

## APPENDIX 1

### CMSS PCORI Engaging Patients in Clinical Registries Engagement Advisory Committee

| Member               | Title   | Organization  | Contribution to Advisory Committee   |
|----------------------|---|---|--|
| Judith Baumhauer, MD | Professor and Associate Academic Chair, Department of Orthopedics   | University of Rochester   | Research, patient-reported outcomes, and patient engagement                  |
| Carol Cronin         | CEO   | Informed Patient Institute  | Patient engagement strategies  |
| Donna Cryer, JD      | Patient Advocate  | Global Liver Institute; Board Member, People-Centered Research Foundation | Patient advocate, research expertise   |
| Joyce Dubow          | Consumer and Patient Advocate (formerly AARP Health Policy)   | None  | Breast cancer patient, consumer advocate, outcomes focus                     |
| Clifford Ko, MD      | Director, Division of Research and Optimal Care   | American College of Surgeons (ACS), UCLA                                  | Registry expertise, leads ACS registries with focus on outcomes and research |
| Eugene Nelson, PhD   | Professor and Director of Population Health and Measurement   | Dartmouth Institute for Health Policy and Clinical Practice               | Registry expertise, patient co-production                                    |
| Sally Okun, RN       | Vice President, Policy and Ethics   | patientslikeme  | Patient engagement, online communities, connection to FDA efforts            |
| Bray Patrick-Lake    | Patient Partner and Former Director, Director of Stakeholder Engagement                                       | Clinical Trials Transformation Initiative (CTTI), Duke University         | Patient engagement in clinical trials, connection to FDA efforts             |
| Eleanor Peretto, PhD | Senior Vice President, Strategic Initiatives  | National Health Council   | Patient engagement, PROs, research   |
| William Rich, MD     | Director, Health Policy   | American Academy of Ophthalmology   | Registry expertise, leads IRIS registry, focus on outcomes and PROs          |
| Dan Solomon, MD      | Professor of Medicine at Harvard Medical School and Chief of the Section of Clinical Sciences in Rheumatology | Harvard Medical School and Brigham and Women's Hospital                   | Research and registry expertise, including patient perceptions of registries |