

**The Repeated Re-referral of Chronic Pain Patients into Musculoskeletal Physiotherapy Outpatient
Departments**

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Thesis submitted for Doctor of Philosophy (Ph.D.)

January 2019

(I confirm that the content of this thesis is less than 100,000 words)

Acknowledgements

Firstly, I would like to acknowledge and thank my supervisory team, Dr Daniel Kerr and Dr Iseult Wilson. I could not have asked for a more steady, knowledgeable and non-turbulent guidance throughout the duration of my PhD. Your organization, advice, mutual respect and friendship have been both an excellent example and a significant help; I will be indebted to both your individual and collective contributions.

Thanks also to those who became valuable advisors and collaborators along the way, including the knowledgeable Professor Ian Bradbury for advice and direction on statistics and sampling. I acknowledge the Department of Employment and Learning for funding my studentship.

To my internal assessors, who have included Dr Joseph McVeigh, Professor George Kernohan, and Dr Paul Slater, and indeed to any or all involved in peer review, filter committees and ethical boards, I appreciate the very constructive feedback and guidance which has helped shape this thesis and its stages of development.

My thanks are extended to all the technicians within the School of Life and Health Sciences at Jordanstown, along with the patient Nick Curry in earlier stages and drafts of protocols. Thanks to Leslie Gourley, for all things technical – including tripods, camcorders, backups of audio or video files, and discussion of fast Volkswagens. Thanks to Mary-Rose Holman for advice and guidance with database inquiries and literature searches.

This effort would have been the poorer without the participation of those patients undergoing NHSCT care in various stages and durations, and who kindly gave of their time to inform the research. These contributions are anonymous, but of much worth. To others who expressed regret that they were unavailable but showed an interest and endorsed the exploration of these occurrences, thank you; I hope to have supplied something of worth in return.

I would like to thank the physiotherapists at each of the involved Trust sites, not only for the willing and informed contribution in focus group studies, but for the invaluable and longsuffering help in compiling and perusing myriads of patient notes to allow data collection to take place. Special thanks are due to all those team leads and senior physiotherapists who supported the research concept, liaised throughout, and guided the research design in its various stages, including (amongst others) Donna McIvor, Sandra Taggart, and perhaps especially Sandra Anderson. Without these, focus group studies, recruitment, and the logistics of data collection would have been a difficult obstacle to negotiate. Thanks to Lorraine Nelson in the Fort Centre for her repeated help throughout a difficult recruitment process.

Of all these, no collaborator did more than Colin Brennan, who has been a truly invaluable driving force in each stage and without whom this research would have been impossible.

Many thanks to those who gave opportunity for teaching: Dr Joseph McVeigh and Dr Diane Liddle, along with my supervisors for encouraging this experience – not forgetting Mark Poulter and Dr Claire McFeeters, with whom, alongside Dr Iseult Wilson, it was a pleasure to share in leading workshops for undergraduate students.

To Martin and Dr Elizabeth Tierney, for giving me opportunity to maintain my clinical skills alongside academia, I will always appreciate the outlet and the variety that Tierney Rehab afforded, alongside the interest and friendship shown by you both.

To my fellow colleagues whom I started this journey with, all in the office and those on a similar journey, I congratulate those who have completed and the rest who will shortly do so, and thank you all for the cups of tea, conversations and friendly faces I encountered along the way.

I need to give special thanks to my family, especially my parents. You have supported me throughout and taught me hard work and perseverance. You have been examples, and not only have done everything possible to let me pursue this challenge but have made so many sacrifices over the past 25 years, long before I ever reached this point. I appreciate everything you have done, and everything that you are to me. Thanks to Luke and Peter for the outlet of late-night brotherly competitiveness, and the banter that goes with it; Sean, Rose and Joseph, for the madness and fun of younger brothers & sisters; Mary and John Phillip et al., for the interest and encouragement along the way; Beth and Adam for the same, and for more than one evening spent at each house! To my wider family and my friends, you were often needed more than you know.

I close these acknowledgements with a special thanks to Naomi. Your company and love have kept me at it more than anything, and I know you are prouder than I am myself. You've been closer than anyone else for the journey, and through all of it been a constant smile and help. Thank you especially, for, in the middle of it all, agreeing to become my wife. Of any achievement I may have, it is of this that I am most proud.

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Presentations/Publications:

Oral Presentations:

Title: "No potential – or no pathway? Investigating a pattern of repeated referral". Oral presentation at the inaugural Life and Health Sciences (LHS) Conference (Coleraine, May 27, 2016).

Title: Perspectives and profiles of repeatedly re-referred patients to musculoskeletal physiotherapy outpatient departments: A focus group study. Oral presentation, CSP Physiotherapy UK Conference (Birmingham, 19-20 October 2018).

Poster Presentations:

Title: Questions asked of a pathway; a pattern identified of repeatedly re-referred patients to musculoskeletal outpatient physiotherapy. Presented a poster presentation at the Irish Society of Chartered Physiotherapists (ISCP) Annual Conference (Wexford, Oct 2016)

Title: Repeated re-referrals; accounting for a pattern in musculoskeletal outpatient physiotherapy. Poster presentation at the CSP Physiotherapy UK Conference (Birmingham, 10-11 November 2017).

Funding:

DEL (Department of Education & Learning) Studentship

Summary

Background

Chronic musculoskeletal pain and its impact is a growing concern within the UK and Europe. Physiotherapy musculoskeletal outpatient departments are one of the main UK secondary care services to which chronic pain patients are referred. A number of patients however appear to not achieve resolution yet are repeatedly re-referred through these departments cyclically.

There is little investigation of repeated re-referrals, and no standardised operating procedure for leading an enquiry. Therefore, the aim of this research was to establish a picture of re-referrals and the patients experiencing them, and, from stakeholders in the referral process, to account for the occurrence and suggest solutions whereby repeated re-referral may be addressed and resolution achieved.

Methods

Statistical output from the LCID database in the NHSCT confirmed the patient segment receiving multiple referrals ($n \geq 3$) over a given time-period. These patients' records (both from LCID and hard-copy notes) were perused securely using data collection forms and descriptive statistics ran to give a detailed picture of the re-referrals. Focus groups explored re-referrals from the perspectives of physiotherapists in NHSCT Msk OPD departments, and patients who had undergone multiple re-referrals, regarding their respective experiences and attempts to account for the occurrence. Finally, a semi-structured questionnaire survey was administered to GPs referring into NHSCT Msk OPD departments, regarding their approach to a hypothetical patient who had been referred to physiotherapy multiple times but not achieved resolution.

Results

Findings from the studies suggested that repeated re-referral of patients into musculoskeletal outpatient physiotherapy are attributable to two sources; expected re-referrals from degenerative conditions, and 'problematic' re-referrals of 'passive' patients who have developed dependency through low self-efficacy, and often present with generalised pain. These are characterised by comorbidity and extended treatments, and yet are re-referred a short time after discharge.

GPs consider there to be existing alternatives to re-referring, whilst physiotherapists feel the benefits of these are difficult to replicate after discharge. Citing a lack of training opportunities or

resources, physiotherapists find it difficult to apply guidelines or engage these patients with active management programmes, due to 'yellow flags' and psychological barriers associated with their condition. They advocate supplying an adjunct to physiotherapy, in the form of CBT from a registered psychologist. Coupled with a more efficient record system, whereby re-referral can be identified, and the 'problem' re-referrals addressed as they occur, provision of the education and advice necessary can assist these patients to achieve the self-efficacy they claim to be pursuing. In turn, this can prevent ongoing chronicity of their pain, and associated repeated re-referral.

Conclusions and Implications

There is evidence that repeated re-referral does occur, with a portion of those repeatedly re-referred not considered problematic, but others causing concern to therapists. Loss of self-efficacy, and resulting yellow flags and psychosocial barriers, with administrative delays, contribute to the inability of physiotherapists to engage sufferers of generalised pain in treatment. The impact upon the patient is that resolution therefore is difficult, and chronicity develops. This occurrence can be overlooked in the administrative data or electronic record systems, and the use of these to allow tracking of such occurrences is warranted. Adjuncts to physiotherapy, which the literature suggests may address these psychosocial factors, are advocated by physiotherapists to facilitate the management and self-management of chronic pain sufferers, prevent re-referral, and achieve the outcome the patient desires.

Abbreviations:

ACL	Anterior Cruciate Ligament
AMED	Allied and Complementary Medicine Database
CBT	Cognitive Behavioural Therapy
CCM	Chronic Care Model
CCG	Clinical Commissioning Group
CHaRT	Centre for Health and Rehabilitation Technologies
CIS	Clinical Information Systems
COPD	Chronic Obstructive Pulmonary Disease
CRPS	Chronic Regional Pain Syndrome
CLBP	Chronic Low Back Pain
DK	Dr Daniel Kerr
DNA	Did not attend
DOB	Date of Birth
DT	Daniel Topley
FG	Focus group
FMS	Fibromyalgia Syndrome
GHS	General Household Survey
GP	General Practitioner
HEP	Home Exercise Programme
HPC	History of Presenting Condition
HSC	Health & Social Care

HSCT	Health & Social Care Trust
HSCNI	Health & Social Care Northern Ireland
ICATS	Integrated Clinical Assessment and Treatment Services
ICT	Information & Computer Technology
IW	Dr Iseult Wilson
LC	Local Collaborator
LCID	Local Community Information Database
MDT	Multidisciplinary Team
MeSH	Medical Subject Headings
MOI	Means of Injury
MRI	Magnetic Resonance Imaging
MSk	Musculoskeletal
NHS	National Health Service
NHSCT	Northern Health & Social Care Trust
OPD	Outpatient Department
OREC	Office of Research Ethics Committees
ORECNI	Office of Research Ethics Committees Northern Ireland
ORIF	Open Reduction Internal Fixation
PI	Principle Investigator
PMH	Past Medical History
QRCA	Qualitative Research Consultants Association
R&D	Research and Development

RTA	Road Traffic Accident
SAD	Subacromial Decompression
SD	Standard deviation
SOP	Standard Operating Procedure
SPSS	Software Package for Social Sciences
THR	Total Hip Replacement
TKR	Total Knee Replacement
UID	Unique Identifier
UK	United Kingdom
US	United States
UU-REC	Ulster University Research Ethics Committee

Notes on Access to Contents

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Daniel Topley

Chapter 1. Introduction

1.1 Musculoskeletal pain

Musculoskeletal pain affects many people across Northern Ireland, the UK and Europe. The Health Survey for England in 2001 reports that 3 million adults in the UK have moderate to severe disability because of musculoskeletal disorders (Parson et al., 2011). Breivik et al., (2006), state that across Europe 19% of the population are affected. In the 'big 5' EU countries, (UK, France, Spain, Germany and Italy), it is suggested that the experience of severe to moderate daily pain eclipses the adverse impact of socio-demographic characteristics and major health risk factors, even including morbid obesity or age 60 years or more (Langley et al. 2010). The same study suggests that severe daily pain has the greatest negative impact of any factor on all dimensions of health-related quality of life (HRQoL).

Alongside individual burdens, the healthcare service is significantly affected by the prevalence of musculoskeletal pain or injury. Interrogation of one regional, and three national UK databases of general practice consultation records, show musculoskeletal conditions account for over 12% of all general practitioner (GP) consultations (Jordan et al., 2007). This figure only describes cases where primary care services are sought; the 2007 General Household Survey (GHS) recorded that 16.3% of women and 12.2% men (14.3% adults) reported a chronic musculoskeletal condition. This is a wider survey of all households, and as such incorporates those who may not necessarily have sought primary care input. It indicates, by the larger percentage quoted, that there is an additional number not accessing primary care for their conditions.

The larger average of 14.3% in the adult population, versus 12% national average (adults plus children) quoted by Jordan et al., (2007), may also suggest that incidence of musculoskeletal pain rises with age; this seems corroborated by Parson et al., (2011), who stated as the elderly population has grown, numbers of people with musculoskeletal conditions has also risen. The Office for National Statistics, in their 2008-based National Population Projections, indicated that the UK population aged over 50 may grow by 32% by 2030. If so, prevalence of musculoskeletal conditions across the population may be expected to rise proportionately. The same projections indicate that musculoskeletal conditions also make up 7% of all reported disability among children aged 10–15 years, indicating that although an older population may feature more, the conditions affect a wide demographic nationwide. The incidence of chronic pain also is suggested to be much higher than previous generations (Harkness et al., 2005). In 1998, chronic back pain alone was estimated to cost approximately £1.6 billion, and since that time, may be estimated to have risen sharply (Maniadakis & Gray, 2000; Hong et al., 2013), though it is difficult to identify any specific follow-up to that study. Hong et al., (2013) also found that primary care for those with chronic low back pain (CLBP), for

example, costs over 3 times the annual amount of those without CLBP. Chronic musculoskeletal conditions then, place a significant burden upon the UK healthcare system and indeed are likely to continue to do so in the future.

1.2 NHS Physiotherapy provision

Within Northern Ireland, the NHS healthcare provision is divided into five Health and Social Care Trusts (HSCNI Online, Accessed 06/06/18). These sites vary in size and area coverage in accord with population distribution. The HSC Trust (HSCT) wherein this research has been undertaken, the Northern Health & Social care Trust (NHSCT), serves approximately 435,000 people and covers the counties of Antrim, Derry/Londonderry and Tyrone. This incorporates four council areas (Antrim and Newtownabbey District, Causeway Coast and Glens District, Mid and East Antrim District and Mid Ulster District) and is the largest Trust in Northern Ireland by geographical area. Taking the national average percentages as stated by Jordan et al., (2007), and the NHSCT coverages, it is possible that approximately 52,200 individuals within the Trust area experience musculoskeletal pain at any one time.

For those who will seek primary care support due to suffering from a chronic musculoskeletal condition, the GP may consider referring the patient to physiotherapy services (Feine et al., 1997). Provision of outpatient physiotherapy is incorporated into these Trusts and takes place at multiple sites within each Trust, including the NHSCT. Physiotherapy outpatient departments are located across the majority of the nine hospital sites within the NHSCT (HSCNI Online, Accessed 06/06/18).

Physiotherapy services provide rehabilitation and injury treatment, with one cross-sectional study within an aged population identifying the main content and diagnoses of physician referrals to physiotherapy being: spinal complaints (20%), joint replacements (10.8%), and fracture management (10%). Other referrals include stroke rehabilitation (8.5%), cardiopulmonary rehabilitation (6.1%), and 5.6% were rotator cuff injuries (Miller et al., 2005). These describe a musculoskeletal outpatient episode of care (i.e. a period, usually several weeks, over which a patient is receiving physiotherapy care following a referral), as opposed to inpatient care, where the physiotherapy provision may be alongside other services. During this period of research in the NHSCT, patients did not self-refer, i.e. they were referred into these services usually by their local general practitioner (GP), or consultant.

1.3 Defining Re-referrals

The definition of a “re-referral”, or “repeat re-referral” used for the purposes of this study, is simply a patient who has already been referred into, treated during, and discharged from an outpatient physiotherapy episode of care, but who then receives further subsequent referrals into the same physiotherapy service.

There is no definitive published data on rates of return to physiotherapy for patients with previous episodes of care. That is, whilst literature may exist regarding initial referral rates of certain conditions, there is no published record available outlining at the same time how long each patient may be expected to remain in an ‘episode of care’ in Northern Ireland before discharge, whether this results in remediation of the musculoskeletal condition or not, and specifically, a published record of whether the patient receives a further referral, if this remediation/resolution is not the case. As physiotherapy utilises a patient-centred approach (Mead & Bower, 2000), with a focus on ensuring as priorities the values, needs and desires of patients, any occurrence that is perceived to detract from this will be of note to the therapists – including such incidence of repeat re-referrals, which may denote for example a lack of resolution from previous treatments or episodes.

In discussion with physiotherapists within the NHSCT, the issue of repeated re-referral into physiotherapy was raised. Anecdotal evidence suggested that physiotherapists saw familiar patients returning to outpatient departments for the same or similar issues. These anecdotal reports suggested that, for whatever reason, some patients who are discharged at the end of an episode of care, are referred again to physiotherapy within a short period, and this will then happen again several times in succession over several months.

1.4 Exceptional report(s)

Within the NHSCT, the perception of re-referral as described above, occurs anecdotally. When confronted with this anecdotal account of the pattern of re-referral, it was necessary to verify the accuracy of this statement, in terms of whether the perceived pattern existed, before designing or commencing the research. To do this, statistical corroboration was sought. The database used by the NHSCT to record patient episodes of care, and details thereof, is the Local Community Information Database (LCID). A facility within this database, known as an exceptional report, allows an authorised member of Trust staff to submit a statistical request to the LCID system administration to gain specific statistical data. The team lead (research team’s clinical contact) within the NHSCT, fulfilling the role of an authorised member of staff in this case, submitted an exceptional report to obtain

numbers of NHSCT patients with multiple episodes of care within three years – in this case, the years 2011 to 2014.

The exceptional report revealed that over those three years, in the NHSCT there were approximately 90,000 referrals made to outpatient physiotherapy. Over 30,000 (30,284) of those were attributed to just 13,274 patients, suggesting that the mean was about 2.3 referrals per patient. These figures included all cases of re-referral, indicating that there was a significant proportion of the population within the NHSCT being re-referred multiple times.

1.5 Accounting for Re-referrals

The exceptional reports do not allow for greater detail than the numbers stated above. It was therefore not possible to ascertain the exact patient demographic and characteristics receiving these re-referrals, the diagnoses in question, and/or the status at presentation and/or discharge. While the evidence from the exceptional report indicated that research into this phenomenon is justified on the basis that there was a population experiencing re-referral, attempts to account for these numbers were not based upon an informed foundation of evidence into patterns of re-referral, time periods and diagnoses involved. Some initiatives such as the Back2Health service used by Herefordshire Clinical Commissioning Group (CCG), a pathway for back pain, reserve the right to limit the number of re-referrals into the service to once in 12 months (Back2 Health, Musculoskeletal Service for Back and Neck Pain, Herefordshire CCG, 2013). No published rationale behind this policy statement has been found yet may indicate a similar perception of a re-referral issue.

Chronic degenerative conditions such as rheumatoid arthritis and osteoarthritis have high prevalence in the UK and US (Jordan, et al., 2007; Miller, et al., 2005), and care for these patients may be focussed towards long-term management. This may eventually require a return to physiotherapy and can conceivably contribute to the picture of repeated re-referrals. However, Miller et al., (2005) found that even in a geriatric population, degenerative joint diseases made up only 4.4% of referrals. It was suggested that these incidences by themselves may not explain repeated referrals of the same patient. That is, as these degenerative conditions are common and associated with exacerbations, patients' reappearance ought not necessarily to be a surprise to outpatient physiotherapists. Anecdotally, conditions/diagnoses suspected as being major causes of repeated re-referrals, include chronic pain conditions that have not the same recognised pathways as these more common complaints, or whose presentations vary but which are still referable to physiotherapy. There is, it is suggested anecdotally, not a defined pathology and some of the

conditions found in this group may be diagnosed as Fibromyalgia (FMS), or 'chronic regional pain syndrome' (CRPS); being distinct conditions but at times misused in the diagnosis of chronic pain originating from other causes (Fitzcharles & Boulos, 2002). Multi-site pain is indeed often thought to be more common than single-site pain (Carnes et al., 2007), therefore it is possible that patterns such as this may be involved in re-referral rates.

1.6 Research Rationale

The incidence of chronic pain, with the associated burden placed upon the NHS physiotherapy services, is high and looks likely to rise. There are indications that a segment of the patient population experiences repeated re-referral, but with little knowledge to date surrounding the occurrence or the cause of this phenomenon. The extent of these repeated referrals, alongside the concerns raised for patient care, merited an investigation and explanation of the occurrence.

However, it was acknowledged that such a large quantity of referrals could not be investigated on a case-by-case basis. A second exceptional report was sought, with the purpose of determining the number of patients referred three, or more, times over the same period. It was felt that due to the number quoted in the first exceptional report, this would be more representative of a population who were experiencing re-referral to a problematic extent and would make possible an in-depth investigation of the occurrence on a referral-by-referral basis. The second exceptional report disclosed 342 patients who experienced three, or more, separate referrals into musculoskeletal outpatient physiotherapy over the period defined. In total, these patients accounted for 1112 referrals between them. Whilst this was a significant reduction in sample population, it highlighted the likelihood that there was a small but defined number of patients who were experiencing repeated re-referral. This more clearly defined the population on which this research would focus.

In view of the prevalence of chronic musculoskeletal pain conditions, the role physiotherapy has in managing patients with these musculoskeletal problems, and the possibility of similar patterns being perceived in other Trust areas, it was judged of interest to the healthcare community to see whether reports of repeated re-referral for a small proportion of the population were well-founded and to explain such patterns should they exist. Thus, it was proposed to carry out a preliminary investigation to describe the picture of repeated re-referral of patients from GPs to musculoskeletal outpatient physiotherapy, and to account for this phenomenon if possible.

1.7 Research Aims

- To investigate the veracity of anecdotal beliefs surrounding the occurrence of re-referral
- To establish a reasoned methodology and standard operating procedure (SOP) for investigating re-referral within the secondary care setting
- To build a picture of the re-referral occurrence in musculoskeletal physiotherapy outpatient departments by identifying rates of re-referrals and defining characteristics of these patients
- To better understand this picture, by investigating the experiences and perspectives of all interested parties or stakeholders in the referral process, including patients, physiotherapists, and referring GPs

1.8 Research Objectives

The aims were accomplished by means of:

- A review of the current knowledge on re-referral into secondary care, including musculoskeletal physiotherapy outpatient departments
- Quantitative data collection from the existing musculoskeletal physiotherapy outpatient department's patient database used within the Trust
- A focus group study with musculoskeletal physiotherapists working within Trust outpatient departments who have opportunity to observe re-referral
- A focus group study with patients who have been referred multiple times into musculoskeletal physiotherapy outpatient departments for treatment of pain
- A semi-structured questionnaire survey investigating decision-making process of GPs who refer patients into musculoskeletal physiotherapy outpatient departments

Chapter 2. Repeated re-referral; a systematic search and narrative review investigating the decision to refer

2.1 Introduction

The issue of repeated re-referrals of patients suffering from chronic conditions was raised by physiotherapists in outpatient departments. The therapists did not expect all repeat referrals could be accounted for by the periodic return of patients with long-term degenerative conditions, such as osteoarthritis, who require management due to recurring exacerbations. Their experience was that familiar patients presented with vague diagnoses of irregular, unspecified chronic pain.

The explanation was offered that patients' presentation as described may have indicated a lack of a suitable – or suitably formatted – pathway, leading to patients' conditions either being incorrectly triaged or being unclear as to the best practice for treatment. If this were demonstrated to be the case, the therapists believed that this may indicate an unmet need for these patients. Computerised statistical outputs ('exceptional reports') from the NHSCT patient database confirmed the extent of the occurrence, and defined a population experiencing re-referrals in a short three-year time-period, which amounted to approximately 2.68% of the Trust's coverage over that period.

The high number of re-referrals required investigation to determine the extent of current knowledge or investigation behind the occurrence of repeated referral under the conditions described, along with any solutions that may have been known or taken. Also, explanations for the decision to refer again, and predictive or influencing factors, including all parties involved in the decision, were of interest. To investigate the current understanding of this phenomenon, and the extent to which it had been investigated, a systematic search of some of the leading healthcare databases was formulated.

2.2 Aim

The aims of this systematic search were

- 1) to identify current knowledge on the issue of repeated re-referral as described (chapter 1.3)
- 2) to understand the decision-making process involved in referring a patient to a secondary care pathway or site
- 3) to understand means of addressing re-referral patterns, if available

2.3 Literature Searches

2.3.1 Background and aims of search

The search was designed to gather as much relevant information as possible around (i) health providers' decision-making regarding referrals (particularly re-referrals), and (ii) the nature of the referral patterns.

To facilitate as comprehensive a search as possible, the search was run utilising keywords, and then with both indexing and MeSH headings. Duplicates were removed and collated for the final data analysis.

2.3.2 Inclusion/exclusion criteria

The scope was kept as wide as possible. There were no temporal restrictions, and all study types were included, including grey literature. Both full text papers and structured abstracts were considered, if relevant. Any study not published in the English language was excluded as translation services were not available.

2.3.3 Databases

The databases searched were:

- Cochrane
- OvidSP databases – AMED, Embase, Medline
- PubMed

2.3.4 Terms

Search terms and Boolean operators were both used.

Search terms used were Referral*, Re-referral*, Physiotherapy, Physiotherapist*, Physical therapist*, Physical therapy, and Musculoskeletal.

Boolean operators used were "Referral AND physiotherapy", "Referral AND physiotherapist", "Referral AND physical therapist", "Referral AND physical therapy", "Referral AND Physiotherapy AND musculoskeletal Referral AND Physiotherapist AND musculoskeletal".

Search terms and Boolean operators were kept as similar as each database allowed. The term 're-referral' was used as a keyword though not used in Boolean phrases since, in the trial search, any study with 're-referral' in the title also arose when 'referral' was searched.

From the Cochrane database, 10 full text papers were kept, along with 2 abstracts. The same search was carried out using the PubMed database, which returned 13 studies. Again, the OvidSP databases were searched, using the same terms and Booleans. There were 13 studies kept based upon titles.

Despite the search's scope, scarcity of relevant results by keyword indicated either that relevant papers were overlooked, or that there was a marked lack of published literature available. To determine which of the two was true and increase specificity, indexing and MeSH terms were used.

By combining the total results of the two searches the widest possible result would be achieved.

Indexing required simple terms that would allow discovery of material relevant to the referral process - and re-referral in particular - in both musculoskeletal outpatient physiotherapy and across wider secondary care.

Terms were chosen for ease of indexing:

- Referral
- Re-referral
- Physiotherapy
- Physiotherapist
- Physical therapist*
- Musculoskeletal
- MSk

These were designed to find more relevant results due to the ease by which they can be indexed.

Indexing is generally more accurate and reduces numbers more effectively than by adding qualifying terms into an AND concept.

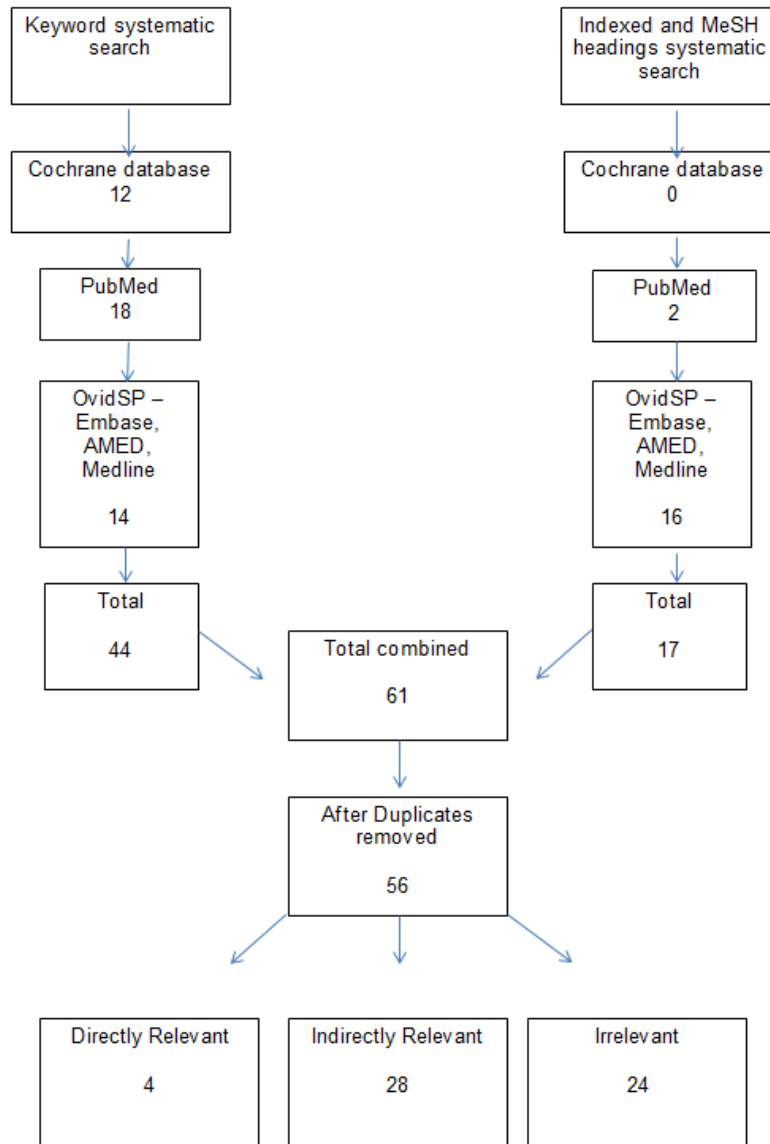
A sample search to test the accuracy of the indexing brought up 172 articles on the Medline Database via OvidSP. No filter dates were applied.

Identical inclusion/exclusion criteria were applied, and the same databases searched using their individual indexing and MeSH formatting. When the second search was completed, the total studies from each search were collated, and any duplicates of studies removed. Both searches were combined, giving a total number of studies by title, and before removal of duplicates, of 61 studies.

2.4 Findings

2.4.1 Number of studies

Studies retained by title from each search were collated, and duplicates removed, leaving a total of 56 studies retained. When categorisation was completed by abstract, 24 of these were deemed not relevant to the study question due to the content being evidently unrelated from a cursory reading, and 32 were deemed in some way relevant, because from reading the abstract, the content dealt with some aspect of the referral process. The latter 32 were categorised further. The figure below describes the process.



2.5 Categorisation

Studies were not screened by quality due to the low numbers of relevant papers. Categorisation of results was first by relevance, as the wide range of study types made meaningful synthesis difficult. The stated aims of the search (to ascertain current knowledge behind the occurrence of repeated referral, with any solutions offered, explanations and predictive factors for the decision to refer again) were used to identify the relevance of each study.

Three categories described relevance to the initial study aims. Firstly, those that were found to have no relevance to the study whatsoever – the 24 studies in this category had no further use and were discarded. The 32 retained studies were categorised into a) 4 studies specifically dealing with re-referral of individuals into the same secondary care pathway or service, and b) 28 studies

investigating initial referral decisions – it was considered possible that the decision-making processes for initial referral to secondary care, and features of these referrals, may inform the study. The two groups were described as directly or indirectly relevant (Appendix A).

2.6 Analysis

The categorisation required two separate levels of analysis – the body of indirectly relevant literature, being of widely varying quality and study types, was difficult to review using systematic analysis, so these papers are presented in a narrative review.

There were no studies found relevant to repeated re-referral to musculoskeletal outpatient physiotherapy. This lack meant that to inform further investigation, it was considered most useful to note the methodology of the directly relevant studies which investigated or noted re-referral to their respective services. This learning could be utilised in further investigation of re-referral within outpatient physiotherapy.

Whilst studies investigated risk factors for re-referral to services for their respective fields, it was not possible to extrapolate their conclusions and directly translate these into a musculoskeletal physiotherapy setting. For example, Connell et al, (2007) investigated re-referral into child protective services, with the strongest predictor being family poverty. To assume the application to GP referral into musculoskeletal physiotherapy would be tenuous without comparable and complementary research investigating poverty and musculoskeletal services. However, these studies did offer insight into methodology (i.e. how the authors investigated re-referral and decision-making) and are discussed in that context. Insights into referral and re-referral, and the risk factors identified, are noted.

2.7 Results

2.7.1 Indirectly relevant (the decision-making process)

Across study types, three themes arose:

- 1) Quality of the secondary-primary care interface, in terms of appropriate referrals and effects of changes/initiatives upon quality
- 2) Written content of referrals, both in detail of diagnoses, and ‘prescriptive’ nature of referrals

3) Predictive/influential factors for referral; including both GP- and patient-related factors.

2.7.1.1 Sample population sizes:

The three systematic reviews looking at the quality of primary/secondary care interface and effect of interventions to improve referral had differing sample sizes, Faulkner et al (2003) (n = 44) being almost twice the size of that of Hussenbux et al (2014) (n = 23). It was a characteristic of half the retrospective reviews that looked at content, that sample sizes were approximately 2100. There were two extremes, with over 30,000 patients in Fritz et al., (2012), whereas Peters et al., (1994) only included 154, and it was difficult to ascertain the total number of patients in Wong et al., (1994).

Freburger et al 2003 undertook a cross-sectional analysis of National Ambulatory Medical Care Survey data, specifically looking at visits to primary care physicians (n = 4911) or orthopaedic surgeons (n = 4201) for musculoskeletal conditions.

Studies using qualitative methods were divided into two camps; three of which used relatively small sample sizes, ranging from 9 through to 35. In contrast, Jorgenson & Olesen 2008, and Miller et al 2005, included 118 and 260 therapists/practitioners respectively. These questionnaires' answers contained details of a larger number of patients, 38,231 and 839 respectively.

2.7.1.2 Aims

Within the 3 systematic reviews, researchers predominantly investigated the quality of the secondary-primary care interface; this included improvements to the process and initiatives in place.

Six of the 12 retrospective reviews focussed upon the actual content of the referrals, i.e. diagnosis, recommendations, length and detail of the referred patient's presenting condition (HPC). Four others covered differences between groups of referrers, either different professions within one setting or characteristics of GPs that explain differences in referral rates and patterns. 1 study looked at the impact of the introduction of a new clinic expansion upon referral patterns. The remaining study looked at issues around inappropriate referral to MSk physiotherapy for somatisation of mental illness.

Two editorials were found in the systematic search; both focussed on appropriate referrals and appropriate provision of care. One cross-sectional analysis was included; this investigated predictive factors for musculoskeletal referral from GPs. Five studies incorporating qualitative methods, either

in part or primarily, were identified. One of these, only available in abstract, involved the referrer and their reasons for referring, in a military setting; another two studies, Miller et al, (2005), and Jorgensen & Olesen, (2008), incorporated qualitative methods as part of two different mixed-method approaches. The former used a questionnaire as a way of obtaining statistical data on referral rates of specific conditions to geriatric physiotherapy, then undergoing a descriptive analysis of the data as the body of the work, while the latter study obtained rates from the relevant county's health insurance register and used questionnaires to identify referring GP characteristics.

Characteristics could be described as those things which vary between GPs professionally, for example size of population, relationship with patients, contact with other professionals, size and location of practice, rank (if applicable) or level/scope of training.

2.7.1.3 Discussion:

Not all studies identified by title and abstract led to further relevant information on the process of re-referral. The conclusions or content of those studies or article categorised as not relevant, were not considered to be an indication of either the success of that study in answering its own research question, nor of its intrinsic quality in methodology or reporting. Studies were tabulated by the primary topic of investigation; in the narrative discussion, it may be evidenced that there is overlap into another of the three areas amongst either the aims, or conclusions of studies.

Three systematic reviews, Akbari et al., (2008), Faulkner et al., (2003), and Hussenbux et al., (2014), investigated characteristics of the secondary-primary care interface, in referrals and effects of various changes/initiatives upon that quality.

Akbari et al., (2008) concluded that the availability of referral sheets that had some sort of structure, coupled with increased relevant education at a local level improved appropriateness of referrals. Faulkner et al (2003), the earliest of these three reviews, noted a lack of evidence surrounding the issue, though predicted it would increase slowly and had begun to do so. Hussenbux et al., (2014), in the most recent review, investigated referral outcomes and the waiting times involved, and concluded that the MSk CATS service in place across NHS Trusts consistently improved quality of referral to secondary care and thus directly affected patient outcomes. Interestingly, both Akbari et al., (2008) and Hussenbux et al., (2014) described agreement upon appropriate referrals after a second opinion from another professional, to be approximately 70%.

Rose et al (1998), concluded, interestingly, that 45% of patients with somatization of mental problems were referred to physiotherapy. They cited O'Dowd, (1988), and Stanley, et al (1999), in suggesting that 'heart-sink' amongst GPs at patients' persistence can result in automatic referral to

secondary care (including physiotherapy) and in turn, if this was not in fact the most suitable pathway for their respective conditions, this could adversely affect the patients' recovery or condition management. It would be of considerable interest to the therapist population to investigate the patient-GP relationship in this regard, as this ('heart-sink') was also suggested anecdotally as a possible cause for repeated re-referral within the NHSCT that led to this review.

East et al (2013) noted a high percentage of 'false positives' in a referral system for orthopaedic services. One of the conclusions reached was that there was a marked need for guidelines to facilitate the referral decision and reduce false positives. A common finding amongst the studies was indeed a resource to refer to, available to the party making the referral to secondary care. Having said this, Clemence & Seamark (2003) concluded that these written guidelines or resources, in whatever form they took, were of less value than direct contact and rapport between referring practitioners and physiotherapists.

2.7.1.4 Referral Content

Many studies investigated actual content of referrals, including patients/conditions, referral detail, and 'prescriptiveness' in terms of diagnosis and/or treatment. Hendricks et al., (2009) carried out a 7-month observational study investigating outcomes of patients and referral patterns after a once-off physiotherapy consultation before referral. 224 of 354 (63%) patients were referred following the consultation, implying all 354 were initially judged suitable for referral and may have been referred had not the consultation occurred – a referral increase, possibly inappropriately, of 58%. Whilst the consultation was used for study purposes and was not normal practice, it implied that there can be disagreement in a significant number of referrals as to the suitability of physiotherapy for a particular patient. Clarification of underlying causes for such a variance whether in perspectives on the condition or expectations of the outcome of physiotherapy, would be intriguing.

Both Davenport et al., (2005), and Clawson et al., (1994) noted that physiotherapists were often in the practice of independently diagnosing and treating patients. Other early studies note similar patterns beginning to characterise referrals, with Wong et al., (1994), describing a marked decrease in referrals containing a diagnosis from the start to the end of the 1980s. There were also reduced requests for specific physiotherapy modalities and a significant increase in more generalised requests and aims. These referrals were stated specifically as initial referrals to a service, which might perhaps be expected to be more detailed. This study was observational in design, without an extended attempt to explain the findings. Wong et al., (1994), acknowledged several possible

reasons for their findings, including that they potentially represented a conscious recognition of physiotherapist autonomy, and/or a lack of familiarity with changing modalities, treatments, or scope of practice in terms of musculoskeletal conditions. Further research may offer additional insight.

2.7.1.5 Influential factors to referral

Several studies, of which Fritz et al (2012), Ehrmann-Feldmann et al (1996) were examples, noted that patient outcomes were more successful with an early referral to physiotherapy. Ehrmann-Feldmann et al 1996, however, suggested that the promptness of a referral and its content was potentially influenced by patient characteristics. This was in the context of a population of workers referred for back pain. Whilst these findings may not directly influence the current study, it gives credence to the belief that it is not only the referrer that influences the referral decision, but that the patient influences the decision.

Robert & Stevens (1997) maintain that direct access to physiotherapy from the GP has better outcomes for the patient, and that greater efficiency in cost and resources are achieved for the service. Equally, O’Cathain et al., (1995), and Peters et al., (1994), noted that the availability of, or familiarity with, a local physiotherapist would appear to correlate with referral numbers. In both studies, referral appeared less likely if the physiotherapist was not in some way connected clinically to the referrer - O’Cathain et al., (1995) finding that a GP-based service increases the use of physiotherapy, and Peters et al., (1994) finding that a musculoskeletal practice in inner London, staffed by a GP trained in osteopathy, had a relatively low referral rate to other musculoskeletal specialists, outside that GP practice. Whether this is transferrable to describe current practice is unclear and merits further research. It may be the case that such a policy was deemed inefficient due to the training available, and in this case the training, or individual competencies of GPs may strongly influence referral to secondary care. It is also possible that this is not current practice across the GP population, and indeed that it is unclear that the proportion of total referring GPs have this or equivalent training, or whether occasions as this would be large enough to significantly influence the referral picture nationally in the UK or even within a Trust.

Gohar et al., (2010) concluded that in some settings, especially if musculoskeletal issues arose as secondary problems to serious medical conditions, there was a need for greater awareness amongst GPs regarding benefits of early physiotherapy integration into treatment. The outpatient setting that the current study has as its background may be different from that of Gohar et al., (2010), which

dealt with children with acute lymphoblastic leukaemia, yet may simply suggest that physiotherapy for musculoskeletal conditions as secondary problems may be discounted or simply overlooked in some cases, tying in with previously mentioned studies that may imply a need for continual awareness by referrers such as GPs, of the relevance of some secondary care options such as physiotherapy.

Freburger et al., (2003) suggested that diagnosis may not necessarily be the determinant of whether a patient is referred, or indeed the content of that referral. In their cross-sectional analysis of orthopaedic surgeons and primary care physicians to physiotherapy, diagnosis, severity and supply of physiotherapy were all controlled for, and the source of referral was still found to be a strong predictor. Whether this was the case for different individuals occupying the same role, e.g. between orthopaedic surgeons, was not investigated, so it remains to be answered whether it is the referrer characteristics themselves, or the medical rank/profession.

Ball et al., (2006), concluded that amongst professions, in this case the emergency department physiotherapist, nurses and doctors, the level of consensus in referral varied with diagnosis. For example, fractures or dislocations were treated similarly, but soft tissue injuries varied in treatment and referral to physiotherapy. Griffiths et al., (2013) also noted that in one audit there was diagnostic agreement between emergency department staff and acute physiotherapy staff in fewer than half of patients referred to acute physiotherapy. Jorgenson & Olesen, (2008), however, conclude that characteristics alone of the GP cannot explain significant variation from other professionals. There appears to be slight disagreement upon the most important factor in determining whether a patient is referred.

Taking the results of these studies together, it appears that ultimately, diagnosis is not the sole indicator of whether a patient will be referred. There are factors that affect this, including the characteristics of the referrer. Further investigation into this subject would be informative, including whether this holds true for repeat referrals, based upon outcomes of previous referrals. Indeed, Brooks et al (2012) found it was possible to identify trends across referring professions, where there were significantly better outcomes for their referred patients versus other referral sources.

2.7.2 Directly relevant (the methods of investigating re-referral)

It was evident from the results of the systematic search that the studies that addressed re-referral, were generally not in an area that was comparable directly with the background setting to this study, which is that of musculoskeletal outpatient physiotherapy.

The 4 studies, Connell et al., (2007), Thompson et al., (2009), et al., (2012), and Lamb et al., (2013), were in the areas of re-referral to child protection services (two studies), a musculoskeletal hub and a colposcopy clinic, respectively. It is difficult to draw comparisons between the conclusions of Connell et al., (2007), and Thompson et al., (2009) on predictive factors for re-referral to child protection services, and the other studies allow little insight on their own. Lamb et al., (2013) found that those who persisted in lifestyle choices that predisposed them to the condition they were referred for, were more than twice as likely to be re-referred. Although the principle may be accepted as transferable, this statistic is difficult to transfer to physiologically different conditions common to the current setting. Freeman et al., (2012), in an audit of a musculoskeletal referral hub in Oxford, England, found that the hub reduced inappropriate referrals, but increased re-referral of appropriate conditions (from 5 out of 150, to 9 out of the same number); again, the relevance of these findings to the current study is inconclusive.

However, for further investigation of the issue forming the background to this study, the methodologies employed by each team was noted. Freeman et al., (2012) used data collection forms to peruse treatment registers, with all other information coming from patient records, and data analysis was carried out using SPSS software. Lamb et al., (2013) gave little detail into the precise steps they used, stating only that outcomes and diagnoses were recorded and evaluated. Connell et al., (2007), and Thompson et al., (2009) used a longitudinal dataset with Cox proportional hazards model, and a Cox regression analysis with time-varying covariates respectively. Successful use of these methodologies was then considered when planning an investigation into repeated referral.

2.8 Conclusions

The initial aim behind the carrying out of this review was to investigate the current knowledge surrounding the perception that certain patients are repeatedly referred into outpatient physiotherapy, potentially inappropriately. It was intended to investigate the accuracy of this belief, and the predominance of both the perception and the practice itself, and thirdly, to understand the explanations for the decision to refer.

The systematic search was unable to uncover adequate evidence to answer these questions. There is a marked lack of available evidence upon the issue of patients repeated being referred into secondary care services for the same conditions/diagnoses, and of the extremely few studies that investigate the issue, none do so in the field of musculoskeletal outpatient physiotherapy.

It was evident from the literature that the decision to refer has several impacting factors. These include characteristics of the GP - in terms of training and education along with awareness of other professionals' scope of practice - the type of GP Practice, the patient's condition and characteristics, including persistence and expectations of outcome. There is a disagreement upon the level of influence each have, and which affects the decision the greatest.

There is a level of consensus that some form of resource that the GP or other referrer can consult, either in a structured referral tool, or a physiotherapist opinion, greatly increases education and thus the appropriateness of referrals to physiotherapy. An isolated study suggested that there was precedent for a GP who had musculoskeletal training to be reluctant to refer outside the practice. Indeed, clinical rank or profession seemed to influence to some degree the referral decision.

Apart from specific diagnoses, the classification of injury, for example, fracture or soft tissue injury seemed to be a strong predictor of referral amongst certain referrer populations. An apparent trend was that, in addition to there being disagreement upon the suitability of referrals to physiotherapy between the referrers and the physiotherapists themselves, with levels of agreement ranging from 50%, through 63%, to 70% in two reviews, there also was disagreement upon the actual diagnosis in many cases. There seems also to be a pattern arising, of reduction in detail for the actual referral content, particularly in diagnosis and treatment prescription, and a focus upon simple goals. This is true even of initial referrals to physiotherapy, seeming to recognise the physiotherapist's autonomy in the diagnosis of the referred patient.

2.9 Implications

It was believed that it would be of interest to determine the influence of each of those factors that affected initial referral, upon the second or repeated referral into secondary care, in this case musculoskeletal outpatient physiotherapy, and patient outcome from previous referrals as an influencing factor to referring again. It would also be of interest to investigate further the relationship between the patient and GP in making the referral decision, and the GP/physiotherapist relationship as a factor in influencing the type of referral deemed appropriate and the content of the referral.

Thus, the issue of re-referral in terms of epidemiology, perception of the occurrence, and effect upon patient outcome required further investigation. Based upon the methodology evidenced in the limited number of studies that investigated secondary care re-referral, the further investigation of

repeated referral in musculoskeletal physiotherapy could utilise data collection forms to peruse treatment episodes and patient records, or a longitudinal dataset if this was available.

2.10 Limitations

The study did not investigate various aspects of the issue of repeated referral, such as outcomes of the decision to re-refer, or costs involved in treating the re-referred patients. Primarily, this was because the study was designed to approach this issue from an investigative and descriptive angle, with the first step involving clarification of whether there was any literature available on the topic. The resultant discovery of the lack of material meant that this question was not possible to answer at that point. Had this lack been fully anticipated, the search could have taken the form of a scoping review, the aims being consistent with those identified by Arksey & O'Malley, (2005) and Tricco, et al., (2016). A follow-up, more specific systematic review may have then followed.

The use of keywords and search terms such as 'recurrence' or 'recurrent' were not used, as a sample search showed results concerned primarily with the pathological processes of chronic conditions, rather than repeat referrals, which were the topic of the initial search. Opportunity for analysis via synthesis of similar study types was limited due to the marked lack in consistently high-quality evidence. It was unclear whether this was due to a lack of awareness surrounding the issue.

Considering the scope of the search, in terms of literature types and the use of a keyword search to widen the scope further, it was somewhat surprising that a greater number of audits were not identified. It is legitimate to expect that the latter processes have in mind the efficiency of both service cost and effectiveness, and had they featured more predominantly, it would have indicated that the possibility of such patients and/or conditions reappearing was at least investigated and that an outcome measure or tool was used to ensure that such occurrences were noted if they did arise. The qualification may be made that such outcome measures, though utilised are not necessarily published, however the featuring of some audits in the search results still raises the question why there were not more.

2.11 Summary

This systematic search and narrative review identified a significant gap in knowledge regarding re-referral into musculoskeletal outpatient physiotherapy, despite evidence confirming the occurrence, and the existence of a body of evidence relating to the initial referral decision and process.

In summary, several factors appeared as predictors to referral (including GP/patient relationship, GP/therapist relationship, education, training, diagnosis, and clinical settings), but with a lack of clarity and inconclusive evidence as to the relative importance of each. Referral detail appears to have diminished with time and increasingly the diagnosis of the patient is made by the physiotherapist alone. The appropriateness of certain referrals is disputed amongst therapists and professionals, with many patients being judged inappropriate upon presentation, despite several resources being identified as facilitating an appropriate referral when used. Often the diagnosis itself was disputed, and there were occasions when there seemed to be no diagnosis made, or recorded on the referral, and the physiotherapist took responsibility for the diagnosis upon presentation of the patient.

Considering the notable gap in the available literature, and issues arising around the characteristics of current referrals, it was concluded that research community firstly, and subsequently the medical and therapeutic professions would benefit from further investigation into repeated re-referrals.

Chapter 3: Theoretical frameworks; guiding a pragmatic mixed-methods investigation of repeated re-referrals

3.1 Mixed Methods

The research study utilised a mixed methods approach. The term “mixed methods”, generally, refers to the combining of qualitative and quantitative research in viewpoints, data collection and analysis, and inferences (Johnson, Onwuegbuzie & Turner, 2007; Happ, 2009). It has been further defined as research in which the investigator collects and analyses the data, integrates the findings, and draws inferences using *both qualitative and quantitative approaches or methods in a single study or program of inquiry*” (Tashakkori and Creswell, 2007, emphasis added).

As such, while there is more than one method of data collection, and by necessity of analysis, the findings of the two contribute to answering the same research question(s). This approach is frequently considered the “third methodological movement”, (Teddlie & Tashakkori, 2003).

Examples exist whereby an exploratory approach in an area where little is known can warrant using such mixed-methods, particularly “collection of extensive rich qualitative data... without which, data from standardized instruments would mean little” (Evans, et al., 2011). In the current exploratory study, a similar approach is taken, albeit less heavily biased towards one methodology, both quantitative and qualitative components providing equally valid insight into the research question, but both having less impact in isolation.

3.2 Pragmatic approach and theoretical frameworks

Evans et al (2011) cite Creswell (2007), describing a pragmatic approach to mixed methods as focussing on the problem in its social and historical context rather than on the method, and where multiple relevant forms of data collection are used to answer the research question. Essentially, the methods chosen are constrained by the setting of the research, either epistemologically or practically, potentially making strict adherence to theory difficult. This was the case in the design of the current study, where knowledge on the subject was limited, the setting of the issue raised has limited sample size and the logistics of data collection have certain limitations. In such a situation, pragmatics can take the lead (Greene, 2008). However, as Evans et al (2011) describes, a mixed-methods study can accommodate both scientific rigour and theory alongside such uncertainty.

The issue however, which Evans, et al (2011) sought to address, was the lack of guidelines for “navigating” such pragmatic mixed methods research (Greene, 2008; and Johnson & Onwuegbuzie, 2004). Evans et al (2011) explored the value of theoretical frameworks in accomplishing this, by their usage in designing and implementing mixed methods research studies. This included their relationship to a pragmatic approach, with an emphasis on usage in health sciences.

They found that benefits include facilitating the researcher to keep returning to the research question, an increased likelihood of a theory-based, credible result, and fostering transferability to further studies. It was emphasised that careful consideration must be taken to ensure the theory fits the data – i.e. that it permits comparisons of the data to its components, and thus offers an organizing framework for representing that data.

Therefore, whilst on pragmatic grounds alone the choice of methodology may be justifiable, it was nevertheless desirable that a suitable framework be selected for guidance in design, and for reference while implementing the study.

It is acknowledged that other approaches such as critical realism, were considered, but it was concluded that these relied upon ontological, epistemological and methodological premises (Lipscomb, 2008), or “*a priori*” truths, and therefore in a solely exploratory approach, where the applicability of some of these cannot be known in advance, a methodology and framework that begins with quantitative collection, interpreted by semi-structured qualitative work, is better suited. A pragmatic, mixed-methods approach can be later interpreted using principles of critical realism (Lipscomb, 2008), and indeed built upon further to aid coherence of the initial exploratory findings; however, in initial exploration of a phenomenon, the chosen approach is felt to be justified.

3.3 Relationship of mixed methods components

Bryman (2007) notes that in mixed-methods research, the relationship of each method to the other needs to be considered – including (but not limited to) which has priority, if any; whether the data will be gathered simultaneously or sequentially; and what is the function of integrating the methods. He also notes, in concluding the same study, that while researchers are to be encouraged to be clear in this regard, the actual outcomes of qualitative and quantitative methods alike (and therefore, the relation of these) are often, in practice, unanticipated.

With these requirements in mind, a theoretical framework that is relevant to the type of data being collected was essential, whereby the relationship of the two methodologies, and of the data gathered in each, could be seen. This framework would not necessarily predict the outcomes of the study but would organise and guide the design and implementation thereof.

3.4 The Chronic Care Model

The Chronic Care Model (CCM) is a well-established organizational framework for chronic care management and practice improvement. There is a significant evidence base to support the effectiveness of the model (Fiandt, 2006). This framework was considered when the issue of repeated referral was identified, considering the population presented as being at risk – those with chronic pain conditions who may be incorrectly managed under current practice.

The CCM was chosen as it outlines components viewed as necessary for managing chronic conditions effectively, and, if an improvement to practice is considered, these same components can be used as ‘organisational hooks upon which to hang a project’ (Evans et al., 2011; Sandelowski, 1999). Therefore, designing the research study around the concepts described within the CCM meant adherence to a framework specifically designed to reflect successful and efficient management of chronic conditions.

As discussed, these components allow an outline as to how the stages of the research study relate to one another, and a context whereby the data is interpreted. Being an exploratory study, it does not predict the outcome of the investigation.

3.5 The 6 CCM concepts

The CCM incorporates 6 components or ‘concepts’, namely organizational support, clinical information systems, delivery system design, decision support, self-management support, and community resources (figure 1 below, based upon that suggested by ImprovingChronicCare.org).

The model assumes that improvement in care requires incorporation of patient, provider, and system level interventions. The first four concepts address practice strategies, with the latter two being patient-centred. The necessity of approaching the investigation from these standpoints was acknowledged, as the presence of these six concepts results in a correctly managed chronic care pathway and evidences this in the patient outcomes.

The model states that either chronic disease management or practice improvement can be based on each of the concepts separately, or the model in its entirety. This PhD incorporated and evidenced four of the six concepts making up the chronic care model. It was envisaged that the study may aid in realisation of the fifth and give rise for further studies to directly address the sixth. The exploratory and novel nature of this study, within the time available, was inappropriate for directly

piloting or designing new resources, but will inform the need and/or direction of these, along with the methods of following studies designed to provide the resources.

The CCM has as its first concept '**organizational support**'. This addresses cultures of practice; the ideal culture being that where chronic illness management and practice improvement are key. As such, the design of the study began here, liaising and discussing with NHSCT staff and representatives regarding patterns and issues identified in that organisation. The rationale of the study took shape when the NHSCT identified their concern at patients who they felt were potentially not receiving the best possible care, thus experiencing repeated re-referral, and they welcomed an investigation into the same, with their collaboration.

The second concept is the correct incorporation of **Clinical Information Systems**. The CCM describes these as structured to organize patient, population, and provider data to describe the health of the population. It was evident that a faithful investigation into the care pathway and the concern over patterns raised within it would feature an interrogation of the relevant database. This communicates both the efficiency of the database itself in noting trends, but also, pertinently to our study, the statistical data and variables that describe the patients in question. Statistical facilities within the database would identify initial patterns of repeated re-referral, in doing so being the first of its kind for this organisation.

The third concept outlined is that of **delivery system design** – including composition and function of practice team and management of follow-up care. The aim is for satisfactory integration and function of the care team. Patients should see teams as a care delivery that *improves outcomes* (emphasis original) rather than in place of primary care (Safran, 2003).

With the study's purpose to explore the occurrence of repeated re-referral, it was appropriate to investigate the patients' perceptions of the care process, not in terms of physical resources, but rather awareness of the success of their referrals/episodes, and indeed of the alternatives or decision-making that took place between themselves and the members of the care team. In this case this would be the referrer from primary care (most likely a GP) and the care provider in the secondary care setting, a musculoskeletal physiotherapist (or more than one).

The fourth of the concepts outlined is **decision support**. This includes evidence base and guidelines, and integration of each into decisions made in practice. An exhaustive systematic search highlighted the current lack of evidence base. For example, there was no awareness of what demographic, diagnoses, or other characteristics were prevalent in those patients re-referred – other than anecdotal reporting of chronic pain symptoms. This is a hindrance to the referrer in primary care, in

making the decision to refer to a suitable pathway. It was the intention of the current study to fill this gap in the literature. Additionally, it was desirable to investigate the perceptions and knowledge of the care providers, considering such a poor evidence base, along with what other resources and/or processes informed decision-making by referrers. Therefore, the research team included both physiotherapists and of GPs in the qualitative stage of the study.

The fifth and penultimate concept is that of **self-management support**. It was a patient-centred ethos that this PhD would ultimately hope to promote. The research must ultimately have the patients' best interests in view, and concern for their care as rationale for investigation has been demonstrated. The ideal scenario for a patient with a chronic condition/s, short of resolution, is to be able to manage this themselves, with the aid of supporting resources.

Within this concept, the CCM cites five skills said to form the core of self-management (Lorig & Holman, 2003). These are particularly problem solving, decision making, resource utilization, the patient-provider relationship, and action taking. Appendix B describes the relevance of each of these to the current studies' outcomes.

The sixth and final concept within the CCM is **community resources**. This includes peer support, care coordination, and community-based interventions. The CCM identifies populations that benefit most from these resources – the current study allows a comparison of these with those experiencing repeat re-referrals. It is beyond the scope of this current PhD to design and put in place a pathway or resource, but the outcomes and key contribution of this research will be the informing of the requirements of such pathways and give rise to further studies on resource provision or utilization.

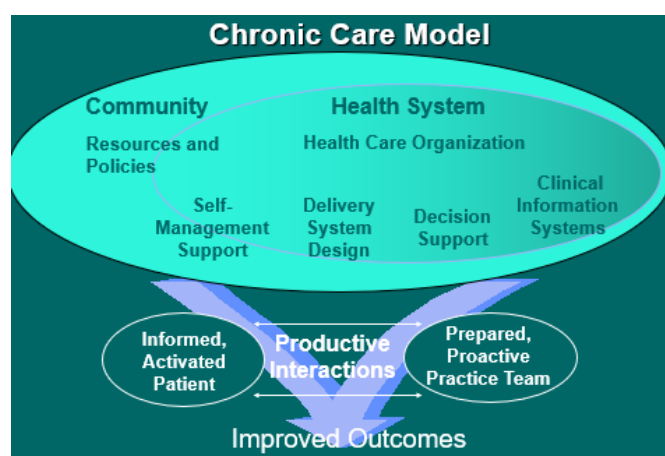


Figure 1. The CCM

3.6 Conclusion

In conclusion, the methodology chosen for this PhD was based upon both the concepts outlined by the CCM, and the methods described in the literature by studies which investigated repeat re-referrals in other settings. The study would utilise a sequential mixed-methods design, of a quantitative stage followed by a qualitative stage, both with equal parity, which incorporates the 4 CCM concepts of organizational support, clinical information systems, delivery system design, and decision support. Facilitation of self-management support and informing further studies to provide further community resources was the goal.

Chapter 4: LCID Database Perusal – A Standard Operating Procedure for investigating re-referral

4.1 Introduction

Having identified an anecdotal pattern, whereby therapists described patients being repeatedly referred to outpatient physiotherapy departments, corroboration was sought by the research team through statistical reports.

This pattern was investigated utilising the LCID database (Local Community Information Database) which had the utility known as an 'exceptional report' – the ability for an approved person to submit a query regarding the data held therein. The collaborating NHSCT Team Lead submitted an exceptional report, on behalf of the research team. Specifically, this was intended to disclose the number of patients in the NHSCT referred more than once, within a set time-frame.

This perceived occurrence was found to be accurate – in that 13,274 patients were found to be referred into outpatients more than once within a three-year window. These accounted for 30,284 referrals between them, out of 90,000 made in that period. The report could not elaborate in any more detail than this, and further expansion was desirable.

Within the confines of this doctoral research, the large sample size would have been impossible to investigate on a case-by-case basis. Therefore, a second exceptional report request was submitted to identify patients who were referred three or more times – more representative, it was believed, of a pattern of repeated referral that was potentially problematic. This second report showed that 342 patients were referred at least three times within the time-frame. These 342 patients being repeatedly re-referred corroborated part of the beliefs of the NHSCT physiotherapists. However, questions remained, including the characteristics of this population, what the referrals were for, and why these patterns existed. In short, while there were clearly patients being repeatedly re-referred, and more than may have been expected, the detail of any problematic referrals was unknown. A clearer picture had to be created.

An extensive and systematic literature search (Chapter 2) showed that there was currently no available literature upon the subject within the setting of outpatient physiotherapy. There was also limited available literature on similar occurrences in any secondary care setting. The research team therefore proposed an exploratory study into the occurrence of repeated re-referral into musculoskeletal outpatient therapy, specifically using an in-depth examination of quantitative data, and guided by an appropriate framework.

4.2 Rationale

It was clearer that a larger, more detailed dataset would be required than could be provided through the exceptional report process. It was determined that quantitative data collection of patient records would allow the building of a complete picture of re-referral rates, patterns, and patients.

By directly perusing the data collected within the Trust's own database, and the records that they kept, it allowed the investigators to interrogate the data, and therefore the actual occurrences over a three-year timeframe. This is also in keeping with the Chronic Care Model (CCM), which advocates the use of Clinical Information Systems (CIS), structured to organize patient, population, and provider data to describe the health of the population (Fiandt, 2006). Specifically, the picture would tell, to some degree, what type of patients were returning to musculoskeletal outpatient physiotherapy departments, in terms of age and gender, and for what diagnoses. The wait for their referral, duration of treatment and overall episode duration, along with the reported status at time of discharge, could be uncovered, along with any other issues within the past medical history of the patients. With this data collected, the patient demographic, patterns of referral, and corresponding clinical pictures would be clearer.

4.3 Aim

To build a fuller picture of re-referral of patients to musculoskeletal outpatient physiotherapy for treatment of the same or different musculoskeletal conditions.

4.4 Objective

To retrospectively retrieve, analyse and describe, using descriptive statistics, anonymised referral information from the LCID within the NHSCT over a three-year period.

4.5 Methods

4.5.1 Design

The study was quantitative in nature, and designed in a pragmatic approach using the CCM, the learning from previous investigators of repeat re-referrals in other secondary care settings, and the collaboration of the NHSCT leads.

Whilst there were very few studies identified by the literature search, the methods of those included were noted. Freeman et al., (2012), used data collection forms in the perusal of treatment registers, whilst gaining other information from patient records; this approach therefore was deemed appropriate for implementation in this study. Data analysis was carried out using SPSS. It was noted that Lamb et al., (2013), gave less methodological detail but made it clear that outcomes and

diagnoses were both recorded and evaluated. It was felt that there was opportunity to use similar methods in the current setting.

The study involved collection of quantitative data from the interrogation of the NHSCT Local Community Information Database (LCID), to quantify and describe rates of re-referrals. LCID is the database system in which healthcare professionals collect and record data regarding patients' episodes of care, operational in some form (or an equivalent system) in the five Community Trusts, including the NHSCT, in Northern Ireland (Information Guide for Equality Impact Assessments, Vol. 3). Quantitative data collection from a database allows efficient and systematic obtaining of numerical trends to fulfil the stated aims, using data collection forms as a bridge between what is reported by original investigators and the final presentation (Cochrane Handbook Section 7.5.1). Data collection forms allow choice of what data is included, what is excluded, and can be tailored to suit constraints or requirements.

4.5.2 Procedure

Data collection was carried out onsite at the NHSCT sites, using specially designed data collection forms (Appendix H) that collect only relevant and specific data.

To access the data an honorary contract for the doctoral student with the NHSCT was required. The chosen study design and its procedures were outlined and explained in person to the relevant team leads within the NHSCT, who participated in the design in its initial stages.

4.5.3 Design Process & Feasibility

An initial meeting was conducted to introduce researchers and collaborating clinicians to each other, and to have a preliminary discussion regarding the incidence of repeated re-referral, with the view to ascertaining the feasibility of an exploratory study, dependent on the report.

A request for an exceptional report was made, the NHSCT physiotherapy Lead having clarified the availability of this and the method of obtaining it. Upon receipt of the report (Chapter 4:1), there was further discussion of the results of the report with the Lead, ensuring correct interpretation thereof, and a second request was made at this time for another exceptional report. Having received the results of the latter, a further meeting was arranged to discuss the design of an exploratory study.

To this end, a meeting with leads in key NHSCT physiotherapy outpatient departments was conducted, to introduce the research team and the proposed study to the leads, and to clarify any burden upon NHSCT staff at their sites. At this meeting, the proposed methodology was outlined and met with feedback. Clarification was sought, and discussion had, on the possibility of access to sites

& records. Consensus on a satisfactory, practical and ethically sound methodology was reached, with the necessary internal NHS R&D requirements clarified to the team. This included the necessity of gaining honorary contracts, temporary Trust email accounts, and being willing to undergo software-specific ICT training. All of this was also dependent on the successful obtaining of Ulster University and OREC ethical approval for the proposed study.

Having obtained the necessary permissions, including ethical, legal and skills-wise, the next step taken was to liaise again with the NHSCT Lead, to clarify the format of the LCID output, and ensure that the format of the data collection forms made data collection efficient. This would not only ensure that the study proceeded successfully but would reduce staff burden.

Another meeting with the NHSCT Lead by the Principal Investigator at one NHSCT site allowed a short trial run of data collection and proved that the chosen and approved methods allowed efficient data collection and established an efficient methodology for data collection in the minds of both researcher and collaborating staff.

4.5.4 Data source

Data available from LCID included dates of referral, date of initial attendance, site at which the patient was treated, discharge date and reason for discharge. These data were recorded for every referral, where available.

The patient diagnosis, age or gender was not included in the LCID output. To collect the data, patient hard copy notes needed to be perused.

Each NHSCT site was given the list of Unique Identifiers (UIDs) and the corresponding patient name by the collaborating lead in the NHSCT. This cross-referencing allowed the collaborating staff member at each Trust site to find the patient notes more efficiently, to collate these and notify the researcher when this was accomplished. The notes were thus identified prior to the researcher's visit. The researcher at no point had patient names; instead, validation to ensure electronic and hard copy notes refer to the same patient and episode was accomplished by referencing dates and UID. Team leads at each site were made aware of the researcher requiring access to each site.

From these notes, the remaining information, namely diagnosis, comorbidities, age and gender, were input into the data collection forms. No notes were removed from the physical site where they were securely held. No treatment aspect was included, nor patient-therapist interaction investigated. The backed-up data collection forms were held securely at the University; the methods avoided risk of loss of personal data due to anonymisation at the point of data collection.

4.5.5 Data forms

The anonymised data collection forms' design had to correspond to the format in which the data was presented. To accomplish this for data from LCID, the research team were provided with a list of codes used within LCID. These codes were a key to the data contained on the database. Their input format is often 3 characters: a letter and two numbers, e.g. in the format K01. Details of a patient's episode of care is entered into the database electronically using these codes rather than prose. For example, a code may record that a patient presented with a fracture or has been treated using Ultrasound therapy. These codes were not included or used by the team but allowed specificity during the preparation of the data collection forms.

To accomplish this for data collected from patient notes, the forms were designed to record items such as comorbidities in the format and categories used on NHSCT assessment forms. Each data collection form was linked to an individual patient, by a unique identifying number allocated to that patient. This was held by the team lead in the Trust.

One data form was completed for every referral; each patient would have three or more. It was considered to have one form per patient, but it soon emerged that the former method (one form per referral) was more practical. Reasons for this included the fact that patient records, despite the best efforts of the staff involved in compiling the notes for data collection, were not necessarily in order, or perhaps not found on the first day at a site. This then would have involved trying to cross-reference back through patient records and data collection forms alike if all episodes/referrals had to be entered on one form. This would have proved inefficient in terms of time and staff burden. The chosen method allowed each episode to be entered on its own form as soon as it was perused, and immediately filed by patient allocated number and date. At the close of the data collection process the investigator (DT) compiled the correct episodes per patient in the correct order.

No additional data were added outside of the data collection forms. There were additional variables added into SPSS, based upon the existing variables; namely, calculations between dates, or additional categorising of data (e.g. of the 'Trauma' variable, from the diagnosis) for ease of analysis. This is explained further in chapter 4.7.7.

4.5.6 Collaborator burden

Due to the procedure outlined and methods of data collection, there was no patient burden. All data was anonymised, and no identifying content recorded. The minimal burden possible was placed upon the NHSCT. The Trust provided the initial exceptional report; following this, the main burden was collation of notes, and time set aside for the provision of the data to the researcher. The

granting of an honorary contract allowed the NHSCT to admit the researcher to the site to complete the data collection process.

The time burden for data perusal and entry was approximately 20 patients' referrals per hour, or 60+ episodes. This meant that some sites required a single hour to complete data collection at that site, whereas others required multiple hours. Where the latter was the case, the Principal investigator liaised with the site contact, to determine whether this was practical to do in one sitting, or whether it was preferable to take an hour over two or three days. The preference of the contact was accommodated in every case.

4.5.7 Ethical constraints

Only anonymised data were removed from the NHSCT sites. Data collection and perusal of the records was carried out onsite, and notes were never physically removed for any purpose. Following the granting of an honorary contract, the researcher was allocated an NHSCT email. Should it be impractical to visit a certain site, the data could then be sent internally between PCs, but only accessible by an approved person with the relevant contract and hence login. This avoided physically transporting data from a site prior to anonymisation. The email was only accessible from an NHS PC, physically located onsite at one of the NHSCT outpatient departments. The LCID output was provided electronically to this internal address, and this data was only accessible by researcher approved by the Trust with the relevant access key.

Any data gathered were used specifically for answering the aims and objectives stated. The data did not include patient-therapist interaction whereby poor practice may have been uncovered. It was unlikely that poor practice be uncovered via the methods outlined, but nevertheless necessary that allowance be made for such an event. Thus, ethical approval granted that any such information be passed on to the physiotherapy manager to be dealt with through Trust policies and procedures.

Data presentation was in an entirely anonymised format, in accordance with the Data Protection Act (1998) and there was no requirement to identify members of staff involved, in data presentation. In accordance with University Code of Practice, anonymised data were agreed to be securely held for 10 years by the University following the study, and only authorised personnel to have access.

The research required, and gained, clearance through the Institute of Nursing and Health Research Governance Filter Committee, and the Office for Research Ethics Committees, Northern Ireland (ORECNI Ref 15/EM/0131), along with the NHSCT Research Governance. All applicable Codes of Ethics and Practice from each institution were adhered to. The research was carried out under the

University Code of Practice for Professional integrity in the Conduct of Research, and the NHS Research Governance Framework (2005, updated 2008).

4.6 Descriptive Statistics

Statistical analysis was carried out in the Ulster University by the Principal Investigator using the Software Package for Social Sciences (SPSS) version 24. Frequencies were calculated, and then collated into tabular format.

Descriptive statistics were used as opposed to inferential statistics – strictly speaking, no specific hypothesis was being tested in the quantitative data. The physiotherapists' belief prior to the study was that there were patients repeatedly referred. This was corroborated by the exceptional reports, not by descriptive analysis of the quantitative data. From this point, the study was exploratory, and the interests in analysis of the data were particularly the frequencies (i.e. how often a value appeared) and the measures of central tendency, as the aim was to build a picture of the referrals which simply was not known prior to the study.

'Descriptive statistics' refers to methods of data analysis that help describe, show or summarise data in a meaningful way in order that patterns might emerge from the data in question (<https://statistics.laerd.com/statistical-guides/descriptive-inferential-statistics.php>). These frequencies represent, for example, what the most common diagnoses were, how long typically a patient might experience treatment for, and the most commonly cited patient status at discharge. It is the examination of these frequencies that were intended to shed light on the patterns typically seen in re-referred patients.

4.7 Variables

Variables included: episode number, duplicate number (if applicable), age, gender, date of referral, date of attendance, diagnosis, co-morbidities, discharge date, and reason for discharge.

4.7.1 Dates

Dates were not run as frequencies, because of the huge range that would result. These were used to calculate time periods (a further variable) but were still entered in the SPSS spreadsheet for ease of reference.

4.7.2 Age/Gender

Age was entered numerically, and gender was entered as a '1' or '2' denoting male or female respectively.

4.7.3 Duplicates

There were occasions where a patient, who had been returned in the LCID output as having had three or more referrals had in fact, in the LCID system, had their first or second referral duplicated. Thus, the patient may have had only two, and therefore strictly not applicable to the current study. These patients were included in the SPSS datasheet for reference. However, the duplicate episode and details thereof was not included in analysis, enabling a truer picture to be gained when the descriptive statistics were run. It was also considered helpful to include a variable to show whether a patient had one (or more) of their episodes duplicated. This was coded as '1' for a positive value.

4.7.4 Diagnoses

Coding of diagnosis could not take place until all sites had been visited, to ensure that all diagnoses or referral reasons were accounted for in a meaningful way. Diagnoses were difficult to code, due to the large variance in both terminology and detail of each referral letter; often diagnosis was not given in terms of an exact pathology, or even in clear symptom description. There were instances where the referral was mainly prescriptive.

Due to the variance involved in diagnoses, it was felt that the best way to represent these was by body chart. Thus, these values included 'lower back', 'upper back', 'hip', 'knee', 'ankle/foot', 'claviculo-sternal', 'shoulder girdle', 'elbow', 'wrist/hand', 'neck/cervical', and 'pelvic girdle'. All diagnoses with a few minor exceptions were encompassed within these. For the exceptions, there were added 'mobility issues', 'modality only' (denoting a prescriptive referral for a modality such as acupuncture), 'whole body or general pain syndrome', and 'other' – the latter of which included respiratory issues, and a prescription for pain relief related to oncology. These values were coded 1-15.

As anticipated from the literature, there was at times variance between GP and physiotherapist diagnoses. In such cases, the physiotherapist finding was preferred where there was a lack of clarity in the initial referral reason given, or where it differed – the justification being that this was clearly the most recent manifestation of the symptoms, and clinically the greatest opportunity for differential diagnosis. The chosen method of coding meant that though there were differences, it rarely affected the final picture presented or the actual entrance of the data (e.g. 'shoulder pain' per

the GP, and 'supraspinatus tendinopathy' per the physiotherapist would both have been coded as '7' for shoulder girdle).

4.7.5 Calculated time periods

Along with variables that were taken directly from the quantitative data collection, it was possible to include additional variables based upon calculations from the dates. These included the calculation of episode duration, treatment duration, length of time between episodes, and length of wait from referral being made by the GP until presentation at the first appointment.

Episode duration was calculated from the date the referral was made, until the date of discharge. Treatment duration, on the other hand, was calculated from the date of first attendance at the outpatient department, until date of discharge. Those small number of episodes which involved a discharge due to a non-attendance (in common medical parlance, DNA, or "did not attend"), may have experienced treatment for a shorter period than the calculated figure. This is due to the practice of allowing several days (anecdotally, five working days) from a DNA to give the patient time to rebook, and/or to be followed up.

Despite this, it was necessary to retain the given values in calculations; despite the possibility of a shorter period than indicated, it was not possible to confidently substitute the given value with an estimated value. At the same time, the referral had been clearly made, and had to be retained. Rather, this possibility was to be borne in mind when discussing results.

Length of time between episodes was calculated from the date of discharge from one episode until the date the subsequent referral was made. In some rarer cases, a second referral was made in advance of the first episode ending. In these cases, this variable was entered as '0', there being no time elapsed since discharge. Should a subsequent referral request be made on the exact date of the patient being discharged, this variable was then entered as '1' – indicating that it was within the first week since discharge.

The length of wait between the referral being made and the presentation at first appointment varied, though it was the norm to be an extended number of weeks. There were a few exceptions, and the exact outpatient setting affected this wait. One site recorded, for example, same-day episodes for the provision of a walking aid, which would have the referral date, attendance date, and discharge date within the same day. In occurrences of this, where 'episode length' equalled '1'.

4.7.6 Weeks as units

All time periods were calculated using weeks as a unit of measure. There were several justifications for this approach as opposed to calculating days. Firstly, it was appreciated that the use of weeks as

a measure of episode length, treatment length, and waiting times from making a referral until the first appointment, was built into common parlance both for health professionals and the public. Therefore, whilst calculating days may have been perceived as preferable in terms of accuracy, it is not necessarily as meaningful, in the sense indicated.

For the same reason, the use of weeks is preferable for the ease of presentation and assimilation of findings. For example, to speak of consecutive episodes of 56 days' length and 84 days' length respectively is accurate, but it accomplishes the same purpose more easily and with more familiarity to present this as episodes of 8- and 12-weeks' duration. Health professionals familiar with, for example, protocols for a given rehabilitation programme (typically measured by progress per week) will also see more quickly a deviance from the norm.

Finally, and most importantly, it is suggested that the perception of days as opposed to weeks being more accurate, has its problems when investigating an outpatient setting. With outpatient departments typically having a 5-day working week, it would not be feasible to differentiate between 'days' and 'working days' in every calculation for every patient (especially considering Bank Holidays, special holidays, and so on). For some patients, depending upon whether 'days' or 'working days' were used, the variance in time periods calculated would be almost 70% - an unacceptable level of variance in a study where issues such as chronic injury progression and care pathway efficiencies have been raised. To arbitrarily choose one definition of 'day' over the other would be difficult to justify for the same reason. The best solution to all these issues was the use of calendar weeks as a measure within these variables, consistently for every calculation.

4.7.7 Traumas

A variable was included to identify episodes that were a direct result of a trauma. It was believed that these might account for an extended treatment time, or for ongoing complications, even if not recent. For example, it was seen that some patients referred for back pain had traumatic means of injury (MOI) despite approaching 20 years since onset following a road traffic accident (RTA). It was judged necessary to account for this within the data.

Episodes treated as physical traumas for the purposes of this study included RTAs (Road Traffic Accidents) including subsequent complications such as whiplash. Complete ruptures of a ligament, muscle or tendon, along with more severe tears, were also counted as trauma, for the purposes of this research. Other examples included crush injuries, severe falls (such as from a roof-space), fractures of any description (including avulsion, comminute and stress fractures), and more invasive surgeries such as total knee or hip replacements (TKR, THR), costoplasty procedures, internal fixators

(ORIFs), mastectomies, anterior cruciate ligament (ACL) reconstructions, spinal decompression and discectomies, or sub-acromial decompressions (SADs). There was one instance of an operation for the removal of a loose body. Typical microtrauma (e.g. from overtraining) resulting in a minor tendinopathy were not recorded as trauma by this definition. Recurrent dislocations of the patella, resulting in soft tissue damage, were however recorded as traumas. These were simply recorded as '1' for a positive value.

4.7.8 Co-morbidities (Past Medical History)

The orthopaedic assessment forms for outpatient departments in the NHSCT facilitated coding of this variable. Comorbidities were recorded as categories – for example, someone with cardiopulmonary issues including, for example, hypertension, angina, myocarditis, or a history of cardiac arrests were recorded in SPSS as '1', denoting 'cardiopulmonary medical history'. Most departments used similar if not the same assessment forms, with a section describing a category of co-morbidity and space to clarify. This approach was adapted, for the data collection and entry into SPSS. The specific co-morbidity headings were 'Cardiopulmonary', 'respiratory', 'endocrine', 'neurological', 'oncological', 'surgical', 'infection/viral', 'rheumatological', 'stress/depression/anxiety', 'metabolic', 'visceral', 'dermatological', 'general pain syndrome' 'musculoskeletal', and 'other'.

The number of categories reflected the wide range of what were considered, in the patient assessments, to be relevant co-morbidities or items in the past medical history. Apart from the more common designations, 'metabolic', was primarily used to denote diabetic disorders of any type. 'Visceral' indicated herniation, diverticulum, and strictures of organs such as the oesophagus. 'Dermatological' included psoriasis, eczema, and dermatitis. 'Other' would include, for example, incontinence and relevant considerations in a musculoskeletal assessment and treatment, such as a pregnancy. The justification for coding by category this way allowed ease of cross-reference with the patient notes during data collection, and simplified data presentation. Should a pattern be identified by category, it could then be investigated to find if the pattern applied to individual pathologies within that category. The data collection forms recorded these individual pathologies and were available to check. These comorbidities were coded as 1-16.

Co-morbidities were difficult to track between episodes. In some cases, for subsequent referrals, no co-morbidities were recorded – making it unclear whether the previously identified comorbidity had been resolved, or whether it was just the habit of the therapist/s at that site to refer to previous notes for these. Similarly, it was not always clear, where in subsequent episodes a new comorbidity

appeared, to define whether it had only recently begun, or had been underlying and ongoing but only recently discovered.

In addition, when collecting data from patient notes it was difficult to question the member of staff, especially as they themselves were simply reporting what they saw on the patient notes. In this study, a referral with no comorbidity recorded had to be assumed to be correct – even in cases where a previous episode mentioned a co-morbidity that would not normally have been expected to resolve in the intervening period.

Finally, logistics of data collection meant that it was necessary at times to return to a site a second day to complete data collection. This was in part due to a coincidental Trust-wide transfer of records between storage locations taking place, concurrently with data collection. Therefore, when entering this data into SPSS, the term used was past medical history (PMH); this accounted for and included all recorded medical history, ongoing or not, which may have predisposed the patient, or affected the presentation/development of the condition.

4.7.9 Reasons for discharge

For coding in this case, the information provided via the Local Collaborator, advising the team on the terms used within the LCID database, was invaluable. The LCID output, given in Excel form, included 14 'discharge reasons', or 'outcome descriptors' as it appeared on LCID. These were 'Discharged – continue programme at home', 'Full potential with treatment', 'Service completed', 'Discharged with DNA', 'Inappropriate referral', 'onward referral', 'Service refusal by patient', 'Discharged with possible recall', 'Patient no longer requires treatment', 'Independent with equipment', 'Lost contact with patient', 'Treatment unnecessary', 'Hospital admission', and 'Other'. When entering these in SPSS, these were simply numbered 1-14.

Most descriptors speak for themselves, while the usage of others may need clarifying. 'Service completed' may be used where a specific modality was offered, a protocol was followed, or for hydrotherapy. 'Onward referral' was never clarified on the LCID output made available to the research team (due to the limitations of the database) as to destination, but clearly intimates that the patient's condition was not resolved by physiotherapy alone. 'Discharged with possible recall' suggests, for example, a pre-op patient expecting to return post-op, or simply that the patient had a chronic issue which seemed to have been asymptomatic, but which was expected to have exacerbations. 'Patient no longer requires treatment' would suggest that the patient's complaint had resolved prior to attendance at an appointment. 'Treatment unnecessary' may have been used interchangeably with this, though further deduction showed that the former usually denoted

resolution between appointments ('no longer' showing that treatment had begun at other appointments), whereas the latter was used of resolution prior to even the initial assessment. In each, the data implied that the patient usually still attended, though with no symptoms. 'Other' could be used for any other eventuality such as moving Trusts, or even patient decease.

The collaborator was consulted to clarify the interpretation of the descriptors used, as correctly understanding situations wherein each was appropriately applied could affect conclusions drawn.

4.8 Data Cleaning

With all data entered, extensive data cleaning was undertaken, to ensure that all data and values were entered correctly, with no omissions unaccounted for, duplicates, or mistakes in calculations, and that the format of each variable was correct, to successfully run descriptive statistics.

4.8.1 Data checking

A process of data checking was undertaken at several stages in the data entry process. This involved taking a section (or sections) of the data randomly and cross-referencing every variable and value with the corresponding data collection forms and Excel spreadsheet from LCID. Two researchers were involved in this process, one of whom had not been responsible for data collection or entry and was therefore independent. 10% of the total patients' referrals completed at each stage, were selected for data checking.

4.8.2 Duplicates

21 duplicated episodes were removed from statistical calculations.

4.8.3 Missing values

There were cases where data were missing from a cell, and therefore from the final tabulation. Reasons were varied. In some cases, the LCID output had not provided certain dates and therefore a calculation could not be completed. The reason for this internal omission was unknown. There were also instances of hard-copy notes which could not be found during data collection. In these cases, it was possible to consult the LCID output for dates, calculations, and discharge reasons.

Thirdly, albeit less often, there were cases where both the patient notes and LCID data were available, but patient notes were also incomplete and omitted details such as age/DOB, or even gender. In some cases, the latter could clearly be discerned by pronouns used, or name (by the facilitating member of NHSCT staff; not disclosed to the researcher for ethical reasons) within the notes, but in other cases this was not possible. If there was any cause for doubt, no value was

supplied. Again, in some cases, the staff member knew the patient, and could provide the data (e.g. gender) whilst maintaining anonymity. At no point during data collection was any personally identifying data released to the researcher, in conversation or in records.

Missing values amounted to 8% in LCID dates, 2% in final age/gender incidences, and 0% in number of episodes, or trauma (being a manually calculated variable). Where comorbidity/PMH was absent in records, it had to be taken as an indication that none applied – a value was entered to account for this.

In all, however, there was data for each episode of each patient, i.e. there were no cases where a patient or episode had no data recorded at all. SPSS excludes missing values from computations (IBM SPSS Statistics 24 Algorithms, IBM 2016; <https://www.spss-tutorials.com/spss-missing-values/>), and this is indicated in the handling of the frequencies. “User missing data”, or data which is not input by a researcher did not apply in this case; in binary variables such as ‘trauma’ there was a value for yes or no, and so there was no omission from data entry by the user. In SPSS, the user guide states that descriptive statistics are not typically disrupted by missing values, as regression analysis or t-testing would be; the output is simply a minimum valid frequency of a given value, with the cumulative frequency still being 100%. The data was scrutinised and judged missing completely at random (MCAR). Generally, multiple imputation of values may be appropriate for the handling of missing values (Schafer, J., 1999; Newgard & Haukoos, 2007). However, it is typically not preferred for descriptive statistics; even if this method would maintain the approximate structure of the original sample (Eddings & Marchenko, 2012), it cannot represent the sample for the reasons descriptive statistics are run (frequency of occurrence of a given value). Therefore, descriptive statistics for the original sample are best run (SPSS automatically excluding missing values) with an acknowledgement of numbers of missing values. The reader can then interpret the frequencies whilst acknowledging this.

4.8.4 Chronology

Usually, the LCID output would have presented data by patient, and grouped each episode per patient in chronological order. For eleven patients, however, this was not the case; episode dates were out of order, sometimes the earliest episode appearing last. It was therefore necessary to re-arrange the patient episodes – i.e. to correct the chronology. The reasons for the lack in chronology in a few patients’ details are unclear – either some episodes may have been entered retrospectively into LCID or may be simply an internal formatting issue within the database.

Each of these occurrences were located and corrected during data collection, with the corresponding diagnoses, discharge reasons, etc., being carried over at the same time. It was important that this chronology was maintained so that periods between each subsequent episode could be accurately calculated.

4.8.5 Cross-referencing episodes

When collecting patient data from hard copy notes at a given site, it had been most efficient to collect the minimal necessary data at a time – for example, dates or reasons for discharge were not necessary to record at this point, as the LCID output provided these. Similarly, patient ages were not written as such on the patient notes; the DOB was recorded, and calculation for each episode was done retrospectively. This reduced burden on staff at the point of data collection, but meant that when entering data into SPSS, each episode had to be cross-referenced and date-checked to ensure the age at each episode was consistent.

4.9 Standard Operating Procedure (SOP)

Given the lack of previous studies investigating the occurrence of repeated re-referral, and based upon the rationale given, the procedure outlined was adopted for the current study, and is suggested to be a suitable SOP for similar studies, in secondary care settings (appendix).

The following chapter expands upon and discusses the data collected via this procedure, and will show the picture emerging therefrom, with the view of better understanding repeated re-referral.

Chapter 5: LCID Patient Database Results & Discussion

5.1 Methods

The results of the LCID data collection process (chapter 4) coupled with supplementary details from patient notes, provided a large dataset from which to divulge a clearer picture of referral patterns and characteristics amongst those patients repeatedly re-referred within three years to the same Trust outpatient departments in the NHSCT.

This dataset was analysed using descriptive statistics, specifically searching for frequencies in the case of each variable outlined in the previous chapter. In analysis of each variable therefore, it is the modes which are most of interest, being the most common number of incidences of a value across a range of values. The use of modes in this way highlights the most common occurrences and therefore expected to bring to light potential patterns in the referrals being made, for example treatment length, where mean was 7 weeks and the median was 6 weeks. The mode however was 1 week. This illustrates why the frequencies (modes) are important – whilst the mean, median, (and indeed the second highest frequency) all are 6-7 weeks' duration, failure to report the highest frequency value (the mode) would miss reporting the fact that the largest proportion of the patient population are discharged extremely soon after initial presentation.

5.2 Results

5.2.1 Overview

In total, 342 patients were included in the analysis. Each had between 3 and 8 referrals. 284 (83%) had 3 referrals, whilst 42 (12.3%) had 4, and 13 (3.8%) had 5 referrals. One patient had 6, one had 7, and one had 8 (each being 0.3% of the total).

5.2.2 Age

In age, the patients ranged from 14 to 86 years of age (measured at their first appointment within the 3-year timeframe). The average age (mean) was 54 years, with a standard deviation of 15.28 years. This excludes 90 patients for whom DOB was not available at data collection, and hence age was not calculable from DOB.

5.2.3 Gender

251 patients (73.4%) had their gender recorded. 80 were male (31.9%), and 171 were female (68.1%), i.e. a ratio of over 2:1 female.

5.2.4 Comorbidities (PMH)

151 patients (44.2%) had at least one comorbidity, or condition of note, in their past medical history. Of the 151 patients with a comorbidity, most had only a single type; almost exactly one third (33.8%), or 51 patients, fell into this pattern.

The most common was an accompanying or previous musculoskeletal injury, accounting for 19.7% of total comorbidities, and found in 65 patients. The second most common were cardiopulmonary issues, with 16.7% of the total comorbidities falling in this category and found in 55 patients. Third was a recent surgical procedure, which was 10.3% of the total, and found in 34 patients.

Disparity between the calculation of percentages and total number of patients, is explained by the fact that many patients (66.2% of the 151 patients with comorbidities) had more than one comorbidity, or type of comorbidity.

5.2.5 Wait in weeks

The wait in weeks from referral until first presentation ranged from 1 to 29 weeks. The mode was 8 weeks overall (14.8% of referrals), with the next most common being within 1 week (14.1%), followed by 4 weeks (9%), 7 weeks (8.9%), and 2 weeks (8.8%) respectively. In total, 77.4% of patients had their first appointment by the 8th week, and 90.2% by the 11th week.

For the wait until first referral, the mode was 8 weeks across patients. The mode for subsequent referrals was 1 week each time.

The episode which saw patients waiting the longest, was the 3rd, with a maximum of 29 weeks, and the second episode had a maximum wait of 19 weeks. The maximum waits for the 1st, 4th, and 5th lay between these, and the 6th, 7th, and 8th, having only 2, 2, and 1 value respectively, were all seen within 2 weeks of referral.

5.2.6 Diagnosis

The most common category of diagnosis was lower back injuries, with almost a quarter (24.7%) or 147 of those which were identifiable. The second most common was shoulder girdle injuries, which accounted for 21%, or 125 instances. These were followed by knee injuries (14.3% or 85 occurrences) and cervical or neck complaints, accounting for 70 occurrences (11.8%). Other joints or injuries were less frequent – ankle injuries and hip injuries were 6.7% (40 instances) and 6.2% (37 instances) respectively, and all others making up less than 4% each. Mobility referrals were accountable for 1.5% (9 instances), and general pain syndromes or whole-body pain was 2.7% (16 instances).

5.2.7 Referrals with trauma

There were 89 instances where the diagnosis/referral involved physical trauma of some description. This was 3.3% of the total amount of referrals made over all 342 patients.

5.2.8 Discharge reasons

At discharge, there were a total of 13 reasons given as per LCID output. The most common was a discharge having reached full potential for the patient. These accounted for 349 (32.4%) discharges. The next most common was a discharge with the intention of continuing a home programme, accounting for 225 (20.9%) discharges. Third was the designation 'service completed', which was used for 186 discharges (17.3%). These three were the most common and accounted for 70.6% of all discharges. The next most common were 'discharge with possible recall', and 'onward referral', with 7.9% and 7.1% respectively. These occurred 85 and 76 times, again respectively.

There were 47 occasions where a patient was discharged, no longer needing treatment – distinct from those above who had resolved by treatment. These accounted for 4.4% of the discharges. DNAs accounted for 38 discharges over the timeframe, or 3.5%. There were 11 (1%) refusals of treatment, leading to discharge. 3.2% were discharged with the designator 'independent with equipment', made up of mobility referrals, and appearing 34 times. There were 7 instances where a patient was discharged due to being deemed an inappropriate referral. This was 0.7% of the total discharges.

Patients who had lost contact were scarce, with only 1 being documented, as were those designated 'treatment unnecessary', with only 2. These were a mere 0.1% and 0.2% respectively. There were 15 occurrences, or 1.4% of discharges, indicated as 'other'.

5.2.9 Episode Length

The range of values for episode length was very large, with 44 different values. The mode was 12 weeks, true of 83 cases. Standard deviation was just over 7 weeks (7.268), and whilst the range was large, over 90% had episodes of less than 23 weeks.

5.2.10 Treatment Length

Again, due to the individual nature of treatments, there was a large range of values, with 37. The mean treatment length was 7 weeks and the mode were 1 week (154 treatments, or 14.8%). The next most common were 5, 6, and 7 weeks, which were 103, 102, and 103 occurrences respectively – i.e., 9.8 – 9.9% each, and 29.7% in total.

Standard deviation was just over 5 weeks; 5.126 as per SPSS. Again, the high range of values hides the fact that over 90% of treatments were completed within 13 weeks. The mode for each of the first 4 episodes by patient was also 1 week, with the rest rising to 5 for each.

5.2.11 Discharge to re-referral

This variable was difficult to calculate using descriptive statistics – the total range of values was extremely high (n=127). Meaningful analysis would be difficult – with the range itself higher than 100, each value is likely to be less than 1%. As it was, the total mode duration (n=74) from discharge to re-referral, over every referral for every patient, was only 1 week, and was calculated manually. When broken down on an episode-by-episode basis, the mode for 2nd, 3rd, 4th, and 6th episodes across patients, was still 1 week.

5.2.12 Referrals for same conditions

Out of the 342, there were 100 patients who were referred at least twice for the same or similar condition, within the time-frame. Of these, 19 had three or more referrals for the same or similar conditions. One patient had 4 referrals for the same or similar condition.

75 of the 100 were re-referred for the same or similar condition, in immediately subsequent referrals – that is, had been discharged, and then referred again for the same or similar condition. Of the remaining 25, it was either unknown as to the reason for any intervening referral, or if the referral was clearly for a different condition.

5.3 Summary of results

83% of patients in the sample had 3 referrals, with average age of 54. There was a ratio of just over 2:1 female to male. 151 patients (44.2%) had comorbidities recorded. Of these, almost exactly a third (33.8%), or 51 patients, had a single type, the most common being another musculoskeletal injury (19.7% or 65 patients), followed by cardiopulmonary (16.7% or 55 patients) or a recent surgical procedure (10.3% or 34 patients). 66.2% of the 151 patients had more than one type of comorbidity.

The most common waiting time was 8 weeks (14.8% of referrals), followed by 1 week (14.1%). The most common diagnosis was lower back injury (24.7% or 147), followed by shoulder girdle injuries (21%, or 125 instances). There were 89 instances where the diagnosis/referral involved physical trauma of some description.

Most commonly patients were discharged having reached full potential (32.4% or 349 discharges), continuing a HEP (20.9% or 225 discharges), or having a particular 'service completed' (17.3% or 186 discharges). These accounted for 70.6% of all discharges. The most common episode length was 12 weeks. The most common treatment length was 1 week, followed by 5-7 weeks. The most common duration until re-referral again, was only 1 week.

100 were referred multiple times for the same or similar conditions, and 75 of these in consecutive referrals. 242 patients were referred for different diagnoses.

5.4 Discussion

5.4.1 Overview

The results that were available from the LCID database, coupled with patient notes, provided insight into the picture of re-referrals. The results showed that most patients had between 3 to 5 referrals over the time frame in question (3 years). Those who had six to eight referrals were rare, with only one occurrence of each. The range of values for age was understandably large, but patients commonly were around the age of 54, with a standard deviation of just over 15 years. Almost two thirds were female. This picture may not surprise those familiar with a typical caseload in musculoskeletal physiotherapy.

Two large groups were identified within the values for PMH (past medical history). Patients usually either had no comorbidities, or many. Over half had nothing recorded in their PMH, whilst 151 did. However, only 51 (one third) of the 151 had a single comorbidity, leaving exactly 100 with multiple issues.

Multimorbidity, or the presence of more than one ailment or morbidity (Foster, et al., 2012), occurs in 58% of the population, and most patients (78%) seen by GPs in primary care present with multimorbidity, according to the same study. When compared with the smaller figures of the General Household Survey (GHS), (2007), which reported chronic musculoskeletal conditions in 14.3% of the total adult population, the larger proportion of those referred to by Foster, et al., (2012), indicates conditions which are not chronic musculoskeletal conditions.

65 patients had musculoskeletal issues in their PMH additional to that which caused the referral – the most frequent. This was followed by cardiopulmonary issues, and thirdly by presence of a surgical history. This pattern seems in accord with the prevalence of musculoskeletal pain and cardiopulmonary health-related disorders in UK and Irish populations (Bhatnagar et al., 2014;

General Household Survey (GHS), 2007). Additionally, each of the referenced sources show that incidence of each is higher in a female population, agreeing with the data, which was approximately two-thirds female.

In the same paper, Foster, et al., (2012) join Lugtenburg et al., (2009), in suggesting that where there are multiple morbidities, the musculoskeletal issues are (rightly or wrongly) not the primary focus of the GP. If this is applicable to the cases seen in the sample, so that musculoskeletal issues are not prioritised, it may be that this can contribute to chronicity. It is not clear whether a similar pattern applies to patients with multiple musculoskeletal conditions, and whether one is prioritised over another. However, it was noted in practically every case, that the written referral was typically made regarding a single diagnosis or symptom – regardless of accompanying comorbidities or PMH.

In relation to waiting times, there were again two large groups, each with just over 14% (14.8 and 14.1 respectively), together accounting for 28.9% of the total. One group had a waiting period of 8 weeks. The other had a notably shorter waiting time, being seen within 1 week, and potentially within just a few days. The data suggests then that there is more than one prominent ‘type’ of patient behind the re-referral, these two groups being of almost equal size but having very different experiences of referral.

The remaining waiting time data did not show a general tendency towards either of these two groups particularly, with 4 weeks (9%), 7 weeks (8.9%), and 2 weeks (8.8%) respectively. Prior to data collection, it may have been expected that waiting times would have been more uniform. It may also have been expected, were a single ‘type’ of patient responsible for these patterns, that one value would stand out prominently as a mode. Whilst the length of waiting times may not by itself render an explanation for repeated re-referral, it is worthy of reporting, illustrating as it does two apparently very different experiences of referral.

Much of the diagnoses described were typical of those seen in a musculoskeletal outpatient department. Lower back, shoulder, and knees were the most common areas of concern – exactly as expected from studies which previously investigated prevalence of musculoskeletal pain conditions, such as Picavet & Schouten, (2003). In that study, these were followed by general widespread pain. Therefore, it may be more of note in the findings of the current study that general pain syndromes (for example, CRPS or FMS) did not appear to feature highly. Not only did this differ from the literature, but also to what physiotherapists anecdotally reported prior to the study design.

The reasons for this are not immediately clear – such diagnoses were not attached to many patients upon referral, so physiotherapists may have been cautious in avoiding ‘umbrella terms’ in their own

diagnoses. Whether patients ought to have been diagnosed with these conditions cannot be ascertained from the present data. It is not inconceivable that some were referred to by pain site, rather than these diagnoses, but this is conjecture without further evidence.

As seen in the results, three designators at discharge accounted for over 70% of the total. These were namely, “discharged with full potential”, “discharged, continuing HEP at home”, and “service completed”. These suggest that the patients had, through their course of treatment, achieved the best outcome they could. The fact that a subsequent referral was made, most frequently within one week, is an apparent contradiction. It is possible that there was a sudden relapse/ exacerbation, or that an entirely different diagnosis was responsible for the latter referral. It is also possible that there is a difference in the physiotherapists’ estimation of the patients’ potential and/or ability to self-manage, and the patients’ own estimation of that.

On 34 occasions a patient was discharged from an episode/referral, being ‘independent with equipment’. The data however only showed 9 occurrences of mobility referrals – the most likely referrals to use this terminology at discharge. It is not clear how the remaining 25 are accounted for. It is conceivable that referrals designated ‘other’, may have had such an outcome, however adding the 15 occurrences of the latter still does not account for all 34.

The large range in lengths of episodes means that it was hard to define meaningful patterns. The majority lasted 12 to 13 weeks in length. Coupled with the mode waiting time of 8 weeks, this would suggest an approximate 4 weeks of treatment, if there was one weekly appointment.

The actual calculated treatment times showed that the mean was in fact a longer treatment, with 7 weeks, and the mode, unusually, was just 1 week, with the second most common being 5, 6, and 7 weeks – the latter being less surprising perhaps, but still longer than the mode waiting time and treatment time might suggest. The mode in this investigation bears explaining – especially as, for the first 4 episodes/referrals across all patients, the mode remains 1 week for each. It appears that there are two groups of patients seen – one large group who, for some reason, are not receiving extended treatment input – they are discharged almost immediately. The other group are receiving several weeks’ treatment. The reasons for this may be that the former are inappropriate referrals in the eyes of the physiotherapists, or that they refuse treatment, or that they have resolved. In fact, several reasons can be conjectured; for example, many of those listed as ‘reason for discharge’ values could be satisfactory explanations for a short treatment time. The point that perhaps requires the most explanation is how a discharge within one week was the most common. The data does not seem to explain this.

5.4.2 Frequencies

Reporting modes in descriptive statistics shows the most frequently seen picture in a set of retrospectively-gathered data. An attempt to construct a 'typical' (or, 'modal') patient based on the most common (mode) values, shows the most common would be a female in their mid-fifties, referred with low back pain, and without additional issues in their past medical history.

Apparently however, such patients would be divided into two categories – being either discharged that same week, or of receiving treatment for a further 5-7 weeks. The data suggest that the majority would be discharged fully resolved, or to self-manage with a HEP. However, the data equally suggest that following discharge, the majority would subsequently receive another referral. There would again be two groups – one group waiting only 1 week until re-referral, the others 8 weeks.

They would, in total, receive 3-5 such referrals over a three-year period. Of these, it is likely that these would be for differing diagnoses – however, if there were any referrals for the same diagnosis, the data suggest that these would be consecutive.

5.4.3 Potential patterns

It is evident that the modes cannot be represented by one patient 'type'. In the variable for past medical history, episode/treatment length, and length of time until re-referral, two distinct groups stand out – not just one. That is, there are two values appearing notably more frequently than other values. The suggestion is then that there is more than one 'type' of patient involved, at least in terms of these values.

Should it be accepted that there are two groups worthy of consideration, regarding the values above, these groups would be characterised by: either no previous history, or multimorbidity; either a discharge within one week, or a lengthy treatment period; and re-referred either immediately or going a long period before requiring re-referral.

It appeared then that these two groups, or 'types' of patient, are quite polarised in each case. This still required explanation – firstly, why after so long a treatment, re-referral for one group takes place almost immediately if potential was reached (as the data suggest), and secondly, why the second group of patients require so little treatment, but the benefits at discharge seemingly last quite a while before re-referral. A consideration was that the statistics or data does not fully represent the picture at all. The use of modes as opposed to mean/median in descriptive statistics is intended to avoid this, and the values accurately reflect the most common incidences even if they

cannot all yet be explained. As seen from this brief consideration of the data and potential patterns, the re-referral picture was not yet fully accounted for or understood.

5.5 Implications

The quantitative data presented built a clearer picture than previously achieved, and patterns began to emerge from the data by analysis using descriptive statistics. Whilst these patterns in the data were becoming apparent, it was desirable to explain them if possible. Some attempt at this was made by inductive means, and by discussion of the results. However, questions remained unanswered. Firstly, if the pictures presented are accurate, what are the causes of these patterns, and what influential factors cause them? Secondly, if there were any aspects of the data that are not an accurate representation of the true occurrence, could that failing in the data be explained, or corrected? Thirdly, is there anything additional being missed?

It was possible that LCID did not record all that needs to be known, despite the concerted efforts of the research team and the NHSCT to gather appropriate data, and the rigors of the data collection form design process. There were limits as to what data was available from LCID and so it was likely that a satisfactory explanation of repeated re-referral may require more than statistical data.

A qualitative investigation was proposed, to examine these issues, and to answer these questions raised. Fuller comparison of the picture portrayed, with what was perceived by stakeholders in the referral process, could also be achieved alongside these answers, by qualitative investigation. These stakeholders were namely, the patients themselves, physiotherapists, and the referring GPs. It was therefore intended to conduct a qualitative investigation to further explain the phenomenon of repeated re-referral, and of the picture obtained through quantitative data analysis of that occurrence, as described in this chapter.

It is acknowledged that characteristics of non-repeaters, or those only referred once in the timeline, may have been valuable for comparison in terms of variables such diagnoses, waiting times, status at discharge and so forth. This would have permitted further level of clarity on whether the characteristics suggested in this picture are unique to those being re-referred. In future studies, investigation of an equal sample size to the current, with data collection consistent, may allow the analysis and further light.

5.6 Conclusion

In conclusion, it was evidenced that many referrals are typically seen in an outpatient physiotherapy setting, and do not differ largely from expectations. However, it was apparent that there are patterns underlying the quantitative data which yet are unaccounted for. The discussion of results has highlighted the fact that understanding the distribution of the modes is key to understanding the patterns.

The most common treatment patterns, and those of discharge to repeat referral, indicate at least two, and perhaps more than two, significant groups of patients - significant due to the proportion of results shared between them. Whether the two patterns suggested in the discussion were the only patterns present, and what causes the suggested patterns, required further investigation.

5.7 Strengths and Limitations

The quantitative study was not without limitations, which merit consideration should the methods be repeated or applied in future. Some limitations were unavoidable, whereas in hindsight others may have been addressed.

The LCID database could not be interrogated for individual patients' treatments on the part of as it was not designed for the purposes of research analysis. There were also ethical considerations as to whether this would potentially identify patients. It was apparent that both the LCID system and patient records were not complete, with some data simply missing from the LCID output, including dates. Some of this may be accounted for in non-attendances, preventing a valid entry being made, though this did not account for all such omissions. Adherence to the LCID format for coding variables may make it necessary to adjust categorisations for cross-reference with future studies. However, this was necessary to be representative of the records as they would appear on the system and so corresponding to the exceptional report and therapists' accounts who record the data.

Time constraints on NHSCT staff and the necessity to follow up sites regularly to verify availability of notes for perusal, occasionally contributed to delays in data collection. It was regrettable that the researchers could not be closer to the data, in terms of the patient notes. Had ethical approval allowed the perusal of notes by the researcher, time delays may have been avoidable with a lower staff burden. It was not practically possible to investigate all patients who had 2 or more referrals, due to the sheer numbers. Similarly, to go beyond a three-year period would have increased the burden. However, an area of strength is that these were felt to be more representative of a

potentially 'problematic' rate of re-referrals. Finally, as outlined, the study itself, being quantitative alone, leaves some questions unanswered.

Chapter 6: Stakeholders' perspectives in repeated re-referral: a rationale

6.1 Introduction

The occurrence of patients, predominantly with chronic pain conditions, being repeatedly re-referred into musculoskeletal outpatient physiotherapy departments, was raised in discussion with Trust physiotherapists. The implications of this, particularly the risk that there may be a significant number of patients with these (or other) conditions whose care pathway does not manage their condition in an optimal manner, merited investigation into re-referrals.

During an extensive systematic search of the available literature (chapter 2), there was found to be a marked lack of material investigating the issue of re-referral to outpatient physiotherapy, as well as to other forms of secondary care. An exceptional report was acquired from one NHS Trust database (LCID), confirming the perception that there was a population having multiple referrals in a short time-period. Subsequent quantitative data collection from the LCID database and patient records provided a certain amount of relevant information; namely, the rates of return of patients, diagnoses, and time periods involved between episodes, and enabled statistical analysis and description of the figures involved.

These data having been obtained, analysis thereof suggested certain patterns which built a fuller picture of the occurrence of repeated re-referral within the Northern Health and Social Care Trust (Chapter 5).

6.2 Rationale

Despite a larger picture having been formed, further information was required to fully understand the phenomenon of repeated re-referrals. It was known from the literature that several factors actively influence initial referrals, including factors seen amongst the key stakeholders; GPs (the referrers in this setting), the therapists, and the patients themselves. It was appropriate to investigate the experiences, attitudes and perspectives of these parties, in relation to the issue of re-referral. The following study therefore investigated referral from the physiotherapists', patients', and GPs' perspectives.

6.3 Aims

The aim was to explain the picture being presented by the quantitative data, i.e. of repeat re-referrals into musculoskeletal physiotherapy outpatient departments in the NHSCT.

The objectives were particularly to

- 1) gain stakeholder accounts of the occurrence and causes of re-referral,
- 2) interpret patterns appearing in the quantitative data,
- 3) identify possible solutions to address those re-referrals perceived as problematic.

6.4 Methodology

6.4.1 Designs

Due to the aims of the research, it was considered appropriate to use a qualitative approach. The Qualitative Research Consultants Association (QRCA) describes qualitative research as facilitating understanding of feelings, values and perceptions that both underlie, and influence decisions and behaviour, along with capturing the language and image associated with an item or service.

This study was exploratory in nature and formed the second part of a mixed methods approach, being supplementary to, and explaining, the quantitative study carried out by perusing the LCID database and collecting data therefrom (chapter 5). For this purpose, a qualitative approach is most appropriate (Creswell 2003, Creswell et al., 2011). Creswell (2003, 2nd ed.) describes a valid format for exploratory mixed methods design as beginning with a quantitative method in which theories or concepts are tested, to be followed by a qualitative method involving detailed exploration with a few cases or individuals. This is broadly the format that this thesis follows, with the current study featuring as this detailed exploration of the issues surrounding the former qualitative study.

This qualitative study was designed to include up to 3 groups of 3-10 participants each. Participants are often more willing to participate in a group setting, perhaps feeling less exposed, which stimulates a different type of conversation/discussion than in a one-to-one setting (Kitzinger, 2013), and this interaction can provide a key part of the data (Kitzinger, 1994).

Topics within the physiotherapist groups included the therapists' own perception of the extent of re-referral with causes thereof; any explanation of, or expansion upon, the quantitative data - a summary of which was presented to the group; management alternatives to referrals if appropriate, and an account of the therapist/referrer interaction and therapist/patient interaction particularly with regards to their consecutive referrals.

Topics within the patient groups included the patients' own perception of their referrals along with any causes; any expectation of what they would receive and whether this was met; an account of

any therapist/referrer interaction and therapist/patient interaction especially around outcomes and reasoning to refer again; and current perspectives on physiotherapy provision having been repeatedly re-referred (Appendix S and T).

Due to the iterative nature of the process, there was a de-brief after each focus group, and some minor changes to the topic guide were agreed, including changes and developments in the way that questions were posed between groups. Following the second group in each case, it was clear that data saturation had been reached; though the latter had not been specifically sought a clear consensus between both groups and similar issues being raised, and sufficient information being gathered to form an answer to the questions posed within the topic guide(s).

6.4.2 Relationship to quantitative

The focus groups were specifically designed to supplement and explain the quantitative data in the first study. For this purpose, one of the lines of questioning in the physiotherapist group involved the presentation of the quantitative data to the participants, with a summary of findings.

The participants were then invited to comment upon these; if possible, to explain and account for the data, to highlight anything that to them seemed to be surprising, and to add thereto with insights of their own.

6.4.3 Population

The participants in the physiotherapist groups were physiotherapists who had experience of working in a musculoskeletal outpatient department, within the NHSCT.

The participants in the patient groups were patients known by the NHSCT to have been repeatedly re-referred into NHSCT musculoskeletal outpatient physiotherapy departments, as described, within the previous three years preceding the study.

In each case, these were aged over 18 and able to take part independently in the discussion. English did not need to be their first language, but they had to be proficient to the point of being able to hold a conversation.

6.4.4 Recruitment

Invitations for the physiotherapist groups were sent to the sites from which the quantitative data had been gathered. Individual therapists were given the opportunity to express interest in the study, or decline. Invitation packs were provided via the team lead at the site, consisting of an information pack, invitation letter and consent form (Appendix M-P). The consent forms from therapists expressing an interest were collected from the department by the Principal Investigator (Daniel Topley).

Invitations for the patient groups were sent to patients who had experienced repeated re-referral. Being representative of the picture described in the first study's quantitative data (chapter 5), these patients were referred within the time periods corresponding to the dates used for the quantitative data collection. These were easily identifiable via the NHSCT, who held a list from the quantitative study cross-referencing anonymised UIDs with the patient name. Importantly, patient's identifying information was not known to the team. At no point were patient details, particularly identifiers such as names or addresses, shared with the research team.

The Principal Investigator made invitation packs which consisted of an invitation letter, an information sheet, a screening questionnaire to verify the eligibility of the recipient, a standardised consent form, and a stamped addressed envelope to facilitate the return of the completed forms (Appendix M-P). The packs were fully made up with the correct postage and brought to the relevant site, where the only burden to a staff member was to address the pack and place it in the external post. The research team did not see to whom these were sent, and the recipients were randomly selected from the list by the collaborating member of staff, from the list. All recipients were instructed to return the packs to the research team directly if they consented to participate. Thus, only patients who had given written consent, were contacted by the researcher.

The screening questionnaire (Appendix K and Appendix O) allowed clarification of, for example, additional requirements for access to the focus group location/room. Each patient who responded was contacted by the researcher and offered an opportunity to ask questions and clarify any queries regarding the study. Times/dates were then confirmed. As per the screening questionnaire, patients were over 18, and able to take part independently in the discussion. English did not need to be their first language, but they had to be proficient enough to hold a conversation. Written consent was again confirmed on the day of each group, in every case.

6.4.5 Data collection

6.4.5.1 Recording

Each focus group was recorded by both audio and video recordings. Each of the two researchers present also made notes during the group. It was recognised that video recording along with audio, is not always carried out; however, there was felt to be strong justification for such an approach.

Use of video recording was judged suitable for: 1) identification of contributors and contributions where the audio file was unclear as to which participant is speaking; 2) distinction between contributors where there are multiple contributions simultaneously; 3) recording of body language, for example gestures of assent or nodding; and 4) other non-verbal actions, significant to the group content, which are not clearly noticeable from the audio file – for example, visible participant disinterest, discomfort or disagreement with a statement. In practice, due to lack of clear standardisation as to how some subtle non-verbal cues may be interpreted, interpretation was only based on those indicating clear assent or dissent with a suggestion, or enthusiasm with a concept was visibly demonstrated.

The proposed use of a video recording was stated in the information provided to the potential participants. There is no evidence that awareness of video recording was detrimental to the conversation or intimidating to a greater degree than audio recording, considering firstly the subject matter, and secondly as informed consent was obtained preceding the group. No feedback was received that cited video recording as a reason for non-participation.

In addition, it was to be made clear to participants, including in the information pack and in person on the day of the group, that the video and audio recordings were primarily to facilitate the anonymous analysis of each topic. Neither data file would be accessible by any other party or kept longer than necessary, as per the Data Protection Act (1998) and the Ulster University Code of Practice for Professional Integrity (Appendix 19, Research Studies Handbook: Code of Practice for Research Study) (Appendix). Identification by an anonymised, allocated number was used, as appropriate in the analysis of focus group data.

6.4.5.2 Sites

The physiotherapist groups were held at the NHSCT site at which the physiotherapists worked. Through dialogue with the respective team leads at each site, it was possible to identify an undesignated in-service slot in the sites' training schedules, along with a suitable area onsite to hold the focus group. This facilitated participation, as well as punctuality, and meant that no reimbursement was necessary – for example, for travel.

The patient groups were held on-campus at the Ulster University, in a reserved meeting room. Permission was granted by more than one NHSCT site to use their location if necessary, but participants in each case were geographically in a close enough radius to allow the use of the campus.

These rooms were reserved by the research team, having considered group sizes, requirements indicated on screening questionnaires, and times/dates suitable. Accessibility was then requested in advance of the group, based upon the needs of the patients, outlined in their screening questionnaires. Rooms were booked ahead of time, and the proposed time and date were presented to the patients in their invitation pack. However, patients were also invited to respond with interest even if times/dates did not suit – it was acknowledged that a further group could be needed, or changes made if recruitment for the original time/date stipulated proved impossible. Access to all these locations was given before and after the group, so that the room could be prepared, e.g. the recording equipment and seating could be set up and ready to begin the discussion at the allocated time.

6.4.6 Validity

Validity was ensured in several ways. Use of multiple researchers meant that the group was not dependent upon one subjective interpretation of the results. In each group, one researcher facilitated the discussion, and another ‘sat in’, observing the interaction and at the close of the group probing, clarifying, or asking an additional question if necessary. Again, one researcher transcribed the data (Daniel Topley), and another member of the research team reviewed and verified the transcriptions. Thereby, every transcript was read by 2 members of the research team – the first being the transcriber and facilitator (Daniel Topley) and the second either Dr I Wilson or Dr D Kerr. The second researcher to read the transcript was always those who had observed the group in question and could objectively attest to the accuracy.

Creswell & Miller, (2000), define validity in terms of how accurately and credibly the account given represents the participants’ reality. Respondent validation was employed in each group, with each participant supplied with a descriptive summary of the transcribed focus group discussion. This allowed participants an opportunity to identify the summary as being accurate and authentic and gave the opportunity to correct or refine if necessary. Maxwell, (1996), describes this approach as the most important means of avoiding misinterpretation.

6.4.7 Coding and data analysis

Each focus group was transcribed in full by the Principal investigator. This was aided by both audio and video recordings, and both verbal and non-verbal interactions were recorded in the transcription.

As described, a shorter descriptive summary, highlighting concisely the main themes of the discussion, was provided to each participant of each group. No analysis by the researcher was included therein.

An original copy of every transcript was kept, along with the appropriate back-ups. This was retained for reference, and included time references, anonymised participant designators, with explanatory non-verbal cues also annotated. A copy was then reproduced and used specifically for coding purposes. A hard copy was printed, and codes were drafted in a margin. An inductive codebook was used alongside this copy, consistent with the methods outlined by Bernard, et al., (2017). A codebook was created for each focus group, with a final set of codes used after each individual group's coding was complete. This reflected the iterative process of the study. The codes were independently by researchers who had not been involved in the original formation of the codes or writing of the codebook; coding was therefore agreed upon by all members of the research team.

A corresponding second copy of the transcription was used for analysis, having the final codes annotated thereon. It was originally intended for the analysis to be carried out using NVivo11 software. However, over the course of the transcription process and the coding, it was decided to utilise a method that allowed the researcher to maintain greater closeness to the data. This was additionally desirable as the researcher transcribed the focus groups himself, without outsourcing this role.

This was done in an adaption of the "long-table" approach, described by Krueger and Casey, (2000). The approach involved the annotating of 'sticky notes' with a code from the codebook, and the use of the focus group transcriptions to understand the context in which these arose. It was possible to note relationships between codes and their context and using this approach these relationships could be represented visually, as they became apparent. It is these relationships that then are translated into the themes discussed in the next chapters. Themes were reviewed by all members of the team, and consensus reached.

By utilising this approach, the analysis maintained the systematic, sequential, and verifiable attributes of the methods endorsed by Krueger & Casey, (2000). In the results and discussion of each

focus group study, each theme is presented narratively, including sample quotations taken from the discussion to illustrate that theme.

Chapter 7: Stakeholders' Perspectives; A Physiotherapist Focus Group Study

7.1 Introduction

As outlined in chapter 6, a series of focus groups were carried out amongst physiotherapists currently working in musculoskeletal outpatient departments within the NHSCT. Individual physiotherapists were recruited using invitation packs (Appendix M-P), provided via the team lead at the site. The physiotherapist groups were held at the NHSCT site at which the physiotherapists worked, and each focus group was recorded by both audio and video equipment, with at least two members of the research team present throughout the discussion.

7.2 Overview of participants

The number of participating physiotherapists varied by site, and each site provided physiotherapists with a wide range of experience in terms of years spent in musculoskeletal outpatient physiotherapy. The experience ranged from approximately 5 weeks, to over 30 years. Some had spent more than one rotation in OPD, and some had previously worked in other disciplines.

Physiotherapists were from Band 5 to Band 7/8, as per the banding within the NHS. The first focus group had 7 participants, and the second had 5 participants.

7.3 Overview of themes

The physiotherapists identified two groups of patients, though the issue focussed upon was regarding 'problematic' patients. Those who were expected to return for degenerative or arthritic conditions, and capable of self-management, were not considered problematic re-referrals and were not the main message. A common understanding being communicated by the physiotherapist groups was that there was a second group of patients who were being re-referred because of an unmet patient need. Following coding and categorisation, it was possible to identify and understand several main themes.

Three themes emerged from this focus group:

The first theme was **the physiotherapist as a 'fixer'**. The second theme surrounds the **encouragement of proactivity in the patients' approach**. The third theme concerns **the GP as the referral gatekeeper**.

It was evidently acknowledged by the physiotherapists, that a fourth theme which wove these three primary themes together was the significant **complexity and barriers to resolution**. This included

societal changes, unmet needs of the patients, and constraints within the care pathway structure with the frustrations of the physiotherapists as a result.

7.4 THEME 1: Physiotherapists as fixers

- **Patient expectation**

Patients view the physiotherapist as the solution to their problem, “genuinely, I’ll go to physio and they’ll help me” and that’s it. It’s up to us to educate them, “you have to keep going with your exercises, you have to help yourself, and this is how you’ll do that. So... it’s making the patient understand what they’re there for, and what we’re there for” (P3, FG2).

- **Patient education**

Physiotherapists believed that lack of patient education specifically surrounding their condition and its prognosis, was a key factor in the referral patterns. Physiotherapists believed that some patients had a “poor understanding of what’s going on” (P4, FG2), and that patients “just want to come back for something else” (P4, FG2).

There was a lack of opportunity, due to time restrictions, for referrers to fully inform the patient about their condition, and patients often went away having misinterpreted what they were told by referrers. One participant gave an example of a patient in their 40s being told by another health care professional they had “the back of a 90-year-old” (P1, FG2), and this meant that physiotherapists also had to deal with related fear, and fear-avoidance.

- **Patient passivity**

Physiotherapists believed that patients sought a passive treatment, and be fixed immediately, even if this often was an unrealistic aim, and they “see ones keep coming back and coming back and coming back - with the same problem, and I think... they expect us to do the treatment rather than taking onus themselves” (P6, FG1).

7.5 THEME 2: Encouraging proactivity

- **Changing approach by education**

Physiotherapists did not want to encourage a passive approach to treatment, but resources and space in departments restricted change from this approach, feeling “there’s still an onus on passive

approaches to these patients - which I think is good, because you, I think that's where the curtain is great, where they sit down and they have that one-to-one time to offload. But then after that, it's trying to get a movement...". Physiotherapists therefore described the importance of talking with patients. They identified themselves as the main opportunity for patients to have time for questions or clarification, or "the ones who are sitting down with their MRI results, x-ray reports, and actually explaining ... being able to change that person's – well hopefully! – change that person's perceptions through proper education". This involved "trying to take on their fears and trying to address those alongside your treatment" (P3, FG2).

Taking time to explain and speak to the patient was judged invaluable. "There may be no hands-on in one of those sessions, just simply explaining – and to see almost bright lights appear in their eyes, going "ah" ..." (P4, FG2). "You want the patient walking out thinking, yes, I understood what that physio was explaining to me", (P2, FG1).

- **The physiotherapists' biopsychosocial approach**

Physiotherapists attributed much of the problematic nature of the referrals in question, to the understanding that the patients in question had a host of accompanying and underlying yellow flags. Yellow flags were identified and considered more in recent years than previously, by "asking questions in a way to kind of understand that patient a bit better" (P4, FG2). This includes probing patients "whole circumstances, what's the background to what's causing this pain, are there psychosocial modifiers" (P4, FG1).

Physiotherapists further understood their role in addressing these to be particularly important as often they are the first "point of contact for, for a patient coming in here who have never offloaded their problems to anyone. And we're maybe the first in a medical, in a professional role that they have offloaded to" (P3, FG1).

Lead physiotherapists felt "I don't want the majority of staff in any department using electro, using tractions, using acupuncture for the majority of the treatments. Y'know, I, I feel very strongly that if we pick up any of our caseloads, we shouldn't have most of those patients having those passive interventions" (P1, FG1).

7.6 THEME 3: GP as the gatekeeper

- **GPs value physiotherapy**

Physiotherapists felt generally appreciated by GPs, who in many disciplines valued the physiotherapists as skilled assessors. This contributed to referrals in this direction, with the physiotherapists acknowledging “as much as we don’t want to see the repeat referrals coming in, that we’re held with very high regard” (P1, FG1). Some GPs encouraged referral to private clinics, as “the GPs are very tuned in to what the physio can offer” (P3, FG2) and “the stakeholder there, the GPs, ... have also seen what benefit we can give” (P1, FG2).

- **Inappropriate referrals**

Treatment of patients was not possible if the yellow flags and the issue of compliance resulting from yellow flags could not be addressed or acknowledged by the patient. Physiotherapists reasoned “if that person isn’t ready to comply and work with physiotherapy, then what’s the point of being referred?” (P4, FG2).

These types of inappropriate referrals were those “who had been through the system and had a lot of treatment... and a lot of modalities... and basically all that could, could be offered... and was discharged, and was very quickly back in the system again”. In this case, the belief was “if they’re not buying into some form of an active management strategy, goal-setting, pacing, education driven” (P1, FG1) therefore, it was not appropriate for a health care professional to keep referring patients for physiotherapy.

7.7 THEME 4: Complexity and barriers

- **The waiting lists**

The presence and scale of the waiting lists was a barrier to patients being screened and referred as they ought and created poor “communication links with gatekeepers” (P1, FG1). The desire was to “see people as soon as they’ve been referred, because obviously as we know, the longer people sit on the waiting lists, the more chronic their conditions are becoming” (P4, FG2).

- **Tracking re-referred patients**

When the LCID data were presented to the participants, the physiotherapists voiced surprise at the low frequency of FMS, as they felt this was not representative of what they were observing daily. Physiotherapists believed that the mechanism for electronically recording the diagnosis in LCID was not accurate for some conditions like FMS, and that FMS may be hidden within another code such as ‘pain’, masking the extent to which these patients were re-referred.

- **Societal changes**

Some re-referrals were attributed to a cultural legacy where, whilst physiotherapists have progressed in their understanding of chronic pain and long-term conditions, the physiotherapists thought that patients were still in a passive mindset, in fact exacerbated by cultural changes.

The physiotherapists elaborated: “way back, we would have had an acute pain; we would have very treatable, definite conditions, not these multitudes of factorial things we’re seeing with patients now” (P3, FG1). Further, a significant factor was that “there’s fewer manual jobs now, so they just get through life totally without being hit with a hard day’s work and pain is a new phenomenon for them” (P4, FG1).

Physiotherapists were surprised at the age range portrayed by the LCID data; however, they offered an explanation, namely, the decreased activity levels in children, and the consequential rise in musculoskeletal pain. Back pain, previously an immediate red flag in that age range, now was increasingly common in their experience, and physiotherapists thought that one reason might be that “children are not as active as they were” (P1 and P4, FG2) and that the increased usage of electronic games resulted in a greater frequency of Msk disorders.

- **Physiotherapist frustrations and scope of practice**

Physiotherapists appreciated the value of a biopsychosocial approach (vs a biomedical approach), feeling they were “well read on the biopsychosocial model”, but limited physical resources made it “difficult to move with the evidence base sometimes because your infrastructure doesn’t allow you to do so. If we were to try and prescribe some sort of movement-orientated, or strength and conditioning programme to our patients, we would already all struggle to move out of, y’know, to have, have an appropriate space to do that” (P1, FG1).

The other major frustration was the opportunity for training which would enable them to “have a little grounding” (P3, FG1) in CBT (cognitive behavioural therapy) or similar, as “we give a pain talk every month, and we’re all, y’know, fairly well versed ourselves, but I just think we struggle, we struggle with... that whole-body pain” (P1, FG1).

Because of a perceived inability to fully address yellow flags identified by a biopsychosocial approach and therefore resolve the patients’ complaint, physiotherapists were conflicted. They felt inwardly compelled to tell patients “let’s leave it at that, because I don’t think there’s anything passive or anything I’m going to do on you or to you’, y’know. But you are, you’re nearly... honour-bound, in

your head, to help and you just must do something” (P4, FG1). This “something”, they felt, invariably resulted in them providing a passive intervention.

- **Unmet need in pathway**

It was strongly felt that a pathway was needed that could address yellow flags and other psychosocial contributors. It was illustrated that the Trust had “only got one clinical psychology post within this Trust, and I really personally feel there needs to be more ...if our people who are presenting with pain as a physical manifestation of something else underlying, that maybe needs to be probed through a person that is really trained in that area” (P1, FG2). If “patients maybe had that support, might take away a wee bit from our recurring chronic pain type patients” (P3, FG1).

At any stage where yellow flags are highlighted, physiotherapists believed there should be opportunity to refer to “CBT teams, clinical psychology teams” (P1, FG2), for a “more holistic approach” (P3, FG2). If, following an assessment, the physiotherapist identified further help was needed, which was outside their scope of practice, that “we should be able to refer directly into the likes of the CBT, or pain management, or just things that would, rather than to have to just send them back to the GP” (P4, FG2). This was what physiotherapists called a “better pathway”.

Due to the lack of such a pathway, GPs were forced to send patients to physiotherapy in successive referrals. This included “heart sink patients your GPs have, and what to do with them. They’re there at the surgery every Monday morning and if they’re demanding physiotherapy, it’s a route for the GP to get a bit of breathing space and refer to us and for us to treat them. And if they’re in with their GP and they’re demanding physio, it’s very hard for the GP to, in a busy practice, to refuse that” (P3, FG1).

Specifically, in the current setting, physiotherapists felt they hadn’t “that avenue for GPs to refer on for to get the psychological, or the intervention from the chronic pain team, because it really up until recently had been non-existent, so there was nowhere else really – like speaking to GPs they’d have said, where else do I send them?” (P7, FG1). “We’re maybe the first in a medical, in a professional role that they have offloaded to. Once they’ve opened that can of worms... where do we go with it, how do we channel that?”. (P3, FG1).

7.8 Summary of results

Physiotherapists in outpatient departments had opinions on most issues raised in the discussion. All therapists but one had seen and experienced patients who returned for repeat referrals as described

by this study. There was one exception to this, being a newly qualified therapist who had only been in outpatient departments for a matter of weeks.

The existence of more than one group of patients suggested in the quantitative data (Chapter 5) was corroborated. There was consensus on categorisation, and reference was made to this, in discussion of most themes. Discussion however focussed on the 'problematic' referrals. There were a range of opinions on the quantitative data results, including attempts at accounting for patterns suggested thereby. Surprise was voiced at the low frequency of FMS diagnoses and the low ages involved in some cases.

Physiotherapists raised concerns about patient awareness of their condition, i.e. of both their expectations, and their own input into management, which was taken to directly influence outcome. Concerns were raised that referrers had insufficient time to discuss the patients' diagnoses and subsequent referral decision. The issue of yellow flags present in certain patients was a major theme, and the problems that therapists encountered when trying to firstly identify, and address these, for the benefit of the patient.

Therapists suggested a range of specific changes that they would like to see, in terms of a provision for these re-referred patients. There was a consensus that the waiting list was a hindrance to dealing with the pattern of repeat re-referrals, and that a more efficient pathway that could manage these patients was required. Specifically, this was in terms of a new, or adjunctive, pathway that allowed the use of CBT or psychological input alongside the physiotherapy care, perhaps as part of an MDT.

7.9 Discussion

At the centre of the discussion was the concept of two main patient groups. The first of these was described by the physiotherapists as 'passive' patients, often returning for the same condition (at times with comorbidities), possessing little knowledge of their condition, having low expectations of physiotherapy and thus uncompliant, and yet re-referred a short time after discharge. The second group stood in contrast, having a solid understanding and a proactive approach to self-management. These were either seeking just a small input from a qualified professional to aid their own management, after which it would be a long time until they were referred again, or else these were not actually referred for the same condition but rather had previously had a positive experience of physiotherapy for one complaint and were seeking input for a second. Positive patient experiences were acknowledged, being a legitimate contributor to re-referral; patients enjoyed the rapport and one-to-one treatment, and referrals were made at times because of previous benefit from

physiotherapy. Where this was the case, patients could voice to their GP a preference for physiotherapy, or even an individual physiotherapist. These could feature alongside other influential factors, though were not seen as problematic by themselves, and physiotherapists acknowledged this.

This picture informed the responses to the other questions and was evidently strongly reinforced in the therapists' minds. Discussion centred on the first of the two groups; it was clear that these were considered the 'problematic re-referrals'. Those belonging to the second group were not judged by the physiotherapists to be a concern, and thus were not discussed at length by them.

Consideration needed to be given as to what caused a 'problematic re-referral' – i.e., what led a patient to be considered amongst the first group. The mind-set of an individual, apart from any other characteristic (such as age, range of treatment options, setting, or number of treatment sessions) was the biggest contributor to this with physiotherapists identifying that the patients in question manifested a host of biopsychosocial factors, or "yellow flags". To clarify this terminology, it appeared that the groups spoke in terms of yellow flags as defined by Nicholas, et al., (2011), for the most part falling short of diagnosed psychiatric disorders or clinical depression ('orange flags'), and not including 'blue flags' which specifically surround perceptions of their workplace (e.g. its safety) which may prevent them returning. The 'yellow flags' could include many things in any individual's life, e.g. personal loss, family issues, financial struggles, job security, and others.

The physiotherapists believed that patients needed education regarding activity and exercise guidelines, for their specific musculoskeletal condition. Occasionally, time constraints on GPs/referrers meant that conditions and prognosis went unexplained and left the patient unclear as to what their symptoms meant. Such a lack of clarity could not be conducive to the patients' confidence in the process, nor to engaging in the management of their own condition. Such assertions are consistent with the literature which shows patient education in chronic disease brings statistically significant benefits in both health outcomes, and even more so, patient compliance (Mazzuca, 1982). Recent literature, (de Melo Ghisi, et al., 2014), attests to the efficacy of educational interventions to achieve behavioural change, and Lager, et al., (2010), who incorporates 35 meta-analyses amongst a number of patient groups (including diabetes, asthma, COPD, hypertension, cardiology, obesity, rheumatology, and oncology studies), agrees with the conclusion that education as an intervention improves health outcomes significantly. Moseley, (2002), attests to its efficacy specifically in musculoskeletal physiotherapy.

From what was expressed in the focus groups, physiotherapists believe that patients do not necessarily appreciate this psychological aspect of their need. This seems to be reflected in what physiotherapists felt the patients were looking for upon referral to physiotherapy. According to the groups, patients' perception of the physiotherapists' role focussed upon the treatment room experience – a “hands-on”, but “passive” receipt of treatment. A supposed physiotherapist reliance upon scans or x-rays for diagnosis was common, indicating that the patient perceives both the need, and therefore the role of the physiotherapist in meeting the need, in largely biomedical terms. Barron, et al., (2009), who investigates patient expectation of physiotherapy in detail, acknowledges what physiotherapists seem to indicate – that physiotherapists have moved from a biomedical model of treatment to a biopsychosocial and seek, often with difficulty, to move the patient to this standpoint also. Barron et al., (2009) cites the identification or “accessing” of a patient's expectation as being key to achieving patient adherence.

However, Barron et al., (2009) distinguishes between types of expectation. They use the pertinent example of a patient referred for physiotherapy following a recurrence of an old complaint, previously treated with electrotherapy. Here, the ‘predicted expectation’ may be receipt of the same treatment, whereas the ‘ideal expectation’ may differ, e.g. full resolution, or equipping for self-management. However, a further type of expectation is defined – that which is difficult for the patient to articulate, being as it is influenced by personal and social factors, and involves their experience, emotions, and perception of consequences. Barron et al., (2009), agree with Thompson & Sunol, (1995), in suggesting that this “unformed” expectation is distinct from the other suggested types of expectation and is extremely prevalent, and conclude that it is the addressing of this that must be considered by the physiotherapists. This suggests the need on the physiotherapists' part for an even deeper awareness of what application of the biopsychosocial model involves, i.e. that the ‘patient expectation’, in the context the physiotherapists speak of, is not distinct from ‘yellow flags’ but is interwoven with it and that therefore that this fuller appreciation of patients' expectations is to be found by yellow flag screening.

Physiotherapists, for their part, acknowledged their responsibility to treat using the biopsychosocial model, yet reportedly often found themselves in a role beyond what they felt capable of fulfilling. The physiotherapists believe that focussing upon passive modalities to achieve short-term goals were not enough without addressing the underlying factors, however, they felt conflicted as the former was at times the only route available. On the one hand, they wanted to do something for the patient, especially if a specific treatment request was made and was available; on the other, they believed from the evidence base that the best means of addressing the patient's needs were not

solely by passive modalities or by regarding pain as a purely biomedical issue, nor did they want to compound patients' perceptions by themselves treating from that standpoint. They were hindered, in part by their own knowledge thereof and in part by opportunities for professional development training. In practice, physiotherapists found it difficult to apply guidelines surrounding the biopsychosocial model, especially highlighting those with general pain syndromes which were a result of, or exacerbated by, yellow flags.

The care pathway structure was felt to be the main constraint in addressing patient needs. Physiotherapists believed that GPs valued the role of the physiotherapist as a skilled assessor, and credited GPs with appreciating the need of the patients. They also believed that for GPs there was no outlet for referral apart from physiotherapy. Patients with yellow flags which prevented compliance or self-management, were not judged appropriate for physiotherapy until these underlying factors were addressed, which patients felt unable to do themselves. Physiotherapists felt that they could for example, indicate to the referring GP the inappropriateness of referring patients with these host of yellow flags, or could refuse treatment, to reduce these referrals. However, they felt that at the core was the need rather of an adjunct to the current pathway, whereby clinical psychological input or CBT could be recruited at any point in the patients' care. In support of this concept in this specific setting, it was disclosed that at the time of the study there was currently only one Clinical Psychologist role trust-wide, illustrating the lack of this adjunctive therapy.

Literature exists which investigates the use of therapeutic "interventions targeting yellow flags" (Nicholas et al., 2011) in treating chronic pain. These have taken various forms, such as basic cognitive behavioural techniques at the hand of the physiotherapists (Hay, et al., 2005), or various methods of activity advice or workplace visits, with some benefit seen. However, the intervention suggested by physiotherapists in the current study, that of CBT, was employed by Linton & Anderson, (2000), in an RCT over six two-hour CBT sessions with a psychologist, alongside physiotherapy. 243 patients were included in the groups, and all groups reported improvements in pain, disability, and mood, with significantly less lost work time over 12 months. Further, the control used by Linton & Anderson, (2000) was the offering of education by the physiotherapist alongside physiotherapy. This would seem consistent with physiotherapists' beliefs within the NHSCT, as the current study's focus groups suggest not only the efficacy of CBT if used to combat these yellow flags, but also of this being offered as an adjunct to physiotherapy from clinical psychologists - and not from the hand of the physiotherapist. The literature seems to suggest a greater benefit using this

– in the situation the current focus groups describe, where physiotherapists seemingly have been unable to address the yellow flags themselves, such an adjunct would seem reasonable.

In further support of this, Linton et al., (2005), conducted a later RCT where two groups (a CBT-only group, and a CBT-plus-exercise group) had a control which received the usual examination and activity guidelines. In each of the two groups, the CBT was led by a psychologist, and in the exercise group, this component was led by a physiotherapist. Both groups showed objective improvements versus the control, especially in terms of health care usage and work absences, however interestingly there was no discernible difference in pain between the two intervention groups, suggesting the value was found in CBT led by a qualified psychologist. The patients recruited by Linton et al., (2005), had non-specific back and/or neck pain, at risk of chronicity.

Having discussed the groups' emerging themes thus, it appears that the provision of such an adjunct would be both supported by the literature and beneficial to the identified patients' care, especially given the apparent self-professed insufficiency of the physiotherapists' current level of training. The physiotherapists had seemingly held discussion on many of these issues amongst themselves prior to this study as reference to earlier conversations amongst themselves was made at points in the groups, and they also anticipated that GPs would agree with their perspective on a lack of referral options. It would therefore be of significant interest to understand other stakeholders' understanding of such a need, including the GPs.

7.10 Strengths and Limitations

A limitation with the chosen methodology was the time constraint encountered by holding the focus groups in an in-service slot. Whilst there were many benefits of this methodology which led to its choice, the maximum discussion time possible was one hour. Allowance was made by each site lead to ensure that the team could prepare the area beforehand, but there was no practical way to increase the discussion time beyond one hour, though the researchers' preference would have been one to two hours.

Due to the delays in the quantitative study, not all quantitative data analysis was complete for the first focus group – thus the first group were commentating on a preliminary picture. Whilst this could have affected results, there was no real change in overall patterns versus the final picture, presented to the next group. The preliminary picture agreed with the final picture.

The smallest focus group, having four members, also included the least experienced of the therapists. Therefore, there was a slightly different dynamic in comparison to the larger group which contained several very experienced physiotherapists, though no effect on consensus between groups was found. Having considered these limitations, it is nevertheless believed that the study stands as a robust work, and accomplishes satisfactorily its stated aims.

7.11 Conclusions

In conclusion, the physiotherapists describe those patients experiencing re-referrals as those with a multiplicity of yellow flags, which they struggled to address and had insufficient opportunity to extend their scope in this regard. They believed that the current care pathway did not adequately address yellow flags or psychological issues which contribute either to chronic pain, or poor compliance. Hence, these barriers to treatment remained with patients, from time of injury, through referral, to discharge. Without an alternative pathway, GPs had little choice but to attempt to refer to physiotherapy again. This results in 'problematic re-referrals' – patients with poor expectations and compliance, poor coping strategies, and indeed a poor prognosis until a solution is found.

The expressed desired solution was the provision of an adjunct (or alternative) to musculoskeletal physiotherapy, in the form of availability of specialist psychological or CBT input. Such an adjunct to the current pathway, the efficacy of which the literature appears to support, would be referred into at whichever stage the issues were identified – at either the primary care (referrer) or secondary care (Msk OPD) stage of a patient's care.

Chapter 8. Stakeholders' Perspectives; A Patient Focus Group Study

8.1 Introduction

A series of focus groups were carried out amongst patients known by the NHSCT to have been repeatedly re-referred into NHSCT musculoskeletal outpatient physiotherapy departments, as described (chapter 1), within the previous three years.

Patients were recruited anonymously, with recipients of invitation packs (Appendix I-L) randomly selected by the NHSCT from a shortlist of those known to have been re-referred multiple times. Recipients were asked to respond directly to the team with consent to be contacted and included in the focus group, following an opportunity to ask questions and clarify any queries regarding the study. The names of those patients on the shortlist and any identifying details were hidden from the research team until the patients responded with consent. The focus groups were held on-campus at the Ulster University in an accessible meeting room, and each focus group was recorded by both audio and video equipment, with at least two members of the research team present throughout the discussion as per ethical requirements.

8.2 Overview of participants

Patients were known to have experienced three or more referrals to musculoskeletal physiotherapy outpatient departments within three years. These patients were within the NHSCT coverage, and they had been treated at one or more sites from which the quantitative data (chapter 4-5) was collected. Each group had 4 participants, with 8 in total. Age or other identifying information was not recorded.

8.3 Overview of themes

Following coding and categorisation, it was possible to identify and understand several main themes (Figure...). Overall, the main theme was centred around patient management. Rather than symptoms or diagnoses/conditions, the groups focussed their discussion on the nature of their care. Within this wider scope, three themes were readily identifiable (figure...).

The first was **patient self-management**. This incorporated any proactivity on the part of patients in attempting to manage their condition, the level of control that they felt they had in their management, and the acknowledgment of this by health professionals including GPs and physiotherapists.

The second of these was the **physiotherapist role as portrayed by the patient**. Discussion included the hope invested in the physiotherapist at the point where patients had given up on their own ability to manage their condition, the expectation of what the provision would be and its value, the outcome of referrals (both positive and negative), and the dejecting impact of those outcomes upon both patient motivation, and later management.

The third important theme was **care pathway inadequacies**. This was largely negative, and described hindrances and delays following administrative issues, frustration felt at each delay, and the lack of options that the patient perceived each stakeholder (including themselves, the referrer/GP, and the physiotherapist) to have.

8.4 THEME 1: Patient self-management

- **Proactive steps**

Patients felt that they themselves were proactive in trying to find solutions to their MSk problems, which included “doing what I could at home anyway to try and ease the pain” (P2, FG1), or in proactively seeking medical help and scans from their GP. At times, they were prepared to pay privately or explore other treatment options, with examples where some “got a chiropractor, but the chiropractor, although I got relief, it didn’t help my shoulder, I did go and see a neuromuscular therapist, I paid a few sessions” (P3, FG1).

- **Control over management**

Despite searching for answers by themselves, patients didn’t feel in complete control of their condition, and unsure of exactly what the best steps would be in management. They confided that they “kind of feel stupid sometimes, you’re thinking, should this be working, am I doing something wrong, why is this - y’know? You begin to doubt yourself” (P3, FG1).

This was detrimental to their motivation, as they were unsure “where you’re going wrong, or whatever... and when, when you do get stiff and all, as I say, you get – this bit of depression starts in. and you think, aw I’m not going to make it” (P3, FG2).

- **Acknowledgment by health professionals**

A source of frustration was the perceived lack of acknowledgment of the GP or physiotherapists, as to what self-management was already tried and exhausted.

Patients felt “they [the healthcare professionals] didn’t ask” (P3, FG2), but “if they’d have actually listened to us, of what we knew wasn’t working and sort of moved on to something that possibly could have helped” (P3, FG1), their referrals would have been more profitable. However, it was consistently felt that “nobody ever asked me that, until I volunteered the information” (P2, FG1).

8.5 THEME 2: Physio role portrayal by patient

- **Hope invested by patient**

A major emphasis was made by the patients, on the extent to which they had invested hope in the physiotherapists’ ability to give answers where they themselves had failed. The patients “would’ve done anything if it’d have helped”, and at this stage were dependent upon the physiotherapists to “just do something” (P4, FG1).

They disclosed that even where motivation/confidence was low, “when you’re being, when they send you to physio, you kind of go anyway, to see if someone’ll help you” (P1, FG1).

- **Expectation of provision**

It was disclosed that initially, and even with later referrals, the patients “went with expectation they’ll fix or give me some relief, get to the root cause of the problem” (P3, FG1).

A recurrent theme was the desire for “instant pain relief” (P1, FG1) first and foremost, but also the patients described themselves as “looking for answers. Looking for someone to take me seriously, and to listen to me” (P2, FG1). Patients however did not feel physiotherapists could diagnose by themselves, believing they relied upon scan and x-rays.

- **Patient dejection**

Patients focussed a lot of their discussion on the various outcomes of each referral. Though positive outcomes were also described, many described a distinct lack of success each time, and it was rare that the condition was completely resolved. This was very demoralising to the patients, who “ended up feeling worse than what I had been, so by the time I saw the third physiotherapist I wasn’t hopeful at all” (P2, FG1). “And then you know it’s the ‘will I go to a different one. This will help me’ and it doesn’t help you. And it gets you down a bit because you say, well am I going to have to live with this?” (P1, FG1).

It was acknowledged by the patients, that there was also “a very close link between depression and treatment. And getting results. It’s so easy to slip into a negative mood and a negative way as opposed to a positive” (P4, FG2).

- **Patient reappraisal of physio**

Despite the lack of outcomes, patients could identify specific situations in which they still valued physiotherapy input and would consider referral. Post-op rehabilitation was thought to be “a lot more worthwhile” (P3, FG1).

One of the most valued provisions was physiotherapy clinical knowledge, and “the opportunity of discussing it with someone technical, and the encouragement, is very important” (P4, FG2), with the aim in view “to know how to live with my back each day” (P2, FG1). “I would like to talk to a physiotherapist and ask questions like tell them how I feel. And where I’m going wrong. And them advising me – that would help me” (P3, FG2).

8.6 THEME 3: Care pathway inadequacies

- **Re-referral despite ineffectuality**

Despite lack of resolution, the patients continued to be re-referred, even when it was “concluded that physio could do nothing for me. The doctor referred me again, and then the doctor referred me *again*” (P2, FG1 – emphasis original). These were generally not at the patients’ request, but the GPs. Outcomes were reportedly not investigated unless offered by the patient, who felt they “ended up having to say, the treatments from the physio, how had they helped, or how had they not helped” (P2, FG1). This was described as “an ongoing process” (P1, FG1), where patients were sent “back and forward” (P2, FG2). Patients were thus re-referred despite no previous outcome.

- **Delays and frustration**

Throughout the discussion, patients were frustrated at the delays involved in their management. Specifically, the frustration “was the waiting” (P1, FG1). This included the delays in waiting to get a referral, in the time it took between referral and appointment date, and the resultant prolonging of their pain and/or condition. There were occasions of administrative errors and inefficiencies also, one patient stating “my referral got lost last year and I had to ask for it again. Eh... and then it got sped up to an emergency referral, because it had been lost for over a year” (P4, FG1).

- **Lack of options**

It was strongly believed that one cause of re-referral was that the GP “ran out of options” (P4, FG1). Additionally, it was felt that the physiotherapists “knew themselves, well in the end she said there’s nothing more I can do” (P1, FG1). The patients perceived that they had exhausted their treatments, and still there was no positive outcome.

8.7 Summary of results

Patients generally described proactivity in trying to find solutions themselves, by exercise, lifestyle adjustments, or in proactively seeking professional input, even if this involved paying privately. Despite this, patients didn’t feel in control of their condition, and acknowledged a discouraging lack of understanding on their part around both condition and management.

Patients described their dependence upon the physiotherapists at this point. The patients expected the physiotherapists to give pain relief, to find the cause of the problem, assist the patient to understand it, and fix this. Both success and lack of success were described, though few patients described complete resolution. Patients were frustrated further by the physiotherapists’ perceived failure to consider their attempts at self-management.

Patients were further frustrated at delays. These included waiting for referral, the time between referral being made and presentation, and the resultant prolonging of their pain/condition.

Despite lack of resolution, the patients continued to be re-referred. These were generally at the GPs request, and previous outcomes usually had to be volunteered. Patients believed that both GPs and physiotherapists had exhausted options and had little hope in the success of re-referrals. Despite this, patients identified situations where they would still value and consider physiotherapy input.

8.8 Discussion

The focus group discussion centred around management of the patients’ condition/s. It was noted that patients spoke in terms of their symptoms or pain site, rather than diagnoses, with some exceptions. This may indicate that the majority had not been given a clear diagnosis, or one that they understood satisfactorily. Alternatively, it could be that they were less concerned with diagnosis and more with prognosis, and with the symptoms that affect their quality of life.

Most patients believed that they were proactive in their approach to their pain. Examples of steps that they had taken, both prior to and while waiting on a referral, to alleviate symptoms or maintain function, were given. These included adjustments to job responsibilities, or changes in routine. Some also described their attempts to self-manage by stretching or exercising, referred to by one patient as 'doing physio' themselves. These terms indicate the patients' perception of physiotherapy provision and indicate an awareness of the need to remain active. However, it may indicate a limited appreciation of the physiotherapists' scope of practice.

The patients however disclosed that they carried out these attempts at self-management with limited clear knowledge of what was correct for their condition. As a result, there was mixed success with their attempts, and they reached a stage where they doubted their ability to continue to manage the condition. More than one patient described feeling depressed at this point. This concept is described in the literature as self-efficacy beliefs, or the confidence to carry out a behaviour necessary to reach a desired goal (Bandura, 1977). Achievement of this is ideally seen when "patients succeed in solving patient-identified problems" (Bodenheimer et al., 2010). The identification of the problem was not the perceived issue; patients consistently stressed their awareness of their pain, movement restriction, or other musculoskeletal injury. An attempt at self-management, Bodenheimer et al., (2010) suggest, is inevitable in chronic pain management, however the patients in the current study openly professed an inability to achieve self-efficacy.

Denison, et al., (2004), note that self-efficacy beliefs are shown to have a greater effect upon disability from chronic musculoskeletal pain, than fear-avoidance (including kinesiophobia and catastrophizing), with both being more important determinants of such disability than even the intensity and duration of the musculoskeletal pain itself. Whilst not couched in these terms, the patient groups professed a lack of self-efficacy and noticed its effects especially upon their mood and motivation. The patients did not go so far as to attribute high levels of fear-avoidance to themselves, however a low level of self-efficacy is likely to lead to elevated pain-related fear, and from that, to greater pain and disability (Woby et al., 2007).

It was at this point in their management where the patients described their hope being placed in the physiotherapist provision. They felt dependent upon professional help, having in their minds reached the end of what they could do for themselves. There were clear expectations of what they expected the physiotherapist to be able to do for them; this was firstly (chronologically, and apparently in priority), the relief of pain. This agrees with the earlier observation that the patients again commonly spoke in terms of symptoms, their pain being the most prominent. Further to this,

they expected the physiotherapist to be able to identify and to help the patient understand the cause, and finally to address the cause.

Of the expected outcomes of physiotherapy then, immediate relief had priority over addressing the primary cause of pain, to the patient. In contrast, the patients perceived the latter goal as being prioritised by the physiotherapist. Explaining the cause of pain, or the treatment, was not felt to have been prioritised. Most patients felt that communication was of great importance; a perceived lack of this could therefore be detrimental to compliance or adherence. This also evidently contributed to patients' loss of confidence in the physiotherapists' assessment skills – represented in the fact that consistently patients voiced doubt whether physiotherapists could diagnose without the aid of scans, x-rays, or results of these provided by GPs. It is noteworthy that focus group studies which examine patients' perspectives upon physiotherapy provision, especially in the chronic musculoskeletal outpatient setting, also describe a lack of confidence in the patient that resolution would be achieved (Hills, 2005), and if there was any expectation at all, it was often unrealistic. Hills, (2005), stated that the establishing of patient needs, particularly the psychosocial rather than the physical, would lead to a more productive experience for the patient.

Frustration was felt where attempts at self-management were not believed to have been acknowledged by the physiotherapist. Patients believed that the physiotherapist must acknowledge the patient as an equal contributor to their management, and not be tempted into prescribing treatment without listening to feedback. In contrast, physiotherapists, according to our study, often voiced frustration at perceived non-compliance, but it was felt that this was a result of missing what patients had already tried themselves. Patient satisfaction with outpatient physiotherapy is generally achieved when patients feel that the physiotherapist understands their problem and their care needs had been met (Johnson, 1993; Thomas & Parry, 1996; May, 2001). Conversely, dissatisfaction is expressed when patients are not involved in decision-making, or there are delays in initiating treatment (Hills, 2007). Patients maintained ownership of their pain throughout, evidencing that their care was felt to be an intensely personal issue.

Both negative and positive experiences were discussed, although in the focus groups it was clear that most judged their previous experiences of physiotherapy to have been negative. In experiences considered to be positive, it was clear that the above shortcomings were not present, and that physiotherapists in those cases stood out as listening to the patient and communicating patiently. Electrotherapy and massage were generally judged as being the most beneficial treatments, although patients were resigned to the fact that receiving these on a constant basis was not sustainable.

It was a cause of frustration that despite unsuccessful outcomes, patients were repeatedly re-referred; with few exceptions, this was felt to be instigated by the GP. Exceptions included patient desire for temporary relief, or the hope that another physiotherapist might offer more treatment options or a more detailed explanation than a previous. These cases were in the minority. Where the GP had instigated the re-referral, there seemed to be consensus that this was due to no other options being left open to the GP, but to refer to musculoskeletal outpatient physiotherapy. Patients in this scenario seemed to feel obliged to go, the referral having been made. In the case of those who expressed this, there seemed to be almost a conscious effort to rekindle hope in the physiotherapist. Again, however, the associated delays were discouraging and frustrating. Patients across each group described this process as wasting time on the part of the patient and the physiotherapist.

Patients in the current study were critical of the inefficiencies of the care pathway. Specifically, there was more than one patient whose referrals were lost or delayed, and there was unanimous criticism of the length of time that it took; both to receive a referral, and then the duration before the appointment itself. Patients' conditions were described as worsening noticeably in the period that they waited until their appointment date. This led to still further frustration, as patients believed resolution may have been achieved had the diagnosis or interventions come earlier in the process. This issue of delays seemed administrative in nature. There is evidence which acknowledges that waiting for further investigations and tests/results can increase distress/anxiety in many settings (Lebel, et al., 2003; Doré, et al., 2013), and across a number of conditions – including, but not limited to, chest pain, low back pain and headache (van Ravesteijn et al, 2012) – despite the referrer intending to provide both reassurance and further insight into the pathology/injury. It is not unreasonable then, that an extended wait, and one perceived as unnecessary, will be extremely frustrating to those suffering from chronic musculoskeletal pain, whatever the origin.

Patients described scenarios wherein they would value physiotherapy input and consider referral again. These included referrals for the same or for a different diagnosis/symptom pattern. Examples included rehabilitation, especially after an operation, and exercise prescription. Instruction and clarification regarding these and education in the correct techniques for exercises was particularly valued. Importantly, some valued this even though it was evident throughout the discussion that they did not expect resolution of their condition; physiotherapy input, especially in terms of advice and instruction, was valued as it would enable the patient to manage the pain themselves having had this input. This is not an uncommon finding in assessing patient satisfaction with physiotherapy provision, with patients at times being found to be satisfied with the receipt of valuable information,

despite actual resolution not being achieved (May 2001). The specific areas in which they needed this advice was in movement, and how to manage function and symptom management daily.

It appeared that throughout the discussion the patients maintained the perception of themselves as proactive managers of their condition, and as seeking self-efficacy. It seems that the focus groups still aspired to this despite their experiences of unsuccessful re-referral, with the input of physiotherapy to receive clear information and guidance in their management.

8.9 Strengths & Limitations

Recruitment was difficult in the patient groups, which was anticipated. A strength of the design, with accompanying permissions, was the flexibility following feedback from patient respondents, whereby adjustments were made to give flexibility in response time, in dates or times of groups, and numbers of invitation packs sent. Each of these were adapted to account for and address the low response rate that became evident and were based on feedback from the small number who did respond. Despite this, a low response rate (approximately 10%) was achieved.

It appears that those who encounter these patterns of re-referral are reluctant to engage in the research process. As a result, the respondents may represent the more proactive patients who are being re-referred as suggested by this study (based upon the quantitative picture in chapter 5 and described further by the physiotherapists in chapter 7). The low response rate may also suggest a higher ratio of 'passive' to 'proactive' patients. However, this cannot be confirmed definitively at this stage. Notwithstanding these limitations, the study can be seen to be robust, and satisfactorily accomplishes its stated aims. Studies have also found that a lower response (lower than, for example, 60%) does not necessarily correlate with poorer quality finding (Holbrook, et al., 2007).

8.10 Conclusions

In conclusion, patients perceive themselves as proactive in self-management, though with low self-efficacy beliefs. They value physiotherapy input, especially where self-management has proved unsuccessful. Patients expect the physiotherapist to provide pain relief, diagnose, help the patient understand their condition, and fix the underlying issue, in that order.

Frustration was attributed to low self-efficacy, repeatedly unsuccessful episodes of care, and repeated delays within the care pathway, consistent with the existing literature. Without these, patients believe that physiotherapy has potential for greater success. Patients believe that

physiotherapists rightfully expect adherence, but do not investigate adequately the reasons behind perceived non-compliance.

Patients identify lack of treatment and/or referral options for secondary care as being a cause of GP re-referral to physiotherapy. Finally, despite negative experiences, patients still value physiotherapy as providers of rehabilitation, and as sources of knowledge and advice to aid self-efficacy.

**Chapter 9. GPs perspectives on repeated re-referral of patients to musculoskeletal outpatient
physiotherapy**

9.1 Introduction

Patients, predominantly with chronic pain conditions, are often repeatedly re-referred into musculoskeletal outpatient physiotherapy departments; implications from this include risk that a care pathway does not manage patients' conditions optimally.

After a systematic search (chapter 2), found a lack of investigation into the issue, an exceptional report was acquired confirming that there was a population having multiple referrals in a short time-period. Data collection from the LCID database enabled statistical analysis and description of the figures involved, suggesting emerging patterns which built a larger picture of the referrals in question. Despite a larger picture having been formed, further information was required to complete this picture. It was appropriate to investigate the experiences, attitudes and perspectives of all interested parties or 'stakeholders', in relation to the issue of re-referral.

9.2 Rationale

Differences in perspectives are often held between stakeholders in physiotherapy treatment – one such stakeholder being the general practitioner, or GP (Grimmer et al., 1999). Repeated re-referral into musculoskeletal outpatient physiotherapy departments has been investigated qualitatively through physiotherapist and patient focus groups in chapter 7 and 8 respectively.

It was viewed as invaluable to also include the experiences and perspectives of GPs who refer into the NHSCOT outpatient physiotherapy departments, being as they are an important stakeholder group within this re-referral system. This survey therefore investigates repeated re-referral specifically from the referring GPs' perspectives.

9.3 Aims and Objectives

The aim of the study was to investigate the experiences and perspectives of the referring GPs, surrounding the issue of repeated re-referral of musculoskeletal patients.

The objectives were more specifically to:

- gather GPs interpretation of patterns emergent from the LCID data,
- understand GP decisions when patients' symptoms are unresolved following the completion of respective physiotherapy sessions
- allow GPs to provide additional insight to that already gleaned from focus group studies

9.4 Methodology

Feedback from a collaborating practitioner indicated that it was not likely to be suitable to carry out individual interviews to gather GP perspectives as time constraints and limited schedules of the GPs would constrain responses. Through dialogue by means of a collaborating practitioner and the Northern Health and Social Care Trust (NHSCT), it was believed to be most practical, and would provoke a greater response, to use the form of a questionnaire, designed around the same topics from the patient and physiotherapist focus group studies. Completing and returning a questionnaire was understood to be less burdensome than requiring GPs to attend an interview or focus group and would facilitate recruitment and engagement in the research process. Thus, pragmatics as well as careful consideration of alternative methodologies dictated that structured questionnaires would be used.

Recruitment being anticipated as difficult, the questionnaire format was designed to facilitate efficient completion and returning of questionnaires, whilst also gathering all data necessary to allow comparison to the focus group studies amongst the physiotherapist and patient populations, and to maintain a relationship with those earlier studies.

The questionnaire was designed in consultation with supervisors, with the team referencing the picture apparent from LCID data and information from the preceding focus groups. Thus, the team could identify questions that ought to be addressed following analysis of those groups and allowing the GPs to comment upon the same areas that other stakeholders had done. In total the design underwent 5 iterations, with all members of the research team agreeing upon a suitable format for the questionnaire, prior to being submitted to OREC and approved by the appropriate sub-committee (Appendix G). Questionnaires were distributed to individual GPs willing to engage with the process, via the collaborating practitioner, and collected from these when complete, thus reducing their burden further. By this method, recruitment of a small sample of GPs was achieved.

9.5 Design

The questions included in a self-completed questionnaire included the concepts of the initial research question (Phellas et al., 2011). Questionnaires were designed to: 1) correspond to the same research question as the focus groups; 2) provide a multiple-choice answer to facilitate completion of the questionnaires and ensure relevant answers were given; and 3) avoid bias. Choices for each

question corresponded to themes arising in the focus groups, but also aimed to account for every reasonable alternative answer to the question, even if not featured in the group discussion.

For example, Q1 (Appendix Q) presented the scenario of a patient with musculoskeletal pain, having been referred more than once with unsuccessful outcomes, returning to their GP with their condition unchanged. It was then asked what approach would be typically taken, and accounted for each reasonable course of action in the choices given, including a) to refer again, b) to prescribe medication, c) to refer to a different secondary care service, d) to request an investigation such as a scan, e) to discuss self-management by lifestyle changes, or f), a further course of action not considered by the previous options. Should the GP select answer a), the questionnaire allowed clarification from the GP on why that choice was made to re-refer to physiotherapy, with multiple influential factors considered, and space again was given for the GP to add any alternative reason not considered. Thus, the survey included limiters to facilitate responses, as well as opportunities to elaborate and provide qualitative data.

Asch et al (1997) discusses explanatory variables for low response rates, including profession (with doctors characterised by a typically lower response rate), anonymity, survey length, and postage. These were -considered, firstly by choosing a methodology that appeared most likely to garner a response as above and by designing the questionnaire to be brief but comprehensive. The questionnaire used a combination of Likert scales, multiple choice questions, and open space in which to give the respondents an opportunity to explain or elucidate upon answers if they wished. The latter, whilst usually insufficient by itself, is valuable in understanding and illustrating responses (Garcia, et al., 2004). Design of the questionnaire thus allowed the GP to respond to a simple scenario with a clear answer, whilst avoiding research bias, and to provide the data required in a time-efficient manner, as it negated the need for lengthy prose or written answers. At the close of the questionnaire, space was given for GPs to enter their contact details. This would allow the research team to contact them should any answer require explanation or elucidation, or should there be unusual patterns emerging. GPs were not required to do so, and supplied details at their own discretion if they consented to being contacted. Otherwise, all responses and analyses were anonymous.

9.6 Response rate & respondents

All consenting GPs received from the research team a hard-copy questionnaire (Appendix). In total, 12 GPs consented to receiving the questionnaires in this manner, and of these 7 responded with a

completed questionnaire; a response rate of approximately 58.3%. All respondents were practising GPs, who refer patients at varying rates to musculoskeletal physiotherapy outpatient departments as they see appropriate.

9.7 Summary of results

The context which framed the questionnaire responses was that of a GP encountering a patient in their clinic/surgery who had been repeatedly re-referred to musculoskeletal outpatient physiotherapy, without resolution. The GPs answering the questions were to do so considering this patient.

Most GPs stated that they would not re-refer, although they would consider doing so if patient requested re-referral, insufficient number of sessions previously, or there was prior experience of success. The last of these would make re-referral highly likely. Prescription of medication, lifestyle changes, further investigation, or onwards referral were preferred alternatives. LCID patterns were comparable, though at slightly higher rates than expected. GPs generally attributed re-referral to more than one cause, but primarily long-term pain conditions, e.g. fibromyalgia. GPs rely upon both patient request/inputs, and upon their own experiences, a significant amount.

9.8 Results

9.8.1 Scenario

Most respondents would not re-refer to PT (Yes: n=2; No: n= 5). Both of those respondents who would consider re-referral to physiotherapy, indicated that they would do so if the patient requested it, of if physiotherapy had worked at another time, or if they felt that there would have been improvement had the number of sessions been greater.

No GP (n=0) described re-referral caused by other options being exhausted, by comparison with a similar case, or lack of any other appropriate service. GPs indicated in the scenario given, that they would prescribe medication (n=6), discuss pain management with the patient through lifestyle changes (n=6), would consider requesting a scan or an x-ray (n=5), or consider a referral to a different secondary care service (n=5).

9.8.2 LCID patterns

Most thought the LCID data were comparable to their own experiences (comparable: n= 4; not comparable: n=1; not sure: n=1), though most GPs expected fewer referrals in the LCID data (more:

n= 0; fewer: n=5; the same: n= 2), indicating that GPs, though aware of the occurrence of re-referral, were not fully aware of the extent of the problem.

GPs differed as to a single leading cause of re-referral, although most attributed this to patients with long-term pain conditions, e.g. fibromyalgia (n=4), followed by expected exacerbations of degenerative conditions (n=2), or specific requests by the patient for physiotherapy (n=1).

6 respondents highlighted more than one reason. Only one GP attributed re-referral to patients with long-term pain, e.g. FMS and/or CRPS.

9.8.3 Influences

Most GPs answered that they relied upon patient request/input a significant amount (n=4), with fewer answering, 'a small amount' (n=2), and fewer still 'very heavily' (n=1).

All respondents relied either a significant amount (n=6) or very heavily (n=1) on their own experiences, when they decided whether or not to re-refer a patient to physiotherapy.

9.8.4 Previous outcomes

Three stated that they would be highly likely to refer a patient to physiotherapy for a condition, if it had previously worked for a different condition for that patient, and four stated that they would be more likely than before to refer a patient to physiotherapy for a condition if it had previously worked for a different condition for that patient.

9.9 Discussion

GPs felt that they would generally not refer again to physiotherapy in the scenario given without the presence of certain conditions; namely, if the patient requested it, if physiotherapy had worked at another time, or if there was reason to suppose a possibility of improvement with more sessions. That is, even though there was no evidence from the current episode that physiotherapy was effectual, there were external considerations that may influence a re-referral. However, they did not feel inclined to refer simply due to other options being exhausted, or there being no other appropriate service. This contrasted with the perceptions of physiotherapist, discussed in chapter 10.

Prescribe of medication, and discussion of lifestyle changes was preferred. Most would also consider a scan or x-ray, or referral to a different secondary care service, alongside all these steps, even in cases where physiotherapy was considered. Most GPs did not take the opportunity to disclose

examples of what these secondary care services might be, and only one GP suggested specifically referral to a pain clinic; fibromyalgia may be referred to such a service, being uncertain in aetiology and having multifaceted treatment approaches (Mease, 2005), but long approached as rheumatological (Wolfe, et al., 1990; Crofford & Clauw, 2002; Goldenberg, et al., 2004). Willingness to focus upon symptom management (i.e. medication and lifestyle changes) or to investigate further (i.e. scans) seems to suggest then, that GPs associate the described scenario with conditions that have less-clear diagnoses – conditions, or pain with verifiable diagnoses, could have a higher likelihood to have clear pathophysiological causes that are directly addressed.

GPs most commonly cited patients with long-term pain conditions, such as fibromyalgia, as causing the re-referral rates seen, and indeed were felt to be the single largest cause. Literature varies in its treatment of fibromyalgia (FMS) diagnoses, even including whether it is ‘underdiagnosed’ (Di Franco, et al., 2011) or misapplied in the opposite extreme as an umbrella term (Hendler & Romano, 2016), but it is widely acknowledged to be diagnosed with a degree of inaccuracy (Fitzcharles & Boulos, 2003). Thus, GPs, according to their the data in our study, may choose to treat or manage symptoms rather than simply refer to physiotherapy repeatedly. In this way, they believe they can address symptoms, and encourage a level of self-management. In contrast, only a minority felt that regular exacerbations of degenerative conditions were one of the main contributors, where treating symptoms as opposed to diagnosis may occur if the degenerative condition (such as osteoarthritis) is perceived as being irremediable long-term.

Whilst GPs would not typically choose to re-refer to physiotherapy, unless there was in their mind enough reason, GPs also felt that they would be highly likely, that is, more likely than before, to refer a patient to physiotherapy for a condition, if physiotherapy had previously brought success for that patient. Though not stated, it may be deduced that GPs therefore do not view patient characteristics as the cause of the unsuccessful episode/s presented in the scenario. In this case, it seems unlikely that prior success possibly with a perhaps unrelated condition would be enough catalyst for re-referral especially if, as a rule, GPs would be reluctant to re-refer to physiotherapy. In this, GPs felt that they relied upon patient request/input and their own experience/beliefs to a significant amount, with no obvious significant preference upon one over the other indicated, though the language chosen may indicate a slightly higher emphasis upon their own experience. ‘Heart-sink’ patients continually re-appearing was not commonly associated with re-referrals. In this case, musculoskeletal physiotherapy re-referrals appear consistent with the larger picture of patients who are “frequent consulters” and reappear before GPs often, where few are likely to conform to “the heart-sink stereotype” (Gill & Sharpe, 1999) that the literature presents. The respondents rather

reflected the view that patient input and feedback was legitimate and valuable. Gill & Sharpe, (1999), who defined 'frequent' in their case as 9-14 GP consultations per annum, suggest that these patients are likely to have multiple complex problems, often including chronic physical disease, with or without psychological and social problems. If it is possible to extrapolate this complexity to the current scenario considered, it may offer further insight into why GPs are willing to consider the various routes they have indicated, when a service such as physiotherapy has not seen results over multiple episodes or referrals.

9.10 Strengths & Limitations

The main limitation was sample size due to difficulty with recruitment. Focus groups, the original planned methodology, could not be recruited for, and a poor response rate was returned from the chosen methodology, despite it being the most suitable pragmatically. It was difficult for non-responses to be accounted for; Cook et al., (2009), allow that if a non-response depends on known characteristics of participants, it can therefore be inferred how these would have answered, based on how responders with those characteristics did so. Having maintained anonymity (unless consent was otherwise given), the known characteristics are few, except for profession and geographical location. Others disagree with this assumption (Richardson, 2005; Nulty, 2008; Goyder, 1982), and Cook et al., (2009) further acknowledges that attempts to account for non-responses cannot compensate for higher response rates. Thus, only the findings from the study could be presented, without extrapolation or assumption along these lines.

Despite identified difficulties, data was obtained with which to inform future research in the area. Despite small size, the perspectives of the GPs as a key stakeholder in referral ought to be attended to. A methodological strength was the avenue included to follow up answers, should patterns emerge which were unexpected or difficult to interpret. The resultant lack of consent to do this was not due to study design. Some answers given may have afforded further explanation. For example, one respondent answered that the rates given were what was expected, however, also added subsequently that they expected fewer. This may be in error or may have indicated that the content of re-referrals was acknowledged but were surprised at how high rates were shown to be. Another avenue that would have been of interest to explore is that of the alternative secondary care service that GPs indicated they would consider. Follow-up may have elicited more detail, but unfortunately was not consented to at this time.

9.11 Implications for practice and future research

Amongst GPs, evidence suggests that salience of the subject matter, along with lack of activity or interest in the area is a strong predictor of response rate (Heberlein & Baumgartner, 1978; Armstrong & Ashworth, 2000; Barclay, et al., 2002). It could then be inferred, that repeated re-referral to physiotherapy outpatient departments is not an area of highlighted concern for GPs; an explanation which, returning to the point made by Cook et al., (2009), seems consistent with responders, who mostly do not envisage themselves as re-referring in the scenario given by the questionnaire and would have expected re-referral rates to be lower.

It would be beneficial to revisit the possibility of recruitment for GP focus group/s, following further advances in the area, and greater awareness of the occurrences and their implications that arise from such research. It would also be beneficial in subsequent research, to address the questions left unanswered from the GP questionnaires; particularly regarding the choice of onwards referral and where GPs feel these patients might be best served, if such a referral is not to outpatient physiotherapy. Also, replication of these methods in other Trust settings would provide a valuable comparison of both the occurrence of re-referral, and of a GP's awareness or research interest therein.

9.12 Conclusion

Re-referral rates were comparable to what GPs expected, albeit slightly higher. These rates, GPs indicate, are twice as likely to be those with diagnoses of general pain conditions like fibromyalgia, as they are to be common exacerbations of degenerative conditions.

GPs would be disinclined to re-refer these patients, however, in practice they would consider referral following certain considerations; namely, only if the patient requested it and/or if there was reason to expect improvement with more sessions. They were highly likely to re-refer, despite their initial reluctance, if physiotherapy had resolved a previous condition of the patient in question. In each referral decision though, GPs reportedly placed significant importance on both their own expertise, and the requests/input of the patient. GPs do not view a lack of alternative pathways as enough reason to re-refer.

Chapter 10. Stakeholders' Perspectives; A Discussion and Comparison

10.1 Introduction

The occurrence of patients, predominantly with chronic pain conditions, being repeatedly re-referred into musculoskeletal outpatient physiotherapy departments, was raised in discussion with Trust physiotherapists. The implications of this, particularly the risk that there may be a significant number of patients with these (or other) conditions whose conditions are not managed through an appropriate pathway, merited investigation into re-referrals.

During an extensive systematic search of the available literature (chapter 2), there was found to be a marked lack of material investigating the issue of re-referral to outpatient physiotherapy, as well as to other forms of secondary care. Primary data was sought through an exceptional report acquired from one NHS Trust database (LCID), confirming the perception that there was a population having multiple referrals in a short time-period. Subsequent quantitative data collection from the LCID database and patient records provided relevant information; namely, the rates of return of patients, diagnoses, and time periods involved between episodes, and enabled statistical analysis and description of the population involved. These data suggested certain patterns of the occurrence of repeated re-referral within the Northern Health and Social Care Trust (Chapter 5).

The 3 stakeholders in the referral process are viewed in this study as the referrer (in this case the GP), the physiotherapist, and the patient themselves. In this study, the views and perspectives of all three of these stakeholders are considered and discussed.

10.2 Aims

The aim of the study (chapter 6) was to explain the picture presented by the LCID data of repeat re-referrals into musculoskeletal physiotherapy outpatient departments in the NHSCT, and to fully investigate the perspectives of the stakeholders regarding repeated re-referrals.

The objectives were particularly:

- 1) To gain further detail into the occurrence and causes of re-referral,
- 2) To account for patterns appearing in quantitative data, and
- 3) To obtain suggestions regarding how to address re-referrals.

10.3 Methods

Focus groups were carried out amongst physiotherapists, and amongst patients being re-referred into physiotherapy. Structured questionnaires were distributed to GPs, who referred into the MSK OPD departments (chapter 9). As described in chapter 7, focus groups for physiotherapists were carried out at NHSCT Msk OPD sites, with two researchers present at each. Focus groups for patients were conducted at meeting rooms in the Ulster University campus. Two researchers attended each focus group. Participants were identified via the NHSCT, with no identifying data used, and personal contact withheld until informed consent on the part of respondents was received. Content and structure of the questionnaires for the GPs was designed to address the research question and issues raised within the focus groups.

10.4 Summary of Findings

10.4.1 Physiotherapist focus groups

Independently, and prior to being presented with the LCID 'emerging picture', physiotherapists introduced the concept of two main patient groups. Physiotherapists focussed upon the first of these patient groups; it was clear that these were considered the 'problematic re-referrals' and were described as 'passive' patients, returning mainly for the same condition (at times with comorbidities), possessing little knowledge of their condition, having low expectations of physiotherapy and thus being uncompliant, and yet re-referred a short time after discharge. The second group stood in contrast to the first, having a solid understanding and a proactive approach to self-management. These individuals sought physiotherapy input to aid self-management, afterwards going a long time until re-referral.

The physiotherapists' perspectives describe those 'problematic patients' as presenting with a multiplicity of yellow flags, which they the physiotherapists struggled to address, and had insufficient opportunity to extend their scope in this regard. They believed that the current care pathway in place did not adequately address yellow flags or psychological issues which contribute either to chronic pain, or poor compliance. Hence, these barriers to treatment remained with patients, from the time of injury, through referral, to discharge. Without an alternative pathway, the physiotherapists believed GPs had little choice but to attempt to refer to physiotherapy again. This resulted in 'problematic re-referrals', i.e. patients with poor expectations and compliance, poor coping strategies, and indeed a poor prognosis until a solution is found. The expressed desired solution was the provision of an adjunct (or alternative) to musculoskeletal physiotherapy, in the

form of availability of specialist psychological or CBT input. Such an adjunct to the current pathway, the efficacy of which the literature appears to support, would enable a patient to be referred into a more appropriate intervention at whichever stage the issues were identified – at either the primary care (referrer) or secondary care (Msk OPD) stage of a patient's care.

10.4.2 Patient focus groups

Patients perceive themselves as proactive in self-management, though with low self-efficacy beliefs. They valued physiotherapy input, especially where self-management has proved unsuccessful. Patients expect the physiotherapist to provide pain relief, diagnose, help the patient understand their condition, and fix the underlying issue, in that approximate order.

Frustration on the part of the patients was attributed to this realisation of low self-efficacy, repeatedly unsuccessful episodes of care, and repeated delays within the care pathway, consistent with the existing literature (Lebel, et al., 2003; Doré, et al., 2013). Without these issues, patients believe that physiotherapy has potential for greater success. Patients believe that physiotherapists rightfully expect adherence, but do not investigate adequately the reasons behind perceived non-compliance. Patients identified the lack of treatment and/or referral options for secondary care as being a cause of GP re-referral to physiotherapy. Finally, despite negative experiences, patients still value physiotherapy as providers of rehabilitation, and as sources of knowledge and advice to aid self-efficacy.

10.4.3 GPs questionnaire study

The context which framed the questionnaire responses was that of a GP encountering a patient in their clinic/surgery who had been repeatedly re-referred to musculoskeletal outpatient physiotherapy, without resolution. The GPs answering the questions were to do so considering this patient. Findings from the questionnaire study were that re-referral rates were comparable to what GPs expected, albeit slightly higher. These rates, GPs indicated, are twice as likely to be those with diagnoses of general pain conditions like fibromyalgia, as they are to be common exacerbations of degenerative conditions.

GPs were disinclined to re-refer these patients, however, in practice they would consider referral following certain considerations; namely, only if the patient requested it and/or there was reason to expect improvement with more sessions. They were highly likely to re-refer, despite their initial reluctance, if physiotherapy had resolved a previous injury of the patient in question. In each referral decision though, GPs reportedly placed significant importance on both their own expertise, and the

requests/input of the patient. GPs did not view a lack of alternative pathways as enough reason to re-refer.

10.5 Key Issues

10.5.1 Deciding to re-refer

Findings from the studies show that GPs do not anticipate re-referring when a patient has had more than one referral to musculoskeletal physiotherapy and has evidently not resolved or changed their condition. In contrast, patients felt that GPs were the stakeholders who initiated re-referrals and did so without probing previous outcomes. It was, the patients felt, they themselves who had to offer that information to the GP if it was to be considered, and having done so, they felt they may have an influence on whether a further referral is made. GPs felt that they put a significant amount of reliance upon patient's requests/preference, therefore it may be that GPs value the patient stepping forward and providing their insight of care, but that they may not always receive or request this after every episode. A deficiency in communication between patients suffering from chronic pain and their doctors is documented in the literature, with the conclusion that even when conversation was instigated, each party spoke at cross-purposes and patients felt strongly that doctors did not listen to them but continued with preconceived routes (Kenny, 2004). The study by Kenny (2004) was mutual, with doctors feeling the same was true of patients. This lack of agreement was founded upon perceived source of pain; the population in question had pain of unconfirmed origin. A process was hypothesised based on the themes emerging from patient and doctors' dialogue; lack of consensus on cause of pain, a struggle on each part for legitimisation of viewpoints, resultant de-legitimisation of the other party with a de-individualisation of the patient coming directly from this. This resulted, finally, in "endless referrals" (Kenny, 2004). Patients testified to the doctor that these provided no resolution, but it seemed that the de-individualisation of the patient and its results was a reluctant, but by-then default, position occupied by the doctor, caused by the process suggested.

Findings show GPs did not feel inclined to refer simply due to other options being exhausted, or there being no other appropriate service. This stands in contrast to the perceptions of both physiotherapists and patients who felt unequivocally that the latter was in fact one of the main causes of GPs re-referring. GPs believed there are existing alternatives to the patient being re-referred to physiotherapy. Specifically, they feel that they would legitimately have the choice of whether to prescribe medication and discuss pain management through lifestyle changes. Most would also consider a scan or x-ray, or referral to a different secondary care service. It appears that

the GPs have a 'wider view' of alternatives – i.e. that they do not necessarily see, judging from their answers in the questionnaires, the need to refer the patient to secondary care service by default. They feel that the conditions in question could be addressed or at least aided by alternatives which lie outside of secondary care – a perspective perhaps not shared by physiotherapists, who believed that secondary care is needed in the treatment of these patients.

To probe the evidence base for specific medicines, success rates of investigations for pathologies, and/or a range of secondary care services either alone or in combination with physiotherapy goes far beyond the scope of the current PhD. Pain clinics are the only named alternative secondary care pathway, which GPs would refer to should they decide to refer onwards, though most GPs, when given the opportunity, did not offer a pathway by name. The literature supports the efficacy of these, for pain, mood and behaviour-related outcome measures such as return to work or use of healthcare – including compared to physiotherapy alone (Flor, et al., 1992). The NHSCT Msk Pain Service includes GPSIs (GPs with special interest) in orthopaedics and an Extended Scope Practitioner (ESP) in physiotherapy and podiatry (<http://www.northerntrust.hscni.net/services/920.htm>). Physiotherapists did not spend a lengthy time in discussion of these, though mentioned them as a possible option. However, they had criticisms of the availability of these options; particularly the nature of them in being 'one time only' and then the difficulty in making available similar benefits in the community following discharge. Patients generally did not speak positively of these initiatives, due in part to individual characteristics of those administering them and citing disagreements with GPs. An avenue of research could be pursued in the NHSCT, as to why these are, in the eyes of the patient, not an appealing option.

10.5.2 LCID data, diagnoses and accompanying conditions

Both physiotherapists and GPs attributed the majority of problematic re-referrals as being associated with general pain conditions, such as FMS. GPs specifically stated as such in their questionnaire responses; however, they did not indicate the specific issue in the management of these patients. Evidence exists regarding options for the treatment of FMS (Chinn, et al., 2016), and whilst treating the condition can be a challenge there is a level of guidance as to how to do so. Physiotherapists stated that it was not only FMS symptoms, but more so the accompanying yellow flags that made resolution difficult, because physiotherapists felt these were a barrier to patients engaging with an active, movement-based programme and moving away from receiving modalities 'passively' at the hands of the physiotherapist. Patients in the focus groups did not all describe FMS, but there were those present who had not yet received a satisfactory (in their eyes) diagnosis or who felt that they had pain that they would be suffering from long-term. Both GPs and

physiotherapists ruled out the recurrence of degenerative conditions as the main cause of re-referral rates. They acknowledged some referrals were accounted for in this manner, but for the most part felt that these were not a significant amount.

Findings showed GPs were surprised, if anything, that re-referral frequency was as high as they were. They reported that the rates resembled their own experience but did expect fewer. Physiotherapists on the other hand were surprised that those which they viewed as 'problematic referrals' (especially patients diagnosed with FMS, those agreed to be the biggest contributors) were not higher. They attributed this to the 'losing track' of re-referrals due to the manner in which these were recorded. Patients, they felt, had their diagnosis recorded simply by pain site; fibromyalgia was not necessarily recorded as the cause of referral. The physiotherapists were willing to acknowledge that the data available from the collection process was only as good as that entered. When viewpoints are challenged by statistical data, caution should be observed before discounting the data; however, it is noted that this criticism of the LCID database is made by those entering the data, and that known inefficiencies, duplicates or missing data (chapter 5) support the idea that LCID is a 'blunt instrument' when it comes to providing precise outputs with all the detail that may be required for research purposes. The CCM (Fiandt, 2006) states that to suitably manage chronic pain conditions, inclusion of CIS systems is required, and it is apparent that LCID requires adjustment to fall into line with this.

Motivation for data entry in this manner is not clear: one explanation which may be considered is uncertainty related to the physiotherapy treatment of fibromyalgia or other widespread pain conditions. This uncertainty seemed to be identified by physiotherapists' introspection, as they felt they struggled with applying guidelines for these pain conditions, with reasons for this including difficulty in accessing training opportunities and difficulties in finding the practical space within their departments - in particular, for advanced exercise prescription (Busch, et al., 2007; Busch, et al., 2013). The broad spectrum of accompanying comorbidities, which form a "constellation of symptoms" and have, even in recent years, undergone redefining (Chinn, et al., 2016). This may further discourage a physiotherapist who self-confessedly struggles to apply the most up-to-date evidence base (for any reason) from attempting to treat under the fibromyalgia label, and rather to treat by isolated symptoms, or single-site manifestations of pain.

Reasons for reluctance to attach an FMS diagnosis to patients can include the concept that patients' response to diagnosis is detrimental long-term; following initial legitimisation of their condition and pain, FMS diagnosis can result in despair when they discover limitations in treatment and understanding surrounding the syndrome (Hughes et al., 2005; Undeland & Malterud, 2007). There

is no unanimity regarding this, and some hold that the comorbidities which so often accompany 'true' FMS such as depression and risk of suicide can be identified early if diagnosis is made (White, et al., 2002; Hannonen, 2011). Nevertheless, should GPs (at point of referral) and/or physiotherapists (at point of assessment or record-keeping) have concerns regarding patient compliance or motivation it might prevent application of a diagnosis to that patient, whether or not they are aware of the literature. It is possible, as outlined above, that reluctance to diagnose FMS can then make it harder to track this diagnosis, and result in less accuracy in LCID and its outputs.

10.5.3 Patient expectations and their causes

Patients assented to the physiotherapists' portrayal of their expectations. They viewed physiotherapists as 'fixers', and expected to receive pain relief, first and foremost, along with an explanation of their pain and the cause thereof. However, there were distinct differences between the two, regarding the background, or lead-up, to this expectation. Physiotherapists felt that patients did so out of a passive mentality, unwilling or disinclined to engage with a programme that involved active self-management. Patients, in contrast, felt that they presented at physiotherapy departments having already proactively attempted to self-manage, and having failed to resolve the self-identified problems (Bodenheimer et al., 2010). They viewed physiotherapy as the solution and came with discouragement and factors known to affect their motivation, and therefore put a large amount of hope in the physiotherapists' provision. Patients feel that physiotherapists do not acknowledge or probe these attempts at self-efficacy made before the patient presents in the OPD. They feel that this is one of their key aims – to receive the input that will enable them to achieve self-efficacy.

In this the physiotherapists and patients appear polarised in their perspectives, however, the patients' narrative shows that whilst they have generally attempted to self-manage prior to presentation, whereby optimism regarding prognosis has suffered, they did not seem to investigate their lack of success. To interpret the patients' inability to achieve self-efficacy, physiotherapists referred to societal change whereby coping with pain is for a growing number of people, a novel experience. Denison, et al., (2004), note that self-efficacy beliefs are shown to have a greater effect upon disability from chronic musculoskeletal pain, than fear-avoidance, though it is likely to lead to the latter and in turn to greater pain and disability (Woby et al., 2007).

This concept of societal change was especially associated with a younger generation and used to account for the low age limits appearing in the LCID data. Whereas in years past the presence of chronic pain in children or young adults would have raised an immediate red flag, symptoms were now occurring more often due to the increase in sedentary lifestyles. Recent literature differs upon

the link between incidence of pain and sedentary behaviour in schoolchildren and adolescence (Wedderkopp et al., 2003; Auvinen et al, 2007; Martínez-López, et al., 2015). However, it was specifically the coping strategies of those who do experience and report pain which was highlighted, and criticised, by physiotherapists. Thus, the suggested reasons why patients arrive with the expectations they have are not necessarily mutually exclusive; it could be postulated that the cause for patients being unable to achieve self-efficacy is due to such unfamiliarity with coping strategies from (for example) increasingly sedentary lifestyles.

10.5.4 Waiting lists and times

All stakeholders were in consensus that waiting times, and the list that delayed referrals, had a detrimental effect upon care and pathology progression; hence, indirectly, upon re-referral rates. This time period, along with the psychological impact of the delay, has implications for developing chronicity (Hasenbring et al., 2001; Koes et al., 2006; Boersma & Linton, 2004) and includes the time that patients spend from onset of injury, during any attempts at self-management or self-efficacy, to the point of referral and presentation. Literature supports the concept that treatment (and by extension, resolution) of chronic pain is different and often more difficult than acute (Grichnik et al., 1991; Van Tulder et al., 1997). Physiotherapists showed concern surrounding this, questioning at what stage in the patients' care either physiotherapy treatment, and/or identification of yellow flags featured. The physiotherapists felt both of these were at the point of presentation. Patients also highlighted a concern around time; i.e. feeling that this cycle of re-referral, especially with delays involved alongside the development of chronicity, was a waste of health physiotherapists' and patients' time, and detrimental to the healthcare process.

10.5.5 Appropriateness of physiotherapy re-referrals

Stakeholders did not negate physiotherapy value for musculoskeletal conditions, and on the part of the patients and GPs, both retained a belief in the provision of physiotherapy for particular conditions and in particular circumstances. However, all parties, either implicitly or explicitly, held the view that there are referrals currently being made to physiotherapy that are not achieving resolution and therefore ought not to be made. Physiotherapists felt that this ought, either as an alternative or as an adjunct, to be directed or referred towards CBT or similar, in order that those barriers to engagement, and expectations of physiotherapy, may be addressed.

Whilst certain CBT techniques can be delivered by physiotherapists (Hay, et al., 2005), physiotherapists specified this should be offered, in the case of the patients considered in the current study, as an adjunct to physiotherapy from clinical psychologists. The literature supports the efficacy of the latter, and improvements in pain, disability, and mood, with significantly less lost

work time over 12 months (Linton & Anderson, 2000) versus a control group offering education by the physiotherapist. In a comparable patient group, Linton et al., (2005), conducted a later RCT where two groups (a CBT-only group, and a CBT-plus-exercise group) showed objective improvements versus a control which received the usual examination and activity guidelines. Improvements were especially in health care usage and work absence. In each, CBT was led by a psychologist, and in the exercise group, this component was led by a physiotherapist. No discernible difference was noted between the two intervention groups, suggesting the value was found in CBT led by a qualified psychologist (Linton et al., 2005). This would seem consistent with physiotherapists' beliefs within the NHSCT, where physiotherapists have struggled to address the yellow flags themselves.

GPs felt that for their part, they would be disinclined to re-refer to physiotherapy, patients with those pain conditions who were not achieving resolution – implying that they acknowledge these are not appropriate. Patients felt, no matter the diagnosis, that it was a waste of time for both patient and physiotherapist, that they be continually re-referred without achieving resolution. Consensus therefore was established that not all patients are appropriate to be re-referred, though reasons varied.

10.5.6 Solutions offered

The conclusions of each stakeholder group were different; physiotherapists felt a change to the care pathway was the solution. This was informed by their belief that the issue in treatment of re-referred patients were the yellow flag barriers that they themselves struggled to address. GPs felt that a solution could be offered by referral elsewhere (particularly to the existing pain clinics offered by the Trust) or use of alternatives such as medications or further investigations – this necessitated no major change to the current provisions. The physiotherapists had anticipated that GPs would have assented to their description of the care pathway and lack of options as being one of the largest issues in re-referral. The GPs however did not necessarily deny shortcomings in the pathway, but seem to deny that it is, in and of itself, just cause for re-referral. Patients felt that their preferred solution was for the physiotherapist to give advice on how they could manage this pain themselves. They gave the impression that they did not expect resolution, in terms of their long-standing chronic pain, but patients still felt that ideally, they could achieve self-efficacy if the physiotherapist directed them and ensured they were taking the correct steps.

10.6 Summary

Each of the stakeholders' perspectives differed in ways, one from the other, reflecting their respective roles in the referral process, and shedding light into those areas in which they most felt affected them personally. GPs apparently view the issue of re-referral as less problematic, expecting fewer rates of re-referral and more alternatives available to them. Physiotherapists identify issues particular to the passage of patients through physiotherapy as a secondary care service. Patients, on the other hand, have an intensely personal view of their pain and their referrals, and sought a personalised solution.

GPs disagreed with physiotherapists and patients, denying that they re-refer when no resolution is indicated from physiotherapy. They believed feel that they reserved viable alternatives, whereas physiotherapists and patients did not believe there existed alternatives. An exception is that GPs and physiotherapists agree upon the value of a multidisciplinary pain clinic or service in the treatment of the patients in question, where both GP and physiotherapists have a role. GPs and patients do not have consensus regarding their interactions following unsuccessful referrals, potentially predisposing the patients to repeated re-referral. Patients feel this applies to physiotherapist-patient interactions also.

GPs and physiotherapists questioned the rates suggested by the LCID data; GPs expected fewer, and physiotherapists expected more – physiotherapists being those who input the data into the system and aware of its shortcomings. Both GPs and physiotherapists ruled out the recurrence of degenerative conditions as a main cause of re-referral rates, and both attributed most problematic re-referrals to general pain conditions, such as FMS. Physiotherapists and patients acknowledge that at presentation, patients have expectations of the physiotherapist as fixers, with a large hope invested in them, and the suggestion is that inability to achieve self-efficacy, whereby patients arrive at this state, is caused by societal changes and sedentary lifestyles. Yellow-flags, accompanying comorbidities, and the psychosocial impact of attempting to achieve self-efficacy and failing, are viewed as the main barrier to resolution. Physiotherapists felt they struggled with applying guidelines to combat these complex scenarios, including difficulty accessing training opportunities, and finding the practical resources for carrying out evidence-based interventions.

Any factor that causes an increase in waiting times and delays to treatment has implications for developing chronicity, psychological impact and pathology progression, therefore making treatment and resolution more difficult. This most particularly includes the time that patients spend from onset of injury, during any attempts at self-management or self-efficacy, to the point of referral and presentation, along with any delays during the referral process.

All acknowledge that a proportion of the current referrals being made to musculoskeletal outpatient physiotherapy, are inappropriate. It is evident that perspectives diverge however, on solutions to, or combatting re-referral, reflecting the roles of each. Physiotherapists feel an alternative or adjunct to the care pathway is needed whereby patients with persistent yellow flags ought to be directed towards CBT. GPs felt that alternatives were already available. Patients preferred professional advice on how to manage their pain, to ideally achieve the self-efficacy that had so far eluded them.

10.7 Strengths & Limitations

This discussion chapter highlights a major strength of this PhD, namely the allowance of each stakeholder in the referral process (GP, physiotherapist, and patient) to comment upon their experiences of repeated re-referrals, so that each perspective can be understood and examined. Both GPs and physiotherapists had their attention drawn to the emerging patterns within the LCID data meaning their perspectives could be compared. Focus groups within the GP population were sought, but proved unachievable, with the resultant change in methodology dictated by pragmatics, and by consultation with a collaborating practitioner. GPs were given space to both expand upon their answers in an open manner, or to add an answer that had not been considered at that stage in the research. They also were invited, if they consented, to make themselves available for further discussion surrounding either the topics raised in the questionnaire in general or surrounding the answers that they had given. Unfortunately, this was not provided.

10.8 Trustworthiness

10.8.1 Credibility

Credibility can be established using triangulation; triangulation involves using multiple methods or data sources to gain a complete understanding of the phenomenon studied.

Methods triangulation involves use of different data collection methods to check consistency of findings. That is, consistency can be established if the same findings are present amongst two or more sets of data, collected using different methods. In the case of the current thesis, the presence of two distinct and polarised groups amongst re-referred patients was suggested by patterns within the quantitative data; this was corroborated by the focus group studies independently, and without leading on the matter by the facilitator of the group.

Triangulation of sources involves utilizing different data sources within the same collection method. In this case, focus groups were carried out amongst more than one stakeholder in the process – namely, patients and physiotherapists. As outlined, there were commonalities between the two –

for example, each party highlighted concerns around waiting times, and delays in receipt of treatment, due to the development of chronicity.

Member-checking was used to establish credibility. This involves preliminary interpretations being shared with participants, allowing these to clarify their intentions in communicating their message, whether they felt they were represented correctly, and provide additional information if necessary. No member of the groups returned an expression of dissatisfaction with the descriptive summary issued.

10.8.2 Dependability

Similar in a sense to analyst triangulation, the principle of dependability uses another individual or researcher outside of those doing analysis and collection, to establish findings as consistent and repeatable. It means that, with the raw data collected, were other researchers were to look over data they would arrive at similar findings, interpretations, and conclusions. Another analyst was used to review the transcript and findings – both who “sat in” during the groups, and who were not present. This can ensure conclusions drawn are reasonable.

10.8.3 Transferability

Transferability involves the provision of evidence so that the methods could be applied externally farther than the immediate study setting. It is believed that use of pragmatics can make this easier, as the account of choice of methods is easily followed. The clear methodological emphasis throughout, including the pragmatic rationale for the inclusion of GP questionnaires, allows the external reader to appreciate the relation of the methods to the research setting; a method known as thick description (Lincoln & Guba, 1985). Clarity methodologically enables the transferability to a reader’s setting to be known. It is also believed that the development of the SOP in the quantitative component, indirectly aids the transferability of the qualitative, as it adds to the rationale for the latter.

10.8.4 Reflexivity

Reflexivity is adopted when collecting & analysing the data; the acknowledgment of researcher background and characteristics to see how these influence the research.

An inherent interest in the concept is acknowledged, due to the background in musculoskeletal physiotherapy. As indicated in chapter 1-2, there was a pragmatic rationale for the choice of methodology; the immediate geographically-closest Trust, and that in which there was dialogue between the researchers regards the incidence of repeated re-referral, had limitations in its database outputs. In terms of methodology, then, there was an open approach to options available,

but a pragmatic approach as to which of the few identified could be appropriated and applied in the NHSCT.

The collection of qualitative data was carried out by video recording; the researcher was involved, for some groups, in facilitation. However, the practice of member checking along with a structured and iterative topic guide minimises the influence of the researcher on any 'leading' of contributions.

10.9 Conclusions

Chronic pain conditions such as fibromyalgia were generally held to be the most common diagnoses featured in re-referrals. GPs however view re-referrals as less common and less problematic than other stakeholders, maintaining that alternatives rather than re-referring to physiotherapy are available. Physiotherapists disagree; the care pathway, they feel, is lacking in that patients with chronic pain and accompanying yellow flags or psychological factors struggle to achieve resolution. Waiting times and delays increase chronicity, psychological impact and pathology progression, therefore making treatment and resolution more difficult. Patients often attempt to achieve self-efficacy prior to physiotherapy, unsuccessfully as societal changes (including sedentary lifestyles) have led to unfamiliarity with pain and coping strategies, which can increase the waiting time period, and cause further dejection when treatment is unsuccessful. Patients therefore present with a high dependence upon physiotherapist input, to the extent where physiotherapists view them as passive, dependent recipients. Patients have an intensely personal view of their pain and their referrals and seek a personalised solution, namely advice on how to manage their pain, to achieve self-efficacy. Physiotherapists feel an alternative or adjunct to the care pathway is needed such as CBT, to adequately treat these patients and thereby combat repeated re-referrals.

Chapter 11. Discussion

11.1 Introduction

The overall aim of this thesis was to investigate and explore the repeated re-referral of patients into musculoskeletal physiotherapy outpatient departments.

The specific aims of this research were to:

- To investigate the accuracy of anecdotal beliefs surrounding the occurrence (chapter 1)
- To identify the current knowledge base surrounding re-referral to secondary care (chapter 2)
- To establish a reasoned methodology and SOP for investigating re-referral within the secondary care setting (chapter 4)
- To build a picture of the re-referral occurrence in musculoskeletal physiotherapy outpatient departments by identifying rates of re-referrals and defining characteristics of these patients (chapter 5)
- To better understand this picture, by investigating the experiences and perspectives of all interested parties or stakeholders in the referral process (chapters 6-9)

The original aims and objectives will be reflected in the context of the discussion of main findings.

11.2 Summary of Findings

In the first instance, a critical review was carried out to examine and critique the available evidence in the current body of literature on repeated re-referral into musculoskeletal physiotherapy outpatient departments. The results highlighted a significant knowledge gap, with no investigations of re-referral in outpatient physiotherapy settings, and few in other settings. The findings of this review thus prompted further investigation into repeated re-referral.

This led to the establishing of a standard operating procedure (SOP) for investigating repeated re-referral, reported in chapter 4. The few studies that investigated or measured re-referral to other secondary care services informed this SOP, as did pragmatic constraints and methods available in the immediate setting. This procedure was used in quantitative data collection from perusing the LCID database and patient notes in the NHSC (chapter 5-6). Descriptive analysis suggested the existence of two distinct patient groups, differing particularly in past medical history/comorbidities, in episode/treatment length, and in length of time until re-referral.

To explain this emerging picture, the perspectives and experiences of all interested parties or stakeholders in the referral process were sought; using focus groups in the case of physiotherapists

and patients, and semi-structured questionnaires in the case of GPs. The physiotherapist focus groups agreed upon the existence of two distinct patient groups; one group consisting of those expected to return for degenerative conditions and capable of self-management with minimal input, with the other group of patients being re-referred because of an unmet patient need. The latter were 'problematic' re-referrals, and corroborated the picture suggested in the quantitative LCID data.

The findings from each stakeholder group demonstrated that chronic pain conditions such as fibromyalgia – and specifically the accompanying psychological symptoms – are held to be the most common diagnoses featuring in re-referrals. Fibromyalgia was specifically identified as typifying these conditions by both GPs and physiotherapists, though it was implied by these that related symptoms or clinical presentations, especially surrounding yellow flags and comorbidities, could be applied to other chronic pain conditions. Analysis of the stakeholders' data demonstrated a divergence of opinion on available alternatives to re-referring into Msk OPDs. GPs felt that there were alternatives available, which they utilize, whilst physiotherapists felt that there was a distinct unmet need for patients with chronic pain and accompanying yellow flags or psychological factors.

Stakeholders agreed that waiting times and delays contributed to re-referral. They believed that these systemic issues increased the chronicity, psychological impact and progression of pathology – therefore making treatment and resolution more difficult. Patients attempted to achieve self-efficacy prior to physiotherapy, which further increases the waiting time prior to referral, and thus, caused further dejection when their self-management was unsuccessful. Findings from the physiotherapist groups suggest that this lack of success could be in part attributed to societal changes (including sedentary lifestyles) causing an unfamiliarity with coping strategies for pain. Patients present, therefore, with a high dependence upon physiotherapy input. Upon presentation, physiotherapists tended to view patients with these chronic pain conditions (who had failed in terms of self-management), as passive, dependent recipients. In contrast, the patients felt that previous attempts at self-efficacy were not probed or recognised.

Consensus was met amongst stakeholders on the need for patient education, albeit with slightly different emphases. Patients felt that advice from physiotherapists on how to manage their pain would help them achieve self-efficacy. Physiotherapists felt an adjunct to the care pathway is needed such as CBT, to best provide these patients with the means to manage their condition and prevent repeated re-referrals.

11.3 Key Issues Raised

11.3.1 A neglected area of focus, with overlooked implications

Early in the term of this research work, it was anecdotally noted that the same patients were being seen frequently and not receiving resolution from their repeated re-referral. The concern was that these patients were not resolving on their current pathway. This suggested that the pathway was in some way not meeting their needs, and so there may be a need to create a new, alternative pathway, specifically to address the unmet needs of people with these complex and challenging needs.

When it was confirmed that repeated re-referral did indeed occur, the next step was to investigate what research was currently available, or what level of knowledge existed in the literature which might explain or inform physiotherapists. It was noted though, that despite re-referral and indeed Msk pain being so widespread and identifiable, both anecdotally and through statistical reports, there was little to no research uncovered. Indeed, there were no audits published, and no studies in a Msk setting, with exceptions being child protective service or smoking clinics (Connell et al., 2007; Thompson et al., 2009; Lamb et al., 2013).

It seems that there is no awareness of the size of the occurrence of re-referral, and it is tentatively suggested that this is the cause for a lack of research interest. Also, it is highly possible that many services do not presently have the direct means of documenting the data in such a format that allows perusal in detail for research purposes; LCID by itself did not have the facility to output the data in a detailed and clear format. If pathways are to monitor this, one of the necessities must be to use information systems to track patient details, as the CCM supports. It is recognised that many settings will monitor and track referral rates, and their internal processes will not require publication.

The current study found value in the methods employed in those studies uncovered, though the actual results were not able to be extrapolated into a different secondary care pathway. A methodology for investigating repeated re-referral was developed from these studies. It was felt that there was much room, using this methodology, for the establishing of a reasoned and replicable standard operating procedure (SOP) for the investigation of re-referral patterns.

11.3.2 Problematic vs. expected re-referrals clarified and defined

Findings from the exceptional reports showed the scale of re-referral. In a period of three years, the data showed that the NHSCT sees approximately 90,000 referrals, and 30,824 of these for

“returners”. The exceptional reports showed that these 30,824 referrals were distributed amongst only 13,274 patients, an average of 2.3 referrals per patient. Not all of these were necessarily ‘problematic’ re-referrals, but it is necessary to distinguish between these, and those patients who were appropriately re-referred. At its simplest level, the ‘problematic’ referrals were described anecdotally as re-appearing unusually frequently within a given period, causing a concern surrounding patient care. The second exceptional report reflects this higher frequency, identifying 324 patients, who had 3 or more re-referrals. These shared 2736 referrals in total between them.

Using descriptive statistics, the analysis of the LCID data achieved a typical picture of these 324 patients. However, the LCID data also identified variables, whereby there was no clearly identifiable a ‘mode’. Specifically, these were past medical history, episode/treatment length, and length of time until re-referral. In these, there were two distinct, polarised values, appearing in similar frequency to each other, suggesting two types of patient, or patient characteristics. The LCID data suggested that the patients may have much in common, but in those specific values, they diverged, being characterised by: either no previous history, or multimorbidity; either a discharge within one week, or a lengthy treatment period; and re-referred either immediately or going a long period before requiring re-referral.

The stakeholders affirmed the picture emerging from the LCID data, including the concept of two distinct groups of patients, and filled in the picture of what these types of patients looked like to them. Those who were expected to return for degenerative or arthritic conditions and capable of self-management were not considered problematic re-referrals and were not discussed at length. These, physiotherapists reported, were characterised by an understanding of their condition and a proactive approach to self-management. These sought a small input from a qualified professional to aid their own management, after which it would be a longer period until they were referred again.

The physiotherapists recognised that the issue for them was regarding ‘problematic’ patients. A common understanding communicated by the physiotherapist groups was of a group of patients who were being re-referred because of an unmet patient need. These were cast as ‘passive’ patients, often re-referred for the same condition (at times with comorbidities), possessing little knowledge of their condition, having low expectations of physiotherapy and thus uncompliant, and yet re-referred a short time after discharge.

It appears that the ‘problematic’ re-referrals are characterised by multimorbidity. Patients receive a longer treatment session and are (as are most patients) discharged with a HEP or having reached their potential in the eyes of the physiotherapist. The physiotherapists, however, receive a re-

referral almost immediately – even if the actual presentation, due to a waiting list, is not immediate. In contrast, those who are re-referred for ‘legitimate’ or appropriate and non-problematic reasons, usually have little accompanying comorbidities, and their conditions are more likely to be degenerative, and characterised by exacerbations which are unavoidable. These patients require minimal input, and the treatment is short. These, being again likely discharged with a HEP, can continue self-managing, and do not receive their subsequent re-referral at least for a matter of months.

11.3.3 Failed attempts at self-efficacy lead to dependence

Physiotherapists portrayed patients experiencing ‘problematic’ repeated re-referral as having a passive mentality, unwilling or disinclined to engage with active self-management. In contrast, patients felt that they present to physiotherapy having already proactively attempted to self-manage but having failed to resolve the self-identified problems. The patients viewed physiotherapy as a potential solution, and following their failure at self-management, came discouraged and with low motivation. This resulted in these patients putting a large amount of hope in the physiotherapists’ provision. Patients felt that physiotherapists do not acknowledge or probe these attempts at self-efficacy. A key aim for the patient is to receive the input that will enable them to achieve self-efficacy; the CCM describes this as self-management support.

However, whilst patients acknowledged low self-efficacy, whereby optimism regarding prognosis has suffered, they did not appear to reflect upon the cause. Physiotherapists cite a societal change whereby coping with pain is, for a growing number of people, a novel experience. It was suggested that problematic re-referrals, as described in this thesis, have not always been a constant in Msk OPD, and that a societal change has taken place, especially over the past decade, which sees self-efficacy as more difficult to attain for chronic pain patients due to poor coping strategies. Denison, et al., (2004), note that self-efficacy beliefs are shown to have a greater effect upon disability from chronic musculoskeletal pain, than fear-avoidance, though it is likely to lead to the latter and in turn to greater pain and disability (Woby et al., 2007).

Characteristics of low self-efficacy are increasingly associated with a younger generation and physiotherapists used the concept of a societal change to account for the low age limits. The age range was large, but patients were commonly in their fifties, with a mean age of 54. However, ages of patients began from as low as 14 years of age. The presence of chronic pain at these ages would traditionally raise an immediate red flag especially in certain circumstances or associated with

certain condition (Kordi & Rastami, 2011). However, it was hypothesised that this presence, and indeed persistence, of pain in younger patients, was occurring more often due to an increase in sedentary lifestyles, and physiotherapists found that this was not so unusual an occurrence in recent years. Further, whilst the relationship of pain and sedentary behaviour in schoolchildren and adolescence bears further investigation (Wedderkopp et al., 2003; Auvinen et al, 2007; Martínez-López, et al., 2015), it was specifically the coping strategies of those who do experience and report pain which was highlighted and criticised, by physiotherapists. This relationship, they felt, was not limited to recent generations, but they believed that societal changes impacted most, and therefore was most dramatically seen in younger patients. Thus, it is postulated that a cause for patients being unable to achieve self-efficacy is due to unfamiliarity with coping strategies.

Stakeholders highlighted further concern around the length of time taken from the onset of pain, to seeing the physiotherapist, i.e. the time taken to: act on the pain (onset etc.), trial various self-management strategies, access the referring clinician and finally, the time waiting prior to see a physiotherapist. In re-referred patients, this cycle, and accompanying time frames, happens multiple times. A patient attempting to address their own pain takes time. When these patients then turn to physiotherapy provision as described, the LCID data shows that patients have a typical wait of 8 weeks from referral to presentation, and most episodes lasted a total of 12 to 13 weeks in length. The psychological impact of this delay, as well as the inherent development of chronicity, (Hasenbring et al., 2001; Koes et al., 2006; Boersma & Linton, 2004), make treatment increasingly difficult (Grichnik et al., 1991; Van Tulder et al., 1997). Stakeholders were in consensus that waiting times were detrimental to the effective management of patients, and thus to the patients receiving input that would enable them to achieve self-efficacy.

11.3.4 Disagreement regards the decision-makers to re-refer to physiotherapy

324 patients shared 2736 referrals in total between them. Most patients had between 3 to 5 referrals over the time frame in question, with one occurrence each of those who had six to eight. However, disagreement remains as to who is the instigator of each re-referral, with GPs surprised that re-referrals were as high as they were. GPs do not anticipate re-referring when a patient has had more than one referral to musculoskeletal physiotherapy that has evidently not resolved or changed their condition.

The findings presented in chapter 9 and 10 show that GPs prefer not to re-refer simply due to other options being exhausted, or there being no other appropriate service. Rather, they felt there are

existing alternatives to the patient being re-referred to physiotherapy. Specifically, they feel they would prescribe medication, discuss pain management through lifestyle changes, and most would also consider a scan or x-ray, or referral to a different secondary care service. GPs have a 'wider view' of alternatives – i.e. do not necessarily see the need to send the patient to secondary care service by default. They feel that the conditions in question could be addressed or at least aided by alternatives which lie outside of secondary care – a perspective perhaps not shared by physiotherapists, who seemingly judge that secondary care, such as a psychological intervention, is needed for the successful treatment of these patients.

GPs profess a significant amount of reliance upon the patient's preference. In contrast, patients feel that GPs initiated re-referrals, without probing previous outcomes, and patients felt they had to offer that information to the GP if it was to be considered. Deficiency in communication between patients suffering from chronic pain and their doctors, is characterised by parties speaking at cross-purposes. Patients feel strongly that doctors do not listen to them but continued with preconceived routes; a finding consistent with Kenny (2004). In patients with pain of unconfirmed origin, this ultimately results in "endless referrals" (Kenny, 2004).

GPs specified pain clinics as a service into which they would refer. The literature indicates that these clinics, rather than physiotherapy, are efficacious for pain, mood and behaviour-related outcome measures such as return to work or use of healthcare, (Flor, et al., 1992). Physiotherapists acknowledge these as an option but have criticisms of their efficacy long-term; they suggested making available similar community initiatives post-discharge. The LCID data observed 'onwards referral' to a service which was not physiotherapy; it is highly likely, given the explanation afforded by the stakeholders, that many of these could have been to such a pain service.

11.3.5 Diagnoses and comorbidities in repeated re-referral

Much of the diagnoses identified in the quantitative patient data were typical of those seen in a musculoskeletal outpatient department. Lower back, shoulder, and knees were the most common sites of pain amongst the LCID data – as expected from literature on the accepted prevalence of musculoskeletal pain conditions (Picavet & Schouten, 2003). Both GPs and physiotherapists discounted recurrent degenerative conditions as the main cause of problematic re-referral rates. They acknowledged some referrals were accounted for in this manner, but for the most part felt that these were not a significant cause of 'problematic' re-referrals. Stakeholders attribute most 'problematic' re-referrals to general pain conditions, such as FMS. Picavet & Schouten, (2003) also

expect this general widespread pain to be the next most common diagnosis. However, in the LCID data, general pain syndromes (for example, CRPS or FMS) did not appear to feature highly. This departure from what was expected required explanation.

Physiotherapists attributed such a lack of pain syndromes appearing in the LCID data to the manner by which pain is approached and recorded. Though stakeholders felt it is responsible for a significant proportion of re-referrals, fibromyalgia was not necessarily recorded as the diagnosis for these patients, and these patients had their pain area simply recorded by site. Data entry in this manner could be explained by uncertainty related to treatment and diagnosis of fibromyalgia or other widespread pain conditions. Evidence exists regarding options for the challenge of treating FMS (Chinn, et al., 2016), and there is an evolving level of guidance as to how to do so.

However, accompanying yellow flags make resolution more difficult. Physiotherapists hold that for diagnoses/conditions that appeared in re-referrals, yellow flags were a defining characteristic and must be a priority. These were felt to be a barrier to patients engaging with an active, movement-based programme and moving away from 'passively' receiving modalities. The biopsychosocial as opposed to a biomedical model was an appropriate approach; however, in practice, physiotherapists found themselves underequipped to deal with the patients in question. Physiotherapists struggle with applying guidelines for this aspect of these pain conditions, with reasons including difficulty in accessing training opportunities and difficulties in finding the practical space within their departments e.g. for advanced exercise prescription or group sessions (Busch, et al., 2007; Busch, et al., 2013).

It is possible that such a struggle with applying guidelines contributed to the tackling of conditions by pain site, rather than approaching from the standpoint of an FMS diagnosis – a diagnosis that physiotherapists felt was out of their remit to make. That this was the norm, was self-confessed by physiotherapists. Other suggested reasons for reluctance to attach an FMS diagnosis to patients include the concept that patients, following initial legitimisation of their condition and pain with an FMS diagnosis, can despair when they discover limitations in treatment and understanding surrounding the syndrome (Hughes et al., 2005; Undeland & Malterud, 2007). However, comorbidities which so often accompany 'true' FMS such as depression and risk of suicide can be identified early if diagnosis is made (White, et al., 2002; Hannonen, 2011). Depression as a comorbidity occurred frequently in LCID data, though not always associated with fibromyalgia. Nevertheless, concerns regarding patient compliance or motivation might conceivably prevent attachment of a diagnosis to that patient, whether or not they are aware of the literature.

However, one detrimental effect of approaching treatment/management of patients by pain site rather than diagnosis is the tracking of these conditions, and their treatment history, in record database systems such as LCID. When these are approached from the standpoint of pain manifestation by site, they are usually entered in the database as such, and the FMS diagnosis (if it ever was formally given) is not noticed. It is possible, as outlined above, that reluctance to diagnose FMS can then make it harder to track – thus explaining the lack of appearance of these pain syndromes in the LCID data, contrary to what was expected by stakeholders and the literature.

Inefficiencies, duplicates or missing data (chapter 5), coupled with data entry methods for diagnoses, suggest LCID is a 'blunt instrument' when providing outputs for research or audit; considering the issues surrounding these re-referred patients, this highlights the CCM component (Fiandt, 2006) which advocates the use of appropriate CIS systems to suitably manage chronic pain conditions. Recent studies have found that this is not an unusual occurrence, with missing values calling into question the fitness for purpose of some data, including in settings farther afield than the UK National Health Service (Liew et al., 2012). That study, covering an area of similar size to the physiotherapy service in the NHSCT (i.e. approximately 30,000 referrals per year) identified missing values in 12-15% of patient cases. Variables which Liew et al., (2012) used include sex, age, arrival date and time, presenting problem, diagnosis, length of stay, discharge date and time, referral on discharge – comparable data collection to that of the current thesis, along with other, setting-specific, values. One of the suggested causes of missing values or other, as with LCID, was omission at point of the data entry (Liew et al., 2012) – by this seemingly having in mind the clinician/health professional's subjective data entry, and not referring to intrinsic failings in the system's formatting e.g. drop-down menus.

Current criticism of databases includes the question as to what the data are used for – especially when the systems appear to be inefficient or user-unfriendly for the health professionals entering the data (Eason & Waterson, 2014). The conclusion was that it is mainly for managerial and strategic requirements. The information within these databases has long been considered an under-used resource (Bain et al., 1997) and it is possible that there is potential for a revision of the format of some systems, to allow greater suitability to use in research, for example (Dugas, et al., 2009). This consideration is one which would have not only made data collection for the current thesis more streamlined, but also would place a greater stress on the need for accurate and comprehensive data entry, with subsequent implications for the improved visibility and tracking of diagnoses and patient care.

11.3.6 Solutions envisaged to repeated re-referral patterns

Stakeholders did not negate the value of physiotherapy for musculoskeletal conditions and retained a belief in the provision of physiotherapy for conditions and in particular circumstances. However, all parties held the view that there are referrals being made to physiotherapy which are not achieving resolution, and therefore ought not to be made in the way they currently are. Consensus therefore was established that not all patients are appropriately re-referred, though reasons varied. This is a major factor; the CCM highlights the need for a sound delivery system design which results in the patient viewing the care provision as a successful, holistic team.

Solutions were suggested by each stakeholder; each acknowledged, in some way, the need of patient education apart from physical modalities. GPs felt that a solution could be offered by referral elsewhere (particularly to the existing pain clinics offered by the Trust) or use of alternatives such as medications or further investigations – this necessitated no major change to the current provisions. The physiotherapists had anticipated that GPs would have assented to their description of the care pathway and lack of options as being one of the largest issues in re-referral. The GPs do not necessarily deny shortcomings in the pathway, but seem to deny that it is, in and of itself, just cause for re-referral to physiotherapy.

Patients' preferred solution was for the physiotherapist to give advice on how they could manage this pain themselves – they gave the impression that they did not expect resolution in the sense of complete removal of their long-standing chronic pain, but they still felt that ideally they could achieve self-efficacy if the physiotherapist directed and guided them with professional, informed advice. Physiotherapists felt a change to the care pathway was the solution – informed by their belief that the issue in treatment of re-referred patients was the yellow flag barriers that they themselves struggled to address. Physiotherapists felt that these patients ought, either as an alternative or as an adjunct, to be directed or referred towards CBT or similar, in order that those barriers to engagement, and expectations of physiotherapy, may be addressed. Whilst certain CBT techniques can be delivered by the physiotherapists (Hay, et al., 2005), physiotherapists specified that this should be offered, in the case of the patients considered in the current study, as an adjunct to physiotherapy from clinical psychologists. The literature supports the efficacy of the latter, and improvements in pain, disability, and mood, with significantly less lost work time over 12 months (Linton & Anderson, 2000) versus a control group offering education by the physiotherapist. In a comparable patient group, Linton et al., (2005), conducted a later RCT where two groups (a CBT-only group, and a CBT-plus-exercise group) showed objective improvements versus a control which received the usual examination and activity guidelines. Improvements were especially in healthcare

usage and work absence. In each, CBT was led by a psychologist, and in the exercise group, this component was led by a physiotherapist. No discernible difference was noted between the two intervention groups, suggesting the value was found in CBT led by a qualified psychologist (Linton et al., 2005). This would seem consistent with physiotherapists' beliefs within the NHSCT, where physiotherapists have struggled to address the yellow flags themselves.

The indication was that all interventions are best led someone who is trained appropriately. Physiotherapist in the NHSCT did not believe they had the expertise, and identified the psychologists as having this knowledge. Physiotherapists could be trained to deliver CBT techniques, but felt that they had minimal affordable or frequent training opportunities, and so an adjunct like CBT would have to be delivered by another.

In addition to these solutions targeted at addressing the symptoms involved, preventative measures for recurrence included the adjustment of CIS databases to be more competent in tracking, in real time, incidence of repeat referrals. It was suggested by physiotherapists that synchronising these electronically with other patient medical records would be of real value, in order that comorbidities, especially those such as depression, might be accounted for in the physiotherapy treatment. Greater synchronisation between healthcare disciplines' electronic records would also give the potential for a closer alliance of real-time records to research or audit initiatives but is accompanied with further considerations such as data protection, permissions of access/use and responsibilities of each healthcare discipline (Dugas, et al., 2009) which may present challenges.

11.4 Overall Strengths & Limitations

Each of the studies had certain strengths as previously described in the corresponding chapters. One of the main strengths of this thesis overall is the robustness of the methodology. Guided by the theoretical framework alongside pragmatic decisions, the findings from each study complement and add to each other, whilst at the same time their robustness stands scrutiny as stand-alone studies. The objectives of the thesis are met, and the exploration of the occurrence of repeated re-referral in this setting has been thorough.

Further, the thesis is novel in that such methods have not been applied before in this manner. The SOP for quantitative data collection from patient databases was specifically designed for this purpose, and the systematic use of mixed methods in exploration of repeated re-referral was unprecedented in the setting.

There are a few limitations acknowledged; one of which being the recurring difficulty of recruiting patients who fall under the description given of being repeatedly re-referred. Patient characteristics may partly explain this, as physiotherapists indicated that in general, it can be difficult to engage these patients with their treatment; this may be applicable also to engagement with research activities. Dyas et al., (2009) found limited evidence surrounding the recruitment of patients for focus groups. However, they felt that two challenges existed: getting potential participants to contact the researcher, and then converting this contact into attendances. Their solution was to recruit via their primary care consultations – a consideration that was not made in this thesis, but may be an option even in secondary care, e.g. musculoskeletal outpatients.

GPs were also difficult to recruit, and the planned focus group could not be formed. A small number were however recruited for the questionnaire survey. Literature suggests (Williamson et al., 2007; Armstrong & Ashworth, 2000; Barclay, et al., 2002) that a lack of interest in the area is a strong predictor of response rate - it could then be inferred that repeated re-referral to physiotherapy outpatient departments is not an area of highlighted concern for GPs.

11.5 Recommendations for future Research

The systematic review concluded that further research needs to be carried out into repeated re-referral, due to a major gap in the existing literature. It is submitted that the SOP developed can be used for the investigation of re-referral occurrence in other settings, where this is reported. Such investigation reveals the occurrence to be one towards the forefront of stakeholders' minds. Greater detail was gleaned which otherwise would have lain dormant – including solutions, which each stakeholder has been revealed to hold strong opinions on. It is evident that re-referral is complex, and further investigation is required to fully understand the phenomenon. This may be the case in other secondary care services, and it is suggested that the investigation of re-referral in other settings, may similarly uncover findings which would otherwise remain undocumented.

Considering some of the solutions identified within the current research, an intervention may be appropriate to provide CBT for patients in this setting following identification of the relevant comorbidities. It is suggested that patients could receive physiotherapy, with CBT delivered as an adjunct treatment by a clinical psychologist. This could be contrasted with receiving 'traditional' physiotherapy interventions. Referencing RCTs which have previously employed this approach (Hay, et al., 2005; Linton & Anderson, 2000), a control group could consist of physiotherapists, with an approach emphasising patient engagement and advice. Whilst those studies have used similar

approaches, these could be investigated specifically in the treatment of fibromyalgia patients with accompanying yellow flags.

It is also hoped that with an increase in the awareness of such occurrences, and their implication for patients' care, it may be achievable to constitute focus group/s amongst referring GPs. It has been acknowledged throughout that certain methodologies have their individual strengths, and the discussion dynamic that takes place in focus group research yields a richness of data that is unique to this engagement. Specifically, there were questions that remained unanswered, or partially answered, from the questionnaire studies in chapter 9. Focus groups can further probe and compare opinions, reaching a group consensus via this interaction.

Janssen et al., (2016), show that physiotherapists struggle to implement research in daily practice and to become involved in research. Greater encouragement for engaging practicing physiotherapists in research should mark the profession. Physiotherapists have described difficulty in reviewing literature and applying evidence. This includes taking time when they leave the practice at the end of the day, to peruse the literature, and thus any lack of specific training is compounded. Janssen et al., (2016), concludes that changing physiotherapists' conception of research, making it more accessible and providing dedicated research time, could facilitate increased involvement. It is believed that increasing collaboration between clinical practice and the evidence base by means of physiotherapists themselves can greatly increase the application of best evidence for the benefit of patients.

In the current study physiotherapists were easily recruited, for several reasons; physiotherapy leads in the NHSCT were involved in the design of the research from the start, were involved throughout in the data collection from LCID, and had flexibility to negotiate times and settings for the groups. Receipt and return of invitation packs were also more easily facilitated, by the fact that in a single department there are enough physiotherapists in one place naturally.

It is also suggested that these considerations may facilitate the involvement of GPs; inclusion of these in the design and aims of the study, gathering data they themselves may feel is of most interest to them to discover, and considering times and settings, such as video-conferencing to reduce travel and therefore burden. Attempts were made to ease recruitment by having a presence at a fortnightly meeting, but slots were not available at the time.

11.6 Implications for Clinical Practice

Whilst it has been shown that basic cognitive behavioural techniques can be administered by physiotherapists (Hay, et al., 2005), the literature indicates a greater efficacy using CBT from clinical psychologists, when it is offered as an adjunct to physiotherapy (Linton & Anderson, 2000). The focus groups (chapters 7-8) identified that there were very few clinical psychologists Trust-wide. Consideration should be given to the benefits of adding CBT posts with a view for referral/inclusion in the treatment of chronic pain patients who have clearly identifiable yellow flags, and who experience re-referral. Piloting of this could be pursued, perhaps by creation of short-term contracts to this end.

It was voiced by physiotherapists that training opportunities, particularly in the region of dealing with fibromyalgia, and its accompanying yellow flags, and even the use of the basic cognitive behavioural techniques described, are scarce and difficult to access, particularly in Northern Ireland. It is evident that there would be value in training being made more accessible – including considering time, location and cost – to physiotherapists especially outside of the mainland UK. Due to the scale of waiting lists and numbers being referred, it is likely that this would be beneficial to pursue in addition to the enlisting of CBT professionals. In-service training, from staff with CPD or qualifications similar to those requested, ought to be encouraged.

Efficacy of CBT in association with physiotherapy has been shown to have support. Whilst economic evaluations of CPD are rare and generally insufficiently informed (Levin, 2002; Brown, et al., 2002), it is clear that if the cost of training (and re-training when required) does not exceed that of care, then this can be an efficient initiative. By definition, reducing inefficacious repeat re-referrals for an individual is a worthwhile pursuit. Physiotherapists criticised the cost to them of attending training generally; indicative perhaps of greater difficulty in the logistics of providing CPD outside of the mainland UK. A possible route would be the piloting of a scheme of CPD amongst physiotherapists with a methodology that incorporates suitable cost-effectiveness analysis (Udvarhelyi, et al., 1992; Casebeer et al., 1997).

A greater onus ought to be placed on the probing of self-efficacy strategies employed by patients prior to their presentation in outpatient departments. Patients were able to distinguish between what they referred to as 'better' physiotherapists; this probing and listening on their part was the main identifying criterion. It is likely in the subjective assessment that this will open up a conversation on yellow flags, duration of re-referral cycle for that patient, and factors affecting the patients approach to physiotherapy; in lieu of CBT training, this is expected to be essential practice for these patients.

There remains a strong need for the addressing of waiting lists by, in part, reducing inappropriate referrals and potentially reducing treatment periods for those who can self-manage. In writing this thesis, it was noted that self-referral was never discussed by stakeholders, though delays in referral were criticised. However, physiotherapists throughout criticise the late stage at which any issues (including yellow flags) are highlighted – if they are indeed ever done in practice. They state, as has been shown (chapter 7), that this is often been at the point where patients present in physiotherapy outpatient departments. Both physiotherapists and GPs are generally comfortable with a form of self-referral to outpatient physiotherapy, thus having physiotherapy as the “first point of contact practitioner” (Holdsworth, et al., 2008). Whilst the self-referral conversation will itself continue, there is still inconclusive data as to its efficiency for particular conditions (Marks et al., 2017), in practice this thesis indicates a need for the continued increase in awareness on the part of the public of physiotherapy provision, and training of physiotherapists as above, prior to further piloting of such services - two areas surrounding which the literature indicates stakeholders have misgivings (Holdsworth, et al., 2008). These being in place, it is suggested that should self-referral become more common practice, the key issues could be identified and promptly addressed for the patient group in question, with the added benefits of the removal of waiting times.

The CCM Model states that, to suitably manage chronic pain conditions, inclusion of CIS systems is required (Lorig & Holman, 2003; Fiandt, 2006). It is apparent that LCID requires adjustment to fall into line with this. Details which required calculation included time since discharge, and durations of treatment. Patient notes were perused for diagnoses, comorbidities, and gender. Details such as these turn out to be a defining characteristic of the patients in question and would be valuable to identify within the system. Physiotherapists envisaged a system which could synchronise with other patient medical records to make such a process holistic.

11.7 Conclusions

In conclusion, reports of repeated re-referral of patients into musculoskeletal outpatient physiotherapy are corroborated by statistics. These are attributable to two sources. The first are from expected re-referrals from those with degenerative conditions, who have few comorbidities, require minimal input, and short treatments. These, being discharged, are self-managing and are not re-referred immediately.

The second, described as ‘problematic’ re-referrals are attributed to ‘passive’ patients who have developed dependency on physiotherapy through low self-efficacy, and often are suspected to have

a general pain condition such as fibromyalgia which may not be officially diagnosed or treated as such. These are characterised by comorbidity (especially yellow flags and psychosocial barriers), longer treatments, can experience lengthy treatment of manual therapy and modalities, and yet are re-referred a short time after discharge.

GPs consider there to be existing alternatives to re-referring, such as multidisciplinary pain clinics. Physiotherapists feel the benefits of these are difficult to replicate after discharge. Citing a lack of training opportunities or resources, physiotherapists find it difficult to apply guidelines or engage these patients with active management programmes, due to 'yellow flags'. They advocate supplying an adjunct to musculoskeletal outpatient physiotherapy, in the form of CBT from a registered psychologist. Coupled with a more efficient and sensitive record system, whereby re-referral can be identified, and the 'problem' re-referrals addressed as they occur, it is believed that provision of the education and advice necessary can assist these patients to achieve the self-efficacy they seek. In turn, this can prevent ongoing chronicity of their pain, and prevent an associated repeat re-referral.

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APPENDICES

Appendix A

Sorting the literature – relevance by abstract

- a) **Relevant** – re-referral rates
- b) **Indirectly relevant** – e.g. initial referral rates/referral pathways/reasons for referral/characteristics
- c) **Not relevant** – any other: self-referral etc.

a)	b)	c)
Connell et al 2004 Freeman et al 2012 Lamb et al 2013 Thompson et al 2009	O’Cathain et al 1995 Akbari et al 2008 Ball et al 2006 Brooks et al 2012 Carey & Freburger 2014 Clawson et al 1994 Clemence & Seamark 2003 Davenport et al 2005 Driver et al 2012 East et al 2013 Ehrmann-Feldmann et al 1996 Faulkner et al 2003 Fransen 2004 Freburger et al 2003 Fritz et al 2012 Gohar et al 2010 Griffiths et al 2013 Hendricks et al 2003 Holdsworth et al 2006 Hussenbux et al 2014 Jorgenson & Olesen 2008 Joyce & Kuperstein 2005 Menzies et al 2011 Miller et al 2005 Peters et al 1994 Robert & Stevens 1997 Rose et al 1998 Wong et al 1994	Birk et al 2005 Carr 2010 Chanou et al 2009 Cup et al 2007 Dick et al 1985 Galley et al 1975 Gallo et al 2004 Griffiths et al 2006 Griffiths et al 2012 Gurden et al 2012 Holdsworth et al 2008 Jorgenson et al 2001 Kooijmann et al 2013 Kruger 2010 Ojha et al 2013 Pendergast et al 2012 Roberts et al 2002 Roddy et al 2013 Schmidt et al 1999 Shamra et al 2012 Simpson et al 1998 Snider et al 2013 Stoll et al 2003 Watt et al 2000
4	28	24

NB categorisation at this stage does not involve screening by quality, only by relevance.

Study	Design	Aim/investigation	Sample size
Akbari et al 2008	Systematic Review	Effect of intervention to improve referral	17 studies
Faulkner et al 2003	Systematic Review	Quality of primary/secondary care interface	44 studies
Hussenbux et al 2014	Systematic Review	Quality of primary/secondary care interface	23 studies
Hendricks et al 2003	Observational study	Effect of 1-off GP consultation of physio	59 pairs
Ball et al 2006	Retrospective Review	Management of MSK referrals	673 pts
Brooks et al 2012	Retrospective Review	Characteristics by source	7971 met inclusion criteria
Clawson et al 1994	Retrospective Review	Content of referrals	2267 referrals
Davenport et al 2005	Retrospective Review	Content of referrals	2183 referrals
Ehrmann-Feldmann et al 1996	Retrospective Review	Characteristics of referral and patient	2147 workers
Fritz et al 2012	Retrospective Review	Timing and content of Rx	32070 pts
Menzies et al 2011	Retrospective Review	Impact of expansion on referrals	4925 pts
O'Cathain et al 1995	Retrospective Review	Pilot scheme; GP based physio	1388 users
Peters et al 1994	Retrospective Review	referral content & rate before & after	154 pts
Robert & Stevens 1997	Retrospective Review	Direct access	Unstated
Wong et al 1994	Retrospective Review	Changes in referral content	292 referrals
Rose et al 1998	Retrospective Review	Inappropriate referral from somatisation	228 referrals
Freburger et al 2003	Cross-sectional analysis	Variations in referrals	9112 pts
Carey & Freburger 2014	Editorials	Appropriate referrals	Unstated
Joyce & Kuperstein 2005	Editorials	Appropriate/facilitation of referrals	Unstated
Clemence & Seamark 2003	Qualitative – interviews/questionnaires	Experiences and views of patients - appropriateness	22 interviews
Driver et al 2012	Qualitative – interviews/questionnaires ABSTRACT	Reasons for referral in unique setting – British soldiers in Afghanistan	9 GDMOs
Gohar et al 2010	Qualitative – interviews/questionnaires	Frequency of physio referral for children with ALL	35 children
Jorgenson & Olesen 2008	Qualitative – interviews/questionnaires	Referral rates and predictors	38231 pts from 260 practices
Miller et al 2005	Qualitative – interviews/questionnaires	Geriatric referral patterns	118 therapists, 839 pts
East et al 2013	Audit	Efficiency of referrals from A&E	108 consecutive patients
Griffiths et al 2013	Audit	Discrepancies of referral consensus	100 consecutive patients
Fransen 2004	Textbook	Appropriate referral & criteria	n/a

<i>Study</i>	Conclusions	Outcome measures	Content date range	Region/ country
Akbari et al 2008	Structured referral sheets & local education affect rates	Appropriate referral rates	- Oct 07	UK
Faulkner et al 2003	Small but increasing evidence, costs manageable	Referral rates	1980 - 2001	UK
Hussenbux et al 2014	MSK CATS consistently improve pt outcomes & referrals	Referral outcomes & waiting times	- Oct 13	UK
Hendricks et al 2003	One-time physio consultation by PCP	Adherence to guideline	Unstated	Dutch
Ball et al 2006	#'s/dislocations treated similarly, soft tissue differently	Rates of modality use: bandage, x-ray	March – May 2005	UK
Brooks et al 2012	LBP pts referred by occ. Med. Drs have better outcomes & fewer visits per EOC	Visits per EOC	2003 - 2005	US
Clawson et al 1994	Physios often independently diagnose without referral info	n/a	1994	US
Davenport et al 2005	Physios often independently diagnose without referral info	Information content of medical diagnoses	6 random months of 2001	US
Ehrmann-Feldmann et al 1996	Referral based on pt characteristics. Early referral sped recovery	Length of absence from work	1988 - 1990	Canada - Quebec
Fritz et al 2012	Early physio = reduced risk of further problems	Use of physio within 90 days	Nov 2007 – Jan 2009	US
Menzies et al 2011	SEM physicians & orthopaedists agree on surgery needs	Referral rate, % recommended surgery,	July 2006 – June 2007	US
O’Cathain et al 1995	GP-based physio can increase service use	Referrals & service use before & after	Nov 1992	UK
Peters et al 1994	Relatively low referral rate to external specialists	Demographics, Dx, Rx & recurrence	1989 - 1990	UK
Robert & Stevens 1997	Reduced waiting lists, costs per pt	wait, costs per patient. recovery time	1981-95 1989-96	UK
Wong et al 1994	Fewer Dx/modalities included, more general aims	Diagnosis & prescriptiveness	1982 – 1989	Australia
Rose et al 1998	45% of pts with somatization of mental problems referred	Unstated	Unstated	UK
Freburger et al 2003	Varying referrals from orthopaedists/PCPs	Presence of referral	1995 - 1999	US
Carey & Freburger 2014	Screening into physio 2-4 weeks following primary care consultation	Start Back Tool	- 2014	US
Joyce & Kuperstein 2005	Wide specialisation/scope of physiotherapists	Unstated	2003 – 2005 literature	US
Clemence & Seamark 2003	Expectations relevant, direct contact more useful than written guidelines	Semi-structured interview	Approx. 2000-2003	UK
Driver et al 2012	Influenced by availability of physiotherapist, manpower, flights and timing of leave	Semi-structured interview	Unstated	UK
Gohar et al 2010	30% referred to physio for msk, need for increased GP awareness	Age, Rx, referral & time thereof	2006 - 2007	US
Jorgenson & Olesen 2008	GP characteristics explain little regarding variation in referrals	Patient gender & age Practice type/location Age & gender of GP	1996-1997	Denmark
Miller et al 2005	Geriatric population increasing and presenting variety of conditions to physio	Referral content; diagnosis; comorbidity; setting; gender & age	Sept 2001	US
East et al 2013	High rate of false positives – need for guidelines	Incidence and severity of adverse events	Sept – Oct 2013	Ireland
Griffiths et al 2013	discrepancies between ED and ESP Dx	Diagnosis & referral source	Approx. 2011	UK
Fransen 2004	therapeutic exercise beneficial; community based more so	Effect size by treatment mode	2004	Australia

Study	Design	Aim/investigation	Sample size
Connell et al 2004	Longitudinal dataset; Cox proportional hazards model	Examine factors impacting likelihood of re-referral	22584 children
Freeman et al 2012	Audit of Msk hub	Efficacy of new hub	150
Lamb et al 2013	retrospective descriptive study	colposcopy follow-ups, treatments & re-referrals in smokers vs non-smokers	494
Thompson et al 2009	Cox regression analyses in longitudinal multisite study	predictors of re-referral among urban children originally referred for maltreatment	149

Study	Conclusions	Outcome Measures	Content Date Range	Region/Country
Connell et al 2004	Children from families with multiple stressors (low SES, substance abuse, disability) are at highest risk	Number of referrals by time; cause of referral	2001-2004	USA
Freeman et al 2012	reduced inappropriate referrals, increased appropriate re-referral	Unstated	Unstated	UK
Lamb et al 2013	Smokers three times more likely to need third follow-up	No. of referrals, incidence of smoking	2001-2007	New Zealand
Thompson et al 2009	Demographic characteristics and characteristics of the index incident of maltreatment are strongest predictors of re-referral	ICQ, CES-D, CAGE, CTS-PC, CBL tools	1990-1995	USA

Appendix B

Chronic Care Model (CCM) relation to study design

Problem-solving	<p>The CCM teaches the problem-solving process of problem identification and definition, solution options, implementation of a solution, and evaluation.</p> <p>In terms of this study, the patients' exact problem was unclear, as were solution options.</p>
Decision making	<p>The skill can include other decisions as well as the question of 'to refer or not refer'. Ultimately, the tools for decision making are based upon information, with this study providing this in an area previously unexplored.</p>
Resource utilization	<p>In general terms, there are numerous resources available for patients with chronic conditions. Knowledge or information is one such resource. A key question however is the existence of a suitable pathway for these patients.</p> <p>One of the primary outcomes of this study was to determine this. With suitable pathways, care providers are better placed to deliver the care necessary and patients better placed to benefit.</p>
Patient-provider relationship	<p>Content, frequency, style (e.g. whether it is collaborative and open) and outcome of the two-way interaction and communication between patient and provider (in this case both physiotherapist and GP) as well as interactions between primary and secondary care providers, were all examined by way of this study, including their role in instigating a repeat re-referral.</p>
Action taking	<p>Linked to the previous skills, for optimal management patients must ideally be able to act on behalf of their own condition, and this regularly.</p>

Appendix C

LCID database perusal favourable opinion



Health Research Authority

NRES Committee East Midlands - Leicester

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Tel: 0115 883 9436

09 March 2015

Dr Daniel Kerr
Room 01F110, Ulster University
Shore Road, Newtownabbey Co. Antrim
BT37 0QB

Dear Dr Kerr

Study title:	Re-referral to musculoskeletal physiotherapy outpatient departments
REC reference:	15/EM/0131
IRAS project ID:	166074

The Proportionate Review Sub-committee of the NRES Committee East Midlands - Leicester reviewed the above application on 06 March 2015.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Ellen Swainston, nrescommittee.eastmidlands-leicester@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

Approved documents

The documents reviewed and approved were:

Document	Version	Date
IRAS Checklist XML [Checklist_09032015]		09 March 2015
Other [Data Collection Form v4 16.12.14]	4	16 December 2014
REC Application Form [REC_Form_26022015]		26 February 2015
Research protocol or project proposal [Protocol v7 09.01.15 (header 09.03.15)]	7	09 January 2015
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	16 December 2014
Summary CV for student [CV D Topley 8.12.14]	1	08 December 2014
Summary CV for supervisor (student research) [CV Dr I Wilson 05.11.14]		05 November 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flowchart v2 16.12.14]	2	16 December 2014

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

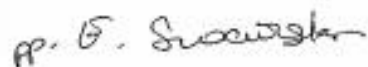
We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

15/EM/0131

Please quote this number on all correspondence

Yours sincerely



John Baker
Vice-Chair

Email: nrescommittee.eastmidlands-leicester@nhs.net

Enclosures: *List of names and professions of members who took part in the review*
"After ethical review – guidance for researchers"

Copy to: *Ms Mary McDonald, Northern Health and Social Care Trust*

Appendix D

Stakeholders Perspectives and Focus Group provisional opinion



Health Research Authority

North West - Haydock Research Ethics Committee

3rd Floor - Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8012

11 May 2016

Dr Daniel Kerr
University of Ulster
Room 01F110
Shore Road
Newtownabbey
Co. Antrim
BT37 0QB

Dear Dr Kerr

Study title: Repeated re-referral: perspectives and experiences of interested parties in the decision to refer to musculoskeletal outpatient physiotherapy
REC reference: 16/NW/0372
IRAS project ID: 195941

The Proportionate Review Sub-Committee of the North West - Haydock Research Ethics Committee reviewed the above application on 10 May 2016.

Provisional opinion

The Sub-Committee would be content to give a favourable ethical opinion of the research, subject to clarification of the following issues and/or the following changes being made to the documentation for study participants:

1. Provide a justification for video recording participants or confirm that you will not do so.
2. Rewrite the Participant Information Sheet to bring it in line with HRA guidance. Information can be found online at <http://www.hra-decisiontools.org.uk/consent/>
Please make sure the revised Participant Information Sheet includes the following:
 - a. What will happen if A section on the benefits, or lack thereof, of taking part in the study.
 - b. What will happen to recordings, including when they will be destroyed.
 - c. Travel expenses.
3. Revise the consent form to bring it in line with HRA guidance.

When submitting a response to the Sub-Committee, the requested information should be electronically submitted from IRAS. A step-by-step guide on submitting your response to the REC provisional opinion is available on the HRA website using the following link:

<http://www.hra.nhs.uk/nhs-research-ethics-committee-rec-submitting-response-provisional-opinion/>

Please submit revised documentation where appropriate underlining or otherwise highlighting the changes which have been made and giving revised version numbers and dates. You do not have to make any changes to the REC application form unless you have been specifically requested to do so by the REC.

Authority to consider your response and to confirm the final opinion on behalf of the Committee has been delegated to .

Please contact Rachel Katzenellenbogen, nrescommittee.northwest-haydock@nhs.net or 0207 104 8012 if you need any further clarification or would find it helpful to discuss the changes required with the lead reviewer.

The Committee will confirm the final ethical opinion within 7 days of receiving a full response. A response should be submitted by no later than 10 June 2016.

Summary of discussion at the meeting

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The Committee noted that the researchers said confidentiality would be maintained but that they also said it might not be possible to maintain confidentiality if they had to report findings of poor practice. The Committee agreed that this information needed to be included in the Participant Information Sheet.

The Committee noted that the researchers would make video recordings as well as audio ones. The Committee could find no rationale for video recordings and agreed that the researchers should either provide a justification for this or confirm that they would only make audio recordings.

The Committee noted that a screening questionnaire would be sent to potential participants. When it came back it would inevitably have identifiable data on it. The Committee agreed that it was acceptable for the researchers to see this information before consent was taken as it was up to the potential participant to decide whether they wanted to return it or not and they knew what data was on it and who would see it. Therefore returning the questionnaire could be seen as implied consent.

Informed consent process and the adequacy and completeness of participant information

The Committee was pleased to see that the Participant Information Sheet was short but noted it did not follow the HRA template at all. This resulted in the information being difficult to read and also not including key areas such as benefits, expenses and what would happen to the recordings. The Committee agreed that the Participant Information Sheet would need to be rewritten and advised the researchers to read the guidance on the HRA website at <http://www.hra-decisiontools.org.uk/consent/>

The Committee agreed that the consent form should also be brought in line with HRA guidance and the preamble removed completely.

Documents reviewed

The documents reviewed were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview schedules or topic guides for participants	2	23 February 2016
Letters of invitation to participant [Invitation letter GP v1]	v1	16 December 2015
Letters of invitation to participant [Invitation letter Physio v1]	v1	16 December 2015
Letters of invitation to participant [Invitation letter Patient v1]	v1	16 December 2015
Non-validated questionnaire [Screening questionnaire Physio v1]	v1	16 December 2015
Non-validated questionnaire [Screening questionnaire Patient v1]	v1	16 December 2015
Other [Application clarification (email)]		03 May 2016
Participant consent form [Consent Form GP v1]	v1	16 December 2015
Participant consent form [Consent Form Physio v1]	v1	16 December 2015
Participant consent form [Consent Form Patient v1]	v1	16 December 2015
Participant information sheet (PIS) [Information Sheet GP v1]	v1	16 December 2015
Participant information sheet (PIS) [Information Sheet Physio v1]	v1	16 December 2015
Participant information sheet (PIS) [Information Sheet Patient v1]	v1	16 December 2015
REC Application Form [REC_Form_21042016]		21 April 2016
Research protocol or project proposal [Protocol FG v4 23.02.16]	v4	23 February 2016
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		15 December 2014
Summary CV for student [Student CV]		
Summary CV for supervisor (student research) [Supervisor CV]		
Summary, synopsis or diagram (flowchart) of protocol in non technical language	1	11 January 2016

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

16/NW/0372	Please quote this number on all correspondence
-------------------	---

Yours sincerely



Dr Tim S Sprosen
Chair

Email: nrescommittee.northwest-haydock@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Nick Curry, Ulster University
Ms Mary McDonald, Northern Health & Social Care Trust



Health Research Authority

North West - Haydock Research Ethics Committee

3rd Floor - Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8012

25 May 2016

Dr Daniel Kerr
University of Ulster
Room 01F110
Shore Road
Newtownabbey
Co. Antrim
BT37 0QB

Dear Dr Kerr

Study title: Repeated re-referral: perspectives and experiences of interested parties in the decision to refer to musculoskeletal outpatient physiotherapy
REC reference: 16/NW/0372
IRAS project ID: 195941

Thank you for your submission of 19 May 2016, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Ms Rachel Katzenellenbogen, nrescommittee.northwest-haydock@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview schedules or topic guides for participants	2	23 February 2016
IRAS Checklist XML [Checklist_19052016]		19 May 2016
Letters of invitation to participant [Invitation letter GP v1]	v1	16 December 2015
Letters of invitation to participant [Invitation letter Physio v1]	v1	16 December 2015
Letters of invitation to participant [Invitation letter Patient v1]	v1	16 December 2015
Non-validated questionnaire [Screening questionnaire Physio v1]	v1	16 December 2015
Non-validated questionnaire [Screening questionnaire Patient v1]	v1	16 December 2015
Other [Application clarification (email)]		03 May 2016
Other [Justification for Video v1]	v1	18 May 2016
Participant consent form [Consent Form GP v2]	v2	19 May 2016
Participant consent form [Consent Form Physio v2]	v2	19 May 2016
Participant consent form [Consent Form Patient v2]	v2	19 May 2016
Participant information sheet (PIS) [Information Sheet GP v2]	v2	18 May 2016
Participant information sheet (PIS) [Information Sheet Physio v2]	v2	18 May 2016
Participant information sheet (PIS) [Information Sheet Patient v2]	v2	18 May 2016
REC Application Form [REC_Form_21042016]		21 April 2016
Research protocol or project proposal [Protocol FG v4 23.02.16]	v4	23 February 2016
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		15 December 2014
Summary CV for student [Student CV]		
Summary CV for supervisor (student research) [Supervisor CV]		
Summary, synopsis or diagram (flowchart) of protocol in non technical language	1	11 January 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports

- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/NW/0372	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Tim S Sprosen
Chair

Email: nrescommittee.northwest-haydock@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Nick Curry, Ulster University
Ms Mary McDonald, Northern Health & Social Care Trust

Appendix F

LCID database perusal approval of amendment for extension of time



Health Research Authority

East Midlands - Leicester Central Research Ethics Committee

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

19 April 2016

Ms Mary McDonald
Northern Health and Social Care Trust
R&D Office, Governance Dept
Bush House, Bush Road
Antrim
BT41 2QB

Dear Ms McDonald

Study title:	Re-referral to musculoskeletal physiotherapy outpatient departments
REC reference:	15/EM/0131
Amendment number:	SA1
Amendment date:	24 March 2016
IRAS project ID:	166074

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering letter on headed paper [From Daniel Topley]	SA1	
Notice of Substantial Amendment (non-CTIMP) [Signed by Dr Kerr and Nick Curry, both Ulster University]	SA1	24 March 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Tracked]		

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/EM/0131:	Please quote this number on all correspondence
-------------	--

Yours sincerely

A handwritten signature in black ink, appearing to read 'PP. Willis', enclosed in a rectangular box.

Mr Ken Willis
Chair

E-mail: nrescommittee.eastmidlands-leicestercentral@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Dr Daniel Kerr*

East Midlands - Leicester Central Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 15 April 2016

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mr John Baker	Radiation Protection Advisor and Senior Lecturer (retired)	Yes	
Mrs Sandra Hall	Principal Lecturer in Clinical Pharmacy & Pharmacy Practice	Yes	
Mr Ken Willis (Chair)	Medical Devices Manager - retired	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Nicola Kohut	REC Assistant



Health Research Authority

North West - Haydock Research Ethics Committee

3rd Floor - Barlow House
4 Minshull Street
Manchester
M1 3DZ

Tel: 0207 104 8001

30 January 2017

Dr Daniel Kerr
University of Ulster
Room 01F110
Shore Road
Newtownabbey
Co. Antrim
BT37 0QB

Dear Dr Kerr

Study title:	Repeated re-referral: perspectives and experiences of interested parties in the decision to refer to musculoskeletal outpatient physiotherapy
REC reference:	16/NW/0372
Amendment number:	Amendment 1
Amendment date:	17 November 2016
IRAS project ID:	195941

The above amendment was reviewed on 24 January 2017 by the Sub-Committee in correspondence.

Favourable opinion

This amendment consisted of the addition of a questionnaire to the study to be used to gather qualitative data, in the cases where the Focus Group cannot be recruited for.

No material ethical issues were raised.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Non-validated questionnaire	v5	19 December 2016
Notice of Substantial Amendment (non-CTIMP)	Amendment 1	17 November 2016
Other [Amendment rationale]		

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/NW/0372:	Please quote this number on all correspondence
--------------------	---

Yours sincerely

PP



Dr Tim S Sprosen
Chair

E-mail: nrescommittee.northwest-haydock@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Ms Mary McDonald, Northern Health & Social Care Trust*
Nick Curry, Ulster University

Appendix H – LCID data collection form template

Data collection Form

Inclusion criteria:

- 1 Patients referred for multiple episodes of care to musculoskeletal outpatient physiotherapy
- 2 Patients within Northern HSCT

Today's date ____ (dd) / ____ (mm) / ____ (yyyy)

Researcher's signature _____

PATIENT DETAILS (Circle correct answers and/or complete blanks)

Patient allocated number: _____

Age: _____

Gender: _____

Original Referral date: _____

Attendance date: _____

Length of wait (weeks): _____

GP diagnosis: _____

Diagnosis from Physiotherapy notes (if different) _____

Number of episodes (state in numericals): _____

This episode number (e.g. 2nd/3rd etc.): _____

Recorded outcome of last episode (if applicable): _____

Co-morbidities (Circle which apply):

Cardiopulmonary	Respiratory	Endocrine
Neurological	Oncological	Surgical
Infection/viral	Rheumatological	Other

Details: _____

This episode of Care

Discharge date: _____

Length of episode: _____

Discharge reason: _____

Follow-up/recommended plan (check which apply):

- HEP/self-management
- GP appointment
- Onwards Referral to another health care professional
(if so, please state): _____
- Referral for tests
(if so, please state): _____
- None/none stated
- Other
(please state): _____

Appendix I – Patient invitation letter for focus group

Dear _____

Date: _____

I am a qualified Physiotherapist currently undertaking PhD research at Ulster University, based in the Jordanstown campus.

You are invited to participate in a piece of research, by our research team within the Centre for Health and Rehabilitation Technology (CHaRT). The study is in the format of a focus group, which involves an open, round-table discussion upon personal experiences, scheduled for early November.

This particular study is concerned with the experiences of those who have repeatedly referred into musculoskeletal outpatient physiotherapy three or more times within the past three years (i.e. from January 1st, 2012). We have noted a section of the population experiencing these repeated referrals within the Northern Health & Social Care Trust (NHSCT), and wish to understand the occurrence more. Your participation in this study, if you consent to it, will aid us in this regard.

This document includes this invitation, a questionnaire, consent form and an information sheet describing the study, as we would like you to be fully aware of what is involved in participation, and so to make an informed decision on whether or not you wish to be involved. We invite you to take time to read the information carefully.

My contact details are provided, and you can use these to contact me for further information, including clarification on the study, or upon your role should you decide to participate. If upon reading the enclosed information you wish to participate, please return the questionnaire and consent form in the envelope provided, to the address below. You will receive a reply as soon as possible.

Please note that this document has been sent to you via the NHSCT. Neither I nor the research team currently know nor hold your personal details. We have requested that this information be sent to those who, following analysis of the NHSCT database, have been repeatedly referred to physiotherapy as described above. **Unless you contact myself or the team directly in response to this invitation, your personal details will be known only to those already providing your care.**

Whether or not you participate, I would like to thank you for your time and consideration.

Yours sincerely,

Daniel Topley

PhD Researcher
Room 01F03
Centre for Health and Rehabilitation Technologies (CHaRT)
School of Health Sciences
Faculty of Life & Health Sciences
Ulster University - Jordanstown Campus
Email: Topley-d@email.ulster.ac.uk
028 9036 8020



“Repeated re-referral: perspectives and experiences”

PARTICIPANT INFORMATION SHEET

These documents contain information regarding Focus Group discussions that the Ulster University plan on organising in coming months. Please take the time to read before deciding whether or not to participate.

Overview

The proposed focus groups, in which you are invited to participate, are designed to discuss the experiences of those within the Northern Health & Social Care Trust (NHSCT) coverage who have been referred to physiotherapy outpatient departments multiple times in the past few years.

You would be asked as part of a group to discuss your experiences of those physiotherapy referrals, structured on a few general questions that a member of the research team will ask. This will be in the knowledge that contributions are voluntary (i.e. you can contribute as you feel you want to) anonymous (i.e. we will neither use nor disclose your name or any other details about you) and helpful to the health professions and the NHSCT.

Participation would require your informed consent – i.e. that you are fully aware of what is involved and agree to it. This is the purpose of the documents you have received. If you do not wish to actively respond with your written informed consent, we will under no circumstances include you, but will respect and accept your decision.

Background to the research and purpose

This focus group study follows a previous investigation into numbers of those patients who had three or more referrals into physiotherapy outpatient departments in the Northern Health and Social Care Trust (NHSCT) in Northern Ireland, over the past 3 years.

There was a possibility that, whilst a referral to physiotherapy was necessary for many cases, there may be a number of people for whom a referral to physiotherapy was not the best or only option. If people return for the same, or even for different problems, it may well be that alternatives can be offered. Both parties agreed that it would be valuable to learn why these individuals have kept being referred to physiotherapy.

The University research team have been able to interact with the physiotherapists within the NHSCT and find the exact numbers and rates of these referrals, and sites involved, which formed the main part of the previous study. The present study, which you are invited to be a part of, will add to our

findings, by learning more about the decision to refer into physiotherapy, especially in repeated cases. We would like to hear experiences and insight that you could provide.

Please note that we, the University, have not in the previous study, seen or recorded personal details. **We do not hold your details or name.** These documents have been written by us, but have been forwarded to you by your care provider, the NHSCT.

Please note also that this invite in no way will affect your care that you are receiving – the aim is not to prevent attendance or referral to physiotherapy, which is a very valuable secondary care provision. We simply would like to know about your experiences.

What would taking part involve?

It is planned to have 3 separate groups, each with up to 10 participants, and all of whom have been referred repeatedly into physiotherapy with various diagnoses. As described above, participants will be asked generally to discuss their experiences of being referred, for example the decision-making process, or any influential factors that led to their referral. Any or all of your referrals can be used for answers, and any alternatives to physiotherapy you were offered or thought you should be offered are of interest also. We are particularly interested in experiences within the NHSCT, though you may have attended in another Trust. The discussion is intended to be open and frank, with the intention being to gather the experiences, concerns, insight and explanations offered by those who are actually being referred. There are no right or wrong answers, and all contributions are anonymous, with no personal identifying details being included in the analysis or potential publication of the findings. It will take no more than 2 hours total of your time.

The group discussion will be recorded using video and audio equipment. You do not have to consent to this recording, however if you do not or cannot consent, you will not be able to participate. We will check your consent again on the day. This recording is necessary for transcription and analysis of the information provided by you and will not be kept longer than necessary, nor made public. You will not be identified by name in either recording. Following the group discussion, the recording will be transcribed (written out) in full, with temporary numbers used to distinguish between participants and no personal names or details used from this point. Anonymity in contribution will be preserved at all times by the team, and all information will be treated in accordance with the Data Protection Act, (1998).

It is likely that you will receive a short summary of the transcription when it is available, and you will have an opportunity to ensure that the group has been accurately represented therein.

The researcher will write a report upon the full findings from the focus group, the content of which will be related to the NHSCT, and will also contribute to one researcher's PhD thesis. It is possible that both this and the previous study will be published in medical and/or healthcare journals. We stress that at no point in any of these processes will you be identified.

Please note that your participation is entirely voluntary, and you have the right to withdraw at any stage for any reason, even following initial consent.

What are the possible benefits of taking part?

This study will help the Trust providing you with your care, to maintain an efficient and productive service to the public. We are concerned with providing the right care to the right people, and we want to ensure that you, and all those sharing the same Trust as you, receive what you need in terms of healthcare.

It may be that the information you provide, and/or experiences you share, will show that changes are necessary – participation will enable that information/experience to be made known.

What are the possible disadvantages or risks of taking part?

There is no intrinsic risk to health by participation. We will not ask you to change your healthcare provision, nor will we take steps to do so. Your participation will not affect your current healthcare provision, nor will we pass your personal details on to any healthcare service or professional.

We would ask that you ensure you are free to attend before committing, and to make the relevant arrangements in your place of work if necessary. However, we plan on carrying out the focus groups on a time and place that will minimise disruption to normal routine and that is practical for all.

It is highly unlikely given the subject of the discussion that something should arise in conversation to offend or upset another participant. Please note that every participant however retains the right to withdraw from the discussion, or to pause if they feel so inclined. Anonymity and consideration of fellow participants, who are contributing of their own free will to inform healthcare provision, will be stressed throughout.

Other questions:

Can I bring someone with me?

Unfortunately only those invited and having provided consent can attend. If you have special requirements, please feel free to indicate these when responding.

Can I choose which group?

The groups will be allocated randomly, to ensure there is no bias or pre-arranged outcomes at any stage, and participants will not meet each other until the group. You will only be required to participate in one group.

Why have I been invited?

The NHSCT, via whom this document has arrived, have seen that you have had multiple referrals to physiotherapy in the past 3 years. You may be able to inform the research team regarding the referral experience. If this is in error, you can disregard this contact. Nothing in your healthcare provision will change.

When and where are the groups held?

Those who respond and give consent will in the near future be contacted to have the place and time confirmed. It is planned to hold these in the Robinson Memorial Hospital, and ideally before Easter. We expect it to be a Friday afternoon in late March or Early April.

What will happen if I don't want to carry on with the study?

At any stage, even during the focus group itself, you have the right to leave. If you do, you cannot return to the study, nor will we contact you again. We would encourage you to commit to the end of the group, but will not challenge any decision.

When do you need to hear back from me?

As soon as possible; ideally within a week of receipt to allow us to address queries or requirements. We will try to give 1-2 weeks from your response reaching us, to the group being held.

How will my information be kept confidential?

As described, we do not currently hold your details. Unless you respond with consent, we will not, and cannot access these. If you respond and consent, we will only use your details to contact you and confirm arrangements. We will not use your name after the group has taken place, and the video/audio recordings will only be seen by the researchers, whom you will meet at the group itself.

What will happen to the results of this study?

The results of the study are intended to be published, to inform the public and healthcare community regarding referral patterns and experiences of those undergoing them. There is a possibility that they will inform changes/improvements to care pathways in the NHSCT and/or further afield. They will be published in association with the previous study mentioned in the background to the current study.

One of the researchers involved will be able to use the results to contribute towards a PhD.

Who is organising and funding this study?

This study is funded by the Department for Education and Learning (DEL).

Who has reviewed this study?

This study could not take place without review and approval from at least two peer reviews within the University, followed by the University Ethics filter committee and approval by the NHS Research & Development (R&D) Office, and proportionate review within the Office for Research Ethics Committees Northern Ireland (ORECNI).

We hope that this sheet, with the accompanying documents, is of interest and provides you with enough information to make an informed decision as to whether you are willing to help us by participating.

Contact details have been provided in this information sheet, and you can use these to contact me by telephone or email if you need further clarification, information or have any questions about your participation. We will return any contact as soon as possible.

Yours Sincerely,

Daniel Topley

Room 01F03

Centre for Health and Rehabilitation Technologies (CHaRT)

School of Health Sciences

Faculty of Life & Health Sciences

Ulster University - Jordanstown Campus

E: Topley-d@email.ulster.ac.uk

028 9036 8020



Appendix K – Screening Questionnaire for patient focus groups

Screening Questionnaire

Researcher: Daniel Topley, PhD researcher, Ulster University

Study Design: Focus Groups

Title: Repeated re-referral – insight into and influential factors for the decision to refer

SCREENING QUESTIONNAIRE

Thank you for taking the time to read and complete this short questionnaire. The questions are intended to ensure that you meet the demographic required as the recipient of this invitation.

The fact that you have received this document means it is likely you meet the requirements, however there are additional inclusion criteria that we must consider other than the number of referrals received. The brevity of the questionnaire reflects the fact that we are collecting only the required information.

Please provide honest answers, as you do not necessarily have to answer 'YES' to all the following.

- Are you 18 years of age or older? Yes No
- Is English your first language? Yes No
- If not, are you proficient enough to hold a conversation with ease? Yes No
- Have you been referred to physiotherapy 3+ times since Jan 1st 2012? Yes No
- Have these been for the same issues? Yes No
- Are you able to remember each individual referral and what it was for?
You do not need to give details here. Yes No
- Is it practical to travel to the Robinson Memorial Hospital, Ballymoney? Yes No
- Do you require any particular facility, for example wheelchair access? Yes No
If yes, you can get in contact to indicate what these are. Alternatively, you can give details here: _____

- Do you understand that in returning this questionnaire to the address indicated, you consent to the research team being able to contact you? Yes, I understand

Thank you for completing the questionnaire. Please forward the completed version to the address indicated, using the envelope provided.

*Daniel Topley, Room 01F03, School of Health Sciences, Ulster University,
Jordanstown Campus, Shore Road, Newtownabbey BT37 0QB*



Appendix L – Consent form for patient focus groups

STATEMENT OF INFORMED CONSENT FOR PARTICIPATION IN AN APPROVED FOCUS GROUP STUDY

Researcher: Daniel Topley, PhD researcher, Ulster University

Study Design: Focus Groups

Title: Repeated re-referral – perspectives and experiences

Please initial box

1. I confirm that I have read the information sheet supplied (dated _____) for the above study. I have had the opportunity to consider the information, ask questions I may have and, if applicable, have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my medical care or legal rights being affected.

3. I understand that the information I provide will be anonymised, may be published used to support other research in the future, and if published, will be in association with a previous study.

4. I have notified the team of any personal requirements and am satisfied with all arrangements.

5. I understand that this giving of written informed consent includes allowing the University Researcher named to contact me as described in the Information Sheet.

6. Having read, understood, and agreed to all the above, I agree to take part in this study.

Please sign the participant section below

Participant Name Date Signature
(to be completed by potential participant)
Address _____
Telephone _____
Email (if applicable) _____

Researcher Date Signature

Appendix M – invitation letter for physiotherapist focus groups

Invitation letter

Dear _____,

Date: _____

I am a qualified and registered Physiotherapist, currently undertaking PhD research at Ulster University, based in the Jordanstown campus.

You are invited to participate in a piece of research by our research team within the Centre for Health and Rehabilitation Technology. The study is in the format of a focus group, which involves an open, round-table discussion upon personal experiences.

This particular study is concerned with the experiences of those who have repeatedly referred into musculoskeletal outpatient physiotherapy three or more times within the past three years (i.e. from January 1st, 2012). We have noted a section of the population experiencing these repeated referrals within the Northern Health & Social Care Trust (NHST), and wish to understand the occurrence more. Your participation in this study as one of the interested parties in a referral, if you consent to it, will aid us in this regard.

This document includes this invitation, a questionnaire, and an information sheet describing the study, as we would like you to be fully aware of what is involved in participation, and so to make an informed decision on whether or not you wish to be involved. We invite you to take time to read the information carefully.

My contact details are provided, and you can use these to contact me for further information, including clarification on the study, or upon your role should you decide to participate. If upon reading the enclosed information you wish to participate, please return the questionnaire in the envelope provided, to the address below. You will receive a reply and consent form, with further details including dates and times. The group will take place within normal Trust working hours, and ought to place no burden upon your private time.

Please note that this document has been sent to you via the NHST. Neither I personally nor the research team currently know or hold your personal details. We have requested that this information be sent to those who are currently working as physiotherapists within the NHST. Unless you contact myself or the team directly in response to this invitation, your personal details will be known only to those already holding them, i.e. your team leads.

Whether or not you participate, I would like to thank you for your time and consideration.

Yours sincerely,

Daniel Topley

PhD Researcher
Room D1F03
Centre for Health and Rehabilitation Technologies (CHaRT)
School of Health Sciences
Faculty of Life & Health Sciences
Ulster University - Jordanstown Campus
E:Topley-d@email.ulster.ac.uk



“Repeated re-referral: perspectives and experiences”

PARTICIPANT INFORMATION SHEET

These documents contain information regarding Focus Group discussions that the Ulster University plan on organising in coming months. Please take the time to read before deciding whether or not to participate.

Overview

The proposed focus groups, in which you are invited to participate, are designed to discuss the repeated referral of a patient group within the Northern Health & Social Care Trust (NHSCT) area to physiotherapy outpatient departments multiple times in the past few years.

You would be asked as part of a group to discuss your perception of this occurrence or experience of patients undergoing repeated re-referral. It will be structured on a few general questions that a member of the research team will ask. This will be in the knowledge that contributions are voluntary (i.e. you can contribute as you feel you want to) anonymous (i.e. we will neither use nor disclose your name or any other details about you) and helpful to current knowledge, to inform the health professions and the NHSCT.

Participation would require your informed consent – i.e. that you are fully aware of what is involved and agree to it. This is the purpose of the documents you have received. If you do not wish to actively respond with your written informed consent, we will under no circumstances include you, but will respect and accept your decision.

Background to the research and purpose

This focus group study follows a previous investigation into a section of the Trust population who had three or more referrals into physiotherapy outpatient departments in the Northern Health and Social Care Trust (NHSCT) in Northern Ireland, over the past 3 years. The process for re-referral over a number of episodes is unclear and we are interested in investigating possible reasons for this.

There was a possibility that, whilst referral to physiotherapy was necessary for many cases, there may be some for whom a referral to physiotherapy was not the best, or perhaps only, option. If people return for the same, or even for different problems, it may well be that alternatives can be offered. Both parties agreed that it would be valuable to learn why these individuals have kept being referred to physiotherapy.

A research partnership between this research group and the NHSCT has resulted in the research team being able to find the volume and rates of these referrals, and sites involved. This formed the main part of the previous study. The present study will add to our findings, by learning more about

the decision to refer into physiotherapy, especially in repeated cases. We would like to hear experiences and insight that you could provide.

Please note that we, the University, have not in the previous study, recorded personal details. We do not hold your details or name. These documents have been written by us, but have been forwarded to you by the NHSCT.

What would taking part involve?

Each focus group is planned for approximately 3-8 participants, all of whom are physiotherapists within the NHSCT. As described above, participants will be asked generally to discuss their familiarity with the concept of repeated referrals, and experiences or observations of patients undergoing multiple referrals, along with any understanding or insight into the decision-making process or influential factors that led to their referral. Any or all experiences can be included, and any alternatives to current practice offered are of interest also. Experiences do not necessarily have to be within the NHSCT, though these are sought.

The discussion will be open and frank, with the intention being to gather the experiences, insight and explanations offered by you who are actually seeing the patients on a regular basis. We need these to fully inform our understanding of the occurrences. There are no right or wrong answers, and all contributions are anonymous, with no personal identifying details being included in the analysis or potential publication of the findings.

The group discussion will be recorded using video and audio equipment. You do not have to consent to this recording, however if you do not or cannot consent, you will not be able to participate. This recording is necessary for the analysis of the information provided.

Following the group discussion, the recording will be transcribed in full, with temporary encoding used to distinguish between participants and no personal names or details used from this point. Anonymity in contribution will be preserved at all times by the team, and all information will be treated in accordance with the Data Protection Act, (1998).

It is likely that you will receive a short summary of the discussion when it is available, and you will have an opportunity to ensure that the group has been accurately represented therein.

The researcher will write a report upon the full findings from the focus group, the content of which will be related (anonymised) to the NHSCT and will also contribute to one researcher's PhD thesis. It is possible that both this and the previous study will be published in medical and/or healthcare journals.

Please note that your participation is entirely voluntary, and you have the right to withdraw at any stage for any reason, even following initial consent. We will respect your decision.

What are the possible benefits of taking part?

This study will help the Trust providing the optimum care and maintain an efficient and productive service to the public. We are concerned with providing the right care to the right people, and we want to ensure that you, as autonomous professionals within that Trust, are facilitated in the best use of your skills and not hindered by inefficient pathways.

It may be that the information you provide, and/or experiences you share, will show that changes are necessary – participation will enable that information/experience to be made known. Some employers or auditing bodies may also favourably consider participation in healthcare research.

What are the possible disadvantages or risks of taking part?

There is no intrinsic risk to your current role by participation. We will never attach your name, Band or current post to any group contribution you make. Your participation will not affect your current role, nor will we pass your personal details on to any healthcare body or professional.

We would ask that you ensure you are free to attend before committing, and to make the relevant arrangements in your place of work if necessary. However, we plan on carrying out the focus groups on a time and place that will minimise disruption to normal routine and that is practical for all.

It is highly unlikely given the subject of the discussion that something should arise in conversation to offend or upset another participant. Please note that every participant however retains the right to withdraw from the discussion, or to pause if they feel so inclined. Anonymity of results and mutual consideration of fellow participants, who are also contributing of their own free will, will be stressed throughout.

Other questions:

Why have I been invited?

The NHSCT, via whom this document has arrived, have forwarded these documents from the University to those who have worked recently as a physiotherapist therein. You may be able to inform the research team regarding the referral experience. If you have received this contact in error, you will not be suitable and can disregard this contact without further implication.

When and where are the groups held?

The group will be held in your department, and use an unfilled, one-hour in-service slot. The exact location will be confirmed well in advance of the group.

What will happen if I don't want to carry on with the study?

At any stage, even during the focus group itself, you have the right to leave. If you do, you cannot return to the study, nor will we contact you again. We would encourage you to commit to the end of the group, but will not challenge any decision.

How will my information be kept confidential?

As described, we do not hold your details. Unless you respond giving consent, we will not and cannot access these. If you respond and consent, we will only use your details to contact you and confirm arrangements. We will not use your name after the group has taken place, and the video/audio recordings will only be seen by the researchers, whom you will meet at the group itself.

What will happen to the results of this study?

The results of the study are intended to be published, to inform the public and healthcare community regarding referral patterns and experiences of parties involved. There is a possibility that they will inform changes and improvements to care pathways in the NHSCT and/or further afield. They will be published in association with the previous study mentioned in the background to the current study.

One of the researchers involved will use the results to contribute towards a PhD award.

Who is organising and funding this study?

This study is funded by the Department for Education and Learning (DEL).

Who has reviewed this study?

This study could not take place without review and approval from at least two peer reviews within the University, followed by the University Ethics filter committee and approval by both the NHS Research & Development Office, and proportionate review within the Office for Research Ethics Committees Northern Ireland.

We hope that this sheet, with the accompanying documents, is of interest and provides you with enough information to make an informed decision as to whether you are willing to help us by participating.

Contact details have been provided below, and you can use these to contact me by telephone or email if you need further clarification, information or have any questions about your participation. We will return any contact as soon as possible.

Yours Sincerely,

Daniel Topley

PhD Researcher
Room 01F03
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Appendix O – Screening Questionnaire for physiotherapist focus groups

Screening Questionnaire

Researcher: Daniel Topley, PhD researcher, Ulster University

Study Design: Focus Groups

Title: Repeated re-referral – insight into and influential factors for the decision to refer

SCREENING QUESTIONNAIRE

Thank you for taking the time to read and complete this short questionnaire. The questions are intended to ensure that you meet the demographic required as the recipient of this invitation.

The fact that you have received this document means it is likely you meet the requirements, however there are additional inclusion criteria that we must consider. The brevity of the questionnaire reflects the fact that we are collecting only the required information.

Please provide honest answers, as you do not necessarily have to answer 'YES' to all the following.

- Are you 18 years of age or older? Yes No
- Is English your first language? Yes No
- If not, are you proficient enough to hold a conversation with ease? Yes No
- Are you currently working as a physiotherapist in the NHSCT? Yes No
- Are you, or have you in the past, worked in a musculoskeletal outpatient post or rotation? Yes No
- Is it practical for you to travel to the site? Yes No
- Do you require any particular facility, for example wheelchair access? Yes No

If yes, you can get in contact to indicate what these are. Alternatively, you can give details here: _____

- Do you understand that in returning this questionnaire to the address indicated, you consent to the research team being able to contact you? Yes, I understand

Thank you for completing the questionnaire. Please forward the completed version along with the consent form, to the address indicated, using the envelope provided. Daniel Topley, Room 01F03, School of Health Sciences, Ulster University, Jordanstown Campus, Shore Road, Newtownabbey BT37 0QB



Appendix P – Consent form for physiotherapist focus groups

STATEMENT OF INFORMED CONSENT FOR PARTICIPATION IN AN APPROVED FOCUS GROUP STUDY

Researcher: Daniel Topley, PhD researcher, Ulster University

Study Design: Focus Groups

Title: Repeated re-referral – perspectives and experiences

Please initial box

1. I confirm that I have read the information sheet supplied (dated _____) for the above study. I have had the opportunity to consider the information, ask questions I may have and, if applicable, have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my medical care/role or legal rights being affected.
3. I understand that the information I provide will be anonymised, may be published used to support other research in the future, and if published, will be in association with a previous study.
4. I have notified the team of any personal requirements, and am satisfied with all arrangements.
5. I understand that this giving of written informed consent includes allowing the University Researcher named to contact me as described in the Information Sheet.
6. Having read, understood, and agreed to all the above, I agree to take part in this study.

Participant Name Date Signature
(to be completed by potential participant)

Researcher Date Signature
(to be completed by researcher)

Appendix Q – GP Questionnaire

Questionnaire

It is suggested that a section of the patient population is repeatedly referred to physiotherapy multiple times within a relatively short period for the same conditions. We would value your insights to aid our understanding of this phenomenon.

The following questions relate specifically to your experience of these patients.

Q1.

A patient presents with musculoskeletal pain, and is referred to physiotherapy on a number of occasions. They are no better/no worse from the intervention.

What would you do when the patient returns to you once more?

Would you:

1a Refer again to physiotherapy YES NO

If yes: Why might you refer to PT? Please tick all that apply

- The patient specifically requests physiotherapy Physiotherapy has worked for similar cases
- Physiotherapy has worked at another time No other service is appropriate
- Other options are exhausted The number of physiotherapy sessions weren't enough

Other (please comment) _____

1b Prescribe medication to address their pain YES NO

1c Refer to a different secondary care service YES NO

1d Request a scan or x-ray on their behalf YES NO

1e Discuss pain management by lifestyle changes YES NO

1f Other (please comment) _____

Q2.

The LCID (Local Community Information Database) indicates that over a 3-year period in the NHSCT, approximately one third of referrals (30,000 out of a total of 90,000) were repeat referrals.

These were distributed amongst 13,274 patients, i.e. on average, 2-3 referrals for each person. A smaller number, approx. 340 patients, had over 3, and up to 5 or 6 separate referrals.

Over half (55%) are aged 40-60, with the majority having a diagnosis, though a small unconfirmed proportion are referred with unspecified chronic musculoskeletal pain.

a) Are these patterns comparable to your own experience of patients' referrals?

YES

NO

b) would you have expected more, fewer, or about the same number of referrals?

more

fewer

about the same

c) How, in your opinion, are these repeat referrals to physiotherapy best explained? Please tick all that apply

These are expected exacerbations of degenerative conditions e.g. OA	<input type="checkbox"/>	These are a result of specific requests for physiotherapy	<input type="checkbox"/>
These are requests/needs for specific treatment, requiring physiotherapy (e.g. acupuncture, hydrotherapy)	<input type="checkbox"/>	These are mainly 'heart-sink' patients who continually re-appear in GP clinics	<input type="checkbox"/>
These are mainly patients with long-term pain, e.g. Fibromyalgia and/or Chronic Regional Pain Syndrome	<input type="checkbox"/>	These are routine sports or work-related musculoskeletal injuries and are normal rates	<input type="checkbox"/>

If you ticked more than one, which, in your experience, is the **most** likely reason for referral?

These are expected exacerbations of degenerative conditions e.g. OA	<input type="checkbox"/>	These are a result of specific requests for physiotherapy	<input type="checkbox"/>
These are requests/needs for specific treatment, requiring physiotherapy (e.g. acupuncture, hydrotherapy)	<input type="checkbox"/>	These are mainly 'heart-sink' patients who continually re-appear in GP clinics	<input type="checkbox"/>
These are mainly patients with long-term pain, e.g. Fibromyalgia and/or Chronic Regional Pain Syndrome	<input type="checkbox"/>	These are routine sports or work-related musculoskeletal injuries and are normal rates	<input type="checkbox"/>

Other _____

Q3.

Where a decision is made to refer, how heavily do you rely on:

a) Patient request/input?

Please indicate on the scale.

Hardly at all

a small amount

a significant amount

very heavily

b) Your own experience/beliefs?

Please indicate on the scale

Hardly at all

a small amount

a significant amount

very heavily

Q4.

If physiotherapy works for a patient's condition, how likely is it that you will refer the same patient to physiotherapy for a different musculoskeletal condition?

Please indicate on the scale



No more likely



more likely than before



highly likely



almost certain

Are there any comments you would like to add about re-referral to physiotherapy?

Many thanks for your time and participation. We would like to interview a number of GPs (this will take about 30 minutes of your time and can be done at your convenience) in order to better understand the results of this brief survey. If you are willing for us to contact you, please provide the details below.

You do not have to complete this section if you prefer not to.

Name: _____

Telephone: _____

Email: _____



Appendix R – GP questionnaires results tabulation

QN	Question content	GP Respondent						
		A	B	C	D	E	F	G
Q1a	Returning patient scenario: Refer again to physiotherapy, if: <ul style="list-style-type: none"> The patient specifically requests physiotherapy Physiotherapy has worked for similar cases Physiotherapy has worked at another time No other service is appropriate Other options are exhausted The number of physiotherapy sessions weren't enough Other 						•	•
Q1b	Prescribe medication to address pain	•		•	•	•	•	•
Q1c	Refer to a different secondary care service	•		•		•	•	•
Q1d	Request a scan or x-ray on their behalf	•		•		•	•	•
Q1e	Discuss pain management by lifestyle changes	•		•	•	•	•	•
Q1f	Other						•	
Q2a	LCID data: Are these patterns comparable to your own experience of patients' referrals? YES NO	•	•	•		•	•	•
Q2b	Would you have expected more, fewer, or about the same number of referrals? More Fewer About the same	•	•	•	•	•	•	•
Q2c	How, in your opinion, are these repeat referrals to physiotherapy best explained? These are expected exacerbations of degenerative conditions e.g. OA These are a result of specific requests for physiotherapy These are requests/needs for specific treatment, requiring physiotherapy These are mainly 'heart-sink' patients who continually re-appear in clinics These are mainly patients with long-term pain, e.g. FMS and/or CRPS These are routine sports-/work-related Msk injuries and are normal rates Which, in your experience, is the most likely reason for referral? These are expected exacerbations of degenerative conditions e.g. OA These are a result of specific requests for physiotherapy These are requests/needs for specific treatment, requiring physiotherapy These are mainly 'heart-sink' patients who continually re-appear in clinics These are mainly patients with long-term pain, e.g. FMS and/or CRPS These are routine sports-/work-related Msk injuries and are normal rates	•	•	•	•	•	•	•
Q3a	How heavily do you rely on patient request/input? • Hardly at all • A small amount • A significant amount • Very heavily	•	•	•	•	•	•	•
Q3b	How heavily do you rely on our own experience/beliefs? • Hardly at all • A small amount • A significant amount • Very heavily	•	•	•	•	•	•	•
Q4	Likelihood of re-referral, if physiotherapy worked for a separate condition for that patient: • No more likely • More likely than before • Highly likely • Almost certain	•	•	•	•	•	•	•

Appendix S – Topic Guide for patient focus groups

Topic guide (patient)

- Ice-breaker e.g. when was your last visit to MSk OPD PT?
- Q1 – Why do you think you were referred to PT MSk OPD?
 - Probe: reasons e.g. particular condition, PT helped before, GP recommended PT, etc.
 - Probe: any patient understanding e.g. Understanding of treatment goals, of pathology etc.
- Q2 – How do each subsequent referral that you experienced compare with the initial referral?
 - Probe: how much discussion was there between you and the GP on prev results?
 - Probe: how did you feel about returning – how did expectation/experience compare?
- Q3 – Do you think that PT was/is the best way to manage your condition?
 - Probe: positives and negatives, reasons
 - Probe: any information regarding ‘success stories’
- Q4 – Do you feel you need, or there already are, alternatives?
 - Probe: internal to physio, any treatments – mention passive/active treatments?
 - Probe: external to physio, additional needs?
- Do you wish to add to anything?

Appendix T – Topic Guide for physiotherapist focus groups

Topic guide (PT)

- Ice-breaker: e.g. how long have you been in Msk OPD?
- **Q1** – We acknowledge some patients return to physiotherapy often. What are your experiences of returning patients?

Probe: examples/contexts of patients, summary of own experience (was this always the case?)

Probe: diagnoses/populations, time periods, numbers of episodes?
- **Q2** – (Present emerging picture) can your experiences help us explain these findings?

Probe: are they what you would expect?

Probe: (offer particular group) could you account for this group particularly?
- **Q3** – Do you feel that there are management alternatives to these referrals, or ought to be?

Probe: inappropriate referrals, are there alternative pathways?

Probe: room for adjustment in exposure to physiotherapy/duration of episodes?
- **Q4** – Have patients expressed opinions of their care pathway/management to you?

Probe: do patients comment upon the referral decision/do they discuss their pain history?

Probe: how would you describe patients' expectations of their care?
- **Q5** – What change would you most like to see?

Probe: regarding the management/addressing of repeat referrals?

Probe: approach of any person including patient/GP? infrastructure? Personally, as an AHP?
- Do you wish to add anything?

Appendix U

The following methodology is suggested as a SOP for investigating the incidence of repeated re-referral into a secondary care service; originally utilized in an outpatient physiotherapy department.

The methodology rationale is explained in further detail in chapter 4 of the PhD thesis “The repeated re-referral of chronic pain patients into musculoskeletal physiotherapy outpatient departments”, 2019. This document below summarises the recommendation of the SOP.

1. Initial corroboration of the incidence of repeated re-referral should be sought, ideally by patient database output
2. Selection of time-frame, identification of referral totals over such a period
3. Database should be interrogated for multiple re-referral incidences over this period
4. If large incidence of re-referral, identification of necessary sample size
5. Anonymised data collection forms, corresponding to format of data output from database
6. One data form per referral. At close of data collection, chronological compilation of episodes per patient
7. UIDs linking data collection forms to records and patient names/other identifying details. This makes cross-referencing with patient notes more efficient. Any hard copy notes thus identified prior to the researcher’s visit. At no point patient names used; instead, validation accomplished by referencing dates and UID.
8. Data variables included: episode number, age, gender, date of referral, date of attendance, diagnosis, co-morbidities, discharge date, reason for discharge.
 - a. **Dates:** Dates generally will have so wide a range that make the use of frequencies meaningless; these can however be used to calculate time periods.
 - b. **Age/Gender:** Age entered numerically, gender as ‘1’ or ‘2’ denoting male or female respectively.
 - c. **Diagnoses**
Coded numerically as per assessment in department from which data is collected. In variance between referrer and AHP (or secondary care provider) diagnoses, or upon lack of clarity in referral content, AHP diagnosis was preferred – being the most recent manifestation of symptoms, and clinically the greatest opportunity for differential diagnosis.
 - d. **Calculated time periods**

Some CIS will provide pertinent time periods; in others, variables may be calculated from dates. Episode duration = date referral made, until date of discharge.

Treatment duration = date of first attendance at the department, until date of discharge. Length of time between episodes = date of discharge until the date of subsequent referral. In cases with a second referral made in advance of the first episode ending, this variable is entered as '0'. Should a subsequent referral be made on the exact date of the patient being discharged, this variable was then entered as '1'. Generally secondary care services will have a waiting time or list to some degree; settings may allow exceptions, for example, single-day episodes for the provision of a walking aid, which would have the referral date, attendance date, and discharge date within the same day. In occurrences of this, 'episode length' = '1'.

e. **Weeks as units**

Time periods calculated using whole weeks as a unit of measure; built into common parlance both for health professionals and the public and used for example, with protocols for a given rehabilitation programme

f. **Traumas**

Included to identify episodes that were a direct result of a trauma. These might account for extended treatment time, or ongoing complications, even if not recent. For example, patients referred for back pain despite multiple years since onset following a road traffic accident (RTA).

Episodes treated as physical traumas can include RTAs (Road Traffic Accidents), and complete ruptures of a ligament, muscle or tendon, along with more severe tears. Other examples include crush injuries, severe falls, fractures of any description, and more invasive surgeries such as total knee or hip replacements (TKR, THR), costoplasty procedures, internal fixators (ORIFs), mastectomies, anterior cruciate ligament (ACL) reconstructions, spinal decompression and discectomies, or sub-acromial decompressions (SADs). Typical microtrauma (e.g. from overtraining) resulting in a minor tendinopathy are not recorded as trauma by this definition. Recurrent dislocations, resulting in soft tissue damage, can be recorded as traumas. These are simply recorded as '1' for a positive value.

g. **Co-morbidities (Past Medical History)**

Assessment forms for the appropriate departments ought to facilitate coding of this variable. Many departments will include space to clarify. Comorbidities recorded as categories – for example, 'Cardiopulmonary', 'respiratory', 'endocrine',

'neurological', 'oncological', 'surgical', 'infection/viral', 'rheumatological', 'stress/depression/anxiety', 'metabolic', 'visceral', 'dermatological', 'general pain syndrome' 'musculoskeletal', and 'other'.

Coding by category allows ease of data presentation. Should a pattern be identified by category, it can then be cross-referenced with patient notes to find if the pattern applies to individual pathologies within that category, via the UID.

Co-morbidities can be difficult to track between episodes; therefore when entering data into SPSS, the heading used should be past medical history (PMH); this accounts for all recorded medical history, ongoing or not, which may have predisposed the patient, or affected the presentation/development of the condition.

h. **Reasons for discharge**

For coding, terms should be in accord with those used within the database. For example, the NHSCT LCID output included 14 'discharge reasons' or 'outcome descriptors'. When entering in SPSS, numbered 1-14. A key ought to clarify descriptors used and identify situations wherein each is appropriately applied.

9. **Data Cleaning.** Data cleaning should be undertaken, to ensure all data and values were entered correctly, with no omissions unaccounted for, duplicates, or mistakes in calculations, and each variable format correct, before running descriptive statistics.

a. **Data checking**

A process of taking a section (or sections) of the data randomly and cross-referencing every variable and value with the corresponding data collection forms and Excel spreadsheet from LCID. At least one researcher should be involved, not responsible for data collection or entry and therefore independent. Approximately 10% at any given stage can be sampled for data checking.

b. **Duplicates**

Duplicated episodes should be removed from statistical calculations.

c. **Missing values**

SPSS excludes missing values from computations; this should be indicated in the handling of the frequencies.

10. **Descriptive Statistics.**

Statistical analysis with frequencies calculated, as opposed to inferential statistics – strictly speaking, no specific hypothesis being tested in an exploratory dealing with of quantitative data, to build a picture of the referrals which simply was not known prior to the study.