



## Patient Volunteer Information and Form

*for involvement in the*

**American College of Rheumatology / American Association of Hip and Knee Surgeons**

### **Guideline Project: Indications for Total Knee and/or Hip Replacement**

The ACR develops clinical practice guidelines for use by physicians, health professionals, patients and other stakeholders who want to ensure high quality, evidence-based care for rheumatic disease patients. ACR guidelines include recommendations for using therapies that are available in the United States, advising on which work best in different clinical situations and patient groups. They are not meant to be prescriptive but to provide guidance based on the most recently published evidence about what helps patients the most without exposing them to unnecessary harms or risks. AAHKS is partnering with the ACR in this guideline project because of its members' subject matter expertise.

Patients play an important role in guideline development work. Involving patients allows their views and experiences to complement both the published evidence and the expertise and experience of physicians, health professionals, and others who are part of the guideline development team.

**The focus of this guideline is on appropriate indications for total knee and/or hip replacement in patients with moderate to severe osteoarthritis or osteonecrosis of the hip or knee. The ACR and AAHKS are looking for patients who have these conditions AND have had either knee or hip replacement surgery, to participate in this project.**

**Would you like to volunteer to help develop guidelines that incorporate the values and preferences of this group of patients?**

**If so, here's what we would ask you to do:**

- *As part of the application process:*
  - Submit a brief profile of yourself so that we can get to know you better
  - Verify that you are a patient with these conditions/experiences who is age 18 or older, with a signed note or email from your doctor or other medical document that indicates that your diagnosis/experience matches the patient population of this guideline
  - *If requested*, participate in a brief phone interview to discuss your interest in more detail
- *If you are confirmed to be involved:*
  - Be a member of a group of 10-12 patients who will examine summarized evidence, provide patient perspectives on what the final recommendations should be, and give input on additional questions from the guideline development team, if any
  - As part of this patient group, actively participate in a 3-4-hour online webinar meeting in April 2022, where the group will be oriented and then review the summaries of the evidence for how to most appropriately determine if a patient needs a knee or hip replacement and provide input into what the guideline recommendations should be.

### What skills are required?

You will receive orientation for this role, but it would be helpful if you are enthusiastic and have good communication and teamwork skills. You also need to have time to commit to the work of the group during the timeframes listed above.

### Costs/expenses

Any out-of-pocket expenses related to your participation in this meeting, e.g., childcare costs, will be reimbursed. In addition, after the project is completed, if you have actively participated (i.e., attended the webinar and responded to follow ups, if requested), you will receive \$300 compensation for your participation.

### What can you expect from the ACR and AAHKS?

- Appreciation and respect
- Support
- Relevant information and instruction, including explanations of how to interpret research study results and how the information you provide will be used

### What training and support will you receive?

The ACR staff leader who will facilitate the meeting will also be available before and after the meeting for questions and orientation by phone and/or email, as needed.

### Disclosure of relationships and confidentiality

Everyone who is involved in this project must complete and sign the following forms:

- *Disclosure of relationships* – This form asks about your personal and non-personal interests in other organizations that might be doing work similar to this project, or commercial companies that might be, for example, involved in producing new drugs. We ask everyone who participates in guideline work to act as independently as possible. If anyone has significant personal interests that may conflict with this project, that person might not be considered to participate. This form must be completed and submitted with your application.
- *Confidentiality* – This agreement asks you to keep all project-related materials, discussions and decisions confidential until the guideline is approved by the ACR **and** publicly available through publication. You would be asked to complete this form if you are confirmed to participate in the project.

### How do you get involved?

You should complete the attached form, which includes a short personal statement detailing your reasons for wishing to participate as a patient representative in this project. Please highlight any relevant skills and experience. **Please email the form, plus the other items listed at the bottom of the form, to Regina Parker at [rparker@rheumatology.org](mailto:rparker@rheumatology.org), no later than February 28, 2022.**

### When will applications be considered, and when will decisions be made?

All complete applications will be immediately considered, and final decisions will be made fairly quickly. All applicants will be notified of their status by email on or by **March 7, 2022**.

### Who may I contact with questions about the application process or this project?

Please email ACR staff Regina Parker at [rparker@rheumatology.org](mailto:rparker@rheumatology.org) or call her at 404-633-3777, ext. 822. Alternatively, you may also email ACR staff Amy Turner at [aturner@rheumatology.org](mailto:aturner@rheumatology.org) or call her at 404-633-3777, ext. 813.

## APPLICATION FORM

Please complete this form to apply to be an **ACR/AAHKS Total Joint Arthroplasty guideline** patient representative. If you have any questions or concerns about the form, please call ACR staff Regina Parker at 404-633-3777, ext. 822, or email her at [rparker@rheumatology.org](mailto:rparker@rheumatology.org).

### Contact details

Your full name: \_\_\_\_\_

Your mailing address: \_\_\_\_\_

Your phone number (preferred): \_\_\_\_\_

Your phone number (alternate): \_\_\_\_\_

Your email address: \_\_\_\_\_

Name(s) of patient's rheumatologist and/or orthopedic surgeon:

\_\_\_\_\_

### Please initial relevant statements below

\_\_\_\_\_ Please initial here to indicate that you would be available to attend an April 2022 online webinar (polling will be done to determine exact date and time).

\_\_\_\_\_ Please initial here to confirm you are age 18 or older.

\_\_\_\_\_ Please initial here to confirm you have had either a total knee or a total hip replacement.

### Personal statement

*(Please detail your reasons for wishing to participate as a patient representative in this project and list any relevant skills and experience. Please also state your disease type and describe any experiences you have had with total knee or hip replacement.)*

**Please return the following to ACR staff Regina Parker ([rparker@rheumatology.org](mailto:rparker@rheumatology.org)) by February 28, 2022:**

1. This completed form.
2. A written statement, signed by your physician, verifying that you are an OA or ON patient who has undergone total hip and/or knee replacement, or other form of medical documentation that includes your diagnosis and surgery.
3. A completed ACR disclosure form (*attached*).

Confidential Disclosure Statement Name \_\_\_\_\_

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In order for the College to most effectively further its mission and to otherwise maintain its excellent reputation in the medical community and with the public, it is important that confidence in the College’s integrity be maintained. The cornerstone of the ACR’s Disclosure Policy is disclosure of actual and potential conflicts so that they can be evaluated by the College in order to avoid undue influence of potential conflicts.

The purpose of the ACR’s Disclosure Policy is identification of relationships which may pose actual or potential conflicts. These actual or potential conflicts can then be evaluated by the College so that adjustments can be made which will avoid any undue influence. This policy is based on the principle that, in many cases, full disclosure of the actual or potentially conflicting relationship will of itself suffice to protect the integrity of the College and its interests.

*Instructions: Please complete each section to the best of your knowledge with reference to your activities and investments currently and for the preceding 12- month period.*

**1. Primary Employment** (and other salaried positions) - If self-employed, but formally paid through a corporation or other entity, indicate “self-employed” under Employer.

| Employer | Position |
|----------|----------|
|          |          |
|          |          |
|          |          |

**2. Sources of Personal Income (salary information from primary employer is not required)** – including speakers bureau, honoraria, royalties, expert witness fees, advisory boards, or any other sources of income (please specify).

| Firm | Activity | Current Value   |
|------|----------|---|
|      |          | <input type="checkbox"/> None <input type="checkbox"/> <\$5,000 <input type="checkbox"/> \$5,001-\$10,000 <input type="checkbox"/> \$10,001-\$25,000 <input type="checkbox"/> >\$25,000 |
|      |          | <input type="checkbox"/> None <input type="checkbox"/> <\$5,000 <input type="checkbox"/> \$5,001-\$10,000 <input type="checkbox"/> \$10,001-\$25,000 <input type="checkbox"/> >\$25,000 |
|      |          | <input type="checkbox"/> None <input type="checkbox"/> <\$5,000 <input type="checkbox"/> \$5,001-\$10,000 <input type="checkbox"/> \$10,001-\$25,000 <input type="checkbox"/> >\$25,000 |
|      |          | <input type="checkbox"/> None <input type="checkbox"/> <\$5,000 <input type="checkbox"/> \$5,001-\$10,000 <input type="checkbox"/> \$10,001-\$25,000 <input type="checkbox"/> >\$25,000 |
|      |          | <input type="checkbox"/> None <input type="checkbox"/> <\$5,000 <input type="checkbox"/> \$5,001-\$10,000 <input type="checkbox"/> \$10,001-\$25,000 <input type="checkbox"/> >\$25,000 |
|      |          | <input type="checkbox"/> None <input type="checkbox"/> <\$5,000 <input type="checkbox"/> \$5,001-\$10,000 <input type="checkbox"/> \$10,001-\$25,000 <input type="checkbox"/> >\$25,000 |
|      |          | <input type="checkbox"/> None <input type="checkbox"/> <\$5,000 <input type="checkbox"/> \$5,001-\$10,000 <input type="checkbox"/> \$10,001-\$25,000 <input type="checkbox"/> >\$25,000 |

**3. Intellectual Property** - Do you currently receive, anticipate receiving, or have a reasonable expectation to receive income from intellectual property sources, including but not limited to copyrights, patents, or licenses?

- YES
- NO

If yes, please describe the nature and source of such intellectual property. \_\_\_\_\_

\_\_\_\_\_

Confidential Disclosure Statement Name \_\_\_\_\_

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**4. Research Grants/Contracts** - If you are currently listed or have in the past 12 months been listed as PI or other investigator (including clinical studies) please indicate the following:

| Funding Agency | Institution/Group/Title of Study |
|----------------|----------------------------------|
|                |                                  |
|                |                                  |
|                |                                  |
|                |                                  |

**5. Investments**

**A. Medical industry** - Do you have any medical industry-related investments, including but not limited to stocks, bonds, options, or other form of investment or ownership in companies in the following industries: pharmaceutical, biotechnology, medical education, medical publishing, medical internet, or other healthcare-related endeavors?

| Firm | Type | Current Value                 |                                   |   |  |                                    |
|------|------|-------------------------------|-----------------------------------|---|--|------------------------------------|
|      |      | <input type="checkbox"/> None | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|      |      | <input type="checkbox"/> None | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|      |      | <input type="checkbox"/> None | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|      |      | <input type="checkbox"/> None | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|      |      | <input type="checkbox"/> None | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |

**B. Non-Medical industry** - Do you have any non-industry-related investments, including but not limited to stocks, bonds, other options or ownership, or contractual relationships with any non-medical companies that might conflict with your duties/position with the ACR? Include any relationship with a company that has or might be considered for a business relationship with ACR.

- YES
- NO

If you answered YES to 5B, please specify below:

Company Name: \_\_\_\_\_ Investment/Relationship: \_\_\_\_\_

[The current value need not be disclosed.]

**6. Organizational Benefit** – Are there any monies obtained or assigned by a university, department, institution, foundation, private enterprise group, or any other entity as a result of your activities (e.g. unrestricted educational grants)?

| Sponsor | Institution | Activity | Current Value                 |                                    |  |   |                                     |
|---------|-------------|----------|-------------------------------|------------------------------------|--|---|-------------------------------------|
|         |             |          | <input type="checkbox"/> None | <input type="checkbox"/> <\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> \$25,001-\$100,000 | <input type="checkbox"/> >\$100,000 |
|         |             |          | <input type="checkbox"/> None | <input type="checkbox"/> <\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> \$25,001-\$100,000 | <input type="checkbox"/> >\$100,000 |

**Confidential Disclosure Statement** Name \_\_\_\_\_  
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|  |  |  |                               |                                    |  |   |                                     |
|--|--|--|-------------------------------|------------------------------------|--|---|-------------------------------------|
|  |  |  | <input type="checkbox"/> None | <input type="checkbox"/> <\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> \$25,001-\$100,000 | <input type="checkbox"/> >\$100,000 |
|  |  |  | <input type="checkbox"/> None | <input type="checkbox"/> <\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> \$25,001-\$100,000 | <input type="checkbox"/> >\$100,000 |
|  |  |  | <input type="checkbox"/> None | <input type="checkbox"/> <\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> \$25,001-\$100,000 | <input type="checkbox"/> >\$100,000 |

**7. Activities with other organizations** – Do you currently serve in any official capacity, including service as an officer, director, committee member, or editorial board member, with any international, national or state professional society, any federal or state agency, any health care organization or any other entity that engages in activities that could be considered competitive to ACR’s interests or activities specifically including, but not limited to, the areas of education, advocacy, registry formation and operation, research and fundraising?

| Organization | Position | Value of stipends, honoraria, etc. received in past 12 months |                                   |   |  |                                    |
|--------------|----------|---|-----------------------------------|---|--|------------------------------------|
|              |          | <input type="checkbox"/> None                                 | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|              |          | <input type="checkbox"/> None                                 | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|              |          | <input type="checkbox"/> None                                 | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|              |          | <input type="checkbox"/> None                                 | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|              |          | <input type="checkbox"/> None                                 | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |

**8. Family or Other Relations** - In accordance with the ACR’s disclosure policies, relevant financial or other relationships of members of your immediate family should also be disclosed. This includes but is not limited to spouse/domestic partner, parents, siblings, children, and grandchildren. Please list any significant relationships or activities where members of your family may be involved.

| Relation (spouse, child, etc.) | Activity/Position | Current Value                 |                                   |   |  |                                    |
|--------------------------------|-------------------|-------------------------------|-----------------------------------|---|--|------------------------------------|
|                                |                   | <input type="checkbox"/> None | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|                                |                   | <input type="checkbox"/> None | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|                                |                   | <input type="checkbox"/> None | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|                                |                   | <input type="checkbox"/> None | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |
|                                |                   | <input type="checkbox"/> None | <input type="checkbox"/> <\$5,000 | <input type="checkbox"/> \$5,001-\$10,000 | <input type="checkbox"/> \$10,001-\$25,000 | <input type="checkbox"/> >\$25,000 |

**Comments/Explanation** - Is there any additional relevant information that you feel should be disclosed or other relationships that you would like to clarify?

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**CERTIFICATION STATEMENT:** The above information is true and complete to the best of my knowledge. I have read and understand the ACR Code of Ethics and other policies relating to my obligations to the American College of Rheumatology. If there are any changes in my circumstances, I will update my Disclosure Statement as promptly as possible.

Name: \_\_\_\_\_ Signature: \_\_\_\_\_

Date: \_\_\_\_\_

*Attach additional pages if necessary.*