Understanding and improving decision-making for joint replacement surgery in older patients with complex health needs

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Executive summary

Background

- Many older people (over the age of 70 years) with severe knee problems, such as osteoarthritis, who are being considered for joint replacement surgery also have other long-term health conditions, both physical and mental.
- Weighing up the risks and benefits of surgery is not easy for them, their carers and healthcare professionals.
- Understanding of the issues involved is needed to help inform decision-making.

Study aims

Our study aims were to:

1. Understand the issues and concerns of older people with severe knee osteoarthritis additional to other physical or mental health problems, when faced with a decision about joint replacement surgery; and
2. use this information to develop a web-based 'patient experience' resource to support older people with multiple health problems and their clinicians in making treatment decisions about knee replacement surgery.

Methods

- Using a qualitative longitudinal approach, we conducted narrative in-depth interviews to collect and analyse the experiences of older people with two or more health conditions in addition to knee problems such as severe osteoarthritis who were being considered for knee replacement surgery in England.

- We recruited 44 participants through four orthopaedic hospital sites. Participants had a wide range of comorbidities, with cardiovascular conditions being the most dominant, and included those with disadvantages that could impact on their access to and experiences of managing their conditions and healthcare (e.g. income/financial instability, health literacy, familial support, carer responsibilities, varying degrees of disability and ill health).
- Interviews took place between February 2021 and April 2023, during the Covid-19 pandemic.
- Participants were interviewed using in-depth narrative methods at two or three time points.
- All participants were interviewed at a 'baseline' before seeing a surgeon in their current referral, and then follow-ups dependent on their decisions regarding knee replacement surgery and whether the surgery actually took place during the study.
- This second interview was either six months following their appointment (if they were not having knee replacement surgery, or if they had been on a waiting list for longer than six months), or six months after surgery if it had taken place in the six months after the referral appointment.
- For those who had surgery after a longer wait (upwards of 6 months), a third interview was then undertaken six months after the surgery.
- The interviews sought to understand what was important to participants when making decisions about knee replacements in terms of their health and illness, wider lives, relationships, hopes and expectations, and, for those who had knee replacement, the subsequent outcomes.

Key findings

- For the people in this study (aged over 70 years), having multimorbidity in addition to knee problems (including osteoarthritis at other joint sites) often compounded the challenges they faced. Many found it further detrimentally impacted on their quality of life. They recognised that some multimorbidities could add to their knee problems or vice versa, or influence their attitudes to medication, for example. The challenges of accessing healthcare during the Covid-19 pandemic could have further ramifications, for example with delayed or cancelled appointments for other health concerns and conditions.
- In deciding whether to have knee replacement surgery, patients weighed up anticipated benefits with risks associated with their multimorbidity, including the operative and anaesthetic risks, amongst other factors.
- Some patients in this cohort did not seem to be aware of the relevance of their existing multimorbidity for knee replacement outcomes, meaning that their expectations may not be aligned with likely outcomes and limitations.
- Views on, and commitments to, decisions about having knee replacement could shift over time, for example with changes in ill health, which was a particular concern for this cohort in the context of long waits for surgery due to Covid-19 restrictions. The experience of waiting for appointments and treatments could have a profound impact on mental distress.
- For those who had a knee replacement, making sense of their recovery and outcomes included understanding the potential role of multimorbidities. Health problems that had emerged since the surgery were more often proposed as explanations for poorer satisfaction, as well as their pre-existing conditions. Other explanatory factors for recovery outcomes included concerns about 'too early' discharge from hospital and difficulties in accessing post-operative physiotherapy support.

Key conclusions

- Individual's wider health and social context, including their coexisting multimorbidities and past experiences of surgeries, accompanies them as they make decisions about whether to have knee replacement surgery and then in how they make sense of their recovery and outcomes.
- The role of multimorbidity in these concerns is not static, and our longitudinal study design allowed us to capture some of the ways in which these could shift, including with the onset of new, concerning, symptoms and diagnoses or more generally declining health.
- Multimorbidity was important to these patients when making decisions about knee replacement surgery, as well as in making sense of recovery afterwards, though not the only or necessarily most important considerations for them.

Recommendations for practice and policy

- The communication of clear and comprehensive patient information is needed to ensure patients are appropriately aware of and supported in including comorbidity considerations in their decision-making.
- Further understanding about and access to prehabilitation support (in preparation of surgery to maintain or increase fitness) would be welcome for this cohort, and this necessitates careful communication around physiotherapy throughout knee pathways to ensure patients recognise the potential benefits as opposed to seeing it as a 'tickbox' in advance of knee replacement surgery being considered.

- Careful policy consideration and mitigation efforts are needed with regards to the potential risks of exacerbating inequalities and unintentional consequences in knee problem management and treatment services. This includes finding ways to ensure that measures intended to ease pressure on NHS knee surgical services, for example, do not inadvertently disadvantage higher complexity patients. There is also a need for further research on older people with multimorbidity from ethnic minority backgrounds and to implement insights.
- Mental health difficulties – including those stemming from a consequence of living with a painful knee but which were exacerbated by uncertainty and long waits in accessing medical appointments and having surgery – are highlighted as an area in particular warranting more attention for these patients, with recognition that depression and anxiety, for example, may be a longstanding co-existing health condition separate to but potentially interacting with knee problems.

Dissemination

- To address some of the gaps in information and support for older people who are facing decisions about knee replacements in the context of co-morbidities, a new section on the Health Experiences Insights (HEXI) website at www.hexi.ox.ac.uk was produced and is available at: https://www.hexi.ox.ac.uk/Making-decisions-about-knee-replacement-as-an-older-person-with-multiple-conditions/overview
- We will publish the main findings of the paper for a clinical audience, and present at the British Association for Surgery of the Knee (BASK) 2025 conference.
- A paper on the temporality of decision-making amongst older people with multimorbidity is in preparation for a social science audience.
- Additionally, two papers drawing on the study in combination with datasets and reflections from other studies are in preparation.
- To maximise best use of the interview collection, the carefully anonymised transcripts will also form part of a University of Oxford archive which is available to other bona fide research teams for secondary analysis.

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Main report

Background

About knee replacements in the UK

Annually, there are 100,000 total knee replacements in England and Wales with median patient age of 69 [1]. The most common underlying reason is severe osteoarthritis [2]. This number is expected to increase due to an ageing population and rising levels of obesity [3].

Total knee replacement improves quality of life, often dramatically, for the majority of patients, although a systematic review suggested that 20 percent of patients are disappointed with their results after surgery [4]. Furthermore, surgery carries risks of adverse outcomes include bleeding, thrombo-embolic phenomena and infections, in addition to other more generic anaesthetic risks [5,6]. Whilst these risks are typically relatively low and well-managed in contemporary knee replacement surgery [7], there can be different perceptions of risk and beliefs about their acceptability amongst patients, surgeons, anaesthetists and wider surgical teams [8]. There are also the short-term post-operative challenges in the time to achieve full recovery and the impact on patients and their families.

The pathway to knee surgery on the NHS varies, based on factors including location and local service configuration which is also subject to change over time (for example, with the Covid-19 pandemic). Whilst some may be referred by a GP directly to a knee surgeon, typically, however, many are referred by a GP to an intermediary service practitioner – such as a Musculoskeletal First Contact Practitioner or an Advanced Practitioner (also known as an Extended Scope Practitioner), which is often a physiotherapist with enhanced training and capacity to assess, diagnose, investigate

and manage patients with conditions affecting the bones, joints, muscles and ligaments. Where it is thought that there will be limited benefit from conservative treatments, referral to a surgeon to discuss knee replacement surgery can be made.

Before Covid-19, the surgical collaborators in this research advised that the typical waiting times for knee replacement in the UK, although varied, was likely to be around 6 months. The pandemic brought profound impacts on healthcare services and pathways for knee problems, including the initial suspension of elective surgery which exacerbated delays and waiting lists further, as highlighted in a report by the Nuffield Trust [9].

Challenges associated with multimorbidity and knee replacement

With an ageing population comes the challenge of accumulating other long-term health concerns, both in terms of physical and psychological conditions. A report summarising the available literature showed around 80% of people aged over 75 years have at least two chronic conditions [10]. Those with more than one such long-term condition have increased risks of adverse events following surgery, particularly in the immediate post-operative period, although there are few detailed studies of those with specific comorbidity combinations.

Of relevance to this study is the lack of data about how additional morbidities impact the likely benefit of surgery on quality of life. Such morbidities include not only other painful or mobility limiting conditions but other chronic physical and common psychological problems, such as depression.

Decision-making for surgery is challenging for patients and health care professionals [11], not least how to balance operative and anaesthetic risk against possible health benefits [12]. Willingness to undergo joint replacement surgery varies by ethnicity [13,14], socio-economic status [15] and age [12,15]. Further factors influencing decision-making include experiences of pain, coping strategies and social context, such as support from family and friends [11].

Conversations with healthcare professionals have a significant impact on decision-making with research highlighting how patients often rely on clinicians to guide their choices [16]. What has not been studied is the impact of comorbidity, despite its ubiquity in older people.

Previous research has used linked national databases to assess the impact of primary care-recorded comorbidities on adverse outcomes and quality of life (using the national PROMS database) following hip replacement surgery [17]. Whilst such data can provide information about the effects of comorbidities on groups of older patients, there is no knowledge of how individuals experience and reflect on such issues in decision-making for surgery, and their subsequent satisfaction with surgical outcome.

Study aims

The ultimate aim of the study was to support individuals with severe knee problems (such as severe osteoarthritis), who also have other long-term health conditions, to make the appropriate decision for their own circumstances about the risks and benefits from joint replacement surgery. The study objectives were to:

(1) Understand the issues and concerns of older people with severe knee osteoarthritis in addition to other physical or mental health problems, when faced with a decision about joint replacement surgery;

(2) Use this information to develop a web-based 'patient experience' resource to support older people with multiple health problems and their clinicians in making treatment decisions about knee replacement surgery.

The guiding research questions were:
(i) How do patients with multiple long-term health conditions assess the relative importance to their lives of their current knee problem?
(ii) How does such an assessment influence their views about the risks and benefits from knee replacement surgery and their decision for surgery?
(iii) For those patients that do undergo surgery, what are the relationships between patients' priorities and expectations and their perceived success of the knee replacement surgery in the context of comorbidities?

Methods

Our study used qualitative methods to collect and analyse the experiences of older people with two or more long-term health conditions, in addition to knee problems, who were being considered for knee replacement surgery in England. It was a prospective design study [18], meaning that, at the point of recruitment into the study, it was not yet known whether participants would or would not have knee replacement surgery.

Ethical approval

The study was approved by Berkshire National Research Ethics Service Committee (South Central) under reference 12/SC/0495.

Sampling and recruitment

The target group for the study was patients over the age of 70 years with severe osteoarthritis of the knee with two or more other long-term health conditions who had been referred by their general practitioner to orthopaedic assessment clinics before a decision about knee replacement surgery was to be made.

Drawing on our knowledge of the literature, the expertise of our co-applicant team and guided by our Advisory Panel, we developed an outline of the types of experiences (including a range of comorbidities) and demographic variables to guide the study sample. We aimed for a maximum variation sample [19] to ensure a range of experiences were represented, and not only those deemed the most typical.

The study was of prospective design [18]; the implication for recruitment being that participants were enrolled into the study when it was known that they would be considered for knee replacement surgery but the decision of whether to offer and have the surgery was not yet decided. It was estimated that approximately half of those who consult about knee replacement would go on to have surgery, and we initially aimed to sample more of those who opted for surgery than those who do not in an approximate 2:1 ratio. However, this proved challenging owing to: the complexity of decision-making (precisely one of the topics our study sought to explore); the impacts of the Covid-19 pandemic in terms of referrals and elective surgery provision; and deteriorating health with long waits.

Previous patient experience studies undertaken by the Medical Sociology and Health Experiences Research Group at the University of Oxford suggested that around 40-60 participants will be required to achieve 'data saturation', and the target sample size was set at 60 participants with the intention to interview each participant twice (n=120 interviews). However, there were a number of barriers and delays related to Covid-19 with site set up during a time when, understandably, all Trusts were prioritising Covid-19 research approvals. Recruitment continued to prove challenging and the total sample size in the study was smaller (n=44) than the target sample (n=60). However, this remains an acceptable sample size for the qualitative analysis, and has yielded rich insight from the target range of patient perspectives.

We recruited interview participants through four NHS Trusts with orthopaedic hospitals in different parts of England (the Northumbria Healthcare NHS Foundation Trust; the Oxford University Hospital NHS Foundation Trust; the Royal Devon and

Exeter NHS Foundation Trust; and the Royal Orthopaedic Hospital NHS Foundation Trust). Each site had an orthopaedic surgeon run referral clinic for the consideration of knee replacement surgery.

There were variations with regards to the pathways for knee referrals at the recruiting sites, including in terms of the intermediary services that held a triaging function. Furthermore, the Covid-19 pandemic and its wider impacts influenced these pathways at different times during the study. This included efforts to reduce the backlog of elective knee replacement surgery and long waiting lists which, in some places, meant contracts for surgery undertaken at private hospitals paid for on the NHS. We recognised the pressures on the clinical sites and sought ways to make setting up the study as straightforward as possible for them. This included updating and tailoring the recruitment processes to site preferences, as outlined below.

Potential participants were given a recruitment pack either handed out in person by clinicians or sent by post, or, as an adaptation to the recruitment process, a poster with contact details for more information and a pack was then sent if appropriate. Each pack contained a cover letter from the hospital, an information leaflet, a questionnaire about their health and a freepost reply slip addressed to the researcher (AM). The questionnaire sought to capture socio-demographic characteristics and medical history, which included a tick box list of the major long-term conditions captured routinely by primary care [20]; the list was reviewed and additional examples added by PPI. Multimorbidity was taken as having two or more long-term conditions in addition to their knee problem, based on the criteria set for multimorbidity in the recent Academy of Medical Sciences Report.

The poster approach was secured as an ethics approval amendment and was intended to save clinician time spent screening patients for details on multimorbidities and medical histories; it entailed posters being sent to a larger cohort of potential participants and, if a patient was interested, they were encouraged to use the contact details on the poster to notify the researcher who helped them to self-assess their eligibility for the study. Another example of a change made based on recruiting site feedback is that we developed a flexible script that staff at sites could use to introduce the study over the phone with eligible patients before offering a recruitment pack.

In all cases, individuals who saw our recruitment materials actively chose whether to contact us to find out more about the study and, subsequently, decided for themselves about participating after receiving information and the offer of having questions answered by the researcher.

During recruitment, we maintained a database of potential and actual participants and reviewed this at regular intervals. This helped us to keep track of our recruitment activity. The researcher (AM) was in regular contact with the sites to request rounds of recruitment and to feedback on response rates. As noted, this also gave us opportunities to seek feedback from sites and tailor sampling and recruitment.

Interviews

Qualitative narrative in-depth interviews were conducted with people over the age of 70 years with two or more long-term health conditions, in addition to knee problems, who were being considered for knee replacement surgery. Participants were interviewed more than once, as per a longitudinal design.

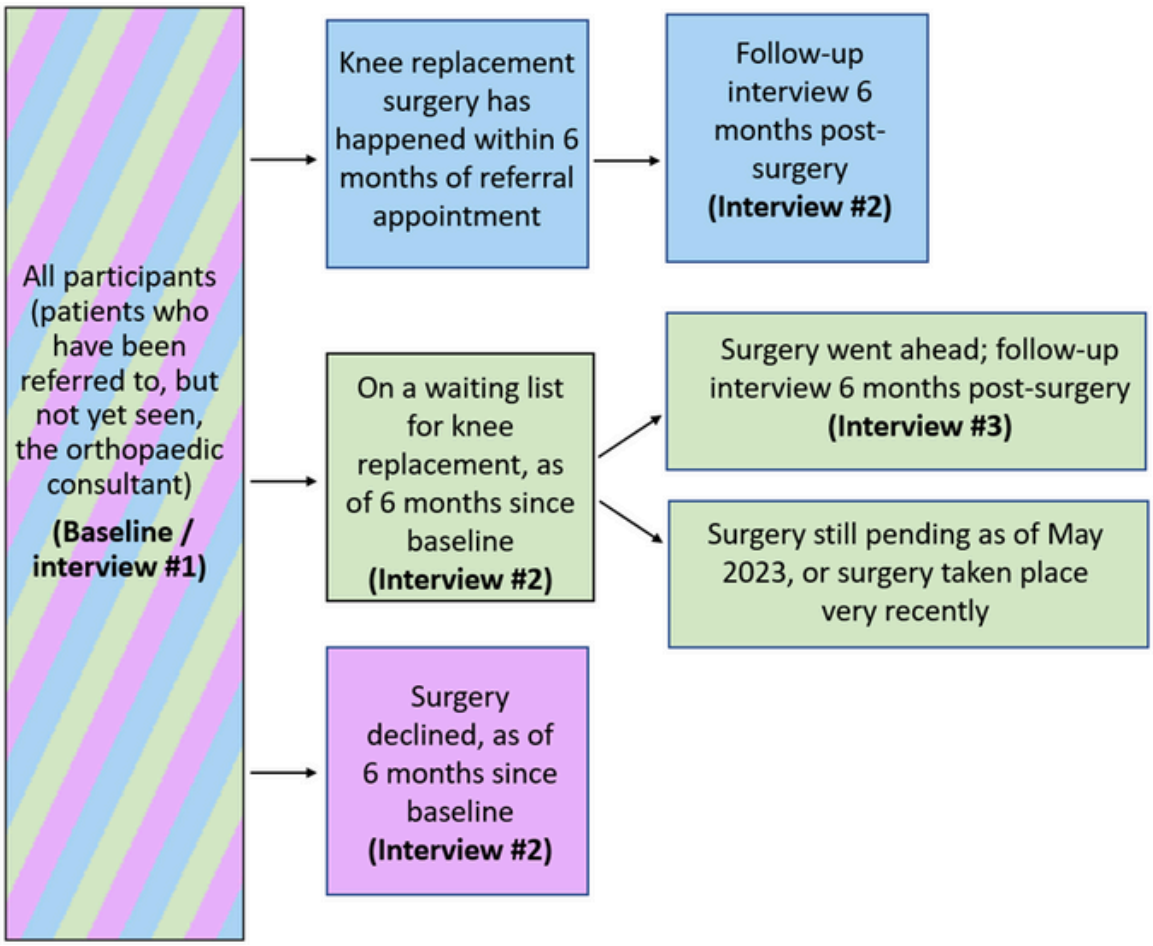
The interviews were originally intended to be face-to-face, and a change to fully remote interviewing was necessitated by the Covid-19 pandemic. Owing at first to Covid-19 restrictions and then subsequently caution about the ongoing risks to participants (many of whom were shielding for additional health reasons), all interviews were conducted virtually. Primarily, based on participant preference, this was by telephone but some participants took part through online video calls (using platforms that comply with privacy and data security university requirements). We provided flexibility in terms of interviewing, including offering to interview during evenings and weekends, and scheduled around participants other commitments.

The timing of the interviews was a key feature of the prospective longitudinal design. The initial study design was based on two interviews, with the gap between these calculated on the basis that the wait between surgical consultation and knee replacement surgery (for those eligible) was approximately 6 months, and that a suitable point at which recovery could be assessed would be 6 months after surgery (this is the time point where patients are likely to experience almost maximum benefit from their surgery and is when the national Patient Reported Outcome Measures/PROMS data are collected). However, owing to impacts of Covid-19 (including initial suspension of elective surgery which exacerbated delays and waiting lists), this approach needed revision as it became apparent that the length of wait for knee replacement surgery had increased substantially. Across the sites in the study, and varying at different times, surgical backlogs at their height led to wait estimates of 12-36 months. The study design was revised to extend the data collection period and to undertake additional interviews to capture the experiences of those participants who had (more protracted than anticipated) waits for surgery.

As a result, and as shown in Figure 1, participants were interviewed up to three times each, with the timings of the second and third interviews based on the outcome of the surgical consultation (i.e. declined knee replacement surgery, or proceeding with this surgery) and next stages (i.e. waits for surgery). All participants had a 'baseline' interview, i.e. in the days/weeks before their orthopaedic referral consultation where the surgical recommendation would be discussed with them; at this stage, participants were undifferentiated in the sense that it was not known if they would go on to be offered and/or accept knee replacement surgery. Depending on the consultation outcome, a follow-up interview was scheduled for six months after the baseline interview if a participant (a) declined surgery, or (b) agreed surgery but were still pending having the surgery and on a waiting list. For those who had surgery (either within the 6 months of the consultation or later on), a follow-up interview was conducted 6 months after recovery.

Data collection ceased at the end of April 2023 and, at this time, some participants were still waiting for their surgery to go ahead or had only recently had the operation.

Figure 1: Diagram showing the interview patterns as based on patient circumstances regarding knee surgery.



As such, the overall number of interviews and their timings were tailored to individual patients' clinical journey circumstances. In order to identify the consultation outcome, surgery dates and other factors dictating the appropriate timing of the next interview (if warranted), the researcher liaised with participants in between interviews and tracked their updates.

The qualitative longitudinal design introduced an important temporal dimension to the research, in recognition that decision making is a process and not a singular discrete moment, and that it can change based on life circumstances and health changes over time – including during the wait for a listed surgery.

It also allowed us to explore hopes, fears, priorities and expectations as they changed over time and, for those who had surgery, during their recovery and as their former expectations unfolded in reality. Such an approach allowed us to explore patient journeys through and beyond their surgery, and explore how the decision to have, or not have, surgery affected perceptions of broader health and well-being over time.

All interviews were audio recorded with participant permission for transcription. In some cases, participants agreed to also have their interview video recorded, but this was not a requirement for participation in the study and it was at the discretion of each participant. The interviews took place between February 2021 and April 2023. All interviews were conducted by AM, an experienced qualitative researcher.

The interviews were in-depth and started with a narrative approach [21, 22], inviting each participant to tell us about their health and to highlight their own concerns and priorities. We asked follow-up questions to prompt reflection on issues raised in the narrative section of the interview, and a topic guide ensured that issues identified in the literature review, through our Advisory Panel and informed by previous interviews were covered.

Participants were asked broadly about their experiences of their health including but not exclusively with regards to the knee problems, including their thoughts on possible causes or contributing factors, the impact on their lives, treatments tried, and healthcare they have received, and their expectations or hopes for any future treatment and engagements with healthcare services.

The baseline interview topic guide included questions about, for example, communication and relationships with healthcare professionals, experiences of referrals so far (including processes, pathways, waits and delays), decision-making around investigations and previous treatments (including how decisions were made, and information given by healthcare professionals), views about conservative treatment outcomes, and expectations for the forthcoming orthopaedic consultation. Factors in decision-making around surgery, both past and potential, was a key topic.

The topic guide for the follow-up interviews asked about experiences of making a decision (for example, if knee replacement surgery was declined), of waiting for surgery and/or of recovery and outcomes from surgery. The topic guide for follow-up interviews also included participant-specific questions, depending on the content raised in the baseline interview – for example, if participants had mentioned investigations ongoing or anticipating a forthcoming change in medication. The complexities outlined previously for the study design with regards to the Covid-19 pandemic and the impact on the provision of knee replacement surgery became a key feature of the interviews, and participants shared their experiences of protracted waiting, challenges with accessing health services, and impacts on their wider health and social lives, including social isolation.

Whilst we sought to understand the clinical contexts and specifics of participants' experiences, our participant-centric approach meant that we accepted there may be gaps in the knowledge and understanding individuals could share with us (for example, about the exact timings of appointments and length of waits) and we did not have access to individuals' medical notes.

Data management and analysis

All interviews were transcribed verbatim and checked against the video or audio recording for accuracy. Participants were given the option to have their transcript returned to them to review and mark any sections which they would like to change. In addition, participants were given the option to see a short biographical summary based on their interview and written by the researcher, and invited to advise on whether it accurately reflected their key experiences and priorities with regards to the research topic. For participants who had more than one interview, this process was repeated each time and the short summary of experiences was expanded to integrate the material.

The transcripts were entered into a specialist software package, NVivo, to help organise and code the interviews. The interview transcripts were analysed using thematic analysis, with themes developed and refined as analysis continued across the collection of interviews [23]. Attention was be paid to emergent (unexpected) themes as well as those that were anticipated using the method of constant comparison [24]. This approach ensured that we identified the issues that were important to participants.

he process involved carefully reading the transcripts to become familiar with the data, coding the data and developing themes through a collaborative process of constant comparison. Each transcript was coded, which involves assigning short phrases to distil meaning, and the codes were then organised into themes around a central idea. An analytical mind mapping process was used to explore patterns and relationships in the data [25].

Results

Participant characteristics

We interviewed 44 people, with a total of 93 interviews conducted. Written consent was given by 42 individuals to use their interview data for qualitative analysis and to make direct quotes from their interviews. Pseudonym names for participants are used in this report. Descriptive characteristics of the participants are shown in Appendices 1 and 2.

Most participants were married or widowed, mostly aged between 70-75 years and over half were women. The oldest participant was 86 years old. Participants had a wide range of comorbidities, with cardiovascular conditions being dominant (Table 1). This included people with high blood pressure, heart conditions, such as mitral valve, atrial fibrillation and enlarged heart, high cholesterol and a previous transient ischemic attack (TIA).

All participants identified as White British, with the exception of one person as Indian and one person as White American. This is a limitation of our sample and has potential implications for our findings, with existing literature highlighting that there are ethnic differences in having joint replacement surgery [13, 26], including variation in patient attitudes and beliefs about knee replacement surgery [14]. We recognise that this means that we may not have captured all of the considerations and experiences around decision-making for knee replacement experienced by racially minoritised older people with multimorbidity in England. This may include experiences in terms of access to and preferences around healthcare services, treatments, information and support in relation to knee problems and other health conditions.

However, a number of potential disadvantages are represented in the sample, including those in relation to income/financial instability, health literacy, familial support (for example, those living alone and/or without nearby family), and carer responsibilities, in addition to varying degrees of disability and ill health.

At the point when data collection stopped (end of April 2023), 20 participants had knee replacement surgery with 6 or more months recovery since, 13 participants were still waiting for knee replacement (or had very recently had the surgery and were in a period of less than 6 months since the surgery), and 9 participants had declined knee replacement.

Table 1: Participant comorbidities

		Count
Co-existing health conditions (in addition to knee problems at baseline interview)	Cardiovascular (e.g. high blood pressure, TIA, heart conditions, high cholesterol)	33
	Diabetes	7
	Cancer	5
	Hearing problems	8
	Eyesight problems	12
	Lung conditions (e.g. asthma, bronchitis, chronic obstructive pulmonary disease/COPD)	7
	Vertigo/dizziness/fainting	3
	Digestive problems (e.g. reflux)	8
	Sciatica/nerve problems	2
	Arthritis (other than knee)	23
	Anxiety/depression/bipolar	10
	Overweight	13
	Urology (e.g. prostate, bladder, gall bladder)	6
	Kidney problems (e.g. chronic kidney disease, kidney stones)	3
	Blood disorder (e.g. MGUS)	1
	Thyroid problems	3
	Polymyalgia rheumatic	1
	Sleep apnoea	1
	Osteoporosis	1
	Spinal stenosis	1
	MS	1
	Neuralgia	1
	Previous knee replacements	9
	Previous joint replacements (other than knee)	4
	Previous surgeries (non-joint)	4

Findings

Structured around the research questions the study sought to answer, we present the following findings under four key themes:

(1) The relationships between, and views on priorities, regarding knee problems and multimorbidity;

(2) Weighing up benefits and risks related to multimorbidity in decision-making for knee replacement;

(3) Shifting health priorities whilst deciding about and waiting for knee replacement surgery;

(4) Multimorbidity and other explanations in sense-making about experiences of knee replacement surgery recovery and outcomes.

Theme 1: The relationship between, and views on priorities, regarding knee problems and multimorbidity

Interacting and exacerbating health concerns

All of the people we talked to were experiencing knee problems in addition to two or more other long-term health problems (see Table 1 for the variety of multimorbidities included). Whilst the recruitment process involved clinical sites screening for eligible patients and therefore the research team were aware that the all participants had an underlying diagnosis of osteoarthritis in their knee(s), many patients preferred to refer to their 'knee problems' rather than use the medical term 'knee osteoarthritis'. Indeed, there is abundant epidemiological evidence, for example, that many in the population have evidence on x-ray of sometimes advanced knee osteoarthritis, but have no clinical sequalae such as pain [27]. We use the phrase 'knee problems' where relevant in this report to capture the different experiences and viewpoints amongst study participants, centring their experiences on the symptoms and the impacts (problems) it had on their lives rather than only or purely on a diagnostic label of osteoarthritis.

Sometimes these conditions or concerns were seen by individuals as having little bearing on or relationship with their knee problems, but other people described there being interactions between their conditions and symptoms or accumulative impacts on quality of life. Having multiple conditions could amplify limitations and difficulties, or mean that a combination of impacts had a more substantial or far-reaching effect. In some cases, other health conditions also limited their access to resources for their knee problems; for example, Susan had a visual impairment and was frustrated that she was given a leaflet of physiotherapy instructions that she could not read.

Knee problems which restricted mobility, including because of pain, could make other long-term health conditions worse through lack of exercise or weight gain. There could be compounding impacts, for example where pain was felt in multiple locations in the body with potentially different underlying causes, which made it harder to cope. Mobility difficulties from pain or joint instability in the knee could be partially offset by using a walker, for example, but breathlessness – such as from chronic obstructive pulmonary disease (COPD) or heart problems – meant that how far a person could walk or participate in other activities remained limited. Some had gained weight since becoming less active and were worried that this and their inactivity could lead to diabetes or heart disease, or make their current health issues worse. Decisions about physical activity were also affected by worries about a greater risk of falls, which might lead to loss of independence.

A few people talked about mental health conditions that co-existed with their knee problems, which could influence and be influenced by one another. Restricted mobility could make existing mental health problems worse, such as triggering longstanding anxiety; it could also lead to new mental health problems developing, exacerbated by social isolation and hopelessness for some people. Poor sleep – caused by ongoing pain in the knee or triggered by actions such as twisting when getting in and out of bed, for example – further compounded poor mental health and wellbeing.

"I can walk fine, it's just when I go to bed I don't sleep. Because I can never get comfortable. The problem is not sleeping at night. That's the main problem rather than pain or immobility. Keeping me awake affects my general abilities. And you know, I'm an anxious person. And I'm not an anxious person in the daytime at all. But the minute I go to bed I start thinking about things and worrying about things. So yes, it affects, it provokes anxiety." (Margaret)

Anxiety, and more specifically health anxiety, was also further confounded by the context of the Covid-19 pandemic, with many people concerned about contracting the virus and/or the potential to overwhelm health services. Many people were either shielding for wider health reasons for themselves or their loved ones.

The healthcare journeys of participants in our study had often been impacted by Covid-19, including in terms of their experiences and understanding of referral pathways, adding in more delays and new layers of mental health impacts, including worry and frustration. The process for most participants had involved referrals which 'moved' them through primary care to consultation with a knee surgeon, with intermediary services in between. These referral pathways vary across the country and Covid-19 measures added new complexities at times, such as having virtual consultation and appointments over the phone which could make it harder for patients to keep track of who they were talking to and for what purpose. With regards to their knee(s), this could contribute to a sense of uncertainty, being in limbo, and frustration at having potentially repetitive or duplicated conversations with different healthcare practitioners.

The Covid-19 pandemic also impacted on healthcare widely – not only in terms of implications for knee referrals, appointments and elective surgery – which, for those with multimorbidities, could mean disruptions to their usual care for a number of conditions. In addition to being on long waiting lists to be seen about their knee, they were sometimes also on growing waiting lists to be seen about their other conditions or health concerns.

As such, for the people we talked to, there was often a build up of impacts across their multiple long-term health conditions – including review appointments that had been cancelled or significantly delayed. Some mentioned concerns about difficulties accessing their general practitioner (GP), for example if they could only do so virtually when they felt a physical examination was needed. A few people expressed concerns about potential interactions between the medications they took for multiple conditions and expressed a preference for deprescribing, but had not been able to get an appointment with their doctor to discuss changing or reducing their medicines.

Because of needing to take medications for their other health conditions, some people were reluctant to also take pain medication specifically for their knee problems. Many highlighted the number of medications they needed to take because of their different health conditions, including those to counteract side-effects, such as omeprazole to prevent stomach ulcers. Anne said, “I just rattle with all these tablets.” For those who were hesitant about taking painkillers, some instead opted to put up with a higher degree of pain and accept more limitations around, for example, physical activity and exercise:

"I don't take painkillers for them. No, I take enough tablets for my angina and all that. I can't be taking painkillers for my knees as well. Not unless, like I say, unless it got absolutely excruciating, in which case, I'd want the surgery then." (Chris, who decided not to have surgery yet)

Reluctance to take painkillers also related to health concerns in other ways for some people, including worries about the long-term negative impact of taking painkillers on their kidneys, liver and stomach. Taking different types of painkillers required a trade-off between the beneficial impact on pain and the negative impact of side effects. A few people had experienced allergic reactions to certain types of painkillers previously which limited their options and could make them more wary to use painkillers.

Although some people avoided painkillers altogether or took painkillers for their knees only occasionally when their pain was acute, others took pain medicine regularly throughout the day most days or every day. This was the case for some people who had multiple conditions causing pain.

Health priorities

Some people we talked to had been living with other health conditions for a long time but said that it was currently their knee problems that were having the greatest impact on their quality of life. Others had other long-term health conditions which were their focus and considered a higher priority than their knee problem. Health conditions could also interact with one another, making them difficult to unpick and the impact could be greater than the sum of the parts.

The balancing and juggling of health priorities varied and could shift over time and circumstance for an individual. How much priority people gave to their knee problems over their other health and wider life concerns depended on, for example, the symptoms involved and how disruptive they are or become. For example, a person might have joint problems affecting their shoulder, hips and knees, but the intensity of symptoms (such as pain) might be greater in one location, or the impacts of symptoms more substantial (such as on driving a car), dictating which was deemed their priority.

Other times, knee problems were seen by individuals as a priority not because they were necessarily the most disruptive in terms of symptoms or the most serious in terms of being potentially life-limiting, but instead because a solution was seen as more accessible or likely. For Gareth, who had heart problems and had lived with rheumatoid arthritis for many years, his knee problems were seen as the one condition he had expected could be "fixed" through knee replacement surgery.

Some people had been asked to decide between having surgery on their knees or on other arthritic joints, such as their hips and shoulders. In some cases, this was a matter of which joint first, or it might be hoped that an improvement in one joint (such as the hip) would benefit another joint (such as the knee). Differing levels of pain and function based on the joints were also weighed up, with the knee seen as vital to mobility and maintaining independence, including through driving:

"But it was a choice between my knee or my shoulder; although my shoulder has been ongoing longer, I thought if it was better to have my knee done because I need to walk. [...] I've got to have mobility otherwise, what happens, I might have to end up in a care home and really I don't want to do that unless it's absolutely necessary." (Alison, who also has arthritis also in her shoulder, ankle and hands)

In addition to their own health context, being a carer for others also affected and was affected by knee problems for some people. This included being a carer for an unwell spouse and/or adult children, with degenerative conditions or life-limiting disability. Knee problems could make it more challenging to manage their caring roles and, at the same time, influenced their decision-making around surgery because of the need to be fit enough to be a carer.

Compartmentalised health

Many people recognised that health services are often set up in a way which compartmentalises their health conditions, concerns or body parts. When people felt confident that there was little overlap or impact connecting two of their conditions or health concerns, this did not cause any major worries for them.

However, when people felt concerns ought to be taken into account in the context of other conditions or that conditions should be considered together, this could lead them to feel frustrated or disappointed at the lack of a more holistic approach towards health and illness. Margaret feels such situations would be better for patients if healthcare professionals and services looked more at "the whole person."

The way that different healthcare specialities and teams shared (or did not share) information with one another was complicated. Some found there were difficulties when health problems were compartmentalised into specialist departments, teams and even across different hospitals as this often meant that they – as the patient – had to be the bridge between them.

> "I was concerned of course the fact that I am on warfarin, and that would have to be adjusted, again we did have this little bit of confusion before my bladder procedure about the warfarin, as I say I was told by the hospital that did the op themselves that I just had to stop the warfarin, and nothing else was necessary. I was then told by my cardiology hospital, "No that's not the case. You, you must have something in, in the meantime." And I felt, I was a little bit like piggy in the middle. However, I did-, I always take medical advice, but I was given two conflicting pieces of medical advice on this, on this occasion." (Ed)

Additionally, some people thought, or had it suggested to them, that the knee problems they were experiencing were actually stemming from another health condition or location, such as problems with their hip that was translating into pain and changes in how they walked which was causing the issue.

"They looked at the whole of my lower body and they said that really one of the problems is affected by the other, and vice versa so they try-, and when they put you through these operations, they try to straighten you up a bit, so if I have my knee done it will affect how my hip is, and if I have my hip done first it will fix how the knee is so we've got to balance the two somehow. He reckoned that they would be probably six months apart and they would make the decision which one was done first. (Steven)

Again, communication and navigating health services was a challenge when a specialist might rule out a problem in the knee and suggest it was to do with another part of the body which meant a new referral needed to be made – but it was not always clear who would be initiating this.

Chapter summary

For the people in this study (aged over 70 years), having multimorbidity in addition to knee problems often compounded the challenges they faced. Many found it further detrimentally impacted on their quality of life. They recognised that some multimorbidities could add to their knee problems or vice versa, or influence their attitudes to medication, for example. The challenges of accessing healthcare during the Covid-19 pandemic could have further ramifications, for example with delayed or cancelled appointments for other health concerns and conditions.

Theme 2: Weighing up the benefits and risks related to multimorbidity in decision-making for knee replacement

In making decisions about whether or not to have knee replacement surgery, the people we talked to raised a wide range of considerations that they balanced with one another. Most people had the expectation that the existence of their other medical conditions might affect whether and how knee replacement surgery would be recommended by a surgeon, and that it could impact on the likely benefits and risks of knee replacement. However, their focus was primarily on the risks associated with the surgery itself and in the immediate recovery period; less consideration in the decision-making processes of participants was given to whether their existing health conditions might negate or limit the anticipated benefits of a knee replacement in the longer term.

As per our longitudinal design, we first interviewed people before they had seen an orthopaedic surgeon to discuss the prospect of knee replacement surgery in their current referral – although most knew a discussion about knee replacement would be a likely feature in their forthcoming appointment. As such, many had thoughts about the pros and cons of having knee replacement surgery, in which their multimorbidity – alongside other considerations – were factors. Other people described a sense of equipoise in their first interviews, suspending their expectations about whether or not knee replacement would be recommended in the context of their age and other health conditions. Many expected, and found it to be the case, that if knee replacement surgery was recommended, they would then be asked at the consultation to indicate whether or not they wanted to proceed with this.

Patient perceptions of what was and was not a relevant multimorbidity in relation to knee replacement surgery and outcomes did not always align with clinical views. Sometimes concerns the participant expected would be raised by the surgeon as having an additional surgical and outcome risk were not flagged, while others – less expected – were. For those participants who took part in two or three interviews, we were able to compare expectations about the relevance (or not) of multimorbidities across different time points.

The longitudinal approach sometimes highlighted where beliefs about, and framings of, the relevance of multimorbidity changed over time and with further clinical encounters or, alternatively, persisted. This was the case for Judith with regards to weight; she expressed concern that she might be declined surgery unless she lost weight and she had expected her surgeon would discuss it at the appointment. Weight management had not been raised in the appointment, though she continued to make this a focus of her preparation for the knee replacement surgery.

Hoped for benefits

Unsurprisingly, it was always hoped that knee replacement would overcome or reduce the knee problems; typically, this involved reduced pain levels and/or less reliance on pain relief, and more stability in the joint and/or less reliance on mobility aids. The extent of this anticipated improvement and how it would translate into their lives in terms of what they hoped they would or could do (or do with more ease), however, varied. For example, some people recognised that they might not be pain-free but hoped to be in less pain overall.

Many of those who elected to have surgery thought that improvements in their knee would also mean improvements for their other health problems. Keeping active was important for people who also had high blood pressure or heart-related conditions or who were overweight. Tom and Alison hoped being more mobile would prevent their health declining, avoiding them "sitting in the chair all day" and a further loss of independence.

Some people experiencing pain in other parts of their body, such as their hips and back, thought that their current knee problems might be causing them to walk or otherwise use their body differently, which was in turn creating or adding to the pain in other joints. As such, there was a hope or expectation that knee replacement would translate to moving more easily and in better alignment for their body, and this in turn could reduce or eradicate the pain elsewhere.

> "I'd like to go walking properly on the moors. That's what I'd like to do. Get fitter. More exercise. Because I think, the more I walk, the more the muscles will support my spine, I'll get fitter, it should help my spine, but I'll have to walk through the pain to do it. But if I haven't got pain in my knee and in my back, and I'm not worried about my knees giving way, then I'll be able to do it better." (Fran)

Those who were carers for loved ones acknowledged that physical demands could be all the harder with knee problems and they hoped that knee replacement would ease this. However, the prospect of having and recovering from knee replacement surgery presented challenges, for example, in finding alternative care arrangements. Living alone was also a consideration for some people when making a decision about surgery.

This included recognising the possible dangers if their knee gave way and they had a fall, balanced with the anticipated challenges of recovery after surgery.

Concerns about risks

Whilst hoped for benefits for their wider health were included in participants' views about the prospect of knee replacement, more often their focus was on the potential risks and added complications of their other health concerns. Some of the conditions people had, such as high cholesterol and high blood pressure, are common amongst older people and, when managed well, are not typically considered a significant additional risk for knee replacement surgery. Other conditions can increase the risks associated with knee replacement surgery, in terms of operative outcomes, anticipated recovery and overall success metrics. For some, including those with heart problems or undergoing investigations for cancer, their other health conditions were of great concern and they recognised that knee replacement surgery may not be recommended as a result.

Worries about having a general anaesthetic were common amongst the people we talked to, and a major focus when discussing potential risks of having knee replacement. Some people were advised that their other health conditions would increase the risk of problems from a general anaesthetic, and some were instead offered an epidural. Fran thought that her general health and her low blood pressure after a previous knee replacement operation increased her risk if she had another knee replacement. Andrew was advised not to have a general anaesthetic for his second knee replacement surgery because of his history of heart and vascular problems and low sodium levels after previous surgery.

Despite being perceived as less risky than a general anaesthetic, an epidural still caused worry for some in relation to other aspects of their health. The thought of being awake for the operation could be very off-putting, and Tom was "absolutely petrified" about the thought of having a spinal injection. Additionally, Jane, who has chronic obstructive pulmonary disease (COPD), was worried about lying flat for the surgery as she found it a struggle to breathe. She felt frightened for the operation and thought it would be better for her not to be awake.

Perceptions of mortality risk varied amongst participants who discussed the topic, but it was overall an area of limited detail in our data. For some, views on mortality – the likelihood and whether they felt it was an acceptable risk – were sometimes challenging to decipher. Some recognised that death was a risk of the surgery and described how this risk featured in their decision-making alongside other potential risks and benefits; as Susan plainly put it, "I don't want to die under the anaesthetic". She went on to give an example of an anaesthetist seen for a different operation who was dismissive about her concerns and assumed she would be accepting of the risk: "he really upset me, he said, 'I expect at your age you're philosophical about death,' and I thought that was an appalling thing to say."

Other participants offered up views which implied that quality, rather than quantity, of life was a priority for them, and felt that suffering in pain or distress was a worse outcome (including in relation to potential other surgical risks, such as disability following stroke).

For most participants, however, the potential risk of death from knee replacement surgery was largely absent or only briefly acknowledged in the interviews. The lack of detail on views and feelings about mortality risk in our data may speak to the view that it was not seen as a particularly relevant or likely risk by participants, and therefore not a topic they offered up or elaborated greatly on, but, conversely, it may have been an 'elephant in the room' in participants' concerns and one so significant that it was difficult to think about or put into words. Where a sense of discomfort with the topic was perceived by the researcher amongst some participants, discussion of the topic was managed carefully to maintain rapport in the interviews.

Past experiences of hospitals, surgeries and recoveries

Previous and ongoing experiences of operations, healthcare teams or hospitals could affect how people felt about the prospect of having knee replacement surgery. Previous good experiences of healthcare positively influenced decisions, as was the case for Ed who felt he had received exceptional care for heart problems in the past: "I feel that I've been most fortunate and I'm just hoping and praying that fortune is going to continue with my knees." For those who already had knee or other joint replacements, the experience of recovery and outcomes were influential; if it had gone well and they were happy with the result, their outlook was positive.

However, difficult and upsetting memories of past surgeries or recoveries could heighten fears:

"I don't seem to come through things easily as you've probably gathered, with even the cataract starting it all off. And that's what they consider to be probably the simplest operation going these days. Then the mitral valve left me in a complete and utter mess and, not only that, but was only partially successful. And then I'm not that happy with how my eye looks and feels from the glaucoma operation. So, and there's smaller things as well. Things don't quite seem to go as they're meant to go. So yes, I do have some anxiety about that. And obviously the longer everything goes on, I'm getting older and older." (Elizabeth, who had a partially successful mitral valve operation and complications following an operation for glaucoma, as well as a previous TIA and ongoing issues with an underactive thyroid, allergies and perennial rhinitis, blepharitis, and coeliac disease)

Some people had also experienced visiting a loved one in hospital, for example for palliative care, and the prospect of returning to and spending time in hospital could trigger concerns about having the knee replacement surgery.

Compartmentalising other health concerns

Whilst the risks and benefits regarding multimorbidities was discussed by most participants in terms of the operation and immediate recovery, some suggested it was outside of, or even superfluous to, their decision about whether or not to have knee replacement. A few people said that they thought their other health conditions were unlikely to be relevant to knee replacement surgery, or that the increase in risks for them was negligable.

A normalisation and acceptance of risk was implied when individuals emphasised that 'all' surgeries, or even everyday activities such as crossing the road, entail risk, and that this was no different. We found that questions around risks and the balance with benefits could be bracketed or even shut down in the interviews.

Some people suggested their other health conditions were not relevant to the prospect of having knee replacement surgery and utilised a type of bracketing or compartmentalisation in how they thought about their body. This included examples of participants suggesting that health problems affecting different parts of their body were unrelated because the body parts were not proximate to one another; for example, that heart problems should not be a concern when thinking about having knee surgery as the heart, as a discrete organ, is not near the knee joint. Such an example highlights how patient perceptions of the relevance of multimorbidity and risk could be at odds with that of clinicians and medical knowledge, which would recognise complications and vulnerabilities in a patient's cardiovascular system as highly relevant to surgery risks. Patient views could, however, change, for example following a discussion with a healthcare professional about anaesthetics in which the cardiovascular risks of knee replacement surgery are highlighted as relevant.

Some patients described trying not to think too much about the additional risks of having knee replacement surgery associated with their other health conditions, because they felt there was little alternative if they wished to have longer term benefits of a knee replacement.

Betty, who had had six knee surgeries before and has type 2 diabetes, said she tried not to let her previous experiences of having a spike in blood sugar levels and high blood pressure immediately after surgery affect her decision on revision knee replacement surgery too much because she saw a revision knee replacement as "the only way around this and I've got to have it done." This approach could embody both an acceptance of risk and a reluctance to think in detail about risks. Given the compartmentalisation of health services and concerns outlined previously, it is perhaps unsurprising that patients sometimes focus on their knee in isolation from their wider health when thinking about the decision whether to have knee replacement.

Furthermore, some participants suggested that knowing about risks in relation to multimorbidity was not their responsibility and that they deferred trust to the surgical team. They expected that they would be told by the surgeon if their other health conditions and medications meant there were extra risks for them. There was a high degree of acceptance for the expertise of the surgeon and surgical team, and a belief that it was the responsibility of healthcare professionals to weigh up the risks and benefits with regards to a patient's multimorbidities. There was a sense that knee replacement surgery would not be offered if the risks were too great because the surgeon would not permit it, though there was little detail with regards to where the boundary between acceptable and unacceptable risk might lie.

"As long as it's a clear-cut decision. If he says, "I think you need this and I think you would benefit from this and I think that you are not going to be put at any great risk, more than what it would be." There's always a slight risk with every operation but, "You're not going to be put at any undue risk because of your, your heart," then I would I would say, "Yes," I would. But if [the surgeon] said, "Oh well I'll do it if you really want me to but you really ought not to be having this operation with your heart," then I would probably say, "Well in that case, I'll live with my knee." [...] I mean I want my knee done but I want to be alive after this operation. I want to, you know, I yes, I want to come through it, I want to come through it safely I think is what I'm saying and to be able to pick up my life again." (Joan, who was in her late 70s and has atrial fibrillation, problems with her vision, bladder problems and high cholesterol)

Chapter summary

In deciding whether to have knee replacement surgery, patients weighed up anticipated benefits with risks associated with their multimorbidity, including the operative and anaesthetic risks, amongst other factors. Some patients in this cohort did not seem to be aware of the relevance of their existing multimorbidity for knee replacement surgery outcomes, meaning that their expectations may not be aligned with likely outcomes and limitations.

Theme 3: Shifting health priorities whilst deciding about and waiting for knee replacement surgery

Decisions and views on the factors involved in decision-making for knee replacement surgery could shift and change over time, circumstances and in light of new information – particularly with regards to multimorbidity. Participants described how this had happened for them across potentially years of expecting that they might need a knee replacement and well before a referral was even made. Some described the shifts involved in their thinking and evaluation of risks and benefits around their other health priorities which influenced how and whether knee replacement surgery became more feasible for them:

> "I delayed my [knee replacement] operation for a long time because I wanted to avoid any surgical procedures because I didn't want to put my heart at risk, you see. But then my mobility got so bad that I've not been able to go out [... which in turn] would have made my heart worse. Yeah, you've got to sort of weigh up the pros and cons" (Ravinder)

The relevance of an individual's other co-existing health conditions in terms of risks and outcomes for knee replacement was sometimes recalled as being part of the conversations with healthcare professionals across many years but, due to the number of discussions and amount of time elapsed, specific details were often vague in people's memories. Other times, there was no recollection of these types of discussions or considerations being raised.

For some, there was a sense that conversations about the relevance of multimorbidity on knee replacement surgery and likely outcomes would be better placed to be held later 'down the line' and nearer to the time of having the surgery. As such, whilst the potential for and benefits of knee replacement surgery had been a presence in people's awareness for many years, discussions about the relevance and risks of comorbidities had not necessarily been.

Changing views and decisions

Over time and for different reasons, some people in the study revised the decisions they felt they had made or expected they would make. There were people who, in the baseline interview which took place before they had seen a surgeon to find out if knee replacement surgery was recommended, expressed a high degree of certainty that they would agree to knee replacement if it were offered – but who later declined the surgery. There were a number of reasons for a change in views or leanings towards a decision to have surgery and included a change in health priorities in which the knee problems came to be ranked lower, including with new risks or concerns highlighted from further medical investigations. Some cited further reflection, or discussions with family members, which placed greater emphasis on the risks over benefits of surgery, or made them re-evaluate whether the impacts of their current knee problems were manageable. For some, changes in views around decisions was based on challenges around care roles for loved ones for whom alternative arrangements could not be made.

"I've got other health problems. [...] It just didn't sound a good idea and if I'd had sepsis or anything else, if I'd had any infection, and being diabetic, you're likely to get more infections, which I knew any rate, so it was a foregone conclusion really, but you live and hope, don't you?" (Fiona)

Sometimes this was a patient's decision, other times it was that of the surgeon in concluding that the risks of surgery in the context of multimorbidity were too great; patient and surgeon views often aligned, but not always.

The ranking of health concern priorities shifted in particular when people received new life-limiting and life-threatening prognoses. Ed's recent cancer diagnosis was a big worry for him and overtook his concerns about his knees. Patrick's priorities shifted away from his knee problems after having a heart attack and being diagnosed with lung cancer. When he felt that these health concerns had become well controlled, he was able to re-consider knee replacement surgery, although he worried that his other health problems would make surgery riskier.

Of the 9 people declined surgery at the time of, or shortly following, their referral appointment, some thought they might revisit their decision in the future, highlighting how the balance of perceived benefits and risks can continue to shift. This included those who, after being advised by their surgeon, decided that the risks of knee replacement surgery were not worth taking currently whilst, for example, they felt they could manage the symptoms in other ways, for example with conservative treatments.

At the age of 86 and with other health conditions, Susan felt that surgery was an "unnecessary risk" when steroid injections were currently working to manage her knee pain. David had been waiting to discuss the possibility of revision surgery on his knee but decided to cancel his referral appointment after re-evaluating his pain levels as manageable and he instead planned to reduce his weight first and then decrease painkillers to see if it helped.

The shifting health of relatives and loved ones was also relevant. Chris decided not to pursue knee replacement surgery because of caring commitments, but said he would still consider it as an option in the future if his pain levels increased:

> "I think they'd have to deteriorate to the point where they were giving out or locking or something, and then I would have to take the plunge somehow or other, you know. [...] And that [not having surgery yet] seems to me to be the best option at the moment. The most influential factors would be the length of time you're off doing anything after the surgery because my wife can't drive. And also [wife]'s situation in the night time which, with her nightmares, I'd be just worried sick for her, if I wasn't there." (Chris)

Protracted waits for surgery

Older people making decisions about and/or waiting for knee replacement surgery during the Covid-19 pandemic faced long periods of waiting and delays, some stretching across several years. There was an initial suspension of elective surgery which exacerbated existing surgical backlogs, delays and long waits for patients considering knee replacement.

Many people conveyed a sense of being in limbo, feeling unable to make plans and commitments for the future which were dependent on knee function, potential surgery dates and sufficient time for recovery. Some struggled with declining knee function and increasing symptoms such as pain and instability as they waited for surgery, which was frustrating and disheartening:

> "My knee was slowly deteriorating, but about three months before the actual op there was a rapid deterioration, I could hardly walk a few paces, I was in- despair is not the right expression - but I was anxious, let's put it that way." (Ed)

Long waits for surgery involved worries that new health problems might emerge or existing ones might deteriorate further, which would affect the balance of benefits and risks of having a knee replacement. In light of this, many people described trying to keep well during the wait but, in the context of Covid-19 and impacts on health services more widely, this could be challenging.

For those who were waiting a long time, it was common for people to say they had little or no communication from the surgical team. They worried that they may have been forgotten or dropped off the list, which compounded their concern about their knee deterioration and impact on their quality of life.

Additionally, our longitudinal approach was based on patients moving through pathways from primary care to consultation with a knee surgeon, often with intermediary services in between, which could add to the sense of having a long care journey.

Whilst pathways vary across the country and were impacted by, for example, Covid-19 measures, study participants were often unsure about who they had seen and for what purposes or what the next steps were in the lead up to seeing a knee surgeon. This contributed a sense of uncertainty, being in limbo, and potentially repetitive or duplicated conversations with different healthcare practitioners – all aspects which formed the background to their experiences of and expectations around decision-making for knee replacement.

Some people experienced changes in their other health conditions whilst they were waiting for appointments or knee replacement surgery. An accumulation of health problems made waiting for knee replacement even worse. Daniel developed blood pressure problems and vertigo while waiting for knee replacement surgery. He was worried about managing the side effects from his medications alongside his knees. Sometimes additional health problems were a result of further decline of the knee, as was the case for Paul who required emergency surgery for his shoulder after seriously injuring it in a fall.

Some people who developed new health conditions during the wait for surgery then needed to have treatment or other operations before their knee replacement surgery could go ahead, which could add extra time to the wait, including referrals to other specialists and awaiting test results. For others, treatment for new or flare-ups of existing conditions could wait until after knee replacement surgery and their recovery.

In some cases, plans for knee replacement surgery were postponed. During her preoperative assessments, Joan discovered she had a heart murmur which led to her knee replacement surgery being postponed.

The surgery eventually went ahead and Joan is very pleased with the outcome, even though a back injury made her recovery more difficult. When Ian was diagnosed with kidney cancer, he was taken off the list for NHS-funded care at a private hospital and put back onto the list for his original NHS hospital. At the time of the interview, he was still waiting for his surgery. Whilst waiting for his pre-operative assessment, Nick had another problem with his heart which resulted in a privately funded ablation and his knee operation was delayed, but he feels the surgery went well.

Other people had knee replacement surgery plans cancelled when they developed new health conditions. Fran's heart problem worsened whilst waiting for surgery; after having three heart attacks, triple bypass surgery and an infection in her leg, her knee problems became less of a priority and she recognised that she was not well enough for surgery.

Long periods of waiting between appointments and for surgery could add to or create mental distress including anxiety for some because it gave them additional time to worry about the risks of the operation. A few people who had agreed to have knee replacement surgery then questioned their decision and worried about what to do. This could then generate a desire to discuss it again with the surgical team but, in the context of Covid-19 restrictions and waits for appointments, this could be difficult and misaligned with service pathways. Betty was considering revision surgery – a decision which she had been weighing up for a long time; she had attended a number of appointments but not always with the same surgeon, and felt she needed continuity of specialist and more information: "it's been left very much up to me [...] it would be nice to just be able to talk it through with somebody who knew what they were talking about."

With recognition of the long waiting times to see a knee specialist to discuss knee replacement on NHS pathways and worries about both knee and wider health deterioration, some people we talked to had opted to pay for a private consultation with an orthopaedic surgeon. Some also considered paying to have the operation privately to avoid long waits for surgery. Others had investigated the cost of paying for surgery but it was not affordable for them or they felt they should not have to pay on principle because of having invested in the healthcare service through paying taxes. For some, paying for private healthcare was not financially feasible.

In an attempt to reduce long waits, some hospitals had arrangements for knee replacement surgeries to be carried out privately but funded through the NHS. We talked to people who had been contacted about this arrangement. A few had agreed to be referred to a different hospital but then this was rejected because of their other health conditions or previous treatments. Sometimes these conditions were pre-existing to their orthopaedic referral, and others developed new health concerns whilst waiting for surgery.

Elizabeth's original surgery was to take place in a private hospital, to be paid for by the NHS, but it was cancelled because the results of her MRI and echocardiogram meant that she was required to have the operation in a hospital with an Intensive Care Unit or High Dependency Unit. This was confusing and disappointing but, after being transferred back to the original hospital's waiting list, Elizabeth's surgery appointment was eventually booked in at short notice. Ed learnt that he was not eligible to have his operation sooner because the alternative hospital he had been referred to did not have a cardiology department in case of any issues with his implantable cardioverter-defibrillator (ICD).

Whilst long waits for surgery were not welcome, nor was the uncertainty of when a surgery date might be given which made planning ahead difficult, having some time to make preparations could be helpful. It could give opportunity to prepare more for care arrangements and preferences anticipated post-surgery. Julia was able to have her bathroom refitted to make it easier to wash, both whilst waiting for surgery with her knee problems and in anticipation of her recovery after the operation. Others looked into and booked arrangements for meal deliveries, sourced alternative toilet facilities such as bedpans, and asked for or gave more notice to family members who might be able to help (for example, with transportation to and from the hospital, and with live-in support in the first few days and weeks after surgery). These affordances, however, required people to have sufficient resources in place, both in terms of finances (to afford the changes made) and social (to have family who were able to offer help).

Those who were carers to others also considered alternative arrangements, though booking formal care for their relatives was challenging as it required both specifics (for example, about when their surgery would go ahead) and advance notice, which they could not always give when waiting for a surgery date and when surgery cancellations were possible.

Chapter summary

Views on, and commitments to, decisions about having knee replacement could shift over time, for example with changes in ill health, which was a particular concern for this cohort in the context of long waits for surgery due to Covid-19 restrictions.

Theme 4: Multimorbidity and other explanations in sense-making about experiences of knee replacement surgery recovery and outcomes

Amongst the 20 people we talked to who had knee replacement surgery, there were mixed views on whether it had been successful. For some people, knee replacement surgery had transformed their everyday and given them a "new lease of life". There had been a considerable improvement in what they could do after knee replacement and, after the initial recovery period, a marked reduction in pain. Being able to walk again could completely change quality of life and make it feel well worth going through surgery and recovery. This included those who felt it had helped shore up a healthier future and reduce the accumulation of multimorbidities:

> It was just that painful and that restrictive, it really was. Instead of being 70, I [felt like I] was 90. [...] I want the last years of my life to be mobile, and now, I cannot stop expressing the transformation in my life of this, and being pain-free, and regaining mobility. My own personal wellbeing, and mentally I've improved. [...] Every morning you sling your leg out of bed and stand up and you don't have to go through 10 minutes warmup, frightened to put your knee down." (Paul)

People who said there had been an improvement in their quality of life since knee replacement often also talked about benefits to their other health conditions. Walking better and getting more exercise improved overall general physical health for people we talked to, which was of particular importance to those who had heart conditions. Pain or discomfort in other parts of the body caused by walking awkwardly for a long time had also improved for some people after knee replacement.

Mental health and wellbeing had improved considerably for many people:

"I feel much more positive. Because, before I went in [for knee replacement surgery], I was getting quite depressed because I thought, as I said, I don't like painkillers, and the pain was so bad I thought 'where's this all going to lead, if I don't want to take painkillers and this pain is so bad, and I'm moving less and less, I can't walk as far, I was getting quite down'. So now, I'm much more optimistic about the future, whatever future I've got, I mean you have to be realistic I suppose when you get to 85. But it's made a real difference to my life and my mood." (Helen)

Some people felt they were now better able to cope with their other health conditions and caring responsibilities as a result of the improvements in their knee:

It has helped, I mean, I've still got asthma and sinus and eczema and all of that good stuff, and the main thing is looking after my husband with Alzheimer's which is exhausting. But I'm managing because I can walk now, I'm not having to think, 'Oh my goodness I can't make it to the kitchen,' or you know, 'I've got to go up those stairs,' or all of those things, it's fantastic. So yeah, it's really, it's literally changed my life, it's fantastic." (Caroline)

However, knee replacement had not had the expected outcomes for some people we talked to. For a few, there had been little change in their overall mobility, knee stability and/or pain levels; this included those for whom other health conditions impacted on these aspects. Debbie and Anne both said they had little change in their overall mobility. They both still used painkillers and mobility aids to manage their knee problem. Eleven months after surgery Debbie's knee was still very painful and swollen which affected her mobility. Anne could only walk a few hundred yards unaided and relied on strong painkillers. Daniel did not feel any more confident walking after his knee replacement, as it highlighted that it was also his other leg that was causing problems with tripping over; this was being investigated in relation to possible nerve problems. Jen still feels unsteady coming down stairs which she thinks is because of instability in her other knee.

Some people were still limited in their mobility following knee replacement surgery because their other health conditions were affecting their ability to walk or stand for long periods of time. Although Richard had seen improvements in his knee function following knee replacement surgery his pre-existing back pain still affected his walking and ability to stand. Tom's knee replacement surgery had a good outcome but a new sensation of electric shocks down his legs and problems with his balance were affecting his walking.

Some were disappointed with specific limits, such as not being able to kneel on the replaced knee, or the slowness of their recovery. Some who had been expecting to have both knees replaced now felt apprehensive about having their other knee done, anticipating another gruelling or frustrating recovery, or decided they did would not go through the surgery again.

When reflecting on the outcomes of their knee replacement surgery, and how it did or did not meet their expectations and hopes, some people had ideas about what might explain their outcomes, such as the impact of new and existing health conditions, including those related to complications from the surgery and during recovery.

A significant detrimental factor influencing experiences of recovery and views on outcomes was the development of new, or flare-ups of existing, health issues during the crucial period of recovery from surgery. More often than not, these health concerns were highlighted by patients as explaining why their recovery was slower, more painful, backwards and forwards, or stalled. New health concerns or complications following the surgery were often raised as explanations for these experiences of recovery and outcomes from the surgery. In some cases, newly developed health concerns made it challenging for participants to articulate whether there was also an impact from their previously existing health conditions or flare-ups of these, or the weighting of different contributors. Joan's recovery had been slower because of a recurrence of her back problems three or four weeks after her knee replacement surgery. Daniel felt less confident in walking, as his other leg was causing problems with tripping over. Debbie had a heart attack which added to her concern over her slow recovery.

Not everyone felt their other health conditions were relevant to their experiences of recovery or their sense of satisfaction with their knee replacement, and other explanations were proposed. Delays to treatment can lead to worse outcomes for patients, and a few patients in our study thought their recovery took longer because of the long wait for surgery during which time their knees had badly deteriorated alongside decline in other aspects of their health.

The impact of the Covid-19 pandemic on NHS waiting times for knee replacement was recognised as a factor in delays for knee replacement surgery.

Other explanations offered by patients concerned the surgeon's skill, methods and/or equipment (with those who had robotic-assisted surgery suggesting it had contributed to successful outcomes), timely (or not) access to physiotherapy, and post-operative discharge support (or the lack of such support). Debbie felt a contributing factor to her poorer outcome had been leaving hospital too soon after her knee replacement, with little to no support at home nor follow-up appointments. Anne thought a three-week delay in having physiotherapy affected the speed of her recovery from total knee replacement – a surgery which, she was later told, had turned out to be more 'complex' in her case. Others reported not having timely access to support aids post-surgery, such as crutches or toilet frames, or having the aids but without instruction and guidance meaning they had not used them or later realised that they had used them incorrectly.

Physiotherapy was highlighted as a key explanation for outcomes. For those people who felt they had received good physiotherapy support after surgery, this was usually depicted as helping their recovery. Those who felt the support received was poor or more delayed than it should have been often suggested this as the reason for poor satisfaction with their knee replacement. A few people highlighted the value of prehabilitation (support with getting ready and fit for surgery), either through organised physiotherapy or by exercising by themselves. Debbie attended a physiotherapy course which she felt had strengthened her knee muscles in preparation for surgery.

Patricia did physiotherapy exercises at home which had helped with her knee stability. Gareth, Caroline and Ravinder felt strengthening their knee through exercise before surgery had contributed to their positive outcome.

> "I've been told to walk and you know get it as, as fit as I possibly can, so that you know and because it's, because the knee isn't very good you can sit in a chair and sort of say "Oh I'm not doing anything cos my knee hurts." You know that's an extreme sort of case, but in actual fact the thing is you should keep going. And get it toned up so that it's, it's as ready as, as it, well at 86 it's about as good as it could be at 86 for the op." (Gareth)

However, more often than not, most participants did not recall having prehabilitation support offered and more generally pre-surgery physiotherapy was negatively framed by participants. Poor understanding of the benefits of physiotherapy as a conservative treatment and in prehabilitation, plus a lack of understanding about the role of the Musculoskeletal First Contact Practitioner / Extended Scope Practitioner and the reason for referral to them led to some people feeling they were being side tracked or 'fobbed off' when they wanted to be considered for knee replacement surgery imminently. The sense that physiotherapy was inadequate to address the knee problem sometimes endured, and may explain views on its potential prehabilitation; most of the patients we talked to were either unaware or not interested in physiotherapy once a surgical referral appointment had been made. This suggests missed opportunities to optimise knee replacement outcomes.

Chapter summary

For those who had a knee replacement, making sense of their recovery and outcomes included understanding the potential role of multimorbidities. Health problems that had emerged since the surgery were more often proposed as explanations for poorer satisfaction, as well as their pre-existing conditions. Other explanatory factors for recovery outcomes included concerns about 'too early' discharge from hospital and difficulties in accessing post-operative physiotherapy support.

Key conclusions

Our findings highlight the myriad ways that an individual's wider health and social context, including their coexisting multimorbidities and past experiences of surgeries, accompanies them as they make decisions about whether to have knee replacement surgery and then in their sense-making around recovery and outcomes. The people we talked to came to different conclusions about their own situation as to whether they felt knee replacement would be or had been 'worth it' for them.

In making decisions, they drew upon benefits and risks in relation to their other long-term health conditions, considered any caring commitments to loved ones with health concerns of their own, and their previous experiences of surgeries and healthcare. These factors and wider contexts influenced individuals' evaluations and weighting of these potential risks and benefits, and this process shifted over time with, for example, their changing health concerns. Furthermore, for those who had knee replacement surgery, multimorbidity continues to shape and impact on patients' recovery, and their perceptions of whether and why they are satisfied with the outcome.

The role of multimorbidity in decision-making and sense-making about knee replacement is not static, and our longitudinal study design allowed us to capture some of the ways in which these could shift, including with the onset of new concerning symptoms and diagnoses or declining health more generally. It also highlighted how views could fluctuate, both in relation to changing information with new healthcare encounters, and how multimorbidity presents an area of uncertainty for patients where clearer guidance and communication across knee pathways from healthcare professionals could be beneficial, including about likely wait times between appointments and listing for surgery (if relevant).

Multimorbidity concerns were important to these patients in their decision-making for and sense-making following knee replacement surgery, but in varied ways. The prioritisation and impacts of wider health conditions and concerns for older patients considering knee replacement are not monolithic nor static, and our longitudinal approach allowed us to capture some of the ways in which these could shift, including with the onset and emergence of new concerning symptoms and diagnoses or declining health more generally. This is particularly relevant in the context of long waits for surgery in this population as for this cohort were exacerbated by the Covid-19 pandemic.

The study sought to understand participants' decision-making, and subsequent reflections on whether decisions were the 'right' ones, with recognition that these can be influenced by past experiences as well as ongoing changes and expectations for the future. Views on decisions can be simultaneously rooted in the past (referencing discussions and conclusions from previous healthcare encounters and interactions), deemed to be inevitable (that there is no choice and is already a foregone conclusion), ongoing (with a shifting balance of weighing up risks and benefits, and expectations about outcomes in light of other health and social situations), as well as incorporating projections for future health and quality of life (short and long term).

Recommendations for practice and policy

The study highlighted some of the ways that patients' informational and support needs are not always being met in health services for their knee problems. This included suggestions from study participants themselves about where improvements might be made, as well as our interpretation of where there seemed to be important gaps in their understanding or common misconceptions held. Healthcare professionals traditionally have adopted the role of advising patients on the potential impact of their multimorbidities on, for example, the benefits and risks of knee replacement surgery; this study considered how patients perceive multimorbidity related risk and benefit at different temporal points and how they can change (e.g. those views held before the appointment to discuss whether knee replacement surgery is recommended, and those views held after the appointment and during periods of waiting for surgery).

This study highlighted the need for a two-way conversation with healthcare professionals that takes into account the varying and shifting situations and views as held by patients. Understanding the patients' prior concerns about the multimorbidities may better inform the treatment decision made during or following orthopaedic surgeon consultation and provides an opportunity to shape their likely expectations on the outcome from any surgery on their general wellbeing.

Some gaps in patient knowledge highlighted in the study were not solely or specifically about multimorbidities, but we highlight them as complementary or contextual to the focus of our recommendations.

Communication about the relevance of multimorbidity across healthcare encounters

Firstly, many patients do not seem to be aware of the relevance of their existing multimorbidity for knee replacement surgery outcomes, meaning that their expectations may not be aligned with likely outcomes and limitations. A focus on surgical risk can overshadow these considerations, and our interviews suggest that more opportunities for communication with healthcare professionals about both sets of considerations around multimorbidity could be informative for patients. We suggest that discussion of the relevance of multimorbidity needs to be embedded across the care and treatment pathways for patients.

The pathways themselves can be a source of confusion and the following recommendations to healthcare professionals and services are made to improve communication and understanding:

- It should not be assumed that patients know about knee referral pathways or that, if they have heard of the one they will embark on (for example from local others who have had knee replacement recently), they will be fully aware of its intended role.
- GPs making referrals should, from the outset, outline the local knee services and related pathway. This may include giving written information about the stages for patients to take home and look back on if they are (or later become) unsure. Additionally, the role of the intermediary services and practitioners (Musculoskeletal First Contact Practitioners / Extended Scope Practitioners), including the value of triaging to assess clinical relevance and need, should be outlined by GPs initially and reinforced by intermediary service practitioners.

- Recognise that some patients will be assuming knee replacement is likely to be offered, or even see it as a guaranteed outcome from the referral, whilst others may be unaware or in equipoise about this. Clear communication that recommendation for knee replacement is a consideration and not a guarantee may help manage expectations.
- Practitioners and administrative staff in intermediary and specialist/surgical services may need to explain again, or reclarify, the relevant knee pathway to patients.
- Patients appreciate being kept informed whilst waiting for various appointments. It gives opportunities to ensure they are aware of the pathway process and, if relevant, any deviations from it for them. If there are delays, communication from services can reassure them that they haven't been 'forgotten'.
- For those patients who decide not to take up surgery when offered and intend to be re-referred if circumstances change, be clear about the process entailed with regards to the current pathway, who to contact/how to initiate this and any potential waiting times.
- Explaining a plan of care can give patients encouragement and direction. This should include information about suitable treatments and other management options, such as mobility aids, that may be helpful whilst waiting for appointments or surgery.

More specifically with regards to supporting decision-making on treatment options with recognition of the relevance of multimorbidity, the following recommendations are made to healthcare professionals across settings:

- Recognise the patient with knee problems as an individual and in the context of their wider health and life circumstances, and that decision-making about knee replacement is multifaceted, taking place over potentially long stretches of time, across multiple settings and interactions with healthcare professionals amongst others, and encompassing wider past, present and future health and social considerations.
- To support decision-making, patients must be informed and have the necessary comprehension about their unique circumstances including the relevance (or not) of their other health conditions to any proposed surgery. This needs to be expanded beyond the traditional concerns on the risks from the surgery and the peri-operative period, to the longer period of post-op rehabilitation.
- Clinicians should ensure their patients have adequate explanation of the condition of their knee(s) and possible treatment options, with conservative treatments frontline. They may wish to delegate to other members of their team such as a specialist nurse or physiotherapist to provide more explanation if needed.
- Patients with severe knee problems and multimorbidities frequently take multiple medications, including pain killers with their accompanying side effects. Clinicians need to explore patients' concerns about their drug treatments and what will be needed both short- and long-term after any surgery.

- Surgeons and members of the multidisciplinary surgical team should provide opportunities to ask questions, so that patients fully understand their potential risks and outcomes from treatments (or non-treatment), including from knee replacement. Be aware that patients may not ask questions or express concerns that are significant to them if they sense a healthcare professional is in a rush.
- Information shared about treatments should be considered in light of patients' expectations, goals and hopes, including any limitations that may be entailed as with kneeling after a knee replacement, and their other health conditions should be taken into account.
- In recognition that this might be the first time a patient has considered or had surgery, and may not know much about knee replacement, they may need more questions answering and for information to be repeated. They may need an opportunity to ask questions later of a member of the surgical team after they have had time to process the information given at the referral appointment. Alternatively, they may have had negative past experiences of healthcare services, settings and treatments which may need unpacking to help them understand if and how this is relevant to knee replacement surgery.
- Honesty about outcomes (including known uncertainties) and the likely length of time for recovery from treatments is appreciated by patients. In particular, surgical clinicians should ensure patients are aware that recovery experiences can vary significantly and that it may take longer to recover fully from knee replacement surgery than is typically expected; if other health conditions are likely to impact on the recovery, this should be highlighted to patients in advance to help them manage their expectations.

- For those whose knee pain is thought to, even in part, stem from a musculoskeletal problem elsewhere, such as with the hip, patients should be helped to understand if and how another opinion or a transfer of referral from a knee service to another service might be useful.
- Furthermore, especially with other morbidities that might impact on the risks and success of any surgery, patients need to be advised when additional secondary care referral is needed. In such circumstances, there needs to be suitable information sharing between different hospital specialities, trusts and primary care so that information is readily available on patient's other medical conditions.

Optimising health with improved access to physiotherapy support

Further understanding about and access to prehabilitation support may help optimise health and overcome other health challenges in the run up to surgery which may in turn improve satisfaction with knee replacement surgery. However, amongst older people with multimorbidity, the benefits of physiotherapy were not widely understood, and we suggest there is a need for careful communication around physiotherapy throughout knee pathways to ensure patients recognise the potential benefits as opposed to seeing it as a 'tickbox' in advance of knee replacement surgery being considered. To improve this situation, the following recommendations to healthcare professionals and services are proposed:

- The potential benefits of physiotherapy across all stages of managing knee problems should be highlighted and, ideally, accessible via the NHS. This includes alongside other treatments, as well as before and after knee replacement. In particular, understanding about the role of prehabilitation and likely benefits following knee replacement surgery can be highly motivating for patients.
- Older people with multimorbidities may need longer and more frequent physiotherapy appointments to check they are doing their exercises correctly. In-person appointments can be especially important for those who find information in a leaflet confusing or inaccessible, for example if they have a visual impairment.
- The timely provision of support aids is key; ideally, these should be in place before or immediately after knee replacement surgery. Encouragement and support to plan ahead for basic care needs after surgery – including toilet access and meals – is important.
- Some patients may be reluctant to use mobility aids, in part because of their impact on self-perception and self-image. Some may prefer the suggestion of alternative supports, such as Nordic poles instead of crutches or a walking stick.

Consideration of the risks of inequalities

Careful consideration and mitigation efforts are needed with regards to the potential risks of exacerbating inequalities and unintentional consequences in knee problem management and treatment services. This includes measures intended to ease pressure on NHS knee surgical services, for example. With recognition of the limits of our study remit and sample, we make the following recommendations to health services, policy makers and researchers:

- Amongst our participants, the initiative for knee replacement at private hospitals funded on the NHS meant that those patients with overall better health and lower risks were more likely to get the surgery (thus reducing waiting times) through this route. Others in our cohort were not offered this or were eventually rejected because of the complexity of their other health conditions. The potential for measures to create a two-tiered impact for patients – with those with more complex health needs and risks having to wait, with potentially their health further deteriorating and risks accumulating – in this cohort warrants careful consideration and mitigation efforts.
- Furthermore, whilst some of our participants were able to consider private healthcare for appointments and treatments (including knee replacement), this was financially out of the question for most. The uncertainty of and worries about the potential costs patients would face in the future, as they aged and in relation to their other health conditions, were factored into this.
- There is a need for more research focused on the barriers experienced by older people with multimorbidity from ethnic minority backgrounds in accessing support for knee problems across treatment and referral pathways and the implications of this in terms of, for example, satisfaction with knee replacement outcomes.

Attention to mental health challenges

Mental health difficulties were highlighted as an area particularly warranting more support and resources for these patients, especially for those experiencing long waits for surgery and between appointments. Depression and anxiety, for example, may be a longstanding co-existing health condition separate to, but potentially interacting with, knee problems; more broadly there is also the distress that can be experienced with the challenges of protracted waits for surgery and/or recoveries that are longer or slower than expected and/or knee replacement outcomes that are more limited than hoped for. Older people may find it particularly challenging to be open about mental health challenges. Some adopted a stoic attitude despite being considerably distressed, overwhelmed and isolated as a result of or additionally because of knee problems and their wider multimorbidities. We encourage the provision of support for mental health and to enhance wellbeing of older people with the following recommendations to healthcare professionals and services across pathways, as well as for patients' families and friends:

- Be aware that patients may be experiencing poor mental health as a result of, or separately and compounded by, their knee problems, but they may not openly communicate it with their healthcare professionals, or family and friends. Healthcare professionals should ask questions directly but sensitively, and should not make assumptions about who is or is not likely to be affected.
- Mental health can be affected during the wait for appointments and surgery, and cancellations, particularly if the knee and/or wider health is deteriorating and social isolation and loneliness is experienced. In this challenging period, being told an approximation of how much longer the wait is likely to be – even if subject to change – can help patients feel more informed and manage their expectations.

- Ensure that patients are signposted to appropriate mental health support and social prescribing opportunities, if they are likely to benefit from it, especially while on the waiting list and in the months following knee replacement surgery. Where necessary, mental health support and social prescription plans should also be tailored in recognition of a patient's other long-term health conditions.
- If prior mental health issues are known, then it is important to consider how these may have changed (or not) following surgery, especially as they may influence the perceived success of the operation. Identifying ongoing or exacerbated mental ill health following surgery presents an opportunity to offer further support.

A thread running throughout many of the recommendations is the need for clear and comprehensive patient information to ensure that patients are appropriately aware of, and supported in, including considerations around multimorbidity in their decision-making. The online resource we produced from the study aligns with and aims to help address this need, providing patient-facing material that patients and their families can access and draw on to inform future engagements with their healthcare professionals when experiencing knee problems, making decisions about treatments, and/or recovering from knee replacement surgery.

Dissemination

There are a range of audiences for which we hope the study findings and outputs will have impact and be useful. These include: patients, the public (including people who are not yet being referred for knee problems but may do so in the future), their carers, families and friends, and charities; healthcare professionals (across NHS and private settings, including those in training and medical students), and researchers and funders. A number of our outputs are aimed at a combination of these audiences, whilst others are more focused.

An online patient experience resource

A new section on the Health Experiences Insights (HEXI) website at www.hexi.ox.ac.uk has been produced and is available at: https://www.hexi.ox.ac.uk/Making-decisions-about-knee-replacement-as-an-older-person-with-multiple-conditions/overview

HEXI is public-facing, non-commercial, and free to access. The new resource is primarily aimed at patients being considered for knee replacement, as well as their carers, family and friends, and the wider public which includes individuals who may be considered for knee replacement in the future. It is also anticipated that the resource will also be useful to clinicians working in surgical teams, GPs referring patients for knee replacements, those working in intermediary musculoskeletal services, those involved in medical education and training, and health researchers.

The online resource consists of 28 accessible summaries of the main study findings to reflect the issues that matter most to the people we talked to and represent the full range of experiences described in the interviews.

Hundreds of written and audio excerpts from the interviews are included to illustrate the findings in an accessible format. In addition are 'profile' pages which summarise the experience of individual participants in the form of short narrative biographies.

The summaries were reviewed by suitably qualified members of the Advisory Panel, including PPI contributors. Research participants were contacted once we had a 'draft' website ready, to give them the first chance to look at the content and provide feedback.

In addition, we undertook an evaluation of the resource in August and October 2024 with 9 patients and carers. We sought feedback from individuals who matched our target audience, namely people who were over 70 years old and were being considered for knee replacement surgery or had previously had knee replacement. Participants were asked to look at the website in their home, which was followed up with a telephone interview from one of the research team (CD) to obtain feedback. One participant gave written feedback rather than over the phone. Questions were asked about style and content of the draft website, in addition to open ended questions to elicit feedback. Feedback was used to improve the resource before it was finalised, in combination with feedback from study participants.

Overall, responses to the draft website were very positive with comments about the site answering all the questions that a user would have before the operation, having an easy to follow layout, demonstrating a good range of experiences, and being very well written and comprehensive. We collated all comments and suggestions given as feedback and discussed as a team which were feasible and desirable to adjust, acknowledging that there were some aspects where evaluation participants were divided in their views and matters of personal preference.

The key areas for change, and our changes or responses, are detailed as follows:

- The imagery (of nature/plants) used to accompany audio recording clips from the interviews:
  - Some evaluation participants liked these and found them engaging, whilst others felt they were bland or disconnected to the subject matter. Some participants had no strong opinion on them.
  - Given the range of views, we felt this was a matter of personal preference and it had been our intention to use backgrounds that were not clinical or subject specific, and instead felt nature/the outdoors was both aesthetically pleasing and connected to a frequently expressed desire for improvements in knee problems to allow participants to spend more time (or be in less pain whilst) gardening and going for walks. As such, no change to the clip backgrounds were made.
- Audio clips from participants:
  - One evaluation participant said they found it hard work to listen to the clips, and preferred to read the accompanying text transcript instead. Another evaluation participant found clips from two study participants tricky to hear. We recognise there will be different preferences as to whether users listen to and/or read the transcript, and therefore this is not a change we made. We re-cut the clips with two participants to enhance the clarity of the audio.
- Text transcripts accompanying clips:
  - Some evaluation participants found the verbatim transcripts difficult to follow. As a result of this feedback, we carefully cleaned up clips to help with clarity whilst ensuring no changes were made to the tone or meaning of clips.

- Areas and topics for further clarification:
  - Some evaluation participants felt there should be more emphasis or information on, for example, how painful recovery from the surgery could be and that it could take a long time, mental distress, and sources of information and support.
  - Some participants also suggested having some clips from a doctor to clear up areas of uncertainty and differences amongst participants.
- We added the requested information in more clearly to the appropriate topic summaries, and added recorded video clips with a surgeon and a physiotherapist to address particular areas of interest.
- Sample and range of demographic backgrounds of participants:
  - Two evaluation participants highlighted that the sample seems to be only/mostly White participants, and one of the evaluation participants felt they were all middle-class. A third participant who identified as "not White British" felt that the information provided remained "relevant and applicable to my situation", but welcomed an acknowledgement somewhere on the website that the sample was limited in some aspects of diversity.
  - One evaluation participant suggested grouping the study participant profile pages under either 'early-' or 'late' onset of arthritis or through cause (e.g. accident).

- With recognition that ethnic diversity in the sample was limited, we disagree that the sample was restricted to only those with class and capital privileges. In response, we added a sentence to the 'Overview' page to recognise some of the different circumstantial (rather than demographics/identity based) considerations that study participants experienced that could be disadvantageous. The idea behind the website is not that a user will find a participant with the exact same demographic and circumstantial context as them, and instead we felt that highlighting some of the circumstances that could affect a broad range of potential users signposts to some of the different life challenges relevant in this context.
- It was not possible to reorganise the grouping of profiles in the ways suggested by an evaluation participant, as these were either not discrete categories (for example, some study participants cited both injuries and wear and tear over time as underlying their knee problems) or we do not have consistent or exact data for all participants (for example, exactly how many years or months they had knee problems for). We did, however, add categories based on participant decisions regarding knee replacement made during the data collection period in terms of whether they had knee replacement surgery, were waiting for the surgery, or declined surgery.

- The quantity and richness of information:
  - Whilst some participants praised the depth and breadth of the resource, some also found it was a lot of information and could feel overwhelming as a whole, including having so many clips from participants. For others, the structure and signposting worked well to manage this. There was recognition that some sections would be relevant to a smaller or more specific audience.

    - We recognise that the approach in the evaluation – asking participants to spend time looking around the website – is likely to differ to the approach used by the average user, who typically arrives on a topic-specific page of a resource through search engines. It is a balance between ensuring the depth of information that a potential user might seek and recognising that they may not view other topic summaries or the website as a whole. As such, we did not change the content and recognise this as a consideration dependent on different ways of consuming online content.
- Navigating to and around the website:
    - The resource was located on the test site under 'M' for 'Making decisions [...]' in the A-Z navigation panel, which could make it challenging to find.
    - In response, we added links to the resource under 'K' for 'Knee replacement' and 'S' for 'Surgery for knees'.
- Rephrasing and clarification of terms:
    - Some evaluation participants suggested being clearer about which 'heart condition' participants referred to.
    - To aid understanding, we have added this – for example, atrial fibrillation – where relevant whilst keeping the broader category ('heart conditions') for language accessibility.

Publications and conference presentations

We will publish the main findings of the paper for a clinical audience, and present the study and related resources at the British Association for Surgery of the Knee (BASK) 2025 conference. A paper on the temporality of decision-making amongst older people with multimorbidity is in preparation for a social science audience.

Additionally, two papers drawing on the findings from this study are in preparation; one as a secondary analysis combined with four other datasets and focused on access to GPs, and one as a methodological reflection piece combined with insights from five other projects and focused on temporality (tempo and timeframes) in qualitative longitudinal research.

Availability for secondary analysis

To maximise best use of the interview data [28], the carefully anonymised transcripts will also form part of a University of Oxford archive which is available on reasonable request to other bona fide research teams for secondary analysis. Queries regarding data sharing should be directed to hergadmin@phc.ox.ac.uk

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Appendix 1: Demographic characteristics of participants

		Count
Age range (years)	70-75	25
	76-79	9
	80-85	6
	Over 85	2
Gender	Female	26
	Male	16
Ethnicity	White-British	40
	White – American/British	1
	British Indian	1
Relationship status	Single	1
	Partnered but not cohabiting	2
	Married/living with partner	19
	Divorced	4
	Separated	1
	Widowed	13
	Not stated	2
Self-identified carer	Yes	3

Appendix 2: Employment backgrounds of participants before retirement

		Count
Occupation group before retirement (categorised according to the 9 major groups of the UK Standard Classification of Occupations (SOC 2020))	Sales and customer service occupations	8
	Professional occupations (including teaching, nursing and midwifery)	8
	Associate professional and technical occupations (including sales, marketing and related associate professionals)	5
	Skilled trades occupation (including construction, food preparation, hospitality)	5
	Administrative and secretarial occupations	4
	Managers, directors and senior officials	4
	Process, plant and machine operatives	4
	Caring, leisure and other service occupations	2
	Not stated	2
	Elementary occupations (including elementary cleaning occupations)	0