Session 2: Patient Engagement in Research

November 18, 2014

Rosy Chang Weir, PhD, Director of Research
Association of Asian Pacific Community Health Organizations (AAPCHO)

Suzanne Schrandt, JD. Deputy Director of Patient Engagement
Patient Centered Outcomes Research Institute (PCORI)

This work was partially supported through a Patient-Centered Outcomes Research Institute (PCORI) Program Award (NCHR 1000-30-10-10 EA-0001).

Homework Follow-up

- Testable Questions:
  - Does using the patient activation measurement tool to identify patients improve targeted care coordination attempts?
  - HIV Integration: Does the addition of care coordination improve patient access to HIV-related services?
  - To what degree does screening for food insecurity improve individual health outcomes?
  - Does the utilization of care coordination improve patient’s access to care?
  - Does identifying patient’s that are moderately engaged in their health improve target care coordination?

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Research Interests

- Providing care to those who are undocumented; impact of the parents' documentation status on their children's health care utilization patterns and mental health outcomes
- 1=patients engagement in depression treatment for pregnant women; 2=access, uptake, acceptance of Long-acting reversible contraceptives (pediatrics)
- Health disparities, Integration of Patient Center Medical Home (PCMH), Chronic disease, vulnerable populations and provider retention
- Health disparities & vulnerable populations, PCMH & provider engagement/retention, Chronic disease management
- Mental Health patients in general presenting a challenges to research; Maternal and Child Health programs including pregnancy
- F2M Transgendered patients not come in for and not UTD for PAP screening
- Native Hawaiian and pacific islanders; high rates of substance abuse; stress among women of childbearing age, how stress relates to health outcomes primarily obesity
- Interested in Adolescent population STD testing, treatment, decreasing pregnancy rates, and fighting obesity

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Results of Literature Search

Session 2: Patient Engagement Training Goals

- Understand patient engagement from PCORI’s perspective
- Learn methods of patient engagement from project beginning to end
- Introduce patient engagement principles and evaluation methods
- Hear from the patient’s perspective
- Increase knowledge to complete a patient engagement plan and patient engagement principles

Presenters

Suzanne Schrandt, JD

Deputy Director, Patient Engagement, PCORI

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Engagement at PCORI

M. Suzanne Schrandt, JD
Deputy Director of Patient Engagement

Patient-Centered Outcomes Research Institute

Our Mission

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.

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Our Review Criteria

During a rigorous merit review process, proposals are evaluated to assess:

- Impact of the condition on health of individuals and populations
- Potential for improving care and outcomes
- Technical merit
- Patient-centeredness
- Patient and stakeholder engagement

We Engage Patients and Other Stakeholders at Every Step


Topic Selection and Research Prioritization

Merit Review

Study Design/ Implementation

Evaluation

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The Engagement Rubric

The rubric is intended to provide guidance to applicants, merit reviewers, awardees, and engagement/program officers (for creating milestones and monitoring projects) regarding patient and stakeholder engagement in the conduct of research. It is divided into four segments:

Planning the Study

Conducting the Study

Disseminating the Study Results

PCOR Engagement Principles

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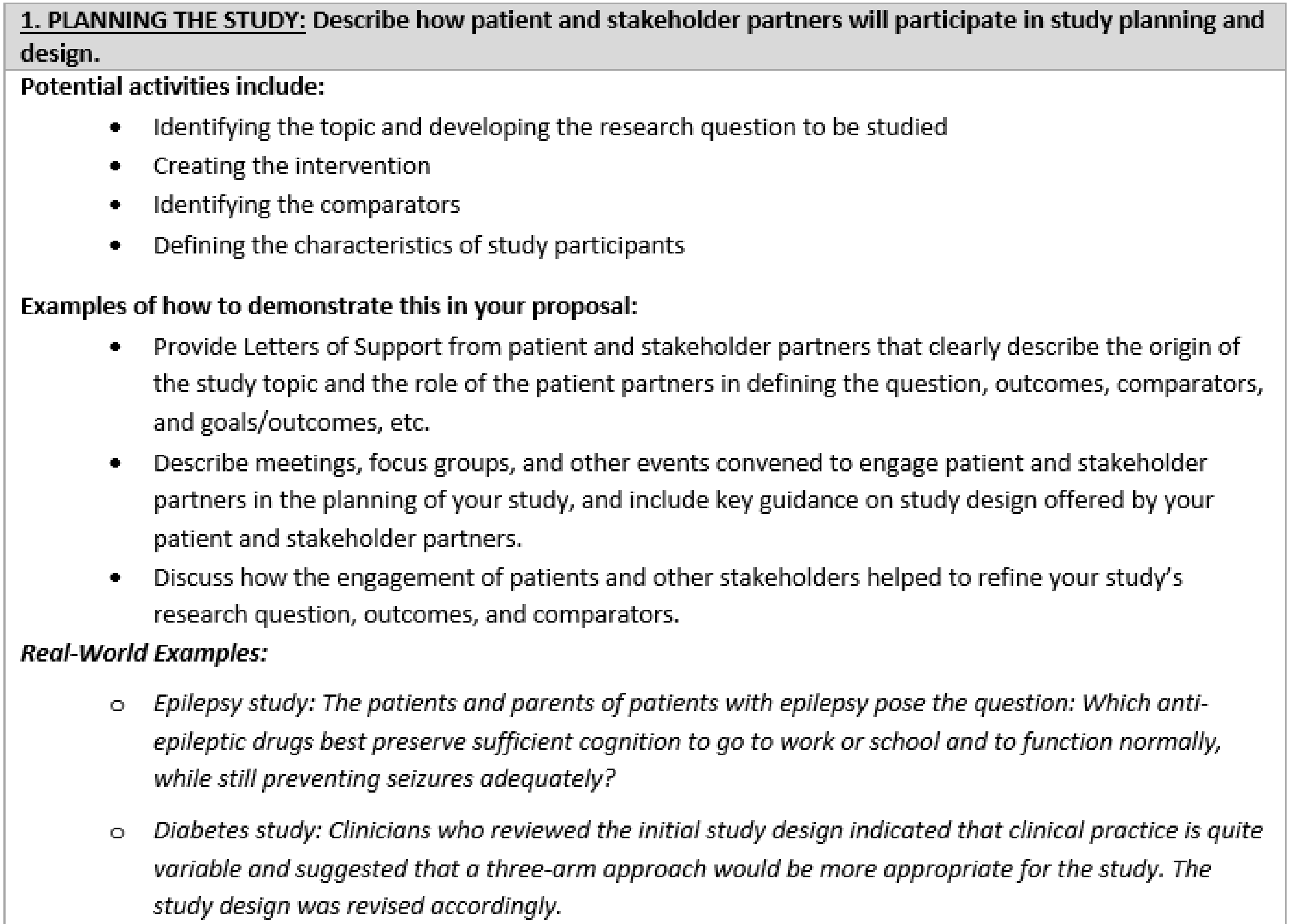
Planning the Study



1. PLANNING THE STUDY: Describe how patient and stakeholder partners will participate in study planning and design.

Potential activities include:

- Identifying the topic and developing the research question to be studied
- Creating the intervention
- Identifying the comparators
- Defining the characteristics of study participants

Examples of how to demonstrate this in your proposal:

- Provide Letters of Support from patient and stakeholder partners that clearly describe the origin of the study topic and the role of the patient partners in defining the question, outcomes, comparators, and goals/outcomes, etc.
- Describe meetings, focus groups, and other events convened to engage patient and stakeholder partners in the planning of your study, and include key guidance on study design offered by your patient and stakeholder partners.
- Discuss how the engagement of patients and other stakeholders helped to refine your study's research question, outcomes, and comparators.

Real-World Examples:

- ○ *Epilepsy study: The patients and parents of patients with epilepsy pose the question: Which anti-epileptic drugs best preserve sufficient cognition to go to work or school and to function normally, while still preventing seizures adequately?*
- ○ *Diabetes study: Clinicians who reviewed the initial study design indicated that clinical practice is quite variable and suggested that a three-arm approach would be more appropriate for the study. The study design was revised accordingly.*

Planning the Study

Potential Activities Include;

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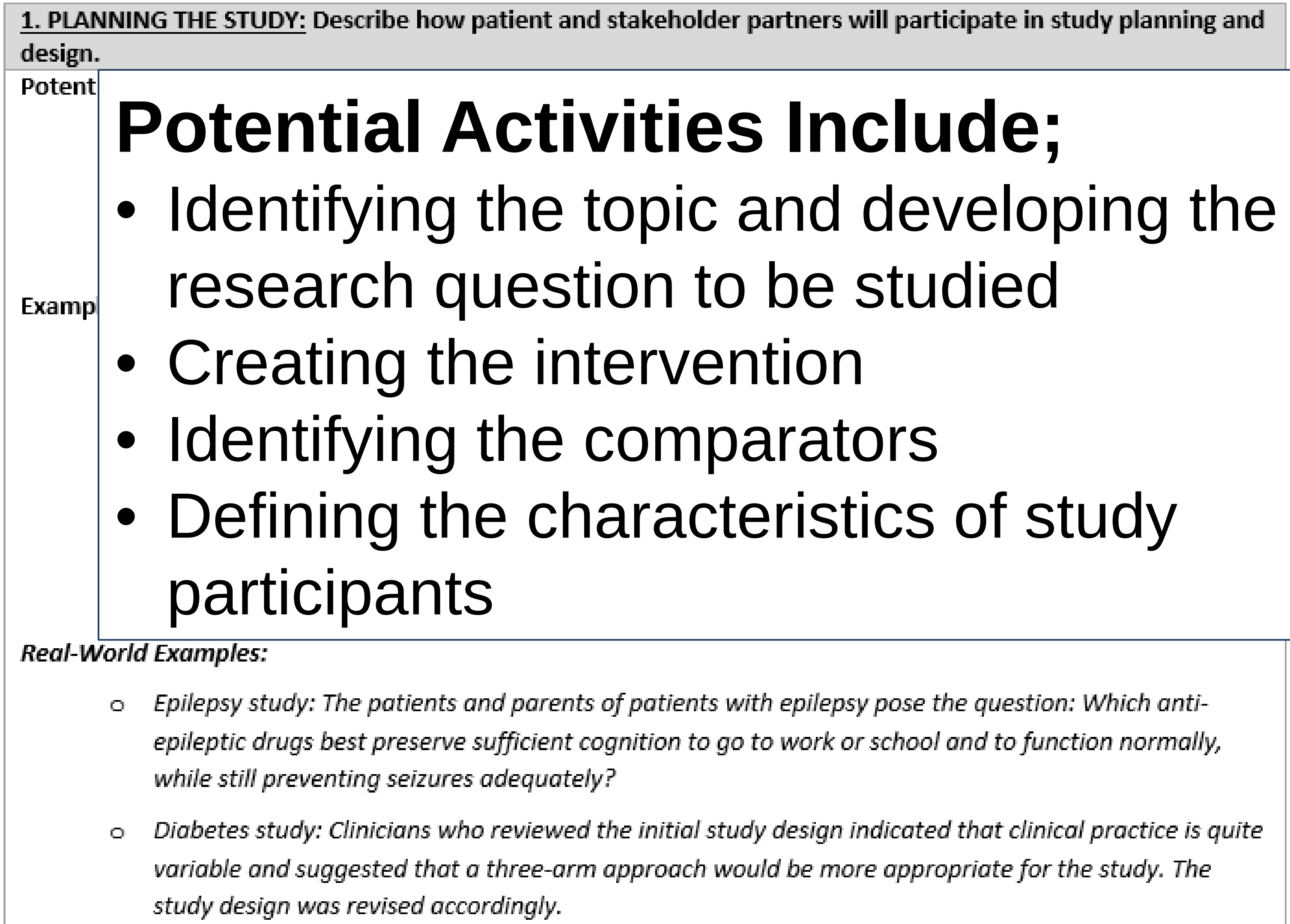

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Real-World Examples:

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Planning the Study

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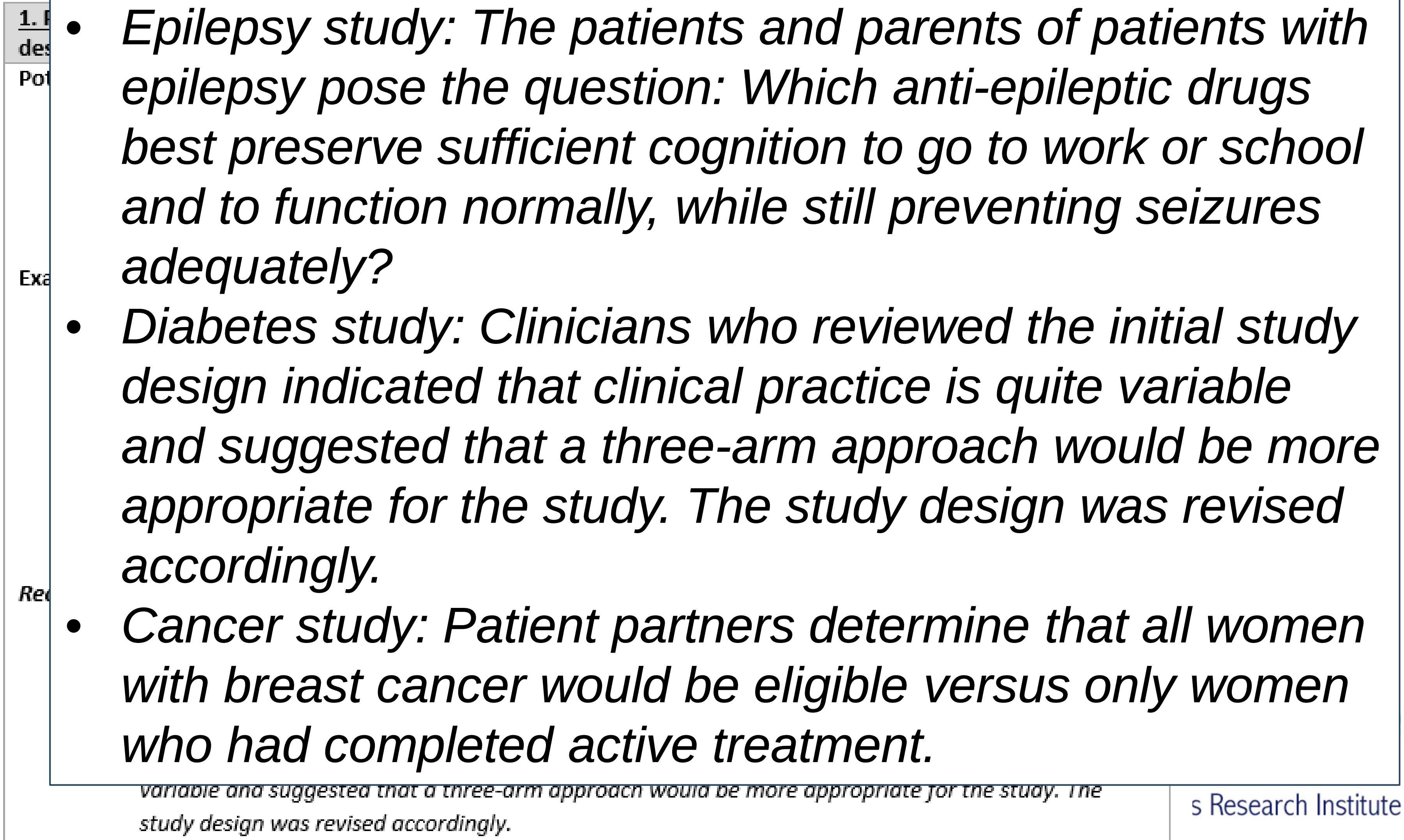
- *Epilepsy study: The patients and parents of patients with epilepsy pose the question: Which anti-epileptic drugs best preserve sufficient cognition to go to work or school and to function normally, while still preventing seizures adequately?*
- *Diabetes study: Clinicians who reviewed the initial study design indicated that clinical practice is quite variable and suggested that a three-arm approach would be more appropriate for the study. The study design was revised accordingly.*
- *Cancer study: Patient partners determine that all women with breast cancer would be eligible versus only women who had completed active treatment.*



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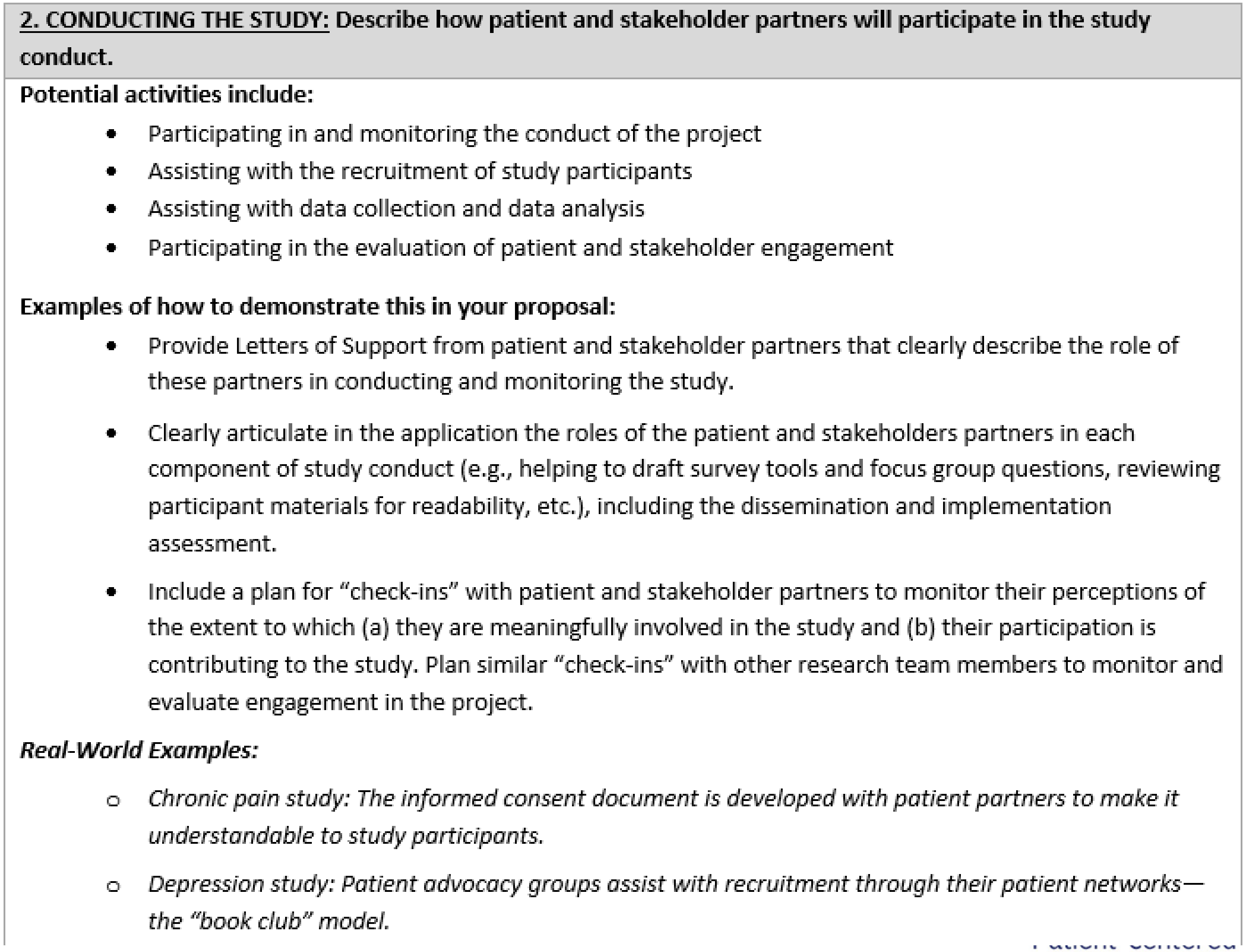
Conducting the Study



2. CONDUCTING THE STUDY: Describe how patient and stakeholder partners will participate in the study conduct.

Potential activities include:

- Participating in and monitoring the conduct of the project
- Assisting with the recruitment of study participants
- Assisting with data collection and data analysis
- Participating in the evaluation of patient and stakeholder engagement

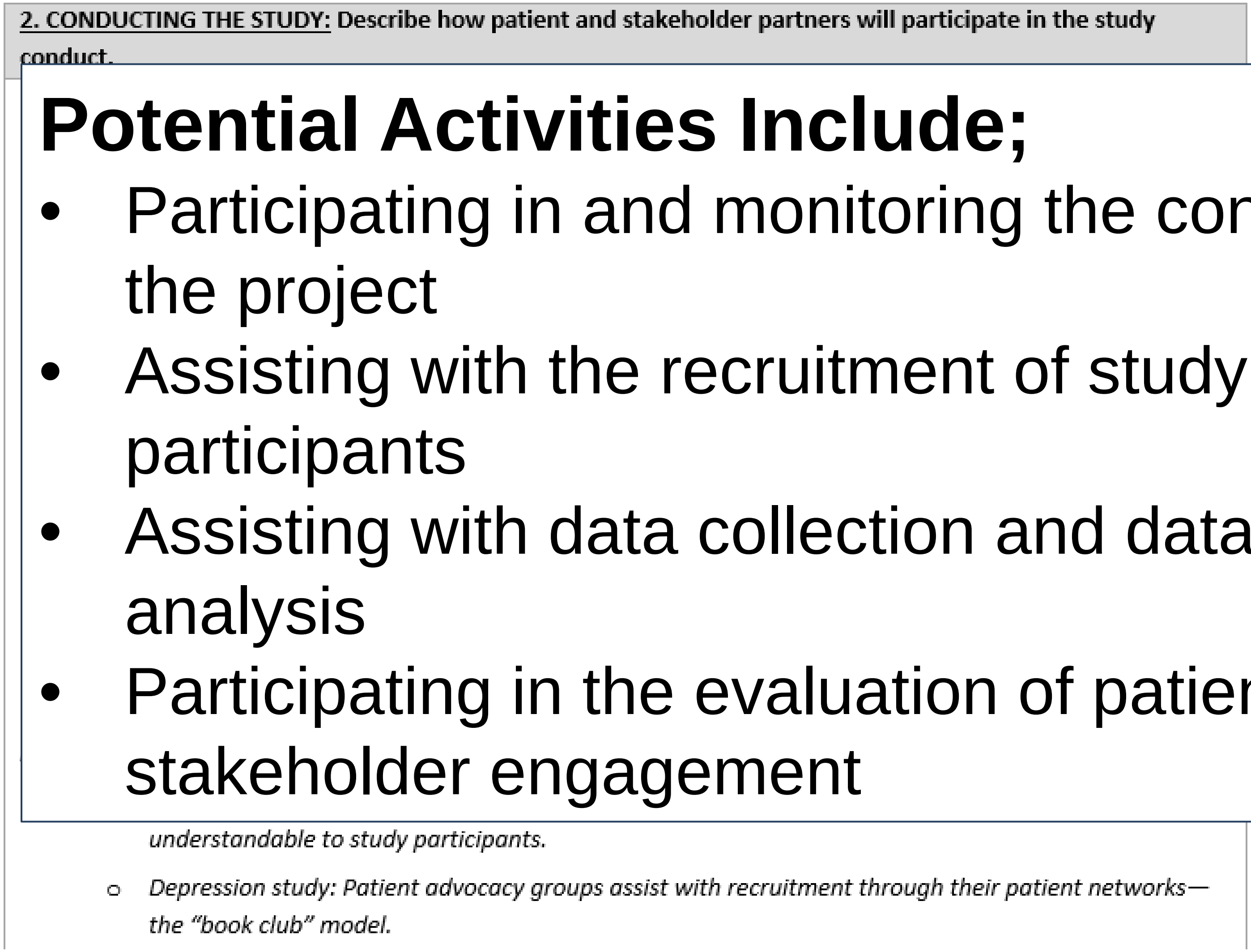
Examples of how to demonstrate this in your proposal:

- Provide Letters of Support from patient and stakeholder partners that clearly describe the role of these partners in conducting and monitoring the study.
- Clearly articulate in the application the roles of the patient and stakeholders partners in each component of study conduct (e.g., helping to draft survey tools and focus group questions, reviewing participant materials for readability, etc.), including the dissemination and implementation assessment.
- Include a plan for "check-ins" with patient and stakeholder partners to monitor their perceptions of the extent to which (a) they are meaningfully involved in the study and (b) their participation is contributing to the study. Plan similar "check-ins" with other research team members to monitor and evaluate engagement in the project.

Real-World Examples:

- *Chronic pain study: The informed consent document is developed with patient partners to make it understandable to study participants.*
- *Depression study: Patient advocacy groups assist with recruitment through their patient networks—the "book club" model.*

Conducting the Study



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Potential Activities Include;

- Participating in and monitoring the conduct of the project
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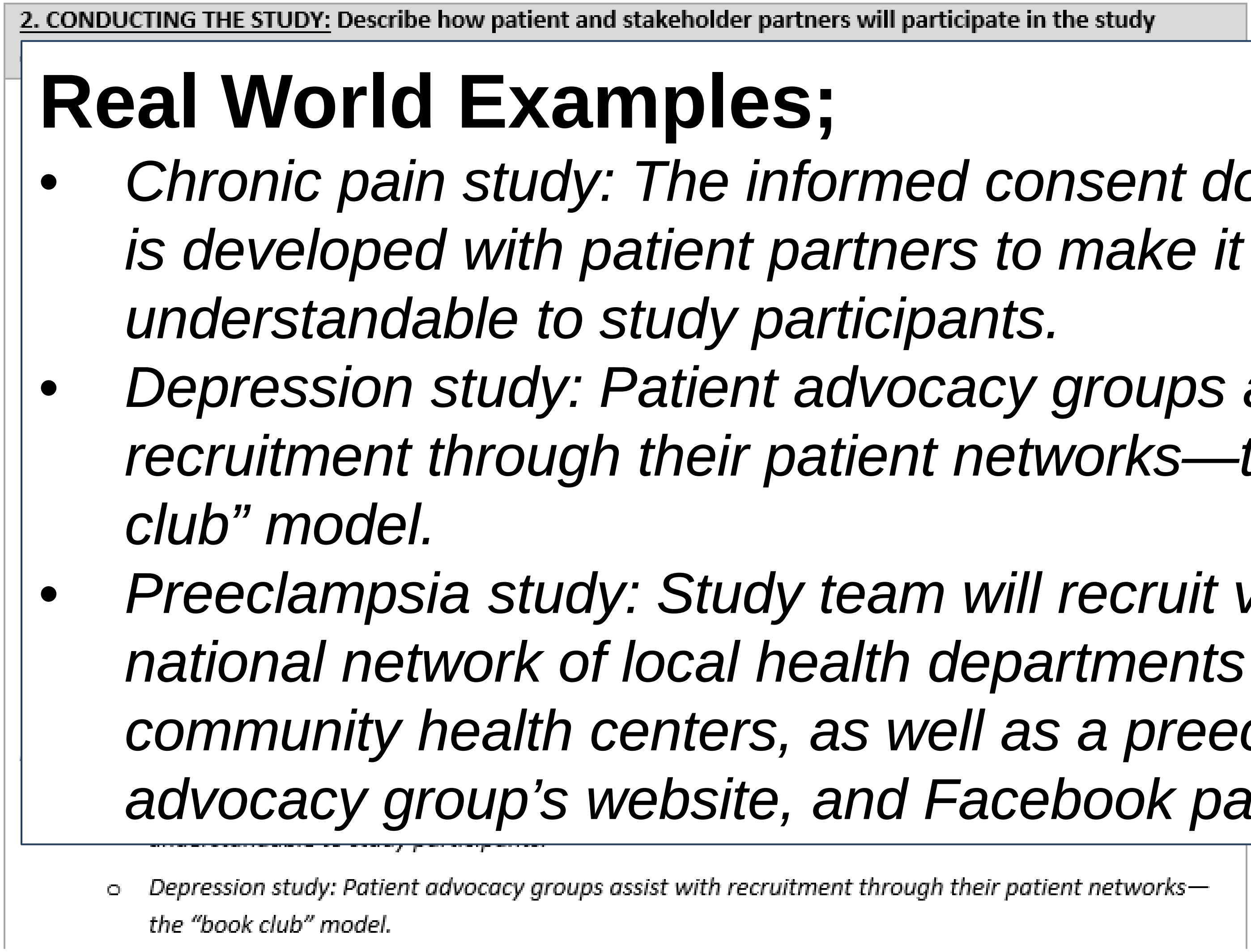

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- *Depression study: Patient advocacy groups assist with recruitment through their patient networks—the "book club" model.*
- *Preeclampsia study: Study team will recruit via a national network of local health departments and community health centers, as well as a preeclampsia advocacy group's website, and Facebook page.*

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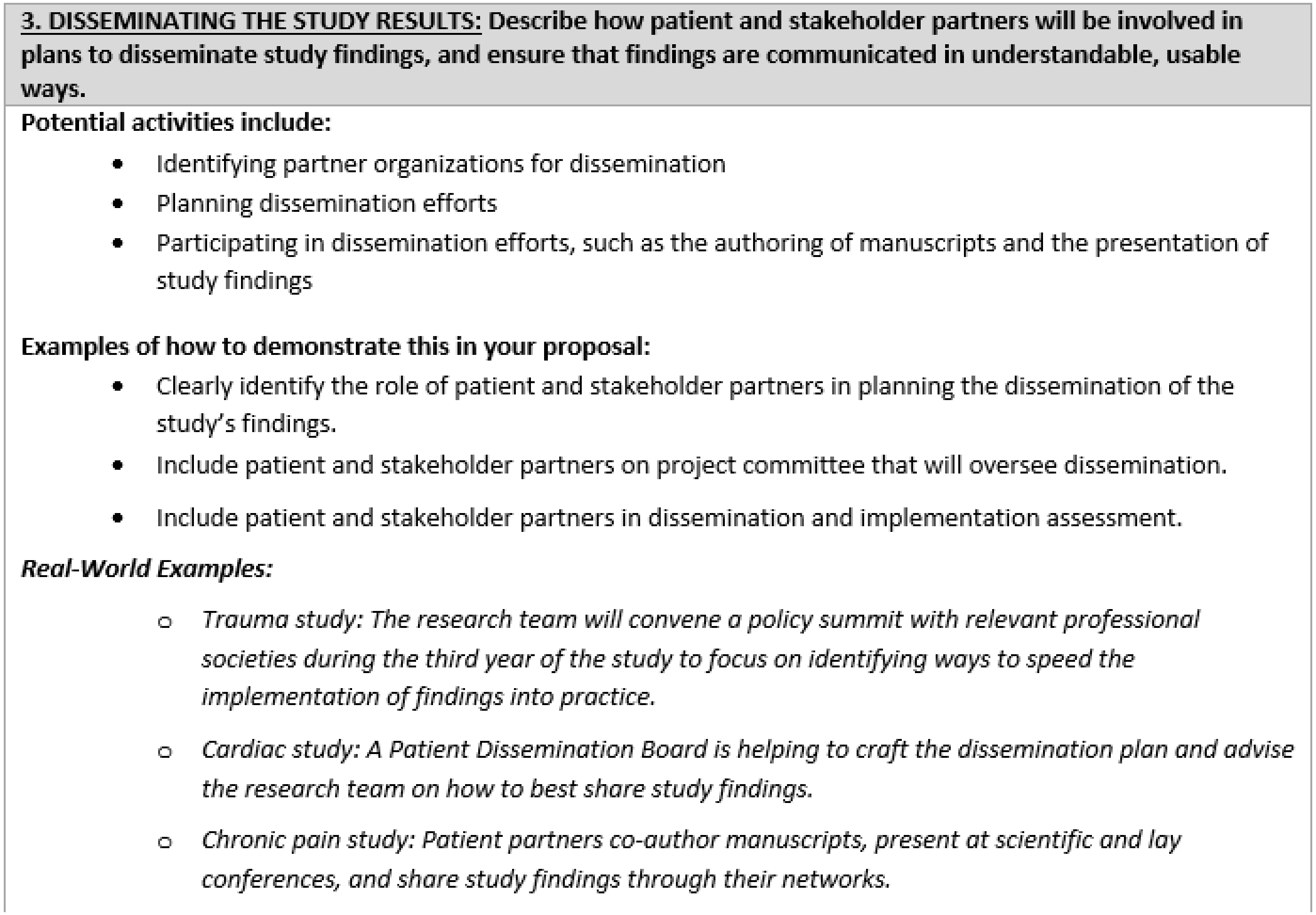
- *Depression study: Patient advocacy groups assist with recruitment through their patient networks—the "book club" model.*

Disseminating the Study Results



3. DISSEMINATING THE STUDY RESULTS: Describe how patient and stakeholder partners will be involved in plans to disseminate study findings, and ensure that findings are communicated in understandable, usable ways.

Potential activities include:

- Identifying partner organizations for dissemination
- Planning dissemination efforts
- Participating in dissemination efforts, such as the authoring of manuscripts and the presentation of study findings

Examples of how to demonstrate this in your proposal:

- Clearly identify the role of patient and stakeholder partners in planning the dissemination of the study's findings.
- Include patient and stakeholder partners on project committee that will oversee dissemination.
- Include patient and stakeholder partners in dissemination and implementation assessment.

Real-World Examples:

  - *Trauma study: The research team will convene a policy summit with relevant professional societies during the third year of the study to focus on identifying ways to speed the implementation of findings into practice.*
  - *Cardiac study: A Patient Dissemination Board is helping to craft the dissemination plan and advise the research team on how to best share study findings.*
  - *Chronic pain study: Patient partners co-author manuscripts, present at scientific and lay conferences, and share study findings through their networks.*

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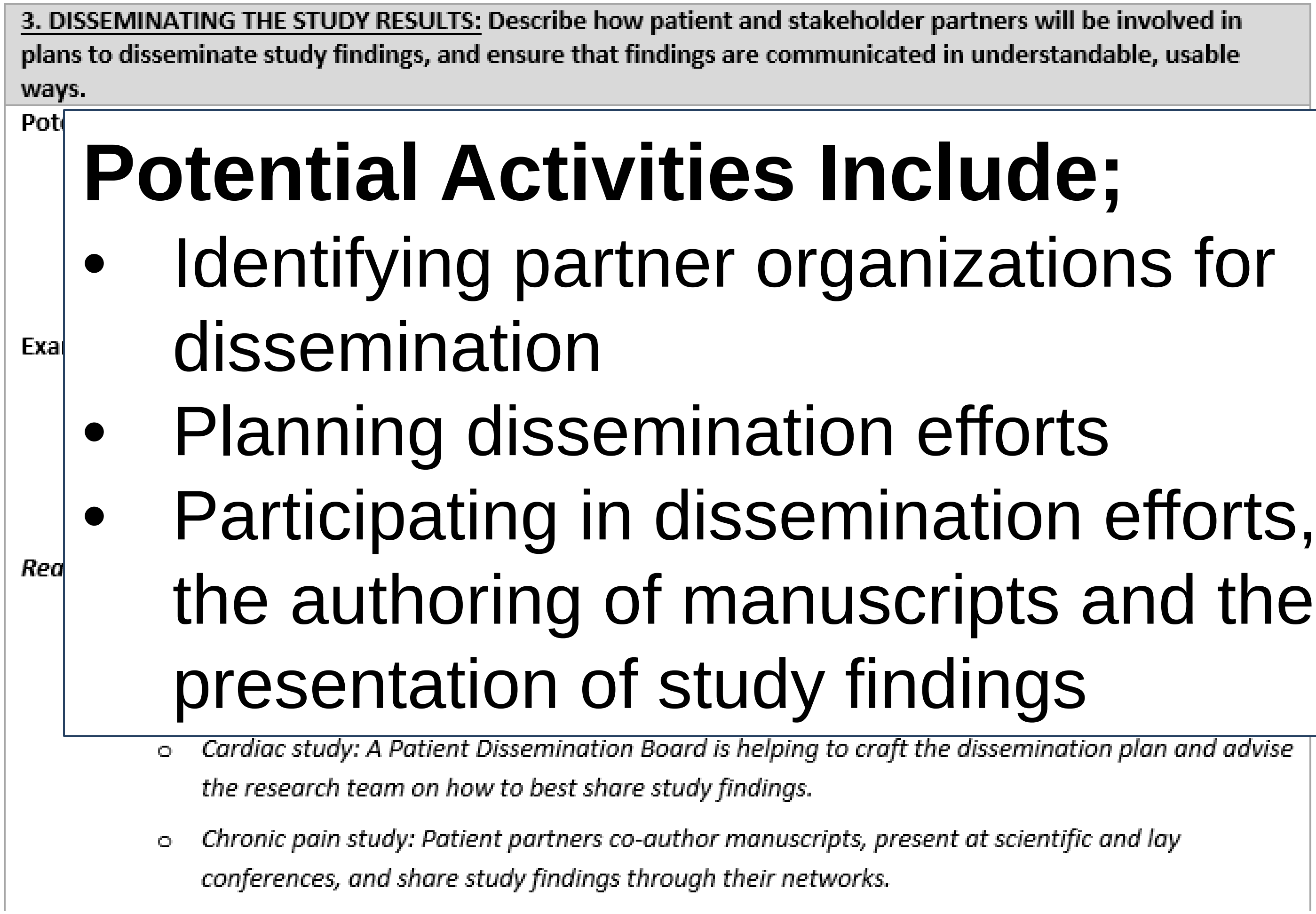

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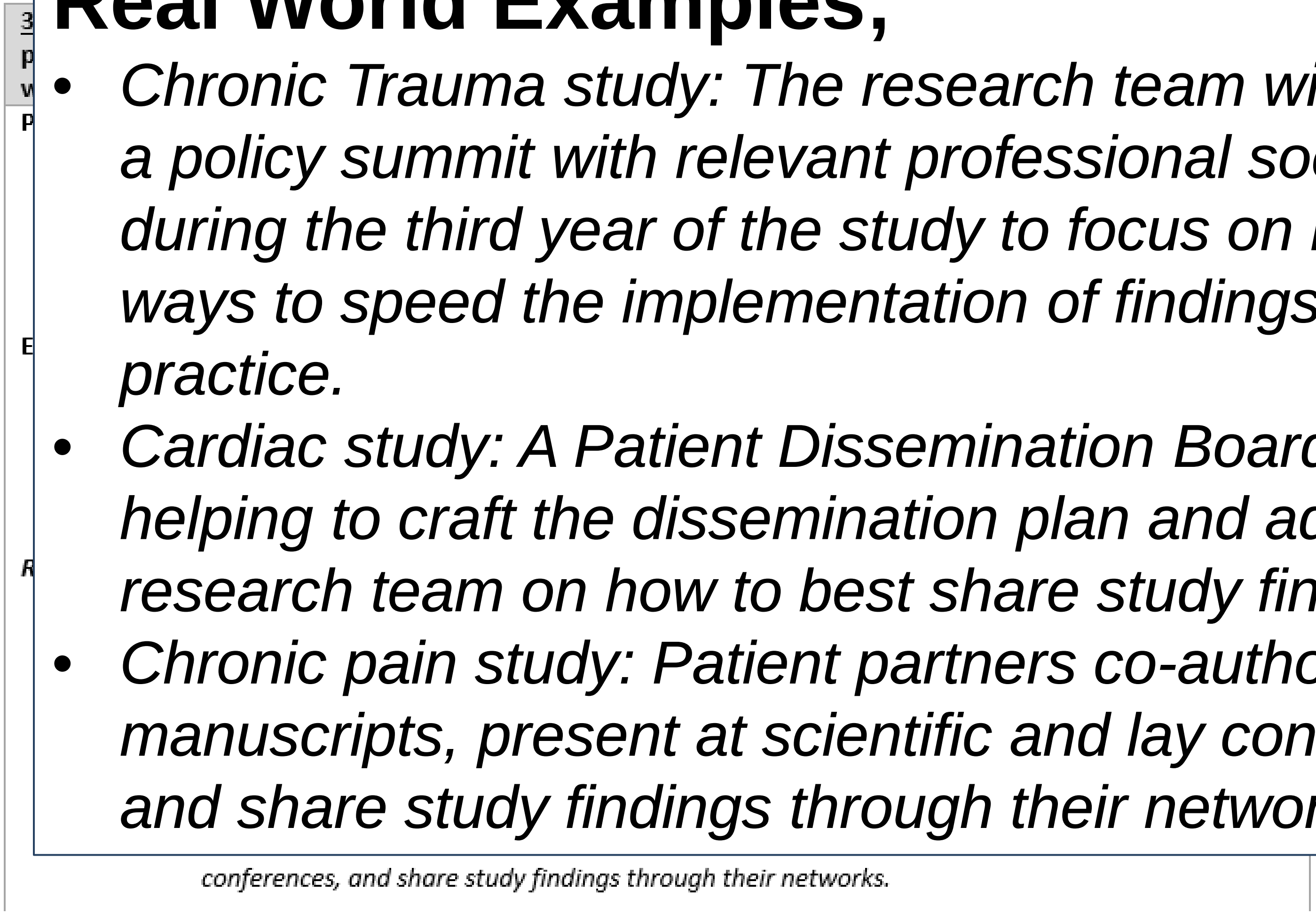
Disseminating the Study Results



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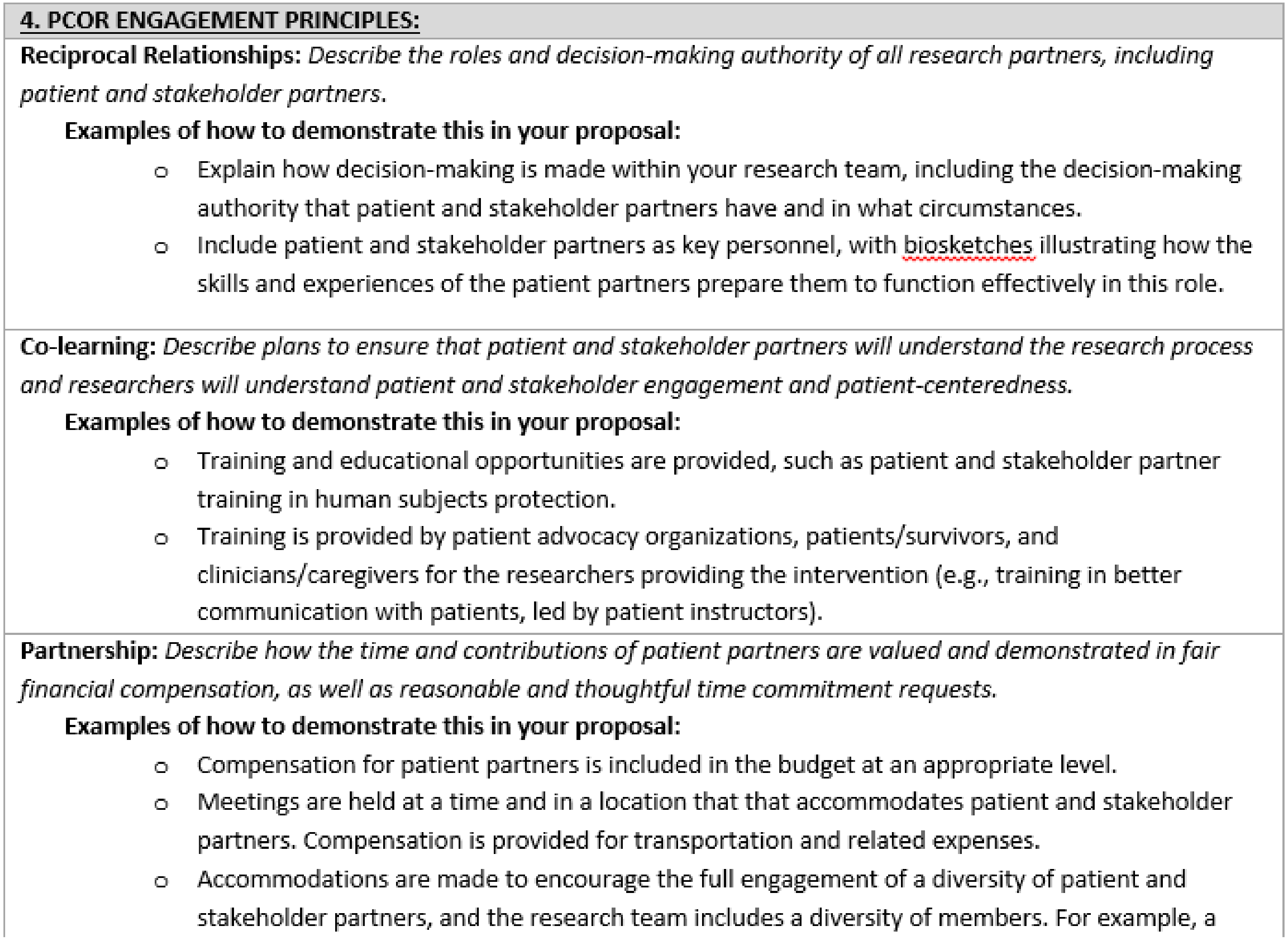
Engagement Principles



4. PCOR ENGAGEMENT PRINCIPLES:

Reciprocal Relationships: *Describe the roles and decision-making authority of all research partners, including patient and stakeholder partners.*

Examples of how to demonstrate this in your proposal:

- Explain how decision-making is made within your research team, including the decision-making authority that patient and stakeholder partners have and in what circumstances.
- Include patient and stakeholder partners as key personnel, with biosketches illustrating how the skills and experiences of the patient partners prepare them to function effectively in this role.

Co-learning: *Describe plans to ensure that patient and stakeholder partners will understand the research process and researchers will understand patient and stakeholder engagement and patient-centeredness.*

Examples of how to demonstrate this in your proposal:

- Training and educational opportunities are provided, such as patient and stakeholder partner training in human subjects protection.
- Training is provided by patient advocacy organizations, patients/survivors, and clinicians/caregivers for the researchers providing the intervention (e.g., training in better communication with patients, led by patient instructors).

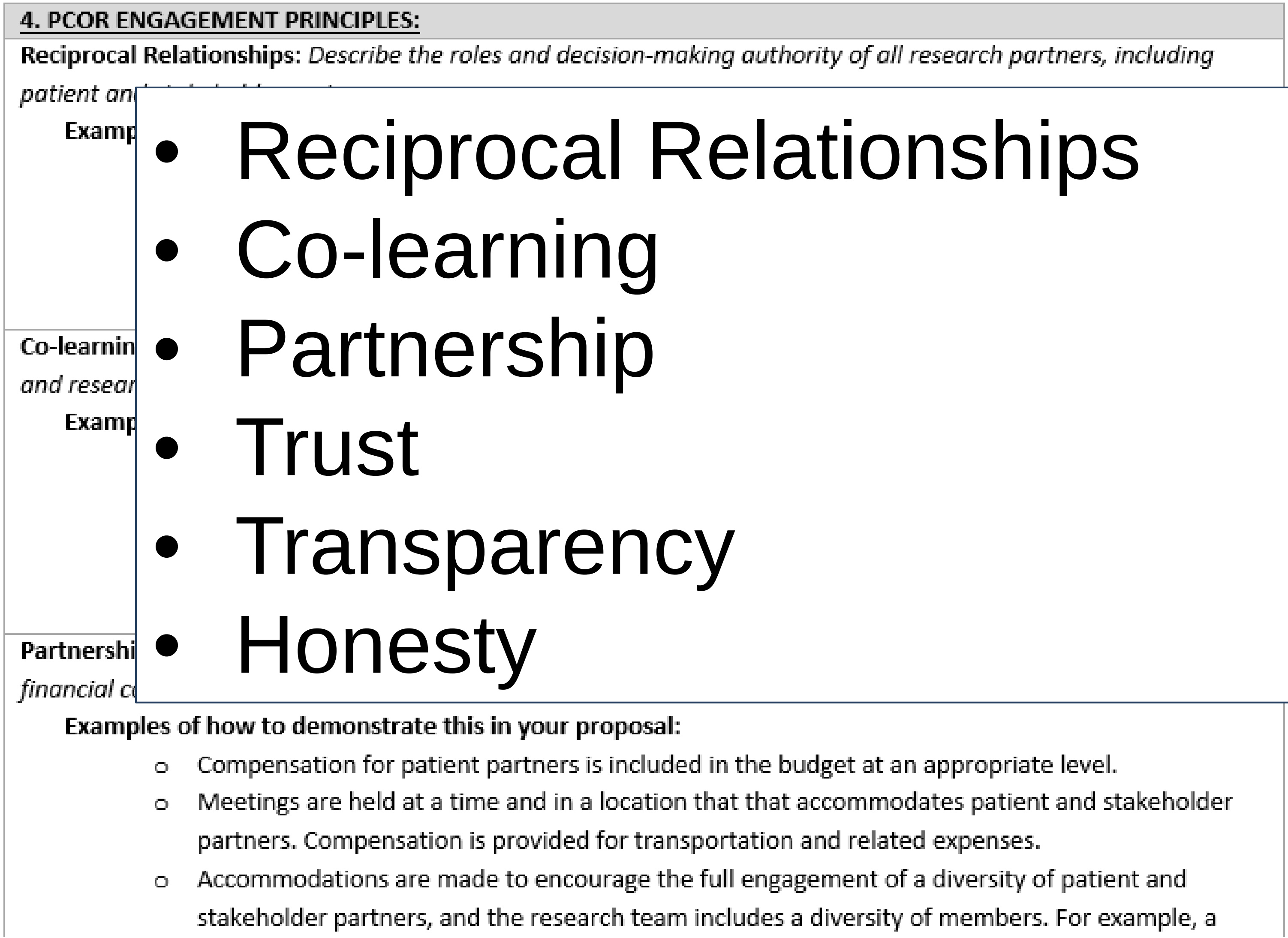
Partnership: *Describe how the time and contributions of patient partners are valued and demonstrated in fair financial compensation, as well as reasonable and thoughtful time commitment requests.*

Examples of how to demonstrate this in your proposal:

- Compensation for patient partners is included in the budget at an appropriate level.
- Meetings are held at a time and in a location that that accommodates patient and stakeholder partners. Compensation is provided for transportation and related expenses.
- Accommodations are made to encourage the full engagement of a diversity of patient and stakeholder partners, and the research team includes a diversity of members. For example, a

Engagement Principles

- Reciprocal Relationships
- Co-learning
- Partnership
- Trust
- Transparency
- Honesty



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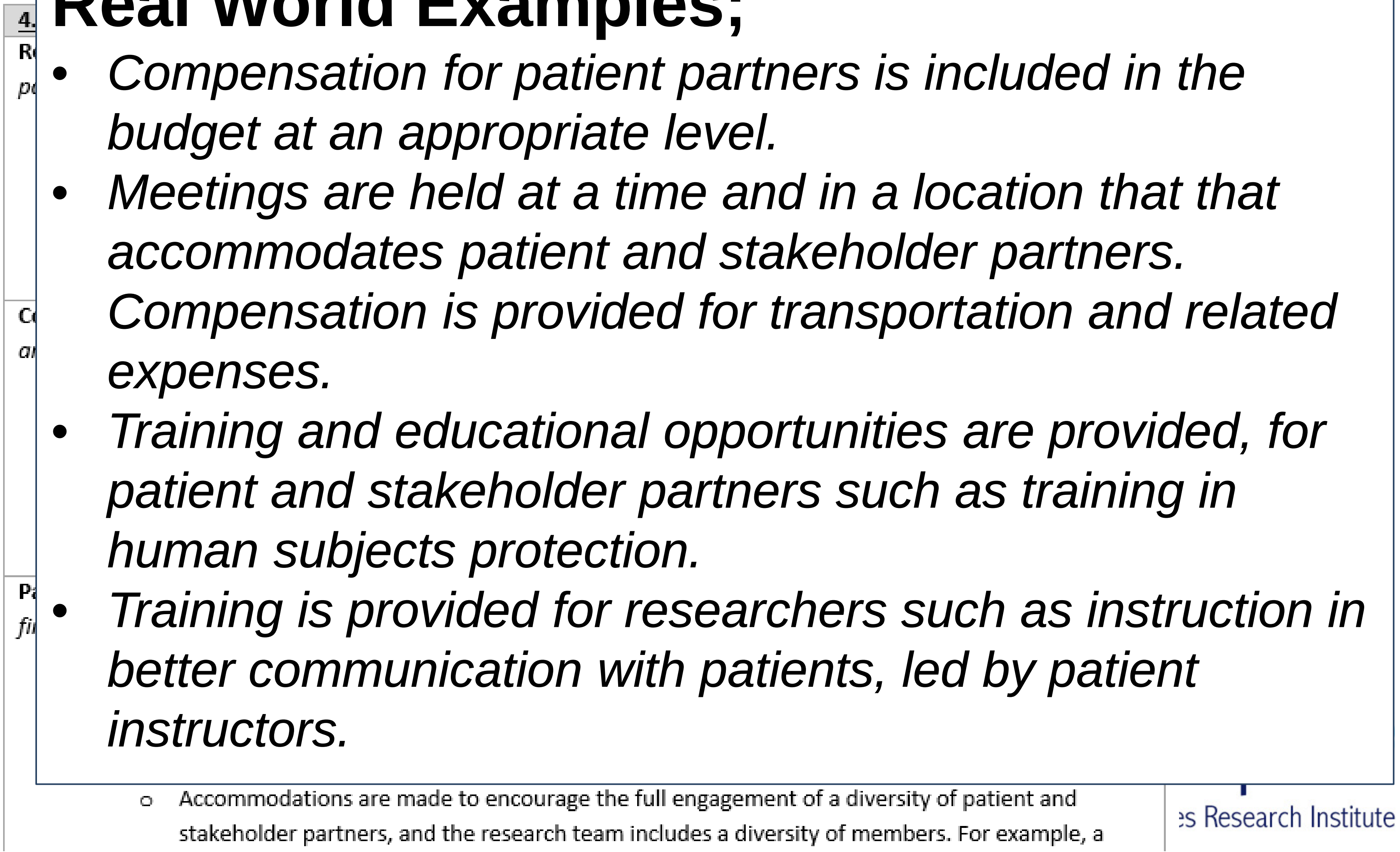

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Putting the Rubric to Work

Greater understanding of engagement

Stronger engagement in proposals

Strong engagement during research?

Engagement Officers: Role and Responsibilities

- New position that parallels the Program Officer role
- Partners with Program Officers and research teams to oversee and cultivate engagement throughout the life of the project
  - Ensures robust engagement is integrated into projects from time of contract formation
  - Participates in ongoing project management activities
  - Available for assistance and discussion
- Gleans promising practices from projects to share and replicate

Evaluation

- Enterprise-wide and individual project level
- Opportunities for comment and feedback
- Research Integration and Evaluation Team

ENgagement ACTivity (ENACT) Inventory

- Who is engaged
- Partnership characteristics
  - How formed, length, frequency of engagement, etc.
- Level of engagement
- When in the research process they are engaged
- Perceived level of influence of partners
- Perceived effects of engagement on research questions, study design, study implementation, and dissemination of results
- Challenges, facilitators
- Lessons learned for engagement
- PCOR principles – respect, co-learning, etc.

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Presenters

Rosy Chang Weir, PhD

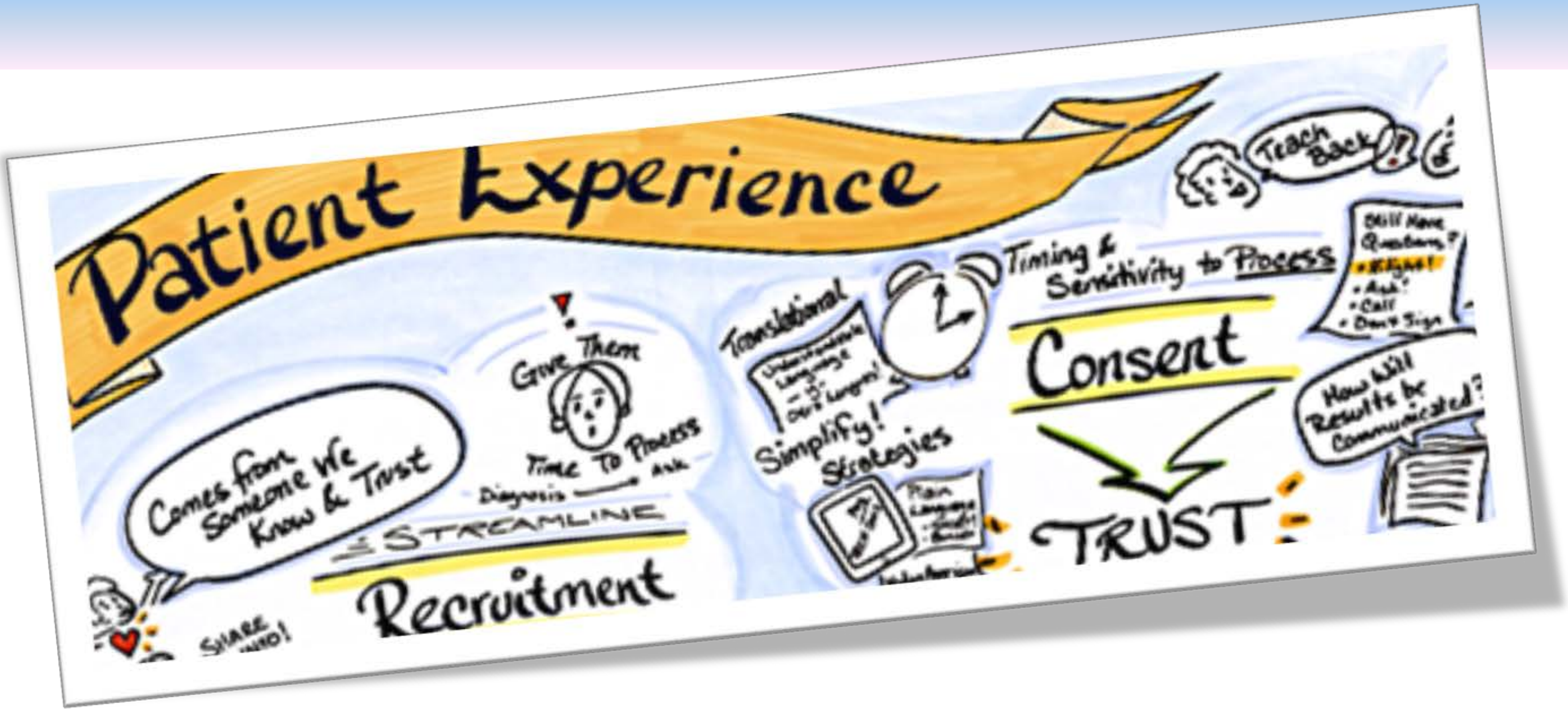
Director of Research, AAPCHO

Presenters

- Plus a patient special guest!!
- Please respect patient confidentiality in the patient presentation.
- If there are sensitive questions/topics, we will potentially defer to email/phone.

About AAPCHO

- Association of Asian Pacific Community Health Organizations
- Non-profit national association established in 1987 with a mission to improve health status and access of Asian Americans, Native Hawaiians and other Pacific Islanders.
- Represents 35 community health organizations, mostly FQHCs serving primarily medically underserved Asian Americans, Native Hawaiians and Other Pacific Islanders.



WHAT IS PATIENT ENGAGEMENT IN RESEARCH?

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PCORI’s Definition

By "engagement in research," we refer to the meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to dissemination of results.

Source: "PCORI." *What We Mean by Engagement*. Web. 31 Oct. 2014.

Why is patient and stakeholder engagement important?

- Such engagement can influence research to be more patient centered, useful, and trustworthy and ultimately lead to greater use and uptake of research results by the patient and broader healthcare community.

Source: "PCORI." *What We Mean by Engagement*. Web. 31 Oct. 2014.

Patient Q&A

What was your role as a patient in your research project?

Why was engaging in a research project important to you?

Traditional Research vs. Patient Engagement in Research

TRADITIONAL RESEARCH	PATIENT ENGAGEMENT IN RESEARCH
Researcher defines problem	Patients identify problem or works with researcher to identify problem
Research IN or ON the community	Research WITH patient as full partner
People as subjects	People as working together
Patients may assist	Patients are partners with researchers
Researchers gain skills & knowledge	Researchers & patients work together to help build skills in the community
Researchers control process, resources & data interpretation	Researcher & patients in the community share control equally
Researchers own data, control use & dissemination	Data is shared, researchers and patients in the community decide its use and dissemination

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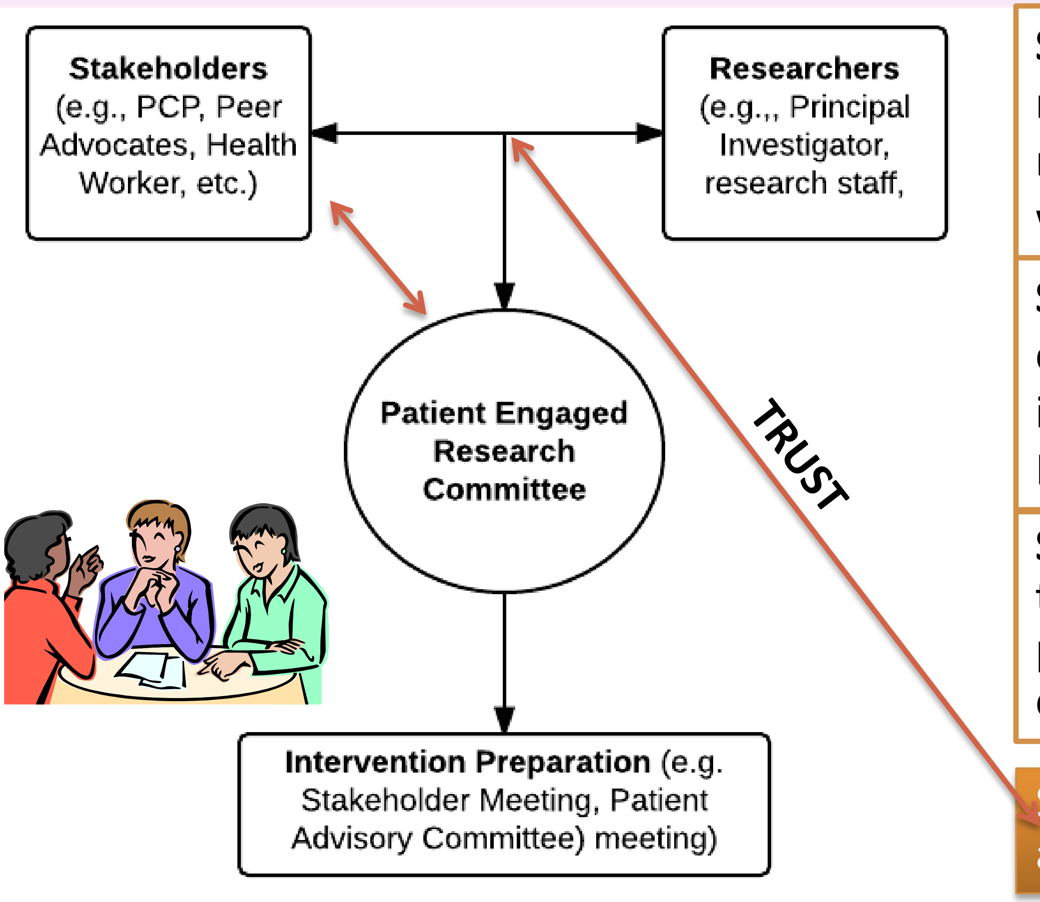
What does patient and stakeholder engagement in research look like?



Step 1: Patient/community members may approach researchers or researchers may approach patient with a proposal for research

Step 2: Patient/community members contributes to research question, ideas on recruitment, advice of Logistics

Step 3: Develop and Implement—tailor intervention, advise on problems, promote the study in community

Share drafts of the research proposal and other written materials

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Principles of Patient Engagement

- Connection between patient, caregiver, and researcher
- Empathy, trust, transparency
- Collaboration, partnership, co-learning
- Empowerment, capacity-building
- Listening, communication in simple language
- Diversity, mutual respect of multiple perspectives

Patient Q&A

Were these principles pertinent to your experience in engaging in research? If so, how?

AAPCHO Community Criteria for Research Participation – Five Domains

1. Community Involvement in Designing the Community Project
2. Alignment with the Mission of the CHC and its Consumers
3. Equitable and Balanced Budget Allocation Between Partners
4. Accountability to the Community and Not Just the Funding Agency
5. Mutually Agreeable Standards for Research Collaborations Between Partners

Reference:

- The Community Criteria for Research Participation, developed August 2012, by CHC, community, and academic partners associated with AAPCHO and CHARN can be accessed at: http://www.aapcho.org/resources_db/community-criteria-for-research-participation/.
- Creating Community Research Participation Criteria for Community Health Centers by Mary Oneha et al. (peer review forthcoming publication, AAPI Nexus)

Questions that patients might ask prior to engaging in research

CHC should prepare to help patients answer these questions:

- Why patient-engaged research, and what does it offer me?
- What is patient-engaged research? What is research at all?
- Why would I be interested in working with the CHC?
- Why is the CHC interested in working with me?
- What might I need to know about how research is done at the CHC?
- How do I know if the researchers will be good to work with? Will they respect me? What do I have to contribute when I'm not even a doctor?
- What's the worse that could happen to me if I join?
- What types of tasks will I be given?

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Questions for CHCs to consider

- What kinds of rules and regulations do researchers have to follow when engaging patients?
- What structures and resources need to be in place to support patients in collaborative research? How might they impact my organization?
- What are some obstacles or drawbacks for patients to participating in research that I should keep in mind?

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Benefits of Patient Engagement

- Patients as "experts”.
- Engaging patients in research leads to better results (e.g. deeper understanding of patient experience)
- Research is more accountable, transparent, and relevant to patient concerns.
- Cultivate ownership and resolution of issues with community.
- Increase real world value of healthcare research.

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PATIENT ENGAGEMENT METHODS

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Engagement Methods

Methods of involving patients from the beginning

- Engage through CHC consumer board members
- Engage a Patient Representative who will attend regular quality meetings and listen to their input on health issues
- Develop Patient Advisory Committees and involve patients in improving their health; Implement positive change based on patient input.
- Partner with community organizations, patient advocacy groups
- Educate patients at community events, patient newsletters, etc about opportunities to engage in their own healthcare decisions at the CHC

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Engaging patients with health disparities or social determinant of health barriers

- Provide FTE or compensation while being sensitive to patient government regulated benefits
- Listen to patient needs and change methods to fit (meeting times/places, sensitivity)
- Be flexible with modes of communication (e.g., phone, mail)
- Develop simple to read and in-language materials
- Create culturally appropriate environments (food, discussion formats, etc.)
- Hire a trusted community leader/staff to work with patients, translators

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Patient Q&A

How did the researchers get you started and engaged in research?

How did they keep you interested in the work?

Review of Patient Engagement Rubric

PCORI's Engagement Rubric: how are patient and stakeholder partners involved in the following four sections?

1) Planning the Study
    - Identifying the topic and developing the research question
    - Creating the intervention
    - Identifying the comparators
    - Defining the characteristics of study participants
2) Conducting the Study
    - Participating in and monitoring the conduct of the project
    - Assisting with the recruitment of study participants
    - Assisting with data collection and data analysis

Source: http://www.pcori.org/sites/default/files/PCORI-Engagement-Rubric-with-Table.pdf

Review of Patient Engagement Rubric

3) Disseminating the Study Results
    - Identifying partner organizations for dissemination
    - Planning dissemination efforts
    - Authoring manuscripts and the presentation of study findings
4) PCOR Engagement Principles
    - Reciprocal relationships
    - Co-learning
    - Partnership
    - Trust, Transparency, Honesty

Source: http://www.pcori.org/sites/default/files/PCORI-Engagement-Rubric-with-Table.pdf

Example from Previous Studies

A Method for Patient-Centered Enrollment in Comparative Effectiveness Trials: Mathematical Equipoise

- Development of project: identified and interviewed four stakeholder groups - patients, patient advocates, clinicians, and researchers
- Stakeholder panel
  - Six patients and patient advocates, seven clinicians and researchers
  - Participate in development and conduct of study
  - Participate in analysis, interpretation, and dissemination of results
  - Meet quarterly throughout 3 years
  - Individual members are interviewed about specific study questions as they occur and participate in the user interface design and testing
  - Panel members are listed in the budget justification and letters of support
- In addition to the panel, 12 patients and clinicians are recruited from the clinics to participate in the development of the user interface

Source: "PCORI." *Sample Engagement Plans from Methods Portfolio*. Web. 4 Nov. 2014.

It’s your turn!

- Please use your “Patient Engagement Plan” worksheet to guide you through the *Engagement Plan* exercise.

Audience Exercise: Develop your Patient Engagement Plan

Patient Engagement Methods

- *Describe your patient partners. What potential patient engagement methods do you use or plan to use in the beginning of your project?*

Develop your Patient Engagement Plan

Planning the Study

- *Describe how patient partners will participate in study planning and design.*

Develop your Patient Engagement Plan

Conducting the Study

- *Describe how patient and stakeholder partners will participate in the study.*

Develop your Patient Engagement Plan

Disseminating the Study Results

- *Describe how patient and stakeholder partners will be involved in plans to share study findings, and ensure that findings are communicated in understandable, usable ways.*

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It’s your turn!

- Please use your “Patient Engagement Plan” worksheet to guide you through the *Engagement Principles* exercise.

Audience Exercise: Develop your Patient Engagement Principles

Reciprocal Relationships

- *Describe the roles and decision-making authority of all research partners, including patient and stakeholder partners.*

Develop your Patient Engagement Principles

Co-learning

- *Describe plans to ensure that patient and stakeholder partners will understand the research process and researchers will understand patient and stakeholder engagement and patient-centeredness.*

Develop your Patient Engagement Principles

Partnership

- *Describe how the time and contributions of patient partners are valued and demonstrated in fair financial compensation, as well as reasonable and thoughtful time commitment requests*

Develop your Patient Engagement Principles

- **Trust, Transparency, Honesty**
  - *Describe how:*
    - *major decisions are made inclusively and information is shared readily with all research partners, including patient and stakeholder partners;*
    - *patient and stakeholder partners and research partners express commitment to open and honest communication with one another*
    - *the study team commits to communicate study findings to the community studied, in a meaningful and usable way.*

Audience Question

Think about your patient engagement plan that you just initiated.

What challenges do you have or do you anticipate you'll run into?

Patient Q&A

What are the challenges in engaging in research from a patient perspective?

What are potential solutions that researchers can consider?

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Challenges and Solutions to Patient Engagement

Challenges

- Patients or stakeholders may not feel comfortable or prepared to be in an advisory group
- Distrust of government programs and health services
- Social stigma and discrimination based on diagnoses or treatment
- Time and communication barriers

Solutions

- Provide training and educational opportunities
- Delivery of interventions in community settings and by organizations trusted by stakeholders
- Archive of patient stories or peer mentor models
- Compensation for participation is included in budget

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Additional Patient Q&A

What are general tips and suggestions you have for those who want to engage patients?

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Benefits of Patient Engagement from Previous Studies

- Development of health materials that are relevant and user friendly
- Higher participation rates when patients are more enthusiastic and involved in the study/intervention
- Empower patients and stakeholders to solve their own problems from their community
- Bi-directional flow of knowledge
- Community members are more engaged when evidence-based guidelines are translated into local language and concepts
- Sustained partnerships between researchers and community
- Community empowerment and health improvement

Source: "PCORI." *Research in Action*. Web. 4 Nov. 2014.

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Questions?

Discussion

- From your experience, how have patients become interested in a patient engagement partnership (and vice-versa)?
- What has your experience been working on research projects with patients?
- What key challenges have you experienced in patient engagement partnerships and how did you address them?

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Wise Words from a Patient / Community Member

"A lot doesn't begin at the community, unless you're intentional, thinking, feeling, and weeping together.

Funding is not enough, money is not enough,

stand with us face to face.

Get to the eye level of the community, what are they seeing, feeling, and saying. Where are we today in empowering community to lead, participate, and be involved in research?"

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Homework

- Use the worksheet to finish your patient engagement plan
  - Finalize patient representatives
  - Finalize patient engagement principles, strategies, and plans

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Next Webinar

Session 3: Community Engagement for Selecting and Designing Interventions for Testing

12/16/14

3:30 – 5:00 PM EST

Michelle Proser, MPP and Rosy Chang Weir, PhD

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Thank You!

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