

The “How Tos”: Starting at the Beginning – How to Identify, Locate and Incorporate Patients in the Planning of Clinical Pain Research

The Voice of the PATIENT
Ms. Gail Graham

Director of Mt. Lebanon Baptist Church
HIV/AIDS Ministry-Outreach Services



PATient-centered Involvement in Evaluating effectiveness of Treatments



Karen Morales, Associate Director of Engagement

PATIENTS Vision:

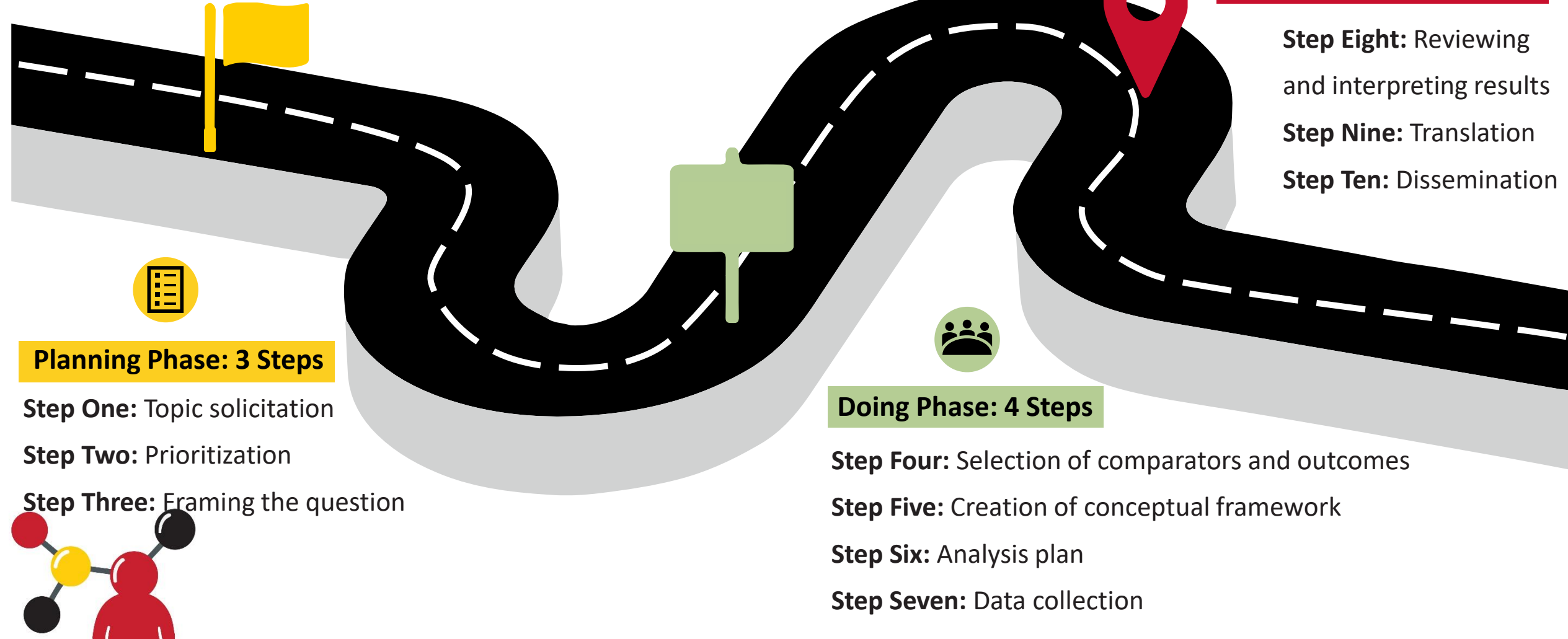
Patients and stakeholders are heard, inspired, and empowered to co-develop patient-centered outcomes research



Transforming the Research Enterprise



10-Step Framework for Continuous Patient Engagement



Transforming the Research Enterprise

Planning

- Setting Expectations
- Advisory Boards
- Use of Language
- Topic Solicitation
- Prioritization
- Framing the Question

Pre-engagement

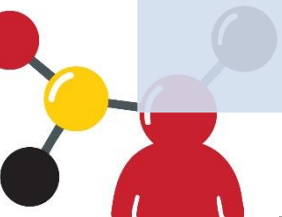
- Understanding the community
- Early and Often
- Working with CHW/Engagement Specialists
- Community Events
- Community Health Fairs
- Partnering with Community Churches, Educational Institutions
- Engaging Community Clinics, Senior Centers, Community Associations, Advocacy Groups, and others

Continuous Engagement

- PATIENTS as Partners
 - What are you interested in?
 - Asking not telling
 - Respecting and valuing
 - Transparency
 - Strategic Planning
- Builds trust
- Newsletters
- Social Media
- Compensation
- Contact Calls
- Demonstrate Trustworthiness

Example: RadComp Breast Cancer Trial

- Clinical question: Does proton therapy reduce major cardiovascular toxicity compared to photon therapy?
- Patient voice: *“Which type of radiation is better for heart health?”*



Transforming the Research Enterprise

Doing

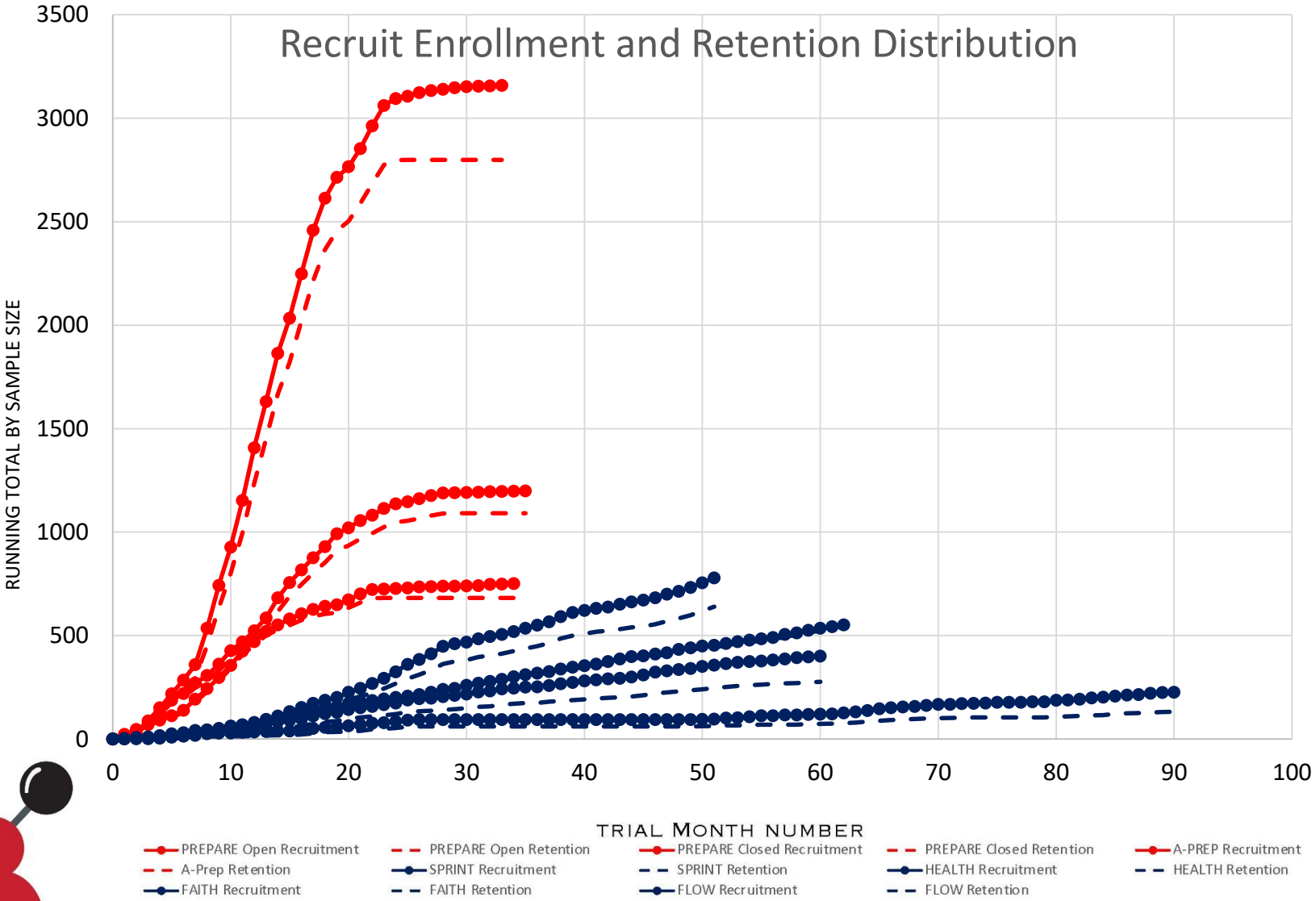
- Patients and Stakeholders
 - Co-develop study protocol
 - Review or select survey instruments
 - Choose when and how to gather data
 - Advise on how to recruit, engage, and retain participants

Delivering Solutions

- Patient advisory groups blogging about our studies
- Videos and infographics created with patients to supplement manuscripts
- PATIENTS Day for bidirectional learning and dissemination



Faster recruitment

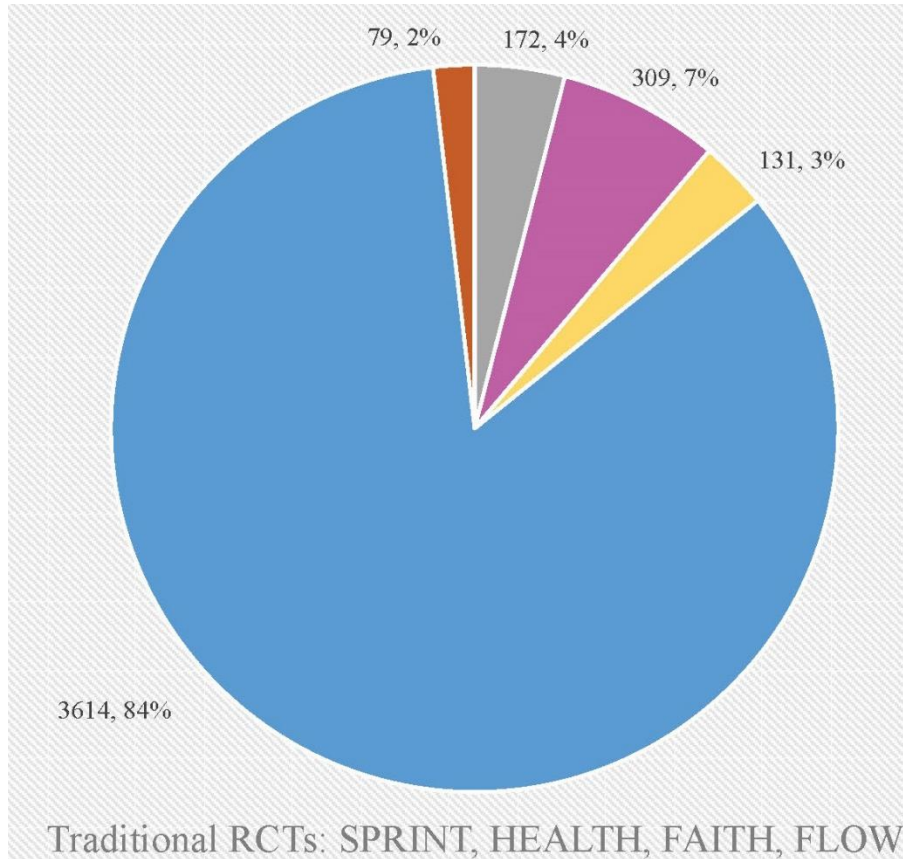


Trials supported by PATIENTS (red) outperform traditional trials (blue).

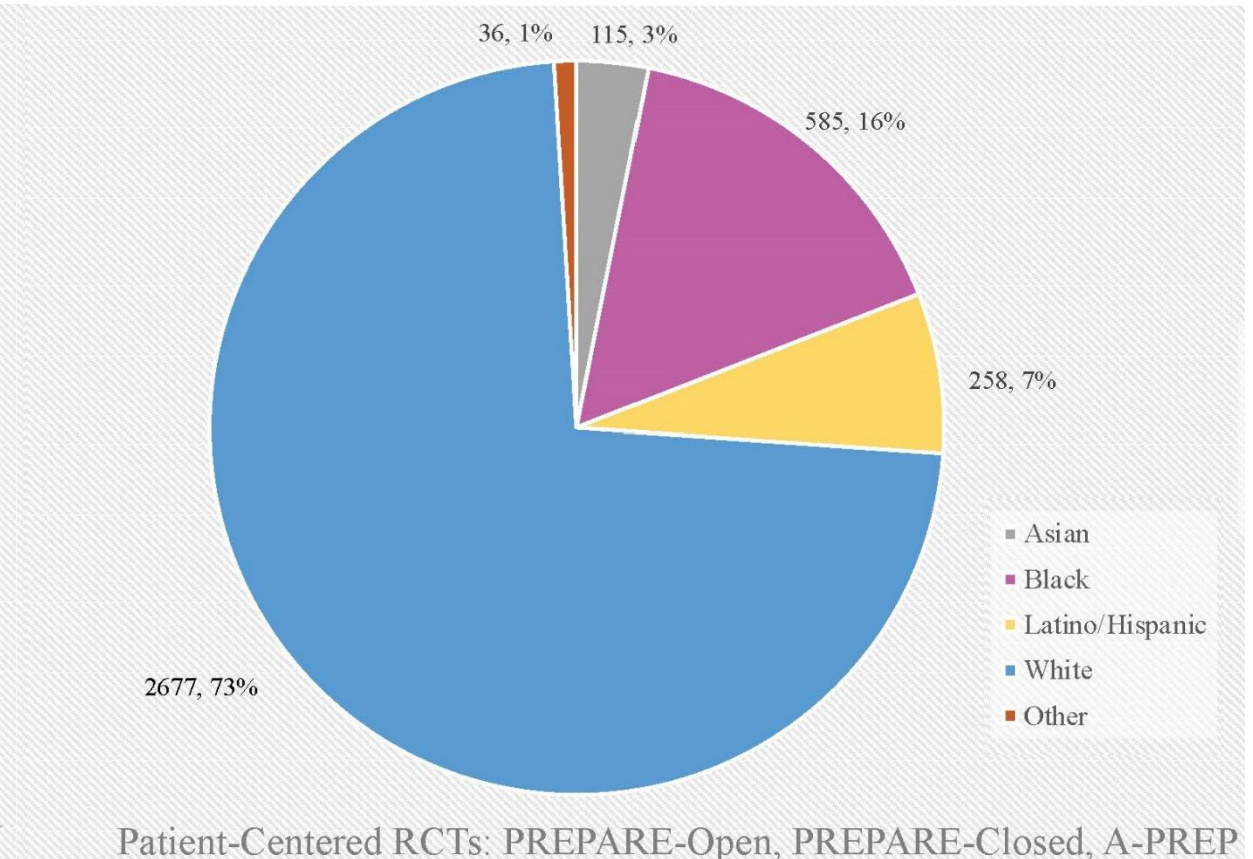


Increased racial/ethnic diversity

Traditional clinical trials



Comparative PATIENTS Program



- Asian
- Black
- Latino/Hispanic
- White
- Other

Our approach leads to greater diversity in recruitment.

Thank You and Q&A!

