

UNIVERSITY OF MARYLAND

MPOWERING THE STATE

Our Roadmap for the Summer Institute: Pre-engagement and the 10-Step Framework for Patient Engagement

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Type I Diabetes Patient; **PATIENTS Program** Advisor

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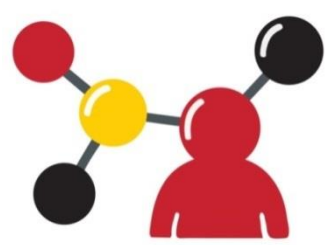
Carolyn Alexander

- My Journey into
 - CER/PCOR
 - The PATIENTS Program
- The Importance of Pre-engagement



C. Daniel Mullins

- Pre-engagement
- The Path to PATIENTS
- The 10-Step Framework



Serendipity

The Three Princes of Serendip...were
“always making discoveries, by
accidents and sagacity, of things
which they were not in quest of”



The Path to PATIENTS

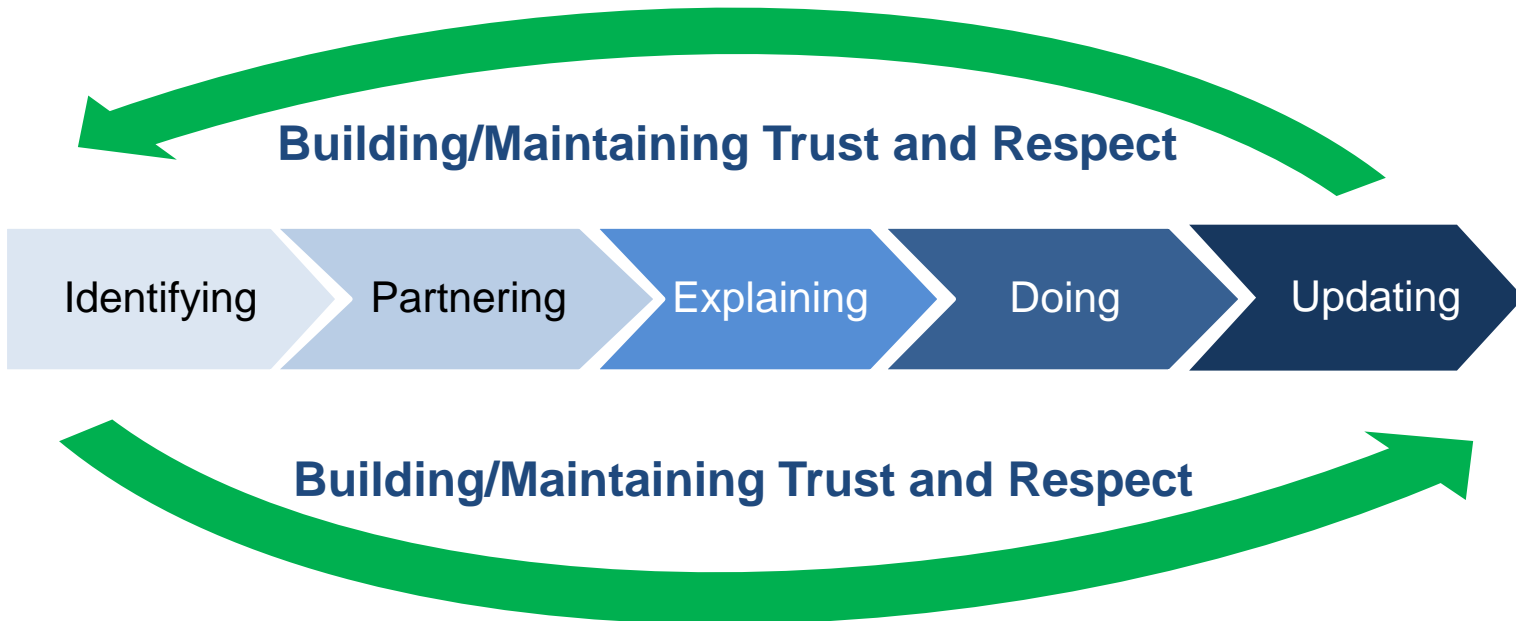


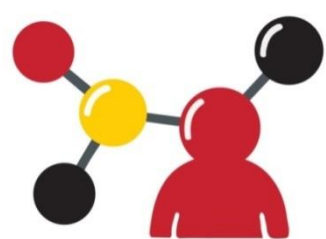
*Interviews to Identify Evidence for Eliciting the
Hard to Reach Patient's Perspective in PCOR*
(PCORI contract: **PCORI-SOL-PCWG-002**)



The Path to PATIENTS (2)

Key Finding from **PCORI** Contract





The Path to PATIENTS (3)

Transform University of Maryland's Approach to (Late-stage) Translational Research

Develop Sustainable Partnerships to Improve Patient Health and Decision Making

PCOR Studies supported by PATIENTS:

- [1] Use Appropriate CER Methods
- [2] Follow 10-Step Framework for Continuous Patient Engagement
- [3] Address Real-World Concerns
- [4] Enhance Sustainability



The PATIENTS Program

The University of Maryland PATIENTS Program

- **Empowers Patients to:**
 - Propose questions about their healthcare concerns
 - Actively participate in studies to answer them
- **Combines the Expertise of:**
 - Researchers from the University of Maryland and our partners
 - Patient communities
 - Healthcare providers and healthcare delivery systems



The PATIENTS Program (2)

The University of Maryland PATIENTS Program

- Challenges the Status Quo by Embracing Patients and Healthcare Systems in Every Component of PCOR



PATIENTS 3 Aims:

1. Foster university-wide SUSTAINABLE partnerships with DIVERSE patient communities and healthcare systems
2. Conduct PATIENT-CENTERED outcomes research in PARTNERSHIP with communities and systems
3. Advance patient-centered DISSEMINATION and efficient implementation of findings to answer QUESTIONS THAT PATIENTS CARE ABOUT



PATIENTS PARTNERS





10-STEP FRAMEWORK FOR CONTINUOUS PATIENT ENGAGEMENT IN RESEARCH*

A. PLANNING RESEARCH

1. Topic Solicitation
2. Prioritization
3. Framing the Question

B. DOING IT

4. Selection of Comparators and Outcomes
5. Creation of Conceptual Framework
6. Analysis Plan
7. Data Collection

C. DELIVERING SOLUTIONS

8. Reviewing & Interpreting Results
9. Translation
10. Dissemination

***Based on:** Mullins CD, Abdulhalim AM, Lavallee DC. Continuous Patient Engagement in Comparative Effectiveness Research. *JAMA* 2012; 307(15): 1587-8.



Authenticity

- Are we truly helping patients and their care providers make more informed decisions?
- Did we make a difference?



QUESTIONS AND DISCUSSION

