


# Engaging Patients and Caregivers to Develop a Patient-Centered Agenda for Comparative Effectiveness Research Focused on the Treatment of Complex Knee Problems

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## Abstract

Complex articular cartilage loss in the knee is being diagnosed more frequently and earlier in life, and patients are faced with major decisions regarding invasive surgical interventions at increasingly younger ages. There is a critical unmet need to provide patient-centered comparative effectiveness research for the hundreds of thousands of patients faced with these treatment decisions each year. Toward filling the need, we developed the Patient Advisor Team in Orthopaedic Research (PARTNORS) program. We recruited a diverse group of patients and caregivers with lived experiences in dealing with complex knee problems to define patient-centered research priorities for comparative biological and artificial knee surgery research for middle-aged adults. Adapting the Stakeholder Engagement in Question Development and Prioritization Method, PARTNORS defined a 20-question list of patient-centered research questions of factors influencing a patients' choice between biological and artificial knee surgeries. The highest prioritized research question related to functional level postsurgery as it relates to daily activities and recreational activities. The second highest prioritized research questions related to insurance coverage and financial costs. Other prioritized research areas included caregiving needs, implant longevity, recovery and rehabilitation time, patient satisfaction and success rates, individual characteristics, and risks. By engaging a group of patients and caregivers and including them as members of a multidisciplinary research team, comparative effectiveness research that includes patient-centered factors that go beyond typical clinical success indicators for knee surgery can be designed to allow physicians and patients to work together toward evidence-based shared decisions. This shared decision-making process helps to align patients' and health care team's goals and expectations to improve outcomes.

## Keywords

- ▶ patient engagement in research
- ▶ SEED method
- ▶ patient-centered research
- ▶ artificial or biological knee surgeries

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Complex articular cartilage loss in the knee is being diagnosed more frequently and earlier in life such that when medical management fails, patients are faced with major decisions regarding invasive surgical interventions at increasingly younger ages.<sup>1,2</sup> When articular cartilage loss results in degenerative knee osteoarthritis (OA), total knee arthroplasty (TKA) or unicompartmental knee arthroplasty (UKA) consistently result in pain relief and improved function for older, less active patients.<sup>3,4</sup> In patients under 60 years of age or those who wish to remain highly active, TKA and UKA are associated with less consistent outcomes, higher complication and dissatisfaction rates, and higher revision rates.<sup>5-14</sup> As such, these patients may pursue other surgical treatment options that include osteotomies, joint distraction, or osteochondral allograft (OCA) transplantation when available and indicated.<sup>9,15-22</sup> Currently, there is evidence to support artificial knee arthroplasty (TKA or UKA) in older (>60 years), sedentary patients and for biological resurfacing using OCA transplantation in younger (<45 years), active patients.<sup>3,15,23-25</sup> However, “middle-aged” patients between 45 and 60 years of age who wish to remain highly active (and their health care professionals) do not have robust guiding evidence such that the default decision is often to delay surgical treatment for as long as possible, take medications, profoundly alter their lifestyle, and wait for years until TKA is definitively indicated. This approach can profoundly affect their work, activities of daily living, recreation, and quality of life.

Data-driven evidence for shared decision-making regarding safe and effective treatment of these complex knee disorders is needed to address patients' concerns and health care system processes. Common patient-based concerns with artificial arthroplasty include complications, persistent pain, activity limitations, and the need for revision, especially with increasing activity levels and lifespans for seniors.<sup>3,24,26-29</sup> Alternatively, patient enthusiasm for biological resurfacing may be tempered by its relative novelty and availability, use of donor tissues, long and restrictive rehabilitation requirements, and historical complication and treatment failure rates.<sup>16,30-38</sup> Patients' expectations regarding postoperative pain, level of function, duration and intensity of recovery and rehabilitation, as well as how long the benefits of surgical treatment need to last to be “worth it” must be addressed to optimize indications, cost-effectiveness, and value. There is a critical unmet need to provide patient-centered comparative effectiveness research (CER) for the hundreds of thousands of patients faced with these treatment decisions each year. The patient perspective is crucial to address this unmet need. Patients must weigh considerable tradeoffs and benefits with treatment options, yet they are rarely involved in defining, prioritizing, interpreting, or applying research objectives and results. Patient engagement in research enhances the quality of research designs, builds stronger rapport with patient communities, allowing for broader impact and application of research findings, and provides insight into gaps and patient-centered research priorities.<sup>39-41</sup> For patients, engaging in research allows them to influence what is being explored and

researched, know their perspective is important and valued, build trust with clinicians and researchers, more fully understand and share expectations, and receive improved care through communicating and implementing research findings.<sup>42-46</sup>

To fill the need for patient-centered comparative effectiveness knee surgery research, we developed the Patient Advisor Team in Orthopaedic Research (PARTNORS) program. Through PARTNORS, we cocreated an integrated system and culture in which patients and caregivers are routinely and meaningfully engaged such that researchers and patients are collaborators, working together as partners in orthopaedic research. One objective of PARTNORS was to define patient-centered research priorities for comparative biological and artificial knee surgery research for middle-aged adults. To fulfill this objective, PARTNORS adapted the Stakeholder Engagement in Question Development and Prioritization (SEED) method.<sup>47-49</sup> This paper describes the implementation of the SEED method to design CER for shared decision-making regarding the choice of surgery for complex knee disorders. This article reviews the PARTNORS program development process and results to provide a template for the implementation of patient-centered outcomes research in orthopaedic surgery.

## Methods

Established in 2021 with partial funding through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EACB-22651), the PARTNORS program is comprised of three teams: a diverse, 12-member patient advisor team, an administrative team, and a researcher team (→Fig. 1). Patient advisor team members, also known as “patient partners,” are committed to monthly meetings over a 2-year period and leverage their individual lived experiences to collaborate with the researcher team to develop studies that meet patients' needs. The administrative team meets and communicates frequently to facilitate the program and includes clinician scientists; individuals with expertise in program development,



**Fig. 1** The PARTNORS program is made up of three teams: a patient advisor team, an administrative team, and a researcher team.

program evaluation, and patient-centered outcomes research; and two patient partners (also referred to as “lead patient partners”) who ensure the patient perspective is integrated into all program activities. The lead patient partners had a prior relationship with the research team from a previous project and offered valuable insight and feedback on the PCORI Engagement Award proposal.

To define patient-centered research priorities for biological and artificial knee surgery treatment options for middle-aged adults, we adapted the SEED Method (→ Fig. 2).<sup>47–49</sup> The SEED Method provides a collaborative framework for systematically engaging stakeholders in the research process and for capacity building. Steps 3 to 5 described below were guided by the SEED Method toolkit resources.<sup>48,49</sup>

### Step 1: Team Recruitment

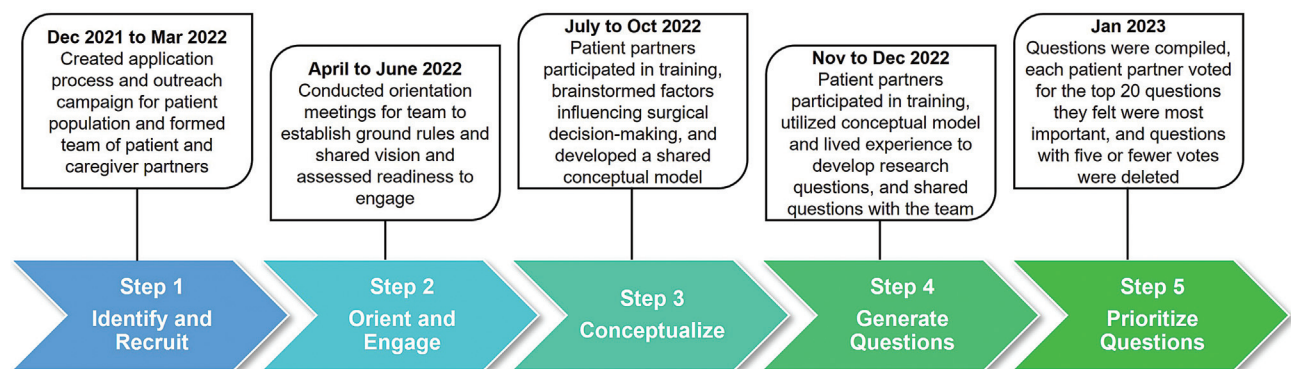
During Step 1 (identify and recruit), the PARTNORS administrative team developed an outreach campaign that targeted our patient community. Outreach materials and mechanisms included a PARTNORS web site (<https://medicine.missouri.edu/partnors>) with information about the program, access to educational resources, and an application form for individuals interested in joining the patient advisor team. A recruitment brochure was developed that explained the program and the responsibilities and benefits of being a patient partner. Brochures were provided to researchers, clinicians, and staff for distribution to patients who have a lived experience of complex knee problems. In addition, announcements about the program were sent via e-mails and phone calls to local community organizations and through news stories and local presentations. Lead patient partners provided valuable feedback regarding the design and content of our recruitment brochure and web site and, then, reviewed all patient advisor team applications and contributed to the selection of other patient partners.

### Step 2: Team Orientation and Engagement

To orient and engage members of the patient advisor team (Step 2), the administrative team facilitated training and team-building activities during two program orientation meetings. Meetings included an overview of the PARTNORS program structure; team member introductions; information about PCORI, patient-centered outcomes research, and the research

program at the host institute; an overview of program objectives and evaluation activities; and a breakout small group activity to establish team ground rules. The administrative team compiled the ground rules offered by each small group and identified concepts and language endorsed by both groups to develop a list of candidate rules. Candidate ground rules were sent to patient partners for review and feedback and finalized during a team meeting in which a group discussion was led by the two lead patient partners (see Appendix 1: PARTNORS Team Ground Rules). In addition, as recommended by PCORI,<sup>50</sup> the patient advisor team created a shared vision to document the team’s common goals. To develop the shared vision, the administrative team analyzed text from patient partners’ introductions during orientation—specifically, their answers to why they decided to bring their experience to orthopaedic research and what they wanted to gain from the experience. From that analysis, a proposed shared vision statement was drafted using language directly from the patient partners. The proposed vision statement was sent to patient partners for review and feedback and finalized during a team meeting in which a group discussion was led by the two lead patient partners (see Appendix 2: PARTNORS Shared Vision). Between orientation meetings, patient partners completed the following:

1. A strengths and readiness survey adapted from the Alberta Patient-Oriented Research Support Unit.<sup>51,52</sup> The survey includes 25 engagement statements to elicit responses that demonstrate receptiveness to engagement, value attributed to engagement, and optimism toward engagement. Responders identified how closely the statement relates to them using a scale of 1 to 5 with 1 being “least like me” and 5 being “most like me.” To score responses, the total number of each rating was added up and then multiplied by a multiplier (i.e., total number of 1 responses  $\times$  5, total number of 2 responses  $\times$  4, total number of 3 responses  $\times$  3, etc.). Results align with levels from a patient and researcher engagement in research spectrum<sup>42,51</sup> and helped determine the level of engagement most appropriate for our patient advisor team;
2. A patient-centered outcomes research knowledge self-assessment pretraining survey using questions adapted from Godfrey and colleagues<sup>53</sup>;



**Fig. 2** Steps to develop a patient-centered research agenda. Steps 3 to 5 were guided by the SEED Method.<sup>48,49</sup>

3. Selected PCORI Research Fundamentals training modules<sup>54</sup>; and
4. A patient-centered outcomes research self-assessment posttraining survey that included the same questions as the pretraining survey.

### Step 3: Develop a Conceptual Model

Step 3 (conceptualize) introduced the SEED Method process, where the patient advisor team developed a conceptual model that explored factors influencing a patient's decision between biological and artificial knee surgery treatments. Steps taken to develop the conceptual model included watching a training video about creating conceptual models and engaging in a training activity (facilitated by the two lead patient partners) that involved creating a model for buying a car. After training, each patient partner completed a "Brainstorming Factors Worksheet" (see Appendix 3) and listed factors that influence a patient's decision-making between surgical treatment options. To encourage holistic thinking, individuals aligned factors with different levels of the socioecological model.<sup>55</sup> The socioecological model is a conceptual framework that recognizes individuals as embedded within levels of social systems that include individual factors (e.g., knowledge and attitudes), interpersonal factors (e.g., friends, family, and interactions with physicians), organizational factors (e.g., health care system and hospital policies), community factors (e.g., access and transportation), and public policy factors (e.g., insurance programs and national and local laws).<sup>55</sup> The administrative team compiled answers from the homework assignment and developed a summary of brainstorming results that included the name and description of each influencing factor. Next, during two 1-hour meetings led by the lead patient partners, each factor was reviewed and discussed individually to ensure shared understanding and then positioned on the conceptual model using Google Jamboard—a collaborative digital whiteboard. Positioning involved how direct of an impact the factor had on the outcome—the choice of biological or artificial surgical treatment options. Factors with a more direct impact were positioned to the right near the outcome and factors with a more indirect impact were placed to the left, further away from the outcome. After the factor was positioned appropriately, the group discussed whether the factor had a relationship to any of the other factors already in the model. Using meeting recordings, the administrative team added arrows to the conceptual model and sent the draft conceptual model and factors description information sheet to the patient advisor team for review. Next, a meeting was held to come to consensus on the shared conceptual model. Understanding that the choice of surgery is an individual decision, and there are differences in opinions, consensus for the team meant that everyone understood and could live with the factors and paths on the model. As a prework assignment to the consensus meeting, patient partners were asked to review the model and come prepared to discuss: (1) whether they understood and could live with the factors and connections on the draft and (2) if they felt any paths were missing. Feedback and decisions made by the group during the meeting were incorporated into the conceptual model and a final draft was sent to the patient advisor team for final review.

### Step 4: Use Conceptual Model to Generate Research Questions

The conceptual model was used to generate research questions (Step 4). This step included a training session that provided an overview of developing patient-centered CER questions and provided examples of research questions. Next, each patient partner completed a "Writing Research Questions Worksheet" (see Appendix 4). The worksheet instructed them to look at the conceptual model and factor descriptions, think about their own personal experience, and identify which factors were most important to them or other patients when deciding between artificial or biological knee surgery. To promote the development of different kinds of research questions, the assignment included five prompts (causes, impact, patient-centeredness, verification, and new directions).<sup>49</sup> Each patient partner was asked to write at least one question for each prompt. Next, during a team meeting, each patient partner shared questions they developed and explained why they felt the question(s) was important. Having the group consider each individual's perspective prompted a good discussion of similarities and differences of opinion which would not have occurred if patients had responded in isolation.

### Step 5: Prioritize Research Questions

For Step 5 (prioritize), the administrative team compiled all research questions and deleted and combined duplicate questions resulting in 56 questions. The compiled list was sent to the patient advisor team and each patient partner voted for their top 20 questions that they felt were most important. Questions with five or fewer votes were deleted resulting in the final outcome of the SEED Method process—a 20-question patient-centered research agenda of factors influencing patients' decision-making between biological and artificial knee surgeries. Questions were categorized into levels of the socioecological model,<sup>55</sup> including individual, public policy, interpersonal, and organizational factors and grouped into topic domains.

### Best Practices for Team Engagement

Development of the PARTNORS program and administration of the SEED Method were guided by the PCORI engagement principles of reciprocal relationships; partnerships; co-learning; and transparency, honesty, and trust.<sup>56,57</sup> To promote reciprocal relationships, the inclusion of two patient partners on the program's administrative team provided the patient perspective for program decision-making, planning, and administration. In addition, these patient partners took leadership roles during the patient advisor team meetings and facilitated group trainings and discussions to decide how SEED Method activities should be customized to our setting and participants. Reciprocal relationships were also fostered when the patient advisor team collaboratively developed the shared vision and team ground rules using language directly from their responses regarding their decision to bring their experience to orthopaedic research and what they wanted to take away from the experience. Collaboratively developed ground rules that patients value support productive



engagement and disagreement and allow team members to comfortably agree or disagree about ideas or content, fostering respectful conversations and productivity as a fully performing group.<sup>50</sup> The time and contributions of the patient partners were valued as critical components to the success of the program—so much so that the program's name reflects it. Patient partners were financially compensated for their time and expertise by providing quarterly stipends based on fair market value estimates for the total time required to participate in training activities, attend meetings, and complete assignments. Another strategy we adopted to promote partnerships was avoiding the use of professional titles (e.g., “Dr.”) during our meetings and calling everyone by their first names. Additionally, meeting agendas and assignments were provided at least 1 week in advance to allow time for preparation and completion and to facilitate a “no surprise” environment during meetings with respect to plans and expectations. The program addressed co-learning through a focused consideration of the necessary knowledge, skills, and attitudes required from both researchers and patients to support the goals and reach the desired outcomes. Establishing a culture of transparency, honesty, and trust requires relationship building. To foster relationship building between patient partners and researchers, informational sessions promoted communication and teamwork skills; exchange of information was bidirectional and included opportunities for discussion that allowed patient partners to contribute to the research process and its impact on the broader patient population; and a project roadmap was presented at the beginning of every meeting to reiterate goals, expectations, and timelines and communicate progress and share results with the team.

## Results

As a result of our outreach campaign (Step 1: identify and recruit), 16 individuals submitted applications to become members of the patient advisor team. Each member of the administrative team reviewed and ranked the applications to determine patient advisor team members. The team consists of 12 diverse patients and caregivers who have a shared experience of living with or taking care of someone with complex knee problems (►Table 1).

To evaluate Step 2 (orient and engage), we reviewed the strengths and readiness and patient-centered outcomes research self-assessment pre- and posttraining survey results. On average, our team was interested and ready for engagement at the “collaborate” level meaning they were ready to partner on equal footing with researchers in all aspects of research (►Fig. 3). Pre- and posttraining results showed, on average, stronger level of agreements after training, and all statements had some level of agreement posttraining (►Fig. 4). All results were shared with the patient advisor team fostering transparency and trust.

Outcomes from the conceptualize step (Step 3) include the conceptual model (►Fig. 5) and “Factor Descriptions and their Relationships” information sheet (see Appendix 5). The conceptual model was used as a tool to promote discussion

**Table 1** PARTNORS patient advisor team member characteristics

Characteristic	Totals (n = 12)
Gender	
Female	7
Male	5
Race/Ethnicity	
White	9
Black or African American	2
Asian	1
Hispanic or Latino	1
Knee surgery	
Artificial arthroplasty	4
Biological restoration	3
Other surgery	2
No surgical treatment	3
Age in years	
45–55	3
55–65	6
> 65	3
Caregivers	4 <sup>a</sup>

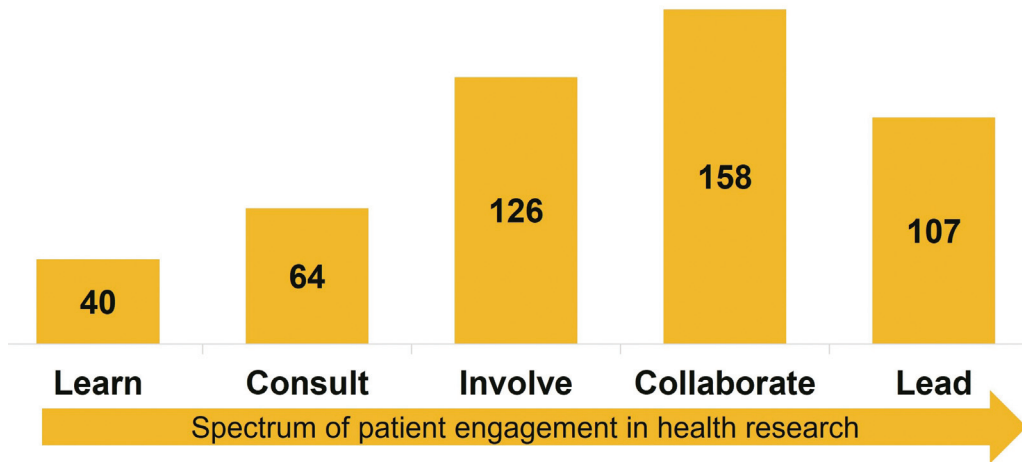
<sup>a</sup>Three caregivers are also patient advisors.

among the team about all of the factors patients consider when deciding between knee surgeries as well as the relationships among the factors. The multiple boxes and lines on the model illustrate the rich discussion about each factor and their perceived relationships.

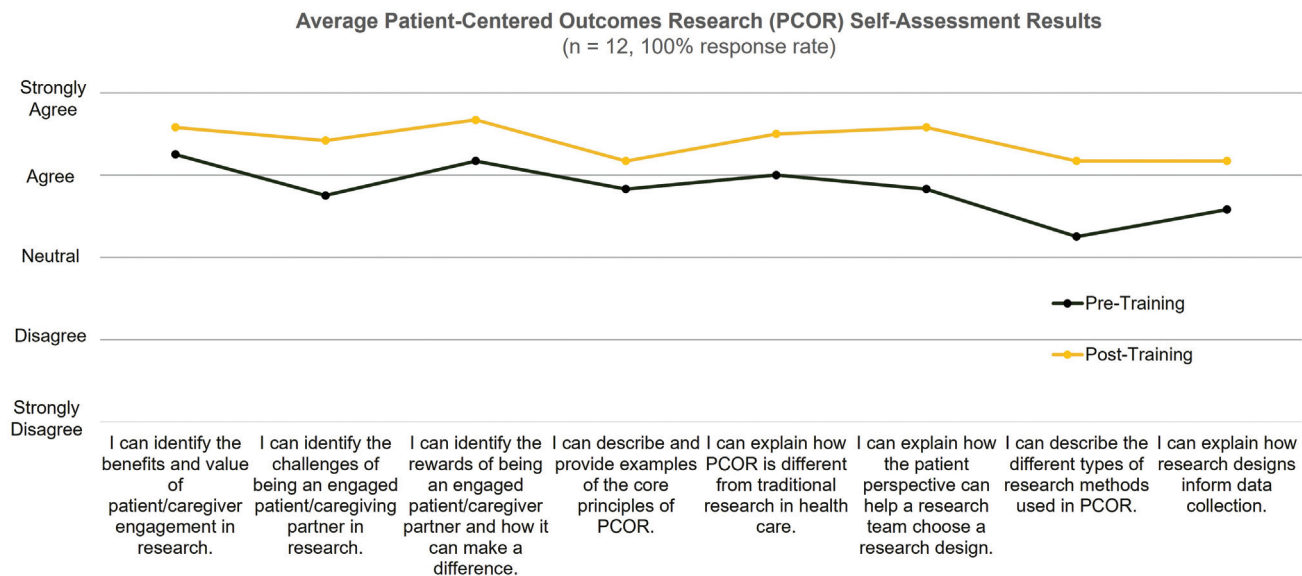
Completion of Steps 4 and 5 of the SEED Method process resulted in a 20-question list of patient-centered research questions of factors influencing a patient's choice between biological or artificial knee surgery (►Table 2). The highest prioritized research question was categorized at the individual level and related to functional level postsurgery: after full recovery, what are the differences in performance (e.g., flexibility and strength) of biological versus artificial knee replacement as it relates to daily activities and recreational activities (e.g., sports, jogging, gardening, swimming, skating, etc.)? Other prioritized research topics at the individual level included implant longevity, recovery and rehabilitation time, patient satisfaction and success rates, individual characteristics, and risks. The second-highest prioritized research questions were categorized at the public policy level and related to insurance coverage and financial costs. Other prioritized research areas included caregiving needs and electronic medical record capabilities categorized at the interpersonal and organizational levels, respectively.

## Discussion

Through the PARTNORS program, we successfully established a group of patients and caregivers with lived



**Fig. 3** Strengths and Readiness Survey Results. Adapted from the Alberta Patient-Oriented Research Support Unit (AbSPORU),<sup>51,52</sup> the survey includes 25 engagement statements to elicit responses that demonstrate receptiveness to engagement, value attributed to engagement, and optimism toward engagement. Responders (n = 12) identified how closely each statement relates to them using a scale of 1 to 5 with 1 being “least like me” and 5 being “most like me.” To score responses, the total number of each rating were added up and then multiplied by a multiplier (i.e., total number of 1 responses × 5, total number of 2 responses × 4, total number of 3 responses × 3, etc.). Results align with levels from a patient and researcher engagement in research spectrum<sup>42,51</sup> and indicated the patient advisor team was ready for engagement at the collaborate level: to partner on equal footing with researchers.

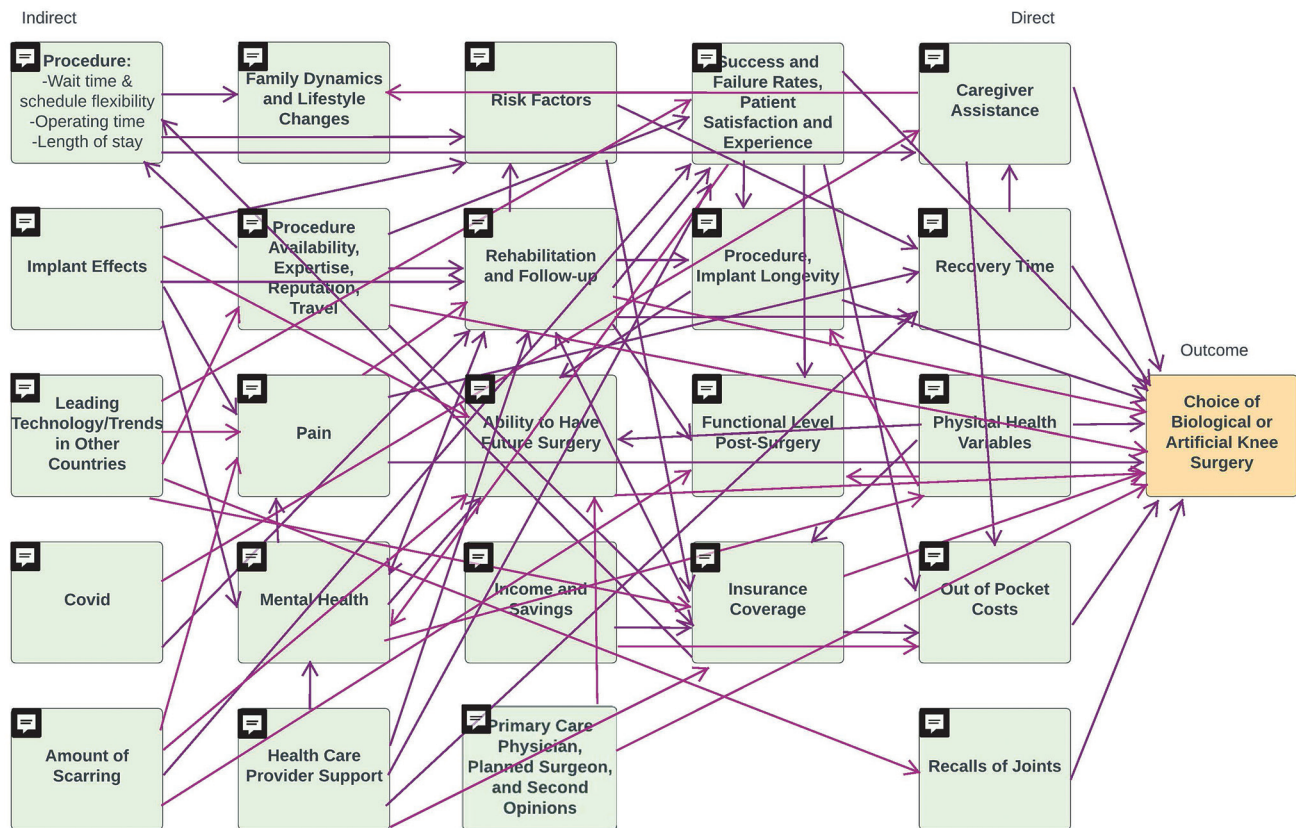


**Fig. 4** Patient-centered outcomes research self-assessment survey results pre- and posttraining. Results showed, on average, stronger level of agreement after training and all statements had some level of agreement posttraining.

experiences in dealing with complex knee problems and engaged them as active members of our orthopaedic research team. Guided by the SEED Method, the team developed a prioritized patient-centered CER agenda that targeted biological versus artificial knee surgery for middle-aged adults. These priorities made it clear that patients consider factors that go beyond typical clinical success indicators when pursuing knee surgery, including treatment costs, recovery and rehabilitation duration and intensity, and caregiver capabilities and resources. Inclusion of these factors in CER is critical because it promotes shared decision-making in which physicians and patients work together toward a health care decision that considers the needs of

the patient. This shared decision-making process helps to align the patients’ goals and expectations with those of the health care team to determine if the chosen knee surgery will be “worth it” for them, which helps to improve adherence and mitigate dissatisfaction. Engaging patients in the research process ensures that the resultant shared decision-making factors are both patient-centered and evidence-based.

Patient engagement in orthopaedic research is limited; however, there are a few exemplars for joint replacement. A systematic review of patient and public involvement in randomized controlled trials in the field of orthopaedic surgery identified two studies<sup>58</sup>—in one, patients contributed to the



**Fig. 5** Conceptual model showing factors that influence a patients' choice between biological or artificial knee surgery and the relationships among the factors. The conceptual model was used as a tool to promote discussion among the team about all the factors patients consider when deciding between knee surgeries as well as the relationships among the factors. The multiple boxes and lines on the model illustrate the rich discussion about each factor and their perceived relationships.

design of the research protocol and<sup>59</sup> in the other, patients were consulted to determine the importance of the research question to them.<sup>60</sup> Based on a review of PCORI-funded studies, Sepucha and colleagues engaged with a six-member patient-advisor committee to design a study that compared decision aids for knee or hip arthroplasty for which patient advisors selected study comparators.<sup>61</sup> Patients advised the research team regarding study design, communication and messaging to patients, strategies to promote patient enrollment and retention, key outcomes of importance to patients, analysis and interpretation of data, and dissemination of findings.<sup>62</sup> In another PCORI-funded study, Piva and colleagues engaged with eight patient advisors for a study comparing targeted exercise programs to standard postoperative care on physical function after TKA.<sup>63</sup> Patient advisors provided feedback regarding the final selection of survey items and outcome measures, provided suggestions to improve the readability of study materials, helped train staff who screened for eligibility, and participated in mock sessions of in-person data collection assessments.<sup>64</sup> A third PCORI-funded study by Selker and colleagues engaged seven patients with or at risk for knee OA to evaluate a decision-support tool designed to detect patient-specific equipoise in predicting associated outcomes among treatment options.<sup>65</sup> Patient stakeholders were involved in the selection of study questions, choice of study outcomes, selection of variables for the modeling database and

the predictive model, and development and testing of the user interface.<sup>66</sup>

In our PCORI-funded project, the development of the PARTNORS program and administration of the SEED Method were guided by the PCORI Engagement Principles of reciprocal relationships; partnerships; co-learning; and transparency, honesty, and trust.<sup>56,57</sup> The SEED Method provides a systematic, stepwise process for involving patients and other stakeholders in defining and prioritizing research questions and allows for colearning. While the SEED Method has been used successfully to create research agendas in other health care arenas,<sup>67-69</sup> our work describes the first reported use of the method in the field of orthopaedic surgery. Inclusion of two patient partners as key personnel on the program's administrative team provided the patient perspective for program decision-making, planning, and administration. Lead patient partners provided valuable feedback and input that improved the design and content of program activities; they identified unclear verbiage and proposed simple-to-read layouts to better communicate information to patient partners. In addition, lead patient partners helped develop trust among the patient advisor team by leading and facilitating trainings and group discussions as neutral community members. The PARTNORS program did not attempt to turn patients into researchers but provided training and education regarding the research

**Table 2** Patient-centered research agenda of factors influencing patients' decisions between biological and artificial knee surgery treatments

Research question	Votes received	
<b>Individual factors</b>		
<b>Functional level postsurgery</b>		
After full recovery, what are the differences in performance (e.g., flexibility and strength) of biological versus artificial knee replacement as it relates to daily activities and recreational activities (e.g., sports, jogging, gardening, swimming, skating, etc.)?	91.67%	11
If the surgeon/team provides and reviews comparative data showing differences in postsurgery functional outcomes/performance levels for each procedure (e.g., 1, 3, 5, 10, and 15-year comparable data), would that affect/help patients determine the best choice for them?	83.33%	10
Which procedure will allow a person who is at a particular activity level (e.g., athlete or highly active person) be able to get back to that level?	50.00%	6
<b>Implant longevity</b>		
What factors (e.g., age, weight, and activity level) are most likely to predict how long artificial knee vs. biological knee will last?	66.67%	8
<b>Recovery and rehabilitation time</b>		
How do the differences in recovery time influence a patient's decision? If we provide in-depth recovery data/information from previous patients, analyzed, and presented to potential knee candidates, would that help people make better decisions on which knee replacement is best for them?	58.33%	7
Given the two options of biological vs. artificial, what are the differences in recovery time and physical therapy requirements for the two procedures? Which option allows a patient to return to work/school/activity/sport the quickest?	50.00%	6
How can we reduce recovery time for biological replacement patients to a period more like artificial replacement by using a better method of connecting the implant to the patient's bone, thereby allowing patients to be weight-bearing and exercising earlier without risking damage to the graft?	50.00%	6
<b>Patient satisfaction and success rates</b>		
If there was a 1-year post surgery "customer satisfaction" report on a meaningful number of biological vs artificial patients, would this affect the decision-making?	58.33%	7
How can we get hard data to compare presurgery vs. postsurgery and show statistically which procedure is more successful—comparing range of motion before and after, strength before and after, and any other functional data that the doctors consider when determining if the surgery was successful?	50.00%	6
<b>Individual characteristics</b>		
How does the artificial knee vs. biological knee compare in health outcomes among patients with BMI greater than 35?	58.33%	7
Do we know enough about physical variables for previous patients, such as age, sex, bone density, BMI, condition of joint, and other factors to begin now to correlate the data and determine success and satisfaction rates for categories of patients?	50.00%	6
How can we create categories of patients for which we can generate surgical success and patient satisfaction statistics and thereby have predictions to provide to patients based on the category in which they fall based on age, sex, BMI, activity level, other health factors, etc.?	50.00%	6
<b>Risks</b>		
Are there more negative risks associated with one procedure vs. the other? What are they?	58.33%	7
<b>Public policy factors</b>		
<b>Insurance coverage and financial costs</b>		
How does insurance coverage/savings influence a patient's decision? In other words, if out of pocket costs were \$0 for both surgical options, would this affect the patient's decision between biological vs. artificial?	83.33%	10
How can we convince or compel insurance companies to cover equally either a biological or artificial replacement for patients in the age group, thereby requiring the decision to be made on which is the most likely method to succeed for that particular patient, rather than which is most affordable?	83.33%	10

(Continued)



**Table 2** (Continued)

Research question	Votes received	
Is there a way that we can use more specific predictions of success to provide data to insurance companies that would allow them to make their coverage decision on a data-informed success prediction rather than less-meaningful factors such as age?	58.33%	7
Which knee replacement procedure requires the least amount of therapy thus reducing the out of cost expenses associated with rehabilitation?	50.00%	6
<b>Interpersonal factors</b>		
Caregiver		
Due to the length of rehabilitation time required postsurgery, which of the knee replacement options requires the most/least amount of time needed from a caregiver?	50.00%	6
If the patient does not have a live in spouse or caretaker, would this affect the patient's decision for choosing biological vs artificial?	50.00%	6
<b>Organizational factors</b>		
Electronic medical records		
If there was a detailed computer-based questionnaire to complete with weighted values, that incorporates medical data from the surgeon and can zoom in on all the patient's factors and concerns, would this help patients decide between biological vs. artificial?	50.00%	6

process and their roles in patient-centered outcomes research. Nonetheless, it has provided superb preparation for patients to participate in the future as patient co-investigators on patient-centered outcomes research projects.

The challenges and limitations of patient-centered outcomes research in orthopaedics must be recognized and considered when implementing this approach. First and foremost, this approach requires considerable commitment of time, resources, and expertise from a multidisciplinary team that includes health care professionals, mixed methods researchers, and patients. This required level of engagement may not be achievable without dedicated funding that includes financial compensation for patient partners. An additional challenge for the PARTNORS program involved implementing the SEED Method within our institution's coronavirus disease 2019 restrictions. The SEED Method, originally designed to be facilitated during in-person workshop sessions, had to be adapted to a virtual format. This involved patient partners completing work independently and then participating in 1-hour virtual workshop sessions as a group. Most activities were led and facilitated by the two lead patient partners; however, there were times when a researcher facilitated activities. To limit potential bias, the two lead patient partners were consulted before meetings to ensure patient buy-in for meeting plans. At the end of the SEED Method, patient partners completed a survey that asked them to reflect on their experience participating in the process. One patient partner felt the timing and pacing of the process moved too slowly. When asked what they liked most about participating in the process, most indicated they liked the collaboration and interaction—specifically, hearing and understanding varying perspectives that they felt built on one another and made them think. When asked what they liked least about the process, two individuals felt the process could be confusing or overwhelming at times and liked working with the team more than figuring things out alone.

## Conclusion

Engaging a group of patients and caregivers with lived experiences in dealing with complex knee problems and including them as members of a multidisciplinary research team resulted in a patient-informed research agenda that will lead to better shared decision-making between surgical patients and physicians in the future. This shared decision-making process helps to align patients' and health care team's goals and expectations to improve outcomes. This approach requires the commitment of time, resources, and expertise from a multidisciplinary team that includes health care professionals, mixed methods researchers, and patients willing to engage in a process based on the principles of reciprocal relationships, partnerships, colearning, transparency, honesty, and trust. This article describes the first reported use of the SEED Method in the field of orthopaedic surgery to design patient-centered CER for shared decision-making regarding the choice of surgery for complex knee disorders. Ongoing work at our institution includes implementing our findings and approach to design clinical trials and applying this approach to patient-centered research in other areas of orthopaedics.

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### Conflict of Interest

None declared.

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## Appendix 1: PARTNORS Team Ground Rules

### Attitude and Culture

- We treat each other with respect and value the individual experiences of each team member.
- We value constructive feedback. We will avoid being defensive and give feedback in a constructive manner.
- We will build on each other's ideas.
- We will respect the confidentiality of our discussions.

### Team Meetings

- Team members are expected to be prompt and to attend and actively engage in all meetings unless they must be absent in which case they should inform the team leader and be prepared to provide input via email prior to the meeting.
- The team leader will publish and distribute an agenda ahead of the meeting.
- Meetings will start and end promptly on time.

### Communication

- One person talks at a time; there are no side discussions or interruptions.
- Each person is given a chance to speak their mind while at the same time respecting the group's time and the meeting timetables.
- We will actively listen, be engaged, be nonjudgmental, and keep an open mind as opinions are presented.
- We will express disagreement professionally and tactfully.
- We will seek to ensure everyone has the opportunity to participate in the discussion.

## Appendix 2: PARTNORS Shared Vision

**Why We Exist:** To share our individual experiences with knee problems to provide insight to individuals facing their own knee issues and assist the caregivers who treat them.

**Mission:** The mission of PARTNORS is to define patient-centered research priorities, provide patient insight into research, and assist with dissemination of research.

To accomplish this mission, we will:

1. Communicate to researchers the lived experience of patient stakeholders (individuals considering surgery, people who had surgery, and caretakers). Specific examples of the lived experience that will better inform research priorities may include:
  - (a) the need for comprehensive pre/postsurgery education
  - (b) concerns in managing pain and concerns of over prescribing pain medications
  - (c) lack of clarity for movement/mobility during recovery
  - (d) conversations of recovery time, including a patient's emotional state and expectations during the healing process as well as the caregiver role
  - (e) the need for comparative data between biological and artificial joint replacement
2. Collaborate with physicians and researchers to characterize patients' experience that leads to the decision to have knee surgery moving from "you'll know when it's time" to more precise examples of patients' lived experiences.
3. Advocate for patients in similar situations by sharing accurate information regarding interventions and communicating the patients' lived experience before and after the intervention.
4. Continuously expand our knowledge of best practices in knee care and interventions, new technologies, emerging technologies, alternative treatments to surgery, and effective prevention strategies, so that we can share accurate and helpful information with others.

## Appendix 3: Brainstorming Factors Worksheet

Instructions: Please complete the following parts in order.

Part 1: Reacquaint yourself with our health research topic.

1. Activity 1 (5 minutes): Watch the segment from our orientation session that describes our health topic: artificial vs. biologic surgical knee treatment options for middle-aged patients.  
Part 2: Brainstorm factors.
2. Activity 2: Based on your own experience, list factors that may influence a patients' decision-making between biologic and artificial knee surgery treatments. Consider information patients need to make a well-informed, evidence-based



decision and factors that impact a patients' ability to have a successful surgery (e.g., how will surgery impact your work or family?). There are no right or wrong answers—don't be afraid to think outside the box!

Part 3: Align factors with domains.

- Activity 3:** Recognizing that individuals are embedded within larger social systems, think about each factor you listed above in Part 2 and organize them into the appropriate domain listed below. Add any factors you feel you left out and feel free to add new domains.

**Individual Factors** (e.g., education, income, insurance, age, sex, race/ethnicity, physical health, mental health, etc.):

**Interpersonal Factors** (e.g., friends, family, social networks, culture, interactions with providers, etc.):

**Organizational Factors** (e.g., health care system, hospital policies, etc.)

**Community Factors** (e.g., access, transportation, relationships between organizations):

**Public Policy Factors** (e.g., insurance programs, public health campaigns, national and local laws):

Other Factors:

## Appendix 4: Writing Research Questions Worksheet

Your Name:

**Health Topic:** Choice of artificial vs. biologic knee surgery for middle-aged patients.

**Instructions:** Look at the conceptual model and factor descriptions and think about your own personal experience. Think about which factors would be most important to you or other patients when deciding between artificial or biologic knee surgery. Think about what specific information related to these factors you or a patient would need to know to make the decision. Then, use the prompts below to write different kinds of research questions. Write at least one question for each prompt but feel free to write as many questions as you want.

**Prompt #1—Causes X → Y:** Looking at the conceptual model, which pathways are critical to a patients' decision-making? To improve surgical treatment decision-making, we need to better understand the relationship between X and Y. Now, you must decide what X and Y are—they can be anywhere on the model, not just factors that lead directly to the outcome. **Example:** Are people more likely to buy a car after having a first child or after a third child?

Research Question(s):

**Prompt #2—Impact:** Looking at the conceptual model, which pathways are most likely to respond to an intervention? If we could change one of the factors in the model, would it have a strong effect (BIG IMPACT) on a patients' decision between the two options? Remember, the strong effect you are thinking of might directly affect the choice or it might affect another factor in the path. **Example:** If we could help people have better credit scores, would that impact their ability to buy a car?

Research Question(s):

**Prompt #3—Patient-Centeredness:** Looking at the conceptual model and thinking about what you know, what questions would help patients make more informed decisions? If we could answer this question, patients would have better information for choosing which treatment or for making other types of decisions. **Example:** If we provided fuel efficiencies across cars, would that help people make better decisions about which car to buy?

Research Question(s):

**Prompt #4—Verification:** Looking at the conceptual model, are there relationships in the model that we need to know more about? Is there something that needs to be proven as fact? Do we need more evidence to show that a particular cause is important? **Example:** Are people who just moved to a new neighborhood more likely to be shopping for a car compared to people who have lived in a neighborhood longer?

Research Question(s):

**Prompt #5—New Directions:** This is time to think outside the box. Is there something important that is missing or misunderstood in the conceptual model? Is there something not related to a factor on the conceptual model that we need to know about? Is there something we know very little about right now? **Example:** What are the factors impacting future sales of self-driving cars?

Research Question(s):

Adapted from: Zimmerman EB, Cook S. *The SEED Method Toolkit for Stakeholder Engagement in Question Development and Prioritization*. Virginia Commonwealth University, Center on Society and Health; 2017.

### Appendix 5: Factor Descriptions and their Relationships

Based on their lived experience with advanced knee problems, patient partners identified the following factors that may influence decision-making between biologic and artificial knee surgery treatments. Next, they developed a conceptual model to identify relationships and causal chains among the factors.

Influencing Factor	Factor Description	Relationships and Causal Chains
<b>Recovery Time</b>	Length of recovery time; time needed off work for recovery	Risk Factors→Recovery Time; Pain→Recovery Time; Rehabilitation and Follow-up→Recovery Time; Healthcare Provider Support→Recovery Time <b>Recovery Time→Choice of Biological or Artificial Knee Surgery</b>
<b>Insurance Coverage</b>	Insurance coverage by private insurance, Medicaid, Medicare	Risk Factors→Insurance Coverage; Leading Technology/Trends in Other Countries→Insurance Coverage; Procedure Availability/Expertise→Insurance Coverage; Income and Savings→Insurance Coverage; Healthcare Provider Support→Insurance Coverage <b>Insurance Coverage→Choice of Biological or Artificial Knee Surgery</b>
<b>Procedure, Implant Longevity</b>	Length of effectiveness; amount of time implant is effective; lifespan of implant; activity level of implant; warranty/life expectancy	Rehabilitation and Follow-up→Implant Longevity; Success and Failure Rates→Implant Longevity <b>Procedure, Implant Longevity→Choice of Biological or Artificial Knee Surgery</b>
<b>Risk Factors</b>	Procedure risk factors; side effects with procedures; dangers of treatments; infection rates	Procedure Time→Risk Factors; Implant Effects→Risk Factors; Rehabilitation and Follow-Up→Risk Factors
<b>Rehabilitation and Follow-up</b>	Rehabilitation intensity and length; ability to be a good patient and follow the therapy protocol; differences in and amount of physical therapy; amount and schedule of follow-up appointments	Procedure Availability→Rehabilitation and Follow-up; Implant Effects→Rehabilitation and Follow-up; Pain→Rehabilitation and Follow-up; Covid→Rehabilitation and Follow-up; Mental Health→Rehabilitation and Follow-up; HealthCare Provider Support→Rehabilitation and Follow-up; Insurance Coverage→Rehabilitation and Follow-up <b>Rehabilitation and Follow-up→Choice of Biological or Artificial Knee Surgery</b>
<b>Pain: Levels, Medication, and Alleviation</b>	Level of pain from procedures; type, amount, and length of pain medication; potential to reduce/remove pain	Implant Effects→Pain; Leading Technology→Pain; Amount of Scarring→Pain; Mental Health→Pain <b>Pain→Choice of Biological or Artificial Knee Surgery</b>
<b>Out of Pocket Costs</b>	Treatment costs; out of pocket costs, including copay expenses and PT costs	Caregiver Assistance→Out of Pocket Costs; Insurance Coverage→Out of Pocket Costs; Income and Savings→Out of Pocket Costs; Success and Failure Rates→Out of Pocket Costs <b>Out of Pocket Costs→Choice of Biological or Artificial Knee Surgery</b>
<b>Caregiver Assistance</b>	Type of at home assistance needed during recovery; length of time assistance is needed; amount of time away from work needed for caregiver; individuals in community to help with recovery	Procedure Length of Stay→Caregiver Assistance; Covid→Caregiver Assistance; Recovery Time→Caregiver Assistance <b>Caregiver Assistance→Choice of Biological or Artificial Knee Surgery</b>
<b>Success and Failure Rates, Patient Satisfaction and Experience</b>	Complication and failure rates to achieve goals/success; success rates; failure to achieve motion; Data on patient satisfaction; successful knee replacement patient can	Leading Technology Trends→Success and Failure Rates; Expertise→Success and Failure Rates; Amount of Scarring→Patient Satisfaction; Rehabilitation and Follow-Up→Success and Failure Rates; Healthcare Provider

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(Continued)

Influencing Factor	Factor Description	Relationships and Causal Chains
	advise other patients using their own experiences.	Support→Success and Failure Rates and Patient Satisfaction <b>Success and Failure Rates, Patient Satisfaction and Experience→Choice of Biological or Artificial Knee Surgery</b>
<b>Functional Level Post-Surgery</b>	Functional ability after surgery, both during and after recovery; range of motion post-surgery; allowable activities during recovery	Rehabilitation and Follow-up→Functional Level Post-Surgery; Amount of Scarring→Functional Level Post-Surgery; Physical Health Variables→Functional Level Post-Surgery; Success and Failure Rates→Functional Level Post-Surgery
<b>Physical Health Variables</b>	Physiological factors that rule people out for procedures; age, weight, weight bearing for athlete vs sedentary; active/healthy adults should be given biologic option if health condition says “yes” despite age	Mental Health→Physical Health Variables <b>Physical Health Variables→Choice of Biological or Artificial Knee Surgery</b>
<b>Ability to Have Future Surgery</b>	Ability to have another replacement, future revision, or knee procedure as needed	Implant Effects→Ability to Have Future Surgery; Amount of Scarring→Ability to Have Future Surgery; Mental Health→Ability to Have Future Surgery; Primary Care Physician→Ability to Have Future Surgery; Physical Health Variables→Ability to Have Future Surgery; Implant Longevity→Ability to Have Future Surgery <b>Ability to Have Future Surgery→Choice of Biological or Artificial Knee Surgery</b>
<b>Procedure Availability, Expertise, Reputation, Travel</b>	Travel time needed for procedure; travel restrictions post-surgery; expertise availability if something goes wrong; availability of second opinion; reputation of surgeon or group	Leading Technology/Trends in Other Countries→Procedure Availability, Expertise <b>Procedure Availability, Expertise, Reputation, Travel→Choice of Biological or Artificial Knee Surgery</b>
<b>Family Dynamics and Lifestyle Changes</b>	Impact on family dynamics; changes in lifestyle routines during recovery; accessibility of home during recovery; overnight stays for family	Caregiver Assistance→Family Dynamics and Lifestyle Changes; Procedure Length of Stay→Family Dynamics and Lifestyle Changes
<b>Mental Health Variables</b>	General well-being; depression	Implant Effects→Mental Health Variables; Health Care Provider Support→Mental Health Variables; Rehabilitation and Follow-up→Mental Health Variables; Success and Failure Rates→Mental Health Variables
<b>Procedure Wait Time/Scheduling Flexibility, Procedure Time, Hospital Length of Stay</b>	Wait time for donor tissue/ flexibility in scheduling; length of surgery times; length of hospital stay	Procedure Availability, Expertise→Procedure Wait Time/Scheduling Flexibility; Insurance Coverage→Hospital Length of Stay
<b>Implant Effects and Effects on Other Joints</b>	Real versus fake in my body; effects of donor tissue	
<b>Income and Savings</b>	Salary, income, savings	
<b>Healthcare Provider Support</b>	Healthcare provider support before and after surgery	
<b>Covid</b>	Precautions and protocols	
<b>Amount of Scarring</b>	Amount of scarring from each procedure	
<b>Leading Technology/Trends in Other Countries</b>	There’s a tendency for Americans to think we have the latest technology and health care but we may or may not; leading technology path	

(Continued)

Influencing Factor	Factor Description	Relationships and Causal Chains
<b>Recalls of Joints</b>	Any recalls on the implants being used; can't have a recall on biological but can on manufactured materials	Leading Technologies/Trends in Other Countries→Recalls of Joints <b>Recalls on Joints→Choice of Biological or Artificial Knee Surgery</b>
<b>Primary Care Physician, Planned Surgeon, and Second Opinions</b>	The PCP knows the patient's history—both physical and mental health histories—and would know if they are a good candidate for biologic or artificial; the planned surgeon would have their input; good to have multiple opinions from the health care team about which surgery	<b>Primary Care Physician, Planned Surgeon, and Second Opinions→Choice of Biological or Artificial Knee Surgery</b>

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