

Exploring MSK Patient Pathways

Patient Experiences: Facilitators and Barriers. And The Way Forward

Full Report

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Contents

Chapter One: Project Background	2
Chapter Two: Project Methodology	7
Chapter Three: Understanding Our Patients and Quality of Life	11
Chapter Four: Overview of Osteoarthritis and the Patient Pathway	15
Chapter Five: Summary of Key Findings	18
1. Booking and Communications About Appointments.....	18
2. Primary Care Appointment Experiences	20
3. Referrals for and Receiving Conservative Management	23
4. Referrals to and Experiences of Secondary Care	27
5. Orthopaedics' Surgery Decision Making	31
6. Patient Surgery Decision Making.....	34
Chapter Six: Patients' Experiences of Self-Management	37
Chapter Seven: The Way Forward - Proposals to Improve Patient Pathways.....	42

Chapter One: Project Background

Strategy Unit Report – Socio-economic inequalities in access to planned hospital care

In May 2021 the Midlands Strategy Unit (SU¹) produced an analysis of 'Socio-economic inequalities in access to planned hospital care'. This looked the presence of inequalities in the levels of treatment received by patients from different socio-economic groups in four condition pathways: COPD, Heart Failure, Hip Arthritis (OA Hip) and Cataracts. The analysis took each pathway and identified treatment measures in both Primary Care (PC) and Secondary Care (SC). A report was produced for the Midlands region as a whole and for individual Integrated Care Systems (ICS), and data trends were available at Place level.

In general, across the region as a whole, the SU concluded that patients from most deprived backgrounds were overrepresented in PC stages of condition pathways and the aligned treatment. In contrast, patients from the least deprived backgrounds were overrepresented in SC stages, resulting in higher levels of surgery for this population. However, when we drilled down to the Black Country (and West Birmingham) this trend was not replicated across all of the four pathways in our ICS.

Across the Black Country and West Birmingham, the most prominent socio-economic inequality was observed in the OA Hip pathway, in particular in relation to levels of Total Hip Replacement surgery (THR). All Places in the Black Country demonstrated a common trend, with the least deprived patients receiving higher levels of THR. In Sandwell and West Birmingham (SWB) and in Walsall, this trend was statistically significant².

In Wolverhampton, SWB, and Walsall the analysis also found the least deprived patients received more outpatient referrals for OA Hip than the most deprived, and this was statistically significant in Wolverhampton³.

Project Focus

The Healthier Futures Academy was asked to review the SU analysis for the Black Country and investigate what could be causing the variation in treatment levels observed. Given the nature of our local results, this led to a clear focus on the OA Hip Pathway.

We committed time to fully understand the analysis, the metrics used and how to interpret the results. (We summarised this in a standalone report). The SU had used the most accessible and reliable metrics they could, which had recognised limitations. For example, there is not a specific list for OA Hip in PC, alternatively the general Rheumatoid Arthritis register was utilised.

The metric used to analyse levels of THR was based on operative codes, providing an accurate account. The trend for fewer THR amongst the most deprived was strongest in statistical terms, followed by the trend for fewer outpatient referrals amongst the most deprived. This suggests something is occurring in the PC stages of the pathway and in the run up to referral, which causes lower rates of referral amongst more deprived patients. Further, once deprived patients are seen in

¹ [Socio-economic inequalities in access to planned hospital care: causes and consequences | The Strategy Unit \(strategyunitwm.nhs.uk\)](https://strategyunitwm.nhs.uk). (Accessed on 04/05/2023).

² The SU analysis was based on pre-covid data, hence was not influenced by issues caused by the pandemic.

³ In Dudley however, the most deprived patients are more likely to gain an outpatient referral, but this is not a significant trend.

SC, inequalities appear to increase, as they are statistically less likely to have surgery. Given this, we decided to explore both the PC and SC stages of the pathway to gain insights into what patient, healthcare provision or other factors, may be causing or contributing to this difference in activity.

The SU refer to the trends as inequalities, others may choose to refer to them as variation, the key question being whether the variation is warranted or unwarranted. For example, variation may be warranted if patients from more deprived backgrounds have more co-morbidities, making surgery a less viable option, and/or reducing the likely benefits, leading to lower rates of surgery. On the other hand, unwarranted variation would be viewed as an inequality, for example if patients from more deprived backgrounds were experiencing lower levels of surgery due to poorer staffing and equipment levels in their local hospitals.

To explore the MSK pathway further, the ICS Insight Team conducted an analysis of Total Knee Replacement Surgery (TKR) received by the most deprived patients and least deprived patients in the Black Country. This also demonstrated the least deprived patients receive higher levels of TKR than the most deprived⁴.

Health Inequalities Context

Health inequalities (HI) are a persistent international problem. The World Health Organisation defines HIs as “differences in health status or the distribution of health resources between different population groups, arising from the social conditions in which people are born, grow, live, work, and age” (WHO, 2018⁵). All health and related systems face the challenge of designing and successfully implementing policies and healthcare practices that prevent and reduce inequalities.

The NHS is a universal service and free at the point of use. However, in practice, different population groups do not have equal access to services, and they do not achieve equity in health outcomes (NHS England (NHSE), 2023⁶).

Tackling HI is essential to build a truly universal service, with equity and fairness. NHSE have created the Core20PLUS5 Framework (2022⁷) to prioritise and give focus to the work of ICS’s in addressing inequalities. Nationally the framework prioritises patients living in the top 20% most deprived areas of the country. In the Black Country this presents a significant challenge with 50% of our total population living in the top 20% most deprived areas. Core20PLUS5 also asks each ICS to identify other local population groups with poorer than average health access and/or outcomes, and prioritise reducing HIs in this population. Alongside these groups, it focuses on five clinical areas: 1) Maternity; 2) Severe Mental Illness; 3) Chronic Respiratory Disease; 4) Early Cancer Diagnosis; 5) Hypertension Case-Finding.

HI can only truly be addressed by focusing on the wider determinants of health including the physical and natural environment, income, education, crime, social and community networks, and lifestyle factors. These determine 80% of our health outcomes, while healthcare services determine

⁴ Across the ICS there are 2.4 times more knee procedures performed per 1000 in the least deprived compared to the most deprived populations, with 1.61 people per 1000 receiving a knee procedure in the most deprived, compared to 3.92 people in the least deprived. (Based on pre-covid data: 1/04/2019 to 31/03/20320).

⁵ [World Health Organization \(2018\). Health inequities and their causes.](#) (Accessed on 10/01/2023).

⁶ [https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities/NHS England. What are healthcare inequalities?](https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities/NHS%20England.%20What%20are%20healthcare%20inequalities?) (Accessed on 10/01/2023).

⁷ [NHS England. National Healthcare Inequalities improvement programme.](#) (Accessed on 15/02/2023).

only 20%. People living in areas of high-deprivation and minority ethnic communities are more likely to be exposed to conditions with a negative impact on health and well-being (NHSE,2023). They are more likely to experience comorbidities, and are likely to need complex healthcare responses (Watt, Raymond, and Ratchet-Jacquet, 2022⁸). For example, The Kings Fund (2021⁹) found obesity rates for men living in the most deprived areas is 8 percentage points higher, and for women 17 percentage points higher, than those living in the least deprived areas.

The impact of the wider determinants of health on disadvantaged population groups is compounded further by barriers patients experience when accessing services including: availability and opening hours of services in local areas; transport and childcare issues; language barriers; illiteracy; poor service experiences in the past; misinformation, and even fear (NHSE, 2023).

Musculoskeletal (MSK) Health Inequalities

MSK conditions affect a significant proportion of the population with hip and knee replacements representing some of the most frequently performed surgeries in the UK (National Joint Registry, 2020¹⁰). Versus Arthritis and Public Health England (2013¹¹) estimate approximately 1 in 5 adults over 45 years in England have Knee Osteoarthritis (OA Knee), and 1 in 9 adults have OA Hip. Between 2000/21 and 2015/16 the number of elective THR increased by 90% (Kings Fund, 2017¹²), and almost 30% of the GP appointments in England are related to MSK conditions, such as arthritis and back pain (NHSE, 2023).

The SU report sits alongside national research, demonstrating a persistent inequality in the levels of THR and TKR during the last two decades. Between 2008/2009 and 2019/2020 levels of THR have increased by 12% per 100,000 in the least deprived areas and decreased by 9% per 100,00 in the most deprived (Nuffield Trust, 2022¹³).

In their systematic review of 16 UK studies (from 2005 to 2021), Ryan-Ndegwa, et al, (2021¹⁴) identified a number of negative trends within specific population groups including:

- Deprivation: Need is greatest amongst the most deprived groups, and more deprived patients have lower levels of Hip functionality before surgery, compared with least deprived patients (their condition is more severe/advanced by the time they have surgery). However, there is significantly less provision for THR and TKR relative to need for patients in the most deprived areas, and THR rates are significantly lower in the most deprived areas*.
- Gender: Women have a greater surgical need for THR and TKR than men, but have less provision. Women also have lower Hip functionality before surgery (their condition is more severe/advanced by the time they have surgery) *.
- BMI: Patients with higher BMI – 30+, were more in need of THR*.

⁸ [Watt, T; Raymond, A; Ratchet-Jacquet, L \(2022\). Quantifying Health inequalities in England. Health Foundation.](#) (Accessed on 10/01/2023).

⁹ [Tackling obesity: The role of the NHS in a whole-system approach \(kingsfund.org.uk\).](#) (Accessed on 04/05/2023).

¹⁰ [National Joint Registry \(2020\). 7th Annual Report 2020](#) (Accessed 12/02/2023).

¹¹ [Versus Arthritis \(2013\). Prevalence of osteoarthritis in England and local authorities: Birmingham.](#) (Accessed on 16/02/2023).

¹² [\(Elective\) hips don't lie | The King's Fund \(kingsfund.org.uk\).](#) (Accessed on 28/04/2023).

¹³ [Deprivation and access to planned surgery | Nuffield Trust](#) (Accessed on 28/04/2023).

¹⁴ [Ryan-Ndegwa, S, Zamani, R, and Akrami, M. \(2021\). Assessing demographic access to hip replacement surgery in the United Kingdom: a systematic review. International Journal for Equity in Health. \(20:224\).](#) (Accessed on 04/05/2023).

- **Ethnicity:** There is some evidence patients from minority ethnic groups have a greater need for THR, however this could also be due to higher levels of deprivation amongst minority ethnic groups.
- **Age:** The overall need for THR increases with old age, however younger patients (under 50 years) are more likely to experience longer term Hip problems than older patients (71 years plus)
- **Health Literacy/Education:** Less educated patients wait longer for surgery.
- **Geography:** Access inequality is greater in the West Midlands, London and North London. The South of England has better provision than the North relative to need. Some rural areas have better provision, although many patients face longer travel times.

(*Statistically significant)

Evidence demonstrates the improvements surgery can make to patients' health and quality of life; however, surgery provision is currently insufficient to meet demand. Overall demand for THR has increased and this pressure has been compounded by covid with 100,000 patients waiting for delayed surgery (Ryan-Ndegwa, et al, 2021). Whilst elective capacity had been on the increase, there has been an overall decline in capacity since 2015/2016 (Kings Fund, 2017). Studies on OA Hip have demonstrated delaying THR has a detrimental impact on patients, leading to mental health problems such as depression and reliance on opioid painkillers (Sharma et al, 2016¹⁵; Inacio et al, 2016¹⁶).

Policy making and funding approaches can create differences in healthcare provision for different population groups and lead to, or reinforce inequalities. A study by McLaughlin et al, (2022¹⁷) funded by the National Institute for Health Research, reviewed the introduction of BMI criteria by CCGs which restricted or altered access to TKR for patients considered to be obese. The study compared 74 CCGs with no policy change, with 56 CCGs that introduced changes based on TKR data from 2009 to 2019. Policy changes ranged from: a recommendation that overweight patients are offered advice on weight management, to mandated extra waiting periods to engage with weight management, through to BMI thresholds for surgical referral.

The study found there was a statistically significant decrease in TKR rates in areas introducing the policy, in comparison to those with no policy change. They reported a 14% reduction in TKR 3 years following the policy, compared with expected levels. Interestingly the reduction affected all patient groups, not just obese patients, however, the impact was greatest on the most deprived. Patients receiving surgery after policy changes were less likely to be from deprived backgrounds, despite the fact people from more deprived backgrounds have higher levels of need. Levels of privately funded surgery also increased, suggesting a further disparity between socioeconomic cohorts. The authors conclude the introduction of such policies may increase health inequalities, with the most deprived patients receiving decreased rates of surgery (McLaughlin et al, 2022).

¹⁵ [Sharma, A; Kudesia, P; Shi, Q; Gandhi, R \(2016\). Anxiety and depression in patients with osteoarthritis: impact and management challenges. Open Access Rheumatol.8: pp 103–113. \(Accessed on 15/02/2023\).](#)

¹⁶ [Inacio, M; Hansen, C; Pratt, NL; Graves, S; Roughead, E \(2016\). 'Risk factors for persistent and new chronic opioid use in patients undergoing total hip arthroplasty: a retrospective cohort study'. BMJ Open. \(Accessed on 15/02/2023\).](#)

¹⁷ [What effect have NHS commissioners' policies for body mass index had on access to knee replacement surgery in England?: An interrupted time series analysis from the National Joint Registry \(bris.ac.uk\) \(Accessed 13/04/2023\).](#)

Another study looked at the introduction of exceptional funding requests for TKR and THR surgery. Reporting on behalf of the BMJ, Lacobucci (2018¹⁸) reviewed a sample of 167 CCGs, gaining data through a Freedom of Information request. Exceptional funding requests were introduced in the 2000's to limit certain types of surgery, such as cosmetic and fertility treatment. However, as finances have become more pressured, they are being applied to a wider range of treatments.

Comparing 2016/7 and 2017/8, the BMJ review found the number of exceptional requests rejected for TKR and THR had increased by 45%. Under the CCG policy the patient's GP was responsible for submitting the request to the CCG panel, when an exceptional request was needed. GPs who are short of clinical time found this a stressful process for them and their patients. Surgeons felt patients were having to beg for what is for a clinically proven and cost-effective treatment. Lacobucci (2018) reports that even when funding requests are accepted, the process causes delays due to the panel process, resulting in patients spending more time in pain and facing potential further deterioration in condition.

Obesity (NHS, 2021¹⁹) and other long-term conditions such as diabetes, chronic obstructive pulmonary disease, arthritis and hypertension disproportionately affect people in deprived areas (Kings Fund²⁰). As such, it is important the introduction policy changes like the above, are party to an equality impact assessment. This should map potential negative and positive impacts to different population groups, to inform whether policy changes are introduced and in what form.

McLaughlin et al (2022) also refer to studies demonstrating that patients with a BMI 40+ rarely manage to reduce their weight sufficiently for surgery through lifestyle and medication interventions alone. When these patients are then asked to lose more weight, this pressure may cause them to withdraw from the pathway despite needing surgery. However, there is no consistent evidence to suggest that patients with a high BMI have significantly worse outcomes from surgery, or that weight loss before surgery reduces the likelihood of infection or readmission.

In summary, our rapid overview of existing research found national and international papers reporting that more deprived socio-economic and other groups received less THR/TKR surgery than others. However, most did not explore the factors underpinning these trends, other than McLaughlin et al's (2022) exploration of BMI policy.

¹⁸ [Nearly 1700 requests for knee and hip surgery were rejected in England last year | The BMJ](#) (Accessed on 19/02/2023).

¹⁹ [NHS \(2021\). Health survey for England. Official Statistics, National Statistics, Survey.](#) (Accessed on 19/02/2023).

²⁰ [Long-term conditions and multi-morbidity | The King's Fund \(kingsfund.org.uk\)](#); Long-term conditions are more prevalent in more deprived groups (people in the poorest social class have a 60 per cent higher prevalence than those in the richest social class and 30 per cent more severity of disease). (Accessed 04/05/2023).

Chapter Two: Project Methodology

Project Focus

The Healthier Futures Academy was asked to investigate what factors might be contributing to the variation in treatment levels observed in the OA Hip pathway by exploring the experience of patients.

Given the trends identified by the SU were strongest in Sandwell and Walsall we decided to focus on these two localities. We sought to compare the experiences of patients with OA Hip from some of the least and most deprived backgrounds, to see if there were differences in patient experiences that might explain some of the variation reported.

We wanted to find patients that had been involved in different stages of the pathway, for example those who had only been seen in PC, patients who had experiences of tier two services, and those who had experience in SC including those who had and had not been offered surgery. This would enable us to explore if there are barriers and facilitators at different stages in the pathway that inhibit and/or support access to, and utilisation of treatment services. We envisaged that patients' experiences would be unique and complex, and that these would be most effectively explored using in-depth interviews.

Project Approvals

We developed our project proposal and took this to the ICS Clinical Leadership Group and the MSK Clinical Learning Network. We wanted to engage the Acute Orthopaedic Teams early on in the process due to the THR and TKR variations identified. We met with both the Sandwell and Walsall Teams to discuss the SU report findings, potential reasons for the variation, and our project plans.

We undertook a full Data Protection Impact Assessment and gained approval under the ICS Caldicott Guardian.

We consulted the Acute Research and Development (R&D) Teams in Sandwell and Walsall to understand the procedures for contacting patients using NHS patient information. In this instance, the Walsall R&D Team felt the project constituted formal research and would need Health Research Authority Approval. This process was not within the capacity of the small project team, hence we needed to change how we would identify relevant patients. Alternatively, we sought to access patients through voluntary and community organisations (VCOs) in the two localities.

Project Design

As with all in-depth projects of this nature, it was important to develop the team's knowledge of the clinical area. We recruited an Expert Clinical Lead Carolyn Casey, who has extensive experience running advanced physiotherapy services, and of PC and SC Orthopaedic settings. Our Clinical Lead provided an in-depth induction into the Arthritis pathway. We worked together to create an interview schedule to comprehensively cover a range of pathway experiences, and circulated this to the Orthopaedic teams in Sandwell and Walsall, and the MSK CLN for comments.

Our aim was to conduct around 10 to 12 interviews in both Sandwell and Walsall, with at least half the interviewees living in the most deprived areas, and the remainder in less deprived areas. We recognised the less deprived patients may be more difficult to identify given the high levels of

deprivation in both Places, and that more affluent patients were perhaps less likely to access support from VCOs.

In practice, due to difficulties securing interviewees, we conducted 15 interviews in total with most patients coming from very deprived areas. Deprivation was measured by IMD linked to postcode which gives us a general understanding of the level of deprivation in the patient's residential area. We did not want to explicitly ask patients about their socio-economic status as this is sensitive information and may appear intrusive. However, patients often gave indications about their position by talking about benefits claimed, resources available to them, or not, and employment status (See Table One page 11 for a full demographic breakdown of the sample).

Inviting Patients to Participate

We spent considerable time mapping VCOs in Sandwell and Walsall who were most likely to support patients with Arthritis. There were only a few organisations dedicated to Arthritis, so more broadly we focused on: health and wellbeing VCOs; leisure and activities VCOs; those supporting more vulnerable, elderly and minority ethnic groups; neighbourhood and community VCOs, and social housing organisations. In practice identifying relevant patients proved very difficult and time-consuming, and we contacted well over 100 VCOs. We also found some patients who had relevant experiences and were interested in taking part, were subsequently unable to do so due to flare-ups in their conditions.

Due to low interviewee levels, we expanded the project to include Knee Arthritis, some of the patients we interviewed had both OA Hip and Knee.²¹

All interested patients were sent an information sheet and a consent form to review before taking part. They were contacted prior to the interview to check they understood and were happy with this information.

Focus Groups

As it became clear we would not reach our interview target we sought to expand our evidence base. We set up two discussions with First Contact Practitioners and Advanced Physiotherapy workers who see a large number of patients with OA Hip and Knee. We wanted to draw on their experiences of working with patients and the pathway journeys patients experienced.

The discussions took place after most of our interviews, enabling us to sound out some of our findings with them. In Walsall six colleagues took place in an online discussion; in Sandwell six attended a face-to-face discussion. The discussions lasted around 1.5 hours and covered both PC and SC experiences. We asked colleagues to reflect on their practice and experiences of working with different patient groups including:

- Patients from lower socio-economic backgrounds
- Patients from higher socio-economic backgrounds
- Patients from different ethnic backgrounds
- Patients with a range of co-morbidities

²¹ The project DPIA and tools were amended at this time to include OA Knee.

Analysis

The interviews were analysed using a thematic analysis approach, bringing together patient feedback on different parts of the pathway and common experiences. The interview guide provided an initial thematic structure. This was refined as we systematically worked through the data to capture the individual experiences of patients under more detailed themes. These are presented in chapters three to six, and linked to the proposed improvement options in chapter seven.

The staff focus groups were analysed in a similar manner. As this is primarily a patient focused project, we do not present these findings in a dedicated chapter. However, the findings played a key role in our proposals, and are presented alongside the improvement options in chapter seven.

Co-Production and ICB Dissemination

When designing our project, we had included a co-production stage where we hoped to bring patients together to discuss the project findings, and co-produce or critique our proposed improvement options. We also hoped to bring together health professionals from different stages of the pathway to undertake a similar process. These two discussions may then provide the foundation to bring patients and health professionals together for a final co-production session.

Before commencing any co-production activity, we wanted to gain an initial feel from ICB stakeholders on their interpretation of the results and proposals, and gauge the ICB's appetite and capacity for the type of improvements included. Any activity would follow an initial ICB dissemination process.

We are planning to disseminate the project findings through a number of ICB groups, these may include the following:

- ICB Clinical Leadership Group
- ICB MSK Clinical Learning Network
- ICB Orthopedic Network
- ICB Electives Board
- ICB Health Inequalities Board
- Place Orthopedic Consultants and aligned professionals
- Place Transformation and Improvement leads
- Provider Collaborative
- ICB Clinical Leaders:
 - Chief Medical Officer and Deputies
 - Director for Primary Care; Medical Director for Primary Care
 - Orthopedic Lead
 - Personalisation Lead

We would welcome advice from ICB leaders on how best to approach dissemination given the range of potential stakeholders who could have a role in refining and implementing the improvement options.

Report Structure

Chapter Three: Understanding Our Patients and Quality of Life

We provide an overview of the patients who took part in our interviews, focusing on their demographic backgrounds and overall life experiences of living with OA Hip and/or Knee.

Chapter Four: Overview of Osteoarthritis and the Patient Pathway

We give an introduction into OA, how the condition develops and treatment options. We reflect on our patients' pathway journeys and the role of self-management, as well as summarising the different pathway positions of the 15 patients.

Chapter Five: Summary of Key Findings

We provide a detailed overview of the project findings under the main themes raised by patients in their interviews, namely:

1. Booking and Communications About Appointments
2. Primary Care Appointment Experiences
3. Referrals for and Receiving Conservative Management
4. Referrals for and Experiences of Secondary Care
5. Orthopaedics' Surgery Decision Making
6. Patient Surgery Decision Making

Under each theme we discuss system and patient factors impacting on patients' pathways and provide patient case studies and quotes illustrating their experiences.

Chapter Six: Patients' Experiences of Self-Management

We bring the discussion back to pathway self-management reflecting on which patients were able to successfully navigate and co-ordinate their pathway, and why this appeared to be the case. Likewise, we reflect on those who were less successful, and how they found this problematic.

Chapter Seven: The Way Forward - Proposals to Improve Patient Pathways

In our final chapter we move onto improvement options as to how some of the 'system' and 'patient' factors impacting on patients' pathways may be overcome. In doing so, we consider changes needed to support patients who are less likely to be successful in self-managing the pathway to gain appropriate treatment and support.

Chapter Three: Understanding Our Patients and Quality of Life

To understand a patient’s journey through a the MSK treatment pathway, we need to understand the context of their daily lives. This has a significant influence over their experience of the pathway, factors that assist them, and barriers that may prevent them from accessing and benefiting from appropriate care.

For many of the 15 patients we interviewed quality of life, or rather reduced quality of life was a central theme. Many patients described pain and mobility issues, and they were restricted in what they could do.

Table One: Summary of Patient Demographics

Patient Profile Summary		
Patient Place Locality:	<ul style="list-style-type: none"> 4 patients from Sandwell 11 patients from Walsall 	
Gender:	<ul style="list-style-type: none"> 4 male patients 11 female patients 	
Ethnicity:	<ul style="list-style-type: none"> 2 Afro-Caribbean 1 Indian Hindu 	<ul style="list-style-type: none"> 1 British Pakistani 11 White British
Age:	<ul style="list-style-type: none"> 5 patients = 50 – 59 yrs. old. 2 patients = 70 – 79 yrs. old. 	<ul style="list-style-type: none"> 5 patients = 60 – 69 yrs. old. 3 patients = 80 yrs. old. +
IMD Deciles: 1 is most deprived	<ul style="list-style-type: none"> 12 patients = Decile 1 or 2 = 12 1 patient = Decile 4 = 1 	<ul style="list-style-type: none"> 2 patients = Decile 8 or 9 = 2
Type of Arthritis:	<ul style="list-style-type: none"> 7 patients had Hip Arthritis 3 patients had Knee Arthritis 	<ul style="list-style-type: none"> 5 patients had both Hip & Knee Arthritis
Co-morbidities: (Other than Hip and Knee Arthritis)	Number of additional Co-morbidities: <ul style="list-style-type: none"> 3 patients = no other co-morbidities 6 patients = 1 to 3 other co-morbidities 6 patients = 4 + other co-morbidities 	Most common additional co-morbidities: <ul style="list-style-type: none"> 4 patients = Diabetes and high cholesterol/pressure 3 patients = High BMI 3 patients = Asthma 3 patients = Mental health 3 patients = Other arthritis and MSK problems

Patient Demographics

Osteoarthritis (OA) affects women more than men and this was reflected in our sample with 11 female and four male patients taking part. OA is more prevalent in older adults than younger adults, but this was not reflected in our sample; a third were under 60 years old, a third were aged 60 and 69 years old, and the final third were 70 years plus.

Condition Severity

Some patients had milder arthritis and were managing their condition conservatively with regular pain relief (e.g., paracetamol and codeine), physiotherapy and moderate exercise (e.g., walking).

Some were pacing their activity, experiencing good and bad days, and adjusting daily activities accordingly.

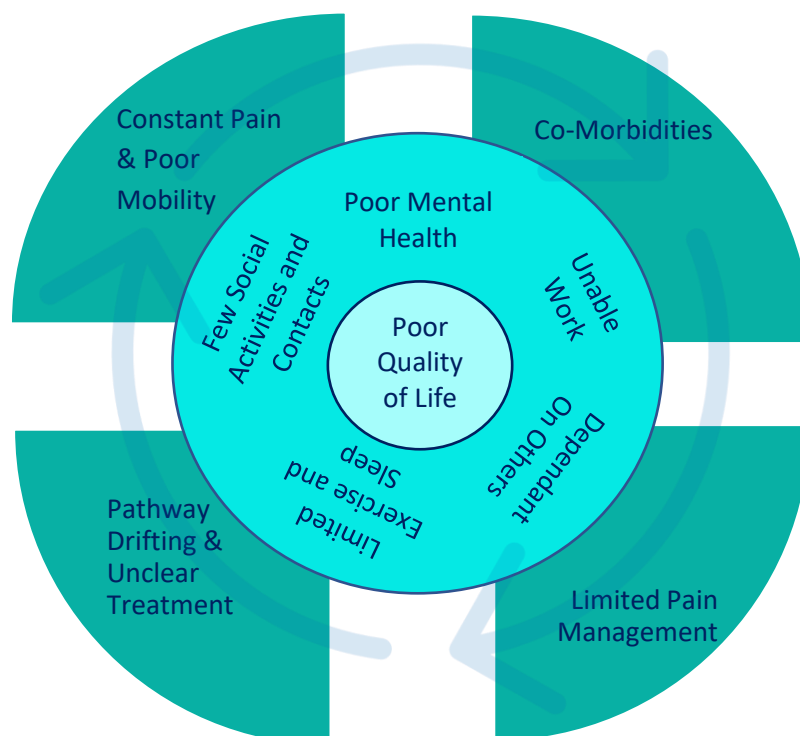
Other patients' conditions were much more severe. These patients had great difficulty walking and were largely housebound. They could no longer do many activities they used to do, including basic household tasks and self-care. Some were using stronger medication for pain relief (e.g., morphine) to manage their condition and get through the day. High levels of pain relief and side-effects resulted in some interviewees being unable to leave their home without assistance, due to drowsiness and fear of falling. Some spent significant parts of the day resting or in bed, and planned the timing of medication to ensure they were sufficiently alert when they wanted to be more active.

More severe symptoms were not necessarily aligned with older age. Several of our older patients had milder conditions, and several younger patients had more advanced conditions.

Quality of Life

Around two-thirds of the patients were experiencing a variation of the 'vicious cycle' represented in Figure One below. Quality of life was restricted by: pain and poor mobility; limited pain management; co-morbidities; and patients 'drifting' in the pathway, waiting for things to happen or being unclear what 'treatment' they were likely to have. This resulted in limited exercise, difficulty doing things for themselves, limited travel options, reduced opportunities for socialising, being unable to work, poor sleep, and overall poor mental health.

Figure One: Vicious Cycle – Severe Patients' Quality of Life



Co-morbidities

Often patients with more severe OA had a range of co-morbidities that interacted with their condition. This created a very challenging set of health needs which further reduced their quality of life. Co-morbidities included fibromyalgia, Type II diabetes, high BMI, heart conditions, asthma, previous cancers, mental health conditions, bowel conditions, cataracts, and hypertension.

Again, co-morbidities were not restricted to older patients in our sample. One 52-year-old cited 10 comorbidities and another 58-year-old cited seven. Clearly, patient co-morbidities interact, and it may be unclear which is having the greatest impact on quality of life. However, patients in our sample often felt their OA Hip or Knee was having the greatest or a significant impact on their lives, and believed there was the potential for improvement with surgery.

Socio-Economic Status

12 of the 15 patients interviewed lived in the top two most deprived deciles on the Indexes for Multiple Deprivation (IMD).

Eight patients were under 65 years old, of which only two were working. At least five patients were claiming one or more benefits in addition to the state pension (if in this age bracket). (However, benefits information was not always captured in the interview).

Some patients indicated they had some financial resources to support their condition. Two used private taxis to get around when needed; one patient was exploring the possibility of private surgery; another patient was able to use their partner's health insurance for private diagnostic investigations.

Work and Social Life

Many patients had given up work and social activities due to pain and loss of mobility. During their working lives our patients' jobs had included: supermarket maintenance worker, school assistant, security officer, health care assistant, rail worker, voluntary sector advice worker, nurse, physiotherapy support worker, and community charity worker. For patients of working age, being unable to work had a significant impact on their mental health, identity, contact with others, independence and financial stability.

Patient Experiences:

'I've had to stop. It was that painful, I thought, 'I can't walk around like this anymore. My daughters said, "I'd pack up if I was you, and go on benefits" It's a bit of a shock when you're on £600 a week and you go to £600 a month. I can't afford anything. It's hopeless' (Int.2)

Many patients were heavily reliant on support from their partner and wider family. In a few cases patients' partners took on the informal role of full-time carer. In many other cases, families were supporting patients by taking them to appointments, shopping, doing household cleaning, and other activities. Patients talked about how this reliance has reduced their own independence and mental health.

Mental Health

Patients often had poor mental health, which they felt had a strong connection with their poor physical health. Poor mental health clearly impacted on patients': mental energy; capacity and confidence to advocate for themselves; and ability to chase professionals at different stages to progress through the pathway.

Patient Experiences: Mental Health

'The arthritis brings on mood swings. You don't want to talk to anybody, to keep telling people you're in a lot of pain because not everybody understands. You just end up stopping, staying at home, watching TV and doing other activities instead' (Int, 13)

'I was really active and busy at work, now that I'm not, it's terrible for my mental health. I've never known anything like it' (Int, 2)

'Mentally I have had to come to terms with it, but I never thought physically I would be incapable of getting my own shopping' (Int, 11)

'I am rely on my wife, it sounds ridiculous, for getting stuff like socks or underwear on, I can't physically bend down. You get desperate, I cannot do the simplest of things' (Int, 14)

'It affects everything. I was used to have good nights, bad nights. Now I have bad nights and worse nights. It's affecting us as a couple, both of us' (Int, 8)

Future Aspirations

Many patients felt if they could resolve their arthritis through surgery, then their overall quality of life would improve due to increased mobility and reduced pain. They saw this as enabling them to re-engage in physical activities (for some this was important to help reduce their weight), with social activities, and for a few, to return to work.

Patients had aspirations to improve their lives and move beyond their current restricted daily activities. Patients talked about their previous lifestyle, how active they were, how much they enjoyed physical exercise, socialising and work.

Patient Experiences:

'I had an active lifestyle with young children, no car walking everywhere. Five years ago, I started getting considerable pain. It got worse and worse until I could barely walk. Then one day my knee gave way completely. I had to use a wheelchair for 3 weeks' (Int, 15)

'My hip pain...if I could chop it off, I would. It's really bad. It's hard all the time. I'd like to go out, I used to enjoy walking from my house to where I used to work in Smethwick. I used to love it' (Int, 1)

Some patients knew they were appropriate for surgery and had this focus for their future treatment. Others, however, were waiting for a solution and living in significant pain without a clear view of how their condition may be treated and improved.

Chapter Four: Overview of Osteoarthritis and the Patient Pathway

OA Condition Development and Treatment

OA is unpredictable and does not evolve uniformly (Arthrolink, 2023²²). Progression of the disease is associated with loss of cartilage which is seen as a narrowing of the joint space on x-ray. Cartilage loss may progress slowly over several decades, be very rapid over just a few months or comprise a combination of steady progression punctuated by aggressive flare-ups. Sometimes, even when x-rays look normal, there may be a rapid phase of deterioration over just a few weeks or months. Alternatively, OA may not manifest as pain and loss of function even when there is significant radiological change.

Patients presenting with OA hip may describe pain (in the groin, knee, thigh, and/or buttock) together with stiffness and problems with everyday activities such as getting in/out of the bath, dressing (especially putting on socks) and mobility. Due to the variable relationship between disease progression, pain, and loss of function (Lancet, 2007²³) the pathway is not linear and may involve repeated support with exercise and lifestyle factors prior to specialist referral.

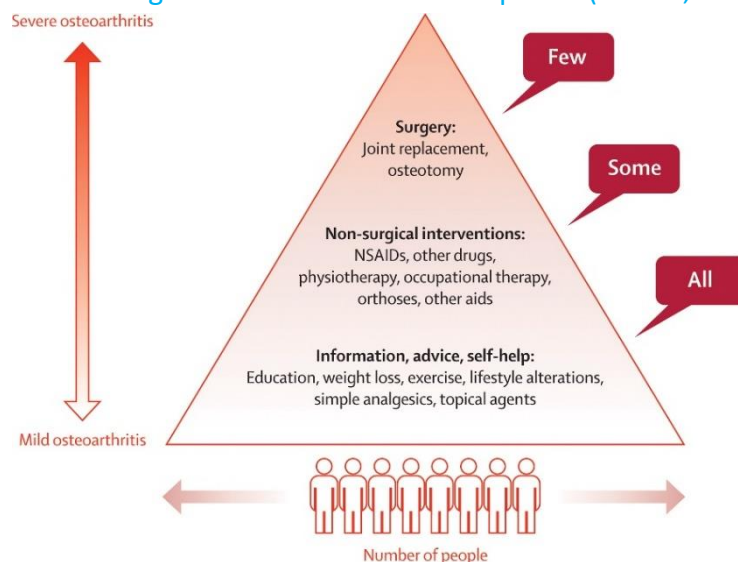
Figure Two, from the Lancet (2007), demonstrates the different OA treatment options. Options like information, advice, and self-help are appropriate for all patients. A range of non-surgical options are appropriate for some patients, and a smaller group would benefit from surgery.

Investing time in education when the patient first presents, particularly in patients with low health literacy, would be useful. Many are not aware the main treatment for OA is therapeutic exercise and weight management, rather than surgery (NICE, Guideline NG226, 2022²⁴).

Best practice would involve biopsychosocial assessment and a shared-decision-making approach (using decision-support tools e.g., NHSE, 2022²⁵), with patients understanding their condition and treatment options; and clinicians being aware of context, relevant social factors and patients' preferences (GIRFT 2023²⁶).

Guidelines state that patients should not be referred to secondary care until conservative management has failed (NICE, 2015²⁷) and as part of a shared-decision-making process. However,

Figure Two: OA Treatment Options (Lancet, 2007)



²² Arthrolink.com, [How does osteoarthritis in the Hip evolve?](#) (Accessed on 05/06/2023)

²³ Lohmander, L, S. and E, M. Roos. (2007). Clinical Update: Treating osteoarthritis. The Lancet. 370. (9605). pp. 2082-2084. [https://doi.org/10.1016/S0140-6736\(07\)61879-0](https://doi.org/10.1016/S0140-6736(07)61879-0) (Accessed on 04/05/2023)

²⁴ NICE, Guideline NG226, 2022. [Management of osteoarthritis.](#) (Accessed on 04/05/2023)

²⁵ NHS hip osteoarthritis decision tool (england.nhs.uk) (Accessed on 19/05/2023)

²⁶ <https://gettingitrightfirsttime.co.uk/wp-content/uploads/2023/03/SWAOC-Hip-and-Knee-Delivery-Guide-March-2023-FINAL-V1-1.pdf> (Accessed on 19/05/2023)

²⁷ NICE, 2015. [Osteoarthritis Quality Standard.](#) (Accessed on 05/06/2023)

joint replacement is often sought following x-ray (sometimes early in the pathway) if the presence of arthritic changes in the joint are confirmed.

Some patients are referred to secondary care by their GP and attend appointments, despite not wanting to have surgery, for example, because they are a carer for a dependant relative or are unable to (afford to) take time off work. Alternatively, patients may request a referral, and this is made before there is sufficient degeneration for surgery to be clinically appropriate. Other patients may be referred when they are not fit to undergo anaesthetic.

These factors not only result in disappointed patients following hospital appointments, but also wasted clinic capacity and longer waits. Furthermore, because the focus of the secondary care appointment is surgery, the Orthopaedic consultation may not produce a management plan – based on other treatment options – to improve the condition and help the patient move forward. These patients will have spent time waiting for the referral to be made, waiting for an appointment, and attending the appointment, but may not have gained any support with their condition through this process.

Patients may be offered joint replacement surgery when their condition is sufficiently advanced, interfering with quality of life, and disturbing sleep. Patients may describe severe pain, swelling and stiffness in the joint, and report problems with everyday activities such as dressing, washing or going shopping (NHS, 2023²⁸). Treatment options should be explained at all stages in the pathway and clinicians should support shared decision-making principles.

OA Pathway: Patient Directed and Self-Management

Our interviewees' experiences of OA and their healthcare journeys highlighted patients need to be able to navigate the OA pathway, and healthcare system, largely on their own. In between touch points with medical professionals, patients had to manage their condition independently and coordinate the various aspects of their treatment and care journey.

Arguably, MSK is not dissimilar to other pathways in this sense, and as such our findings are likely to be transferable to other long-term conditions. However, other long-term conditions, such as Diabetes, have reviews and care processes designed to create regular contact with health professionals to: monitor patients' conditions; prompt action by patients and professionals; and achieve more effective condition management. OA, which could be considered a long-term condition in its own right, does not benefit from a similar approach. There is often too much focus on surgical management, which is only appropriate for a small proportion of all patients.

Along the OA pathway, we found there are a number of system factors (e.g., appointment systems, pathway processes, treatment criteria, professional practice etc.) which can support or create a barrier to patients managing their condition. There are also a number of patient factors (e.g., other health conditions, confidence, family support, etc.) that can be a support, or act as a barrier.

Many of the patients we interviewed experienced both system and patient barriers to progression and treatment, and were less able to utilise support. This reduced their ability to effectively direct and self-manage their condition through pathway in both PC and SC. Indeed, several patients were

²⁸ NHS, 2023. [Osteoarthritis Symptoms](#) (Accessed on 05/06/2023)

arguably unaware they needed to take this active role and were relying on health professionals to do this for them. This caused delays in care and exacerbated patients' distress.

Often system and patient factors were repeated along stages of the pathway. For example, access to appointments and communications about appointments is a system factor present in both PC and SC. Similarly, the beliefs, skills and perceptions of patients, such as the ability to advocate for themselves, are patient factors influencing treatment in both PC and SC.

Interviewee Pathway Stages

The 15 patients interviewed for the project were at different stages in the pathway, as summarised below:

- **Ten** patients were being managed in PC. Three of the ten had only been seen in PC, two had received some SC investigations and/or treatment and were now under PC. The remaining five had been seen in SC and were declined surgery on the basis of age and/or BMI, two of which were waiting for new referral appointments to re-assess their condition and eligibility for surgery.
- **Five** were under Secondary Care, of these four were waiting for surgery. One patient was having more investigations to decide the way forward.

Chapter Five: Summary of Key Findings

1. Booking and Communications About Appointments

Often patients talked about difficulties they experienced throughout the pathway gaining appointments and communications about appointments.

Difficulty of Phone and Online Bookings

In primary care, there were many comments about barriers when making appointments by phone. Patients find it hard to get through, which can discourage them from trying again. This can mean that appointments are not made when they are needed, or they are delayed.

One patient had taken to writing physical letters to their GP, as they found this more effective in getting a response.

Patient Experiences:

'There are many days when you can't get through on the telephone. The system cannot cope with the amount of people who are ringing up' (Int, 15)

'I haven't got around to ringing and making an appointment yet because you can't get through' (Int, 3)

Patients also talked about changes in the way appointments are made, particularly in hospital physiotherapy and Orthopaedic departments. Rather than receiving letters with an appointment date and time, patients are asked to call a number to arrange this, or to do this online. Patients then said they encounter problems getting through to departments to book, and do not necessarily have the IT skills or equipment to do online bookings.

A patient in their 80's talked about having to book primary care appointments online. They were asked to provide a lot of information. As an infrequent keyboard user they found time consuming. After completing the form, which appeared to be a screening stage, they then had to call their Practice anyway to arrange an appointment.

Patient Experiences:

'They used to phone or send a letter with the appointment details, and you would just go. Now they send a letter "Thank you, book an appointment". We aren't very good with all these technologies. I'm 66, we don't have great phones. Self-booking, getting through to them on the phone it's hard' (Int, 4)

'You fill it all in online and at the end, it says, "You must now ring your GP for an appointment". It gives you permission to ring and I am very slow on it' (Int, 3)

(We discuss in detail the process of chasing up secondary care appointments in section four of this chapter).

Influence of Patient Values and Beliefs

We also observed how patients' values and beliefs can influence whether they seek help through GP appointments, and how quickly they do this.

Some patients held off contacting their GP for support or did not push for appointments, until their conditions appeared to be quite advanced. These patients described not wanting to be a burden and draw on limited NHS resources. They often felt others may be more in need of appointments than themselves, and pressures of covid compounded this.

Patient Experiences:

'I'm not one of these people who complain, you just march on. I called the surgery before to tell them that I was having burning sensation, stinging all down my leg and stabbing pain. Then the one morning ... I couldn't get out of bed...couldn't move my leg. I was just stuck in one position. My wife called the ambulance. In A&E they did MRI scans on me, and the consultant came in, told me the news, he says, 'Your left hip is bone on bone' (Int, 4)

'I hate being a nuisance, I'll put up with things until they are really getting to me. So, I didn't go to the GP for quite a while, and I had so many other problems, I did not mention this' (Int, 9)

In another case a patient's negative beliefs about how health professionals respond to patients pushing for appointments caused a delay in receiving appropriate care. (Patient Case Study A²⁹).

Patient Case Study A: Barriers of Confidence and Mistrust

Tania is a 52-year-old, Afro-Caribbean patient living in Walsall. She spent most her working life in NHS Administration roles and as a Health Care Assistant. She had an accident at work, falling directly on her arthritic knees.

Tania called her GP for an appointment, which was a two week wait. Despite being off work and in a significant amount of pain, Tania did not push her Practice for an earlier appointment:

'I slipped my knees went bang on the floor. The next morning, this one ballooned. I had to wait two weeks for a GP appointment and by that time they said, "You should have come in earlier", But I said, "That's the earliest I could get". They filled out all the forms and wanted me to go straight for an MRI scan'

This accident marked the end of her working life, due to the resulting severity of pain and lack of mobility.

Given Tania's NHS background we were surprised she had not used her working knowledge to push for an earlier appointment. However, Tania also talked about her lack of trust in how GP Practices are run. She feared the implications of being 'too pushy' and potentially being de-registered.

'I used to work in the surgery. So, you just know, even the slightest things, if you pee them off, then they're ready to go down that route. They can strike you off'

When we asked Tania why she did not go to A&E, she said she does not like hospitals and could not handle the waiting time there. (Int, 13)

²⁹ Please note case study names in this report are fictional.

One patient was concerned they had not been physically seen by a consultant for a long time, and that other patients may be being seen face-to-face. They worried this may result in other patients being prioritised because they appear worse, as the consultant could not see how their own condition had deteriorated.

Patient Experiences:

'It's lost that human touch, that's the way everything went during Covid, it become very non-personal' (Int, 8)

'They can't see if your hands swelled, or your knees are swelled, can they?' (Int, 6)

'Both legs from thigh to groin, right down to toes, are really swollen. The consultant cannot see that, face-to-face would have been better' (Int, 14)

Reliability of Phone Appointments

A few patients told us phone appointments in secondary care often do not run-on time.

One patient had difficulty receiving hospital calls, despite leaving several hours free around the appointment time. The call would then come hours later when they were at work or busy. They said the hospital then appeared to blame them for missing appointments.

Another patient had similar issues missing hospital telephone appointments as they did not pick up calls from private numbers, did not hear the phone, or when they were unwell. This patient said they were discharged as a result.

Patient Experiences:

'They said, "You haven't answered the phone calls", I said, "I have tried to answer the phone calls"' (Int, 2)

2. Primary Care Appointment Experiences

Positive Primary Care Communications

Patients had mixed experiences communicating with GPs in appointments, and often compared good and bad experiences.

Some patients talked about good communications with their GP regarding their arthritis and other conditions. They felt listened to and said their GPs explained things well. There were examples of GPs taking additional time to fully understand the patient's situation and being empathetic. Patients appreciated this greatly.

Several patients praised their GPs' personal manner, and how they adapted their approach to meet patients' needs. One GP communicates with a patient who is very hard of hearing on email, and this suits them better. A few patients were travelling quite long distances to see GPs who they rated highly, rather than moving to a closer Practice.

Patient Experiences:

'My current doctor has listened; I wouldn't know what was wrong if it wasn't for to him. He is the only one, he explains more than the hospital. He takes time out' (Int, 1)

'They are very good GPs here, very sympathetic. A gentle doctor and takes time' (Int, 3)

'My GP is 100% for me. Understands my problem with my hearing and makes sure that I understand' (Int, 9)

Negative Primary Care Communications

Other patients said their GPs did not listen properly to what they were saying and did not explore their symptoms.

Some patients felt dismissed and sometimes felt undermined. As a result, investigations and treatments into their conditions were delayed.

Patient Experiences:

'The Doctors kept put everything down to my fibro. But it wasn't in my head, I knew there was something else. They said, "If you were taking your pain medications, you wouldn't be in pain".

I felt angry because I'm taking all them. I have depression and anxiety, you sit there, you don't cry in front of them, when I leave, I end up crying.

They don't understand, I'm really struggling with this hip' (Int, 1)

'I had been to see a GP who was excessively dismissive. He said, 'Well, what do you expect? We all get knee pains as we get older". He just focused on my weight, he wanted me to get a gastric band, made a judgement, he did not listen' (Int, 15)

Impact of Negative Communications on Patients

It is important to recognise the overall impact that negative experiences trying to book appointments, and negative communications in appointments has on patients and their ability to progress to appropriate care.

In terms of mental health, one patient talked about being made to feel their condition was

'in their head'. Their GP did not look into their wider symptoms and dismissed them, and this impacted on them emotionally. The patient had an existing mental health condition, and no-one to advocate for them. Arguably this kind of interaction may reduce the likelihood vulnerable patients will approach that GP again, or other health practitioners for help.

Another female patient talked about her deep frustration with one GP who focused her weight, rather than her arthritis, and how she felt judged. Again, we have to reflect and think, how do these interactions play out? How sensitive and empathetic are we in our communications and explanations with vulnerable patients? Our interviewee's described how these experiences reduced their willingness and resilience to engage with health professionals.

Short Appointments and Lack of Continuity In Primary Care

Many patients highlighted issues about the short length of GP appointments and trying to communicate their health needs, and have these properly dealt with, in 10-minute appointments.

Many of our patients had a range of health conditions, and they could not talk about everything they needed in the given time. Some were also told they could only discuss one thing, this meant they needed to prioritise what to focus on.

Patients also commented they were not able to see the same health professional. They found re-explaining a complex background of health conditions in 10 minutes unrealistic.

Clearly, seeing the same practitioner would mean the staff member would already be aware of patients' needs and could start off the conversation from a more informed position. These combined factors put some patients off booking appointments. One

patient with multiple conditions told us they have been waking up having panic attacks but have not discussed this with their GP because of all the other health issues they are dealing with.

Patient Experiences:

“That’s about 4 things you’ve asked me about now. You’ve had your 10 minutes”. They couldn’t wait to get rid of me. I’m on my stick limping out, and she didn’t ask me about my hip’ (Int, 2)

‘When you’re going to the doctor, it must be for only one thing. For a lot of elderly people, you’ve got a few things that are worrying you’ (Int, 3)

Primary Care Diagnosis and Referrals

Often patients talked about their GP actively investigating their arthritis when they presented with symptoms.

In five cases GPs ordered imaging investigations which were conducted in SC, and the GP gave the patient the results. In just one case the GP diagnosed HA through a physical examination only.

In 10 cases the GP referred patients to SC for diagnosis; in two of these the GP had already ordered images and communicated the results.

We only had one patient who appeared to have an appointment with a First Contact Practitioner in PC. Their role is to fully assess MSK conditions, order investigations and refer for further support and diagnosis where appropriate.

Some patients talked about having timely GP referrals for investigations and SC appointments, and were happy their GP had listened to their symptoms and acted.

Patient Experiences:

‘I said “I think I have something wrong with my leg. I want a scan”. They referred me, I didn’t think I’d get a scan, a lot of the time you can’t get what you want’ (Int, 2)

‘Once I saw the GP, everything moved very quick. I waited 6 months for the consultant, which really isn’t long during covid’ (Int, 10)

Some patients spoke about the need to push GPs to make referrals. One patient whose GP would not refer them ended up going privately, using their partner’s health insurance to have investigations and reach a diagnosis. Another patient felt their GP was not referring them due to budget restrictions (7, 15,12)

Other patients gained the confidence to push for referrals after receiving advice from friends, family members or other health professionals.

Patient Experiences:

‘You have to keep pushing and pushing to get something done. They are afraid of making too many referrals. I remember one doctor saying it’s costing too much, it’s not efficient’ (Int, 12)

‘It was a bit hard to convince the GP to get the x-ray done. I told them my son and my son-in-law [who are consultants] are concerned and they feel that she should have this x-ray for the pain. Only then, they sent her’ (Int, 7)

Patient Case Study B: Advice from Other Professionals

Dawn is a 58-year-old Afro Caribbean patient from Sandwell. She was diagnosed with fibromyalgia and referred to a Living Well Centre for support. Dawn felt there was something else going on with her health causing her significant pain, but her GP dismissed her concerns.

When she visited the Centre, they felt she had symptoms of OA Hip and encouraged her to re-approach her GP. This gave Dawn the confidence to push and resulted in an Orthopaedics referral, through which she was diagnosed with OA Hip. (Int, 1)

3. Referrals for and Receiving Conservative Management

Physiotherapy

Primary Care Referrals

Four patients recalled being referred for physiotherapy by their GP. A fifth patient was also offered, but because she had worked in physio support herself, she felt the referral was not needed. A sixth patient wanted physiotherapy, but her GP did not refer her. She ended up accessing support through occupational health at work. At least two others wanted physio: one was told this was not possible due to covid; another was on a waiting list and did not hear back.

Patient Experiences:

'I think the physio would have helped. Because when I had my right knee done, I found that the physio was a big help'

'They just put me on the list that's all but I haven't heard anything more'

Secondary Care Referrals

Seven patients recalled referrals for physio in SC, two of these patients had also been referred by their GP (as above). For at least two patients the SC referral was at pre-operative, or post-operative stage, and as such was not a conservative management approach. For one the referral appeared very late in their pathway, many years after being diagnosed.

Engagement and Benefits

Physio had been a mixture of virtual (phone) and face-to-face appointments due to Covid restrictions. In both cases, patients found it useful to be given handouts explaining the exercises. Often appointments appeared to be a one off or a short course of treatment. Before Covid, one patient had had a series of around six gym-based sessions through the hospital which she was impressed by.

Four patients appeared to have engaged for a sustained period. Many patients were conscious of the importance of exercise and keeping moving to help their arthritis, but did not necessarily do their physio. For example, despite being in significant pain, patients on morphine were still persevering with mild walking, but often had fatigue and pain afterwards.

Patient Experiences:

'I did exercises to strengthen the thigh and calf muscles, it helped reduce my pain for a long time, and made me a little more flexible' (Int, 15)

'It's less painful. It's still fairly painful when you are doing the exercises, but it's definitely helped' (Int, 9)

Disengagement and Barriers

Often patients did not appear to be following their physio routine, some talked about being unsure if it was helping. Many talked about being in significant pain during and after exercises, which was a clear barrier to sustained engagement. Patients also spoke about mobility issues they experienced trying to do the exercises due to lack of flexibility and needing someone to be there for balance/safety.

Patient Experiences:

'I didn't see any improvements because I was in so much pain'

'They might have been helping, I'm not a physio so I don't know. I was doing them, so maybe if I wasn't doing them, I would have been worse'

"I try and do the exercises because that will help" but I don't feel like they listen. I'm trying to tell them about the pain I'm in after because my fibro flares up'

The limited number of appointments per patient also had an impact on sustained engagement; this may have been due to Covid.

More appointments may have improved self-management via exercise, providing opportunities to motivate patients to continue despite the pain, reinforcing the benefits and checking if patients are doing exercises correctly.

Barriers: 'I am already active!'

One patient said they were not doing their physio exercises because they were not convinced it would help. They walked as much as they could and felt this was enough exercise.

Interestingly, they attended the physio appointments anyway, as they liked the contact with people. They did not appear to see the strengthening benefits other types of exercise could provide.

'They gave me exercises on paper. I just threw them in the bin. I'm thinking you're not teaching me anything new. I didn't feel it was beneficial to me' (Int, 13)

Barriers: 'It's too far'

One patient decided not to attend after being referred to Darlaston for physio, which they felt was too far to travel. This patient also talked about waiting times as a barrier, but he had received an appointment and had not attended.

'They'll give you an appointment in about 3 months' time. There are that many people waiting, so I didn't bother' (Int, 2)

Barriers: 'They discharged me'

One patient went to their first physio appointment at Walsall Hospital, but he was told there was no record of his appointment. He was asked to leave his details and said they would be contacted.

He then received a letter taking him off the physio list without being seen. This patient is largely housebound. He did not end up having physio as he did not chase up this apparent error, nor did his GP when he told them.

'I had a letter from City Hospital, "You will be no longer be seen again", I'm thinking, but you've hardly seen me, so how do you work that out?' (Int, 4)

Referrals for Wider support

Only one patient talked about a GP referral for wider support services to help her arthritis. This was to an Independent Living Centre and the Local Authority Home Adaption Team.

She rated support from the Independent Living Centre highly. The LA also made several home

adaptions including a lift, wet room and a powered support chair. Her GP also did a referral to get a motor scooter, but the council will not put a ramp in her house.

Patient Experiences:

'The GP said my walking stick was no good and sent me to the Independent Living Centre to be assessed. Adaptions also put in a wet room, and I've got a plug-in chair, it gets you up and down.

The Council won't put a ramp in, the scooter would be a lot easier for me to get around. When the pain is really, really bad'. (Int, 2)

Pain Relief

Effectiveness of and Pain Relief Prescriptions

Many patients had been offered and were using a range of pain relief to manage their arthritis. However, there were many examples where pain relief was not working effectively. Often GPs did not appear to proactively review the effectiveness of medications, and patients did not raise issues themselves.

11 patients were taking lower amounts of pain relief. A few just took paracetamol; others were adding in co-codomal and ibuprofen either continuously or when needed. A retired physio and a nurse seemed to be particularly on top of their pain medication, using this effectively, e.g., taking the right dosage, spreading medication through the day, taking paracetamol continuously.

Of the 11, five said the pain relief was not effective. Many talked about pain relief taking the edge off, but not managing their pain. Four experienced gastro or sickness issues with co-codomal. Three did not like the idea of being dependant on medication and did not take the

full prescribed dosage, clearly this may have limited the effectiveness of the medication.

Four patients were using a combination of the above medications, with neuropathic (nerve) pain relief medication (e.g., gabapentin and pregabalin) and morphine. These patients talked about needing to plan activities and the times they did get out the house, around when they took their morphine, as this made them spaced out and lethargic.

Conversations around Pain Relief

When asked why they had not raised issues with their pain relief with their GP, patients said different things.

Some felt their GP would tell them they are already on the maximum dose. Others felt their GP would want to increase the dose, and they did not want to take more medication.

Some patients described having difficult conversations with their GP about pain medication. One patient who raised pain issues with her GP felt dismissed and patronised:

'They said, "If you were taking your pain medications, you wouldn't be in pain". I felt angry because I'm taking all of them. They don't understand, I'm really struggling' (Int, 1)

Few patients seemed to ask about alternative medications, as opposed to increasing dosages for existing prescriptions. One patient who did request a change found this led to confusion around his medication routine (See case study C overleaf).

Patient Case Study C: Managing Medication

Paul is a 62-year-old White British patient from Walsall. He was scheduled for surgery which was delayed due to covid. He was struggling to manage his high level of pain and to leave his flat, living up several flights of stairs.

He raised the option of morphine patches with his GP, and they were prescribed. However, Paul did not recall his GP saying he would need to stop his existing opiate.

“What about the morphine patches?” He said, ‘Oh yes, you can try them’. So, I was on them as well, then all of a sudden, they stopped my tramadol. They said, “You can’t have patches and tramadol”, I said, “Well, you never told me”.

Paul also described his general confusion around the combination of pain medication he should be taking. He did not feel listened to and felt his GP should have looked at his medication more:

‘I don’t know whether I’m supposed to be having aspirin and ibuprofen, and paracetamol, I’m having them anyway, I’d have anything if the pain went.’ (Int, 2)

Steroid Injections

Five patients had received steroid injections in the past for their Arthritis. As the medical advice suggests injections had mixed success, with pain relief lasting between weeks and months depending on patients’ condition³⁰. Two patients found it helped their Arthritis; three found it had not helped, or that pain only improved for a few weeks.

³⁰ [Steroid Injections | Side-effects, uses, time to work \(versusarthritis.org\)](#) (Accessed on 05/06/2023).

Two were currently considering this option. One previously had an injection in her knee which had helped. This was the patient who had worked within a physiotherapy service. She had observed patients receiving injections, was aware of the process and had no concerns.

‘I’m quite pleased. It has helped the pain. My knee doesn’t catch me out in the night now. Sometimes they last around 6 months. The nurse said, “you can come back for another one”’ (Int, 9)

The second patient was worried about the injection taking place at their GP practice, and how they would cope with the procedure:

‘Next it will be that injection. I had it in my knees, didn’t do anything at all. They’re not very nice. I’m a bit of a coward, I might have to just bite the bullet. I hope my nerves don’t let me down, what if I scream or jolt from the pain?’ (Int, 3)

Around a third of patients had not discussed or been offered an injection option by health professionals. (We cannot comment on whether it may or may not have been appropriate). One patient had independently researched injections in advance and the consultant had explained why it was not appropriate for their condition³¹.

Two patients were impacted by long waiting times. One decided not to pursue the injection and wait for the surgery, as they were given similar waiting times for both. The other had been waiting for two years and they did not feel they were a priority due to covid. This patient has not been contacted, and has not chased because they have given up:

“We can’t give you the steroid injection because of lockdown”. After waiting this long, you lose faith. Eventually you think, what’s the point of phoning? They’re not going to help, it’s like talking to a brick wall’ (Int, 6)

³¹ Note: Steroid injections were not discussed in all interviews.

Patient Case Study D: Authority of Medical Professionals

Gale is a White British 85-year-old patient. She lives in the most affluent area of all our interviewees and was very articulate.

Gale had been diagnosed with Arthritis by her GP and offered a steroid injection at her Practice. We interviewed her over 6 months after this diagnosis. She had concerns about the injection and had not been back to discuss treatment.

Gale previously had a steroid injection in her knee by her GP, which did not work. She was unsure whether her GP was best placed to do the proposed Hip injection, but did not want to appear to challenge his expertise.

Gale had been talking with friends about their experiences, including one who had good results after an injection under x-ray in hospital. She asked if we had information we could send her about the options, which we did.

'My friend went to the hospital, a special person with an X-ray, so they can see what they're doing. I don't think our doctors use an X-ray. She thinks it helped'.

Her concern about appearing rude to her GP and not understanding the options had discouraged Gale from pursuing help, even though she could only walk short distances with walking sticks.

'He's a doctor. He's been trained. I don't want to suggest I know better than him. I might quote my friend... I don't like criticising. It's knowing the right words. How am I going to say to, is it possible it could be done in a hospital?'

4. Referrals to and Experiences of Secondary Care

Waiting For and Chasing Appointments

Some patients talked about not receiving appointments from referrals or follow-up appointments, and a lack of communications over delayed periods of time. Some chased and felt this prompted appointments being booked, and did not feel they would not have got these without chasing. Patients highlighted the need to be active and assertive to ensure things moved forward, others felt lost in the system.

Patient Experiences:

"'We'll call you back in 3 months". We gave it 3 months, they never rung back. If we hadn't phoned, I don't think I'd have got this appointment. You have to take the onus and be pushy. You, have to ring, ring, ring' (Int, 14)

'I rang up and said I want to see somebody. I hadn't been seen for ages. Then I got an appointment in the post' (Int, 2)

Patients talked about difficulties chasing referral appointments via consultants' secretaries and appointment lines, and problems getting through.

Patient Experiences:

"'If you've got a problem, just ring". But 9 out of 10 times, they never respond. It's the answer machine, you leave a message, but when they call back you are not free' (Int, 7)

Of course, to do this, patients need to have some awareness of NHS processes, for instance that consultants have medical secretaries, that it is ok to call them, and that this is what other patients do. Not all patients have this knowledge.

Appointment Cancellations

A few patients received multiple hospital appointment cancellations, with the same appointment being re-scheduled several times. This was frustrating, increasing patients' waiting times sometimes by additional months and causing confusion due to the number of letters received. Further, hospitals did not always get back to them when appointments were cancelled.

Patient Experiences:

'They'd send appointments and cancel them 6 or 7 times. I got appointment letters, and the next day another saying it's cancelled' (Int, 4)

'If something is cancelled you kind of go off the radar' (Int, 14)

Impact of Chasing

It is important to recognise the impact communication and process issues have on patients and their families. In particular, the time and effort it takes to make and chase appointments, find out how to get in touch via medical secretaries, etc. Patients talked about trying to understand unknown NHS processes, and the challenges of navigating them.

Patients were also negatively impacted when appointments were not being made in the first instance, they waited long periods for appointments and long-awaited appointments were cancelled. Patients were worn out trying to juggle these things whilst in significant pain, often with few resources. This resulted in a lack of confidence that the system will help them.

Patient Experiences:

'I've [wife] done most of the pushing, he does not have the energy. It's draining, taking a lot of time and energy chasing things up' (Int, 14)

Patient Case Study E: Chasing Delayed Appointments

Daniel was originally diagnosed with Knee Arthritis at the Orthopaedic Clinic in Walsall at 50 years old. The disadvantages of early surgery were explained, and he was prescribed pain medication, but he was not referred to physio.

In his late 50's his knee pain had escalated, and he was re-referred. He was listed and consented for surgery in 2019, but this was cancelled due to covid. He waited for another appointment to be made during the years of the pandemic.

Daniel's wife works as a Health Care Assistant in Walsall hospital. This couple understand NHS processes, but Daniel rarely leaves the home and lacked the confidence to chase his referral. After more than two years waiting, Daniel's wife approached the Orthopaedic medical secretaries to find out what was happening about the delay.

'I'm obviously aware where things are in the hospital. I went to the office where the secretaries work, and said, "He has been left behind". It had been almost 3 years and we hadn't heard anything. I told her what had happened, and they chased it'.

As a result, Daniel had an appointment in August 2022. The couple talked about how their mental health has suffered from the cancellations, the lack of progress and Daniel's worsening condition, with his wife taking on a lead carer role for him. They asked our researcher for help. We made enquiries and the couple we were advised to contact PALS.

We found it interesting this couple waited so long before utilising the wife's job to chase the delay, particularly given the length of time they were waiting. (Int, 14)

Patient Case Study F: Multiple Discharges

Elliot is a 65-year-old White British patient who seemed to have a confusing series of appointments with Orthopaedics.

His GP referred him at the beginning of Covid, but Elliot said he was discharged without being seen, after missing hospital phone appointments. When he told his GP, they did not look into this.

'The GP turned around and said, 'Well, that's strange'.

Elliot did not think there was any use trying to push the referral. He spoke about not wanting to complain and felt professionals know best. He was also trying managing a complex set of co-morbidities and their respective treatments, including: fibromyalgia, previous heart attack, surgery on discs in his neck, Type II diabetes and Asthma.

Then in 2022, another health professional from the hospital contacted him about his Asthma. They picked up on the discharge error and organised for the appointment to be rearranged. However, when Elliot was seen, the allocated Consultant ended up being a Knee specialist.

'I sat down, shook his hand. He said, "I'm sorry for the long wait but I'm a knee doctor, you're seeing the wrong one"'

The consultant said he would refer Elliot to a hip specialist; this was seven months ago and they have not heard back from the hospital. (In, 4)

Patient Choice: Perceptions of Providers

A few patients had preferences around secondary care providers but had not raised this with referring professionals. This had the potential to create barriers in their pathway.

Patient Case Study G: Lack of Patient Choice

Dawn is a 58-year-old Black Caribbean patient from Sandwell. She is waiting for a consultant appointment from a re-referral following a gap of several years from her original diagnosis.

She had been to both City and Sandwell Hospital for various appointments and procedures. She recalled negative experiences of Sandwell and wants to be seen in City. These experiences had not involved Orthopaedics but had impacted on her overall opinion of the hospital.

Dawn did not know which hospital the new appointment would be with but said she would reject Sandwell and ask for City, if it came through as Sandwell. Her ideal preference was the Queen Elizabeth in Birmingham, this was based on her sister working there. Dawn had not discussed any of this with her GP. This unexplored preference for City clearly had the potential to delay her pathway.

'I do not like Sandwell, I prefer city. I had a lot of things go wrong at there. I have never had the option. If it is Sandwell, I will ask to be changed. I wished I could have gone to the specialist hospital in Birmingham where my sister works' (Int, 1)

Another patient worked in Walsall Manor and had a bad perception of the hospital. She felt it had too many trainee members of staff and did not like the idea of them undertaking her treatment.

Patient Experience:

'I used to work at Manor, it's a training ground, so they need guinea pigs. I had my operation done by a professor at the Royal in Birmingham' (Int, 13)

Another patient was concerned about their history of smoking and talked about people dying during surgery at Walsall Manor.

The overall point is that public perceptions of NHS providers also play a role in pathway progression and choices. If patients do not openly raise provider concerns or preferences, and/or if health professionals do not discuss provider options and patient choice, these views may not surface until they are causing a real barrier, with the potential to delay care.

Benefiting from Patient Choice

In two cases, patients used their awareness of choice to progress through the pathway faster and gain smoother access to treatment.

Patient Case Study H: Exploring Options

Sarah is a 79-year-old White British retired orthopedic nurse. She used her knowledge of the NHS and private options to understand her options.

Sarah pro-actively asked her consultant about waiting list times and if she could go on the cancellation list. She also asked about the consultant's private waiting list to explore all options.

Unlike other patients, Sarah had no co-morbidities that may prevent her from having surgery at short notice. This may not be an option for other patients.

'I said I would take a cancellation. I asked "What is the waiting list like?" It was about 12-14 weeks. I researched how much it would be to go private, £11,000, but also 14 weeks wait!' (Int, 10)

Patient Case Study I: Using Patient Choice to Reduce Waiting

Jason is a White British 53-year-old from Walsall who works in supermarket maintenance. He had hip pain for around a year, but initially delayed going to the GP due to the pressures of Covid of the NHS.

He understood how large organisations operate from his work, giving him a good starting point for pathway navigation. When he contacted his GP, he was offered a face-to-face Orthopaedics appointment with a nine month wait, or phone appointment within four months. His father had arthritis, so he recognised the symptoms. His health literacy made him confident enough to do this virtually, but he still felt this approach was impersonal and would have preferred a physical appointment.

After the initial virtual appointment and subsequent imaging, he was referred to a consultant. Jason was asked if he had a preference where he went. He opted for a consultant with a shorter waiting list further away, rather than the closest. Once allocated a consultant, Jason researched their medical secretary and contacted them to make sure things pushed forward.

His relatively straight forward diagnosis and lack of co-morbidities, along with his flexibility resulted in a surgery date within six months of being diagnosed.

'They asked me if I've got a preference, do I want to go to a local hospital. I said, "No, I'll travel, just get me to the one with the shortest list". I also chase. As soon as I knew the consultant's name, I gave it a little time and then I was on the phone asking for an update'

Other patients did not appear to have been asked about preferences and patient choice. Jason also said he knew this was an option even before he was asked. (Int, 8).

5. Orthopaedics' Surgery Decision Making

Consultant Surgery Decision Making

Nine patients had reached the stage where they had surgery discussions with consultants. They talked about three main themes when recalling whether consultants felt surgery was appropriate: 1) The severity of their condition; 2) Age considerations; 3) BMI considerations.

Condition Severity

Some patients talked about their diagnosis results being essentially clear cut, that their condition was that advanced, surgery was the obvious answer.

'My consultant said, "Oh yes, it's worn out. You need a hip replacement. When do you want to come in? It will seize up in the end if you do not have it done"' (Int, 2)

One patient delayed seeking help for his first hip replacement, because his wife was terminally ill. Sometime later, after his wife had passed, he seized up in bed. An ambulance was called, and he was diagnosed with OA Hip in A&E. He is now waiting for his second side to be replaced.

Patients' Age

Three patients recalled being told they were too young to have replacement surgery, (during their initial), and that this may be an option in the future. This left these patients discharged wondering when they might be able to have surgery.

Patients were not told when surgery might be appropriate and talked about facing an unknown length of time living in pain. This created clear anxiety and patients talked about their poor quality of life.

Patients had a mixed understanding as to the role that age played. Some referenced the limited life span of replacements, but none the

fact that a revision (a second replacement operation) is more complex.

Orthopaedic consultants prefer to wait until condition severity and age are at a stage that a replacement is needed and will be of benefit, and patients are unlikely to need a revision due to their more advanced age.

Patient Experiences:

'If you have hip surgery, it only lasts for so long. I don't know if that's true. Ten years? He was leaving it until I'm a bit older. Now I am, I'd like it to be done' (Int, 1)

'What am I supposed to do for 20 years? The pain is getting worse. There are no reviews, and you don't get any other information. Will it get to the stage I can't walk? That's what I'm afraid of' (Int, 12)

'I understand about the lifespan of the knee replacement, but what about my quality of life? I have no quality of life whatsoever anymore' (Int, 14)

One of our patients said she had initially been declined due to age. She was now on daily morphine, was in a terrible amount of pain and had a very restricted life. She was waiting for a new appointment, but she was still relatively young at 58-years-old, and has no idea what the outcome will be. She requested the re-referral herself, rather than being reviewed in PC and a professional actively making this suggestion.

Patient Experiences:

'Originally, they said I was too young...surgery wasn't an option then, but maybe now? I went to see my doctor, I said "I just can't cope with the pain". I'm waiting, he's done a referral for me to go back and see someone' (Int, 1)

Body Mass Index

Three patients were told they could not have a Hip Replacement at the time of their consultation, because their BMI was too high. Other patients were also told during the run up to surgery that reducing their BMI would be beneficial.

Patients who were told they were ineligible due to their weight were disappointed and felt helpless. They had been discharged from SC and were living in significant pain, without a view on when, and if they might be able to have surgery.

These patients spoke about how they had gained weight from the lack of mobility caused by Arthritis and other health conditions, and the difficulties of losing weight with limited mobility.

Patient Experiences:

“You’re obese due to the steroids, so we cannot operate. The bad news is we have to take you off the list”. I was devastated, I really thought I was going to have it. To, wait so many years, with the other bone and muscle pain. Now they’re trying to me back in, 3 years later’ (Int, 4)

‘Obviously if you are incapacitated you can’t exercise, you just sit and consequently you gain weight’ (Int, 14)

One patient talked about feeling discriminated against because of their weight, and had lost faith.

Patient Experiences:

‘It’s completely discriminatory, refusing surgery on BMI. In my case and I’m sure many others, they are committing you to a life of pain. I cannot make them understand how hard it is to lose weight when you can barely move your leg, walking on crutches’ (Int, 14)

We asked patients if they received support to lose weight following their discharge. Support appeared to be either very limited or totally absent. One patient was discharged twice due to his BMI. The first time no support was offered; after the second discharge his consultant said he would be referred to a dietician, he was still waiting for this.

There did not appear to be effective joining up between PC and SC to support these patients to improve their health for surgery.

Through our discussions with professionals, we learnt that Sandwell and Walsall currently have different policies in relation to surgery eligibility and BMI. In Walsall consultants need to make a special request/case for patients with higher BMI to have surgery. This is currently not a requirement in Sandwell.

A new Harmonisation Policy for Hip Replacements in the Black Country ICB will, however, introduce a similar requirement across the whole system. In order to operate on patients with a BMI of 40 or over, consultants will be required to request funding on a case-by-case basis. (Elective Hip Replacement Surgery, BICB Harmonisation Policy, Issued June 2022).

We feel this will create a greater barrier to surgery, particularly for our more deprived populations, who have higher levels of obesity. We have shared our concerns and project findings with the relevant ICB leads.

On a positive note, the Harmonisation Policy introduces a clear requirement to link patients with services to reduce their weight:

‘If the patient’s BMI will impact on either technical difficulty and/ or safety of the procedure, then the patient’s surgery will be deferred and a referral to commissioned weight management services will be made to support the patient with weight loss’ (p6).

Patient Case Study J: Reducing BMI for Surgery

Elliot is a 65-year-old White British retired train worker. He lives in a small social housing flat in the most deprived area of Walsall. He had one side of his hip replaced several years ago and years later was referred for his second side.

When Elliot was seen by the consultant, he was discharged as his BMI was considered to be too high for surgery. He has very restricted mobility and the consultant said he was 'bone on bone'. Elliot has difficulty walking about his home and goes out rarely with the help of his partner. This clearly limits the ways he can lose weight. He was taking steroid medication for another condition, which he feels contributed to weight gain.

When Elliot was discharged, he does not recall being told how much weight he would need to lose, or when and how to get another appointment once his BMI was reduced.

Elliot was referred to a dietitian who gave helpful advice about healthy eating. He has been following this, but he only had one dietitian appointment.

He has also reduced his steroid intake to manage the side effect of increased hunger. This has increased his pain significantly, but he has persevered in order to be eligible for surgery.

His partner has been critical in supporting him to change his eating habits and manage this pain. Other than the one dietitian appointment, Elliot has not had any other support to lose weight. He is now waiting for another consultant appointment to find out if he has lost sufficient weight to have the surgery. (Int, 4)

Positive Experiences of Orthopaedic Appointments

Some patients talked about their positive experiences in Orthopaedics, how well consultants explained their condition and their open approach. They felt consultants understood how their condition was impacting their lives.

A few patients recalled conversations about the advantages and risks of surgery, waiting list times and recovery. They felt able to ask questions and consultants were professional.

Patient Experiences

'He seemed really good. He had the x-ray up and explained it well. He was very professional and helpful, and you could ask them anything' (Int, 2)

'The appointment was much better; they were very receptive. They understood there was an injury to the knee as well as the arthritis' (Int, 15)

The supermarket employee was particularly impressed with his consultant. They had a detailed discussion about his options, and the pros and cons of a Hip Replacement versus a Bone Skim procedure. The consultant felt the latter would be better for this patient's future working life.

Patient Experiences

'We had a look at the x-ray together. He said there's a procedure which he'd recommend because of getting up and down all the time at work.

He blew me away...how he explained things to me, he wasn't treating me like an outsider. He knew my lifestyle, my job, what I liked doing, he also knew what the risks were' (Int, 8)

Investigations in Secondary Care

A few patients commented on how impressive it was to have their imaging done and get their results on the same day.

Patient Experiences:

'He managed to get my x-rays done on the same day, my knee, back and hip. It was very good really. He got the results and explained to me I'd got severe arthritis in my left knee, my hip and my back' (Int, 5)

For one patient it was a little overwhelming, being diagnosed and offered surgery within a few hours.

Improvement Areas for Orthopaedic Appointments

A few patients talked about not being given enough information during their conversations with consultants. One patient had low health literacy and poor memory due to a stroke. She did not understand the consultant's explanation and had to rely on her GP to explain this from her discharge letter. She always tries to take someone to appointments with her now.

She felt the consultant could have adapted their communication style to help her understand. For example, she suggested: writing explanations down, demonstrating conditions visually, providing leaflets, breaking explanations down and using simple language. If the consultant had asked this patient to recall what she understood about her condition and treatment from the appointment, her confusion may have been picked up.

Patient Experiences:

'They could explain things a lot better. When they tell me I've got osteoarthritis, explain what it is, what are the changes, what's going to happen. Don't just say, "You've got arthritis in your hips". Write things down for me' (Int, 1)

Interestingly the retired Orthopaedic Nurse also felt more information could have been provided. She wanted information about the operation itself, but was not given any literature, and she asked us for this. Hence it is not just patients with lower health literacy who would benefit from these types of resources.

Patient Experiences:

'He didn't give me any information about the operation itself, no. That's something I would have liked to have known really. But you don't always think to ask at the time, do you? That's the trouble' (Int, 5)

Another patient felt that hospital appointment letters could be made clearer. For example, they had received a new appointment in Orthopaedics, but they did not understand the purpose or remit of the appointment. These things may seem obvious to professionals, but supporting patients to understand a bit about who they are going to see and what to expect, could help them prepare better for appointments and feel more reassured.

6. Patient Surgery Decision Making

Patients talked about a range of factors when deciding whether to have surgery.

1. Pain and Managing Overall Health:

Most commonly patients talked about their pain levels, believing that surgery was the only option to reduce their pain. Some had concerns about the surgery, but their pain was so great they felt they had no option. They described the decision as "easy" or "straight forward".

Some patients felt if they could resolve or improve their OA Hip/Knee condition through surgery, this would help them with their overall health in terms of reduced pain and more mobility; increasing their exercise (reducing weight); and getting out more (improving mental health).

Patient Experiences:

'I was worried about having the hip operation, because of things that could go wrong, but I needed it done because I was in so much pain' (Int, 4)

'If they can do my knees, then the rest of my health will fall into line, I will be able to lose weight. Until I can be more active, it's a vicious cycle' (Int, 15)

2. Previous Experience of Surgery:

A few patients who had experienced other surgical procedures with long recovery periods were put off the idea of joint replacement surgery.

In contrast, two other patients had already undergone replacement surgery on one hip. They found this beneficial, and this positively influenced their decision making.

3. Work and Finances:

Three talked about needing to work and finances.

One patient had kept working for as long as possible, despite significant pain. He wanted to save up for the recovery period when he would be off work. In the end, he had to finish work earlier than he would have liked due to increased pain, whilst still awaiting surgery.

Patient Experiences:

'I wanted to earn as much money as I could, for after the operation. I will need someone to look after my dog, and all the rest of it' (Int, 2)

We have already described the detailed conversation one patient had with his consultant about types of surgery, given that they wanted to return to work in a manual

role. The patient's decision was very much influenced by the consultant's professional recommendation to have a bone skim procedure.

Another patient, currently unemployed due to their poor health, talked about the possibility of being able to return to work after the surgery.

4. Recovery:

Three patients talked about having the right support to recover from surgery in their homes and having suitable accommodation for post-operative needs.

These patients did not want to burden others during their recovery and did not necessarily have family and friends with enough capacity to draw on. When asked, one of these patients said they would probably look to their social prescriber for support instead. Another was considering paying for a care home place for their recovery period, rather than pulling on family.

Patient Experiences:

'My daughters are busy with their children. My Social Prescriber will probably keep an eye on me. If she saw I was struggling, I'm sure she'd point me in the right direction of help while I was recovering' (Int, 2)

The patient with the social prescriber had been living in a van when he initially offered surgery. This was clearly inappropriate for recovery.

He made housing applications, but could only find accommodation in an upper level flat. He was struggling to use the stairs and was worried how he would manage after the surgery. The Housing Association Social Prescriber fortunately managed to move him to a bungalow and in lieu of the operation.

5. Health Risks:

One patient was concerned that their history of smoking could be a potential surgery risk. They did not talk to their consultant about this, but had stopped smoking in preparation after reading a surgery information leaflet. However, this patient did not attend their first pre-operative appointment due to anxiety.

'Dead worried, I've been smoking for years. This was in my mind...[but] it didn't occur to me to ask the consultant at the time. He'd have said, 'You shouldn't smoke anyway'.

I got the pre-op, but I missed it, I couldn't do it. I've got anxiety and depression as well, and all these things all together, with the pain, I couldn't walk anyway' (Int, 2)

6. Word of Mouth:

One patient had spoken to various people they knew, who had already had replacements to understand the benefits and the options. In this case, these conversations were positive and encouraged the patient to have surgery.

'All these people you talk to, they've had operations, or know of somebody. You get to know a lot of information through talking to people' (Int, 5)

Chapter Six: Patients' Experiences of Self-Management

The Role of Health Literacy

We found the extent to which patients can utilise positive 'system' and 'patient' factors, and overcome barriers, is largely dependent on the extent to which they, or those around them, have a sufficient level of 'health literacy' and wider resources.

There are various definitions of health literacy. Urstad et al, (2021³²) maintain health literacy is commonly understood as:

'Cognitive and social skills that determine the motivation and ability to understand and use health information, and adequate health literacy is seen as a prerequisite for healthy behaviours'.

The Centre for Disease Control and Prevention³³ divides health literacy into abilities that need to be developed at both the personal patient level, and the organisational/service provider level:

- **Personal health literacy** is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.
- **Organisational health literacy** is the degree to which organisations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

The latter definition separates the individual's level of health literacy that enables them to engage successfully with services, and the extent to which organisations are designed so that patients from different backgrounds are equally able to engage successfully with services.

Reflecting on these definitions, we would highlight that effective patient health literacy includes having the interpersonal skills and confidence needed to act on health information. Some of our patients had reasonable levels of health literacy, but they did not have necessary skills including: confidence, personal capacity, beliefs and values, resources, mental and physical health to utilise their health literacy.

Thinking about some of the vulnerable patients we have interviewed, it is clear that services are often not designed to enable equity. In chapter seven we set out some options as to how the barriers and issues we have identified could be addressed. These act at both levels, to utilise and strengthen existing patient health literacy and to better design services to move towards greater equity.

³² Urstad et al, (2021). Definitions and measurement of health literacy in health and medicine research: a systematic review. *BMJ Open Access*. [e056294.full.pdf_\(bmj.com\)](https://e056294.full.pdf_(bmj.com)) (Accessed on 04.05.2023).

³³ [What Is Health Literacy? | Health Literacy | CDC](#) (Accessed on 04.05.2023).

Sources of Health Literacy

Patients we interviewed with high levels of health literacy appeared to have gained this through different sources:

- Four had worked in the NHS including: a retired physio support worker and an orthopaedic nurse; and two NHS administrative workers (one retired and one working).³⁴
- A patient with low health literacy relied on her husband - who drew on knowledge from their consultant son, son-in-law consultant Rheumatologist, and connections with an Orthopaedic consultant.
- One patient worked for a large supermarket in maintenance and compared their workplace to the NHS to navigate the system.
- One patient had significant experience working as an advisor in the voluntary sector and was used to advocating for others, they had also volunteered as a patient expert in the past. Another worked for a community charity. Both had stopped working due to poor health.

Many of these patients had a relatively **smooth pathway**:

Patient	Utilising Health Literacy
Retired Orthopaedic Nurse	<p>Quick Process</p> <p>This 79-year-old patient was listed for surgery and acknowledged the advantage she had in the pathway:</p> <p><i>'Because I was a nurse, I knew how to manage the pathway. I waited six months to see the consultant during covid I was pleased with that. Then I saw the consultant and had the pre-op in three weeks. Really quick'</i></p>
Retired Orthopaedic Nurse and Physio Support Worker	<p>Good Self- Management</p> <p>Both had the knowledge to self-manage their condition, planning their own physio and exercise routine, and using strategies to manage the pain.</p> <p><i>'I knew how to cope with the pain, what exercise to do, and when to rest'</i></p>
Retired Orthopaedic Nurse and Physio Support Worker	<p>Treatment Options</p> <p>Due to their working careers both were aware of treatment options from conservative management to surgery. The physio support worker had supported procedures like steroid injections, which they went onto have themselves.</p>
Supermarket Employee	<p>Pathway Navigation</p> <p>Knowing how large organisations work, he was conscious of the need to identify people working behind the scenes who he could approach or</p>

³⁴Our interviews attracted a high number of NHS staff - past and present - who may have been interested in the project due to this connection and are more likely to be health literate due to their work. This may have skewed our results, leading to an over-representation of more health literate patients than might be reflected in the general population.

Patient	Utilising Health Literacy
	<p>chase in order to progress his care. He also understood he could speed up treatment by exploring different NHS providers and their waiting lists.</p> <p><i>'I think it's the profession I work in, I work a lot behind the scenes in a supermarket chain, so I see things a lot of customers will not see'</i></p>
Family links with consultants	<p>Medical Connections</p> <p>This patient's husband used family's connections to understand what might be causing her pain and to push their GP for an Orthopaedics referral. They also took family members to some appointments to advocate for them and had a private steroid injection through connections.</p>

High health literacy did **not always translate to a smooth pathway**:

Patient	Pathway Barriers
Employed NHS Administration Worker	<p>Lack of Support From GP</p> <p>This patient went back and forth to their GP with leg pain. She was not diagnosed by her GP, who advised taking paracetamol, and declined her request for an Orthopaedics referral.</p> <p>She felt unsupported and used her husband's health insurance to see a private consultant. She was diagnosed with OA Hip at 40 years old. The consultant explained the disadvantages of having surgery at that stage, given replacements last around 10 years. She is now 50 years old and thinks she will not be offered surgery until she is at least 65 years old. She knows people of this age and older who have had replacements.</p> <p>Her GP did not refer her to a physiotherapist, and steroid injections were not discussed. She gained physiotherapy through work.</p> <p><i>'They [GPs] don't really listen, you are left to your own devices. It was like – "there is nothing we can do" because of my age. The pain is getting worse, there are no reviews, they don't give you any information'</i></p> <p>This patient overcame barriers, but did not have a smooth NHS pathway. She developed more health literacy confidence though this experience:</p> <p><i>'Before I would take a GPs word for it, now I wouldn't. Now I would push further for investigations, for something to happen'</i></p>
Community Charity Worker	<p>Lack of Support from GP and BMI Barrier</p> <p>This patient described being dismissed by an initial GP when seeking help with her pain. The GP focused on her weight and suggested a gastric band.</p>

Patient	Pathway Barriers
	<p>She was not referred onto any services and did not have any support for her arthritis at this time, despite being very articulate.</p> <p>A year later, a second GP prescribed pain medication and made an Orthopaedics referral. She was diagnosed with OA Knee, but was told she is not eligible for surgery due to her BMI.</p> <p>Due to poor mobility is it hard for her to lose weight. She feels stuck in the system and described BMI criteria as discriminatory.</p>

One patient with high health literacy and multiple health issues, had **competing personal challenges**, and was **exhausted by NHS pathways and surgeries**:

Patient	Pathway Barriers
<p>Retired Voluntary Sector Advisor</p>	<p>Multiple Conditions and Caring responsibilities:</p> <p>This patient had various forms of arthritis and was undergoing hip diagnosis. She had various previous surgeries for arthritis, as well as preventative cancer, and was well versed in navigating pathways. In the past she had also been part of the NHS patient expert Programme.</p> <p>This patient was exhausted from: engaging simultaneously in multiple pathways; previous surgery; and wider life challenges, including caring for poorly family members. She was daunted by the prospect of more surgery and intended on withdrawing from the hip pathway.</p> <p>She articulated the challenges of navigating NHS pathways:</p> <p><i>‘It’s not integrated at all; this is a problem for patients. I’m referred to someone different for every part of my body, I’m worn out. You go to the knee person, foot person, have the MRI there, the x-ray there, surgery there. It took two years out of my life, waiting for surgery.</i></p> <p><i>‘The timelines are exhausting. You have to proactively ring, to get on the list and find out what is going on. You really have to push. Some do not get back to you. I think ... don’t get mad... I have anxiety, so call when I am in the right frame of mind.</i></p> <p><i>I shouldn’t have to work my way around PA’s for an appointment. I shouldn’t have to justify the severity of my pain. But if you are not proactive, you do not get anywhere’.</i></p>

Patients with Moderate and Low Health Literacy

The remaining patients had moderate or much lower levels of health literacy. Some patients had moderate levels but lacked skills and confidence to use this. Other patients with lower levels lacked both the health knowledge and skills to apply it. These patients' experiences are described in full in the findings chapter, including a range of case studies briefly summarised below:

- Case study A described a patient who had worked in the NHS for many years in office and health care roles but did not use their health knowledge to gain quicker treatment when needed. This was due to a lack of trust and skepticism in medical professionals.
- Case study B recalled the experience of a patient who lacked the confidence to push her GP to explore her symptoms and felt dismissed. After receiving advice from another professional, she gained the confidence to push her GP and received an OA Hip diagnosis following a referral.
- Case study C illustrated the confusion patients can experience around medication instructions and changes, and that more guidance is needed for effective use of prescriptions to support pain reduction.
- Case study D showed this patient lacked the confidence to explore steroid injection options with their GP, despite being very articulate, and as a result had delayed action for over six months. During this time, she had sought knowledge about different options by speaking to friends but did not know how to broach this with her doctor.
- Case study E recalled the journey of a patient who was set for surgery before covid, which was then cancelled. He waited over two years for another appointment to reorganise the surgery and did not have the confidence to chase. His wife finally approached the medical secretaries through her work at Walsall Manor, and it was chased up. The period waiting, with further deterioration, had a significant impact on the mental health of the couple.
- Case study F described a patient with a very complex pathway, who was incorrectly discharged from both Physiotherapy and Orthopaedics. He had several co-morbidities and was engaged in other treatments. He did not want to be a burden and felt health professionals knew what was best, so he did not chase these up. An unrelated health professional picked up the error and helped him gain another Orthopaedics appointment. However, he ended up with the wrong type of consultant and a further wait for another appointment with a hip specialist.
- Case study G explored the lack of discussions around patient choice. This patient had a preference for City hospital, and maintained she would not attend appointments at Sandwell. This had not been discussed with professionals and had the potential to delay her treatment. (Conversely, Case study H and I demonstrated that patients with knowledge of provider choice and the required health literacy, potentially used this to speed up their treatment).
- Case study J illustrated the challenge of reducing BMI for surgery for a patient with multiple health conditions who received very limited support from professionals. This patient had lost weight but with no contact with Orthopedics or other relevant professionals, did not know if it was sufficient for surgery. As a result, they were waiting for another consultant appointment to shed light on his progress.

Chapter Seven: The Way Forward - Proposals to Improve Patient Pathways

Our findings demonstrate that while some patients experience a relatively smooth journey through OA Hip and Knee pathways, others do not have the health literacy and wider resources needed to navigate it effectively. System barriers like appointment delays and cancellations, inconsistent conservative management referrals, lack of shared decision making and surgery criteria, interact with patient barriers like perceptions, lack of confidence and limited pathway and treatment knowledge.

We often talk about siloed services in health and social care, and the challenges these create for patients. Like others, the MSK pathway has been set up around areas of professional expertise, segmenting the care patients need to manage their condition effectively. Arguably, patients are less aware of these divisions until they experience them. As one patient said the pathway is not integrated and it is exhausting trying to proactively bring it together.

In designing and operationalising service improvements, we need to focus on how to better connect professional areas of expertise, increasing awareness of each other's roles and the transition between roles and services. We need to explain these to patients to help them move between services and piece together how each part can support them and when that support is appropriate. Shared decision making (SDM), and educational tools will be key to this. Some providers have introduced Patient Passports alongside education sessions for patients (NHSE, 2017³⁵). These have cross system leadership and could potentially bring the pathway together for patients and support transitions.

We recognise our findings do not represent evidence of a causal relationship between the barriers and issues we have identified, and variations in the level of Hip and Knee replacement surgery between socio-economic groups. However, these barriers and issues are more likely to have the greatest negative impact on patients who are most vulnerable, have low health literacy and fewer wider resources, namely patients from lower socio-economic groups. These barriers and issues have led to more complex pathway journeys for vulnerable patients and slow progression with appropriate treatment.

We present a list of improvement options that could be introduced (or refined if already in existence in some places), and link each to our patient interview findings. We also link these to the findings from our discussions with First Contact Practitioner staff (FCP - Physiotherapists specialising in MSK assessment in Primary Care) and Specialist Community Physiotherapists.

Our list is by no means exhaustive. The intention is to stimulate discussion amongst a diverse range of MSK health professionals and stakeholders about how to better deliver services and support patients to gain better patient outcomes. Our options should be considered alongside the GIRFT pathway and how this is delivered in each of the four ICB Places. We recognise each Place has different structures and service arrangements, which may mean some options are more appropriate than others, and local arrangements will influence if, and how options can be adopted and implemented.

³⁵ NHS England (2017). Transforming musculoskeletal and orthopaedic elective care services. (Referenced as: NHSE 2017, Transformation).

MSK professionals may work through these options and identify some they feel could and should be implemented as generic changes for all patients. Other options could be introduced, for the most vulnerable patients. Together these should assist patients' journeys through the pathway, including surgery where this is the most appropriate option.

Criteria could be established to identify the most vulnerable patients for intensive support, for example, those with:

- Low health literacy, including low levels of confidence and experience engaging with health services
- Multiple Long-Term Conditions (LTC)/Co-morbidities
- Poor overall quality of life and/or mental health (acting as a barrier to self-direction and management through the pathway)
- Low levels of resources that support pathway navigation, including travel, practical support and support with advocacy from friends and family, caring responsibilities for others, etc.

Alongside the proposed options, pathway professionals should consider how they might change their individual and team practice to better enable and empower more patients to self-manage through the pathway. However, as NICE recognises, not all patients want to, or have the skills for self-management. Alternatively, additional support needs to be in place to enable more patients in this position to have 'assisted pathway management'.

Pathway Improvement Options:

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>1. FCP Assessment Appointments</p> <p>We propose consistent introduction and use of FCP appointments across PC in the ICB. These appointments should be used to complete an in-depth assessment of patients' MSK needs and refer on as appropriate. This should free up GP time and allow MSK patients to be booked in sooner.</p> <p>FCP assessments will help ensure patients are going through the necessary assessment steps and conservative management before being referred to Orthopaedics, where this is appropriate³⁶. It is also important to raise awareness of the FCP's expertise amongst PC staff and patients as first port of call for specialist opinion, rather than an Orthopaedics referral.</p>	<ul style="list-style-type: none"> • Difficulties gaining PC appointments. • Five patients reported their GP had sent them for imaging before they were referred to SC. Many patients appeared to have been sent straight to SC, without Triage, with only one patient recalling an FCP appointment. NICE 2015³⁸ states that adults over 45 years should be diagnosed without investigations if they have activity related joint pain and any morning joint stiffness that lasts no longer than 30 minutes. Passing the patient onto the FCP for assessment, rather than ordering investigations or making a referral, may save on unneeded investigations and inappropriate SC referrals. 	<ul style="list-style-type: none"> • Often GPs are still referring patients straight to Orthopaedics, who may not have received conservative treatment. A better alternative (supported by the GIRFT pathway), is to refer to Orthopaedic assessment/Triage/Tier 2 services, such as COS in Sandwell. This would avoid patients who are not appropriate for surgery being referred, taking appointments which could have been used by surgery appropriate patients. This also consumes patient time and resources, waiting for and attending an inappropriate appointment. • Levels of referrals to Orthopaedics varies significantly between GP practices. FCP assessments may address this. • GPs refer directly to consultants. They see consultants as the MSK expert and do not view FCPs or Orthopaedic Triage /Physiotherapy-led interface services as

³⁶ Only 1 patient appeared to have been by a FCP and/or Tier 2 Orthopaedic Services before being referred to SC. This means patients may be referred to consultants without a dedicated period of conservative treatment, at a point when their condition is not appropriate for surgery. NICE standard states patients should have received at least 3 months conservative management before surgery is considered.

³⁸ NICE (2015). Osteoarthritis Quality Standard. 11 June 2015 (Referenced as: NICE OQS, 2015)

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>FCP assessments should strengthen the role and use of Triage services, providing a specialist opinion and expert diagnostic services to ensure patients receive the right treatment.</p> <p>This will require work to ensure FCP posts are more consistently present in PCNs across the four ICB places, and that Triage arrangements are in place to ensure patients are seen by FCPs as the first port of call in PC (or very early on in their MSK journey)³⁷.</p> <p>FCP assessments would also link into the provision of personalised support – see option 4 below.</p>		<p>part of the pathway. There needs to be awareness raising on the role of FCPs, Tier II Interface services and the appropriate pathway steps for these patients.</p> <ul style="list-style-type: none"> • Patients are on pain medication for too long before a physiotherapy referral is made. FCP assessments could resolve this. • More deprived areas often have fewer GPs per population. Embedding FCPs as the PC MSK expert, would particularly help GP capacity in these Practices.
<p>2. Longer PC Appointments for MSK Patients</p> <p>We propose longer appointments in PC to: better manage patients’ MSK conditions; explore the impact of OA on wider aspects of health, e.g., mental health, mobility and pain management; raise awareness of and ensure all potential conservative management</p>	<ul style="list-style-type: none"> • The limitations of 10-minute GP appointments, leading to multiple appointments, and the challenge of bringing different GPs up to speed with complex needs. 	<ul style="list-style-type: none"> • That 10-minute GP appointments are very challenging for patients and GPs, with patients having to focus on their most pressing issue. Patients from deprived areas can struggle to articulate their symptoms and may be dismissed. Longer appointments would help PC practitioners

³⁷ NHSE 2017, Transformation. The guidance states, FCP roles should be integrated into local referral pathways, positioning FCP in the GP team and wider physio or multi-disciplinary team in SC. FCP should be able to order investigations.

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>options are being taken; medication reviews, etc. In doing so, it would be beneficial to strengthen links with PC Mental Health Practitioners and Community Mental Health Teams to better support patients.</p> <p>Appointments could explore interactions between MSK and other LTCs, and where actions in the two pathways need to be joined up to progress treatment (e.g., diabetes management, heart conditions).</p> <p>Longer appointments should take place face-to-face to physically assess the patient's MSK condition, and support a deeper exploration of patient needs and their understanding of potential treatments.</p> <p>Medication reviews could assess the effectiveness of current medications, check patients' understanding of medications and compliance with prescription instructions, and explore required changes. (Patients could be given a clear medication plan to take away, detailing the role of each medication, dosage per day and spacing medication, etc.).</p>	<ul style="list-style-type: none"> • Limited levels of referrals to and engagement in conservative management options. • Having to prioritise what issue to ask or push for support with, meaning other needs are not explored and left unsupported. • The impact of MSK and other LTCs on patients' mental health and overall quality of life. • Pain medication is not working effectively for many, but they did not raise this with their GP. Longer appointments may enable GPs to explore this. 	<p>to understand patients' needs better, make a good diagnosis, and refer accordingly. It would provide more space to explain treatment options, so patients navigate the pathway more effectively.</p> <ul style="list-style-type: none"> • GP phone appointments are very challenging for MSK issues, there is no physical assessment and often pain killers are just prescribed. The number of FCP appointments provided by phone should kept to a minimum. • Different cultural practices and languages can present barriers when patients explain pain. This is in addition to generic problems faced by MSK patients understanding and articulating the origin of pain, e.g., back, hip and knee pain can all be connected. These communication issues may require professionals to gain a more in-depth understanding of individual patients, use interpreters, and spend more time on education and explanation to address low health literacy.

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>Question for Professionals: If longer appointments are not feasible, what other solutions do colleagues think there might be?</p>		
<p>3. Regular MSK Reviews in PC</p> <p>Regular MSK reviews should be introduced in PC to: oversee the long-term management of MSK conditions, monitor progression, establish next steps, review medication, make referrals, address any drift and barriers (e.g., waiting times for steroid injections, physio referrals, consultant appointments, etc). Consideration should be given to whether annual reviews could be conducted as part of the FCP role³⁹.</p> <p>To identify patients requiring MSK reviews, PC could introduce an OA/MSK register. Better still, this would be incentivised in a similar way to the Quality Outcomes Framework to provide the focus and motivation to work more in-depth with MSK patients.</p>	<ul style="list-style-type: none"> • Drift and lost within the system e.g., not gaining appointments, having to chase, lack of progress, waiting long periods for treatments, being discharged without a clear plan for support/treatment, etc. • Long periods without a professional physically assessing whether there have been sufficient changes for surgery. • No contact with professionals and a lack of a long-term OA support plan. Patients feeling they are left to live in significant pain with no effective support, and no view when treatments might be appropriate. • PLUS Patient feedback from option 1. 	<ul style="list-style-type: none"> • See FCP feedback above for Option 1 and 2.

³⁹ NHSE (2015) OA quality standard recommends regular OA reviews and states these should: explore further deterioration, impact on quality of life, use of medication, and whether additional treatments/referrals like surgery are now appropriate.

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>4. Personalised Support for MSK Condition Management</p> <p>Identify staff resource in PC, Community (e.g., FCPs, MSK Health Coaches⁴⁰, Nurses), and/or Tier 2 Orthopaedic Assessment Services to provide personalised support.</p> <p>The design of personalised support services must ensure support options are tailored towards patients from different cultural backgrounds and for different languages.</p>	<ul style="list-style-type: none"> • Often patients did not have the knowledge and confidence to self-navigate the pathway effectively. Patients also said they were burnt-out, or had given up due to the challenges involved. • Patients had little awareness of, and only one appeared to have used patient choice for their NHS provider. One had used a private provider through their partner’s health insurance. • PLUS Patient feedback under option 1, 2 and 3 above. 	<ul style="list-style-type: none"> • Cultural and language differences present challenges supporting patients. We need proper multilingual resources and interpreters. Patients from different cultures may have experienced other healthcare systems, with different processes, expectations etc. to the NHS. • To provide effective support, staff delivering personalised care must have in-depth knowledge of MSK pathways and how to help patients through it.
<ul style="list-style-type: none"> • Engaging patients in early discussions through shared decision making/educational materials to explain: the pathway, treatment options from conservative management onwards, benefits and risks, and to explore and document patient preferences and choice (NHSE (2015) OQS). Ensuring SDM 		<ul style="list-style-type: none"> • More affluent patients with health literacy are more likely to understand the benefits of treatment options and follow guidance. More time should be spent with patients with lower health literacy to increase understanding, and have regular check ins to encourage patient action. • Affluent patients are more aware of patient choice and benefit from this. Raising awareness amongst less affluent patients

⁴⁰ MSK Health Coaches may be an option to increase capacity in PC. These roles would need to be knowledgeable and have hands on experience of MSK conditions and pathways or receive dedicated training in MSK policy and practice once in the role. We would envisage these roles would be a Band 5+. Alternatively, if less experienced staff were recruited as MSK Health Coaches, to be effective, these would need to be closely supervised and/or mentored by FCPs.

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>materials are gauged at the right level of health literacy for the general population.</p>		<p>could help reduce inequalities. Some affluent Walsall patients are benefiting from private consultations, and bypassing the NHS queue.</p>
<ul style="list-style-type: none"> SDM would involve educating and managing expectations as to when surgery is appropriate (e.g., the Lancet treatment triangle p.15). This would include: the implications of undertaking surgery when patients are younger and/or conditions not advanced; and the potential for more complex revision procedures. It should also raise awareness of the focused clinical role of consultants, and that of MSK specialists in supporting them more holistically. Supporting patients with surgery where this is the right treatment, helping overcome any logistical barriers, concerns etc. Linking in with other professionals, like social prescribers, for relevant support. 	<ul style="list-style-type: none"> Variable awareness of support and treatment options. Patients wanted investigations and often viewed surgery as the answer. They were less aware of conservative options. SDM and information tools could support this; explaining when options are or are not appropriate and why. Patients reporting issues around access to surgery due to age and BMI, logistical issues for recovery etc. 	<ul style="list-style-type: none"> Some patients demand to be referred to Orthopaedics, even when it has been explained they are not a case for surgery. FCPs have more knowledge of: MSK pathways, referring patients onto relevant services and wider support like Social Prescribers.

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<ul style="list-style-type: none"> SDM could include the use of tools like paper and/or electronic Shared Care Plans. These would detail: patient preferences; PC and SC appointments and treatments; professionals’ and patients’ actions; medication overview; physio programme and appointments; coping strategies; next steps, etc. These could be taken to all MSK appointments⁴¹. Care plans could detail patients’ multiple pathways/health issues, how they interact with each other, and when steps in one pathway may need to take priority, before MSK actions can be taken forward. 	<ul style="list-style-type: none"> Patients with multiple health issues had difficulties simultaneously managing several pathways, various appointments and co-ordinating interacting treatment timescales. Patients were often not aware of: what the next steps were; the reason for their appointments; who they should contact, or who would be in contact with them; estimate timescales, etc. Small amounts of information were fragmented in: appointment letters, leaflets (if provided), verbal conversations in PC and SC, etc. Patients were left with the challenge of piecing this information together, without the necessary pathway understanding. 	<ul style="list-style-type: none"> DNAs are a significant issue in Physiotherapy and Orthopaedics. An analysis by ICB Insight Team has demonstrated higher levels of DNA amongst lower socio-economic groups in the Black Country. More hands-on support and help co-ordinating patient actions may help reduce this.
<ul style="list-style-type: none"> SDM could help prepare patients to get the most out of Orthopedic consultant and other secondary care appointments. For example: what patients should expect in appointments, questions to ask, information to record (e.g., medical 	<ul style="list-style-type: none"> Preparation for SC appointments could help address patient reported issues, such as: not fully understanding their condition, what should happen next, who they should contact and how; having the confidence to ask professionals to write 	<ul style="list-style-type: none"> Patients should already be aware of the pros and cons of surgery before they go to Orthopaedics. Patients attending SC should be appropriate for and open to considering surgery.

⁴¹ (NHSE (2015) OQS recommends OA self-management plans).

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>secretary contact details) and information they may want to provide, e.g., a timeline of symptoms and support/treatment to talk through with the consultant.</p> <p>This is particularly important given the waiting time for SC appointments, and the limited duration and frequency of these appointments through which they can benefit from this expertise.</p>	<p>notes, draw diagrams, repeat explanations; patients requesting information they can take away to e.g., what is arthritis, what does etc.</p>	
<ul style="list-style-type: none"> • Support patients to overcome pathway progression issues and other barriers, e.g.: <ul style="list-style-type: none"> • Providing patients with advice and information about actions/people they can contact to move things forward, or professionals doing this on behalf of patients; • Chasing referrals, appointments, investigations, follow-ups; • Exploring/resolving discharge errors; • Coaching patients on self-management so they can progressively become more independent⁴². 	<ul style="list-style-type: none"> • Several patients were discharged by Orthopedics due to their BMI, and/or current condition severity. They often drifted, lost in the system after discharge with limited or no support. • SDM and discussions could advise patients when they should re-contact PC or SC about their condition (e.g., as pain and mobility becomes worse, or BMI reduces), and when it is appropriate to chase for referral appointments, investigation results, etc. These steps could be set out in a patient Care Plan. 	<ul style="list-style-type: none"> • Patients from deprived backgrounds have lower health literacy, are less able to advocate for themselves and have a poorer understanding of NHS processes. More affluent patients have more knowledge, making them better able to navigate the pathway. • FCPs/Physiotherapists have the skills to coach and support patients through the pathway.

⁴² NHSE, 2017. Transformation. Includes Self-Management Education for MSK conditions.

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<ul style="list-style-type: none"> • Support patients to improve and manage other LTCs through hands-on support, and techniques like motivational coaching. Co-ordinating support so patients remain in touch with health professionals and can be directed back to Orthopaedics as appropriate. • To lose weight in preparation for (or to become eligible for surgery), linking in with other services as needed e.g., Social Prescribers - physical activity providers/wellbeing activities, dietitians, etc. • To be active: NHSE (2015) OQS states exercise is key to managing pain. Patients should be supported and encouraged with weight loss and exercise. • Support with other co-morbidities that may prevent patients from having surgery. 	<ul style="list-style-type: none"> • Three patients were discharged from Orthopaedics, being told their BMI was too high for surgery. Only one talked about having a single dietitian appointment, and it appeared patients were left to lose weight independently of support. 	<ul style="list-style-type: none"> • Patients with more challenging lives may not be ready to engage with weight loss services. Competing demands, poor mental health and busy daily routines are a barrier. • Physios are well placed to support BMI and other co-morbidities. More deprived patients are more likely to have co-morbidities and less likely to understand the risks for surgery. • Walsall Council has cut free physical activity, which would really help people with MSK conditions to lose weight. • Patients with co-morbidities are on multiple siloed pathways, waiting on one condition list, whilst another delays progress.
<ul style="list-style-type: none"> • Strengthen Physiotherapy services: <ul style="list-style-type: none"> • Raise awareness of the role of physio and the positive impact on mobility; • Ensure referrals to physio are more consistent across patients to support 	<ul style="list-style-type: none"> • Not all patients were referred to physio and some only had 1-2 appointments. This was not sufficient support for patients to develop an exercise routine; check technique is correct, progress exercises, etc. 	<ul style="list-style-type: none"> • Patients with lower health literacy may be less likely to do physio exercises because: <ul style="list-style-type: none"> • They do not know how physio can help; • Might not understand the importance of some exercises; • Think physios will give them a massage and the pain will go away;

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>conservative management and consider promoting self-referral;</p> <ul style="list-style-type: none"> • Provide rolling/several appointments of physio; • Provide support and motivational coaching to increase the likelihood patients will engage in and routinely do their exercises; • Reinforce messages that some pain is ok when building up physical exercise to address patient concerns; • Review interpretation support and language resources for physios. 	<ul style="list-style-type: none"> • Not all patients were doing their Physio exercises fully or at all. Some dismissed its value in supporting their condition. • For many doing physio exercises was painful, this and the fact patients were not sure of the benefits put them off. 	<ul style="list-style-type: none"> • Have manual jobs and believe as they are physically active, they do not need to do physio; they are also tired after work; • Patients with more challenging lives may not be ready to engage because of competing demands. Poor mental health and busy daily routines are also a barrier; • Not having leaflets in different languages; • Patients are struggling to pay parking in Walsall town centre to attend appointments and the service is struggling for space.
<ul style="list-style-type: none"> • Pain management – exploration, advice, coaching and training. • Patients reported high levels of pain, which may be better managed through advice and support from a range of organisations, like Versus Arthritis. 	<ul style="list-style-type: none"> • Many were living with moderate to very high levels of pain which they did not feel was being managed effectively. One patient reported they had attended a pain management course. 	<ul style="list-style-type: none"> • Patients from lower socio-economic groups can experience more persistent and restricting pain, and patients with lower health literacy can find it difficult to understand different pain relief options. • As specialists FCPs can offer better solutions for pain relief especially for patients with BMI/comorbidities.

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<ul style="list-style-type: none"> • Signpost to wider support resources to help overall condition. E.g.: <ul style="list-style-type: none"> • Organisations providing home adaptations and mobility support inside and outside the home. • Sources of advice and support on relevant state benefits to help live with and manage their condition. • Peer support activities. 	<ul style="list-style-type: none"> • Only one patient talked about receiving wider support from an independent living service and their Local Authority home adaptations service. 	<ul style="list-style-type: none"> • Physios are well placed to refer patients into Social Prescribing and other resources.
<p>5. Improve communication and explanations in Secondary Care</p> <ul style="list-style-type: none"> • Encourage consultants to use visual diagrams to explain conditions and treatment; provide patient leaflets; encourage patients to write notes, or write notes for them; have a printout of relevant departments and staff contact details, etc. • Identify staff (e.g., Orthopaedic Nurses) to debrief patients before leaving Clinic to ensure they understand information they have been given, next steps, provide contact details, leaflets, etc. Staff could also ask patients if they have any concerns regarding proposed operation, and how to 	<ul style="list-style-type: none"> • Some patients left Orthopaedics without sufficient knowledge and information of their condition and treatment options. • We were asked for information on THR surgery and steroid injections during our interviews, demonstrating a lack of knowledge from existing appointments. • Some patients had concerns about surgery but did not discuss this with the consultant. This could be picked up in a Clinic debrief, or follow-up calls. • Some were concerned their consultant had not physically seen their condition progression due to phone appointments and were worried they would not be prioritised. 	<ul style="list-style-type: none"> • Patients from deprived areas may have lower health literacy, impacting on ability to understand and recall consultant explanations. High levels of pain relief medication can also impact understanding and recall.

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>get in contact if patients think of something they want to discuss.</p> <ul style="list-style-type: none"> Review the use of phone appointments, ensuring where possible patients have the choice between physical and phone. 		
<p>6. Surgery decision making and communication to patients:</p> <ul style="list-style-type: none"> Improve patients’ understanding of and engagement in surgery decision making. Shared decision making: Review the extent to which consultants are equipped in and are using SDM in surgery decisions, and the extent to which this is possible within consultant appointments. BMI: Review how consultants incorporate BMI in their decision making, and the impact of the new Hip Harmonisation Policy across the four Places. The new policy states surgery for patients with a BMI over 40 will be considered on a case-by-case basis. In the past Sandwell had no restrictions. Their consultants will now need to go through this added process to gain approval for these patients. As 	<ul style="list-style-type: none"> Several patients were told they were not eligible and/or fit for surgery due to a high BMI. Several patients were also told they were not eligible due to age, and that surgery would be appropriate in the future. Some patients felt they had been told surgery was not an option and that they had no influence over this. Patients felt they were being left to live with chronic pain for an unspecified amount of time before they could have surgery. Patients talked about things they would like to do, if their condition improved from surgery, both in terms of returning to work and having a more active life. 	<ul style="list-style-type: none"> There are higher levels of obesity amongst patients from deprived backgrounds, hence they are more likely to experience BMI as a surgery barrier. Consultants approach BMI differently, some will work with it, others will not. Patients with high BMI and good health literacy are better able to push their case for surgery. Patients with lower literacy, from lower socio-economic groups, are more likely to have a high BMI and other co-morbidities, and less able to push their case. Consultants take into consideration current work and leisure activities, and whether surgery would help them continue these. More deprived patients are often less active. Consultants may decide less active patients do not need surgery, as their condition is not a barrier.

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>demonstrated by studies cited in our introduction, this may reduce levels of surgery, particularly for the most deprived, reinforcing and increasing inequalities.</p> <p>In the past consultants from the other three Places were required to gain approval for patients with a BMI of 35 over, so this change is less of a restriction for them.</p> <p>We recommend that the impact of this new BMI criteria on different population groups is assessed using the Health Equality Assessment Tool process.</p> <ul style="list-style-type: none"> • Age/severity: Review consultant explanations regarding age/longevity of replacements and severity of patients' condition; when surgery would be appropriate and how to manage until then. • Patient aspirations: Review how consultants take current activities and future aspirations into consideration in surgery decision making. Decisions should consider how reduced pain and 		<p>This does not take into account future aspirations.</p> <ul style="list-style-type: none"> • There is limited SDM between consultants and patients. Some patients do just want to be told, and this can be a cultural belief that doctors know best. • Some patients do not have surgery because there is no one to look after them, or do not want to be a burden. Patients also worry about the impact on employment. • Surgery is viewed by some South Asian populations as a last resort and an indication of weakness.

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>increased mobility may expand patients' current activities and aspirations.</p>		
<p>7. Review Surgery Measures and Funding to encourage surgery with more complex patients:</p> <p>To support changes in practice across the pathway, we may also need to review the nature of outcome measures and funding. The current focus is often on frequency, e.g., numbers of appointments, waiting times and lists, and surgery levels.</p> <p>Can outcome measures be designed so that Orthopaedics are 'incentivised' to work with more complex and vulnerable patients? These patients are likely to require more resources and may have poorer surgery outcomes. Ideally this would be in the QOF.</p> <p>Do outcome measures take into account the relative complexity of working with more complex patients e.g., those with co-morbidities, low levels of health literacy, etc.? Could this be linked into the Core20+5 agenda in addressing health inequalities?</p>	<ul style="list-style-type: none"> • See patient feedback under Option 6. 	<ul style="list-style-type: none"> • Surgery outcome measures do not support and encourage consultants to work with patients where there are risks, or potentially reduced benefits. Measures do not give a positive weighting towards working with more deprived patients; they do not capture 'relative' improvement in patients' quality of life.

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>Are surgeons recognised for their level of expertise?</p> <p>Do funding tariffs take into account the relative complexity of surgery in terms of patients’ co-morbidities and other factors? (Including that revisions are more resource intensive and require an ICU bed?)</p>		
<p>8. Review MSK Patient Initiated Follow-Up (PIFU) Policy</p> <p>The four Places/ICB should review how the PIFU process should operate for MSK patients. PIFU should allow patients to request a follow-up appointment with a relevant SC professional within set timescales of their previous appointment. E.g., if another LTC has stabilised meaning surgery can now go ahead; if a patient originally declined surgery and would now like to go ahead; a change in condition severity, or if BMI has been reduced.</p> <p>Places/ICB would need to decide on a set of criteria whereby patients could use the PIFU to be reviewed in SC, rather than commencing the referral process again. This</p>	<ul style="list-style-type: none"> • Drift and being lost within the system – e.g., not gaining appointments, having to chase and not making progress, waiting long periods of time for support and treatments, being discharged without a clear plan for support/treatment, etc. • Being seen in SC some time ago and long periods without a professional assessing whether there had been sufficient changes in their condition for surgery. • No contact with professionals and a lack of a long-term OA support plan leaving patients feeling they are left to live in significant pain with no effective support, and no view when treatment options might be appropriate. 	

Pathway Improvement Options:	Links to Patient Findings:	Links to FCPs/Specialist Physio Findings:
<p>process needs to work for patients from a range of backgrounds.</p> <p>The PIFU process needs to be promoted and explained to patients so they understand how it can be used to overcome barriers experienced in re-referral and drift.</p>		

Surgery Variation Conclusions

Our report demonstrates a number of barriers and issues some patients experience when attempting to progress along the MSK pathway. This may make more vulnerable patients less likely to access SC appointments, and to understand their condition and how to request, or advocate for the right treatment, once they are in SC.

When surgery is considered the right course of treatment, BMI was one reason why surgery was not offered. However, very little support was offered to help patients to lose weight and patients were not informed how much they needed to lose, and how to re-engage with SC when they had. This meant patients were re-starting the SC referral process.

Other patients were also told surgery would be appropriate, but not yet, given their current age and severity of condition. These patients were discharged and commonly drifted attempting to manage their condition, without knowledge of when it may be appropriate to re-engage in the process.

PC professionals did not appear to be active in overseeing conditions to provide patients with this guidance in both BMI and age/severity related examples. The lack of guidance from SC at discharge and help from other health professionals may make these patients less likely, and able, to re-engage in the surgery process, particularly if they have other LTCs that require more immediate attention and other life stressors.

Vulnerable patients had other concerns that impacted on surgery. One patient who was listed for surgery missed appointments due to mental health; this patient had also lived in unsuitable accommodation for surgery recovery so could not progress.

Healthier Futures

Black Country Integrated Care System

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Exploring MSK Patient Pathways | 60

