


A Patient and Public Involvement Study to Explore the Need for Further Research into the Experience of Younger Patients Undergoing Total Hip Arthroplasty

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Abstract

Background: Total Hip Arthroplasty (THA) is one of the most commonly performed operations in orthopaedics. It is an operation usually performed in older patients, however the need for THA in younger patients is increasing. There is a lack of literature examining whether current recovery pathways address the specific needs of younger patients. Public and Patient Involvement (PPI) is a core aspect of good research practice and is recommended throughout the research process, including the formulation and refinement of pertinent research questions. Therefore, the explicit aim of this PPI study was to collect qualitative data from patients on the feasibility and requirement for further research into the experience of younger hip arthroplasty patients. **Methods:** Qualitative data was collected via an online questionnaire that was advertised on social media, requesting the input of anybody who had experienced a lower limb musculoskeletal injury or condition before the age of 50. The survey asked the respondents to describe their experiences and reflect on their priorities and goals throughout their recovery. **Results:** There were 71 respondents, of which 90% were female, with an average age of 43. Qualitative responses identified many concerns that were issues that could be translated across all patient ages. However, other priorities were raised that are not always recognised as important when measuring successful outcomes after a THA. Furthermore, many respondents described not feeling listened to by clinicians or treatment options not being sufficiently addressed and explored. Multiple respondents reported being told they were too young to have anything serious or that nothing could be done until they were older. **Conclusions:** The responses to the survey indicate that current care pathways are not fulfilling the needs and priorities in younger patients. Further research is required to explore these priorities and goals in more depth in order to understand how healthcare professionals can address them.

Keywords

Patient Experience, orthopaedics, Total Hip Arthroplasty, rehabilitation, Public and Patient Involvement, PPI

Plain English Summary

To understand if healthcare delivery is meeting patients' needs, we need to ask those patients what their needs are. This is particularly true when the clinical treatment, such as hip arthroplasty, is typically required by an older population but is increasingly used in patients of all ages. To understand the needs of younger patients undergoing a lower-limb total joint replacement, a survey was posted online asking for responses from people under 50 years of age, who had a hip, leg or foot injury or condition. The respondents reflected on their priorities and goals throughout their diagnosis and recovery and on whether they felt these needs had been met by healthcare staff. The responses described areas of dissatisfaction in the care received and highlighted a need for more research into

the aspects of recovery important to them as individual patients. Any lower limb injury or condition will have an impact on a

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patient's quality of life and affect their daily activities. Therefore, common themes in experiences and recovery priorities may emerge in the responses regardless of the body part affected. The outputs of the survey have influenced the development of the research question and the design of a planned future study. Using PPI in this way ensures the planned research is user-led. This makes certain that researchers and healthcare professionals are addressing the aspects important to the patient as opposed to what clinicians or researchers consider a priority.

Background

Total Hip Arthroplasty (THA) is a common operation performed in Orthopaedic Surgery. The National Joint Registry (NJR) within the United Kingdom (UK) reported that a total of 101,384 THAs were performed in 2019 (1). This number is predicted to increase year by year as the age of the general population increases (2). Although most of these operations are performed on older patients, the demand amongst younger patients' is increasing (2–5). For example, 5708 (5.6%) of the patients undergoing THA recorded in 2019 were under 50 years old, 14,376 (14%) of the recorded patients were aged between 50 and 59 years of age. This presents a significant increase from the numbers recorded in 2011, when 4,828 patients (6%) under 50 and 10,516 patients (14%) between 50 and 59 years, from a total of 76,357 patient records (1). However, the current care pathways used are traditionally based on the needs of older patients (>65 years), and little attention has been paid to the potential differences between them and the growing younger population requiring THA (2,5,6).

The National Institute for Health and Care Excellence (NICE) (7) provides guidelines for clinicians and professionals caring for patients recovering from THA. The recommendations specify that additional rehabilitation support is only indicated in patients with additional needs, such as dementia and cognitive impairment. Younger patients are not included in this category, despite their rehabilitation needs potentially being more complex than that of the older patient population usually associated with THAs (5,8,9). Further research into the goals and priorities of these younger patients is essential to ensure they are met and supported.

Patient Reported Outcome Measures (PROMs) are routinely used after treatment to measure the success of the operation from the patients' perspective (10–12), and Enhanced Recovery Pathways are used to prepare patients for surgery and to expedite recovery and discharge from hospital (13–15). There is a lack of literature examining whether these measures and pathways are effective with younger patients and whether they completely address factors important to them in their recovery. The expectations of a successful post-operative outcome, in terms of function and mobility, are much higher for the younger patient from both a patient and surgeon perspective (8,16). However, standard PROMs have revealed that long term outcomes of THA are worse in younger patients compared with older patients (17). Factors such as sex, age and pre-operative quality of life all appear to influence patient-reported

outcomes (17). In addition, the way a successful outcome is measured is unclear (18–20), and there is little agreement and high variability between patients' and surgeons' opinions (8,21–23).

Evidence recognises that surgeons and patients often differ in their assessment of health priorities, symptom status and surgical outcomes (8,22,23), leading to concern that some outcomes important to the patient may not be considered or addressed. Surgeons' expectations appear to be significantly associated with joint related clinical data and radiological assessments, for example, positioning and survival of the implant, alleviation of pain and function of the joint (5,21,24). In contrast, patients seem to rate expectations on criteria that are mainly psychological and non-joint related, such as ability to participate in recreational activities and effect on mental wellbeing (8).

Incorporating patients into research improves the relevance and quality of results and can demonstrate methods of adopting research findings into practice (25,26). Clinicians have expertise on the illness or disability, but patients experience the daily impact of living with the health condition (27–29). It is therefore practical to "ask the experts" when identifying the factors to explore and the outcomes to assess (28). Just because a proposed research question is *scientifically* relevant does not necessarily mean that it is important from the patient's perspective (29).

Public and Patient Involvement (PPI) has become a core aspect of good research practice and is increasingly recommended in the design, conduct and dissemination of health and social care research (30). PPI in research is often defined by three levels of involvement: consultation, collaboration or user-led research (31). Though the method of PPI selected depends on many factors with each research study, user-led research is arguably the more effective and highest level of involvement (32). The method of user-led PPI was utilised in this study. This approach incorporates the inclusion of patients and the public in all aspects of the research cycle (30), beginning with the research topic to be explored and the design of the research question. Identifying the lack of literature in the field of younger patients' priorities when undergoing a THA does not automatically reinforce the assumption that there is a need for it. Nor does it confirm that a proposed clinical research question will cover the necessary topics. Thus, it is essential that patients are given the opportunity to identify the issues, questions, and objectives they want exploring. This helps enforce the relevance and usefulness of the future research results (33). The themes identified in the PPI responses can be used to ensure the appropriate topics are addressed in the study, optimising the relevance of the results. The PPI survey results are reported using the GRIPP2 reporting guidelines. These guidelines are recommended as a way of promoting transparency, quality and consistency of PPI work ensuring it is based on best practice (34).

Aim

The survey's primary objective was to determine the necessity of further research in the area of younger people undergoing THA. It was also intended to inform and support the design of a qualitative research project exploring the goals and priorities of the younger patient (aged 50 years and under) undergoing a THA. Although there is a recognition of a lack of research or literature, there is also little evidence indicating the potential need for it. Without asking the patients what priorities they have throughout their recovery and whether they personally feel they were addressed, there is a risk that the proposed research could be irrelevant (31). Using PPI ensures that the research addresses the issues important to the relevant patient population and may identify areas for exploration previously unconsidered by the researcher (33,35).

Methods

The purpose of this study was to inform the requirement for the proposed research topic and influence the design of a future research study. A survey was developed which asked respondents to describe their experience related to their expectations, priorities, and outcomes throughout their treatment journey from injury and diagnosis to rehabilitation and recovery. The survey questions were open ended giving the respondent complete control of the topics and issues they described. For clarity, questions divided the patient's journey into three periods (1. Diagnosis and initial treatment, 2. Rehabilitation stage of recovery, 3. When returning to function) with an additional section available for further comments. The survey as presented to the respondents can be seen in Appendix 1. The survey was directed at anybody who had experienced a lower limb musculoskeletal injury or condition before the age of 50 years old rather than carers or family members. The survey was deployed through Survey Monkey and shared on the social media platforms, Twitter and Facebook.

The survey asked respondents to explain what their own goals and priorities were throughout their treatment and recovery. A loose time period guide was provided, and respondents were asked to feedback their own experiences at that point. To clarify the different journey periods, there were prompts and key words such as "diagnosis", "treatment", "rehabilitation", "relationships" amongst others. These "prompt words" were provided in order to invite respondents to discuss potentially sensitive or uncomfortable topics they may not have felt were necessarily important to the researcher (36), for example the effect the injury or condition had on their sexual activity or relationships. Using virtual surveys is preferable to face-to-face or group situations for collecting information about sensitive topics, as participants can disclose intimate details without feeling uncomfortable (37).

It was unclear how many respondents the survey would attract via social media platforms. Due to this, the survey was designed to be relevant to anyone who had suffered a lower limb injury or condition when they were under 50 years of age. The aim was to collect a sufficient level of responses to identify common themes and goals important to the specific age group of 50 years and younger. Inviting individuals who had suffered an injury or condition on any lower limb significantly increases the relevance of the questions to a wider portion of the population. The survey's goal was to influence the design of a proposed research question exploring the specific priorities experienced by individuals undergoing THA. As the survey was designed purely to inform the design of the main study and future research question, the answers provided by the respondents were not going to be extensively analysed nor used to make recommendations on future practice. Any person under 50 years who has lived through or currently suffers with a lower limb injury or symptoms will have experienced some impact on their quality-of-life daily activities. Therefore, their experiences and individual priorities in their recovery may emerge as a common theme throughout the responses no matter the body part affected. Consequently, targeting the survey at all people experiencing any injury or condition of any lower limb was a justifiable approach that maximised the potential number of relevant responses.

The survey was initially advertised through Twitter and Facebook via local groups and through persons associated with Milton Keynes University Hospital and Bournemouth University sharing the link on their individual profile. This was extended to support groups for individuals pre- and post-lower limb joint replacements. As responses were submitted it became clear that many of the respondents were Caucasian females and therefore, not representative of the relevant patient population. In order to target a more diverse group of people the survey was advertised on social media groups for Black and Ethnic Minorities (BAME) Healthcare workers and University Students (with permission from the administration teams of these groups). It was also advertised on support groups for patients suffering from Avascular Necrosis (AVN), as this condition is known to present in patients living with Sickle Cell Disease (38). Sickle Cell Disease is a condition more common in certain ethnic groups, predominantly in people of African descent, but also Hispanic-Americans and people of middle Eastern, Asian and Indian descent (39). These efforts were ineffective, however, with no increase of responses from ethnic minority groups.

In addition, the survey link was also posted on numerous arthroplasty support groups on Facebook including: Young Hip Replacements (UK); Hip Replacement group for Active people; Avascular Necrosis Support - UK group; Musculoskeletal Disorders Forum; Knee Surgery Support Group; Sickle Cell Disease; BAME Healthcare Professionals UK; and Avascular Necrosis Young Support Group

The survey was reposted two weeks after the initial posting. As these were groups for people seeking support and advice in these fields, the author was conscious that despite the groups' administrations approvals, over-frequent reposting could overshadow posts by members seeking help and advice as per the group's purpose. It could also become irritating to members who had no interest in the survey, or those who had already completed it.

Other social media platforms were considered before selecting Facebook and Twitter as the most useful platforms to use. Facebook is reported to be the most popular social media platform worldwide with a reported 2.5 billion active monthly users (40). The only other comparable platform is YouTube which does not lend itself to this type of survey advertisement. However, due to the volume of responses collected through Facebook and Twitter, it was unnecessary to broaden the survey scope to encourage further responses. The practicalities of a single researcher working through the responses and time constraints limited the quantity of contributions possible to accept.

Results

The survey attracted a high level of response. It was initially posted online on social media platforms on 22/04/2020. By 11/06/2020 there were 71 completed responses. The responses were all from the patients themselves as opposed to family members or carers. A potential saturation of data was indicated in the later responses as no new themes were emerging. Consequently, the survey was closed after 71 responses.

The mean age for respondents was 43.4 years (median age 44, interquartile range 39-49) with the mean age at the start of symptoms as being 31.8 years (median age 31, interquartile range 24 - 44). Participant's current ages ranged from 17 to 61, with their ages at the start of symptoms stated as "from birth" to 52 years. Out of 70 respondents (this question was skipped by one participant), 90% were female, and 10% being male. 65 respondents described themselves as white or Caucasian, 2 respondents were Asian or Asian-American, 3 described themselves as another race and 1 participant declined to answer. Respondents were not directly asked what their diagnosis was, nor did they have to specify the limb affected. Of those responses that did describe the injury or condition, 22 were hip conditions, 8 were knee conditions and 3 were ankle conditions. 38 respondents did not specify the limb affected.

52.1% of respondents described pain and loss of function as a major concern. Frustration and dissatisfaction with the explanation of the diagnosis was cited by 63.4% of respondents, along with 45.1% reporting they had not felt listened to, or that their concerns had not been addressed by clinicians. There were also frustrations expressed by 46.5% of respondents over how long their recovery had taken. Exercise and recreational sports were considered important to 40.8% of participants and 38% described sexual activity and intimate

relationships as a priority. These themes will now be explored further.

Pain and loss of mobility and function were identified by 37 respondents in the section relating to initial diagnosis and treatment. Over half of respondents (n = 45) also described feelings of frustration and dissatisfaction with the explanation of the diagnosis and reasons for their condition. The information given by healthcare professionals was described as inadequate and difficult to understand.

"I was put in a class of people who were 30 + yrs older than myself who were also getting joint replacements" "I know that my recovery, my needs, my physio, all of it was different since I was more mobile" "I wish that providers wouldn't lump us into the same category as others getting the same thing." Respondent 16

32 respondents described not feeling listened to by healthcare professionals, feeling that treatment options were not sufficiently addressed and explored. Age was identified by several individuals as a potential reason why clinicians potentially came across as dismissive or unbelieving. Multiple respondents reported being told they were too young to be suffering from anything serious or that nothing could be done until they were older.

"After countless doctors telling me they didn't know what to do with my condition at my age, I finally found one that said it will continue to get worse and there is nothing to be done but manage symptoms until I'm old enough for a replacement."

Respondent 10

"Was told it would just be a muscular problem as I was "too young for it to be anything serious". Respondent 31

29 respondents (40.8%) reported being eager to return to exercise such as running or high impact sporting activities. The ability to return to sport and exercise (regardless of clinical recommendations or level of sporting activity) was identified as a high priority throughout the survey by multiple respondents. Frustration was expressed regarding differing recommendations by different clinicians on when to return to exercise and what level of exercise was advisable post-surgery. This inconsistency of advice was reported by 29 survey respondents (40.8%) and was identified as a significant reason for the anxiety and nervousness they experienced when regaining function and undergoing rehabilitation.

"The hip consultant agreed that I could run. My physio wouldn't let me start running because they didn't understand the differences between my risks and the risks for the elderly." Respondent 15

“Consultant said I would be able to run again and altered his treatment accordingly, Physio disagreed.” Respondent 60

“As a keen sportsman, surprised to find that different doctors had range of attitudes as to expectation of resuming “before” activities.” Respondent 48

“Felt advice could sometimes send mixed messages” Respondent 32

One participant was frustrated that when measuring functional recovery, it was the standard PROMs that provided proof of a successful outcome, as opposed to the patient’s own specific goals.

“The hip specialist just wants to know that I can walk “50 metres unaided” and sit/ stand. These are great but I wanted more.” Respondent 15

Practical considerations emerged further down the recovery journey. Aspects such as returning to work or regaining the ability to drive increased in importance to many respondents in the latter questions. 33 respondents felt that recovery was taking far too long for their injury and that the potential time frame had not been fully explained by healthcare professionals.

“My expectations for the speed of recovery were unrealistic.” Respondent 57

“Was told 6 months should be back to normal. It actually took 18 months.”

Respondent 70

The negative impact on patients’ mental health of undergoing a THA at a younger age featured strongly throughout the responses and was regularly highlighted as not having been addressed or discussed by clinicians.

“Effects on mental health etc should be given more focus. Perhaps more so in younger patients who have potentially lost a large part of their future.” Respondent 6:

“I don’t feel the mental health side of this is considered at all.” Respondent 39

The primary issue identified in the final section (addressing any further information the respondent may want to provide) centred on relationships and sexual activity. Over a third of participants (n = 27) described this as a priority. Several respondents described feelings of embarrassment and a lack of confidence when engaging in sexual activity with their partner. These feelings were not limited to the functional aspect or positioning but also related to body confidence and feeling limited in their sexual ability.

“My body shape has changed significantly due to surgery. When I see myself in the mirror, I don’t recognise my body, it feels like a stranger.” Respondent 2

“It was embarrassing. Bedroom activity was difficult. I felt embarrassed at the lack of function of my hip at that time.” Respondent 38

Concerns regarding pain and the risk of dislocation of the hip joint were also expressed by multiple respondents. Participants recognised that this issue was also having an adverse effect on their partner and many respondents expressed that their injury and symptoms had had a negative effect on their relationship.

“It essentially ruined my marriage being in pain for so long.” Respondent 20

“I am single and won’t date, because I am a burden at this point.” Respondent 10

In addition to sexual relationships, other relationships were also impacted. Those with young families described being unable to play with their children on the floor, or to take part in activities together. 1 respondent expressed her upset at being unable to take her son to his primary school and being reliant on others for this task.

“I feel like a bad mother.” Respondent 29

Participants expressed concerns over potential future pregnancies and how their hip condition may adversely affect this.

“I gave up trying to have a 2nd child as all sex had stopped 2 years prior to the op and also post op.” Respondent 20

“I don’t have children due to fear of what pregnancy could do to my body.” Respondent 39

The responses indicated a frustration with the expectations of a poorer outcome of clinicians and healthcare staff compared to the patient’s own individual goals. 20 respondents believed that it had been their own determination and persistence outside of the professional care provided, sometimes in direct contrast to the professional advice, that had achieved their desired outcomes.

Participants felt “let down” or as if they “had been left to get on with it”.

“I was encouraged to go on disability. I did not find this reasonable.” Respondent 10

“I was put into a (physiotherapy) group with 8 senior citizens. I felt unseen and not understood at all.” Respondent 15

“Basically left to my own devices.” Respondent 71

Different themes emerged throughout the survey, as individuals described their journey through initial diagnosis and treatment to rehabilitation and recovery. New concerns and goals were identified and increased in importance to the respondent, whereas previous concerns became less of a priority. The reason for these changes, whether the previous concern had been resolved or alleviated, or why other priorities had become more prominent is not explored in this survey. The graph in Figure 1 is a visual representation of the numbers of respondents highlighting linked themes.

Discussion

Many immediate concerns (for example, pain, mobility, and function) identified in the survey were issues that can be translated across all patients, regardless of variables such as age and gender. There were other priorities described that are not always recognised as important objectives when measuring successful outcomes in patients undergoing a THA. The primary goals of a THA are pain relief and improvement of mobility (8,41). These themes were amongst the most common identified by the respondents in the section relating to initial diagnosis and treatment, and are concerns and issues commonly experienced in patients undergoing THA across all age groups and patient populations. However, it is important to consider the potential differences between what the younger person considers necessary for a good quality of life compared with the priorities of an older patient. For example, younger patients often require the ability to work, to care for young children or dependents, or desire a more active lifestyle in terms of exercise and other physical activities (8). The effect that symptoms of pain, mobility and lack of function in the joint can have on these different considerations of the younger patient are not addressed in the current literature and clearly needs further exploration.

The impact on exercise and sport featured as one of the more prominent concerns in the survey responses. There is some literature exploring the topic that participation in exercise and sport is one of the least fulfilled expected outcomes after THA (5,8,42), yet it is one of the higher rated expectations in younger patients (8,42). What a younger person wishes to achieve in functional outcomes may, understandably, be different to that of an older patient, for whom a lower functional ability may be perfectly acceptable (43). A significant number of younger patients return to recreational or impact sport after THA (39,44). Some even wish to return to a sport not recommended by clinicians (8). A young person with an isolated condition of the hip would be reluctant to substantially limit important parts of their life, thereby causing a considerable deterioration of lifestyle (45–48). The survey responses reinforce these findings. Respondents describe the inconsistency of advice regarding exercise between professionals as a major obstacle in their recovery. Some clinicians advised no exercise or recommended

considerably less than the patient expected or wanted. Other clinicians had fewer concerns in that area and were confident that the patient would regain their desired ability. The variation between clinicians' advice on sporting activities after THA is acknowledged frequently within the literature and is recognised as a potentially significant factor in managing the expectations of the patient (49,50). Equally, the expectation of some clinicians that the younger patients would "bounce back" and recover quicker than older patients was a common theme. The literature reports evidence that clinicians often have higher expectations of speed of recovery in a younger patient than that of an older person (8,10). Respondents reported feeling considerable pressure to recover faster and meet to these expectations. Young patients undergoing THA often recorded lower levels of function, activity and mobility post operation, despite clinician's higher expectations. The assumption that a younger patient should experience successful outcomes is inaccurate (5,50).

The negative effect on respondents' emotional and mental health in addition to feelings of losing independence featured strongly throughout the responses, but was an especially prominent topic in the final two questions. Within the scope of the survey, it was impossible to explore the reasons behind this effect on the patient's mental health satisfactorily, however, it is widely recognised that the impact on younger patients' mental health pre and post injury or diagnosis can be enormous (5). The negative effect on employment, quality of life, sleep and social life is well known (9) and could be potential factors. Though a large majority of patients successfully return to work after recovery (44,51,52), a considerable number are forced to work fewer hours than previously (52). Employment and exercise are important for both physiological and psychological well-being (53,54). The possibility of being unable to return to the same level of employment could create a feeling of increased burden on the patient's partner or family. The considerable pressure and impact on the patient's mental health caused by this, amongst other factors, cannot be ignored. Depression and anxiety can, on average, be far more debilitating and severe in a 20-year-old than that in a 63-year-old (5).

There is limited data available supporting the proposition that undergoing a THA significantly affects sexual activity, whether through pain or anxiety regarding positions (46,55). There is evidence in the literature that this topic can cause much anxiety and insecurity in patients, but it is often unaddressed by clinicians during appointments (56–58). It was not specified in the responses if patients had broached this subject in appointments. However, the issue was of significant concern for many respondents, and participants claimed it had not been addressed or discussed satisfactorily with clinicians at any point between diagnosis and rehabilitations.

Though some topics highlighted in the responses were anticipated (for example, pain, function, mobility), others were unexpected. Body confidence and self-image were previously unconsidered areas when exploring this subject. The

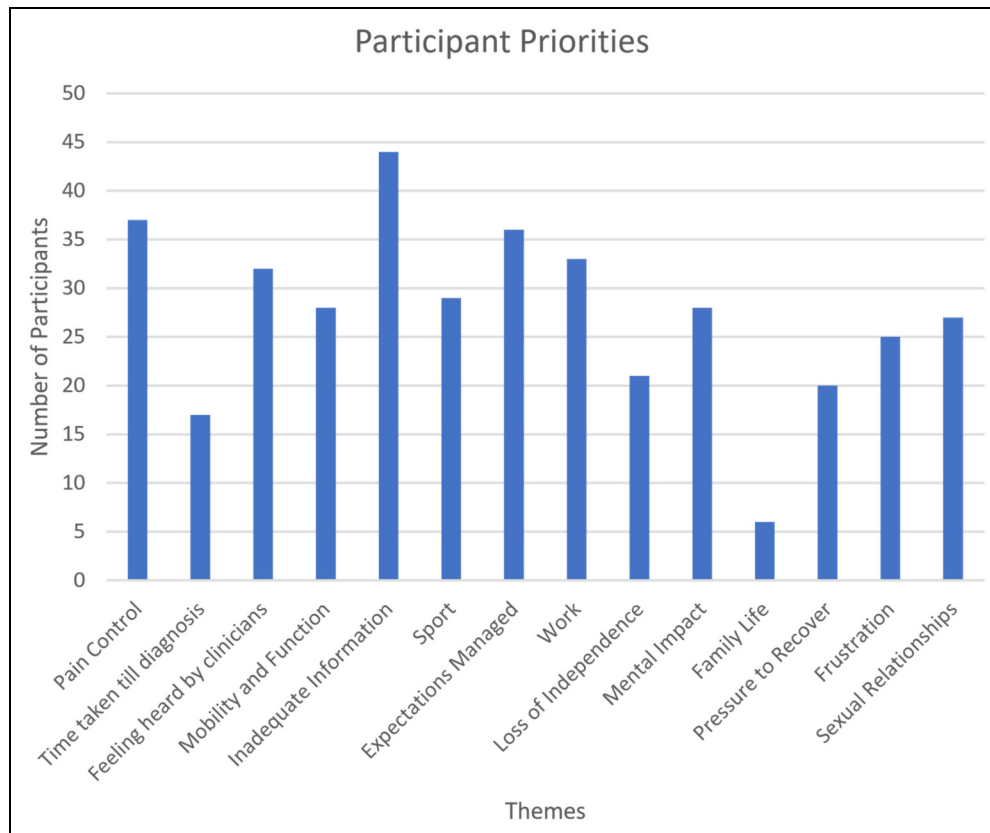


Figure 1. This graph shows the number of participants that highlighted common themes within the survey.

reported increased pressure to recover, whether from clinicians, family and friends, or themselves was also unexpected. The design of the future research project will incorporate the common themes reported in the PPI work into any study interviews to ensure they are addressed by the patient if relevant.

Though the study results are not being used to directly inform practice or intended to be generalisable across the wider population, it is important to identify and highlight the limitations of the survey and study.

Interestingly, despite the larger population of female respondents compared to male, there did not appear to be any significant differences in their experiences. The priorities and issues identified were similar throughout and not influenced by gender (with the exception of pregnancy and childbirth). Regardless of this, due to the inequality of male representation there is potential that some concerns specific to men have not been identified.

The lack of ethnic and cultural diversity in respondents may limit the broadness of the data. Despite the overall high response rate, numbers of respondents from black and ethnic minorities were low. Efforts to include a more diverse population in this PPI work were ineffective. This could lead to an omission of an important topic when exploring proposed the future research. The issue of under-representation of ethnic minorities is identified as a

common problem throughout healthcare research (59) and is certainly not unique to this project.

The method of using an online survey was largely influenced by real world constraints. The emergence of the Coronavirus 2019 (COVID19) pandemic and the implementation of a lockdown across Britain occurred during the initial planning stages of the PPI. The initial intent was to secure patient involvement by use of paper questionnaires in the out-patient department, or by inviting appropriate patients to participate in face-to-face focus groups. COVID19 safety concerns and the policies the National Health Service (NHS) put in place to protect patients, staff and the public on hospital grounds rightly prevented these ideas becoming anything more than suggestions. On-line surveys are not without their limitations. Completing the survey on-line limited the depth and detail into which topics could be explored. The information provided by respondents and the amount of detail revealed was completely dependent on the individual. The survey also had no time constraints on how long ago the injury or diagnosis had occurred. People's memories can be unintentionally altered (60), and priorities that were important to the individual at the time of the experience may not now feel significant. This indicates that proposed future research in this field should take place during the patient's diagnosis and treatment journey as opposed to retrospectively. The wording of questions in a survey comes with

added considerations and the way a respondent interprets the question can influence the answer they provide. If the wording is unclear or confusing the respondent may either decline to answer or provide what they believe to be the “correct answer”. For example, the answer they believe the questioner would like to hear or one that agrees with other respondents (61,62). This survey attempted to avoid this issue by using open-ended questions, allowing respondents to make the decision about a response to give. Due to the pandemic’s impact on face-to-face interaction, the options for collecting responses were limited; however, advertising the survey via social media also limited the target audience to those that used these social media platforms. It is recognised that this method of advertisement excludes individuals who do not have access to these platforms or choose not to use them.

Conclusion

The aim of the PPI is to generate findings to inform on the design of a qualitative research project exploring the goals and priorities of younger patients undergoing and recovering from a THA. Data collected from this survey strongly indicates the necessity of further research into this area and patient group. The PPI findings will help focus the study on the issues important to the relevant patient population and frequently uncovered areas of knowledge, previously unconsidered by researchers (36,63). The feedback obtained will influence the topics addressed in the planned semi-structured, informal interviews between the researcher and participants. Current research has not sufficiently explored the priorities and goals of younger patients undergoing THA and it has been identified that clinicians and patients can differ in their idea of successful recovery (8). This PPI study ensures that issues addressed within the proposed future research are not based on the researcher’s or clinicians’ assumed areas of importance (prior to PPI feedback) and explore the participants own individual concerns.

Using an online survey for this PPI had numerous positive aspects in facilitating access to a wide population group. Respondents could complete the survey at a time and place convenient for them, with no need for consideration of extra travel or timings. It is uncertain how the world will adjust after the COVID19 pandemic or if COVID19 will be something that needs taking into consideration indefinitely. Remote methods of incorporating PPI into research may be required in order to ensure appropriate patient involvement in the design and delivery of high quality, relevant, patient-centred research. The simplicity of the survey set up and the large response rate demonstrate the practical benefits of this method.

Appendix

1 Survey advertised on Social Media as was presented to participants.

Feedback from Young People (50 years and under) with Musculoskeletal injuries or conditions.

Why we need your feedback.

My name is Louise Mew and I am a Research Nurse in the NHS, I am trying to discover the priorities and goals in the recovery of young people with a MSK lower limb injury or condition.

What is a MSK lower limb injury or condition?

It is a chronic or acute musculoskeletal problem to the lower part of the body, including the hip, knee, pelvis or ankle. This could be the result of an injury or another illness or condition.

Why do we need your help?

We are asking any young person (50 years or under) who has a lower limb injury or condition, about what concerns we, as healthcare professionals should be addressing if we are to improve patient care and recovery.

What will we do with your survey results?

We will use your results to highlight any common themes in patient priorities and use these to inform and design a full research study exploring the priorities and goals in younger patients undergoing lower limb orthopaedic surgeries, for example total hip replacements. All answers are anonymous and no identifiable information is necessary. Any identifiable information provided will be anonymised and not stored.

1. **During your initial treatment, (whether in-hospital treatment, GP treatment or other healthcare settings). What were your priorities and goals in working towards your recovery? Were there any areas in your treatment in which you felt these were not addressed?**
This question relates to the initial diagnosis, expectations of recovery, pain management, operation or other treatments.
2. **During the rehabilitation stages in your recovery (mental and physical support, including physiotherapy and occupational therapy). What were your priorities and goals in working towards your recovery? Were there any areas in your treatment in which you felt these were not addressed?**
3. **When returning to function, (expectations for return to work, driving, sport and other hobbies). What were your priorities and goals in working towards your recovery? Were there any areas in your treatment in which you felt these were not addressed?**
4. **Is there anything else you would like to tell us (e.g. personal experiences, effect on relationships and sexual activity?)**
5. **ABOUT YOU?** It is important that we know a little bit about you so we can ensure we have collected the views of a wide range of people with different

experiences. However, you do not have to provide the following information.

6. **Are you Male or Female?**
7. **What is your age?**
8. **How old were you at the time of injury/ onset of symptoms?**
9. **What is your ethnic group?** please select from options below:

White or Caucasian
 Black or African American
 Hispanic or Latino
 Asian or Asian American
 Another race

Availability of Data and Material

The datasets analysed during the current study are available from the author on reasonable request.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.




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Ethics Approval and Consent to Participate

HRA approval was not required for this study due to no identifiable or personal details being collected, no vulnerable groups being approached and the study using social media and not an NHS trust to identify potential participants. This was confirmed by both the Health Research Authority and Milton Keynes Research and Development Department.

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