PCOR & Reproductive Health Summit
DAY 1 – October 20, 2015
WELCOME, GOALS, & INTRODUCTIONS
PPFA Research

- One tenet of the Planned Parenthood Mission is:
  
  “... to promote research and the advancement of technology in reproductive health care and encourage understanding of their inherent bioethical, behavioral, and social implications.”

- **Research Department** consisting of 7 staff members, including clinical and public health researchers.

- Three main areas of responsibility:
  - technical assistance to affiliates on all research related matters and approval of all research conducted at affiliates (~ 70 studies per year);
  - leadership of the PPFA Clinical Research Network (CRN) to coordinate multi-center trials; and
  - PPFA led research such as investigator-initiated studies, EHR-based research, and program evaluation.
Background

• Inherent in the Planned Parenthood mission is a respect for each individual’s right to make informed, independent decisions about his or her health — a principle that is also central to the patient-centered outcomes research (PCOR) framework.

• Given the value we place on providing patient-centered care, we saw a need for more patient-centered reproductive health research.

• Then the Eugene Washington PCORI Engagement Awards appeared.

• As a leading national reproductive health care organization, Planned Parenthood is uniquely positioned to convene stakeholders for a PCOR & Reproductive Health Summit.
Goals

• The overall goals of the project are to translate the principles of PCOR into patient-centered reproductive health research priorities and build capacity for increased patient engagement in reproductive health research.

• Our objectives are to:

  1) Convene a group of stakeholders to explore the promise of PCOR for advancing reproductive health.

  2) Increase participant awareness of emerging practices in patient engagement in reproductive health research and identify potentially unique challenges and solutions.

  3) Develop and disseminate research priorities for PCOR in reproductive health to encourage more patient-centered reproductive health research.
Introductions

- Name
- Role/Title
- Organization
Working Agreements

- Listen, hear, respect
- Welcome differences
- Assume good intentions
- Limit acronyms and jargon
- Be aware of generalizations – speak from experience
- Challenge yourself
- Step up/hold back
- Be present
- Limit use of technology
- Feel free to share outside the meeting, but do not attribute remarks to individuals or organizations without permission.
- Anything else?
Housekeeping

- Restrooms
- Pantry
- Do not open patio doors
- Access to building/security
Agenda

DAY 1
1:00–1:45pm  Welcome, Goals, and Introductions
1:45–2:15pm  Review of PCOR Principles & Working Definitions
2:15–3:00pm  Review of Pre-Summit Planning Activities & Outcomes
3:00–3:15pm  Coffee Break
3:15–5:00pm  Emerging Practices in PCOR & Discussion
5:00–6:00pm  Networking Cocktail Hour (joined by other PPFA stakeholders)

DAY 2
*Breakfast available 8:00–8:30am*
8:30–9:00am  Review and Reflections from Day 1
9:00–10:00am Overview and Discussion of Priority-Setting Framework
10:00–12:00pm Engaging with Priorities: Part I
12:00–1:30pm  Lunch Presentations from current PCORI-funded researchers
1:30–3:30pm  Engaging with Priorities: Part II
3:30–4:00pm  Bringing it Home
4:00–4:30pm  Final Reflections, Post-Summit Plans, and Evaluations
I would consider this a success if...

• Each participant learns something new.

• Each participant identifies one thing they will do, or do differently, as a result of attending the summit.

• Each participant meets at least one new person they might collaborate with in the future.

• We get some great input and ideas for a way forward!
WELCOME FROM PCORI
ACKNOWLEDGMENTS
OVERVIEW OF PCOR PRINCIPLES & WORKING DEFINITIONS
PCOR Principles, Working Definitions & Models for Collaboration
PCOR Reproductive Health Summit

Alison Rein, Senior Director, AcademyHealth
Alison.Rein@AcademyHealth.org
@alr5
Vision
AcademyHealth envisions a future where individuals and communities are made healthier by the use of evidence in decision-making.

Mission
Together with its members, AcademyHealth works to improve health and the performance of the health system by supporting the production and use of evidence to inform policy and practice.
Principles

Evidence is important
We believe policies affecting health and the performance of the health system should be informed by the best and most relevant evidence. We will promote both the production and use of evidence from health services and policy research to improve health, health care, and public health.

Evidence is a common good
We maintain that the production of evidence about what works to improve health and the performance of the health system, for whom, under what conditions, and with which outcomes, is a common good. We advocate for and support the development of the workforce, data and information infrastructure, and funding necessary to produce relevant, high quality, timely evidence.

Diversity of opinion and perspective produces better evidence
We believe that diverse perspectives lead to richer and more nuanced understanding of issues related to health and the performance of the health system. We support a big tent approach and encourage participation from all. Our activities are nonpartisan and seek to encourage and support diversity in the field.

AcademyHealth is ‘of the field and for the field’
We strive to develop high quality programs and services that address the needs and concerns of our field and members, as well as anticipate, respond to, and raise awareness of a changing environment for health and the performance of the health system. The richness of these activities is enhanced through the efforts of our member volunteers. We will recruit and retain highly trained and motivated staff who represent, reflect and promote the field.
AcademyHealth Works with its Members & Partners to:

- Build a diverse community for evidence producers & users
- Advance the science of health services & policy research
- Move knowledge into action through synthesis, translation, dissemination & technical assistance
So What is PCOR Anyway?

- Engages patients / other stakeholders in research process
- Investigates questions that matter to patients
- Helps people make informed health and care decisions
PCORI wants:
Research focused on approaches known to be efficacious but not (yet) adequately compared

Inclusion of / attention to needs and concerns of patients distinguishes PCOR

Direct comparison of two or more interventions distinguishes CER

Greatest Needs & Opportunities for Field of Reproductive Health?
# CBPR or PCOR?

<table>
<thead>
<tr>
<th>Dimension</th>
<th>CBPR</th>
<th>PCOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who is engaged</td>
<td>Community members (lay people)</td>
<td>Patients/consumers, and caregivers</td>
</tr>
<tr>
<td>Primary purpose</td>
<td>• Improve health / well-being</td>
<td>• Improve health outcomes</td>
</tr>
<tr>
<td></td>
<td>• Eliminate health disparities</td>
<td>• Help people make more informed health care decisions</td>
</tr>
<tr>
<td></td>
<td>• Use research for social action and change</td>
<td>• Vehicle for patient, consumer, and caregiver voices to be heard</td>
</tr>
<tr>
<td>Other outcomes</td>
<td>• Action to improve health / well-being of the community</td>
<td>• Action may / may not occur</td>
</tr>
<tr>
<td></td>
<td>• Can lead to benefits for particular communities, including increased local knowledge and capacity, self-empowerment, improved health outcomes, and community planning</td>
<td>• Benefits may / may not be immediately experienced</td>
</tr>
<tr>
<td></td>
<td>• Increases racial and ethnic minority participation in trials</td>
<td>• Can provide value by contributing evidence to the field</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Incorporates wide variety of settings / diversity of participants</td>
</tr>
<tr>
<td></td>
<td></td>
<td>to address individual differences / barriers to D&amp;I</td>
</tr>
</tbody>
</table>
What *is* (Meaningful) Engagement in PCOR?

- Opportunities for engagement in PCOR span full spectrum of the research process
  - Inclusive of dissemination & implementation

- Represents transition
  - from doing research *on* people, versus doing research *with* them
PCOR Stakeholders

- Patient/consumer*
- Caregiver/family member of patient*
- Patient/consumer/caregiver advocacy organization*
- Clinician (e.g. nurse, physician)*
- Clinic/hospital/health system
- Purchasers (e.g. employer)
- Payers (both public & private)
- Industry (i.e., life sciences)
- Research
- Policy maker (e.g. state legislator, executive agency employee)
- Training institution (e.g. academic medical center, residency program)
- Media
When and where…

❖ A “community” engages in something new (to them) and/or faces common challenges
❖ There are opportunities for shared discovery, learning, and collaboration
❖ There is a chance to advance knowledge and action…

AcademyHealth Builds & Supports Communities of Practice
AcademyHealth Approach to Building (Learning) Communities of Practice

- Actively listen, harvest, and synthesize
- Facilitate collaboration
- Capture issues with potential to inform field
- Support Dissemination
Questions?
PRE-SUMMIT ACTIVITIES & OUTCOMES
WHERE WE’VE BEEN . . .
Where We’ve Been

• Convened 25 stakeholders for a virtual brainstorming session to generate a preliminary list of topics.

• Conducted a stakeholder survey of PP clinicians and researchers to assess knowledge, attitudes, and experience in patient engagement in research and identify additional research topics.

• Formed a smaller summit planning committee members drawn from the larger workgroup.

• Conducted scan of funded projects.

• Developed research topic briefs on 10 selected areas.

• Participated in a panel at the PCORI Annual Meeting.
Initial Culling of Priorities

- Society of Family Planning priorities list
- PCORI’s topic database and original public call for topics
- PCOR & Reproductive Health Workgroup brainstorm
- Stakeholder survey of PP clinicians & researchers
Scanned research funded between January 2010 and June 2015 with a focus on PCOR or explicit patient engagement in the research process and adhered to WHO definition of reproductive health.

<table>
<thead>
<tr>
<th>Source</th>
<th>Studies</th>
<th>Relevant Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCORI</td>
<td>548</td>
<td>26</td>
</tr>
<tr>
<td>AHRQ</td>
<td>228</td>
<td>6</td>
</tr>
<tr>
<td>ClinicalTrials.gov</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>NIH</td>
<td>115</td>
<td>5</td>
</tr>
</tbody>
</table>

These 38 research studies further examined . . .
Scan of Funded Projects: Results

- Total of 38 research projects that met the inclusion criteria, with some including more than one topic area:
  - sexually transmitted infections (n=10);
  - prostate cancer (n=9);
  - contraceptive use and method decision support (n=6);
  - gynecological cancers (n=4);
  - pregnancy-related topics (n=4); and
  - uterine fibroids (n=2)
- 2 studies on sexual health in the transgender community, with one focused on sexual health screenings and the other on general health outcomes after reassignment treatment or surgeries.
- 1 study to test a personalized education campaign using community health workers (CHWs) to help women navigate reproductive health services.
- 1 study to improve assessment for and counseling of intimate partner violence and reproductive coercion.
The objectives of the survey were to:

- Assess knowledge, awareness and attitudes toward PCOR (including comparative effectiveness research and patient engagement in research).

- Identify research priorities of stakeholders working directly with patients.

- Provide respondents an opportunity to offer topic areas for future research in reproductive health of interest to providers and patients.
Stakeholder Survey Methods

• A voluntary electronic survey administered in June 2015

• Respondents were Planned Parenthood clinicians, medical directors, and researchers

• Allowed forwarding of survey link to increase reach (to, for example, per diem clinicians).

• Included closed- and open-ended questions
Stakeholder Survey Results

• 150 stakeholders completed the survey (RR not yet calculated).

• Levels of knowledge and awareness:
  – 44% of respondents were moderately or very familiar with PCOR
  – 39% of respondents were moderately or very familiar with CER

• Attitudes towards PCOR:
  – 94% responded that it was either moderately or very important that research facilitates shared decision-making between providers and patients
  – 87% of respondents either agreed or strongly agreed that CER can improve how patients and providers make health care decisions
Stakeholder Survey Results

Top three areas where more comparative effectiveness research is needed

- Contraceptive counseling methods
- Interventions to improve preconception health
- STI diagnostic and treatment options
- HPV vaccine initiation and completion
- Body weight/BMI and contraceptive efficacy
- Comparative effectiveness and safety of abortion methods
- Comparative effectiveness and safety of contraceptive methods
- Patient-reported outcomes for reproductive health
- Health care delivery systems and models
- Other (please describe):

![Bar chart showing the top three areas where more comparative effectiveness research is needed, with providers and patients' perspectives indicated.](chart.png)
Stakeholder Survey
Conclusions

• Moderate levels of knowledge and awareness of PCOR
• Favorable attitudes towards PCOR
• Providers’ own research priorities differed slightly from perceived priorities for patients
10 Topic Briefs

- Adapted PCORI’s prioritization process to develop briefs on specific research topic areas.
- Chose 10 topics to delve into to provide a framework for exploring specific reproductive health research topics for PCOR.
- These are not THE priorities – they are examples to help us to think through promising research topics together.
- You will be hearing A LOT more about the briefs on Day 2!
Where We’re At

- **Convene Summit** of 30 reproductive health stakeholders on October 20–21, including researchers, patient advocates, policy leaders, and PCORI representatives.

- **Engage with Initial Priorities** through topic briefs and developing new ways to think about PCOR research topics.

- **Develop strategy** for engaging patients in priorities.
Where We’re Going

- **Evaluate Summit** to determine initial outcomes and inform next steps.
- **Draft Summit Report** describing the summit proceedings, outcomes, emerging practices, and initial research priorities.
- **Conduct Listening Sessions** with ~ 100 patients and elicit patient input on priorities.
- **Disseminate Final Summit Report** widely and host a public stakeholder webinar (June 2016).

... toward a patient-centered outcomes research agenda for reproductive health and more PCOR!
Q & A
COFFEE BREAK
EMERGING PRACTICES IN PCOR
Emerging Practices in PCOR from the PCORI Pilot Projects
PCOR Reproductive Health Summit

Alison Rein, Senior Director, AcademyHealth
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@alr5
Agenda

I. PCORI Pilot Projects Learning Network (PPPLN)
   a. Goals
   b. Results
   c. Participant perceptions

II. Pilot Projects Overview
   a. Summary meta data
   b. Stakeholder engagement
   c. Project examples
PPPLN Goals

- Synthesize knowledge & facilitate shared learning across projects / disciplines
- Foster new collaborations
- Advance strategies for effective stakeholder engagement
- Support Pilots as they encourage their institutions to conduct, promote, or use PCOR
- Accelerate the D&I of Pilot Project insights & findings
# In Their Own Words: Reasons for PPPLN Participation

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>To network with / learn from other PCOR researchers</td>
<td>86%</td>
</tr>
<tr>
<td>To gain a stronger understanding of PCORI and its initiatives</td>
<td>57%</td>
</tr>
<tr>
<td>To improve my research knowledge and skills</td>
<td>57%</td>
</tr>
<tr>
<td>Saw it as a professional development opportunity</td>
<td>54%</td>
</tr>
<tr>
<td>To network with / learn from engaged stakeholders</td>
<td>50%</td>
</tr>
<tr>
<td>Thought it would be enjoyable</td>
<td>29%</td>
</tr>
<tr>
<td>Thought it was required by the PCORI Pilot Project contract</td>
<td>14%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>4%</td>
</tr>
</tbody>
</table>

Other: I hoped it might lead to some cross-project developments of papers and proposals  
N=28
## PPPLN Goal Attainment

<table>
<thead>
<tr>
<th>Goal</th>
<th>Very Well</th>
<th>Somewhat</th>
<th>Not at All</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encourage my institution to conduct, promote or use PCOR in new ways</td>
<td>25%</td>
<td>45%</td>
<td>25%</td>
<td></td>
</tr>
<tr>
<td>Foster new collaborations among participants</td>
<td>43%</td>
<td>41%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Advance new strategies for effective stakeholder engagement</td>
<td>25%</td>
<td>57%</td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>Accelerate the D&amp;I of the research findings and products</td>
<td>32%</td>
<td>57%</td>
<td>15%</td>
<td></td>
</tr>
<tr>
<td>Synthesize knowledge and facilitate shared learning</td>
<td>50%</td>
<td>42%</td>
<td>8%</td>
<td></td>
</tr>
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</table>

N=28
## Pilot Project Priority Areas

<table>
<thead>
<tr>
<th>Priority Area</th>
<th>Number of Projects*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improving Healthcare Systems</td>
<td>12</td>
</tr>
<tr>
<td>Communication and Dissemination</td>
<td>31</td>
</tr>
<tr>
<td>Health Disparities</td>
<td>12</td>
</tr>
<tr>
<td>PCOR Infrastructure/Methods</td>
<td>23</td>
</tr>
</tbody>
</table>

*Number does not sum to 50 because categories are not mutually exclusive
## Patient Centered Approaches

<table>
<thead>
<tr>
<th>Patient-Centered Approach</th>
<th>Number of Projects*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Decision Support Tools</strong></td>
<td>21</td>
</tr>
<tr>
<td><strong>Patient/Care Team Relationships</strong></td>
<td>23</td>
</tr>
<tr>
<td><strong>Patient-Centered Outcomes Instruments</strong></td>
<td>22</td>
</tr>
<tr>
<td><strong>Medication Adherence</strong></td>
<td>3</td>
</tr>
</tbody>
</table>

*Number does not sum to 50 because categories are not mutually exclusive*
## Pilot Project Study Populations

<table>
<thead>
<tr>
<th>Study Population</th>
<th>Number of Projects*</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Americans</td>
<td>7</td>
</tr>
<tr>
<td>Latinos</td>
<td>6</td>
</tr>
<tr>
<td>Asian Americans</td>
<td>1</td>
</tr>
<tr>
<td>Native Americans</td>
<td>1</td>
</tr>
<tr>
<td>Men</td>
<td>3</td>
</tr>
<tr>
<td>Women</td>
<td>5</td>
</tr>
<tr>
<td>Children</td>
<td>4</td>
</tr>
<tr>
<td>Older Adults</td>
<td>5</td>
</tr>
<tr>
<td>Underserved/Low Income Populations</td>
<td>7</td>
</tr>
</tbody>
</table>

*Number does not sum to 50 because categories are not mutually exclusive*
## Pilot Project Conditions

<table>
<thead>
<tr>
<th>Disease Area</th>
<th>Number of Projects*</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Chronic</em></td>
<td>26</td>
</tr>
<tr>
<td><em>Acute</em></td>
<td>4</td>
</tr>
<tr>
<td><em>Behavioral</em></td>
<td>7</td>
</tr>
<tr>
<td><em>Pediatric</em></td>
<td>5</td>
</tr>
<tr>
<td><em>Geriatrics</em></td>
<td>5</td>
</tr>
<tr>
<td><em>Rare Diseases</em></td>
<td>2</td>
</tr>
<tr>
<td><em>Other</em></td>
<td>3</td>
</tr>
</tbody>
</table>

*Number does not sum to 50 because categories are not mutually exclusive*
PILOT PROJECT ENGAGEMENT
Extent & Nature of Engagement

- Projects reporting stakeholder engagement: 39
- Common mechanisms for engagement:
  - Advisory (individual & group)
  - Focus groups
  - Interviews
  - Surveys
  - User testing
PCORI Engagement Principles

Six Principles of PCORI Engagement:
1. Reciprocal relationships
2. Co-Learning
3. Partnerships
4. Transparency
5. Honesty
6. Trust
(PCOR) Research Stages

<table>
<thead>
<tr>
<th>Research Stage</th>
<th>Discrete Activities</th>
</tr>
</thead>
</table>
| **Study Planning (pre-award)** | • Conceptualization of research question  
• Identification of study population(s)  
• Drafting of study design & methods  
• *(Establishment of engagement approach)*  
• Proposal development |
| **Study Planning (post-award)** | • Refinement of research question  
• Refinement of study design & methods  
• Refinement of study populations  
• *(Refinement of engagement approach)* |
| **Study Conduct**            | • Finalization of processes & protocols  
• Study population recruitment  
• Data collection  
• Data analysis  
• *(Implementation & assessment of engagement approach)* |
| **Dissemination & Implementation** | • Synthesis & Translation  
• *(Evaluation & reporting of impact)* |
## Communities Engaged by Pilot Projects

<table>
<thead>
<tr>
<th>Role</th>
<th>Percent Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient(s)/Consumer(s) (unaffiliated individuals)</td>
<td>90</td>
</tr>
<tr>
<td>Caregiver(s)/Family Member(s)/ of Patient (unaffiliated individual)</td>
<td>41</td>
</tr>
<tr>
<td>Patient/Consumer/Caregiver Advocacy Organization(s)</td>
<td>41</td>
</tr>
<tr>
<td>Clinician(s)</td>
<td>87</td>
</tr>
<tr>
<td>Clinic/Hospital/Health System Representative(s)</td>
<td>44</td>
</tr>
<tr>
<td>Purchaser(s)</td>
<td>3</td>
</tr>
<tr>
<td>Payer(s)</td>
<td>3</td>
</tr>
<tr>
<td>Industry Representative(s)</td>
<td>10</td>
</tr>
<tr>
<td>Policy Maker(s)</td>
<td>18</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
</tr>
</tbody>
</table>
Common Challenges Reported

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Percent Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of stakeholder time</td>
<td>46</td>
</tr>
<tr>
<td>Lack of research team time</td>
<td>35</td>
</tr>
<tr>
<td>Lack of stakeholder training/background</td>
<td>30</td>
</tr>
<tr>
<td>Difficulty in finding the appropriate representatives to engage</td>
<td>27</td>
</tr>
<tr>
<td>Lack of research team resources</td>
<td>24</td>
</tr>
<tr>
<td>Lack of research team training/background</td>
<td>22</td>
</tr>
</tbody>
</table>
PILOT PROJECT EXAMPLES
Public Deliberation on Research Priorities: Pre-Research Engagement Exemplar

“By emphasizing the inclusion of underserved minority and rural communities, the proposed study expands public input on PCOR priorities geographically and demographically, beyond the limited settings in which much public engagement currently functions.”

<table>
<thead>
<tr>
<th>PI</th>
<th>Susan Goold</th>
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</thead>
<tbody>
<tr>
<td>Affiliation</td>
<td>University of Michigan</td>
</tr>
<tr>
<td>PPPLN Group</td>
<td>Research Prioritization and Analytic Methods</td>
</tr>
</tbody>
</table>

**PCORI Priority Areas**
- Improving Health Systems
- Addressing Disparities

**Stakeholders Engaged**
- Patients
- Policymakers
- Providers
- Healthcare Management
- Researchers

**Study Population & Conditions**
- Minority and underserved communities
- Chronic illness
“After completion of this project, a newly developed and pilot-tested patient-centered decision support tool to improve primary medication adherence will be freely available for use by patients, physicians, and pharmacists. It will be the first of its kind.”
Health Outcome Instrument Development: Intervention Design Exemplar

“Our project will develop and evaluate novel methods for eliciting and prioritizing children’s health outcomes that are comprehensible to both patients and clinicians and ready for integration into research.”

<table>
<thead>
<tr>
<th>PI</th>
<th>Katherine Bevans</th>
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</thead>
<tbody>
<tr>
<td>Affiliation</td>
<td>Children’s Hospital of Philadelphia</td>
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<tr>
<td>PPPLN Group</td>
<td>Outcomes Instruments</td>
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</tbody>
</table>

PCORI Priority Area
- Communication and Dissemination
- Health Disparities

Stakeholders Engaged
- Patients
- Caregivers
- Clinicians

Study Population & Conditions
- Children with autism spectrum disorder and their families
- Clinicians
Community Boot Camp: Translation Exemplar

“A crucial, yet currently incomplete step is the translation of scientific evidence-based guidelines and recommendations into constructs and language accessible to every-day patients and community members.”

<table>
<thead>
<tr>
<th>PI</th>
<th>Larry Green / Don Nease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affiliation</td>
<td>University of Colorado, Denver</td>
</tr>
<tr>
<td>PPPLN Group</td>
<td>Research Prioritization and Analytic Methods</td>
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</table>

<table>
<thead>
<tr>
<th>PCORI Priority Areas</th>
<th>Stakeholders Engaged</th>
<th>Study Population &amp; Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication and Dissemination</td>
<td>Community Members</td>
<td>Guidelines on heart disease, asthma, cancer screening</td>
</tr>
<tr>
<td>Patients</td>
<td>Providers</td>
<td>Researchers</td>
</tr>
<tr>
<td>Researchers</td>
<td></td>
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Methods Comparison: Dissemination Exemplar

“This study fills an important gap in our current knowledge and enables researchers to make evidence-based decisions when designing focus group and mixed-method research.”

<table>
<thead>
<tr>
<th>PI</th>
<th>Stephen Guest</th>
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<tbody>
<tr>
<td>Affiliation</td>
<td>Family Health International</td>
</tr>
<tr>
<td>PPPLN Group</td>
<td>Research Prioritization and Analytic Methods</td>
</tr>
</tbody>
</table>

PCORI Priority Areas
- Accelerating Research and New Methods

Stakeholders Engaged
- Community Members
- Providers
- Healthcare Management

Study Population
- African Americans
Virtual Reality Gaming Platform: Implementation Challenge

“Our project creates a novel mechanism for deploying a ‘gold standard’ rehab treatment to increase access and uptake of this treatment.”

<table>
<thead>
<tr>
<th>PI</th>
<th>Lynne Gauthier</th>
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<tbody>
<tr>
<td>Affiliation</td>
<td>Ohio State University</td>
</tr>
<tr>
<td>PPPLN Group</td>
<td>Technology &amp; Infrastructure</td>
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</tbody>
</table>

**PCORI Priority Area**
- Communication and Dissemination

**Stakeholders Engaged**
- Patients
- Clinicians

**Study Population & Conditions**
- Chronic stroke survivors with hemiparesis
Questions?
IS UNINTENDED PREGNANCY A PATIENT-CENTERED OUTCOME?
Public health framework:

- *Unintended pregnancy is a problem to be solved:*
  
  - Associated with a number of adverse peri-natal behaviors and outcomes
  
  - Leads to missed opportunities to optimize health in the preconception period
  
  - Derails women and couples on pathway toward educational and career goals and thus contributes to poverty and disadvantage
Patient-centered framework

- Not all unintended pregnancies are created equal
  - Many women welcome unintended pregnancies
  - Pregnancies “just happen” – can not/ should not be planned
  - A planned pregnancy is an unattainable ideal for some women
  - Dimensions beyond intendedness seem to matter when thinking about the acceptability of their pregnancies: happiness, finances, social support, etc.
Questions

• What language or approach is appropriate to help women think about their reproductive desires and/or goals?

• Are there ways to help women better prospectively identify whether a pregnancy would be unacceptable?

• Could moving away from a planning paradigm and towards the concept of preparation be more inclusive?

• How do we begin to create more multi-dimensional measures of pregnancy outcomes?
POTENTIAL BENEFITS AND CHALLENGES OF PCOR IN REPRODUCTIVE HEALTH
Brainstorm

• What might be some of the benefits of conducting PCOR in reproductive health?

• What might be some of the challenges of conducting PCOR in reproductive health?

• Are there other unique considerations in this arena?
Homework

• You have been assigned one of 10 topic briefs, which we will distribute.

• Read your assigned “brief” *before* the start of the meeting tomorrow morning and come prepared to discuss it in groups.
RECEPTION