



**Oxford Biomedical Research Centre**  
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**NHS**  
*National Institute for  
Health Research*

**Gathering treatment uncertainties from patients/carers using different  
methods: Evaluation Report for Oxford Biomedical Research Centre**

**In association with the Oxford Health Experiences Research Group and the  
JLA Hip and Knee Replacement for Osteoarthritis Priority Setting Partnership**

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**James  
Lind  
Alliance**

Priority Setting Partnerships

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## 1. Executive Summary

### *Background*

The James Lind Alliance (JLA) Priority Setting Partnership (PSP) in Hip and Knee Replacement for Osteoarthritis gathered unanswered questions (known as uncertainties) from patients, carers and health professionals using three methods of collection – survey, discussion groups and by extracting data from existing interviews with people who had hip replacement (for which information was provided by Healthtalkonline – HTO).

It is the first time that a PSP has used three methods together, and this paper aims to understand which of these might be the most impactful, and cost-effective way to collect uncertainties.

### *Method*

We appraised the data collected through each method, with a focus on the patient/ carer voice. We analysed how the data from the three different methods populated the categories in the Health Research Classification System (HRCS) which was used to code and assemble questions from all sources. Once the prioritisation process was complete we counted how many questions in the final Top Ten were informed by each approach. We kept track of the direct costs for each method and considered the hidden costs, for each method.

### *Results*

We found that the survey data populated the HRCS categories more completely than either of the other two methods. There was a degree of overlap in the HRCS categories between the survey and the discussion group, less overlap between these two and the HTO data.

We found that in the final prioritised list nine of the Top Ten were contributed by the patient/ carer survey, of which five also came from patient/ carer discussion groups, and one from the hip interviews. Of the five that came from the patient/ carer discussion groups, two also came from hip interviews. Priority question number ten came from the hip interviews alone (as distinct from the survey or discussion group).

Six of the nine questions in the Top Ten that were contributed by the patient survey were also contributed by discussion groups and hip interviews; we could conclude that only three questions were truly contributed by the survey. Two of the five questions contributed by the discussion groups were also contributed by the hip interviews; we could say that only three questions were contributed by the discussion groups.

All three methods were an efficient way to collect suggestions for treatment uncertainties from patients, carers and the public with the exception of one discussion group (that was not convened for this purpose).

The data extraction of the HTO hip interviews did not cost this PSP, as it was an experiment to see if HTO data could make a valuable contribution to the PSP process and outcome. This makes the four contributions to the Top Ten priorities, including one unique patient question, very cost-effective. However in future costs will be incurred; so it will be important to capture this information with

other PSPs that are using HTO data, compare it across PSPs to check consistency, and establish how feasible it is to use this source of information about treatment uncertainties.

### *Limitations*

This study appraised patient/ carer contributions to a PSP process and not those of health professionals, although it is possible to see the professionals' voice in Table 4. Also, we have only considered the costs of using different methods for gathering patient/carer contributions, not the benefits, although we have made some observations in this regard and think that decisions about which methods to use should also include consideration of the benefits, so identifying these is helpful.

Evaluation of James Lind Alliance PSP methods is an important issue, not least so that PSP Steering Groups can make informed decisions about which methods to use within their resource constraints. We hope that this modest evaluation project has made a contribution of one aspect of the process; gathering treatment uncertainties from patients, carers and the public. We have made some specific recommendations in section 4 page 21.

Section 2 provides the background to this study, Section 3 compares the different collection methods, and Section 4 sets out our conclusions and recommendations.

## **2 Introduction**

This study ran in tandem with a James Lind Alliance (JLA) Priority Setting Partnership (PSP) in Hip and Knee replacement surgery for osteoarthritis (2013 – 2014), chaired by Sally Crowe, supported by Louise Locock from the Health Experiences Research Group (HERG) and Sophie Petit-Zeman, Director of Patient Involvement from the NIHR Oxford Biomedical Research Centre (BRC) and the NIHR Oxford Musculoskeletal Biomedical Research Unit (BRU).

### **2.1 Project objectives**

This project aimed to:

1. Compare and contrast the results of three approaches to gathering treatment uncertainties from patients and carers, namely: a) retrospectively, via existing Healthtalkonline (HTO) interview transcripts, b) prospectively via discussion groups of people with osteoarthritis who had or were awaiting knee and/or hip replacement; c) prospectively, via a postal and online survey of the same populations as in b).
2. Assess the feasibility of using HTO data (i.e. uncertainties gathered from secondary analysis) to gather patient and carer uncertainties relevant to JLA PSPs.

It is important to note that, although uncertainties were also collected from healthcare professionals via survey and a discussion group, this study concentrates on the patient voice in order to understand which methods of collection work best. That said, Table 4 shows how the professionals' voice contributed to the Top Ten Questions.

The work was carried out during the period covering November 2013 to May 2014 – the milestones are included at Appendix 1a.

An overview of the whole PSP timeline for gathering treatment uncertainty questions is available at Appendix 1b.

## **2.2 Background literature**

Traditionally, PSPs work with primary data, gathered via survey and sometimes through discussion groups. The HTO data was the result of secondary analysis, thus marking a variation from usual practice. The literature on the current thinking and issues that surround the concepts of secondary analysis of qualitative data and data mining as legitimate research processes was reviewed in order to provide context for this study. The detail of this review is available at Appendix 2.

The literature suggests that, whilst there are compelling arguments to re-use original qualitative data for the purposes of a research priority setting process, there are also arguments that secondary analysis has serious flaws. These include: the lack of detailed contextual knowledge about the circumstances of data collection possessed by the primary researcher; the state in which the data is retrieved i.e. if researchers knew that people may do secondary analysis of their work, might they present it differently – or even collect different data? The 'secondary analysers' may have poor understanding of the context within which the data is being expressed, (although in this example HTO modules follow a standard context and process of data collection), data may be used in an inappropriate way, or in a way that doesn't reflect well with the original research; and finally, there may be issues of confidentiality, anonymising data and ethics approval for re-use of data.

Of the different methods for secondary analysis reviewed, the most promising in relation to the PSP approach was developed by Brunton and Oliver (2006), and is called Framework Synthesis. This is based on the assumption that qualitative research produces large amounts of data in the form of transcripts, field notes etc. and organising this data provides structures within which to analyse it. An existing framework is used, informed by background material and discussion, in which to populate and synthesise the findings.

There seemed to be parallels between this approach and how the PSP approached the collation and interpretation of data, using a taxonomy that is adapted by the PSP Steering Group, as new topics emerge. Data is collected in an excel spread sheet, with summary headings, and is the main tool for organising and interpreting the many hundreds of research questions that are received. There were several discussions with members of the Steering Group that informed this structure, and it evolved over time both in response to the data being collected, and the views and experiences of the Steering Group upon reflection.

The framework that the PSP used is adapted from the UK Clinical Research Collaboration (UKCRC) Health Research Classification System (HRCS). The Classification consists of a number of headings, with sub-classifications. Table 1 shows the elements of the HRCS that were used by the PSP – the non-sequential numbers reflect the fact that they were drawn from a larger set of headings.

**Table 1: UKCRC Health Research Classification System (HRCS)**

|               |   |
|---------------|---|
| <b>1</b>      | Underpinning Research   |
| <b>2</b>      | Aetiology   |
| <b>3</b>      | Prevention of Disease and Conditions, and Promotion of Well-Being |
| <b>3.3</b>    | Nutrition and chemoprevention                                     |
| <b>3.5</b>    | Resources and infrastructure (prevention)                         |
| <b>4</b>      | Detection, screening and diagnosis                                |
| <b>4.1</b>    | Discovery and preclinical testing of markers and technologies     |
| <b>4.1.1</b>  | Predictors of postoperative success                               |
| <b>4.2</b>    | Evaluation of markers and technologies                            |
| <b>4.5</b>    | Resources and infrastructure (detection)                          |
| <b>5</b>      | Development of Treatment and Therapeutic Interventions            |
| <b>5.3</b>    | Medical devices   |
| <b>6</b>      | Evaluation of Treatments and Therapeutic Interventions            |
| <b>6.1</b>    | Pharmaceuticals   |
| <b>6.3</b>    | Medical devices   |
| <b>6.3.1.</b> | Safety  |
| <b>6.4</b>    | Surgery   |
| <b>6.4.1.</b> | Co-morbidity  |
| <b>6.4.2</b>  | Surgical techniques and intervention                              |
| <b>6.4.3</b>  | Success of intervention   |
| <b>6.6.</b>   | Psychological and behavioural                                     |
| <b>6.7</b>    | Physical  |
| <b>7</b>      | Management of Diseases and Conditions                             |
| <b>7.1</b>    | Individual care needs   |
| <b>7.3</b>    | Management and decision making                                    |
| <b>7.3.1</b>  | Preoperative management and decision making                       |
| <b>7.3.2</b>  | Post operative management and decision making                     |
| <b>7.4</b>    | Resources and infrastructure (disease management)                 |
| <b>8</b>      | Health and Social Care Services Research                          |
| <b>8.1</b>    | Organisation and delivery of services                             |
| <b>8.2</b>    | Health and welfare economics                                      |
| <b>8.3</b>    | Policy, research ethics and governance                            |
| <b>8.4</b>    | Research design and methodologies                                 |

## **2.3 Methods of collecting uncertainties**

The Steering Group of the PSP wanted to explore uncertainties from a variety of sources;

- a) retrospectively, via existing HTO interview transcripts (hip replacement only);
- b) prospectively via discussion groups of people with osteoarthritis who had or were awaiting knee and/or hip replacement ;
- c) prospectively via a postal and online survey of the same population in b).

Each method is described below, as well as a summary of the data management process.

### 2.3.1 Collecting uncertainties from Health Talk Online transcripts

The set of 16 transcripts was inspected and reported on by Alix Brazier, a medical student on a four week placement with the Health Experiences Research Group (HERG), who was supported in the task by Louise Locock and Helen Salisbury, GP and HERG medical adviser. The transcripts concerned the perspectives of hip replacement surgery only, and was a smaller set of interview transcripts compared to the normal size of approximately 40 interviews for an HTO exercise. Approximately three weeks was spent analysing the interviews and producing the PICO (Population, Intervention, Comparison and Outcome) formatted questions, which are favoured by the JLA. The most interesting challenge in completing the task was applying the concept of 'treatment uncertainty' to the interviewee's natural talk. Louise Locock made the point that people don't "*identify things in that way and a throwaway comment about what they were told might reveal their own uncertainty as to whether that was correct*".

The key skills needed to undertake this sort of task (as identified by HERG) were the ability to qualitatively interrogate and interpret people's accounts, and see beneath the surface of the interview transcript. There was some speculation about the role of social science and clinical skills that may help to spot uncertainties and the team felt that, on balance, having both skill sets would be the safest approach to ensuring that nothing was missed from the exercise, and enabled a degree of testing of each others' perspectives.

Currently a GP colleague at HERG is reproducing this exercise in a collection of transcripts concerning Depression for another JLA PSP, and a medical-student led analysis on Parkinson's has been provided for another PSP so these will be interesting to compare and contrast.

The results were presented to the JLA PSP Steering Group, who reviewed the material and were happy to include it in the data set, with some exclusions. These were about aetiology and pain relief unrelated to replacement surgery and not included. The remaining questions covered a range of issues including; effective pain relief, predicting success of the operation, long term effects of replacement surgery, the safety of anaesthetic, post-operative home modifications, thrombotic events post operatively, and post-operative posture.

Here is an example of the work on the one of the extracted uncertainties:

**Theme:** Insufficient effective analgesia post-operatively if patient allergic to morphine.

**Original data (HIP03)** 'when I'd had the operation, I wasn't free of pain for a long time. They were very good to me in the hospital, they gave me masses of painkillers, but I'd showed an intolerance to opiates and that made it extremely difficult because nearly everything has got morphia in it, that is a good painkiller.

**Interpreted** from original data in black, suggested data in red:

- Synthetic morphine, Tramadol, equally good at pain relief?
- Can tramadol still cause allergic reaction in those allergic to morphine?
- **P: patients post-hip replacement, allergic to morphine**

- **I: non-morphine medications; to see which is most effective at pain relief**

Resulting in the **PICO question**: *Which drugs are most effective in relieving pain in patients, who are allergic/intolerant to morphine, after hip replacement?*

The full summary of the data extracted from the interview transcripts is available in Appendix 3. It is worth noting that, as this was an exercise in extracting data from an existing source, the items identified were those that were looked for i.e. *treatment* uncertainties. It may be that the data held a wider range of uncertainties that were not identified as not matching this brief. In collecting data from primary sources (i.e. from the patients/ carers themselves) PSPs are increasingly gathering uncertainties that go beyond the issue of treatment and care.

### **2.3.2 Patient, and carer discussion groups**

These were held in the summer/autumn of 2013, at the Botnar Research Centre in Oxford. In addition, the NIHR Manchester Musculoskeletal Biomedical Research Unit, which has an Arthritis Research UK Research User Group, offered to host a short session in September 2013 to talk about the PSP, and discuss treatment uncertainties.

#### ***i) Oxford patient and carer discussion group***

##### *Objective*

To discuss treatment uncertainties with people who have had hip and knee replacement surgery due to osteoarthritis (OA), in order to highlight uncertainties for the hip and knee replacement priority setting partnership (PSP).

##### *Participants*

There were 8 participants, drawn from across the UK via partner organisations and from the Nuffield Orthopaedic Centre. All 8 individuals had OA and hip and/or knee surgery. Participants came from a variety of background and contexts and had differing treatments including, but not limited to, total knee replacements (TKR) and unicompartmental knee replacements (UKR), hip replacements, femur replacement, knee cap removal, revision surgery and meniscectomy. Some of the participants had more than one of these surgeries; some was recent surgery (3 weeks prior to the meeting) whereas some had experiences from many years previously.

It is worth noting that the PSP Co-ordinator invested a lot of time in building relationships with a number of the participants in advance, providing written information, and organising travel arrangements where appropriate.

##### *Process*

Following an informal lunch with the facilitators to put participants at their ease, they were given an overview of the JLA PSP process and UK DUETs, with the opportunity to ask questions. The group were reminded that this was not a forum for complaints but a place to discuss treatment uncertainties, specifically;

- Any experience (personal or otherwise) that had caused frustration in terms of their treatment.
- Any questions about surgery for OA that they thought needed to be answered.



- Any aspects of OA treatment, focussing on surgery, that they thought were uncertain.

After a warm-up exercise, the group worked in 3 smaller groups to generate written questions. These were then discussed one at a time in the whole group, culminating with the facilitator paraphrasing and recording the question with the groups' agreement. Some questions were initially felt to not be valid. An interesting example was "Does 'making a fuss' help referral?" This was initially not considered a real question; however, the group discussed it and agreed that it was valid and concerned how the interplay between Doctor and Patient worked in getting seen quicker or getting a better consultation. It made the long list and nearly the shortlist of questions - Rank 39.

In addition, one of the PSP Steering Group members, who was unable to participate in the discussion group, contributed a series of written experiences and associated questions. These were added into the appropriate categories identified at the discussion group and are highlighted as 'contribution from FO' in the full report which is available separately.

### *Output*

The output from the discussion, suggested treatment uncertainties, fell into the following categories; primary care (GP) and referral, pre-operative assessment, criteria for surgery, timing and expectations of surgery, differences in surgical practice and opinions, pre-operative information and support, the role of co morbidity in success, post-operative care and infection, use of TED stockings, joint replacement failure, allergy to joints, long term effects of devices, long term effects of anaesthesia, physiotherapy and structured exercise, normal exercise and daily living activity, measuring quality of life, pain relief (both post-operatively and longer term).

All the treatment uncertainties suggestions generated by this discussion group are in Appendix 4a.

In summary;

- The quality of the debate was excellent, and it felt very 'social';
- Participants were very respectful of each other's experiences and views;
- The yield of questions was high, and people worked hard to generate them;
- Feedback response was high, with most of the group sending postal or online changes and suggestions on receipt of the discussion group report.

### ***ii) Manchester patient and carer discussion group***

A much shorter session was run with the Manchester based BRU Research Users Group (RUG). This was at their normal half day meeting where researchers present their studies for comments and feedback and, as such, was not a dedicated session in the same way as the Oxford Group. The makeup of the group was very mixed and included people with a wide range of musculoskeletal arthritic conditions; of the total group, 4 had experience of Osteoarthritis and hip and knee replacement.

A similar short presentation was given about the JLA PSP and UKDUETs which prompted a lot of discussion and questions. This reduced the time available for generating uncertainties; however, they were discussed and generated into a short report which is available separately. This was checked with the participants for any inaccuracies and amendments.

The group made eleven suggestions - available at Appendix 4b – of which only one suggestion was actually relevant to this PSP and included in the data set (Why is surgery usually considered the last option in OA?). The rest were kept to one side for the next PSP looking at earlier OA.

It is worth noting that the PSP Co-ordinator had no direct contact with participants at this group, and so the preparatory work was not the same as for the Oxford group.

In summary;

- This opportunity produced fewer uncertainties compared to the specific PSP discussion group in Oxford;
- For this approach to be more useful, it would need the whole session to be dedicated to the PSP discussion, and for information to be provided in advance directly to the participants.

### **2.3.3 Online and postal survey**

The initial starting point for the survey was a review of existing examples from other PSPS, where a survey approach is the most commonly adopted. One of Andrew Price's Doctoral students – Kristina Harris - dedicated a generous amount of time to this task – developing the survey in Survey Monkey in such a way that patient/ carers and health professionals could follow an appropriate path through the questions. The first draft was reviewed and discussed in detail by the Steering Group, together with a communications plan for recruiting to the survey. Several iterations later, and following internal piloting, it was ready to distribute (with supporting information) and was available between July - September 2013 online. Fewer than anticipated postal surveys were sent out on request, to interested individuals and Musculoskeletal Patient and Public Involvement groups, and were also made available in some orthopaedic clinics (with postage paid return envelopes).

Overall 266 completed surveys were returned via postal and online routes, the majority being online. Most of the surveys contained more than one suggested research question. Initial analysis of these yielded 269 questions from professionals and 239 from patients and carers.

It is not the objective of this project to provide a detailed account of the postal and online survey process and results, however the spread of people who responded is shown in Appendix 5. Many of the questions from the surveys overlapped with questions generated from the discussion groups, and from the extracts from Healthtalkonline transcripts – Section 3 discusses this.

In summary;

- Online and postal surveys are the default method for collecting treatment uncertainties from patients and carers and health professionals;
- The process of developing and piloting the survey is an early activity that unites the partnership in terms of process and outcome;
- It is relatively easy to set up online using survey monkey, which allows for patients/ carers and health professionals to take separate pathways through the survey;

- Managing the responses through survey monkey is easier than from hard copy, although preparing pdf copies of either the patient/ carer or professional version to print is straightforward;
- It is easy to advertise the survey using online social media, via e-mail through partner organisations, and more traditional routes such as clinics;
- The survey alone yields a high number of treatment uncertainties;
- It is important to have a data manager in place who has experience of handling large amounts of quantitative and qualitative data items.

## **2.4 The data management/ prioritisation process**

The survey data sets from healthcare professionals and patients/ carers were kept separate from each other, the PICO questions generated, and the HRCS classification applied. The discussion group and HTO uncertainties were fed in, either to support existing questions or to create new ones. Just before an interim prioritisation workshop, the HRCS classification framework was reviewed and amended in order to make it more relevant to the hip and knee replacement for osteoarthritis data. Following this review, some questions were merged (either against existing or newly formulated PICO questions), and some removed for decisions about inclusion at the workshop. The data sets were combined for presentation to the workshop participants, following which more questions were merged – again either against existing or newly formulated PICO questions; some questions were set aside for the next PSP on earlier OA, and some removed as being either out of scope or already answered and therefore not uncertainties. The remaining long list of questions was formatted to allow the members of the Interim Group to vote for their personal top 30 questions, and the results were collated to arrive at the collective top 30, with some last minute finessing of the questions. The top 30 were then presented to the Final Workshop, which resulted in final prioritisation and some further merging (see Appendix 6).

## **3. Comparing the methods and treatment uncertainties**

### **3.1 The comparison process**

In order to understand the spread of questions from each method across the HRCS framework (see Table 1), what happened to the HTO data, where the top ten questions came from, and the costs involved, we reviewed the data at the following time points:

- the personal data set following the revision of the HRCS codes, prior to the Interim Workshop;
- the merged data set following the Interim Workshop;
- the results of the Interim Voting exercise;
- the top 30 as presented to the Final Workshop;
- the top 21 resulting from the Final Workshop.

In addition, we reviewed the Minutes of the Steering Group meetings, the budget/ expenditure records, the HTO data report provided by Alix Brazier (see Appendix 3), and the reports from the two patient discussion groups. Finally, we drew on the work to prepare the top 10 for the UK Database

of Uncertainties about the Effects of Treatments (DUETs). This was a complex process, highlighting the need for clear version-tracking of the data set as it progresses through many iterations.

Section 3.2 shows the spread of questions across the HCRS classification framework; Section 3.3 discusses what happened to the HTO data; Section 3.4 sets out where the top 10 questions came from; and Section 3.5 considers the costs involved.

## 3.2 The spread of questions

Table 2 maps the three data collection methods to the HCRS classification codes. The survey (data from patients and carers) has the most categories populated by suggested uncertainties, which may reflect the increased diversity of people making suggestions compared to the discussion groups, and the HTO interviewees.

Category 6 (evaluation of treatments) shows the most correlation across the different collection methods of suggestions for uncertainties; this is perhaps not surprising given that many contributors will be making suggestions based on the lived experience of hip and knee replacement. Category 6 has the most similar questions across the three collection routes, and the largest amount of questions compared to other categories.

**Table 2: Uncertainties collected by different methods according to HCRS code**

| UKCRC HCRS Code | Topic area  | JLA Survey | Discussion Groups | Excerpts from HTO transcripts (hips only) |
|-----------------|---|------------|-------------------|---|
| 1               | Underpinning Research   |            | x                 |   |
| 2               | Aetiology   | x          | x                 | x   |
| 3               | Prevention of Disease and Conditions, and Promotion of Well-Being | x          | x                 |   |
| 3.3             | Nutrition and chemoprevention                                     |            |                   |   |
| 3.5             | Resources and infrastructure (prevention)                         |            |                   |   |
| 4               | Detection, screening and diagnosis                                | x          | x                 | x   |
| 4.1             | Discovery and preclinical testing of markers and technologies     | x          |                   |   |
| 4.1.1           | Predictors of postoperative success                               | x          | x                 | x   |
| 4.2             | Evaluation of markers and technologies                            | x          |                   |   |
| 4.5             | Resources and infrastructure (detection)                          |            |                   |   |
| 5               | Development of Treatment and Therapeutic Interventions            | x          |                   |   |
| 6               | Evaluation of Treatments and Therapeutic Interventions            | x          | x                 | x   |
| 6.1             | Pharmaceuticals   | x          | x                 | x   |
| 6.3             | Medical devices   | x          |                   | x   |
| 6.3.1           | Safety  | x          | x                 | x   |
| 6.4             | Surgery   | x          | x                 |   |
| 6.4.1           | Co-morbidity  | x          | x                 | x   |
| 6.4.2           | Surgical techniques and intervention                              | x          | x                 |   |
| 6.4.3           | Success of intervention   | x          | x                 | x   |
| 6.6             | Psychological and behavioural                                     | x          | x                 |   |
| 6.7             | Physical (physio/exercise)  | x          | x                 |   |
| 7               | Management of Diseases and Conditions                             | x          | x                 |   |

| UKCRC<br>HCRS<br>Code | Topic area  | JLA<br>Survey | Discussion<br>Groups | Excerpts from HTO<br>transcripts (hips only) |
|-----------------------|---|---------------|----------------------|--|
| 7.1                   | Individual care needs                             | x             |                      | x  |
| 7.3                   | Management and decision making                    | x             | x                    |  |
| 7.3.1                 | Preoperative management and decision making       | x             | x                    | x  |
| 7.3.2                 | Post-operative management and decision making     | x             | x                    | x  |
| 7.4                   | Resources and infrastructure (disease management) |               |                      |  |
| 8                     | Health and Social Care Services Research          |               |                      |  |
| 8.1                   | Organisation and delivery of services             | x             | x                    |  |
| 8.2                   | Health and welfare economics                      | x             |                      |  |
| 8.3                   | Policy, research ethics and governance            | x             |                      |  |
| 8.4                   | Research design and methodologies                 |               |                      |  |

There are 5 categories (highlighted in **brown text**) where only the survey has picked up suggestions for uncertainties, including development of treatments, economic questions and research design. This may reflect the much wider base of patients and carers that contributed to the survey, compared to the much smaller numbers of people that were involved in either discussion groups or HTO interviews. It may also reflect the challenges inherent in analysing secondary data (see Appendix 2 for the review of the literature) for treatment uncertainties, as well as being able to identify questions of relevance that may not be as obvious as an uncertainty. One category (highlighted in **blue text**) was populated only from the patient Discussion Groups. The HTO data informed topics already informed by the other two methods.

### 3.3 What happened to the HTO hip uncertainties?

The hip uncertainties were located and tracked for their progress. Table 3 gives the detail for the outcome of each HTO uncertainty. Of the 14 PICO questions that were formulated, six were removed (for different reasons), two remained in the dataset but did not progress in the prioritisation process, and one was merged with similar questions and made it to the long list stage and so was included in the interim prioritisation, but did not progress to the shortlist stage.

Five were merged with similar questions and made it to the shortlist, and thus were discussed at the final prioritisation workshop. All of these then progressed to the Top Ten (see Section 3.4).

The questions about predicting longevity of replacement surgery and predicting post-operative pain were combined with a bigger question about pre-operative predictors for post-operative success, which was prioritised to number 3. The question about non-morphine pain relief was merged with similar questions about pain relief and prioritised to number 5, and the question about protecting patients from thrombotic risks was number 10.

**Table 3: Tracking the HTO hip uncertainties**

| ID  | PICO Question                            | Outcome of question (NB. ID relates to HCRS Classification)  |
|-----|--|--|
| 221 | What are the causes of end stage hip OA? | <b>Removed</b> - does not address issues of hip replacement - this uncertainty will be used for another PSP that will address earlier OA |

| ID  | PICO Question   | Outcome of question (NB. ID relates to HRCS Classification)   |
|-----|---|---|
| 222 | Propensity to develop arthritis in contralateral hip if already affected one hip?   | As above  |
| 232 | What are the predictors of post op pain?  | <b>Top Ten (Number 3)</b><br>Merged with questions concerning post-operative outcomes (ID 4) " <i>In people with OA, what are their pre operative predictors of post operative success (and risk factors of poor outcomes)</i> ".   |
| 235 | What are the predictors of hip/knee implant longevity?  | <b>Top Ten (Number 3)</b><br>Merged with questions concerning post-operative outcomes (ID 4) " <i>In people with OA, what are their pre operative predictors of post operative success (and risk factors of poor outcomes)</i> ".   |
| 250 | What are the risks and benefits of steroid injections into hip to relieve pain?   | <b>Removed</b> - does not address issues of hip replacement - this uncertainty will be used for another PSP that will address earlier OA  |
| 255 | Does smoking influence the postoperative recovery?  | <b>Removed</b> - it is a certainty.   |
| 256 | How effective is a non-morphine based postoperative analgesia?  | <b>Top Ten (Number 5)</b><br>Merged with similar Q's (ID 6.1) " <i>What is the optimum pain control regime pre-operatively, peri-operatively, and immediately post operatively for hip and knee joint replacement surgery?</i> "  |
| 263 | How can negative effect of general anaesthetic be predicted and minimised?  | <b>Removed</b> – to PSP on anaesthesia  |
| 267 | What are the consequences of dislocation of the replaced hip?   | <b>Original data set</b> - did not progress   |
| 272 | What are the long term effects of hip replacement surgery?  | <b>Long list and interim vote</b><br>Merged with similar Q's (ID 6. 4.1) " <i>What are the long-term outcomes of conservative treatment compared to operative treatment for patients with knee/hip OA?</i> "  |
| 278 | Are patients undergoing hip replacement surgery under increased risk of forming blood clots?  | <b>Top Ten (Number 10)</b><br>Merged with 2 similar questions from health professionals, concerning the role of TED stockings - (ID 6.3) final Q amended at the workshop to; " <i>What is the best way to protect patients from the risk of thrombotic (blood clots, bleeding) events associated with hip/knee replacement?</i> " |
| 284 | What are the necessary postoperative home modifications?  | <b>Top Ten (Number 9)</b><br>Merged with questions concerning post-operative care<br>" <i>What is an ideal postoperative follow up period and the best long term care model for people with OA that have had hip/knee replacement?</i> "  |
| 329 | Are patients who have a revision post Birmingham hip resurfacing having better outcomes than patients undergoing a revision following standard hip replacement? | <b>Removed and sent to National Joint Registry for their attention</b><br>Merged with similar Q's (ID 6.4.3) " <i>Which type of replacement or prosthesis has the best survival and outcome?</i> "  |
| 332 | Does lying flat post operation reduce oedema risk?  | <b>Original data set</b> - did not progress   |

### 3.4 Data sources for the Top Ten questions

Following the final prioritisation workshop a Top Ten were agreed by a mixed group of patients, carers and health professionals. An overview of the prioritisation and data management process is described in Section 2.4 above, and summarised in the flow chart in Appendix 7. Table 4 below provides an overview of how many PICO questions inform each of the top ten, together with the number of original submissions and their source.

In some cases, the final question was a PICO question that was formed early in the process, which easily encompassed a number of other questions. In other cases, the final question was formed at a later stage to better describe the range of questions included. In the former case, the original PICO question is counted in the number of questions included, because it also had original submissions directly against it. In the latter case, the final question is not counted in the number of questions because it did not have original submissions directly, but gathered together all the contributing submissions – these questions are denoted by the asterisk in the table.

Looking at the table it can be seen that:

- 9 out of the 10 questions were informed by the patient/ carer survey responses;
- of those 9, 5 were also informed by the patient/ carer discussion groups and 3 by the HTO data;
- of the 5 that were also informed by the discussion groups, 2 were also informed by the HTO data;
- one question (number 10), was informed **only** by the HTO data, in addition to the health professional voice;
- the number of patient/ carer original submissions that informed each question varied from 1 single voice (questions 6 and 7), to 27 voices (question 2);
- the patient/ carer voice was present in ALL the top ten questions thanks to the HTO data;
- the patient/ carer voice was strengthened in question 5 thanks to the HTO data;
- the patient discussion group contributions don't appear to add much to the mix.

**Table 4: The Top Ten questions and where they came from**

|   | Uncertainty  | No. of PICO questions included | No./ source of original submissions  |
|---|--|--------------------------------|--|
| 1 | What are the most important patient and clinical outcomes in hip and knee replacement surgery, for people with OA, and what is the best way to measure them? | 16*                            | Uncertainty identified by 12 patient/carers, 15 clinicians, and <b>2 from patient/ carer discussion groups</b>                         |
| 2 | What is the optimal timing for hip and knee replacement surgery, in people with OA, for best post-operative outcomes?  | 4                              | Uncertainty identified by 26 patient/carers, 2 clinicians, and from <b>1 patient/carers discussion group</b>                           |
| 3 | In people with OA, what are their pre-operative predictors of post-operative success (and risk factors of poor outcomes)?                                    | 28                             | Uncertainty identified by 21 patient/carers, 41 clinicians, from <b>1 patient/ carer discussion group</b> , and from <b>3 HTO data</b> |

|    | Uncertainty  | No. of PICO questions included | No./ source of original submissions  |
|----|--|--------------------------------|--|
| 4  | What (health service) pre-operative, intra-operative, and post-operative factors can be modified to influence outcome following hip and knee replacement?                          | 26*                            | Uncertainty identified by 8 patient/carers, 30 clinicians, and <b>2 from patient/carer discussion group</b>                  |
| 5  | What is the best pain control regime pre-operatively, peri-operatively, and immediately post-operatively for hip and knee joint replacement surgery for people with OA?            | 14*                            | Uncertainty identified by 2 patient/carers, 21 clinicians, and <b>2 from HTO data</b>  |
| 6  | What are the best techniques to control longer term chronic pain and improve long term function following hip and knee replacement?  | 7*                             | Uncertainty identified by 1 patient/carers, and 14 clinicians  |
| 7  | What are the long-term outcomes of non-surgical treatments compared to operative treatment for patients with advanced knee/hip OA?   | 6                              | Uncertainty identified by 1 patient/carer, and 6 clinicians  |
| 8  | What is the most effective pre and post-operative patient education support and advice for improving outcomes and satisfaction for people with OA following hip/ knee replacement? | 25                             | Uncertainty identified by 10 patient/carers, 32 clinicians and 1 from <u>clinician discussion group</u>                      |
| 9  | What is an ideal postoperative follow up period and the best long term care model for people with OA that have had hip/knee replacement?   | 11                             | Uncertainty identified by 20 patient/carers, 4 clinicians, <b>1 from patient discussion group</b> and <b>1 from HTO data</b> |
| 10 | What is the best way to protect patients from the risk of thrombotic (blood clots, bleeding) events associated with hip/knee replacement?  | 3*                             | Uncertainty identified by 2 clinicians, and <b>2 from HTO data</b>   |

### 3.5 Costs associated with each method

The main aim of this report is to attempt to capture the costs and benefits of gathering suggested treatment uncertainties in different ways, by reviewing the experience of the PSP on hip and knee replacement for osteoarthritis. In particular, the report aims to understand the viability of using existing HTO transcript data to inform research priorities.

Where possible, we gathered the direct costs associated with each data collection method, identified the areas of hidden costs, and then attempted to estimate the total costs. These are summarised in Table 5 below, together with the total number of original submissions and the contributions to the top ten.

Hidden cost areas included meeting rooms, copying/ printing and post, the time of the PSP Co-ordinator and Chair, as well the time and expertise of Kristina Harris and Jessica Davies in data management. The HTO data extraction exercise had no direct costs for this particular PSP as it was a pilot to help determine the value of the contribution that HTO data might be able to make, but did involve time of Alix Brazier, Louise Locock and Helen Salisbury, GP and HERG medical adviser. It is worth noting that the actual cost to future PSPs of HTO involvement would depend on factors such as the length of transcripts (there are usually about 40 in a collection) and whether the person conducting the analysis is working as a volunteer or not.



The notes to Table 5 explain on what basis costs were estimated. The exercise is by no means complete, but provides an indication.

Appraising Table 5 – and revisiting the spread of question across the HRCS codes in Table 2 – initially suggests that the survey is the most cost effective approach in terms of numbers of uncertainties suggested by patients and carers, breadth of coverage of topic areas, and the likelihood of their prioritisation to the Top Ten.

The specific discussion group (Oxford) yielded a large number of suggestions for treatment uncertainties across a smaller spectrum of topics, and these were represented in 5 of the Top Ten in the final prioritisation exercise. As noted in Section 3.4, however, they did not provide any unique questions, neither did they add weight to any questions where the patient voice was low.

The non-specific discussion group (Manchester) proved interesting, but did not yield many useful suggestions for this PSP, although some will be carried through to the next PSP.

Although, on the surface, it seems as if the HTO data yielded the least amount of usable questions for the process, and the least breadth of topics, four of these items were included within the Top Ten, adding the patient voice to a question that would otherwise have been clinician-led. This could be interpreted as providing a unique question from the patient/ carer perspective. In addition, as noted in Section 3.4, the HTO data also added weight to one question where the patient voice was very low.

Referring back to Table 4, we can map the patient/ carer contribution to the Top Ten as follows:

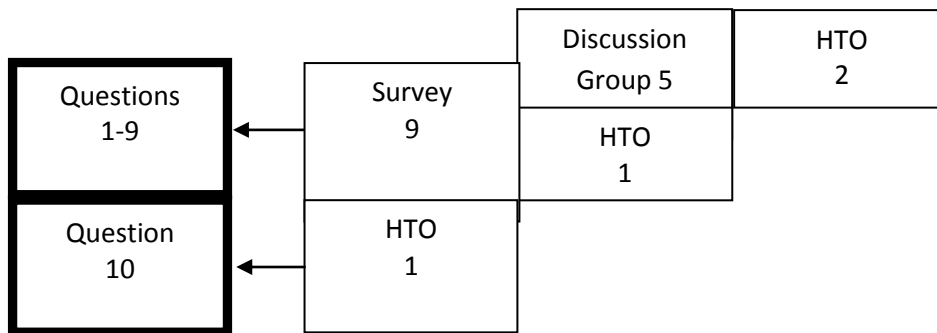
**Table 5: Costs and results**

| Method                              | Direct costs   | Estimate of hidden costs where possible   | Total estimated costs  | Number of questions suggested                 | Contribution to top 10 questions (where currently known) |
|-------------------------------------|--|---|--|---|--|
| Survey                              | <ul style="list-style-type: none"> <li>Data management/ analysis £3000</li> <li>Survey monkey upgrade £303</li> <li>Poster for clinics £22.50</li> </ul> <b>Total £3325.50 (inc. VAT where applicable)</b>   | <ul style="list-style-type: none"> <li>Additional time spent on data management/ analysis (see Note 1)</li> <li>Co-ordinator support time (see Note 2) £1575</li> <li>Copying/ printing and mailing &gt;£23.85 (see Note 3)</li> </ul> <b>Potential additional costs total &gt;£1598.85</b>   | <b>&gt;£4924.35</b>  | 508 in total<br><br>239 from patients/ carers | 9  |
| Oxford patient discussion group     | <ul style="list-style-type: none"> <li>Travel £338.10</li> <li>Refreshments £187.20 (inc. VAT)</li> <li>Costs of facilitator and observer, and write up £916.80 (exc. VAT)</li> </ul> <b>Total £1,442.10</b> | <ul style="list-style-type: none"> <li>Meeting rooms provided by Botnar Research Centre (see Note 4) £300</li> <li>Co-ordinator time to arrange, liaising with patients especially (see Note 2) £1575</li> <li>Stationery and copying/ printing (see Note 3)</li> <li>Participants' time (see Note 5) £550</li> </ul> <b>Potential additional costs total £2425</b> | <b>&gt;£3867.10</b>  | 42  | 5  |
| Manchester patient discussion group | <ul style="list-style-type: none"> <li>SC travel and time £720 (exc. VAT)</li> </ul>   | None – assume room costs and participant time covered as part of their regular meeting  | <b>£720 exc VAT</b>  | 11  | 0  |
| HTO hip data                        | None for this PSP (see Note 6)   | <ul style="list-style-type: none"> <li>Medical student's time spent on analysis, PICO formation and reporting (see Note 6)</li> <li>Louise Locock's and Helen Salisbury's time in support</li> </ul>  | <b>£0 (pilot) Estimated cost for future PSPs &lt;/&gt;£3000 (see Note 6)</b> | 14  | 4  |

**Notes:**

1. Some of Kristina Harris' time was compensated to her directly, in recognition of the amount of time spent over and above her normal hours of work. If we had an estimate of the total number of hours spent by KH and Jessica Davies, we could estimate the additional hidden cost.
2. As PA to Prof. Price, this was contributed by NDORMS. For the period covering the Survey and Discussion Groups, this was running at 50-60% FTE at Grade 5. Assuming 3 months at 50% this is approximately £3500 of salary (excluding costs of salary), the majority of which was spent in supporting the survey and arranging the Patient Discussion Group. An estimated split of time across the 3 activities is 45:45:10 – Patient Discussion Group and Survey £1575 each, and Clinician discussion Group £350.
3. As well as office space, NDORMS provides paper, pens, copying facilities and access to the postal services offered by the NOC. Where surveys or letters were mailed to the public, they were accompanied by a return envelope, the costs of which would have been also borne by the Department. There was not a huge amount of mailing – we don't have records; an estimate would be 30 letters/ surveys sent out, with a 50% return. This would be 45 items – based on current 2<sup>nd</sup> class costs, this is equivalent to £23.85. The Department probably has some way of calculating the overhead that might be attributable to this activity.
4. The Botnar Research Centre has a number of meeting rooms, some of which are big enough to accommodate the Discussion Groups. Each Oxford Discussion Group tied up two interconnected rooms for half a day. Equivalent Meeting Rooms in the Magdalen Centre on Oxford Science Park run at £300 for half a day, so this equates to £600 (exc VAT).
5. 8 patient/ carers, and 14 clinicians participated in the Oxford Discussion Groups for half a day. That equates to 4 days of patient/ carer time and 7 days of health professional time. If we assume patient/ carers are retired, how would we value their time? If we assume they are working professionals, and we assume an annual salary of £30k with 220 days per year available for work, that equates to circa £550. If we assume an average salary for the mixed group of health professionals of £55k with 220 days per year available for work, that equates to £1750. NB. Calculations exclude travel time.
6. If we knew how much time Alix Brazier and Louise Locock spent on the activity, and had day/ hourly rate assumptions to work with, we could estimate the hidden cost. For future reference, HTO has estimated an amount of £3000 based on 7 days of transcript reading, 3 for analysis/ general communication with the commissioning team, and 2 for workshop participation, at £250/ day. This would be less if the bulk of the work were done by a volunteer.

## Map of patient/ carer contribution to the top ten



This shows that only 3 questions were generated **uniquely** by the patient/ carer voice in the survey.

The question then becomes one of how to attribute value. We could look at it in three different ways:

a) We could divide the direct costs by the number of uncertainties generated in terms of original submissions. This would result in a cost per original question of:

- Survey - £6.55 (£3325.50/ 508 );
- Oxford Discussion Group - £34.34 (£1442.10/42);
- Manchester Discussion Group - £65.45 (£720/11);
- HTO - £0 (£0/14). NB. if this PSP had paid £3000 for the HTO work, the result would be £214.26 (£3000/14)

b) We could divide the direct costs by the number of questions that formed part of the top ten. This would result in a cost per question of:

- Survey - £173.94 (£6.55\*239=£1565.45/9);
- Oxford Discussion Group - £288.42 (£1442.10/5);
- Manchester Discussion Group – no questions, therefore £720 for nothing;
- HTO - £0 (£0/4). NB. if this PSP had paid £3000 for the HTO work, the result would be £750 (£3000/4)

c) We could: attribute the direct costs of the survey to the 3 questions uniquely contributing; assume that as 2 of the 5 contributed by the patient/ carer discussion group were also contributed by the HTO data, the remaining 3 were unique to the discussion group and so attribute those direct costs to 3 questions; and attribute the 4 HTO questions to those direct costs. Then we would have a per question cost of:

- Survey - £521.82 (£1565.45/3);
- Oxford Discussion Group - £480.70 (£1442.10/3);
- Manchester Discussion Group – no questions (therefore £720 for nothing);
- HTO - £0 (£0/4). NB. if this PSP had paid £3000 for the HTO work, the result would be £750 (£3000/4)

In all 3 scenarios the HTO data cost this PSP nothing directly, and the data can be seen to have made 1 unique patient contribution to the top ten. However, if the HTO data had cost this PSP £3000 the story would be different and, in all scenarios this would become the least cost-effective method.

In scenarios (a) and (b) the survey can be seen to be more cost-effective than the Oxford Discussion Group, with the Manchester Discussion Group being not effective.

However, in scenario (c) where we assume the survey to be responsible for 3 unique questions and the Oxford Discussion Group to be responsible for 3 unique questions, the Discussion Group becomes marginally more cost-effective than the survey.

#### **4. Conclusions and recommendations**

There is no doubt that in the case of this particular PSP, the HTO data made a valuable contribution in the patients' voice, with no direct costs. HTO data contributed to an impressive proportion of the Top Ten considering the small number included in the data set to begin with. The HTO data yielded 1 unique patient question, and ensured the patient voice was present in all the Top Ten questions. In future PSPs this data source will need to be paid for, not least the man hours in extracting the relevant data. On HTO cost predictions this doesn't represent such value for money compared to survey and discussion group approaches, but addresses the wider issue of waste in research by using existing data rather than creating new data for the PSP.

There are issues around the currency of the HTO data, and a PSP will need to be assured that the population of interviewees represents a reasonable sample of people with the health condition that is being considered, but there is merit in exploring secondary use of HTO data for JLA PSPs we feel.

It is also clear that the Discussion Group which was not dedicated to the PSP, and was not organised by the PSP Co-ordinator, did not contribute enough to the process to consider it a useful option for the future. That is not to say that it wasn't an interesting experience, and we were lucky to be allowed time with a group of people with musculoskeletal conditions.

Both the Survey and the specific Discussion Group yielded many suggestions for treatment uncertainties from patients, carers and the public. We observed that the survey 'covered more bases' in terms of categories of suggested treatment uncertainties than the Discussion Group or the HTO data, but there was still an encouraging degree of overlap between them.

The Survey and Discussion Group data was well represented in the shortlist of treatment uncertainties that were discussed at the final PSP workshop, as well as the final Top Ten.

However if we differentiate between the Survey and the Discussion Group on a cost basis, our conclusion is that the survey is the most cost effective approach in terms of numbers of uncertainties suggested by patients and carers, breadth of coverage of topic areas, and the likelihood of their prioritisation to the Top Ten. However there are considerations about the different processes to consider; for example the Discussion Group didn't generate the number of suggestions for treatment uncertainties as the Survey, but they were well formed, had context attached to them and were entirely in the words of the patients and carers. Unlike the survey data

which, in many cases, had to be interpreted by the researcher (with help from the patient and carer members of the Steering Group) due to the free text design of the survey, and the variability of the responses.

As well as hidden costs, it is worth pointing out that there can be hidden benefits in the different approaches, for example the numbers of people reached through the survey created added publicity for the PSP. In addition, both the Survey and the Discussion Group allow recruitment of people to the final prioritisation process. However, these benefits have not been collected formally for this report – this may be another limitation of this study.

It should be noted that the Survey also collected health professional data, and a separate clinician discussion group was held. It was not the aim of this study to include the clinician voice in the comparison. It should, however, be acknowledged that their voice was present in all the Top Ten questions – but their discussion group contributed to only one question (question 8, see Table 4). Without the survey, the PSP would not have collected their contributions as effectively.

It may be a limitation of this study that the methods of collecting the clinician voice were not also considered in the comparison.

A further limitation may be that this study focused on the contributions to the Top Ten questions, and not the top 20 or 30, which would have taken more time in tracking the contributions. It should be noted that the data in Table 4 was generated by the work to prepare the Top Ten for publication in the UK DUETs, and that work has not yet been carried out beyond the ten questions.

Based on this evaluation, we would recommend the following:

1. As mentioned in Section 2.3.1, HTO data is also being piloted in two other PSPs - Depression and Parkinson's Disease. It would be useful to review the spread of sources in the Top Ten questions of each of those PSPs, in order to gain further understanding of the role of HTO data, as well as the other methods used. This would provide a more solid evidence base (in keeping with JLA values) for deciding collection methods.

It is worth noting that tracking the HTO data was a particularly challenging task, compared to the Discussion Group questions. The former were not quite so clearly defined as the latter. With this in mind, we would recommend that the HTO data report concludes with a clear list of the questions that emerge.

We also suggest that actual costs of data extraction are collected to allow comparison with estimated costs, and that the scope of uncertainties is extended beyond treatment in keeping with the wider scope of many PSPs.

2. Evaluating across PSPs the practical usefulness and costs of different collection methods could enable PSPs to make more informed decisions about which methods they use and why. This project has prompted the team to consider several evaluation questions, for example do discussion groups generate more specific and 'research friendly' questions than a survey? Does the survey approach generate a wider selection of questions, from a more diverse population? Does one particular method suit health professionals (or carers) more than other groups? Can the survey be improved to elicit categorisation of

suggested uncertainties, instead of this being decided by the analyst? This is an area worth exploration, especially with such a large number of PSPs being conducted presently.

3. It may be helpful to conduct an evaluation of different methods within a PSP e.g. different modes of collection of uncertainties are used for specific groups of people only, and results compared post hoc.
4. Future evaluation studies should explicitly include methods to capture the clinician voice and costs of these .
5. Future evaluation studies could describe more fully the benefits of collection methods, beyond their contribution to the PSP data set. These could provide additional measures of success for PSPs in terms of engagement for example.
6. All future PSPs should consider making their data process and collections easily tagged so that evaluation of outcomes can be tracked to methods and sources of data more readily.

## Appendices

### Appendix 1a: Project milestones

| Task  | Milestone                      |
|---|--------------------------------|
| Pragmatic review of published literature on secondary analysis of qualitative data.   | <b>Jan 2014</b>                |
| Review the Healthtalkonline (HTO) data mining experience including appraisal of transcripts, Alix Brazier's and Louise Locock's experience and draw conclusions about the usefulness of the data to the PSP (time taken, usefulness of outputs, relevance to PSP) | <b>Nov 2013</b>                |
| Run 1 specific patient and carer discussion groups, and visit one generic discussion group  | <b>July and September 2013</b> |
| Review the patient discussion group experience (time taken, usefulness of outputs, relevance to PSP)  | <b>Nov 2013</b>                |
| Review and describe the process of the PSP survey, and its outcomes (time taken, usefulness of outputs, relevance to PSP)   | <b>March 2014</b>              |
| Note overlaps in the data, and also what is taken through to prioritisation   | <b>April 2014</b>              |
| Develop a draft report for funder, HERG and the JLA   | <b>March 2014</b>              |
| Keep a budget record for transparency purposes  | <b>April 2014</b>              |
| Write evaluation report   | <b>May 2014</b>                |



## Appendix 1b. Timeline for gathering questions

| Time point   | Survey  | Discussion Groups   | Comments  |
|--|---|---|---|
| 2 <sup>nd</sup> Steering Group Meeting, February 2013  | Following discussion on pros and cons, the decision was taken to use both a Survey and separate Discussion Groups for Patients/ Carers and Clinicians to gather uncertainties                                     |   |   |
|  | It was decided that Kristina Harris, a Research Physiotherapist doing her Doctorate with Prof. Price, would set up and manage the survey which should go live in the Summer                                       | It was decided that the Groups would take place in the Summer following assessment of the business case   |   |
| 3 <sup>rd</sup> Steering Group Meeting, May 2013       | The first draft (based on earlier PSP examples) was reviewed and discussed, and amendments were requested; a Survey Monkey upgrade was agreed to allow greater flexibility; once revised, survey would be piloted | Dates were agreed as July 3 <sup>rd</sup> for patient/ carers and August 22 <sup>nd</sup> for clinicians; participants should be drawn from as wide a geographic area as possible |   |
|  | It was agreed that patients and clinicians could be contacted via Newsletters of various research studies   |   |   |
| July 2013  | Survey live until mid-September   | Patient/ carer discussion group held on 3 <sup>rd</sup>   | See Reports on each Discussion Group  |
| August 2013  |   | Clinician discussion group held on 22 <sup>nd</sup>   |   |
| 4 <sup>th</sup> Steering Group Meeting, September 2013 | A review of responses to date identified the need to prompt greater input from GPs, patients and psych professionals  |   | Action was taken to encourage greater response from these groups  |
| September 2013   | Survey closed with 266 responses  |   | No of questions generated by online/ postal survey: 269 from professionals and 239 from patients and carers |
| 5 <sup>th</sup> Steering Group Meeting, December 2013  | An overview of the results was presented – at this stage, there were 647 questions: 296 from professionals, and 351 from patients/ carers   |   | This total also included questions identified from HERG data  |

## Appendix 2 – Review of the literature on the use of secondary data

For clarity, the following definitions apply:

**Secondary analysis:** involves the utilisation of existing data, collected for the purposes of a prior study, in order to pursue a research interest which is distinct from that of the original work.

**Evidence summary and synthesis:** where multiple sources of evidence that are related in topic or by the research question are considered as one whole piece of evidence

**Data mining:** is to extract information from a data set and transform it into an understandable structure for further use, although the term is often misused and so will not be used in this paper.

There is now a cultural shift towards reviewing and reinterpreting existing literature to inform new research, either as secondary analysis and/or as synthesis for reviews of research. There is a 20 year history of retrieving and analysing quantitative data for secondary analysis, either narratively or numerically (meta analysis) as part of clinical and systematic reviews. While the same cannot currently be said for qualitative research, this is changing. For example, the Cochrane Qualitative and Implementation Methods Group [www.http://cqim.cochrane.org/](http://cqim.cochrane.org/) has been exploring the different methods that can be used for synthesis of primary qualitative research where a common research question is being addressed. There are now several published guides for utilising existing qualitative research for secondary purposes; Campbell R et al (2011), Candy B et al (2011) and Popay J et al (2006).

Heaton J (2004) suggests that the rationale for collecting qualitative research data for secondary analytic purposes is straightforward: a great deal of work goes into producing these data sets, and it is not always possible for the original researchers to find the time to analyse them fully. It is both economical and ethical to analyse existing data sets rather than collect new ones, as long as the data sets are adequate to answer the research questions being asked. As well as potentially saving public money, and being efficient it can also be argued that it deals with the issue of waste in research (Chalmers and Glaziou 2014), and that the original researcher gets the reflected awareness of their original work (if cited correctly).

There are also practitioners (Castellani and Castellani, 2003) who propose that large amounts of quantitative data can be reinterpreted for meaningful patterns to inform qualitative research questions.

Furthermore, Corti and Thompson (2004) suggest six uses for archived qualitative data:

1. *Description:* For example, a study of the City of London business district (Kynaston, 2001) drew on interviews done by other researchers (Courtney and Thompson, 1996) for accounts of working lives.
2. *Comparative research, re-study or follow-up:* For example, Franz et al. (1991) used data in the Murray Research Archive to follow up the children of mothers interviewed in 1951 about their child-rearing practices, comparing this later sample with the earlier one.
3. *Re-analysis:* For example, Fielding and Fielding (2000) re-analysed data collected by Cohen and Taylor (1972) on men in long-term imprisonment, identifying new themes in the material.
4. *Research design and methodological advancement:* For example, the interview guides of other researchers investigating similar topics can assist a researcher's own development of

an interview.

5. *Verification*: If a study makes important claims, other researchers can examine its original data to assess the evidence in support of those claims.
6. *Teaching and learning*: Examining original research materials can be an important resource in learning how to do research. The 'Edwardians Online' project (containing interviews with people recalling life in Britain between 1900-1918) within QUALIDATA has been designed with this purpose in mind.

Whilst there are compelling arguments to re use original qualitative data for the purposes of a research priority setting process, there are arguments within the research community that secondary analysis has serious flaws. These include; the lack of detailed contextual knowledge about the circumstances of data collection possessed by the primary researcher, the state in which the data is retrieved i.e. if researchers knew that people may do secondary analysis of their work, might they present it differently – or even collect different data? The 'secondary analysers' may have poor understanding of the context within which the data is being expressed, (although in this example HTO modules follow a standard context and process of data collection), data may be used in an inappropriate way, or in a way that doesn't reflect well with the original research, and finally, there may be issues of confidentiality, anonymising data and ethics approval for re-use of data.

I thought it helpful to consider the different methods for secondary analysis, and Barnett-Page and Thomas (2009) have collected these in one paper, and have reviewed them critically. This proved the most useful summary document to explore different methods as a background to this project, and as a non researcher I found it accessible and succinct.

They identify nine separate and distinct forms of secondary analysis and synthesis plus a category they call 'fledgling' methods, in that they were emerging at the time of publication of the review (2009).

The most obvious method that related to this project was Ecological Triangulation, formulated by Jim Banning in work with young people with disabilities. He borrows the well known triangulation theory of studying phenomena from a variety of different perspectives, to fully understand what works for individuals (in terms of interventions) in different contexts.

By gathering research perspectives from an online and postal survey, discussion groups and from existing transcripts we are exploring research questions of people with Osteoarthritis and hip and knee replacement, and those that look after them, from different vantage points. The authors suggest that the ecological triangulation "unpicks the mutually interdependent relationships between behaviour, persons and environments". The method requires that, for data extraction and synthesis, 'ecological sentences' are formulated following the pattern: 'With this intervention, these outcomes occur with these population foci and within these grades (ages), with these genders ... and these ethnicities in these settings". In this project we are not reaching anywhere near this level of exploration, and after consideration I decided that this was not a relevant theory and method for this project.

The second most promising approach and the one that I subsequently refer to was developed by colleagues at the Social Science Research Unit, Brunton and Oliver (2006), and is called Framework Synthesis. In this they apply a framework synthesis to their systematic reviews of qualitative and other evidence. This in turn is based on work by Pope, Ziebland and Mays (2000) amongst others and is based on the assumption that qualitative research produces large amounts of data in the form

of transcripts, field notes etc. and organising this data provides structures within which to analyse it. This approach uses an existing framework informed by background material and discussion, in which to populate and synthesise the findings.

There seemed to be parallels between this approach and how the Priority Setting Partnership (PSP) approached the collation and interpretation of data, using a taxonomy that is adapted by the PSP Steering Group, as new topics emerge. Data is collected in an excel spread sheet, with summary headings, and is the main tool for organising and interpreting the many hundreds of research questions that are received. There were several discussions with members of the Steering Group that informed this structure, and it evolved over time both in response to the data being collected, and the views and experiences of the Steering Group when reflecting on them.

### Appendix 3 Full PICO questions from HTO data on hip replacement surgery

#### Diagnosis and treatment

| Original data with examples of quotes from interviews   | Suggested data for PICO   | PICO question  |
|---|---|--|
| <p>Synthetic morphine, Tramadol, equally good at pain relief? Can tramadol still cause allergic reaction in those allergic to morphine? Insufficient effective analgesia post-operatively if patient allergic to morphine.</p> <p>HIP03 'when I'd had the operation, I wasn't free of pain for a long time. They were very good to me in the hospital, they gave me masses of painkillers, but I'd showed an intolerance to opiates and that made it extremely difficult because nearly everything has got morphia in it, that is a good painkiller.'</p> | <p>P: patients post-hip replacement, allergic to morphine</p> <p>I: non-morphine medications; to see which is most effective at pain relief.</p>  | <p>Which drugs are most effective in relieving pain in patients, who are allergic/intolerant to morphine, after hip replacement?</p>   |
|   | <p>P: patients diagnosed with hip osteoarthritis, in need of hip replacement.</p> <p>I: whilst still explaining risks and possible negative outcomes, inform patients greatly about positive outcomes, giving stories or putting patients in contact with those who have been pleased with their hip replacement.</p> | <p>Would more patients agree to hip replacement if there was more knowledge of the positive outcomes in the general public?</p> <p>OR</p> <p>Do patients not agree to having hip replacements due to lack of knowledge of the positive outcomes?</p> |
| <p>Back pain and leg pain presentation of hip arthritis. Delay in diagnosis due to misleading location of pain. (Eg HIP01 and HIP03)</p>  | <p>P: retrospective study: osteoarthritic hip patients who presented with back pain/ back pain and hip pain.</p> <p>I: identify any clues that could help speed the hip osteoarthritis/ back problem differential diagnosis</p>   | <p>Hip pain and back pain are often both symptoms of osteoarthritic hip. Could the causes of these symptoms be identified faster to speed diagnosis of hip osteoarthritis?</p>   |

| Original data with examples of quotes from interviews   | Suggested data for PICO   | PICO question  |
|---|---|--|
| <p>For many patients, time from start of pain to diagnosis or to treatment is very long. For those patients who then went on to have the same problem in their other hip- much faster diagnosis and treatment. Could we put more information out into the general public about how these hips feel so that patients can get their first hips treated faster and avoid pain? Or can we create a diagnostic tool or criteria to enable faster diagnosis? (One patient reports finding it hard to describe the pain, so maybe having knowledge about this in the general public could aid faster diagnosis.)</p> <p>HIP04 'the second hip... I recognised in time what was happening... everything just went the way I expected it to go'</p> <p>One patient told that 'doctor will only do the operation when the damage reaches a certain level' (HIP06). Patients living in pain for years longer than necessary to decrease chance of need for revision in a decade or so.</p> | <p>P: general public</p> <p>I: give more information about type of pain experience in osteoarthritic hip and encouragement to see doctor if experiencing such pain.</p> | <p>Could more information in the general public about the pain experienced in hip osteoarthritis speed diagnosis? (patients thinking pain will go away so waiting a long time till they see the doctor; young patients not being able to describe their pain and due to their age diagnosis is missed; diagnosis of second hip osteoarthritis much faster than first: if patients already knew what it felt like could they be diagnosed faster?)</p> <p>Aim: for patients to spend less time in excruciating pain.)</p> |
| <p>Benefits of steroid injections into hip to relieve pain. Described by several of the interviewees to not be very effective. One even reports hip hurting more after the injection.</p> <p>HIP04 'And I [um] was given steroid injections into, directly into the hip joint... (later) I was crawling up the walls in pain; I was in absolute agony and just didn't know what to do with myself. They must have caught a bit of a nerve when they did that'</p> <p>Allergy to nickel- component of hip replacement. Ceramic replacement used instead. One patient reports it making a grinding noise (HIP13). Perhaps heavier than a metal one. Could nickel be replaced by alternative metal (nickel allergy relatively common)?</p> <p>Benefits of Birmingham hip resurfacing, which conserves more</p>   | <p>P: patients post revision of Birmingham hip resurfacing or total hip replacement</p> <p>I: identify success rates: pain, functionality etc</p>                       | <p>Do steroid injections relieve osteoarthritic hip pain?</p> <p>Could nickel be replaced in the hip prosthetic to give more options to those allergic to nickel?</p> <p>The Birmingham hip resurfacing: better (in terms of duration and outcomes after future revision) for younger patients?</p>  |

| Original data with examples of quotes from interviews   | Suggested data for PICO | PICO question |
|---|-------------------------|---------------|
| original bone, meaning greater success if revision needed at a later date, compared to revision post standard hip transplant. |                         |               |

## Recovery

| Original data (or Summary) and examples of quotes from interviews (in blue)  | Suggested data for PICO  | PICO question  |
|--|--|--|
| <p>Risk of clot post-operatively. Benefit of using the anti-DVT stockings? Difficulties putting on the compression stockings as patients cannot bend past 90 degrees at the hip post-op.<br/>HIP12 'blood clot, because obviously when you're stationary that is a concern, especially post surgery'</p> <p>Hip dislocation post operation- very serious?<br/>HIP07 'Not knowing how bad the, the hip was in terms of, [um] how, what would happen to me when it came out.'</p>  | <p>P: Patients post hip replacement</p> <p>I: stockings vs no stockings</p>  | <p>Compression stockings: benefits (reducing oedema and reducing risk of DVT) versus risks (hip dislocation when putting on the stockings) in patients after hip replacement.</p>  |
| <p>Lack of support groups to discuss the operation and hear the outcomes, both positive and negative, with people who have also had or are about to have the hip replacement. Several patients say how beneficial it would be to have more knowledge in the public about the positive outcomes of hip replacements<br/>HIP08 No, and that's what I would have liked. I mean, support in the, in the sense of just have a chat with somebody. I don't know anybody who's broken a hip, and then people say to me, 'Oh, you're doing very well,' and I think, 'Well, what do you know about broken hips?' Probably nothing [laughs]. '</p> <p>One patient reports not being told anything about the operation by the surgeon (HIP08). Whether this was because the surgeon did indeed fail to explain the procedure, or whether the patient was too distressed and in pain to understand what they were being told.</p> <p>Support for more pre-operative sessions and written information explaining the procedure, what to do before, precautions to take afterwards, and possible outcomes.</p> | <p>P: patients post hip replacement</p> <p>I: inclusion in support group</p> | <p>Do patients included in a support group post-operatively recover faster than those recovering alone?</p> <p>Does extensive pre-operative education about the procedure and things to do in recovery speed the rate of recovery?</p> |

| Original data (or Summary) and examples of quotes from interviews (in blue)   | Suggested data for PICO  | PICO question  |
|---|--|--|
| <p>Benefits of lying flat post operation - avoids compression of lymph nodes (reducing oedema)?</p> <p>HIP11 'The other interesting thing was he told me to lie down flat, because sitting like this, that's where the lymph nodes are, which causes, can cause a swelling in your legs. And because you've had that type of surgeries my legs would perhaps never go back to their normal size'</p>      | <p>P: patients post hip replacement</p> <p>I: lying flat</p>   | <p>Is lying flat post-hip replacement beneficial?</p>  |
| <p>Post-operative home modifications: raised toilet seat, raised chairs, raised bed etc. all thought to reduce chance of over flexion of the joint and dislocation risk.</p> <p>HIP01 'Also, the seating arrangements, I have heard stories of people who've, whose seating, especially in the toilet, hasn't been sufficiently high, and this has actually prevented the thing seating in properly.'</p> | <p>P: patients post hip replacement</p> <p>I: home modifications</p>   | <p>Are home modifications after hip replacement, including raised loo seats, mattresses and chairs, beneficial in preventing complications post-operatively?</p> |
| <p>Many interviewees state the importance of doing the exercises prescribed rigorously. They say it aids speed recovery. Also importance of pre-operative fitness and exercise noted- might also promote faster recovery.</p>   | <p>P: patients pre hip replacement, in need of replacement</p> <p>I: (Every patient has same degree of post-op exercise.)<br/>Varying degree of pre-op exercise.</p> | <p>Does pre-operative exercise and fitness improve rate of recovery after hip replacement?</p>   |
| <p>Effects of weight, exercise and smoking on need to have revision years after replacement.</p> <p>'INT: Okay, what kind of factors do you think affect healing and recovery from hip replacements. HIP14: Weight.'</p>  | <p>P: retrospective study: patients post hip replacement of varying weights</p>  | <p>Does increased weight slow rate of recovery after hip replacement?</p>  |
| <p>Effects of smoking- does it slow the recovery process of the operative trauma.</p> <p>HIP14 'I think I read with smoking it can slow down the healing process of any trauma'</p>   | <p>P: retrospective study: smoker patients post hip replacement</p> <p>I: smoking vs not smoking</p>   | <p>Does being a smoker slow recovery rate after hip replacement?</p>   |



| Original data (or Summary) and examples of quotes from interviews (in blue)  | Suggested data for PICO   | PICO question   |
|--|---|---|
| See below  | <p>P: patients post hip replacement</p> <p>I: varying degrees of post-operative physiotherapy</p>         | What degree of post-operative physiotherapy is most useful in aiding recovery post hip replacement?   |
| <p>Inefficient communication between doctor and patient. Patients have not fully understood: causes for hip degeneration creating need for replacement; reasons behind and methods used in their care; possible risks of hip replacement; possible effects of general anaesthetic; benefits and risks of epidural anaesthesia versus general anaesthetic; possible future implications of having a hip transplant and long term effects; how serious a complication it is if hip dislocates post operation.</p> <p>Patients receive contradictory information from various branches of the healthcare staff: one patient says the surgeons told him/her to restrict movement after the operation; physiotherapists promote maximum movement and exercises (within reason- one patient faints after physiotherapy).</p> <p>HIP06 ‘... it’s this sort of slight tension between the doctors and the nurses kind of saying, you know, ‘Be really careful. Don’t do this, don’t, because it has these consequences which will set you back,’ and the physios and the occupational therapists saying, you know, ‘The sooner you get up and about and do things. You know, get out there. If you want to go for a walk go for a walk,’ you know. It’s a sort of... and so you feel, as a layperson, sort of not really quite able to judge where the balance should be in this’.</p> | <p>P: patients post hip replacement</p> <p>I: supervised physiotherapy for varying number of sessions</p> | Reinstating confidence after hip replacement: could supervised physiotherapy for a longer time course be beneficial for patients who feel anxious or unconfident after hip replacement? |
| <p>Lack of confidence in walking, coping alone, and generally in themselves post-operatively. Potential benefits of continued supervised physiotherapy or even psychotherapy to be seen.</p> <p>HIP12 ‘how unsure of myself I was when I actually went out by myself for the first time...I felt a little bit anxious. I felt my confidence had gone, and I was just...it was such a weird experience being by myself in the big bad world.’</p>   | <p>P: patients post hip replacement.</p> <p>I: psychotherapy vs no psychotherapy</p>                      | Reinstating confidence after hip replacement: could psychotherapy help patients feel more ‘recovered’?  |

## Appendix 4 Data from patient discussion groups

### a) Oxford

#### Primary care (GP) and referral

1. What are the criteria GPs use to refer a patient?  
There was a reported reluctance for GPs to refer to a consultant; some GPs expect 'bone grinding' before they will refer. If referral is too late does this affect the outcome of the surgery (see question 9)? Reports that GPs expect patients to live with OA and that it is part of the wear and tear and '*it's part of growing old*'. Does '*Making a fuss*' to help referral? Some GPs have used a diagnostic questionnaire to help them decide when to refer.
2. Do GPs know about all the possible treatments available for OA?  
Now CCGs hold the finances will this impact on treatments for OA? GPs openly say '*there is no cure for OA*'. Do GPs know about potential advances in surgery?
3. Is referral age related rather than using valid diagnostic criteria/decision aides?  
GPs say that some people are too young, at 56 a person with OA was told they were too young – '*too young for what*'? Do some GPs expect patients to be too old and die before they would be able to have surgery. Decision aides are reported to not be widely used.

#### Pre-operative

4. Does the pre-op assessment really capture all the issues that the surgeon needs to be aware of in order to address those issues?  
The pre-op assessment should investigate what the particular difficulties are for that patients, it may be that the surgeon needs to be aware of these issues fully in order for the operation to be a success. Patients should have the opportunity to highlight any specific difficulties and expectations of each patient.
5. What is the effect of better pre-op assessment of the likely effects of anaesthetics on memory, especially in older patients, on overall outcome?  
*There needs to be better assessment of the suitability of epidurals vs general anaesthetics in older patients Contribution from FO*

#### Surgery

6. What criteria are used to judge the success of surgery?  
Patients, clinicians and health care professionals (HCPs) have differing views on this. Clinician focus may be on the technical success of the surgery and x-rays etc whereas for the patient the focus would be on resulting pain and mobility. After a hip replacement '*Is walking with 2 sticks really a success*'?
7. What role does the interplay of patient/surgeons expectations of the surgery have?  
The expectations of the patient need to be managed i.e. The level of pain may be less than the current agony of OA but the knee will not necessarily become pain free. If these expectations are managed appropriately the surgery may be more successful.

8. What is the best method of deciding the timing of the surgery?  
 There is discrepancy between surgeons as to when best to do the operation, some would wait whereas some people have had surgery to be told that they should have had it done earlier. Some evidence that questionnaires about pain and activities have been completed in the past. Some surgeons want to wait until a patient is older – is this to prevent possible revision surgery? *Is it better to intervene early to prevent further degradation, or hold off in the hope of some non-surgical improvement? (Also relates to differing experiences in Germany and UK)*  
*Contribution from FO.*
9. Why are the opinions of surgeons so different, do they have different criteria to work from?  
 Some are pro-surgery and some are not, is this due to cost, opinion, chances of success, chance of requiring revision surgery?
10. How many times can you have knee revision surgery?  
 Is this all down to advances in technology? Is bone density a factor too?
11. Are outcomes better with a TKR rather than a UKR followed by a TKR?  
 UKR is less invasive but do you with better/worse mobility with a UKR?
12. What is the role of osteoporosis in replacement surgery?  
 Is surgery less successful, how does it affect the outcome? *'with hindsight they would not have had the operation because the outcome was poor'*
13. What is the best way for patients to get all the information they need to make their decision on surgery?  
*'I wasn't told all the pitfalls of the surgery and of having no kneecaps'*
14. What is the role of co morbidity (other health factors in the mix) in making a decision about knee surgery?  
*"I hope it gives you an idea of how the orthopaedics, analgesia and neurology combine in a rather complex fashion to form her experience and determine her attitude to knee replacement, an attitude which I am sure would be different if the joint replacement could be considered in isolation"* *Contribution from FO*

#### Post-operative care and infection

15. What is the effect of the immediate post operative aftercare?  
 Comments included;
- Staff mix/stability of staff
  - Who managed the ward
  - Number of carers/assistants/bank staff on the ward – some ignoring advice from the physiotherapists
  - Skills mix
  - Quality of care
  - Length of stay on the ward
  - Noisy ward environment
  - Infection control issues
  - Use of convalescence/community hospitals as a staging post to home

16. What are the best treatments for post-op infections?
17. What are the risks of devices failing/loss of integrity due to infection?  
Is post-op infection the main reason for devices failing?
18. What is the evidence that pre-op advice, information and antibacterial washes help with post op infection rates?  
Some people have received advice from elsewhere such as the MRSA support group.
19. What is the evidence for using TED stockings pre and post op?  
Has this just become a matter of procedure rather than evidence based?
20. What is the evidence for using heparin (14-28days) post op?  
Has this just become a matter of procedure rather than evidence based?
21. What is the evidence for stopping methotrexate pre- op?  
Has this just become a matter of procedure rather than evidence based?
22. What is the evidence for using blood transfusion post op?  
Is there a standard Hb level that a person has to drop to before they can have a transfusion?
23. What is the evidence for internal scarring and bursitis after multiple surgeries?
24. What are the long term effects of prolonged spinal anaesthetic, especially in POCD (post operative cognitive dysfunction)? (Contribution from FO)

#### Physiotherapy and exercise

25. Why does the NHS not capitalise on post operative physiotherapy?  
Does the lack of physiotherapy after the surgery result in poorer result of the surgery; physiotherapy is so difficult to access?
26. What is the impact on the long waiting times and lack of accessibility for post operative physiotherapy?  
Would physiotherapy sooner after surgery improve the outcome of the surgery and in the long-term reduce the burden on the NHS?
27. What impact does the degree of exercise teaching/instruction of the physiotherapist have on the outcome of the surgery?  
There is a discrepancy between what happens at each hospital, some have experience of one to on physiotherapy and some have had very little input. *'I know someone who has had better physio for a broken ankle'*.
28. What provides the best result in terms of progression of exercises and mobility?  
How long should physiotherapy go on for and when should you progress form one set of exercises to the next in order to get the best result?

29. Does pre-operative advice to improve muscle tone in the area of surgery improve the outcome of the surgery?  
There will be degeneration of the muscle post-surgery but some surgeons advise that improving muscle tone prior to the surgery may improve the outcome, recovery time and pain. Some patients have also been advised to practise on crutches prior to surgery. *'It takes minutes to slice through the muscle but months to get the strength back'*.
30. Can you exercise too much following surgery?  
At what point might exercise cause a problem with the device? Is there an intolerable stress level for devices? Mixed messages from physiotherapists and surgeons are confusing. Is there a role for specific exercises, repeated, extended movements?
31. What is the best way to safely exercise the whole body and not just the affected joint?
32. What advice is there to cope with compensating movement patterns due to limited mobility post-op?

#### Quality of life

33. How best can quality of life be measured?  
What is the best method for surgeons to measure quality of life, pain etc rather than assessing x-rays? What age is too young to have surgery if quality of life can be measured then age becomes less relevant.
34. What are the factors that could be measured to assess quality of life?  
Free of pain/reduced pain, mobility, self sufficiency, different needs and expectations for different people.

#### Devices

35. How are the devices used in surgery recorded and registered?
36. What considerations are given to potential allergies to devices and the device components?  
There may be unknown allergies, this could impact on patient choices.
37. What research is being done into the long term effects of the devices?  
There are current lawsuits about the failure of the Pinnacle hip implant.
38. How do we know which are the best crutches to use for the best mobility?  
Some good input from some GPs about the use of solid crutches, mobile crutch feet and cost of crutches.

#### Pain relief and control

39. What is the most effective analgesic for orthopaedic pain?

*“it's an interesting topic because presumably the pain is a warning about joint condition?” “It's a bit like taking the batteries out of the smoke alarm because you don't like the noise”. Contribution from FO*

### Other

40. What research is being done into the basic causes of joint disintegration?
41. What treatments are there as an alternative to total joint replacement?  
Is artificial cartilage an option?
42. What preventative treatments are there to prevent disintegration of the joint and to reduce the need for joint replacement surgery?

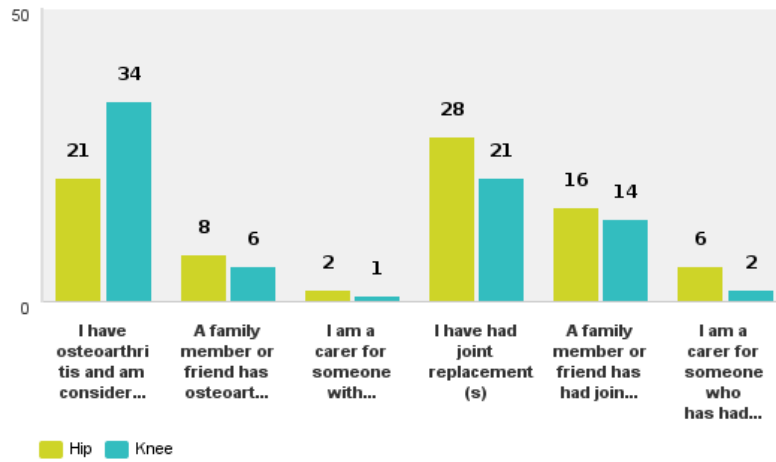
### **b) Manchester**

- What is the effective use of Cannabis Based Medicine for pain and inflammation in arthritis?
- What is the best way to measure how OA affects everyday living?
- How do we measure calcium intake and is it useful in OA?
- How does the weather affect pain in OA?
- What is the effectiveness of natural anti inflammatory therapies for OA?
- **Why is surgery usually considered the last option in OA?**
- What is the role of nutrition in good management of OA?
- What is the long term effect of a Slipped Upper Femoral Epiphysis (SUFE) on joint hip health Juvenile Idiopathic Arthritis (JIA)?
- Are magnetic bracelets and devices effective for joint pain?
- Are dietary supplements useful in treating OA?
- What is the best way to treat morning joint stiffness (also in lupus)?

## Appendix 5: Overview of responses to the online and postal survey

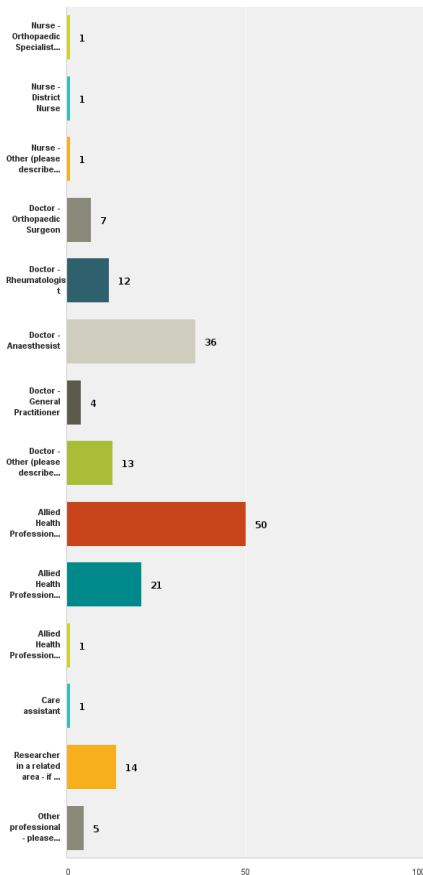
### Q4 Which of the following describe(s) your personal connection to hip or knee replacement? Please select all that apply.

Answered: 98 Skipped: 2



### Q3 If you have a professional connection to hip and/or knee replacement, what is your professional role? Please tick all that apply.

Answered: 146 Skipped: 128



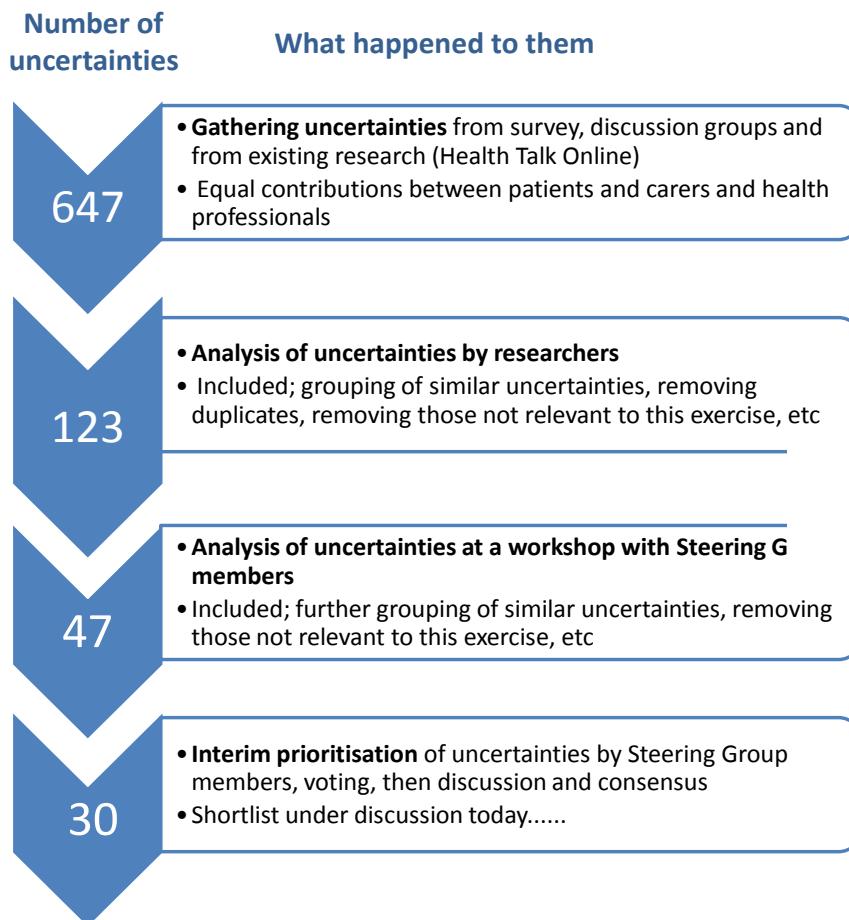
## Appendix 6: The Top 21 Questions

|    |  |
|----|--|
| 1  | What are the most important patient and clinical outcomes in hip and knee replacement surgery, for people with OA, and what is the best way to measure them?                       |
| 2  | What is the optimal timing for hip and knee replacement surgery, in people with OA, for best post operative outcomes?  |
| 3  | In people with OA, what are their pre operative predictors of post operative success (and risk factors of poor outcomes).  |
| 4  | What (health service) pre-operative, intra-operative, and post-operative factors can be modified to influence outcome following hip and knee replacement?                          |
| 5  | What is the best pain control regime pre-operatively, peri-operatively, and immediately post operatively for hip and knee joint replacement surgery for people with OA?            |
| 6  | What are the best techniques to control longer term chronic pain and improve long term function following hip and knee replacement?  |
| 7  | What are the long-term outcomes of non surgical treatments compared to operative treatment for patients with advanced knee/hip OA?   |
| 8  | What is the most effective pre and post operative patient education support and advice for improving outcomes and satisfaction for people with OA following hip/ knee replacement? |
| 9  | What is an ideal postoperative follow up period and the best long term care model for people with OA that have had hip/knee replacement?   |
| 10 | What is the best way to protect patients from the risk of thrombotic (blood clots, bleeding) events associated with hip/knee replacement?  |
|    |  |
| 11 | What are the differences in characteristics between those patients who benefit from knee/hip joint replacement and those who do not?   |
| 12 | What is the most effective Enhanced Recovery Programme for patients with OA undergoing knee/ hip joint replacement surgery?  |
| 13 | What non surgical treatments can reduce the need for hip/knee replacement?   |
| 14 | What is the optimum pre-operative management for best outcome for knee / hip replacement for people with OA?   |
| 15 | Are patients with a history of metal allergy at risk of poor/failed outcome due to an allergic response to the metal hip/knee implant?   |
| 16 | Are shared decision-making support (aids) for guiding patient choice of hip/knee replacement effective (and cost effective) in managing patients with hip/knee OA?                 |
| 17 | What is the best type of prosthesis/implant for best and safest outcomes?  |
| 18 | What factors contribute to deterioration and postoperative stiffness following knee/ hip joint replacement surgery?  |
| 19 | What is the cost-effectiveness of knee/hip joint replacement and the best financial model for the management of patients with osteoarthritis?                                      |



|           |   |
|-----------|---|
| <b>20</b> | Does attendance at a pre-operative "hip/knee school" reduce the length of post operative hospital stay in people with OA undergoing knee/hip joint replacement? |
| <b>21</b> | What causes and what is the best treatment for prolonged orthostatic hypotension in patients following hip/knee replacement surgery?                            |

## Overview of process to achieve the list of 30



## References

Campbell R, Pound P, Morgan M, Daker-White G, Britten N, Pill R, Yardley L, Pope C, Donovan J. Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technol Assess*. 2011 Dec;15(43):1-164.

Candy B, King M, Jones L, Oliver S. Using qualitative synthesis to explore heterogeneity of complex interventions. *BMC Med Res Methodol*. 2011 Aug 26;11:124.

Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N (2006) *Guidance on the conduct of narrative synthesis in systematic Reviews*. A Product from the ESRC Methods Programme. Version 1. Swindon: ESRC, 92 pages.

Chalmers I, et al (2014) How to increase value and reduce waste when research priorities are set *The Lancet*, Volume 383, Issue 9912, Pages 156 - 165, 11 January 2014

Brian Castellani and John Castellani Heaton, J., *Qual Health Res* 2003; 13; 1005, DOI: 10.1177/1049732303253523

*Reworking Qualitative Data*. London: Sage. Corti and Thompson (2004)

### Methods for the synthesis of qualitative research: a critical review

Elaine Barnett-Page\* and James Thomas Cochrane Collaboration *BMC Medical Research Methodology* *BMC Medical Research Methodology* 2009, 9:59 doi:10.1186/1471-2288-9-59

Brunton G, Oliver S, Oliver K, Lorenc T: *A Synthesis of Research Addressing Children's, Young People's and Parents' Views of Walking and Cycling for Transport*. London: EPPI-Centre, Social Science Research Unit, Institute of Education, University of London; 2006.

Pope C, Ziebland S, Mays N: Qualitative research in health care: analysing qualitative data. *BMJ* 2000, 320:114-116.

Oliver S, Rees R, Clarke-Jones L, Milne R, Oakley A, Gabbay J, Stein K, Buchanan P, Gyte G: A multidimensional conceptual framework for analysing public involvement in health services research. *Health Expect* 2008, 11:72-84.