Methodology for Selecting Ad Hoc Workgroup Members for Treatment Options for Uterine Fibroids

Our goal for this workgroup is to provide input on the topic of Treatment Options for Uterine Fibroids from the diverse perspectives of researchers, patients, and other stakeholders. To do this, we will convene a workgroup small enough to encourage meaningful contribution from each participant, but large enough to ensure a balanced and informed discussion. The targeted size for this group is 12 to 18 people, with an even distribution of researchers, patients, and other stakeholders.

Researchers
We began by performing a number of online database searches (PubMed, Google Scholar, Google) using combinations of relevant terms such as “uterine fibroids,” “treatment,” “expert,” “panel,” “researcher,” and “conference” to access reports such as Identification of Future Research Needs in the Comparative Management of Uterine Fibroid Disease [AHRQ], the Howard University Fibroid Summit, websites, organizations, and articles that referenced names of researchers and other experts specializing in this area. From this search, we compiled the names of more than 100 researchers and other experts. Again, using online searches, we researched each individual and narrowed our list of potential candidates from 100 to 17 using the following criteria:

- Expertise and interest areas
- Main focus of work on research rather than clinical practice
- Awards and professional recognition in field of study
- Published a significant number of scholarly publications
- Publications frequently cited by other researchers
- Participation in expert panels
- Delivery of presentations in area of expertise

We then identified four critical study areas within this topic (comparative effectiveness of treatment options; optimal sequencing of treatments in subpopulations; expertise and research interest in one or more treatment options; general expertise in uterine fibroid treatment) and categorized our list of researchers based on these study areas. Lastly, we reviewed the list of potential workgroup members and narrowed the list further to assure balance with respect to study area, as well as geographic, institutional, ethnic, and gender diversity.

Patients
We began by identifying patient organizations associated with uterine fibroids. To do this, we performed online searches by combining the term “uterine fibroids” with terms such as “patient,” “group,” and “advocate/cy.” We also used the existing PCORI patient engagement database to identify other relevant groups and individuals who had not been identified through our online search process. This process yielded a list of three relevant patient groups and one patient.
Other Stakeholders
We began by identifying organizations associated with uterine fibroids. To do this, we performed online searches by combining the term “uterine fibroids” with terms such as “stakeholder,” “advocate/cy,” and “group.” We also utilized the existing PCORI stakeholder engagement database to identify other relevant groups that had not been identified through our online search process. This initial process yielded a list of 12 relevant stakeholder groups.

To narrow this list, we categorized the stakeholders into broad groups (ie, providers, payers, industry, and other topic-specific groups) and conducted an internal PCORI balancing process. Balancing criteria were designed to promote inclusiveness and result in a well-rounded set of stakeholder perspectives that included representation from obstetricians/gynecologists, minority health providers, industry, and payers. To complete the process, we cross-referenced this list with stakeholder lists generated for our other Targeted PFA workgroups to ensure stakeholder diversity across all workgroups.

We asked each stakeholder and patient organization to designate a representative to serve on the workgroup, naming someone with expertise in the workgroup’s subject matter and considering the broader context of PCORI’s core values of diversity and inclusiveness.

Evaluation of Proposed Workgroup List
A draft list of potential workgroup members was presented to PCORI’s Board and three committees—Program Development, Communications Outreach and Engagement, and Methodology—for their evaluation and input. We also shared the list with the invited moderator for additional input. PCORI staff synthesized all suggestions to develop a final list of invitees.

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The Patient-Centered Outcomes Research Institute (PCORI) helps people make informed health care decisions, and improves health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care community. This document is excerpted from Summary of Process to Generate PCORI Targeted Funding Announcements, available at http://bit.ly/WMt6ii.