PATient-centered Involvement in Evaluating effectiveNess of TreatmentS
Training of Researchers, Partners, and Trainees

- Built upon the existing UMB Clinical and Translational Science K30 Program.
- Addresses the needs of our community partners and will take advantage of numerous opportunities for bidirectional learning.
- Includes general research principles as well as topics related to IRB, ethics of community-based research, pragmatic clinical trials, grant development and observational study designs designed for both researchers and community partners.
- Utilizes a variety of learning approaches including but not limited to didactic and experiential learning, partnered co-mentoring, online training, and shadowing experiences, whereby researchers and community partners will provide opportunities for others to “shadow them” to obtain exposure to and appreciation for the skills and abilities to conduct CBPR that is culturally competent.
Training Activities

Catalog / Online Training
- Feedback from needs assessment
- Initial search
- Discussions with external partners
- With HS/HSL: Systematic search procedure for updating

Mentoring
- CER/PCOR Working Group Collaboration
- Pilot funds

Experiential / Shadowing

Seminar Examples
- Sean Sullivan (K12) [11/2013]
- PCOR Funding Information Session [12/2013]
- Housing Health And Wellness Fair [3/2014]
Capacity Building by the Numbers

• 179 Videos in curated playlists
  • 18 in Campus & Community
  • 16 in CER-PCOR Training
  • 6 in PCOR at UMB Resources
  • 4 in Introduction to PCOR

• PCOR Pilot Funding
  • 40 Submissions – $245,000 requested in funding
  • 21 Funded - $120,000 released in funding (+ 4 pending)

• PROEM Summer Institute
  • Over 200 faculty, stakeholders and trainees completed intensive training course
Digital and In-Person Experiential Learning

• Online portal for trainings and videos
  • Researchers learn how to engage community
  • Community learns how they impact research
• CER-PCOR Summer Institute – 111 learners
• CER-PCOR Workgroup – 142 members
• PATIENTS Pilot Funding
  • $5,000 and $10,000 awards designed to help researchers obtain meaningful patient interaction before research activities officially begin
### Selected Projects from the PATIENTS Portfolio

<table>
<thead>
<tr>
<th>Agency</th>
<th>P. Investigator</th>
<th>Contract or Grant Title</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>PhRMA Foundation</td>
<td>Perfetto, Eleanor (UMB)</td>
<td>Patient-Centered Research for Outcomes, Effectiveness, and Measurement (PROEM)</td>
<td>$350,000</td>
</tr>
<tr>
<td>PCORI</td>
<td>DosReis, Susan (UMB)</td>
<td>Methods for Prioritizing Surrogate Desired Health Outcomes for Patients</td>
<td>$935,000</td>
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<tr>
<td>AHRQ</td>
<td>Mullins, Daniel (UMB)</td>
<td>PATIENTS: PATient-centered Involvement in Evaluating effectiveNess of Treatments</td>
<td>$5,000,000</td>
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<tr>
<td>PCORI</td>
<td>Bekelman, Justin (UPenn)</td>
<td>Pragmatic Randomized Trial of Proton vs. Photon Therapy for Patients with Non-Metastatic Breast Cancer Receiving Comprehensive Nodal Radiation: A Radiotherapy Comparative Effectiveness (RADCOMP) Trial</td>
<td>$11,800,000</td>
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<tr>
<td>PCORI</td>
<td>Mullins, Daniel (UMB)</td>
<td>Interviews for Eliciting the Hard-to-Reach Patient</td>
<td>$125,000</td>
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<tr>
<td>PCORI</td>
<td>Mullins, Daniel (UMB)</td>
<td>Mapping and Resourcing Patient and Stakeholder Engagement Along 10-Step PCOR Continuum Framework</td>
<td>$1,215,000</td>
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<tr>
<td>PCORI</td>
<td>Carter-Pokras, Olivia (UMCP)</td>
<td>The Patient Voice in Cultural Diversity Training for Patient Centered Outcomes Researchers</td>
<td>$250,000</td>
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<tr>
<td>PCORI</td>
<td>Perfetto, Eleanor (UMB)</td>
<td>Patient-Community Capacity to Engage in Quality of Health Care Research and Programs</td>
<td>$246,000</td>
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<tr>
<td>PCORI</td>
<td>Tambor, Ellen (CMTP)</td>
<td>Clinician Participation in PCOR: Defining a Framework for More Effective Engagement</td>
<td>$250,000</td>
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<tr>
<td>PCORI</td>
<td>O'Toole, Robert (UMM)</td>
<td>A Randomized Pragmatic Trial Comparing the Complications and Safety of Blood Clot Prevention Medicines Used in Orthopaedic Trauma Patients</td>
<td>$11,200,000</td>
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<tr>
<td>Merck</td>
<td>Mullins, Daniel (UMB)</td>
<td>Co-developing Sustainable Learning Health Care Communities (LHCC) using CBPR</td>
<td>$250,000</td>
</tr>
<tr>
<td>US Dept of Defense</td>
<td>Slobogean, Gerard (UMMC)</td>
<td>Aqueous-PREP: A Pragmatic Randomized trial Evaluating Pre-operative aqueous antiseptic skin solutions in open fractures</td>
<td>$2,998,673</td>
</tr>
<tr>
<td>PCORI</td>
<td>Slobogean, Gerard (UMMC)</td>
<td>A Pragmatic Randomized trial Evaluating Pre-operative Antiseptic skin solutions in fractured Extremities (PREPARE)</td>
<td>$10,889,262</td>
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<tr>
<td>PCORI</td>
<td>Mattingly, Joey (UMB)</td>
<td>Engaging an Underserved Patient Community to Inform and Improve Comparative Effectiveness Research for Hepatitis C Treatments</td>
<td>$49,500</td>
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<tr>
<td>PhRMA Foundation</td>
<td>dosReis, Susan (UMB)</td>
<td>Center of Excellence for Patient-Driven Value Assessment</td>
<td>$500,000</td>
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</tbody>
</table>
K-Awardee Support

• “Prioritizing Quality Improvement for the Treatment of Psychiatric Disturbances Following Traumatic Brain Injury” Source: AHRQ (K01HS024560) 03/01/16-2/28/21 – PI: Jennifer Albrecht, PhD

• “Enhancing Clinical Guideline Development via Patient & Stakeholder Engagement” Source: AHRQ (K08HS024159) 7/1/2015-6/30/2020 – PI: Melissa Armstrong, MD, MSc, FAAN
Training and Education

Community Partners
- Stakeholder Engagement
- Cultural Competence
- Using Online Platforms

Bidirectional Learning

UM Faculty and Staff
- Research Methods
- Clinical Trial Design
- Grant Infrastructure

Ethical Conduct of Research

Didactic  Experiential  Mentoring

Online  Shadowing
Community Partner Experience

Aurelia Laird, RN, BSN
Director of Clinical and Community Research
Bon Secours Baltimore Health System
Bidirectional Learning with Bon Secours and UMB

• Bon Secours is committed to training University of Maryland researchers, students and faculty in cultural competency and community engagement best practices

• We educate on the importance of community education and strategies on how to engage communities and individuals in the research process

• Roundtable discussions on the process of identifying individuals in the community and educating them on the importance of participation in research activities and partnering with researchers to answer health related questions

• Reviewed and discussed outcomes from our interactions with individuals at Community day and made recommendations on how to further understand and meet needs of the population we serve
Bidirectional Learning

• The university of Maryland supports the development of a sustainable research infrastructure at Bon Secours Baltimore

• This support takes place through informal in person meetings and customized training videos. The video training archive includes topics such as “Partnering and Invoicing for Federal Proposals” to discussions on CER, collaborating on writing proposals as well as applying for funding opportunities

• All educational programs are provided through in person learning or classroom setting
Mentee Experience

Melissa Armstrong, MD, MSc, FAAN
Director, Mangurian Clinical-Research Center for Lewy Body and Parkinson's Disease Dementia
University of Florida
Enhancing Clinical Guideline Development via Patient & Stakeholder Engagement

• PI: Melissa J. Armstrong, MD, MSc
• Grant: ARHQ K08HS024159
• Program Announcement/FOA: PA-13-039 ARHQ Mentored Clinical Scientist Research Career Development Award (K08)
• Dates: 7/1/2015-6/30/2020

• Overall aim: To investigate the effect of patient/family/advocate involvement on guideline question formation during the guideline development process
  • Methods: Parallel group study design, survey
  • Mixed methods approach (qualitative, quantitative)
Use of R24/PATIENTS Program Mentorship

• Primary mentor: C. Daniel Mullins

• Recruitment for pilot focus group to investigate how the public would want to be engaged in a guideline panel if invited (July 2015)

• Reverse site visit to Patients Like Me (July 2015)

• CER-PCOR Summer Institute (August 2015)

• PATIENTS Program site visit (September 2016) and video creation

• Collaborations with other program participants resulting in publications

• Writing “blurb” for PATIENTS newsletter about focus group results
PCOR Training Activities

• Formal training (see prior slide)
• Research conduct
• Incorporating community “give-back” as part of career development activities
  • Presentations to patient advocacy groups, creation of lay summaries of grant and what guidelines are, patient blogs (professionally edited and published), presentations to support groups, radio segment for The Academic Minute on NPR about shared decision making, etc.
• Co-presenting with patient in lecture to medical students about patient engagement
Output to Date

• Publication of framework/models relating to grant topics

• Publication of grant results

• Patient-facing publications, presentations
  • Multiple professionally edited and published blogs, including two specifically relating to grant (one on shared decision making and one on guidelines) published on The Conversation

• Training others
  • Lecture for medical students regarding patient engagement, co-presented with patient
THANK YOU!