<td>Polymyalgia Rheumatica</td>
</tr>
<tr>
<td></td>
<td>Systemic Lupus Erythematosis</td>
</tr>
<tr>
<td></td>
<td>Vasculitis (not otherwise specified)</td>
</tr>
<tr>
<td><strong>NEUROLOGICAL</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cerebral Palsy-Associated Dystonia</td>
</tr>
<tr>
<td></td>
<td>Cluster Headaches</td>
</tr>
<tr>
<td></td>
<td>Motor Neurone Disease (Dynactin Mutation)</td>
</tr>
<tr>
<td></td>
<td>Multiple Sclerosis (MS)</td>
</tr>
<tr>
<td></td>
<td>Neuropathy (not otherwise specified)</td>
</tr>
<tr>
<td></td>
<td>Paralysis and epilepsy</td>
</tr>
<tr>
<td></td>
<td>Parkinson’s Disease/Syndrome</td>
</tr>
<tr>
<td></td>
<td>Shingles/Post-herpetic Neuralgia</td>
</tr>
<tr>
<td></td>
<td>Trigeminal Neuralgia</td>
</tr>
<tr>
<td><strong>TRAUMA/SURGERY</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Accidents</td>
</tr>
<tr>
<td></td>
<td>Amputation</td>
</tr>
<tr>
<td>SPECIFIC PAIN SYNDROMES</td>
<td>Complex Regional Pain Syndrome</td>
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<tr>
<td>-------------------------</td>
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</tr>
<tr>
<td></td>
<td>Fibromyalgia</td>
</tr>
<tr>
<td></td>
<td>Myalgic Encephalitis/Chronic Fatigue Syndrome (ME)</td>
</tr>
<tr>
<td>MALIGNANCY</td>
<td>Angina</td>
</tr>
<tr>
<td></td>
<td>Cancer (not otherwise specified)</td>
</tr>
<tr>
<td></td>
<td>Chronic Pancreatitis (includes inflammation of the pancreas/pancreatitis)</td>
</tr>
<tr>
<td></td>
<td>Crohn’s Disease</td>
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<tr>
<td></td>
<td>Endometriosis</td>
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<tr>
<td></td>
<td>Myeloma neuropathy</td>
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<tr>
<td></td>
<td>Ovarian Cysts</td>
</tr>
<tr>
<td></td>
<td>Pelvo-ureteric Junction Dysmotility</td>
</tr>
<tr>
<td></td>
<td>Ulcerative Colitis</td>
</tr>
<tr>
<td>OTHER</td>
<td>Crushed membrane</td>
</tr>
<tr>
<td></td>
<td>Dercum’s Disease</td>
</tr>
<tr>
<td></td>
<td>Lymphoedema</td>
</tr>
</tbody>
</table>
**APPENDIX 2**

**Pain Clinics/Pain Management Services in Northern Ireland by Health and Social Care Trust area**

Please note that the information given is correct as of 30 September 2013. Information provided by Health and Social Care Trusts

<table>
<thead>
<tr>
<th>Belfast Health and Social Care Trust</th>
<th>Belfast City Hospital</th>
<th>Knockbreda Health and Wellbeing Centre</th>
<th>Mater Hospital</th>
<th>Musgrave Park Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Belfast City Hospital</strong></td>
<td>Consultant led clinics x 5</td>
<td>Consultant Led clinics held in Knockbreda Health &amp;Wellbeing Centre x 4.5 per week</td>
<td>Consultant led outpatient clinics x2</td>
<td>Day case theatre session x2.5 (0.5 alternative weeks in the month)</td>
</tr>
<tr>
<td></td>
<td>Nurse led clinics x3</td>
<td>Nurse led clinics x13 per week</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Day case theatre sessions x3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Knockbreda Health and Wellbeing Centre</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mater Hospital</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Musgrave Park Hospital</strong></td>
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</tbody>
</table>

5x consultants in Chronic Pain Medicine (1 wte for chronic pain, 4 remaining consultant staff are split between chronic pain/anaesthetics)

3x Nursing Band 7 wte, 2.6 Nursing Band 6, 0.58 wte Nursing Band 5 and 1 Nursing Band 3 1.00wte (Please note that nursing staff are required to support outpatient and day case workloads)

1 Clinical Psychologist Band x 1wte, 1 Physiotherapy Band 6 x 0.30wte, Occupational Therapist Band 7 x 0.30wte

Pain Management Programme sessions x 3, supported by Clinical Psychologist, Physiotherapist and Occupational Therapist

Clinical Psychologist sessions (1:1 caseloads) x 7 sessions
<table>
<thead>
<tr>
<th>Northern Health and Social Care Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Antrim Area Hospital</strong></td>
</tr>
<tr>
<td><strong>Causeway Hospital</strong></td>
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<td></td>
</tr>
<tr>
<td><strong>Mid Ulster Hospital</strong></td>
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</tbody>
</table>
### South-Eastern Health and Social Care Trust

<table>
<thead>
<tr>
<th>Location</th>
<th>Description and Staffing Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ulster Hospital</strong></td>
<td>14 doctor-led clinics per week comprising of:</td>
</tr>
<tr>
<td></td>
<td>2 x consultants who do 3 clinics/week</td>
</tr>
<tr>
<td></td>
<td>1 x consultant who does 2 clinics/week</td>
</tr>
<tr>
<td></td>
<td>1 x GP with Specialism who does 1 clinic/week</td>
</tr>
<tr>
<td></td>
<td>1 x staff grade who does 2 clinics/week</td>
</tr>
<tr>
<td></td>
<td>These clinics all staffed also by chronic pain clinic nurses (Band 5) x2 part time (30hrs and 33hrs/week)</td>
</tr>
<tr>
<td></td>
<td>1 x Nurse-led TENS Clinic/week (clinical nurse or nurse specialist)</td>
</tr>
<tr>
<td></td>
<td>4 x Nurse-led telephone clinics/week (nurse specialist)</td>
</tr>
<tr>
<td><strong>Ards Community Hospital (Outpatient Dept)</strong></td>
<td>1 x Nurse-led clinic/week (nurse specialist)</td>
</tr>
<tr>
<td><strong>Bangor Community Hospital (Outpatient Dept)</strong></td>
<td>1 x Nurse-led clinic/week (nurse specialist)</td>
</tr>
<tr>
<td><strong>Pain Management Program – Comber Leisure Centre</strong></td>
<td>Run by:</td>
</tr>
<tr>
<td></td>
<td>Consultant anaesthetist – 1 x session/week</td>
</tr>
<tr>
<td></td>
<td>Consultant psychologist – 3 x sessions/week</td>
</tr>
<tr>
<td></td>
<td>Physiotherapist – 4 sessions/week</td>
</tr>
<tr>
<td></td>
<td>This involves 3 x assessment clinics/week carried out by psychologist and physio</td>
</tr>
<tr>
<td></td>
<td>8 week program once week on Tues afternoon at Comber Leisure Centre</td>
</tr>
<tr>
<td></td>
<td>Review clinics x 2 week when PMP not running</td>
</tr>
</tbody>
</table>
South-Eastern Health and Social Care Trust also does an average of 8-10 Waiting list Initiative clinics per month to help achieve targets. These are carried out by consultants, staff grade and GP.

South-Eastern Health and Social Care Trust also organises ad hoc theatre sessions for interventional management of trigeminal Neuralgia – max 2 sessions / year

Total no of nurse specialists = 2 : - 1 x Band 7 (1 w.t.e) and 1 x Band 6 (1 w.t.e.)
<table>
<thead>
<tr>
<th>Hospital</th>
<th>Services/Week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Craigavon Area Hospital</td>
<td>2.5 Doctor-led clinics / week, 1 nurse-led clinic per week; 7 psychology clinics/week</td>
</tr>
<tr>
<td>South Tyrone Hospital</td>
<td>2 theatre sessions / week; 2 consultant clinics/week; 1 nurse clinic /week; 7 psychology clinic/week</td>
</tr>
<tr>
<td>Daisy Hill Hospital</td>
<td>1 consultant and 1 GP clinic/week; 1 nurse-led clinic/week; 7 psychology clinics/week</td>
</tr>
<tr>
<td>Armagh Community Hospital</td>
<td>2 consultant clinics/week</td>
</tr>
</tbody>
</table>

2 consultant anaesthetists (approx 1.6 wte) plus a GPwSI who does 2 clinics per week, 1x 1 x 0.8 wte specialist nurse and 2x 0.2 wte specialist nurses
1x physiotherapist, 0.8 wte and 1x physiotherapist, 0.1 wte
1 x psychologist, 0.7 wte and 2 x psychologist 1 wte
1 associate psychologist, 0.4 wte
## Western Health and Social Care Trust

<table>
<thead>
<tr>
<th>Location</th>
<th>Description</th>
</tr>
</thead>
</table>
| **Altnagelvin** | 3 consultant delivered sessions on outpatients’ basis  
There is one full-time band 6 pain nurse on the Altnagelvin site shared between Acute and Chronic Pain. She performs one acupuncture/TENS clinic weekly as well as ad-hoc telephone reviews (0.1-0.2 WTE) for chronic pain. There are no side-by-side clinics. |
| **Tyrone County** | 1 consultant delivered session on outpatients’ basis  
There is one full-time band 7 Chronic pain sister in the Tyrone County site (1 WTE)  
She performs 2 acupuncture/TENS clinics weekly. One of those Clinics is alongside the Pain Consultant session. The nurse sees her own patients, however if a patient attending the Consultant clinic on that session is referred for acupuncture/TENS this is initiated by the nurse at the same time (i.e. there is no waiting list)  
This nurse is also involved in the Administration and teaching on the Pain Management Program.  
There is a PAIN MANAGEMENT PROGRAM delivered on the Tyrone County Site only.  
There are an O.T, Physiotherapist and a Psychologist (as well as the pain sister as detailed above)  
The Allied Health Professionals are funded as 0.5 WTE (band 7)  
There are usually 2 PMP classes weekly on a Tuesday and a Friday morning. These run on a rolling basis for 10 weeks for 2 different groups - Physio/OT/Nurse/Psychology attend. They also perform pre-PMP assessments/follow ups/Admin on these days as well.  
The Physio/OT have one other session in addition to above allocated but there are no formal outpatient arrangements for them to see new/review pain patients; however they do have one-to-one patient contacts.  
There are no community based clinics under the auspices of Chronic Pain |
anywhere in the Trust, however there is a ‘managing the challenge for long-term conditions’ clinic which we refer to and a ‘moving with pain’ clinic (Physio Dept). There are no joint assessment clinics with Allied Health Professionals for chronic pain patients.

There are a total of 6 consultant delivered sessions within the trust weekly (that would be 1 W.T.E), 4 of which are outpatient sessions (so 0.7 WTE approx. for outpatients.)
3 of those sessions are on the Altnagelvin site, with 1 being on the Tyrone County Hospital site. There are no sessions on the Enniskillen site.

A psychologist also provides outpatient clinics twice weekly usually on the Tyrone County Site. She does see some patients on The Altnagelvin site, as she is based there as well (for the other half of her job) however there is no formal demarcation of her services on the Altnagelvin site.
APPENDIX 3

Questionnaire used in this study

Patient and Client Council
Your voice in health and social care

Do you suffer from Long-Term (Chronic) Pain?

WHO ARE WE?
The Patient and Client Council is your voice in health and social care. We are part of the Health and Social Care system and provide a listening ear and an independent voice for patients, clients and carers. By being a critical friend in this system, we are best placed to influence the health and social care services which people value.

WHY DO WE WANT YOUR VIEWS?
We are facilitating a group which includes patients and doctors who treat people who are experiencing long-term pain. We want to find out about people’s experience of the treatment and care they have received for long-term pain.

The purpose of this work is to make sure that the voices of people affected by long-term pain are heard by decision makers in health and social care with a view to developing a pain strategy for Northern Ireland.

We will use what you tell us to produce a report for decision-makers that is based on your experience. We will make recommendations for changes and improvements based on what you tell us. Your views are important as they will inform and help develop future services.

HOW DO I GET INVOLVED?
All you need to do is fill in this questionnaire. You can also call us and request a questionnaire be sent out to you, or complete it online by going to our website. Our contact details and online questionnaire link are listed below.

DO I HAVE TO GET INVOLVED?
Taking part in this project is entirely voluntary. Taking part will NOT affect the treatment or care you currently receive from the Pain Clinic now, or in the future.

CONFIDENTIALITY
Your personal views will remain anonymous and no personally identifiable information is collected on the questionnaire.

HOW CAN I GET MORE INFORMATION?
For more information on this project or for help to find a support group, please contact Sorcha Forbes or Avril Craig at the Patient and Client Council on: 0800 917 0222 or 028 90 321230.
You can also get in touch by email: sorcha.forbes@hscni.net
avril.craig@hscni.net

If you would like to share your views, please complete the questionnaire overleaf. Alternatively you can complete the questionnaire online at:
https://www.surveymonkey.com/s/LongTermPainNI

This questionnaire is anonymous and all information will be treated in the strictest confidence.
SECTION 1
ABOUT THE PERSON COMPLETING THIS QUESTIONNAIRE

Are you... (Please tick one box only)
☐ ...the person who is experiencing long-term pain?
☐ ...the carer for someone with long-term pain and are completing this form with them.

Please note: All questions in this questionnaire must be answered from the point of view of the person experiencing pain.

SECTION 2
PAIN DIAGNOSIS AND APPOINTMENT TIME

Q1: Where is your pain?

Q2: Do you understand what is causing your pain?
☐ Yes
☐ No (Skip to Q4)
If YES, what is the cause of your pain?

Q3: How long did it take to get a diagnosis approximately? (Please specify length of time from when you first sought help with your pain)

Q4: Were you satisfied with the initial response from your GP?
☐ Yes
☐ No

Q5: What action did your GP take when you first saw them about your pain? (Please tick all that apply)
☐ Offered a prescription
☐ Provided a leaflet
☐ Made a referral (Please answer Q6)
☐ Other (Please specify):

Q6: If your GP made a referral, what service(s) were you referred to?

Q7: How long did you wait for an appointment after the referral?

Q8: When you went for your referral appointment, did you get a diagnosis?
☐ Yes
☐ No (Skip to Q10)

Q9: How satisfied or dissatisfied were you with the diagnosis that was made?
☐ Very satisfied
☐ Satisfied
☐ Quite satisfied
☐ Not satisfied

Q10: If you did not get a diagnosis, were you referred to other medical departments?
☐ Yes
☐ No (Skip to Q12)

Q11: How many times were you referred to a different medical department/specialty?

Q12: Were you given any written information about your condition?
☐ Yes
☐ No

Q13: Were you given any treatment to help manage your pain?
☐ Yes
☐ No
If YES, what options were given to you to manage your pain?

Q14: Were you given information or support on how to manage your own pain?
☐ Yes
☐ No
SECTION 3

ABOUT YOUR MEDICATION AND TREATMENT

Q15: Have you ever attended a pain clinic?
☐ Yes
☐ No (Go to Q17)

If YES, what treatment did you receive at the pain clinic? (Please tick all that apply)
☐ Referred to pain management
☐ Referred to clinical psychologist
☐ Was given injections
☐ Other (Please specify):

Q16: Have you been discharged from the pain clinic?
☐ Yes
☐ No

Q17: Do you take medication for your pain?
☐ Yes
☐ No

If YES, how effective or non-effective is this medication?
☐ Very effective
☐ Somewhat effective
☐ Not effective at all

Q18: How often is your medication reviewed?
☐ Every 3 months
☐ Every 6 months
☐ Every year
☐ Less often
☐ Don’t know

Q19: Who reviews your medication? (e.g. Consultant, GP, Nurse)

SECTION 4

HOW CHRONIC PAIN AFFECTS YOUR LIFE

Q20: Has long term pain affected: (Please tick all that apply)
☐ Your ability to work
☐ Your home life
☐ Your participation in leisure activities
☐ Other (Please specify):

Q21: Please let us know how long-term pain has made an impact on your life:

Please consider the following statements and tick the response that most represents your view.

Q22: Long-term pain has had a negative impact on my mood:
☐ Strongly agree
☐ Agree
☐ Neither agree, nor disagree
☐ Disagree
☐ Strongly disagree

Q23: Long-term pain has not disturbed my sleep pattern:
☐ Strongly agree
☐ Agree
☐ Neither agree, nor disagree
☐ Disagree
☐ Strongly disagree

Q24: In general, friends and relatives accept that I am experiencing pain:
☐ Strongly agree
☐ Agree
☐ Neither agree, nor disagree
☐ Disagree
☐ Strongly disagree

Q25: Healthcare staff acknowledge my symptoms:
☐ Strongly agree
☐ Agree
☐ Neither agree, nor disagree
☐ Disagree
☐ Strongly disagree
SECTION 5
HOW CHRONIC PAIN AFFECTS YOUR LIFE

Q26: Between the time symptoms started and receiving treatment, how would you rate the way health and social care services have responded to your needs?
☐ Excellent
☐ Very good
☐ Average
☐ Poor
☐ Very poor

Q27: What worked well for you in the treatment and/or support you received?

Q28: What did not work so well for you in the treatment and/or support you received?

Q29: What kind of treatment, care or support would improve your life?

Q30: What do you want from future services?

Thank you for answering all our questions. The space below is for you to use to tell us anything about your experience of long-term pain and diagnosis. We are interested in hearing any part of your story.
(Please continue on a separate sheet if necessary)

Are you:
☐ Male
☐ Female

What is your age group?
☐ Under 16
☐ 16-24
☐ 25-34
☐ 35-44
☐ 45-54
☐ 55-64
☐ 65-74
☐ 75-84
☐ 85 or Over

What is the first part of your postcode? (e.g. BT17 or BT28) or nearest town/village?

Please return this questionnaire using the FREEPOST envelope provided. If you don't have one, you can put this questionnaire into an envelope and mark it:
FREEPOST
PATIENT AND CLIENT COUNCIL
APPENDIX 4

List of Focus Groups

<table>
<thead>
<tr>
<th>Group</th>
<th>Date</th>
<th>Location</th>
<th>No. of People</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>12/06/13</td>
<td>Physical Disability Group, Lurgan</td>
<td>12</td>
</tr>
<tr>
<td>Group 2</td>
<td>13/05/13</td>
<td>ME Support Group, Portadown</td>
<td>11</td>
</tr>
<tr>
<td>Group 3</td>
<td>22/04/13</td>
<td>Fibromyalgia Support Group, East Belfast</td>
<td>3</td>
</tr>
<tr>
<td>Group 4</td>
<td>14/06/13</td>
<td>Disability Action Focus Group, Lurgan</td>
<td>2</td>
</tr>
<tr>
<td>Group 5</td>
<td>26/06/13</td>
<td>Station Road Resource Centre, Armagh</td>
<td>2</td>
</tr>
<tr>
<td>Group 6</td>
<td>28/05/13</td>
<td>Condition Management Programme, Derry</td>
<td>4</td>
</tr>
<tr>
<td>Group 7</td>
<td>27/06/13</td>
<td>Derriaghy Day Centre, Belfast</td>
<td>7</td>
</tr>
<tr>
<td>Group 8</td>
<td>29/04/13</td>
<td>Fibromyalgia Support Group, Groomsport</td>
<td>9</td>
</tr>
<tr>
<td>Group 9</td>
<td>18/06/13</td>
<td>Fibromyalgia Support Group Lisburn</td>
<td>9</td>
</tr>
<tr>
<td>Group 10</td>
<td>12/06/13</td>
<td>Arthritis Care, Newcastle</td>
<td>12</td>
</tr>
</tbody>
</table>
APPENDIX 5

Focus Group Questions and Facilitator’s Brief

BRIEFING PAPER LONG-TERM (CHRONIC) PAIN

Project description

1. Introduction

The Patient and Client Council is undertaking a study which seeks to find out about people’s experience of services provided for the treatment and support of those living with long-term (chronic\(^6\)) pain. It is estimated that one in five people in Northern Ireland live with long-term pain caused by a range of conditions. These include multiple sclerosis, diabetes, musculoskeletal problems or endometriosis. This is not an exclusive list. The voices of these people are seldom heard and it is timely to collect their views and experience with a view to informing a future Pain Strategy for Northern Ireland.

2. How the project will be delivered

Participants will be asked to complete a questionnaire. We intend to target people with long-term pain and recruit them in a number of settings. Part of this process will be to ask people attending pain clinics to complete a questionnaire. The consultants running the service will promote the survey to their patients and we will work with GPs to ensure that they too promote the study. It is intended to send out an information leaflet with medical appointments for the Pain Clinic. This will be done over a 2-month period (April – May). Posters informing people of the study will be displayed at the Pain Clinics and at GP surgeries. Questionnaires and Freepost envelopes will be left with the receptionist at the Pain Clinics.

\(^6\) Long-term (chronic) pain is defined as pain that has lasted more than 3 months. It can be caused by many different diseases or conditions or indeed the cause may be unknown.
The questionnaire will be distributed to regional organisations such as the Women’s Institute, churches, and other voluntary organisations (MS Society, Diabetes UK etc). The target is 2000 across Northern Ireland.

Focus groups will take place with patient support groups and people with learning disabilities. The number of these is still to be determined.

**Focus Group Brief – Long-Term Pain**

**Summary of Questions**

<table>
<thead>
<tr>
<th>Section</th>
<th>Question/Action</th>
<th>Time (indicative)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Opening remarks</strong></td>
<td>Thank you for coming</td>
<td>5mins</td>
</tr>
<tr>
<td></td>
<td>Introduce yourself</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Confirm consent (especially if recording)</td>
<td></td>
</tr>
<tr>
<td><strong>Introductory questions</strong></td>
<td>Please introduce yourself (first name only if you like) and tell us how long you have been living with long-term pain and its causes</td>
<td>5-10 mins</td>
</tr>
<tr>
<td><strong>Transition questions</strong></td>
<td>1. Would you tell us about how long it took you to get a diagnosis of your long-term pain?</td>
<td>15-20 mins</td>
</tr>
<tr>
<td></td>
<td><strong>Prompts</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>First episode</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Treatment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Did you see a GP or other health professional?</td>
<td></td>
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<tr>
<td></td>
<td>Was treatment successful?</td>
<td></td>
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<tr>
<td></td>
<td>Did you have to see a specialist?</td>
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<tr>
<td></td>
<td>Did this happen a number of times before you finally received a diagnosis?</td>
<td></td>
</tr>
<tr>
<td>Section</td>
<td>Question/Action</td>
<td>Time (indicative)</td>
</tr>
<tr>
<td>---------</td>
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</tr>
<tr>
<td>2.</td>
<td>What treatment do you receive for your long-term pain?</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Prompts:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do/did you attend a pain clinic?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Prescription drugs/painkillers</td>
<td></td>
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<tr>
<td></td>
<td>Alternative therapies</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Is your medication reviewed? If so, by whom?</td>
<td></td>
</tr>
<tr>
<td>Key Questions</td>
<td>3. Were you given any information about your long-term pain?</td>
<td>20-30 mins</td>
</tr>
<tr>
<td></td>
<td><strong>Prompts</strong></td>
<td></td>
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<tr>
<td></td>
<td>Were you given advice (verbal or written) on how to manage your pain?</td>
<td></td>
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<tr>
<td></td>
<td>Who from?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>When?</td>
<td></td>
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<tr>
<td></td>
<td>Was the information relevant?</td>
<td></td>
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<tr>
<td></td>
<td>Was the information easy to understand?</td>
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<td></td>
<td>4. How does pain affect your life?</td>
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<tr>
<td></td>
<td><strong>Prompts:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Are you able to work (include work at home/ housework/ work on a farm)?</td>
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<tr>
<td></td>
<td>Did you have to reduce your working hours?</td>
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<tr>
<td></td>
<td>Do you need help with tasks at home?</td>
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<tr>
<td></td>
<td>Do you need help with personal care tasks) e.g. taking a bath or shower/dressing?</td>
<td></td>
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<tr>
<td></td>
<td>How does it make you feel?</td>
<td></td>
</tr>
<tr>
<td>Section</td>
<td>Question/Action</td>
<td>Time</td>
</tr>
<tr>
<td>--------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td></td>
<td>Does it affect your mood?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do other people/health professionals accept you are in pain?</td>
<td></td>
</tr>
<tr>
<td>Ending Questions</td>
<td>5. Please tell us about the services you received.</td>
<td>10-15 mins</td>
</tr>
<tr>
<td></td>
<td><strong>Prompts:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>How do you feel about the treatment you received?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What worked well for you?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What did not work so well for you?</td>
<td></td>
</tr>
</tbody>
</table>
## APPENDIX 6  List of groups that supported survey data collection

<table>
<thead>
<tr>
<th>Name of Organisation/Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABC Community Network</td>
</tr>
<tr>
<td>Action Mental Health, Bangor</td>
</tr>
<tr>
<td>Action Mental Health, Londonderry</td>
</tr>
<tr>
<td>After Care Service</td>
</tr>
<tr>
<td>Age NI</td>
</tr>
<tr>
<td>Arthritis Care</td>
</tr>
<tr>
<td>Arthritis Support Group, Ballymoney</td>
</tr>
<tr>
<td>Ballykeel Pharmacy</td>
</tr>
<tr>
<td>Bradley’s Pharmacy</td>
</tr>
<tr>
<td>British Heart Foundation</td>
</tr>
<tr>
<td>Carers NI</td>
</tr>
<tr>
<td>Chest Heart &amp; Stroke</td>
</tr>
<tr>
<td>Chester Nursing Home</td>
</tr>
<tr>
<td>Community Development and Health Network</td>
</tr>
<tr>
<td>Conditions Management Programmes</td>
</tr>
<tr>
<td>Cookstown &amp; Western Shores Network</td>
</tr>
<tr>
<td>County Down Rural Community Network</td>
</tr>
<tr>
<td>CPS Northern Ireland</td>
</tr>
<tr>
<td>Daycare centres</td>
</tr>
<tr>
<td>Dentists</td>
</tr>
<tr>
<td>Disability Action</td>
</tr>
<tr>
<td>Donnelly Motor Group</td>
</tr>
<tr>
<td>Fermanagh Rural Community Network</td>
</tr>
<tr>
<td>GPs</td>
</tr>
<tr>
<td>Holywell Hospital Gurteen CBT Service</td>
</tr>
<tr>
<td>Involvement &amp; Community Development</td>
</tr>
<tr>
<td>Marie Curie Belfast Hospice</td>
</tr>
<tr>
<td>Mental Health Forum, Craigavon</td>
</tr>
<tr>
<td>MS</td>
</tr>
<tr>
<td>Newry and Mourne Fibromyalgia Network</td>
</tr>
<tr>
<td>NI Rural Women’s Network</td>
</tr>
<tr>
<td>NICHS</td>
</tr>
<tr>
<td>North Antrim Community Network</td>
</tr>
<tr>
<td>North Belfast Partnership</td>
</tr>
<tr>
<td>North West Community Network</td>
</tr>
<tr>
<td>Nursing Homes</td>
</tr>
<tr>
<td>Omagh Forum for Rural Association</td>
</tr>
<tr>
<td>Name of Organisation/Group</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
</tr>
<tr>
<td>Pain Alliance of Northern Ireland</td>
</tr>
<tr>
<td>PCC Membership Scheme</td>
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<tr>
<td>Peninsula Healthy Living Partnership</td>
</tr>
<tr>
<td>Presbyterian Churches</td>
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<tr>
<td>Presbyterian Women’s Group</td>
</tr>
<tr>
<td>Rapid Area Partnership</td>
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<tr>
<td>Rare Disease Partnership</td>
</tr>
<tr>
<td>Residential Homes</td>
</tr>
<tr>
<td>Sandville Nursing home</td>
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<tr>
<td>South Antrim Community Network</td>
</tr>
<tr>
<td>South Eastern Carers Co-ordinators</td>
</tr>
<tr>
<td>Syringomyelia Arnold Chiari Association</td>
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<tr>
<td>TADA Rural Support Network</td>
</tr>
<tr>
<td>The Migraine Trust</td>
</tr>
<tr>
<td>University of the Third Age, Londonderry</td>
</tr>
<tr>
<td>Western Carers Newsletter</td>
</tr>
</tbody>
</table>