STRENGTHENING DIVERSITY IN RESEARCH PARTNERSHIPS:

Knowledge to Action Guide

EXECUTIVE SUMMARY

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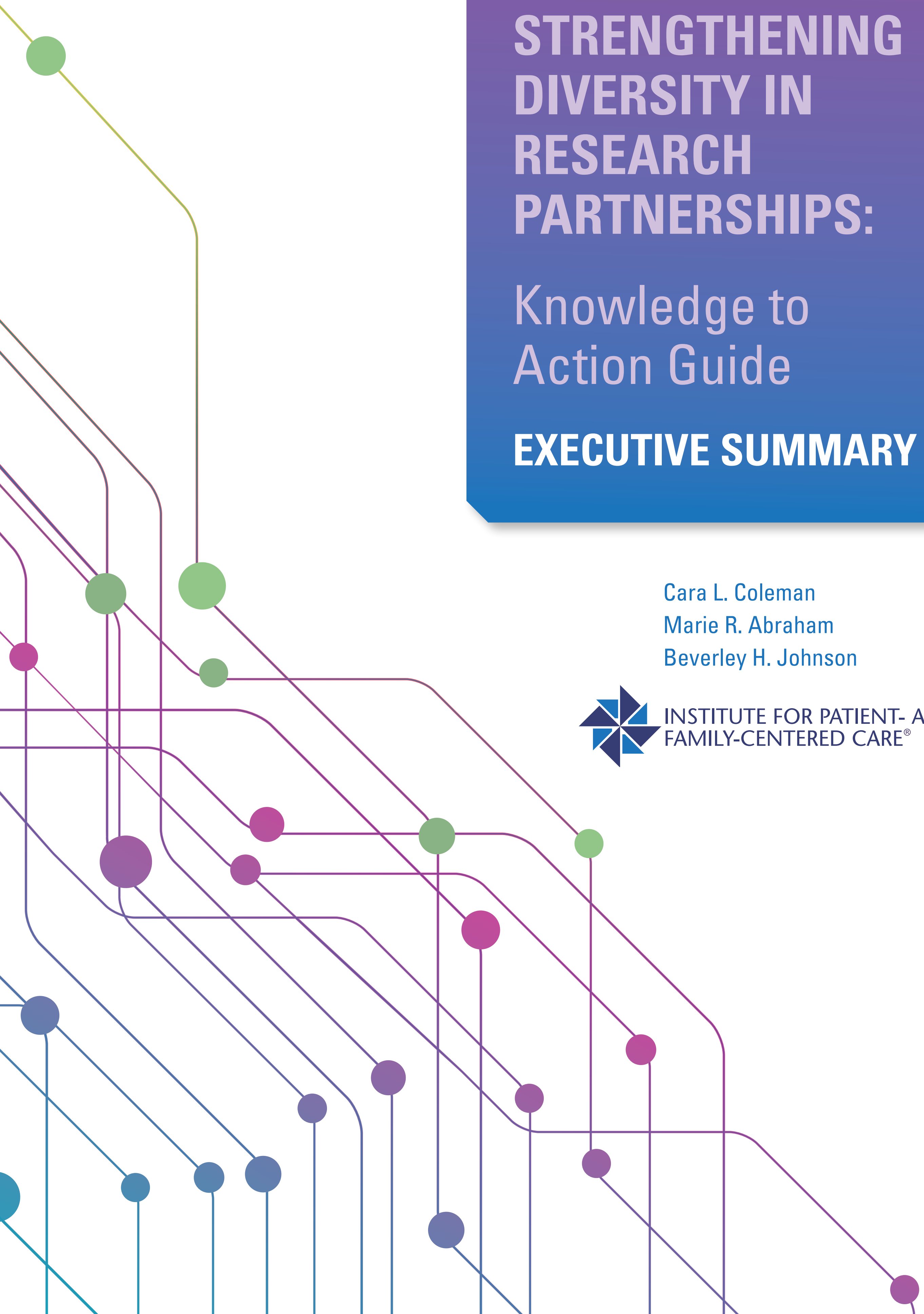

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> *"As academic health centers seek to expand their goals to embrace a model that promotes health as well as health care, it is imperative to integrate community-engaged research."*
>
> McElfish et al., 2015

Understanding the Problem

Diverse, vulnerable, and underserved populations are under-represented as participants in health care research. Lack of representation of diverse groups limits the generalizability of research and may also significantly contribute to health disparities. Authentic partnerships with under-represented communities in all stages of research represent a key strategy to address the inequity and disparities. Collaborative models of research, such as community-based participatory research (CBPR), offer methods for engaging diverse groups in research. However, CBPR is a relatively recent approach used in health care research and has not been widely adopted. To support partnerships in research and broader adoption of collaborative approaches to research, researchers need guidance to change the long-standing culture and beliefs in academic and research centers that may lead to reluctance or inability to collaborate with diverse patient, family, and community partners (PFC partners).

Project Background

In 2017, the Institute for Patient- and Family-Centered Care (IPFCC) received a two-year Eugene Washington PCORI Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI) for the project, **Strengthening Diversity in Research Partnerships: Knowledge to Action.** This funding supported two major efforts:

- Special programming at IPFCC's *8th International Conference on Patient- and Family-Centered Care: Promoting Health Equity and Reducing Disparities* held in Baltimore, MD in June 2018 featuring partnerships with diverse and underserved communities in health care research; and
- Development of a Knowledge to Action Guide and Resources providing guidance and best practices for creating partnerships with typically under-represented PFC partners in research. The Guide includes content gleaned from:
  - An extensive literature review
  - Consultation and input from a project Expert Advisory Panel comprised of researchers, health care professionals, and diverse PFC partners
  - Interviews with experts who are involved in partnerships in health care research

  - Conference presentations
  - Site visits to three exemplary programs that authentically partner with diverse and vulnerable populations in research

While a collaborative approach to health care research has not been widely adopted, we learned through the project activities that there are researchers and PFC partners across the country committed to partnerships to plan, conduct, and disseminate research. We are grateful to the researchers and PFC partners for sharing their knowledge and insights and helping us build an understanding of how to advance partnerships with diverse PFC partners in research.

Overview of the Guide

To achieve its aim of conducting patient-centered outcomes research, PCORI created the PCORI Engagement Rubric, as a framework to offer concrete ways to operationalize engagement that incorporates patients and other stakeholders in all phases of research. The framework includes Principles of Engagement; definitions of stakeholder types; key considerations for planning, conducting, and disseminating research; engagement activities; and examples of promising practices from PCORI-funded projects (Sheridan et al., 2017).

Building on the foundation of the Rubric, the Strengthening Diversity in Research Partnerships project team expanded the original Principles of Engagement to recognize and address the unique circumstances that arise when partnering with diverse and typically under-represented communities in research. This expansion was based on the lessons learned about meaningfully and authentically engaging these communities from researchers, clinicians, and PFC partners who participated in project activities (see the table listing the expanded Principles and Strategies on page 4 of the Executive Summary).

Principles of Engaging Diverse PFC Partners in Research

- Trust
- Reciprocal Relationships
- Honesty
- Transparency
- Cultural Competency
- Co-Learning
- Partnerships

Each section of the Guide presents one of the seven principles and offers an Overview, Strategies and Insights, Stories from the Field, Top Tips, and Selected Resources. The Guide offers practical guidance to learn about, facilitate, and strengthen engagement of diverse PFC partners such that research can be co-designed and co-implemented and we can move forward toward the elimination of health disparities.

Engaging Diverse Patient, Family, and Community Partners in Research

PRINCIPLES	STRATEGIES TO ACHIEVE PRINCIPLES
Trust	• Research is planned, conducted, and disseminated in a way that honors the trust developed with diverse patient, family, and community partners (PFC partners) and does not further marginalize and stigmatize a community. • Each person's experience, insights, and voice are listened to, acknowledged, respected, and valued. • Commitment to building trust recognizes that cultural competency, an understanding of historical perspectives/experiences, and current realities of PFC partners, are paramount. • Researchers are accountable to the community being studied and share information in an ongoing and authentic manner.
Reciprocal Relationships	• Roles and decision-making authority of all research partners, including PFC partners, are clearly stated and, where possible, defined collaboratively. • Shared values are elicited and made explicit to all partners. • Relationships are reciprocal or bi-directional such that there is enriching benefit, investment, and/or improvement for the PFC partners and the community studied. • There are opportunities and processes in place for PFC partners to solicit research partners based on community-driven needs and community-identified research priorities.
Honesty	• PFC partners, other stakeholders, and researchers are committed to open honest communication with one another recognizing that this is essential to building trust, and ultimately, the success of the partnership. • Honest communication is jointly defined (i.e., what it is, how it is experienced, and how it can be achieved) by all partners.
Transparency	• Information is shared readily with all partners in the language, method, and manner that is most encouraging and supportive of engagement of PFC partners. • Goals and timelines for projects are clearly identified and agreed upon by all partners. • Major decisions are made inclusively, and whenever they cannot be, the reasons are clearly communicated to PFC partners.
Cultural Competency	• Cultural competency is viewed as more than a checklist and is thoughtfully woven into how all partners approach the project, how they work together, and how research is conducted. • Diversity is thought about in expansive terms, drawing from the pulse of the community, not traditional paradigms. • The diversity of the community selected for a study is reflected in the membership of the research team and in the PFC partners.
Co-Learning	• All partners are committed to learning from each other. • Opportunities exist in all stages of the research process so that all partners are able to continuously learn from each other • Efforts are focused on helping PFC partners understand the research process, rather than trying to turn PFC partners into researchers. • Researchers will learn about patient- and family-centered care and strategies to meaningfully engage PFC partners.
Partnerships	• Requests for time commitment of PFC partners are reasonable, respectful, and flexible. • PFC partners receive fair financial compensation for their participation. • Researchers meet diverse PFC partners "where they are" and honor their preferences for level and types of engagement. • Accessibility and inclusiveness are viewed broadly and accommodations are planned and implemented to support engagement. • Commitment and support of leadership in research and stakeholder organizations are viewed as essential to build and sustain engagement of PFC partners.

Conclusion

It was clear from all of the experts—patient, family, and community partners and researchers—who shared their wisdom that developing meaningful and authentic partnerships takes leadership, time, resources, flexibility, and most importantly, a firm commitment to be open to learning from each other. By engaging in true partnerships we will be better equipped to design and conduct research that ultimately leads to knowledge benefiting all and fostering the elimination of disparities existing in health and health care.

References

McElfish, P. A., Kohler, P., Smith, C., Warmack, S., Buron, B., Hudson, J., . . . Rubon-Chutaro, J. (2015). Community-driven research agenda to reduce health disparities. *Clinical and Translational Science, 8*(6), 690–695. doi:10.1111/cts.12350

Sheridan, S., Schrandt, S., Forsythe, L., Hilliard, T. S., & Paez, K. A. (2017). The PCORI engagement rubric: Promising practices for partnering in research. *Annals of Family Medicine, 15*(2), 165-170. doi:10.1370/afm.2042

Additional Resources

Spotlight Videos were produced from site visits to exemplary organizations that partner with diverse individuals and communities and interviews with researchers and PFC partners at IPFCC's ***8th International Conference on Patient- and Family-Centered Care: Promoting Health Equity and Reducing Disparities.*** You can view these at **Strengthening Diversity in Research Partnerships.**

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