

6TH ANNUAL VALUE IN CANCER CARE SUMMIT 2019

HICOR
at FRED HUTCH

Patient Partners in Research – from Concept to Practice



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Patient Partners in Research - From Concept to Practice

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HICOR VCC Summit

Goals for today

- Understand the rationale for patient engagement in research (CCDR)
 - Importance of diversity and cultural competence
- Understand how patients are engaged in all research phases
 - Design
 - Conduct
 - Dissemination
- Describe common barriers to patient engagement
 - Strategies to overcome barriers



Why
involve
patient
partners in
cancer care
delivery
research?

: Esmail L, Moore E, Rein A. (2015). Evaluating Patient and Stakeholder Engagement in Research: Moving from
to Practice. *J. Comp. Eff. Res.*, 4(2), 133-45.

Levels of Patient and Researcher Engagement in Health Research

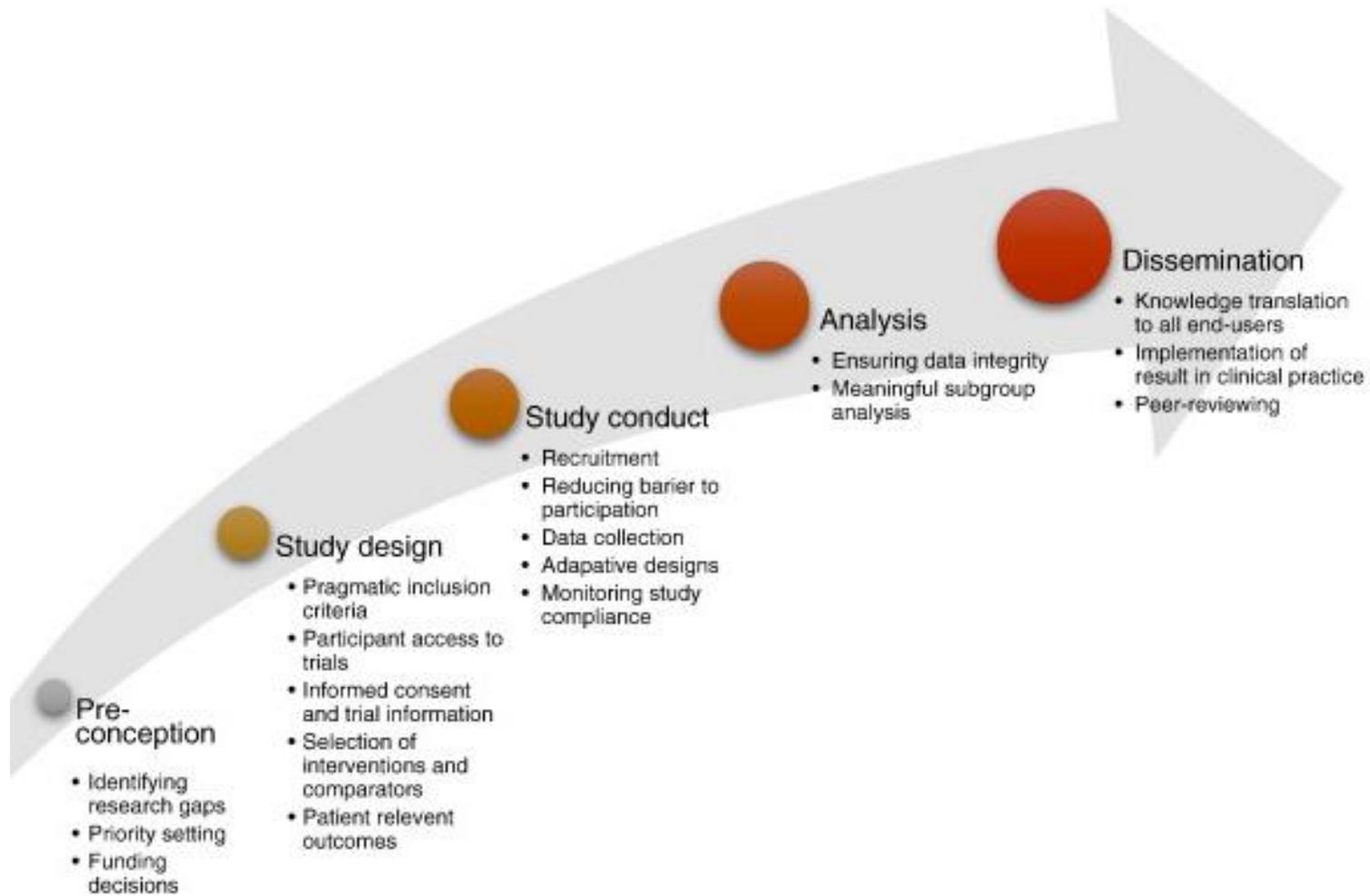
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TIME AND KNOWLEDGE NEEDED

+

	LEARN/INFORM	PARTICIPATE	CONSULT	INVOLVE	COLLABORATE	LEAD/SUPPORT
Patient's Goal	To ask questions and learn about how to get more involved	To act as a subject or participant in a research study	To provide feedback and advice on specific research activities	To work directly with a research team throughout the project	To partner on equal footing with researchers in all aspects of research	To make final decisions and lead research activities
Researcher's Goal	<i>To provide information, listen, and answer questions honestly</i>	<i>To act ethically and respectfully in the conduct of research</i>	<i>To seek your input on an ad hoc basis</i>	<i>To include you as standing members in an advisory capacity</i>	<i>To partner equally with you as team members</i>	<i>To follow your lead and support your decisions</i>
How This Can Be Done	In an open atmosphere for sharing through orientation and information sessions, and media campaigns	Through quantitative, qualitative, or mixed methods research	Through scientific cafes, focus groups, priority-setting activities, and as members of ad hoc working groups or expert panels	As members of standing working groups and advisory committees or panels	Patients as co-investigators and research partners, and as members of research steering committees	Through patient or community steering committees and patients as principle investigators

The
Engagement
Continuum



Examples of how patient partners are engaged in research

Evidence that patient engagement has an impact – analysis of 126 published PCORI-funded studies

Acceptability

- Research designs, procedures, interventions intended to be well received by patients or clinicians
- Based on burden, usability, alignment with values, preferences and needs

Feasibility

- Mitigating potential or actual research roadblocks
- Making interventions, enrollment, retention and data collection more doable in real-world settings

Rigor

- Choices that minimize bias and enhance data quality
- Includes when or how to collect data, selection or assessment of measures, decisions to re-order, shorten or add items to data collection measures

Relevance

- Applicability and importance of the research for patients and clinicians making decisions
- Includes importance of research questions and outcomes, generalizable study samples, interpretations of findings in real-world context, more effective dissemination

Barriers to patient engagement in cancer clinical trials

Results of qualitative interviews of investigators and survey of research patient advocates at SWOG, one of 5 NCTN groups funded by NCI.

Deverka, et al. A New Framework for Patient Engagement in Cancer Clinical Trials Cooperative Group Studies. JNCI 2018;110: 553-559.

- Researchers
 - Do not have a shared understanding of the importance of patient engagement
 - Lack of understanding of team member roles
 - Need for training on collaboration and engagement skills
- Patient advocates
 - Lack of relationship with PI
 - Lack of procedures for working with PI
 - Lack of researcher skills/training for engaging patient advocates

Barriers to patient engagement in CCCR

*Culture is pattern of learned beliefs, values and behavior that are shared within a group. Shaped by race, ethnicity, religion/spirituality, language, nationality, region, gender, sexual orientation, SES, education, affiliation, customs

- Lack of physical and emotional energy
- Time, transportation, financial support
- Fear/trauma of going back into cancer treatment environment
- Language/Cultural* barriers
 - Minority community mistrust of research and researchers
 - Lack of people of color working as research staff
 - Lack of benefits to the community

Hard-to-reach patient partners

Kaiser BL, Thomas GR, Cox ED. Hard-to-reach patient stakeholders: An engagement guide (HARPS). University of Wisconsin - Madison, 2016. Available at: <https://www.hipxchange.org/HARPS>

- Racial and ethnic minorities
- Low-income and low-literacy populations
- Children and adolescents
- Older adults
- LGBTQ populations
- Other groups who may not be accessible using traditional recruitment processes and materials.

Cultural Competence in Research*

Rationale

- Understand the needs and perspectives of different groups
- Community outreach and engagement
- Contextualization of research knowledge
- Increase in the community relevance of research findings

Consequences if ignored

- Stereotyping
- Tokenism
- Mistrust
- Inability to engage certain communities
- Poor health and research outcomes

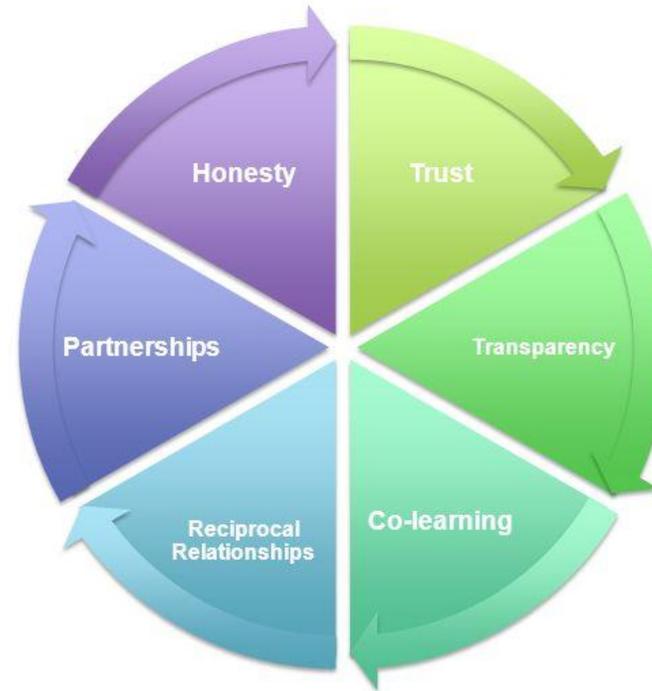
* The ability of researchers and research staff to provide high quality research that takes into account the culture and diversity of a population when developing research ideas, conducting research, and exploring applicability of research findings

- An ongoing process
- Value and respect for others
- A willingness and openness to change attitudes and behaviors

The path forward

- Adequately fund patient engagement efforts
- Define team member roles
- Provide culturally competent engagement training to patient partners and researchers
- Develop innovative research designs and validated measures to assess engagement processes for CCDR
- Meet patients where they are and use various communication modalities to sustain engagement

PCOR Engagement Principles



Incorporates the **Engagement Principles*** and conceptual framework of patient engagement in research developed by PCORI's scientific team (Source: Curtis, P, Slaughter-Mason, S, Thielke, A, Gordon, C, Pettinari, C, Ryan, K, Church, B, King, V(2012). PCORI Expert Interviews Project)



Questions?



THANK YOU!

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We don't see things as THEY are,
we see things as WE are.

- Anaïs Nin