**Clearinghouse Requests (Jan. 1 2013 – present)**

| **Partner organization information** | **Consumer representative information** | **Activity** |
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| *Organization name (name of contact, email address, phone)* | *Consumer org name (name of representative, email address, phone)* | *e.g., “Bell’s Palsy Guideline Review”* |
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| American Academy of Orthopedic Surgeons  (Leeah T. Gross, gross@aaos.org) | All CUE members | Knee Replacement Survey |
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| American Academy of Otolaryngology- Head and Neck Surgery Foundation (Caitlin Drumheller, [cdrumheller@entnet.org](mailto:cdrumheller@entnet.org)) | National Committee to Preserve Social Security and Medicare (Bill Vaughan, wkvjee@hotmail.com) | Bell’s Palsy Guideline Review |
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| SHARE, Breast Cancer Coalition (Mary Helen Foglia, [maryhelenfoglia@gmail.com](mailto:maryhelenfoglia@gmail.com), [maryhelen.foglia@ppfa.org](mailto:maryhelen.foglia@ppfa.org),  212-260-4328 (H),  813-838-0469 (M)) |
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| American Academy of Otolaryngology- Head and Neck Surgery Foundation  (Peter Robinson  [probertson@entnet.org](mailto:probertson@entnet.org)) | CCNet (Liz Whamond) | Tinnitus Guideline |
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| PCORI/NIH | TMJ Association (Terrie Cowley) | Multiple Chronic Conditions Conference Washington DC |
| American Academy of Otolaryngology- Head and Neck Surgery Foundation (Lorraine Nnacheta, [lnnacheta@entnet.org](mailto:lnnacheta@entnet.org)) | CABCO (Sandy Walsh) | Allergic Rhinitis Guideline |
| National Coalition for LGBT Health (Barbara Warren) |
| Guidelines International Network (Richard Rosenfeld,  [rich@richrosenfeld.com](mailto:rich@richrosenfeld.com)) | Ovarian Cancer Alliance of San Diego (Peg Ford) | Steering Group Member |
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| PCORI/IOM ([implementation@pcori.org](mailto:implementation@pcori.org))? | National Women’s Health Network (Kate Ryan  [kyran@prochoiceamerica.org](mailto:kyran@prochoiceamerica.org)) | Dissemination and Implementation Roundtable Washington DC |
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| Guidelines International Network  (??) | Homebirth Summit (Jennifer Holloman  [hollomanjl@hotmail.com](mailto:hollomanjl@hotmail.com)) | Global Conference, San Francisco, CA |
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| LymeDisease.org (Pamela Cocks Could not contact—Lorraine Johnson may know her phone or email) |
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| CABCO (Sandy Walsh) |
| SEDL's Center on Knowledge Translation for Disability and Rehabilitation Research (KTDRR), a center funded by the National Institute on Disability and Rehabilitation Research (NIDRR) in the US Department of Education | Nominated:  National Committee to Preserve Social Security and Medicare (Bill Vaughan, [wkvjee@hotmail.com](mailto:wkvjee@hotmail.com)) | Consumer Review Panel input |
| Blue Cross Blue Shield Association (BCBSA) Technology Evaluation Center (TEC) | Nominated: National Consumers League  (Rebecca Burkholder) TMJ Association (Terrie Cowley) National Committee to Preserve Social Security and Medicare (Bill Vaughan) CABCO  (Sandy Walsh) | Medical Advisory Panel Consumer & Patient Representative |
| Cochrane Heart Group  (Anne Ehlinger,  [anne-ehlinger@northwestern.edu](mailto:anne-ehlinger@northwestern.edu)) | California Heart Connection (Deb Hilton [info@caheartconnection.org](mailto:info@caheartconnection.org))  949-653-6421 | Advisory Committee |
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| PCORI Methodology Committee (Mark Helfand, [helfand@ohsu.edu](mailto:helfand@ohsu.edu)) | LymeDisease.org (Lorraine Johnson  [lorrainejohnson@outlook.com](mailto:lorrainejohnson@outlook.com)  310-365-3233) | Feedback on stories developed for the PCORI Methodology Report |
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| SafeMinds (Sallie Bernard  [sbernard@safeminds.org](mailto:sbernard@safeminds.org)) |
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| Center for Medical Consumers (Maryann Napoli, [marnapnyc@gmail.com](mailto:marnapnyc@gmail.com)) |
| National Coalition of LGBT Health (Barbara Warren [bwarren@chpnet.org](mailto:bwarren@chpnet.org)) |
| RTI-UNC Evidence-based Practice Center  RTI International (Meera Viswanathan, PhD (Director)  [viswanathan@rti.org](mailto:viswanathan@rti.org)) | Our Bodies, Our Selves (Ayesha Chatterjee) | Consumer collaborator to join scientific team |
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| Cynthia Boyd, MD  [cboyd1@jhmi.edu](mailto:cboyd1@jhmi.edu)  Associate Professor at the Johns Hopkins University School of Medicine | National Partnership for Women and Families (Christine Broderick  [cbroderick@nationalpartnership.org](mailto:cbroderick@nationalpartnership.org)  (202) 986-2600) | Consumer Collaborator (PCORI grant application) |
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| Institute of Medicine (Diedtra Henderson, [dhenderson@nas.edu](mailto:dhenderson@nas.edu), 202-334-1665) | National Committee to Preserve Social Security and Medicare (Bill Vaughan, wkvjee@hotmail.com) | Consumer input on Discussion Paper from ECIC event |
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| American Academy of Otolaryngology—Head and Neck Surgery (Lorraine Nnacheta, lnnacheta@entnet.org) | CABCO (Sandy Walsh) | Clinical Practice Guideline Update: Adult Sinusitis |
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| CHEER Practice-based Research Network  Division of OHNS, Duke University Medical Center  (Kris Schulz,  Director of Research, 703.216.9176 (m),  [kristine.schulz@duke.edu](mailto:kristine.schulz@duke.edu)) | N/A | Stakeholder request for Letter of Intent for the PCORI RFA Improving Methods |
| National Quality Foundation (Ann Phillips, aphillips@qualityforum.org) | N/A | Standing committee concerns |
| American Society of Clinical Oncology Cancer (ASCO) | Ovarian Cancer Alliance of San Diego (Peg Ford) | Subcommittees of the ASCO Learning Intelligence Network for Quality (CancerLinQ) |
| Nan VanDenBerg |
| American Academy of Neurology  (Thomas S. D. Getchius, (612)928-6060,  [tgetchius@aan.com](mailto:tgetchius@aan.com)) | Nominated: LymeDisease.org (Lorraine Johnson) | Lyme Disease CPG |
| American Academy of Otolaryngology—Head and Neck Surgery Foundation | Nominated: Breast Cancer Care and Research Fund (Michele Rakoff) | Allergic Rhinitis CPG External reviewers |
| Mathematica Policy Research, Inc.  (Laura Kimmey, [lkimmey@mathematica-mpr.com](mailto:lkimmey@mathematica-mpr.com)) | All CUE members sent survey | Crowdsourcing activity on consumer preferences for info to make healthcare decisions |
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| Lewin Group ([robin.graham@lewin.com](mailto:robin.graham@lewin.com)) | N/A Pending funding | R01 Grant application AHRQ |
| Mayo Clinic (Erik Hess,  [hess.erik@mayo.edu](mailto:hess.erik@mayo.edu)) | National Committee to Preserve Social Security and Medicare (Bill Vaughan, wkvjee@hotmail.com) | Breakout session on Patient Centered Outcomes Research at a consensus conference organized by the Society for Academic Emergency Medicine. |
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| G-I-N NA (Richard Rosenfeld, [rich@richrosenfeld.com](mailto:rich@richrosenfeld.com)) | National Coalition for LGBT Health (Barbara Warren) | G-I-N Webinar |
| Ovarian Cancer Alliance of San Diego (Peg Ford) |
| NCQA | Nominated: Ellen Ullman | Diabetes measurement advisory panel |
| American Academy of Otolaryncology- Head and Neck Surgery (Maureen Corrigan,  [mcorrigan@entnet.org](mailto:mcorrigan@entnet.org)) | Sandy Walsh | Clinical Practice Guidelines for Otitis Media with Effusion |
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| Evidence-based Research Network (EBRNetwork) (Dr. Karen A. Robinson, krobin@jhmi.edu) | Ovarian Cancer Alliance of San Diego  (Peg Ford, [pegford2@hotmail.com](mailto:pegford2@hotmail.com)) | Request for CUE Representative for Steering Committee |
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| American Academy of Orthopaedic Surgeons  (Kaitlyn Sevarino) | All CUE members | Survey on Clinical Practice Guidelines for Surgical Site Infection |
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| American Academy of Neurology  (Tom Getchius, [tgetchius@aan.com](mailto:tgetchius@aan.com)) | Cherab Foundation (Lisa Geng, [lisa@cherab.org](mailto:lisa@cherab.org), (772) 919-1417)) | Neurologic Adverse Events Following Immunization CPG |
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| American Academy of Otolaryngology- Head and Neck Surgery  (Gene Cunningham, 703-535-3750, [gcunningham@entnet.org](mailto:gcunningham@entnet.org)) | CABCO (Sandy Walsh, sawalsh@prodigy.net) | Cerumen Impaction Clinical Practice Guideline Update |
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| American Society for Hematology (Rob Kunkle, [rkunkle@hematology.org](mailto:rkunkle@hematology.org)) | Nominated: National Committee to Preserve Social Security and Medicare (Bill Vaughan) | Venous thromboembolism (VTE) clinical practice guideline |
| American Academy of Family Physicians (Melanie Bird, [mbird@aafp.org](mailto:mbird@aafp.org)) | National Committee to Preserve Social Security and Medicare (Bill Vaughan, [wkvjee@hotmail.com](mailto:wkvjee@hotmail.com)) | Management of Newly Detected Atrial Fibrillation Clinical Practice Guideline Update |
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| American Academy of Otolaryngology—Head and Neck Surgery (Lorraine Nnacheta, [lnnacheta@entnet.org](mailto:lnnacheta@entnet.org)) | Association of Cancer Patient Educators (Sandy Finestone, [sandyfinestone@aol.com](mailto:sandyfinestone@aol.com)) | Rhinoplasty Clinical Practice Guideline |
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| American Academy of Otolaryngology—Head and Neck Surgery (Maureen Corrigan, [mcorrigan@entnet.org](mailto:mcorrigan@entnet.org)) | Nominated:  National Committee to Preserve Social Security and Medicare (Bill Vaughan, [wkvjee@hotmail.com](mailto:wkvjee@hotmail.com)) | Benign Paroxysmal Positional Vertigo (BBPV) Clinical Practice Guideline Update |
| American Academy of Otolaryngology- Head and Neck Surgery  (Gene Cunningham, 703-535-3750, [gcunningham@entnet.org](mailto:gcunningham@entnet.org)) | N/A | Peer Review of Cerumen Impaction Clinical Practice Guideline Update |
| American Academy of Otolaryngology—Head and Neck Surgery (Maureen Corrigan, [mcorrigan@entnet.org](mailto:mcorrigan@entnet.org)) | Association of Cancer Patient Educators (Sandy Finestone, [sandyfinestone@aol.com](mailto:sandyfinestone@aol.com)) | Neck Mass Clinical Practice Guideline |
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| American Academy of Otolaryngology—Head and Neck Surgery (Lorraine Nnacheta, [lnnacheta@entnet.org](mailto:lnnacheta@entnet.org)) | CABCO (Sandy Walsh) | Hoarseness (Dysphonia) CPG Update |
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| American Academy of Otolaryngology—Head and Neck Surgery | N/A | Peer Review of Rhinoplasty Clinical Practice Guideline Update |
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| American Academy of Otolaryngology—Head and Neck Surgery (Maureen D. Corrigan, (703) 535-3746, [mcorrigan@entnet.org](mailto:mcorrigan@entnet.org)) | Association of Cancer Patient Educators (Sandra Finestone, [sandyfinestone@aol.com](mailto:sandyfinestone@aol.com)) | Peer Review Benign Paroxysmal Positional Vertigo (BPPV) Clinical Practice Guideline Update |
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| American College of Physicians  (Wendy K. Nickel, 215-351-2802, WNickel@mail.acponline.org ) | Association of Cancer Patient Educators (Sandra Finestone, [sandyfinestone@aol.com](mailto:sandyfinestone@aol.com)) | Clinical Guidelines Committee Public Involvement |
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| Maryland Health Care Commission (MHCC) | N/A | Workshops to help design a new health care public reporting website |
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| American Academy of Otolaryngology—Head and Neck Surgery (Maureen D. Corrigan, (703) 535-3746, [mcorrigan@entnet.org](mailto:mcorrigan@entnet.org)) | N/A | Peer Review of Evaluation of Neck Mass CPG Update |
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| American Society of Hematology (Starr Webb, [swebb@hematology.org](mailto:swebb@hematology.org), (202) 629-5086) |  | Management of acute and chronic complications of sickle cell disease (SCD). |
| The American Academy of Family Physician(Melanie Bird, [MBird@aafp.org](mailto:MBird@aafp.org), (913) 906-6000) | SCAD Alliance (Katherine Leon, [katherine.leon@scadalliance.org](mailto:katherine.leon@scadalliance.org), 571-259-0001) | Post-Myocardial  Infarction Depression guideline |
| The American Academy of Otolaryngology—Head and Neck Surgery Foundation (AAO-HNSF)( Lorraine Nnacheta, [lnnacheta@entnet.org](mailto:lnnacheta@entnet.org), (703)-535-3751 | California Breast Cancer  Organizations (CABCO) (Ms. Sandar A. Walsh, [sawalsh@prodigy.net](mailto:sawalsh@prodigy.net), 530-756-7672) | AAO-HNSF Tonsillectomy in Children CPG Update Review |
| American College of Emergency Physicians (ACEP) (Rhonda Whitson, [rwhitson@acep.org](mailto:rwhitson@acep.org), 1-800-798-1822, ext 3231) | Washington Advocates for Pa􀆟ent Safety group (Yanling Yu, [yy8@uw.edu](mailto:yy8@uw.edu), 206-366-1629) | Clinical Guideline development for: Opioids  Imaging in suspected renal colic  Acute heart failure syndromes  Headache  Mild traumatic brain injury  Community-acquired pneumonia |
| American Society of Plastic Surgeons (Lauren Loeding, [lloeding@plasticsurgery.org](mailto:lloeding@plasticsurgery.org) , 847-981-5417) | N/A | Clinical Practice Guideline on Post-Mohs Reconstruction |
| American Society of Plastic Surgeons (Caryn Davidson, cdavidson@plasticsurgery.org  847-228-3349) | CABCO (Sandra Walsh, [sawalsh@prodigy.net](mailto:sawalsh@prodigy.net), 530-756-7672)  Our Bodies, Ourselves (Caroline Morton, carolinemtwo@gmail,com, (917)807-1473) | Develop measures around autologous (or flap) breast reconstruction |
| MAGIC Project (Lyubov Lytvyn, [lytvyn.lyubov@gmail.com](mailto:lytvyn.lyubov@gmail.com), [lyubov.lytvyn@sickkids.ca](mailto:lyubov.lytvyn@sickkids.ca)**,** +47 948 46 259) | Washington Advocates for Patient Safety (Karie Fugate, [katurnage@comcast.net](mailto:katurnage@comcast.net) , 425-793-7377) | Guideline on on using steroids to prevent sepsis. |
| American Academy of Sleep Medicine (AASM) (Sarah Hashmi [shashmi@aasmnet.org](mailto:shashmi@aasmnet.org), Direct: 630-737-9369  I Main Phone: 630-737-9700) | Washington Advocates for Patient Safety (Tracy Jones, [tracya.jones@live.com](mailto:tracya.jones@live.com), 206-284-3377) | Guideline project on “ **Indications for Polysomnography and HSAT (non-OSA)**”.  Patients with suspected sleep-related breathing disorders (excluding obstructive sleep apnea), sleep-related movement disorders, central disorders of hypersomnolence, parasomnias, and for monitoring of patients undergoing treatment for obstructive sleep apnea. |
| The American Academy of Otolaryngology—Head and Neck Surgery Foundation (AAO-HNSF)( Lorraine Nnacheta, [lnnacheta@entnet.org](mailto:lnnacheta@entnet.org), (703)-535-3751) | Association of Cancer Patient Educators  (Sandy Finestone, [SandyFinestone@aol.com](mailto:SandyFinestone@aol.com), 949-261-6020) | Tonsillectomy in Children” clinical guideline update |
| Editorial Office for PCORI Peer Review (at OHSU)(Ms. Kira Lesley, [lesley@ohsu.edu](mailto:lesley@ohsu.edu), (503) 560-4150) |  | Consumer representatives to serve as peer reviewers for PCORI studies |
| The American Academy of Family Physician(Melanie Bird, [MBird@aafp.org](mailto:MBird@aafp.org), (913) 906-6000) | Association of Cancer Patient Educators  (Sandy Finestone, SandyFinestone@aol.com, 949-261-6020) | Diabetic Neuropathy Rapid guideline |
| American Academy of Sleep Medicine (AASM) (Christopher Harrod), Main Phone: 630-737-9700) |  | Guideline development project on patients with OSA |
| American Academy of Sleep Medicine (AASM) (Vanessa Gonzalez), Main Phone: 630-737-9700) |  | Guideline development for Narcolepsy and Hypersomnia |
| American Thoracic Society (ATS) (Renda Soylemez Wiener, ([rwiener@bu.edu](mailto:rwiener@bu.edu)) |  | To develop an official ATS statement identifying the knowledge gaps and suggesting an agenda for future research related to incorporating co-morbidity information into clinical decisions between patients and clinicians about whether to pursue low-dose **CT lung cancer screening** |
| MAGIC Project (Lyubov Lytvyn, [lytvyn.lyubov@gmail.com](mailto:lytvyn.lyubov@gmail.com), [lyubov.lytvyn@sickkids.ca](mailto:lyubov.lytvyn@sickkids.ca)**,** +47 948 46 259) |  | Primary care (urology-related) guideline. This guideline is considering whether prescription of alpha blockers for ureteric stones patients would be useful |
| MAGIC Project (Lyubov Lytvyn, [lytvyn.lyubov@gmail.com](mailto:lytvyn.lyubov@gmail.com), [lyubov.lytvyn@sickkids.ca](mailto:lyubov.lytvyn@sickkids.ca)**,** +47 948 46 259) | National Committee to Preserve Social Security and Medicare (Bill Vaughan, wkvjee@hotmail.com) | PSA screening guideline. (and potentially those who have been screened and are considering their options) |
| American Society of Plastic Surgeons (Caryn Davidson, [cdavidson@plasticsurgery.org](file:///\\sph-cct\cct\PI\Shared\Cochrane\12%20CUE-ConsumerCoalition\2d-%20%20Dissemination&partnerships\CUE%20Clearinghouse\Report%20on%20Clearinghse%20activities\5%20Report%20on%20Clearing%20house%20activ\cdavidson@plasticsurgery.org)  847-228-3349) | Association of Cancer Patient Educators  (Sandy Finestone, SandyFinestone@aol.com, 949-261-6020) | Measure development project which will develop measures around rhinoplasty |
| MAGIC Project (Lyubov Lytvyn, [lytvyn.lyubov@gmail.com,](file:///\\sph-cct\cct\PI\Shared\Cochrane\12%20CUE-ConsumerCoalition\2d-%20%20Dissemination&partnerships\CUE%20Clearinghouse\Report%20on%20Clearinghse%20activities\5%20Report%20on%20Clearing%20house%20activ\lytvyn.lyubov@gmail.com,%20) lyubov.lytvyn@sickkids.ca, +47 948 46 259) |  | Colorectal cancer  screening guidelines |
| American Society of Plastic Surgeons  (Katelyn Stermer, [kstermer@plasticsurgery.org](file:///\\sph-cct\cct\PI\Shared\Cochrane\12%20CUE-ConsumerCoalition\2d-%20%20Dissemination&partnerships\CUE%20Clearinghouse\Report%20on%20Clearinghse%20activities\5%20Report%20on%20Clearing%20house%20activ\kstermer@plasticsurgery.org), +1(847) 981-5433) |  | Clinical practice guideline panel for Upper Eyelid Blepharoplasty for Field Vision Loss |