

# **Implementing low-cost individually tailored cognitive behavioural therapy (CBT) for patients with chronic musculoskeletal pain in Salford**

## **Full Project Report**

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Karina Lovell  
Michael Spence  
Kate Woodward-Nutt  
Judith Gellatly  
Anthony Jones  
Paul Wilson  
Phil McEvoy  
Jody Comiskey  
Val Derbyshire  
Caroline O'Donnell  
Laura Anselmi  
Gosia Pelikan

<b>Contents</b>		<b>Pages</b>
	<b>Glossary</b>	3
	<b>Lay summary</b>	4
<b>1.</b>	<b>Introduction</b>	5-6
<b>2.</b>	<b>Methods and research objectives</b>	7-8
<b>3.</b>	<b>Description of CWP Pain Platform</b>	9-14
<b>4.</b>	<b>Quantitative Data Analysis</b>	15-18
<b>5.</b>	<b>Professional Stakeholder Consultation</b>	19-26
<b>6.</b>	<b>Patient and Public Involvement</b>	27-31
<b>7.</b>	<b>Overall Discussion/Conclusions</b>	32-34
<b>8.</b>	<b>References</b>	35-37
	<b>Appendix A</b>	38

## Glossary

<b>CWP:</b>	Chronic widespread pain
<b>CBT:</b>	Cognitive behavioral therapy
<b>T-CBT:</b>	Telephone delivered cognitive behavioral therapy
<b>PHQ-9:</b>	Patient Health Questionnaire
<b>GAD-7:</b>	Generalized Anxiety Disorder Scale
<b>HRA:</b>	Health Research Authority
<b>REC:</b>	Research Ethics Committee
<b>PPI:</b>	Patient and Public Involvement
<b>PWP:</b>	Psychological Wellbeing Practitioner
<b>IAPT:</b>	Improved Access to Psychological Therapy
<b>WSAS:</b>	Work and Social Adjustment Scale
<b>SRS:</b>	Session Rating Scale
<b>PGIC:</b>	Patients' Global Impression of Change
<b>NPT:</b>	Normalization Process Theory
<b>GMMH:</b>	Greater Manchester Mental Health NHS Foundation Trust
<b>CMHT:</b>	Community Mental Health Team
<b>IMD:</b>	Index of Multiple Deprivation
<b>LSOA:</b>	Lower-layer super output area

## Lay Summary

Chronic widespread pain (CWP) is the principal symptom of fibromyalgia and is a major public health problem associated with poor mental health and quality of life.

GPs have previously reported a lack of knowledge and understanding about chronic pain, and have highlighted the need for timely access to appropriate resources to improve the health and wellbeing of their patients. This includes supporting patients not only with the physical symptoms but also helping them to access to psychological support should they require it.

Cognitive behaviour therapy (CBT) is widely used for a range of health problems and is effective in enhancing patients' attitudes and ability to manage their condition. Recent research with people with chronic widespread pain found that a short course of telephone delivered CBT resulted in sustained improvements in wellbeing. Working with Six Degrees Social Enterprise, we aimed to increase access to this evidence based treatment for patients with CWP in Salford.

We did this by offering telephone delivered cognitive behavioral therapy (T-CBT) as part of a stepped care model using both high and low intensity evidence-based interventions delivered by specially trained practitioners. Patients could be referred directly by their GP or via a new process of direct referral from specialist hospital based services. Patients referred to Six Degrees were assessed and offered an appropriate psychological intervention. Options included: face-to-face CBT, mindfulness or T-CBT. The decision on which service was provided was based on clinical need and patient preference.

Over the course of 9 months the service received 146 Salford referrals. Feedback on the service from professional and lay stakeholders was generally very positive; having a single point of access into a range of psychological interventions was seen as a helpful addition to the entire pathway of care for patients.

Implementing the service was not without challenges and a number of modifications were made to referral processes during the project. In particular, a lack of access to secure '[nhs.net](#)' email accounts for electronic referrals meant that the referral process itself was a major barrier to patient access.

In December 2016, the option of '*supported self-referral*', where referrers could provide their patient with the contact details for service so that they could contact the service directly was introduced. This was a short-term solution solely for the duration of the project and as yet no workable and sustainable referral process has been established between providers and referrers.

T-CBT will continue to be made available for patients with CWP accessing the Six Degrees based on individual preference and clinical need via their GP.

## 1. Introduction

Chronic widespread pain (CWP), the principal symptom of fibromyalgia, is a major public health problem, affecting between 11-16% of the population (Fayaz et al, 2016). It is defined as skeletal and body pain persisting for more than three months and may lack pathologic features (Parsons et al 2007). Individuals experiencing CWP frequently experience additional clinical comorbidities such as irritable bowel syndrome, chronic fatigue syndrome, joint pain and headaches (Kato et al, 2006). CWP is associated with poor quality of life (Morales-Espinoza et al, 2016; Toblin et al, 2011; Nicholl et al, 2009 Becker et a 1997) and many are likely to be experiencing a mental health disorder such as depression or generalised anxiety disorder (White et al, 2002; Benjamin et al, 2000). In many cases complete relief from symptoms is unlikely but with appropriate treatment the impact upon quality of life, functioning and mental health symptoms can be significantly reduced.

Aside from the impact CWP has upon individuals it additionally has considerable healthcare economic implications, greater than the majority of other health conditions (Maniadakis and Gray, 2000). The management of CWP has presented challenges, given the complexities in understanding its etiology (Bergman et al, 2002).

CWP in some cases requires access to specialist secondary or tertiary care pain services; however the majority of individuals will be managed within a primary care setting. Primary care practitioners have previously reported inadequacies in the available support, lack of knowledge and understanding about chronic pain, and have highlighted the need for a holistic driven approach (e.g. Parsons et al, 2007; Foster et al 2003; Chew-Graham & May, 1999). It is therefore vital that primary care practitioners have access to timely and appropriate resources to improve the health and wellbeing of their patients. This includes supporting patients not only with the physical symptoms of their condition but also to enable access to psychological support should they require it.

Cognitive behaviour therapy (CBT) is widely used for a range of health problems and is effective in enhancing patients' attitudes and ability to manage their condition. It is frequently offered as part of a stepped care approach in low and high intensity formats, where the low intensity CBT-based intervention likely to be effective is offered initially. Impact of the intervention is monitored and it is acknowledged that stepping up to a higher intensity CBT format or different treatment approach may be required if no benefit is achieved. CBT and exercise has previously been shown to be associated with modest short-term improvements in patients with fibromyalgia and or chronic pain (Williams 2012; Bernardy 2013). Recent research with people with CWP found that a short course of telephone delivered CBT (T-CBT)<sup>1</sup> resulted in short term improvement (3 months post treatment) which was sustained in the longer term (24 months) (McBeth 2012; Beasley 2015). It was also found to be highly cost effective and has the potential to facilitate faster access to CBT for patients with CWP. However, this approach to the management of CWP has not been implemented into routine clinical practice and evidence of effectiveness does not mean that T-CBT will be taken up in practice. There is a large literature indicating that efforts at implementing and sustaining new technologies and practices remain problematic (e.g. Romanelli, 2016; Barnett et al, 2011).

Drawing upon the research evidence the importance of improving access to such interventions is recognised. This report presents the findings of a feasibility study that

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<sup>1</sup> 8 sessions with a total therapist time of 4.5 hours

harnessed the opportunity for service innovation by implementing a Pain Platform within Six Degrees, a Social Enterprise commissioned by NHS Salford CCG to provide an Improved Access to Psychological Therapy (IAPT) service. The Pain Platform offered a stepped care approach for interventions, (including T-CBT) as part of a coherent and flexible approach to the delivery of evidence based therapies. It was predicted that this would help increase access to treatment.

## 2. Research objectives and methods

The research objective for this study was to:

Develop and explore the implementation, impact and sustainability of a coherent pain platform offering a stepped care approach (using both high and low intensity interventions) including T-CBT (delivered by specially trained IAPT practitioners) as part of flexible approach providing evidence-based therapies.

To achieve the research objective the following research questions were explored:

The extent to which key stakeholders perceive the way in which the Pain Platform becomes incorporated, integrated and sustained into routine clinical practice. Including exploration of:

- the development of organisational infrastructure to support the pain platform and;
- the implementation of an alternative treatment modality (T-CBT) including
  - The extent to which the T-CBT service was accessed
  - The impact of a T-CBT service on health outcomes
  - The extent to which patients utilised the identified psychological intervention(s)

### 2.1 Methods

#### 2.1.1 Analysis of routinely collected service data

Six Degrees utilise a number of routine outcome measures to monitor the impact of service provided interventions. These include the - Patient Health Questionnaire (PHQ-9) (Spitzer et al 1999) to identify levels of depression symptoms and Generalized Anxiety Disorder Scale (GAD-7) (Spitzer et al 2006) to identify levels of anxiety. It was therefore agreed that within this feasibility study we would collect this data for any patients accessing the service via the Pain Platform to assess symptom impact.

Initially we had additionally proposed that we would collect and analyse data on a) levels of functioning using Work and Social Adjustment Scale (WSAS) (Mundt et al 2002) and b) patient satisfaction using the Session Rating Scale (Miller et al 2000), however due to time constraints and with additional data collection this data was not routinely collected during the project by Six Degrees and thus the data was not available.

Analysis of routine data on numbers of patients referred, services that refer to the service, demographics and numbers of patients who commence, complete and drop-out of the T-CBT service was also collected for analysis. The number of sessions attended and their duration was also collated.

#### 2.1.2 Additional Outcome measures (non-routine for research purposes only)

We were also interested in exploring the impact of accessing psychological support on two other health outcomes – perceived change compared to study onset and quality of life. We proposed to use the Patients' Global Impression of Change (PGIC) Scale (Guy, 1976) to measure perceived change. This validated measure asks patients to evaluate their overall change from seven possible scores from 'very much worse' (score 7) to 'very much better'. The EuroQoL-5D-5L (EQ-5D-5L) was identified as the most appropriate tool to measure

quality of life. The EQ-5D-5L is a development of the original EQ-5D but gives greater choice of response and is more sensitive to changes in health state than the original (Herdman 2011). The revised measure consists of five health dimensions: i) mobility, ii) self-care, iii) usual activities, iv) pain/discomfort and v) anxiety/depression. Each dimension has 5 levels: a) no problems, b) light problems, c) moderate problems, d) severe problems, and e) extreme problems. To assess pain intensity and unpleasantness the Visual Analogue Scales (Brown et al 2010; 2012) were identified.

As the PGIC, EQ-5D-5L and visual analogue scales were not part of routine outcome measurement within Six Degrees, an ethics application was submitted and approved by proportionate review by the West of Scotland REC 5 (REC REF: 16/WS/0118; IRAS project ID: 204601) and received Health Research Authority (HRA) Approval. Patients who were referred to Six Degrees for support with their CWP were informed of the research project exploring the implementation of the Pain Platform and were provided with an information pack asking them if they would be happy to consent to completing two additional research measures over the phone alongside the routinely collected measures. Verbal consent to complete the additional measures was taken and recorded by the psychological wellbeing practitioner (PWP) who the patient was allocated to for the T-CBT sessions.

Unfortunately the numbers of patients consenting to complete the non-routine outcome measures was low. From the 13<sup>th</sup> July to 13<sup>th</sup> March only 16 patients had agreed to take part, a decision was therefore made to discontinue the additional research component of the study. Given the lack of available data for the PGIC and EQ-5D a decision was made not to analyse the data.

### **2.1.3 Semi Structured interviews**

Successful implementation of research into NHS practice requires that new interventions are accepted and welcomed by both key stakeholders and patients.

The views of key stakeholders including psychological wellbeing practitioners (PWPs), IAPT senior managers, general practitioners (GPs), Clinical Commissioning Group (CCG) members and other relevant stakeholders were sought via individual qualitative interviews. Interviews aimed to explore views, expectations and experiences of the service within the broader contextual issues regarding the organisation and delivery of care for people with CWP.

Patients were also consulted regarding their views of the implementation of the pain pathway. This included a group discussion with a local fibromyalgia group and a PPI event where patients who had accessed the Pain Pathway were invited to share their views and experiences. During the two consultation exercises the findings of the professional interviews were drawn upon to gain a better understanding of the key issues from a patient perspective. Information regarding these discussions is presented in [section 6 \(p27-31\)](#).



## 3. Description of CWP Pain Platform<sup>2</sup>

### 3.1 Name

A Pain Platform for individually tailored psychological therapy for patients with CWP.

### 3.2 Why?

To improve patient care by improved access to evidence based psychological treatment for patients with CWP within Salford. The core elements of the pathway were to:

1. To implement a coherent and flexible pain pathway, offering a stepped care model using both high and low intensity evidence-based interventions including telephone CBT delivered by specially trained IAPT practitioners
2. Ensure patients receive the most appropriate treatment.
3. Take account of patient preferences

Existing referral process was via primary care only; referrals from secondary care were not accepted. Potential referrals from secondary care required clinicians to contact patients GPs and request that the GP make a referral to Six Degrees. Patients who were referred to the service would be offered service as usual face-to-face CBT delivered by a PWP with no specialist pain training. Patients were required to travel to a Salford Gateway or GP practice for psychological support. Fortnightly sessions of 30 minutes were offered. Access to the existing service provision was protracted for referrals from secondary care due to the multiple steps required for referral; resource use was high which may have impacted upon patient adherence and satisfaction and experience.

Existing secondary care services in Salford where patients experiencing pain may be referred to the Pain Centre, General Rheumatology, the Musculoskeletal and Neuropathic Pain Clinic, the Musculoskeletal Clinical Assessment and Treatment Service (MSK CATS) service, Physiotherapy (general physiotherapy and Active8 rehabilitation programme), the Chronic Fatigue Clinic (endocrinology) and the Irritable Bowel Clinic. All services have different access and thresholds for access to psychological services.

### 3.3 What?

A period of 12 months was funded from 1<sup>st</sup> May 2016 for the set up and delivery of the pilot Pain Platform. The pilot was implemented on 6<sup>th</sup> June 2016, finishing on 30<sup>th</sup> April 2017 (the data collection period for the study finished on 31<sup>st</sup> March 2017)

#### 3.3.1 Who is it for?

Patients experiencing fibromyalgia and CWP were eligible to access the service.

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<sup>2</sup> using a modified TIDieR template

### **3.3.2 Referral pathway**

Patients could continue to be referred directly from primary care e.g. by their GP. This pathway introduced a new, direct referral from secondary care e.g. by pain, fibromyalgia or rheumatology specialist or physiotherapist.

The Pain Platform referral pathway is illustrated in [Appendix A](#)

Within the Pain Platform patients were referred to Six Degrees where they were triaged and a decision made on the appropriate psychological intervention. Options included: face-to-face CBT, mindfulness or T-CBT delivered by a PWP. The decision on which service was provided was based on clinical need and patient preference.

### **3.3.3 Referral procedures**

Referral procedures involved referrers either completing a Six Degrees referral form and sending to the service via NHS approved electronic encryption pathways, usually an [nhs.net](mailto:nhs.net) email account or sending a recent clinic letter in lieu of the referral form; hardcopy/paper referrals are not accepted by Six Degrees. On receipt of a referral a CWP-trained Six Degrees PWP would conduct a telephone triage to identify suitability for the service. The patient was then offered access to a psychological intervention based on their presentation and preferences. In circumstances where the service was not appropriate to meet patient needs, the patient would be 'stepped up' to receive a higher intensity psychological therapy in primary care or via psychology services (referred to an alternative service) or the referral was returned to the referrer. Alternative service choices were dependent on patient need and included GMMH Psychology (step 3 or step 4 therapies) E-therapy, Later Life Psychology, EDIT/Early Interventions (pre-psychosis symptoms), CMHT (community mental health – secondary care), specialist clinics: eating disorders or psychosexual clinics (via GP) or Achieve (drug and alcohol service). Other forms of social/practical support could also be considered such as START (art on prescriptions) or Active Lifestyles (exercise programme for patients with long term conditions), Carers Centre or Offload (a new programme for men facilitated by Salford Red Devils looking at resilience/coping).

### **3.3.4 Telephone CBT**

As part of the Pain Platform a new evidence-based psychological service was offered; T-CBT for CWP.

T-CBT was supported by a guided self-help book titled '*Managing Chronic Widespread Pain*' (Lovell et al, 2016). The book, used during the previous research trial, was amended with input from the PPI lead<sup>3</sup>, specifically to ensure that case studies were more applicable to those receiving the intervention.

The book is divided into four steps:

- Step 1: What is this 'Managing my CWP about'?
- Step 2: Understanding the way I feel
- Step 3: My Programme

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<sup>3</sup> further detail is provided in the PPI section 6, p27-31

- Step 4: Continuing to manage my pain

An audio CD providing commentary of the booklet was also made available. The CD did not provide an audio word-for-word version of the book but provided audio detail on the key aspects of each step.

Nine weekly telephone sessions are provided over the course of the intervention by a PWP:

- Session 1 (45-60 minutes) - Initial assessment including development of problem statement and goals
- Sessions 2-7 (30-45 minutes each) – choosing an intervention, implementation and monitoring of interventions.
- Booster sessions at 3 and 6 months (30 minutes each) – review of progress and goals, relapse prevention.

### **3.3.5 Practitioner time**

The funding allowed for a 1.0 WTE PWP to support the delivery of the T-CBT. This time was split between two practitioners to manage periods of leave and other absence(s).

- 19.5 hours was dedicated clinical time - therapy sessions, triage, telephone contacts to discuss the research and obtain consent where applicable, supervision sessions.
- 18.00 hours was allocated to administrative tasks, including clinically related admin tasks including - recording/sending notes to GPs, sending research study packs to participants, processing referrals, liaising with referrers, producing data reports, attending implementation research team meetings.

Sessions were available for patients on Fridays (am/pm clinics), Tuesday (am) and Thursday (pm). If, for any reason, the patient was unavailable during those times, the practitioners would offer an appointment outside of their routine clinics. In general, patients could attend their sessions between 7.30am and 4.30pm. Individuals who were unavailable during the standard office hours were signposted to other forms of support such as Take Control/Mindfulness groups which were held in the evening, or e-therapy.

- i. *Mindfulness for Pain Platform Pilot* - Six Degrees adapted their mindfulness course in order to additionally provide a course that would better meet the needs of clients with CWP. Adaptations included:
  - The 8-week course was adapted into a 6 week course
  - Regular breaks were scheduled to accommodate patients with CWP
  - Content was adapted specifically for people with CWP.
- ii. *Face to face pain specific CBT* - Face to face CBT to specifically address pain issues was also available to patients referred to the service. There was some take up of this from patients for whom English was not their 1<sup>st</sup> language and where it was felt that this would facilitate better communication.
- iii. *Face to face CBT* - Standard CBT, was also available to patients referred through the pain platform

### **3.4 Who provided?**

The Pain Platform (including T-CBT) was provided by Six Degrees Social Enterprise, a Community Interest Company based in Salford and commissioned by NHS Salford CCG to provide support for people who are experiencing common mental health problems. Six Degrees work closely with their partner organisations (including NHS and third sector organisations) to support to people aged over 16 in Salford.

11 PWP's working within Six Degrees received two days of training - '*CBT for Chronic Widespread Pain*' - delivered by Prof. Karina Lovell. It drew upon lessons learned from the research trial of T-CBT (McBeth et al 2012) and the acceptability data (Bee et al 2015). Dr John McBeth delivered expert sessions on pain during the two-day training. The training utilised a range of methods including small and large group work and skills practice. Training manuals were also provided to all PWP's who attended the training<sup>4</sup>.

Not all PWP's were subsequently involved in the support of patients accessing the T-CBT but it provided them with the knowledge and skills to provide pain specific support while supporting patients in their usual capacity. Furthermore it raised awareness of the service options to all members of the team ensuring that patients receive support via the most appropriate delivery model.

Face to face bi-weekly or weekly supervision was provided by Dr Julia Hose, a qualified psychologist. Support/advice was also accessible via email in between those sessions.

### **3.5 How?**

Information on the modes of delivery of the T-CBT is provided in [3.3 \(What\)](#).

### **3.6. Where?**

T-CBT sessions were delivered by telephone from the Six Degrees Office in Salford. Patients could access face-to-face CBT or Mindfulness group at a relevant Gateway (Eccles, Walkden or Swinton Gateways). Face-to-face CBT was also available in GP practices.

### **3.7 When and how much?**

It was possible to arrange T-CBT sessions from 7:30am (if this was the patient's preference), however the booking of face-to-face appointments was dependent on the opening times of the GP surgery or Gateway (usually 8:00/8:30am).

The Mindfulness group course for CWP took place at 10am once a week for 6 weeks. Standard mindfulness groups were available in early afternoons (1pm-3pm) and evenings (6pm-8pm) on an 8 week rolling program of venues.

### **3.8 Tailoring**

Practitioners were asked to adhere to the guidance provided in the training manual regarding session length and content of each support session. However, it was

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<sup>4</sup> Training manual can be sent on request.

acknowledged that individuals have differing needs and work through things at a different pace so there was flexibility to adapt sessions to ensure needs were met.

The following examples provide information as to some aspects that were modified:

- More flexible approach adopted when patients did not wish to work with the self-help book
- Audio CD posted to patients who reported difficulties with focusing on written materials and those with visual impairments.
- Session length increased due to patients complexity
- Occasionally the initial assessment time was reduced to 30 mins (from 45-60 mins) due to patients' busy schedules and other health appointments they had to attend
- Additional materials discussed/provided (as not covered in the handbook) such as 'boom & bust cycle of pain', pacing, central desensitization and Mindfulness resources.

### **3.9 Modifications**

***Traditional service working*** - Standard working practices previously involved face-to-face one-on-one bi-weekly 30 minute sessions of CBT. This intervention was non-pain specific and delivered by practitioners who had not received training regarding CWP. Patients were offered appointments via '*supported self-referral*' pathway or standard referral form (email referrals). Double sessions were available for patients who required an interpreter to attend the sessions.

***Modifications to accommodate the Pain Platform*** - A number of modifications were made to accommodate the Pain Platform with respect to standard working practices, further changes were made following initial implementation:

- To ensure that the access protocol, predominantly the delivery of T-CBT, was adhered to the Pain Platform accepted clinical discharge letters rather than standard referral forms, increased initial assessment time to 60 minutes and provided sessions on a weekly basis via the telephone and offered two booster sessions at three and six months. In relation to the content of the intervention, more time was spent exploring impact and normalising prior to commencing behavioural activation/cognitive restructuring than in standard practice.
- In addition the PWP conducting the triage assessment was also required to inform the patients about the additional research questionnaires that they had the opportunity to complete, if they chose to participate in the additional research component, and send information packs in the post if applicable. (Taking part in the additional research was not a requirement of access to services through the Pain Platform)

- Changes were additionally made to the Mindfulness course to make it more accessible for patients with CWP. This was piloted during the course of the Pain Platform implementation. These changes related specifically to adaptations to support patients with CWP. Eight two hour sessions were reduced to six. Frequent breaks were offered during the two hours to facilitate the management of pain. The content of the course focused on pain rather than anxiety and depression.

***Modifications to the Pain Platform during the pilot*** – Relying on the learning and feedback throughout the pilot the team agreed a number of modifications throughout the pilot:

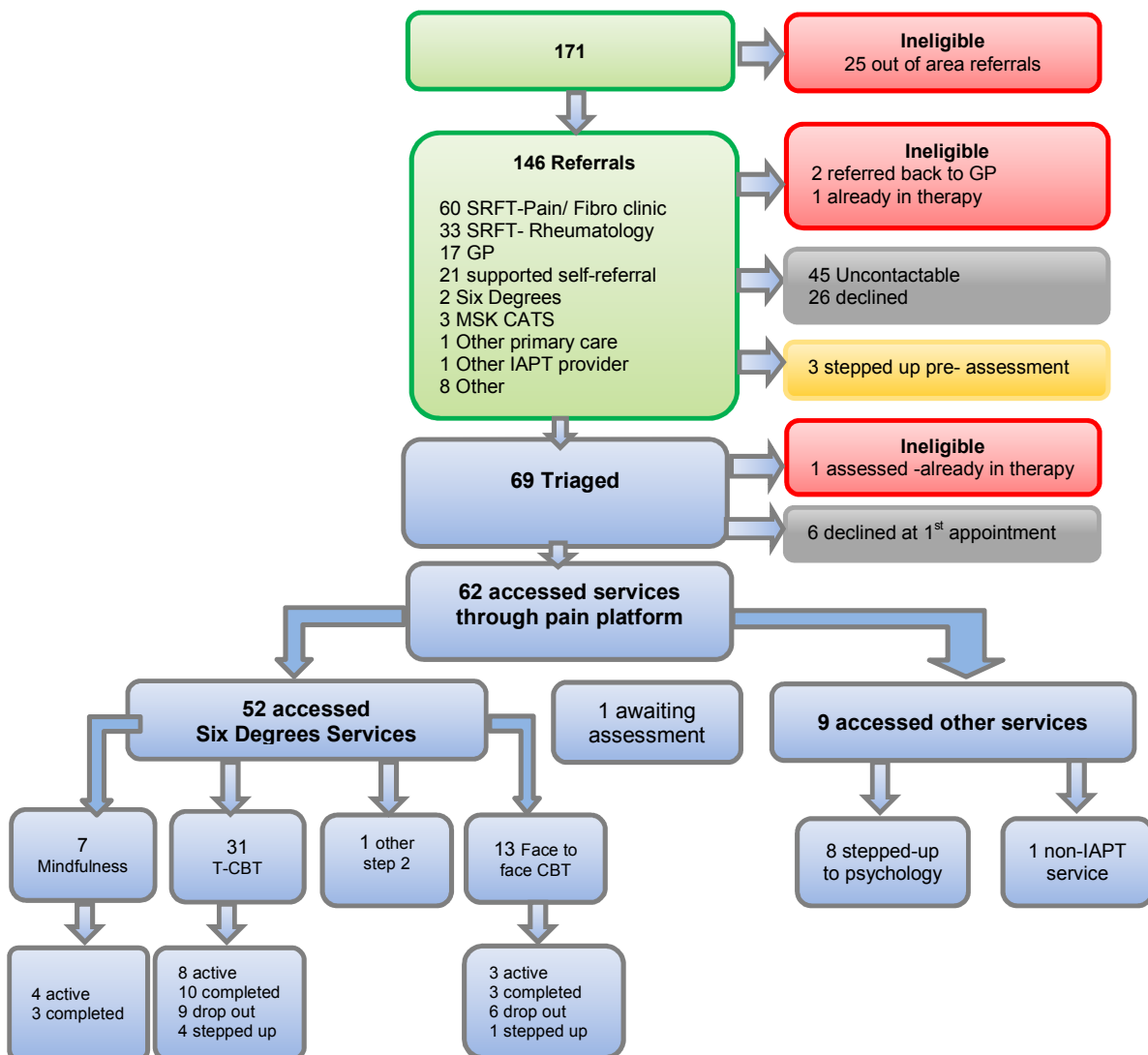
- At the outset referrals were only accepted direct from a primary or secondary care service. In December 2016 it was agreed that the option of '*supported self-referral*' should be made available in an attempt to resolve the difficulties associated with many secondary care staff not having access to an [nhs.net](https://www.nhs.net) account for electronic referrals. This option opened up the opportunity for the referrer to provide their patient with the contact details for Six Degrees so that they could contact the service directly. To support this referral letters were sent to a total of 138 patients who were waiting for a follow-up review by Professor Jones' clinic (representing all patients waiting who had a Salford GP). As a result of this new self-referral option an additional 10 minute triage over the phone was introduced by Six Degrees (conducted by a CWP trained PWP).
- During the initial six-months of the study discussions were held as to whether it would be suitable to include patients experiencing chronic pain outside the definition of chronic widespread pain/fibromyalgia e.g. pain conditions such as chronic back pain. This was agreed by the research team and Six Degrees and the service inclusion criteria was extended.

## 4. Quantitative Data Analysis

Data relating to rates of referral, source of referral and service access were collected for all patients referred via the pain platform. Levels of depression (PHQ-9) and anxiety (GAD-7) were collected at initial contact and subsequent contacts. Descriptive statistics are provided.

### 4.1 Referrals

The flow chart below illustrates the referrals into the Six Degrees pain platform and the outcome of those referrals. Of the n=171 referrals n=25 have been from out of area and of the n=69 patients triaged through the pain platform n=52 were treated by Six Degrees.



**Table 1:** Monthly referrals to Six Degrees Pain platform

Month	No of referrals
Pre May 16	2
May 16	2
Jun 16	30
July16	9
Aug 16	8
Sep 16	12
Oct 16	11
Nov 16	6
Dec 16	16
Jan 17	12
Feb 17	26
March 17	12

Table 1 shows monthly referrals<sup>5</sup> and two clear spikes in referrals are apparent. The first (June 2016), at the point that the service commenced is predominantly due to the fact that one of the main referrers had been identifying potential patients for the service in anticipation of the service launch.

The second spike in referrals (February 2017) was a consequence of was a consequence of inviting patients on the waiting list for the pain clinic to refer themselves via the ‘*supported self-referrals*’ with n=26 such referrals being received in February.

Of the 146 Referrals to the service referrals were predominantly female n=125; (86%) with n=5; (3%) missing data. Mean age of referrals was 50 years (range 18-80 years). Table 2 shows the ages of those people who accessed each of the six degrees services and the mean number of appointments. The mean total time of the interventions is also detailed, with the mean time patients spent receiving T-CBT = 128 mins.

**Table 2:** Patients referred through the pain platform and treated by Six Degrees

Service	N	Mean age	Age range	Mean number of sessions booked	Mean number of sessions attended	Mean total intervention time (minutes)
Face to face CBT	13	53.8	39-70	4	2	108
Mindfulness	7	42.9	31-59	4	3	276
Other step 2 service	1	67	67-67	1	1	60
T-CBT pain	31	46.8	18-70	5	3	127
All 6 Degrees Services	52	48.4	18-70	5	3	141

<sup>5</sup> NB the service went live for referrals on 6/06/16



Table 3 shows the index of multiple deprivation (IMP) for all patients referred to the pain platform based on the lower-layer super output area (LSOA) of their GP practice.

**Table 3:** Patients referred to the pain platform by IMD decile (1 most deprived)

IMD	Frequency (n)	Percent (%)
1	61	42
2	22	15
3	2	1
4	40	27
5	6	4
6	2	1
7	2	1
8	7	5
9	0	0
10	4	3

As outlined in Table 3 the largest proportion (n=61; 42%) of patients referred into the Pain Platform are from GP practices in the most deprived areas (IMD 1), with n=40 (27%) from IMD 4, and n=22 (15%) from IMD 2.

Tables 4 and 5 below show the mean initial and last recorded scores for patients receiving Six Degrees Services through the pain platform for the PHQ-9 and GAD-7.

**Table 4:** PHQ9 scores for patient treated by Six Degrees

Treatment option	Mean Initial	Range initial	SD initial	Mean last recorded	Range last recorded	SD last recorded
Face to face CBT	16	7-24	4.9	12	0-24	8.5
Mindfulness	12	7-20	5.1	12	6-20	5.2
Other step 2 service	21	21-21		21	21-21	
T-CBT pain	17	7-25	4.7	15	2-24	5.0
<b>All</b>	<b>16</b>	<b>7-25</b>	<b>5.1</b>	<b>14</b>	<b>0-24</b>	<b>6.2</b>

**Table 5:** GAD-7 scores for patient treated by Six Degrees

<b>Treatment option</b>	<b>Mean Initial</b>	<b>Range initial</b>	<b>SD initial</b>	<b>Mean last recorded</b>	<b>Range last recorded</b>	<b>SD last recorded</b>
Face to face CBT	12	3-20	4.7	10	3-19	6.3
Mindfulness	7	3-12	2.8	8	3-12	3
Other step 2 service	15	15-15		15	15-15	
T-CBT pain	13	2-21	5.1	12	2-21	5.5
<b>All</b>	<b>12</b>	<b>2-21</b>	<b>5.0</b>	<b>11</b>	<b>2-21</b>	<b>5.6</b>

## 5. Professional Stakeholder Consultation

Research question 4 aimed to address the extent to which key stakeholders perceive the way in which the pathway becomes incorporated, integrated and sustained into routine clinical practice. An element of this involved speaking with professional stakeholders involved in the implementation, delivery, management and sustainability of such services. This section provides detail on the methods used and presents key findings of this piece of research.

### 5.1 Theoretical perspective

A qualitative approach was drawn on to explore the views, expectations and experiences of relevant stakeholders of the implementation and sustainability of service and with respect to broader contextual issues regarding the organization and delivery of care for people with CWP.

A variety of theories exist that can be applied to the understanding of implementation processes, individual and group behaviours (Nilsen, 2015). Normalisation Process Theory (NPT) is a relatively recent theoretical approach that facilitates the understanding of how new interventions become part of existing practices through social organisation of the work and integration into social contexts (May and Finch, 2009). NPT is comprised of four main constructs that represent individual and collective levels of work involved in the implementation of new practice – coherence, cognitive participation, collective action and reflexive monitoring (detailed further in Table 6).

We aimed to capture the views of as wide a variety of individuals as possible. Participants were recruited via purposive sampling (Teddlie and Yu, 2007) from professionals who were working across the chronic widespread pain pathway. Snowball sampling where existing professional participants assisted with the recruitment of relevant colleagues/acquaintances also took place. This involved those commissioning, referring to, managing and delivering interventions within the existing service and newly implemented Pain Platform.

Individual interviews were conducted 3-7 months after commencement of the Pain Platform to ensure that initial embedding had occurred and communication of the opportunity to refer had been established among appropriate services. To ensure consistency across interviews, a topic guide incorporating key topics and open-ended questions linked to the study aims and conceptual ideas of NPT was developed. The topic guide included questions to elicit participants' perceptions and experiences of implementing and delivery of treatments within the pain pathway and how it compared to pre-existing process of care delivery. The opportunity was also offered to participants to make any additional comments about issues relating to implementation of the service.

One member of the research team who was independent of the service(s) involved within the pathway conducted all interviews face-to-face or by telephone, dependent on participant preference. All participants provided written consent which included consent to

audio record the interview. The interviews were transcribed verbatim; the data was entered into NVivo software where a thematic analysis (Braun & Clark, 2006) informed by NPT (May, 2009) was performed. The researcher who conducted the interviews analysed the interviews supported by a PWP from Six Degrees who had supported patients accessing T-CBT.

14 people took part. Participants included PWPs supporting patients accessing low intensity interventions within the pathway (n=3), operational/service managers (n=3), general practitioners (n=2), from rheumatology (n=3) and physiotherapy (n=1), PWP supervisor (n=1), and mental health commissioning (n=1).

## **5.2 Results**

Emergent themes were mapped into the NPT framework. All themes were accounted for within the framework. The themes are presented in Table 6 and are structured around the four key constructs.

**Table 6.** Study findings presented using NPT core constructs

NPT construct	Study themes
<p><b>Meaning (Coherence):</b> <i>the sense-making work (meaning) that is conducted by individuals or collective groups of individuals e.g. organisations when they are faced with promoting or inhibiting the implementation of a new practice.</i></p>	<ul style="list-style-type: none"> <li>- The Pain Platform has the potential to overcome existing access issues</li> <li>- The Pain Platform incorporates shift towards parity of esteem (valuing mental health equally with physical health)</li> <li>- The Plain Platform is advantageous for patient access and need</li> <li>- The Pain Platform demands an increase in professional understanding/awareness</li> </ul>
<p><b>Commitment/Buy-in (Cognitive Participation):</b> <i>the relational work (commitment/buy-in) that individuals and organisations have to do in order to ensure engagement with the new intervention.</i></p>	<ul style="list-style-type: none"> <li>- Professionals working in the Pain Platform will need to foster patient engagement</li> <li>- Availability of the Pain Platform is valued</li> <li>- Front-line support of the Pain Platform may be variable</li> <li>- Service user acceptability of the Pain Platform influenced by personal beliefs</li> <li>- The Pain Platform is aligned with existing service procedures</li> </ul>
<p><b>Action (Collective Action):</b> <i>the operational work (action) that individuals and organisations are required to do to endorse implementation of the new practice.</i></p>	<ul style="list-style-type: none"> <li>- The Pain Platform implementation requires addressing professional beliefs about CWP</li> <li>- Mixed delivery methods may be required for the CWP T-CBT</li> <li>- The Pain Platform is aligned with existing service goals</li> <li>- Pain Platform implementation requires additional resources</li> <li>- Pain Platform implementation requires alignment with existing referral protocols</li> </ul>
<p><b>Appraisal (Reflexive Monitoring):</b> <i>the appraisal (formal and informal) work that individuals and organisations do once implementation has occurred to assess and understand the advantages, disadvantages and impact of the new practice.</i></p>	<ul style="list-style-type: none"> <li>- Feedback for professionals regarding impact of the Pain Platform will enhance learning</li> <li>- Need to enhance opportunities to foster good collaborative care to ensure success of the Pain Platform</li> <li>- The Pain Platform’s success and sustainability is reliant on further development of the organisational infrastructure</li> <li>- The Pain Platform’s success is reliant on practitioner training and support</li> <li>- Pain Platform referral protocols need to align with existing service procedures</li> </ul>

### 5.2.1 Coherence: understanding and making sense of the pain pathway

Implementing new approaches to the management of any condition relies on individual workforce members collaboratively developing an understanding of the new practice and its potential value. Current access to psychological therapies for people experiencing CWP was identified as an indirect, and potentially lengthy process, resulting in patients not receiving the support they required at the point that mental health problems became a concern:

*“I work in a GP practice...at the moment, the only way of me getting any form of psychology, or interventions which are tailored to patients with pain, is to refer them to the hospital, and they will go to the pain clinic [Pain Centre], they’ll be assessed there and then and if they are deemed to be appropriate for psychological interventions then they’ll have their sessions. So that can take a few months...”*

The new Pain Platform was identified as not only offering a quicker response but also opening up new opportunities for improving patient acceptability, choice and subsequently their overall experience:

*“mostly I think they [patients] really like it [being referred to the service]. They like the idea of something happening reasonably quickly, because they’re just used to being fobbed off from one thing to another, one consultant to another, one service to another...that might have been over two to five years sometimes and then finally they get somewhere where they can actually get the therapy that they need...that’s a disaster really. So this is [an] improvement. So I think it’s brilliant.”*

Implementation of the Pain Platform was also regarded as a way to address the need to achieve parity between mental and physical health, aligning services with national policy initiatives (e.g. Royal College of Practitioners, 2013) and guidance that recommends incorporation of psychological support for the management of CWP. In drawing upon their experiences of the limited benefits that one treatment approach in isolation can have on patient outcomes, participants recognised the value for the adoption of a holistic care approach:

*“It was a missing piece of the jigsaw [the CWP Pain Platform]... I think as a patient living with a chronic pain condition no matter what the psychological support is, you need an outlet to be able to moan essentially. Even if it’s counselling or something you need some kind of support from that level – possibly even with a normal HADs scale score. Certainly for those patients that score higher and therefore it’s NICE guidance recommend I think is an essential part of the service really.”*

Despite views regarding implementation of the Pain Platform being positive, several participants deliberated upon the diverse levels of understanding of CWP presentations by referring practitioners and the impact this may have upon their support of and engagement with the service. Given the lack of guidance within services practitioners often work in isolation, developing their own ‘systems’. As a result the new pathway may be underutilised as a result of not being confident in its suitability or unaware of its purpose.

*“I think the main thing for me is just like being clearly exactly who it is and what it is that we’re trying to work with.”*

*“I think the main thing is to get your communication across, that it exists, and it works...because unfortunately we’re all kind of bombarded the whole time with do this, do that, do the other, and we just...we forget, and unless someone’s constantly reminding us that this is there, we just stop referring, you know, and that’s the way life is really. So it’s kind of getting it embedded into the department in a way, in some kind of way.”*

### **5.2.2 Cognitive participation: professional engagement with the pathway**

Implementing new models of health care provision is reliant, in part, to changes to existing systems, procedures and conduct. The participation of individual stakeholders affected by such changes is paramount and is influenced by the extent to which their participation is promoted and how committed they are to implementing and adapting to the new ways of working.

The value of the new pathway was acknowledged by all participants and was regarded as being aligned with existing working practices. Some drew upon the concept of parity of esteem within mental health care, taking a more considered approach towards the management of mental health problems within physical healthcare systems:

*“...when we think of physical health conditions the way we probably need to move and the direction we need to go in is to start to develop things in a way where further down the line we have wherever it’s appropriate psychological intervention going on as a core part of a service. Rather than everything being seen as it should be referred to specialist mental health services and seeing psychological wellbeing as more of a core thing that’s addressed and provided for within services.”*

For some, however, the recognition that the move towards giving equal priority to mental health in line with physical health had not been accepted fully across all services was identification of the potential variability of commitment by all parties:

*“It just takes some random thing where you get, like, a new manager who just, like, doesn’t...is insensitive to this, is wanting to get something done immediately, and he starts, like, saying, well, this has to be done, and then it’s just like, can there be a bit of a spark that would probably...my worry would be place at risk some of the hard work that’s been put into it.”*

### **5.2.3 Collective action: implementing the pathway into practice**

Collective action is the work that individuals need to perform in order to implement new procedures and practices. It takes into account how people interact with others, the emerging skills, knowledge and confidence developed over time, allocation of roles and tasks and resource availability and usage. Despite initial optimism of the implementation of the Pain Platform, several participants reflected on potential barriers to its integration and sustainability. These barriers incorporated issues relating to both the implementation of new treatment modalities and also to the organisational infrastructure required to ensure sustainability.

*"I think potentially there are [barriers]... it can be simple things like locating the intervention, have the practitioners got a stable base where they can go and run a clinic or however...through whatever route the interventions are being delivered. If it's just via telephone support, are the systems are all set up and stable, there's nothing going to disrupt them. Having a commitment to putting that resource in place and ensuring that it stays in place, so sometimes it can be very physical things about accommodation, phone access, all those kind of things. We see it all the time in the broader IAPT services where we've hit problems with that and you end up with, apart from anything else, wasted capacity. But, yeah, you've got the financial components about long term funding, who's going to provide that and is the money there for it? You've got the whole attitudinal thing and then you've got the physical dimensions of locating a service somewhere and giving it a home for long periods so it can be stable and do its job well."*

Although being regarded as a viable option for patients experiencing pain to overcome potential access problems, for many referrers negative perceptions were held regarding the use of the telephone as a mode of treatment delivery. Some lacked insight into the approach and in comparison to traditional face-to-face approaches it was sometimes regarded as a barrier to patient engagement and service success:

*"I am probably a bit sceptical about the phone. I think that is due to that you lose body language cues and facial cues. I think in terms of all that we do in consulting I think the telephone is sometimes far from ideal. You don't know just how much of the attention you've got of the person on the other end. Like I'm sat talking to you today and I can tell you I'm sat on my sofa with a cup of tea but I could be well be sat reading my work computer or flicking through Facebook or doing all sorts of things and you wouldn't be aware. So I think that for me and I also think that in terms of communication is that you don't necessarily...can react if you've said something that somebody doesn't seem happy with, especially when you're exploring that notion that somebody's physical symptoms may have a psychological grounding that I think for some people they may get offended by that."*

Investment in communicating the purpose of the Pain Platform to patients was an additional threat to patient engagement and cause of uncertainty. Given the physical nature of CWP patients are not predominantly offered a psychological treatment option. The incorporation of the Pain Platform caused concern for some participants who did not feel confident about how it would be perceived by patients and their ability to communicate its purpose in an effective and timely manner.

*"I guess for them they seem to have a lot of appointments generally, so it's kind of another appointment; and because I think for some people they're not sure how psychological therapies can help with a physical health problem, so they see that physical health appointments at rheumatology, for example, as important, but they're also face to face, they've got to attend that appointment; and I think initially they're not sure what we're about or why, how it might help, so I think perhaps they don't have the same connection with it in that respect."*



Furthermore, issues with the pathway infrastructure, in particular referral protocols, caused concern for some with one referrer indicating that they were “*terrible*”. Difficulties obtaining access to [nhs.net](https://www.nhs.uk) accounts required to securely send referrals to the service was recurrently identified as a barrier, and differed to usual postal procedures. Some thought that adaptation to referral procedures deterred some from referring. Others didn’t feel a change in procedures was warranted.

#### **5.2.4 Reflexive monitoring: appraising the pathway and future directions**

Participants deliberated upon the implementation of the Pain Platform reflecting upon existing pathways in their thoughts about future sustainability and benefits. As many were unclear of the expected benefits for patients, attention shifted to the value of feedback. To optimise patient care and service operationalisation all valued feedback. Given the short implementation period many had not had the opportunity for direct patient feedback.

*“I don’t want to be referring in forever without knowing that it’s useful. And particularly for a condition where I may not follow people up. So, if I see somebody with a new diagnosis of fibromyalgia where I am kind of confident that that’s the diagnosis, I can review some results afterwards and know that they haven’t got any other problems. I think that I have referred them into a service that is going to help them, but then never know whether that has been useful over many years.”*

Working under the auspice of collaborative care was considered as the most appropriate way to optimise the implementation of the pathway. Lack of collaboration in the way in which the Pain Platform was implemented was identified as a barrier to creating a successful organisational infrastructure to enable efficient and effective delivery. Establishing links between physical and psychological services in respect to locality of services and building relationships and sharing ideas and knowledge between different services was important to reduce service complexity.

*“Making sure that there is good links between all the different services so it doesn’t just become a siloed thing...”*

*“...from my point of view, is that we know what we’re looking for, and we know where we’re trying to get, but we listen, build relationships and don’t try and push it faster than it will naturally go...and involve other people, so it’s like, kind of, you come in so that it takes out the thing where it could be them and us... the ideal thing that we’d all be coming from exactly the same perspective and we’re all working together, totally harmoniously supported by this great infrastructure, you know, like...no matter what you’re doing, you never quite get there, so you’re always working with a bit of a compromise. It’s just that this once, the compromise seems to be a little bit more tenuous... we’ll try and bear in mind what’s the best for the people involved and try and make the best of what we can make of it.”*

Recurring discussions related to sustainability and the demand for more efficient referral procedures to be implemented. Current procedures that did not fit with existing referral protocols were of concern. Reducing the amount of additional work that is required was viewed as important to ensure efficiency.

*“we probably need some kind of online referral process, a button we press ideally...if you’ve got a clinic, everything’s in the clinic letter, press the button, that’s all you need to do. That would be the ideal thing. Not repeating everything again.”*

## 6. Patient and Public Involvement

Service user input, involvement and dissemination of the study was integral to the study. Prior to commencing the study consultation with two fibromyalgia Support groups in Salford, who were highly supportive of the study, took place. The importance of CBT and in Pain Management was additionally explored at a *'Pint of Science'* event in Manchester (May 2015), a Fibromyalgia Family Day at SRFT (October 2015) and during the *'Pain, Brain and a little bit of Magic'* North West tour 2016<sup>6</sup>

Valerie Derbyshire, Lead of one of the Salford fibromyalgia support groups, was a co-applicant on the study. Valerie reviewed and contributed to the amendments made to the intervention booklet used in the previous research trial to overcome some issues concerning user relatability with the case studies presented.

Valerie attended project meetings to discuss opportunities for PPI involvement with the research. It was identified that members of the Salford Fibromyalgia Support group could assist with the promotion of the Pain Platform and that they would be willing to assist with the qualitative research evaluation by attending a consultation group discussion to comment on the findings from the qualitative interviews. The findings from this consultation are presented below.

### 6.1 Salford Fibromyalgia Group Discussion

On the 19<sup>th</sup> January 2017 a discussion group was held with the Salford Fibromyalgia Support Group.

#### 6.1.1 Participants

The group meet on a monthly basis at Eccles Gateway Centre. They are actively involved in local and national fibromyalgia awareness events and value the opportunity to engage with research activities. One of the members is the Patient and Public Involvement representative and applicant of the CWP implementation research group.

The group's aim is to *'empower those with Fibromyalgia through the provision of knowledge and support, encouraging them to take control of their condition and improve their quality of life'*. They are also *'committed to raising awareness among UK health professionals and the general public, so that everyone with Fibromyalgia can access the help and support they need.'*

Six members of the group, all female, of varying ages with differing experiences of fibromyalgia attended the two hour meeting. Two of the attendees had had the opportunity to access the pain platform, however one had declined as she did not want therapy over the phone and the other had issues when calls were scheduled due to her work commitments.

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<sup>6</sup> (<http://research.bmh.manchester.ac.uk/pain//events/PainTheBrainandabitofMagic>).

### 6.1.2 Aims and Procedures

The aim of the event was to obtain feedback from the group in response to the preliminary findings from the professional stakeholder interviews.

A presentation was delivered by one of the research team members to the group. It provided detail on what the Pain Platform was about, detail on the T-CBT intervention, referral routes into the service and what professionals said about their views of the Pain Platform during the qualitative interviews.

It was emphasised to the team that the aim was to exploring their views and perceptions of the pain pathway including:

- What they perceived to be positive and negative about the service
- What they thought about the telephone delivery approach
- If they thought the service had the potential to meet their needs and how
- The best ways of communicating information about the service
- Any suggestions about what changes could be made

Two members of the research team facilitated the discussion which was audio recorded following verbal consent from all participants.

### 6.1.3 Findings

**Reducing isolation** - Participants identified one of their biggest worries as being “*left in limbo*” due to the lack of long-term support. They often felt that their expectations were initially raised when accessing support but that the support was removed too soon. They recognised the benefits the opportunity for follow-up sessions within the T-CBT model had and expressed a need for other CWP services to match such a model. Particular emphasis was placed on maintaining contact with services and the ability to access support in a more time-efficient manner:

*“...even if it's like once a year check-up or something, at least it would be that contact, rather than saying, oh, you know, well, just get re-referred if you want, like. But then you've got to go through all the system again.”*

Having to re-access previously utilised services first was considered to be a “*waste of resources*”.

**Accessing treatments to meet needs** - Participants identified the current lack of accessible and suitable services for people experiencing fibromyalgia. Access to suitable treatment, however, in part, was reliant on having access to a GP who “*believes in you*”:

*“I think one of the difficulties is, there doesn't seem to be a uniformity of provision. It depends on your GP and how switched on he is to fibromyalgia. We've had horror*

*stories of people who have gone to the GP and been told, right, you've got fibromyalgia, see you, you know, and that's kind of it."*

Some felt that in order to access suitable help that they needed to be proactive, without being so the likelihood of receiving suitable support was low:

*"I think you've got to do a lot of it yourself as well, you know. I mean, 12 years now I've been diagnosed with fibromyalgia. And I was ill years before that. So what you did at the beginning, there's been nothing. And it's only that I've gone back to it and said, you know, I need help with this, that you get it. You're just left. You know, and then there's people being diagnosed with it and they seem to be getting more than you've ever had, you know, you think, well, why did I not get that. I mean, I know new things are happening all the time but you're not picked back up."*

**Educating professionals** - The Pain Platform was regarded as a way to improve access to timely and appropriate support; however it was acknowledged that improving professional awareness of fibromyalgia, its presentation, impact and management was required.

*"If GPs, I suppose, had more awareness of fibromyalgia, I guess, rather than just saying, oh, well, I know somebody's who [inaudible 0:33:40] and this tablet works for them, have this tablet, I guess they could try and offer the options if they knew. Because I take great offence every time I go to the doctor's because they say, do more exercise. And I just go, oh, exercise, exercise, that's all you hear."*

*"I mean, this irritates me enormously that doctors will say to people, well, there's no such thing, I don't believe that it exists. But I remember my own grandmother had fibrositis, which they now say, well, fibrositis was the same as fibromyalgia. So it's been around a long, long time, you know."*

Despite much of the focus being on educating GPs, some participants acknowledged that they had had conversations with specialists who identified their uncertainties surrounding supporting people with fibromyalgia:

*"I think it's interesting that you said about perhaps doctors don't have the confidence to understand. I was doing a stand at one of the rheumatology conferences last year, it happened to be held in Manchester and Fibromyalgia UK said can some of your people help out. So I went and one of the other ladies. But whilst we were there, quite a number of specialists who saw themselves as specialist in fibromyalgia said, we don't know what to do. You know, even though we've had the information and we think we understand it, when people present, we don't know what we can offer them...And that came from various areas, it wasn't just sort of a local issue."*

Educating GPs and other health care professionals about fibromyalgia was regarded as an important aspect of the Pain Platform to ensure its success.

**Incorporating choice** - The Pain Platform was viewed as an opportunity to open up different treatment choices to patients. They considered themselves to be 'choosers not users'. Many felt that medication was the only option offered and that this was not satisfactory.

*"You have to have the choice. In fact, talking about the quality of life...one of the things we were trying to establish when we were doing that quality of life thing was that people should be...we were talking about users of the service. And we were saying people should be choosers not users, you know, and you should have that option, this is what's available, this is the treatment for fibromyalgia, you can have that, you can have that, you can have that or, you know, whatever."*

Some participants recognised the impact that experiencing pain has upon their mental health and that for some support to manage this may be beneficial.

*"I think quite often people don't realise that the things that they are suffering do impact on their mental health as well. You know, because like we said, there's this stigma about mental health issues, I'm not mad, and all of this. But nevertheless, I think the emotions that you go through, you know, very often you need support like this, but it may not suit everyone, that's the other thing."*

**Collaborative working** - The benefits of offering the opportunity to access psychological services via the Pain Platform were recognised. Despite this participants also highlighted that from experience the involvement of different professionals working in different services can be a source of frustration. Many felt that communication was lacking between individual professionals and services which resulted in negative experiences and the need to repeat previous conversations over and over again:

*"And you know full well you've already gone through this previously. And I think that's a frustration that you constantly have to keep going over stuff. It's quite funny because I actually got it so many times that I used to...keep sort of a note of all my medication, so that if I get asked what medication I'm on, I go, there you go. And, you know, oh, that's very organised. But you just get sick of it going over the same thing."*

## **6.2 Consultation event with Six Degrees patients**

In addition to speaking with the Salford Fibromyalgia Support Group members, a listening event was also held with patients who had been referred to receive psychological support from Six Degrees.

A listening event was held with patients who had been referred to receive psychological support from Six Degrees.

On 30<sup>th</sup> March 2017 a patient participation and involvement group was held to hear the views of patient that had been referred to the project.

### **6.2.1 Participants**

Patients who had been referred to the project were invited to attend the event by phone call and written invitations sent by Six Degrees. Those invited represented a range of

perspectives including those who had used Six Degrees services recently, those known to have had a positive or negative experience, people of different age groups and gender. The event was attended by 3 participants, all of whom were female and various ages, therefore the feedback cannot be generalised to the wider patient group.

A greater number of people were invited but contacting patients and gaining their consent and agreement to take part had proved difficult.

The event was facilitated by staff from Six Degrees. It lasted 2 hours with refreshments provided and included an overview about Six Degrees' work, followed by group discussions about patient's experiences of accessing T-CBT and suggestions for improvement.

### **6.2.2 Experiences of T-CBT**

Overall, participants reported accessing the therapy as being different from their expectations; however felt that accessing telephone delivered therapy was a positive experience. Those participants who had been discharged from therapy felt they were motivated to continue mood improvement techniques. It was reported that the specific pain booklet received was helpful.

Participants reported two different referral routes. One participant felt it was a helpful addition to the pain management programme they were on. Participants reported that therapy was a positive addition to pain medication, in that it helped normalise how they were feeling through some focus on the pain itself. Overall it was felt accessing therapy helped with acceptance of the pain condition. One participant reported that mindfulness, which she had accessed via Six Degrees, had been helpful in providing her with a technique for managing pain.

One participant reported the timing of the appointment (early morning) was helpful due to being at work. Each participant reported that telephone delivered therapy was helpful due to not having to travel to appointments, and that they felt comfortable over the phone. Participants reported that they didn't feel the telephone was a barrier to the "therapeutic alliance", in fact it was reported as a positive therapeutic alliance. However, at times being on the telephone allowed for interruptions, a face-to-face appointment might not have, e.g. family or visitors. Consensus was obtained regarding the length of appointments; it was felt 30 minutes was too short and 1 hour was too long. An agreement of 45 minutes was felt appropriate.

### **6.2.3 Suggestions to improve the experience**

Participants did not expect SRFT and Six Degrees to liaise together in relation to their progress, however, it was felt this would be a smoother and collaborative approach should this be something that would be an option.

Participants felt emailing information such as the pain management booklet instead of posting it would be beneficial. Alongside this it was felt that for future reference having it on email would be beneficial.

It was felt by all participants that re accessing the service was something that they felt able to do should they need to. It was agreed a care plan, especially relating to expectations should there be missed appointments and clear information on re-accessing the service, would be something that would be helpful. Alongside this it was felt appropriate that there should be follow-up should an appointment be missed i.e. an SMS.

## 7. Overall Discussion/Conclusions

The Pain Platform received 146 referrals over a 9 month period which was in line with the predicted number of referrals that could be managed in this period by one PWP at Six Degrees. Feedback on the service from professional and lay stakeholders was generally very positive; having a single point of access into a range of psychological interventions was seen as a helpful addition to the entire pathway of care for patients. Furthermore feedback from the PPI groups indicated that the longer term components (ie booster sessions) of the T-CBT may help alleviate feelings of abandonment at the end of therapy.

The service has robust longstanding referral procedures in place to manage any incoming referrals and schedule appointments. Due to the difficulties with implementing those pathways within the pilot, there was an unexpected outcome related to the amount of admin work generated by not being able to contact the patients to discuss the study and liaising with the referrers, before the appointments could have been offered, which resulted in the clinician being required to assist with the administrative work related to the programme.

### 7.1 What worked, and why?

- Access data is grossly compatible with data for population of patients accessing Six Degrees services as a whole
- Access to service; 109 patients were referred directly to the service, or made supported self-referral without the need for additional process through primary care
- Patients were able to access a range of services tailored to their specific needs with 71% of patients who accessed services through the Pain Platform accessing services through Six Degrees; and 60% of them receiving telephone delivered CBT
- PPI feedback- liked idea of booster session/ follow up
- Successful use of supported self-referral for patients currently on pain clinic waiting-lists. Letters inviting supported self-referral were sent out to 138 patients on the waiting list with n=21 (15%) patients taking this up. This was not trialled with other groups of patients due to risk and governance concerns regarding the lack of access to referrers.

### 7.2 Biggest challenges

- Development of organisational infrastructure to support Pain Pathway - Despite considerable investment of time, more work would be required to ensure an efficient and effective delivery model is executed. The service provider has concerns over the maturity and sustainability of the current working model and believes without the support of the research team that it would be challenging to continue supporting patients via the Pain Pathway without adaptation due to concerns over patient risk.
- Building in the need to allow for space for co-production doesn't work with one-off planning – need to develop a common sense of purpose over time with all stakeholders holding shared levels of agreement.



- Development of collaborative working to assist with the understanding of patients' psychological and emotional journey through the platform. In common with patients experiencing a variety of conditions, patients with CWP may be distressed about a variety of life events. No clear pathway/ethos to manage this was established and it was dependent on individual practitioner's clinical judgement/ reasoning.
- Patients completing treatment - referral rates were just under the proposed target figure of 150. 30.8% of patients referred were uncontactable. Patients who were difficult to contact presented practitioners with challenges booking appointments and being faced with non-attendance at appointments. Subsequently this resulted in practitioners spending additional time on administrative tasks e.g. attempting to obtain contact details or re-arranging appointments. Further exploration and development of the organisational infrastructure would require development to ensure sustainability of the Pain Pathway.

When uncontactable patients were removed, the proportion of patients entering treatment (attending at least one treatment appointment) through the pain platform was 61%.

Due to the small numbers involved, the data relates to patients with CWP referred into the pain platform as a whole, rather than to specific types of intervention; consequently caution should be taken when comparing the data to Six Degrees and to the National IAPT data (2015-16).<sup>7</sup>

- Electronic referral process - This remained a challenge for referrals from SRFT throughout the course of the project. Although a short-term solution was established during the project this was not sustainable and no alternative, other than supported-self referral was found that was acceptable to both provider and referrer. Six Degrees did not feel that the supported self-referral was a suitable long term solution due to concerns over governance.
- Contact phone numbers - Early in the study referrals were received without contact telephone numbers. This was addressed and subsequently numbers were typically provided on referrals forms/ clinic letters however these were frequently incorrect, possibly due to phone numbers not being updated on the hospital systems. This resulted in an increase in administrative time obtaining contact details and/ or writing to patients.
- Access to referrers - Due to the provider and referrers not being co-located, and some referring services/ clinics being run by lone practitioners it proved difficult for the providers to contact referrers to return or discuss referrals. This also raised concerns over risk and governance for the provider.
- Flexibility of timing of appointments.

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<sup>7</sup> <http://content.digital.nhs.uk/catalogue/PUB22110/psych-ther-ann-rep-2015-16.pdf>

### 7.3 Lessons learned for future development

- Workable referral transfer process.
- Clear process for the discussion of complex cases.
- There is a need to develop a common ethos between services and referrers to ensure that the psychological needs of patients are managed effectively and will allow them to build with services. Furthermore it would allow practitioners from different services to reflect upon patient' experiences across the entire patient pathway.
- Possible co-location of services and/ or regular clinical meetings to increase team working and overcome the '*silo*' culture.
- Consider administrative implications for the service provider to ensure appropriate skill mix for the project.
- PPI involvement throughout the project is essential to ensure that service changes are in line with patient preference and clinical need.

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## Appendix A: Pain Platform / Referral Pathway

