



Patient-Centered Outcomes Research

KIDNEY RESEARCH CONNECT TRAINING WEBINAR



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What is Patient- Centered Outcomes Research?

- Assists patients and caregivers in the *engagement* and *informed decision-making* of health care
- Encourages their *voices to be heard* in determining the importance of health choices.
- Answers questions and addresses concerns related to the *beliefs, preferences, and needs* of patients and caregivers





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Questions for Patients Answered by Patient-Centered Outcomes Research

- ① “Given my personal characteristics, conditions and preferences, **what should I expect** will happen to me?”
- ② “What can I do to **improve the outcomes** that are most important to me?”
- ③ “What are my **options** and what are the **potential benefits and harms** of those options?”
- ④ “How can clinicians and the care delivery systems they work in **help me make the best decisions** about my health and healthcare?”

Aspects of Patient-Centered Outcomes Research

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 - Assesses the **benefits and harms** of *preventive, diagnostic, therapeutic, palliative, or health delivery system* interventions to inform decision making, highlighting comparisons and outcomes that matter to people
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 - Is inclusive of an individual's preferences, autonomy and needs, focusing on outcomes that people notice and care about such as survival, physical function, emotional and physical symptoms, and overall quality of life

Aspects of Patient-Centered Outcomes Research



- Incorporates a **wide variety of settings and diversity of participants** to address individual differences, *barriers*, and *facilitators to implementation and dissemination*



- Investigates **optimizing outcomes while addressing burden** to individuals, resource availability, and other stakeholder perspectives

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Why Engage in Patient-Centered Outcomes Research?




- Researchers and clinicians *do not fully represent* the patient perspective
- Research findings and interventions developed can be targeted to patients/community needs
- Putting *patients at the center of research shifts the inherent power differential* that exists between patients and researchers

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Why Engage in Patient-Centered Outcomes Research?

- Improves relevance of research outcomes to *patients' daily lives*
- Shifts research focus to outcomes *prioritized by patients*
- Improves study recruitment and retention
- Improves ability *capture patient voice*
 - Patient-reported outcome measures (PROMs)

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Key Players in Patient-Centered Outcomes Research

-  **PATIENT +/- CAREGIVER**
-  **CLINICIANS, INCLUDING ALLIED HEALTH PROFESSIONALS**
Nurses, social workers, dieticians, pharmacists
-  **RESEARCHER**
-  **HEALTH SYSTEMS ADMINISTRATOR**
-  **COMMUNITY ORGANIZATIONAL PARTNER**
-  **PATIENT ADVOCACY ORGANIZATION**

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Best Practices for Patient-Centered Outcomes Research

- Determine which patient stakeholders represent the perspectives that are needed to answer the research question
- Choose most rigorous study design to answer research question
 - Consider quantitative and qualitative (mixed-method) and longitudinal studies
- Clearly define *roles, responsibilities, and expectations* (including time commitment)

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Best Practices for Patient-Centered Outcomes Research

- Invest the *time, effort, humility* to partner with groups underrepresented in research
 - Extremes of age, medically complex, racial or ethnic minorities
- Determine patient knowledge of research question – **deliberative sessions**
- Determine most appropriate method of patient involvement
 - Telephone/video/in-person individual interview

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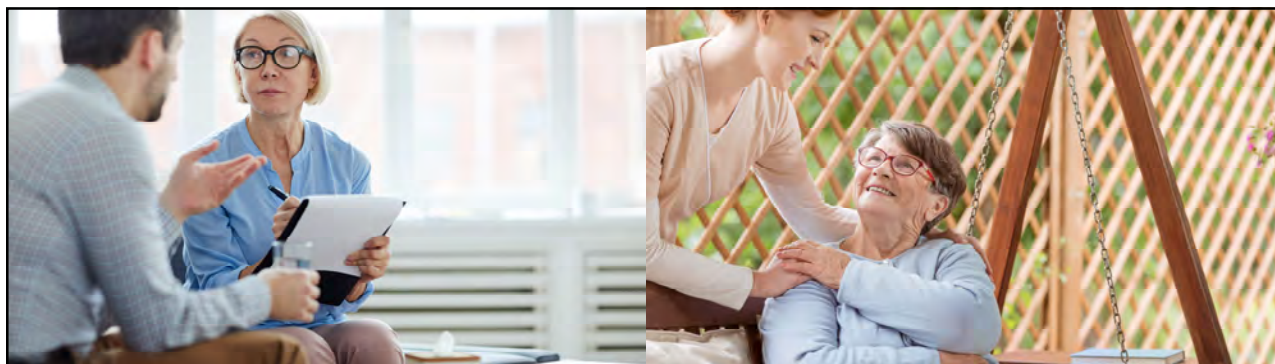
Best Practices for Patient-Centered Outcomes Research

- Develop strategies for dissemination *beyond peer review* and conferences
- Include *how the results influenced your practice*, knowledge, or skill
 - “Lunch and learn” sessions at study sites
 - Newsletters and social media
- Define clear expectations for data ownership and sharing
- Consider developing a group of registry-based ‘research ready’ patients



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Multi-level Barriers to High Quality Patient-Centered Outcomes Research



PATIENT-LEVEL

- Age
- Activation level
- Health literacy
- Trust



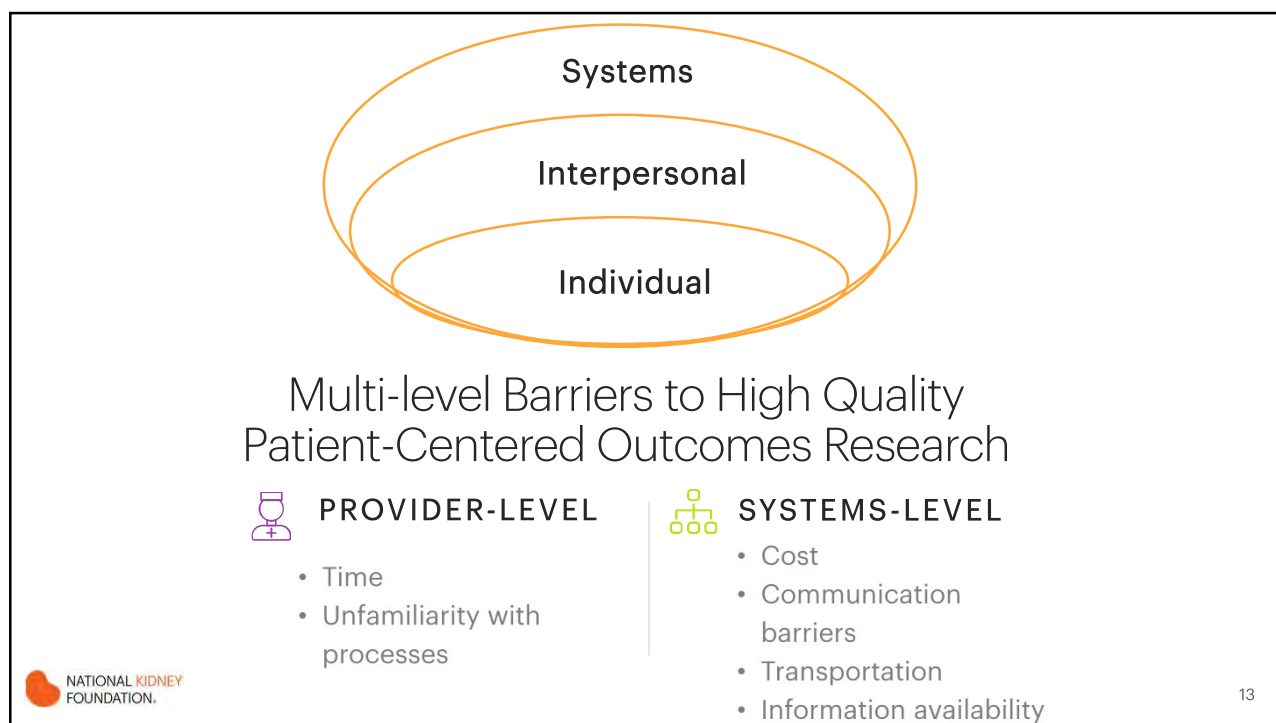
DISEASE-LEVEL

- Stigma
- Physical disability

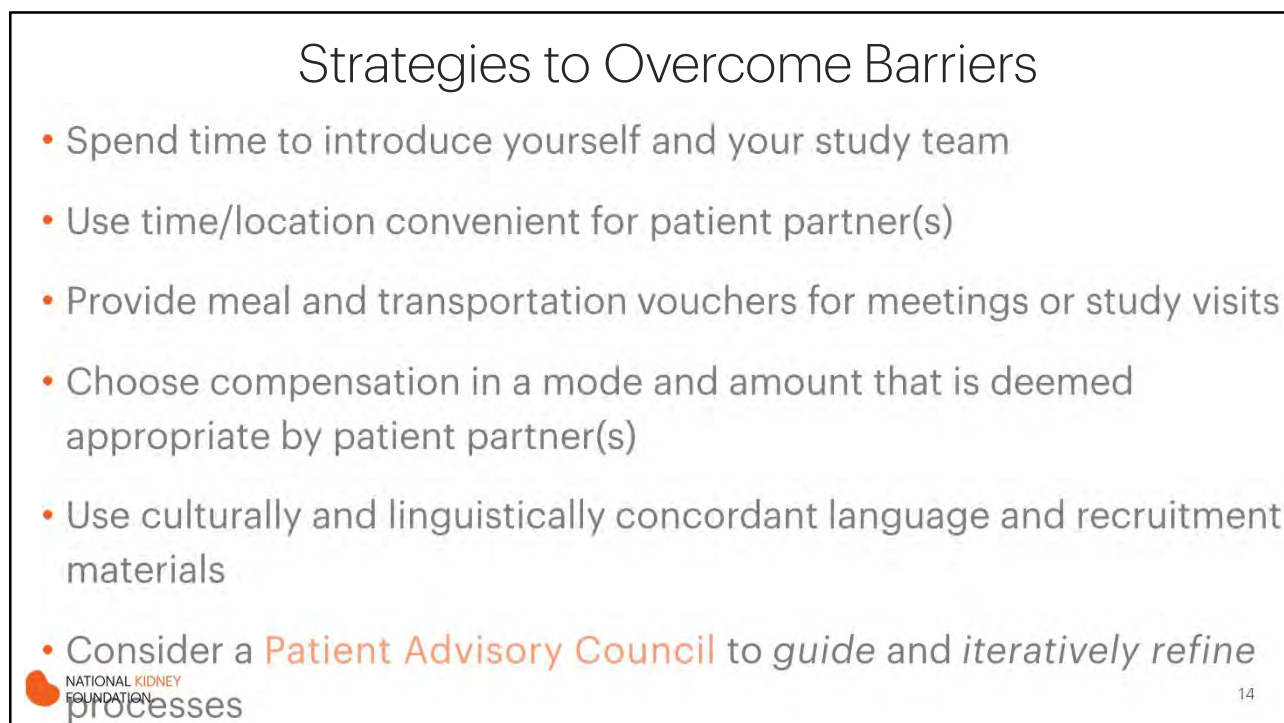


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Examples of Studies

Bringing Care to Patients: A Patient-Centered
Medical Home for Kidney Disease

EMPOWERING PATIENTS ON CHOICES FOR
RENAL REPLACEMENT THERAPY



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Engaging with Groups Underrepresented in Research

- Partner with community leader/champion
- Consider providing relevant training to community members
- Prioritize areas that are of primacy to stakeholders and communities
 - Define **how study will benefit** patient/community
- Maintain engagement after study close
- Return of results in language and mode that is easy to comprehend
- Ensure equitable allocation of resources and credit



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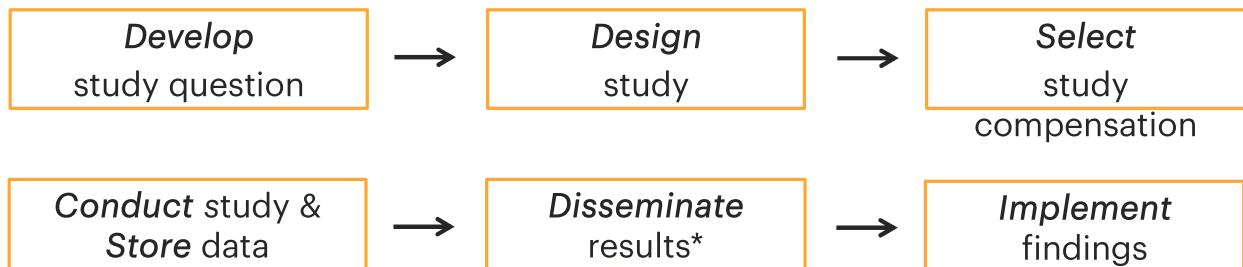
Engaging with Groups Underrepresented in Research

	GIVES	GETS
Patient/Community	• •	• •
Researcher	• •	• •

Treat participants as equals/as you would want to be treated

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Involve patient as partners in **all** aspects of research, **early** and **frequently**



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*Cultivate the **time and humility** needed to establish
bi-directional relationships with
patients and community organizations*



No “one size fits all” approach

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