Addressing Equity, Diversity, and Inclusion in GU Cancer Research and Care: From the Community to the Bedside

Masters in Therapeutic Oncology Summit (GU Edition)

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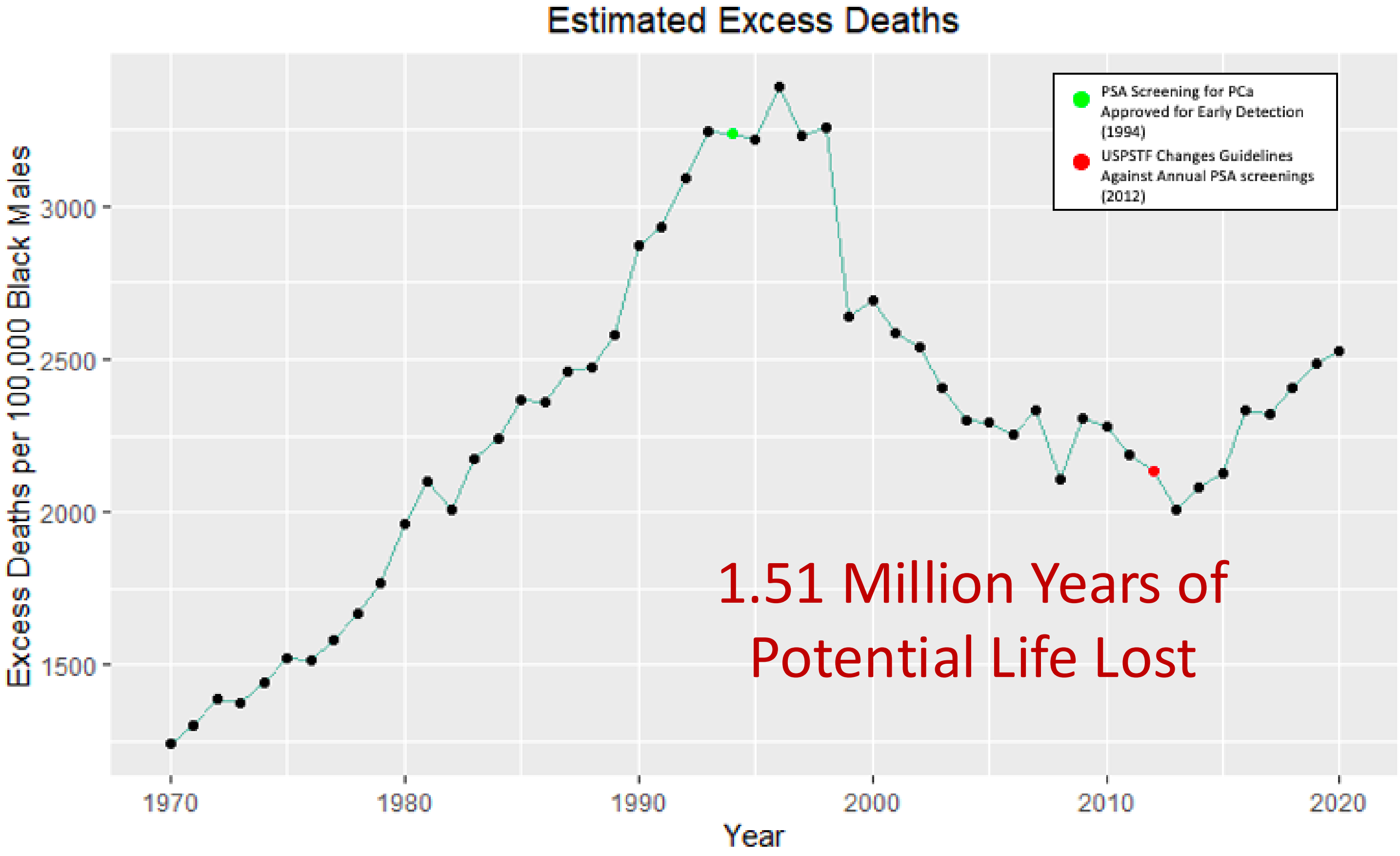
Objectives

I. GU Cancer Disparities
II. Barriers to Research Participation
III. Interventions that Create Equity and Inclusion
IV. Patient- and Community- Partnered Research
V. Black and African-descent Collaborative for Prostate cancer ACtion (BACPAC)

Excess Death & Life Years Lost Among Black Prostate Cancer Patients



1.51 Million Years of Potential Life Lost

Nana Frimpong

Sarah Holt

Manuscript in progress, please do not share

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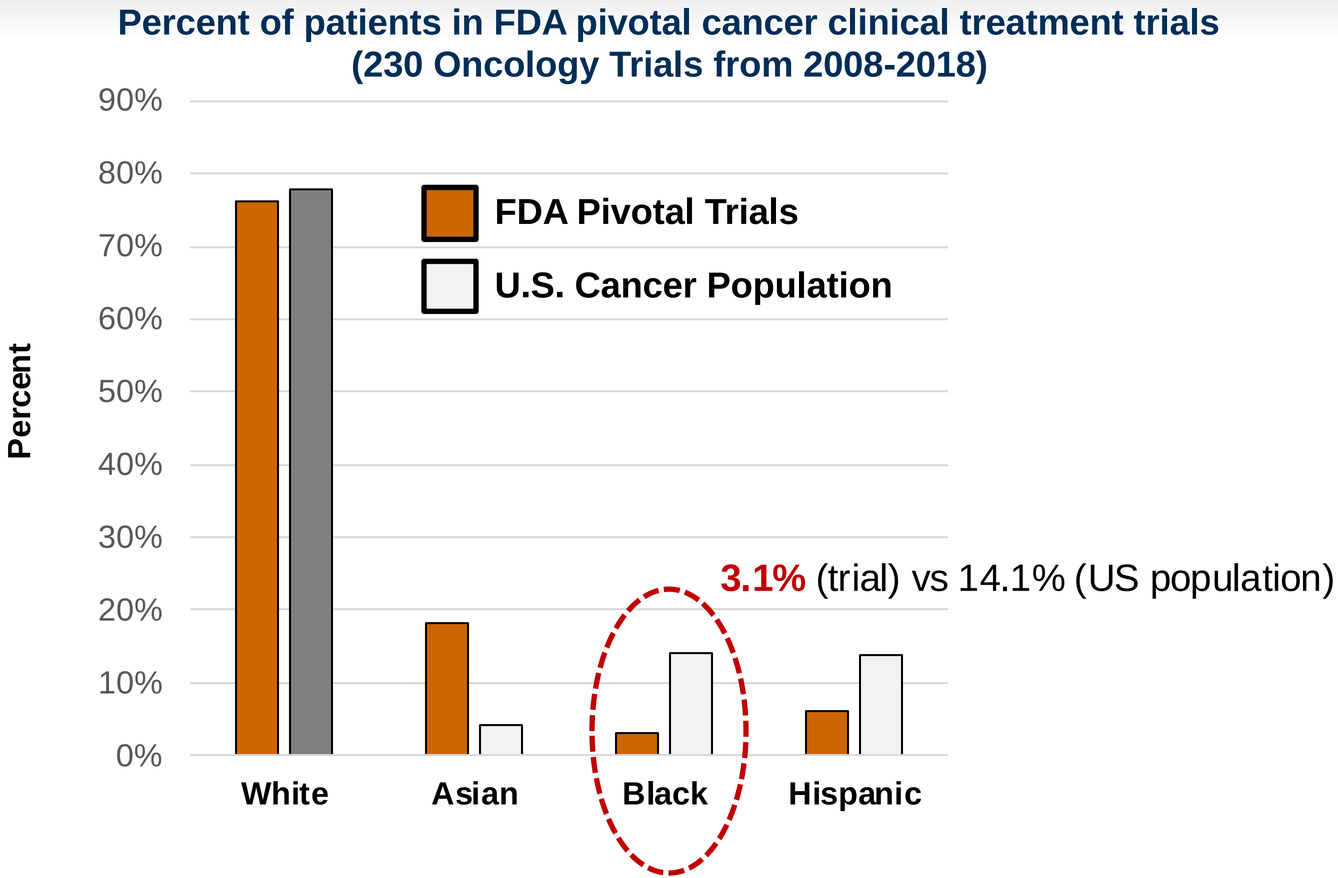
Racial/Ethnic Disparities in Enrollment

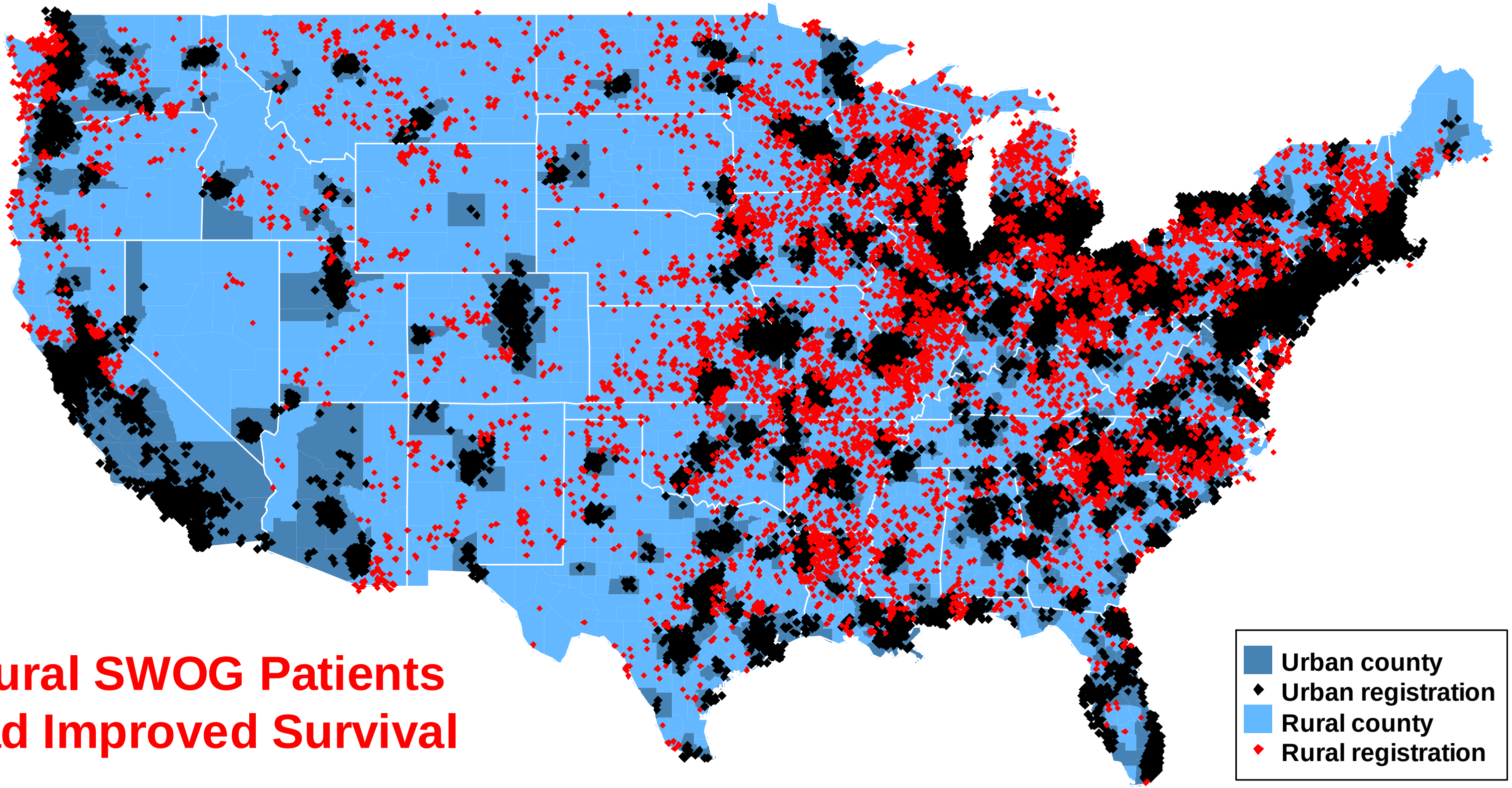


3.1% (trial) vs 14.1% (US population)

Loree et al, JAMA Oncology, 2019
Courtesy of Joe Unger, PhD

Rural/Urban Disparities in Clinical Outcomes

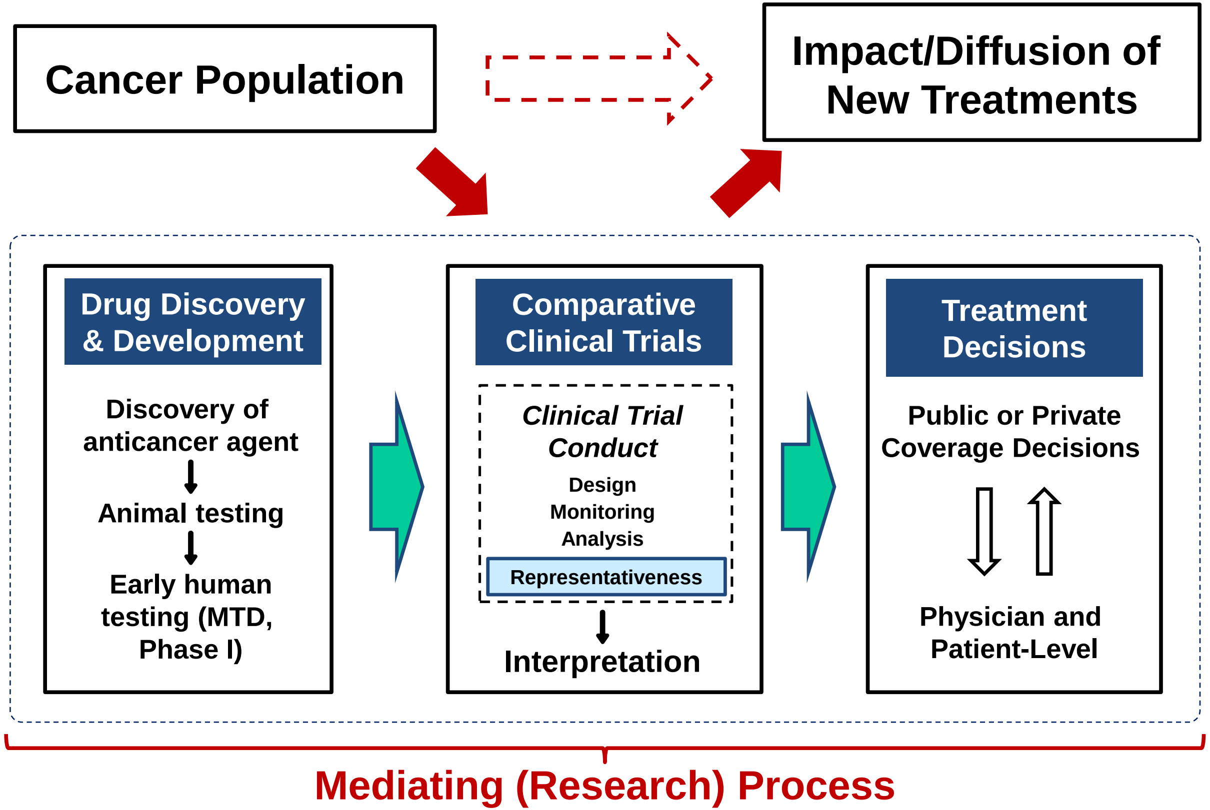
SWOG Enrollments from 1986-2012 by Rural vs Urban County of Origin (N = 36,995, 44 Phase III Trials)



Rural SWOG Patients had Improved Survival

Unger et al, JAMA Netw Open, 2018
Courtesy of Joe Unger, PhD

Conceptual Model – Role of Cancer Clinical Trials in New Treatment Discovery and Dissemination



Cancer Population

Impact/Diffusion of New Treatments

Drug Discovery & Development

Discovery of anticancer agent

↓

Animal testing

↓

Early human testing (MTD, Phase I)

Comparative Clinical Trials

Clinical Trial Conduct

Design

Monitoring

Analysis

Representativeness

↓

Interpretation

Treatment Decisions

Public or Private Coverage Decisions

⇩ ⇧

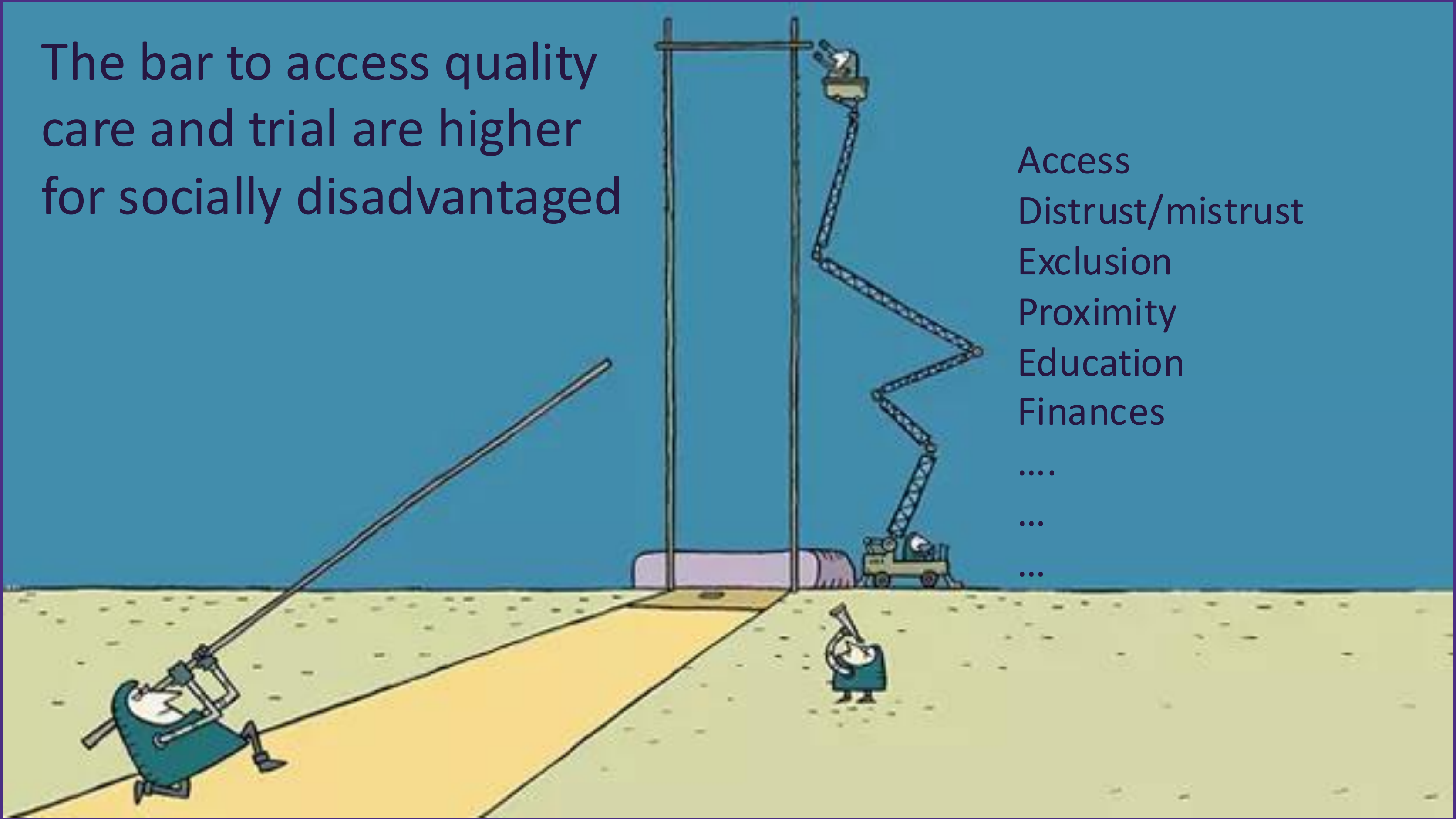
Physician and Patient-Level

Mediating (Research) Process

- Clinical trial patients receive protocol-directed care by design
- Patients are uniformly staged, treated, and followed up under protocol-specific guidelines
- Reduces influences of inconsistent pretreatment evaluation, care, and post-treatment surveillance

Courtesy of Joe Unger, PhD

The bar to access quality care and trial are higher for socially disadvantaged



Access
Distrust/mistrust
Exclusion
Proximity
Education
Finances
….
…
…

Inclusive Approaches

Navigation
(nurse, patient,
technology based)

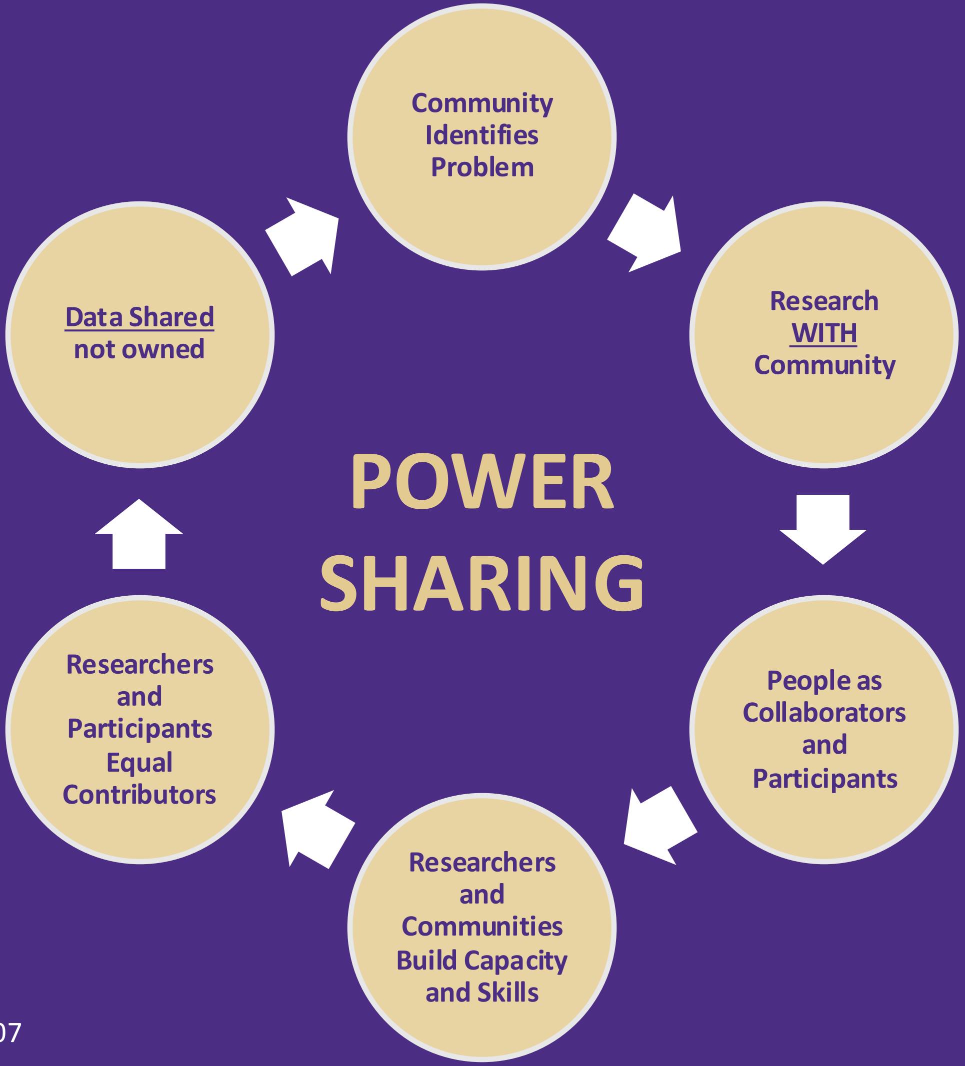
Decentralization

Partnership

Power.

Power. ability to act or produce an effect

Merriam-Webster Dictionary



POWER SHARING

Community Identifies Problem

Research WITH Community

People as Collaborators and Participants

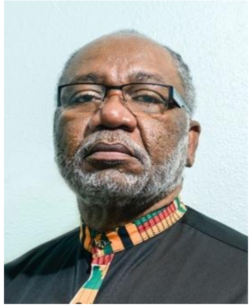
Researchers and Communities Build Capacity and Skills

Researchers and Participants Equal Contributors

Data Shared not owned

Jones L and Wells K, JAMA, 2007

BACPAC: Black and African Descent Collaborative for Prostate Cancer Action



BAC PAC

Board of Directors: Ben Young, Victor Tolbert, Ken Hutchinson, Robert Ginyard, Ullyses Wright, Yaw Nyame

Patient Advisor/Scientists (20+ members), Advocacy Partners (PHEN, ZERO, PCF), Virtual Research Community (2500+ participants)

www.bacpacnetwork.org

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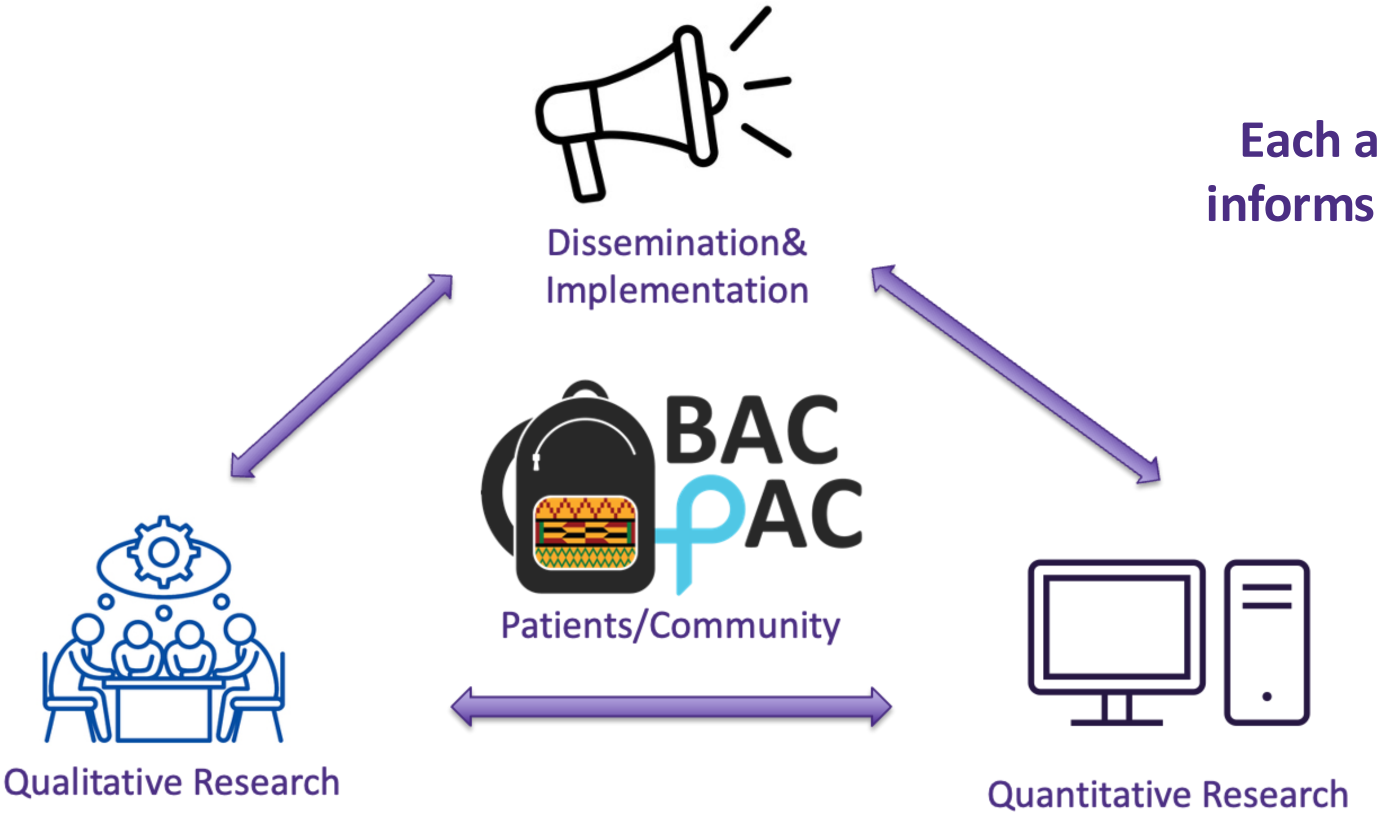
Beyond Engagement

Prioritize research questions

Develop partnerships/
advocate researchers

Design and conduct
research studies

Transdisciplinary Approach to Equity



Dissemination&
Implementation

Patients/Community

Qualitative Research

Quantitative Research

Each approach informs the other

RESEACH PRIORITIZATION

Multi-Stakeholder Engagement to Create Equity in Prostate Cancer Outcomes through Early Detection (EDAB)

Build capacity for community members to be researcher partners

Build a Virtual Research Community to prioritize research topics and study methods

Develop a research plan/clinical trial to improve the early detection of prostate cancer among Black individuals.

Funded by the Patient Centered Outcomes Research Institute (Engagement Award)

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If you are a Black Prostate Cancer survivor, family member, or caretaker then join our Virtual Research Community!

Take our community survey and help shape the future of prostate cancer equity research

www.BACPACnetwork.org/join

BAC PAC

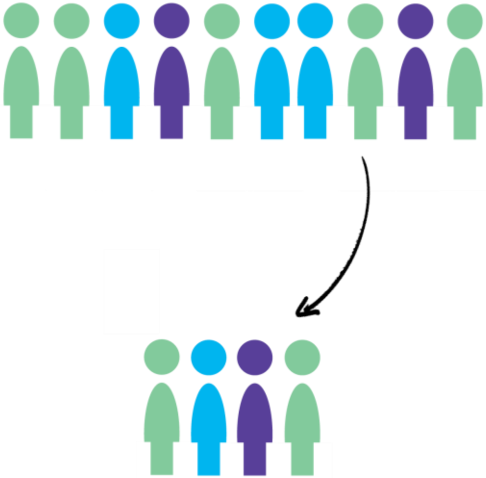
SCAN HERE

Virtual Research Community (at time of survey)

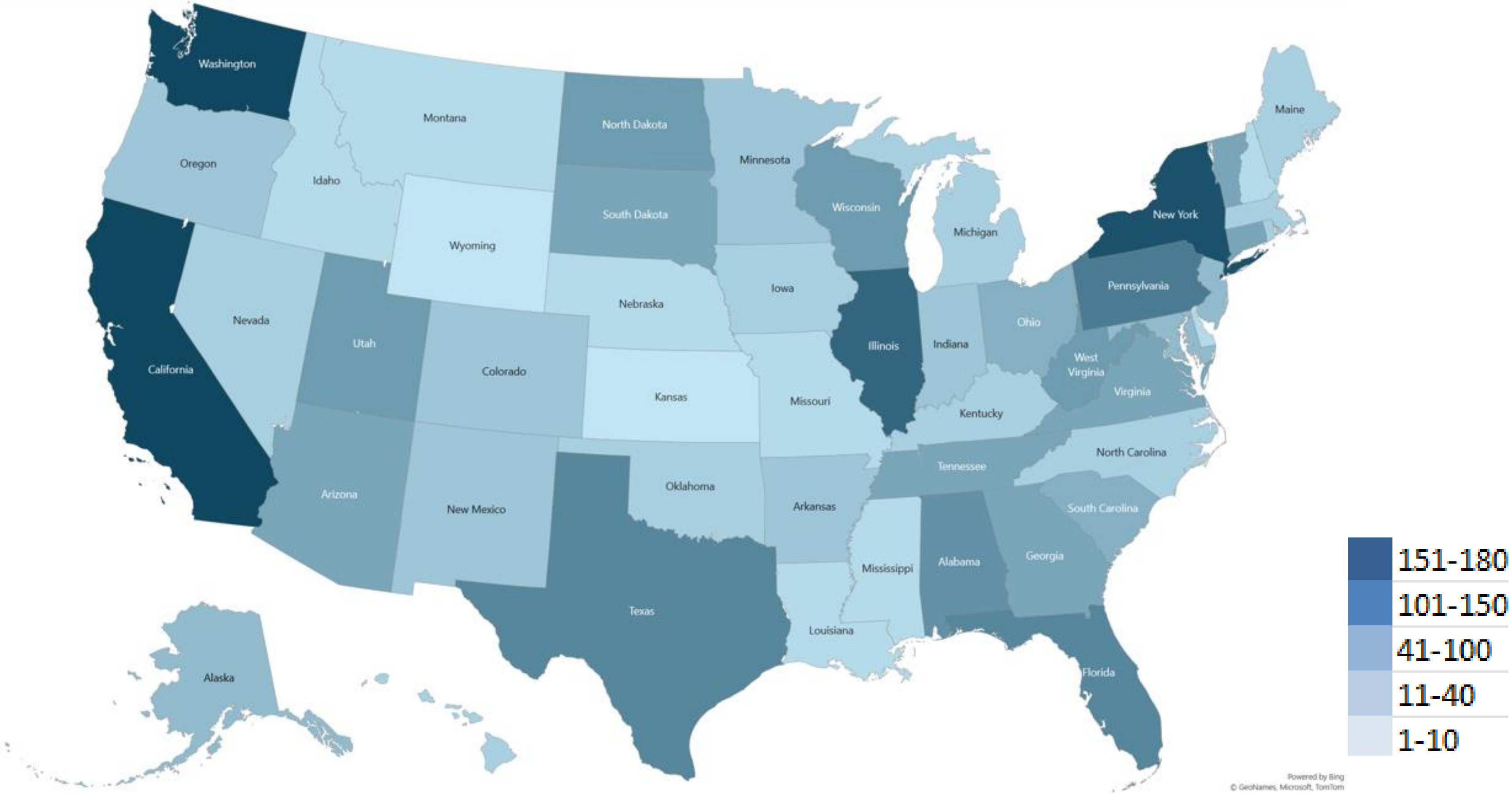

Jenney Lee

- **VRC Membership**
  - **2,105 total members**
  - **1,265 prostate cancer patients/survivors**
  - 857 caregivers
  - 184 other community members
  - **94.4% Black/African American**

- **Research Prioritization:**
  1,200+ responses (~80% of eligible participants)



Distribution of VRC Members/Survey Respondents



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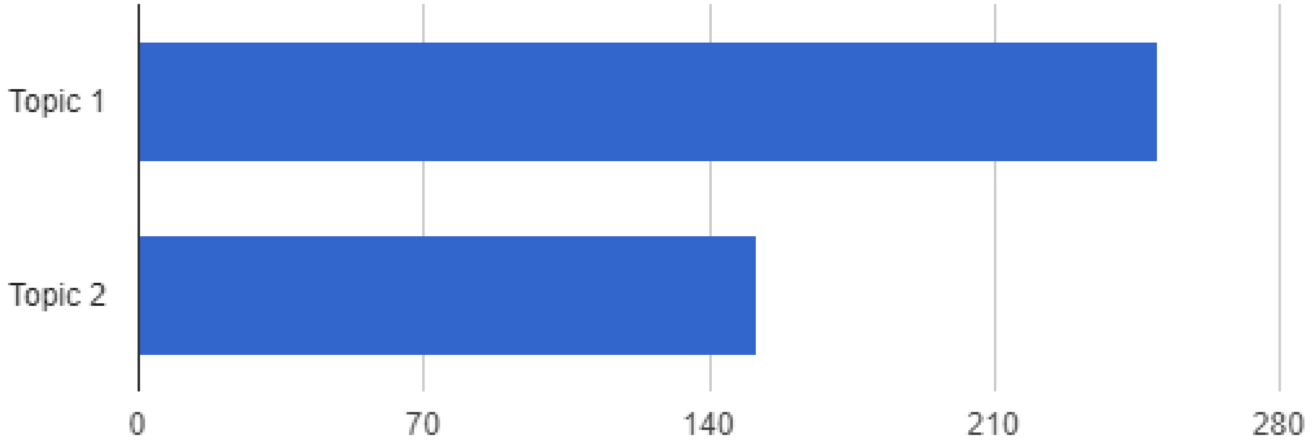
Research Priorities Among BACPAC VRC Respondents (Round 1)

Survey Topic Questions	**Ranked Important and Very Important**
Impact of genetic testing on cancer risk in other family members.	92.8%
Should PSA testing start at a younger age (40-45)	91.8%
Giving financial assistance to increase screening	91.8%
Using MRI to improve screening	91%
Genetic risk, measured by polygenic risk score, to improve screening	90.7%
Customized PSA testing schedule, based on baseline PSA at ages of 40 to 50 (Survival)	90.6%
Impact of one-on-one support from a Black prostate cancer survivor	90.6%
Customized PSA testing schedule, based on a baseline PSA at ages 40 to 50 (Compliance)	90.3%
Using educational materials created by Black patients to improve PSA testing	89%
Using educational materials created by Black patients to improve biopsy compliance	88.8%
Genetic testing (germline testing) program to increase the use of PSA testing	88.3%
Evaluating additional blood tests, in patients with elevated PSA, to improve screening	87.6%
Evaluating additional blood tests, in patients with elevated PSA, to reduce death	86.8%
Using educational materials created by Black patients to improve MRI and PSA adjunct use	85.3%
Genetic risk, measured by polygenic risk score, to reduce over-detection	85.1%

Unpublished date, please do not share

Research Prioritization Survey (Round 2)

Topic 1: The best time for Black individuals to start PSA testing, and how often PSA testing should be done



Topic 2: When PSA levels are elevated, whether using additional tests (for example, urine, blood, or MRI tests) can help distinguish between aggressive and non-aggressive prostate cancers in Black individuals

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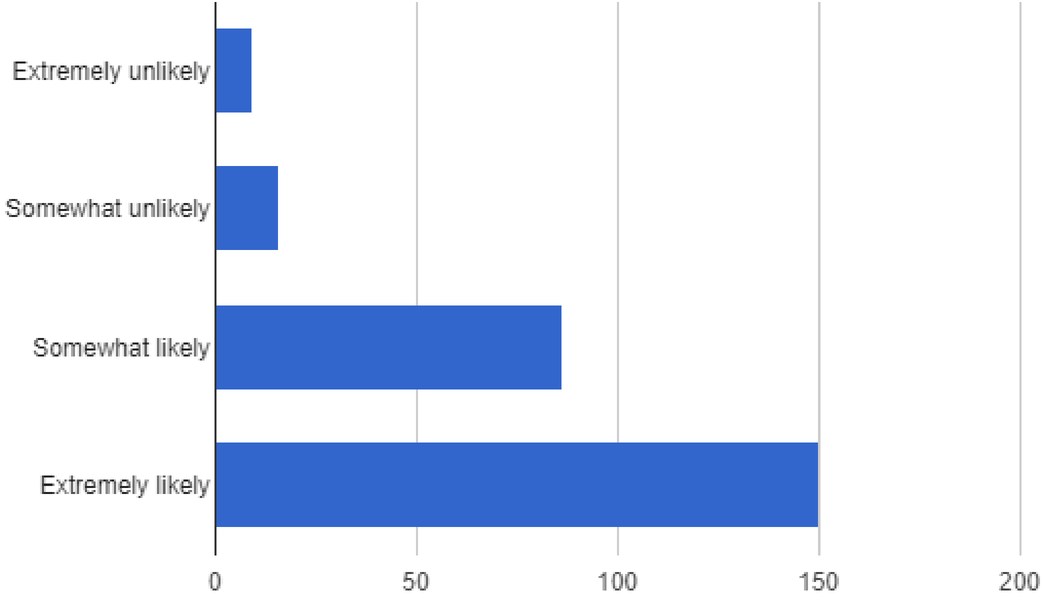
Research Prioritization Survey (Round 2)



Majority of survey respondents willing to be randomized in study addressing early detection in prostate cancer

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Action! How to Influence Policy and Care

Survivor Scientist Research Summit

What Will Our Trial Address?

RANDOMIZED

Focus on different primary endpoint

(compliance, patient reported outcomes)

HELP EVERYBODY

MRI

Younger Screening Population

(40-70 years old)

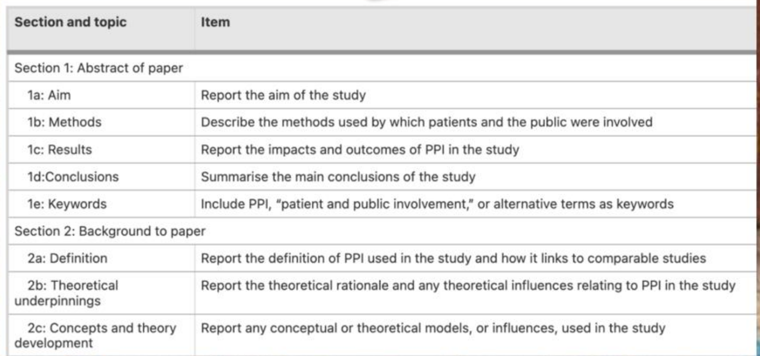
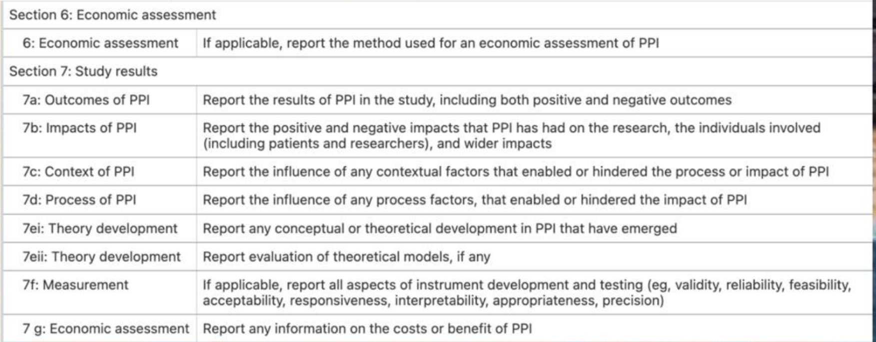
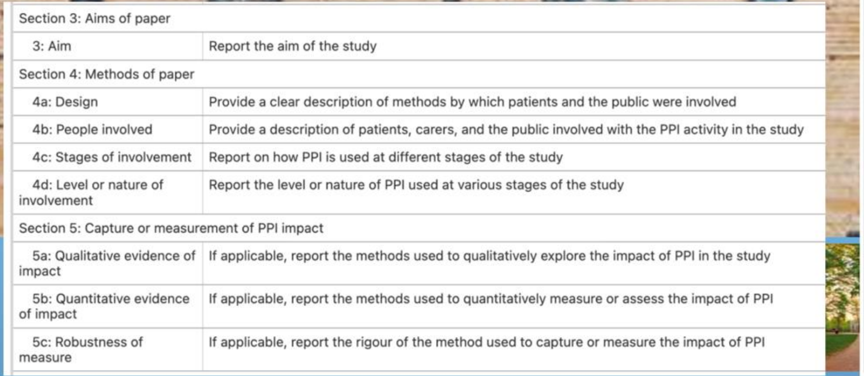
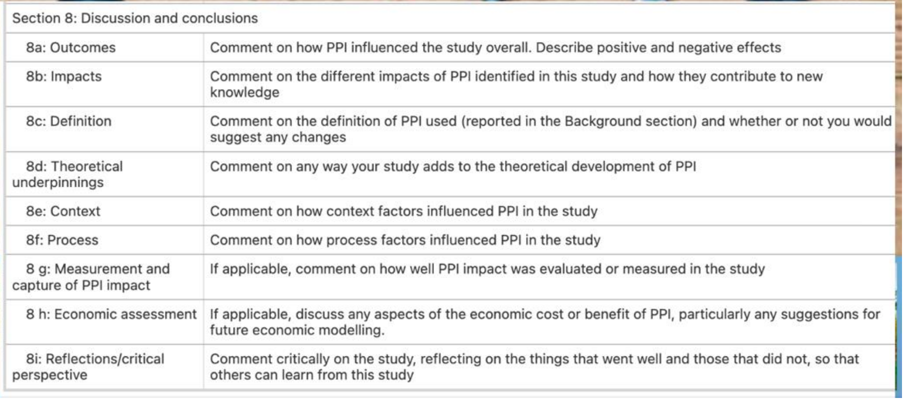
Quick. Final Recommendations.

Use Existing Tools

LONG FORM

GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research

S Staniszewska,[1] J Brett,[2] I Simera,[3] K Seers,[1] C Mockford,[4] S Goodlad,[5] D G Altman,[6] D Moher,[7] R Barber,[8] S Denegri,[9] A Entwistle,[4] P Littlejohns,[10] C Morris,[11] R Suleman,[4] V Thomas,[12] C Tysall[4]

Section and topic	Item
Section 1: Abstract of paper	
1a: Aim	Report the aim of the study
1b: Methods	Describe the methods used by which patients and the public were involved
1c: Results	Report the impacts and outcomes of PPI in the study
1d:Conclusions	Summarise the main conclusions of the study
1e: Keywords	Include PPI, “patient and public involvement,” or alternative terms as keywords
Section 2: Background to paper	
2a: Definition	Report the definition of PPI used in the study and how it links to comparable studies
2b: Theoretical underpinnings	Report the theoretical rationale and any theoretical influences relating to PPI in the study
2c: Concepts and theory development	Report any conceptual or theoretical models, or influences, used in the study
Section 3: Aims of paper	
3: Aim	Report the aim of the study
Section 4: Methods of paper	
4a: Design	Provide a clear description of methods by which patients and the public were involved
4b: People involved	Provide a description of patients, carers, and the public involved with the PPI activity in the study
4c: Stages of involvement	Report on how PPI is used at different stages of the study
4d: Level or nature of involvement	Report the level or nature of PPI used at various stages of the study
Section 5: Capture or measurement of PPI impact	
5a: Qualitative evidence of impact	If applicable, report the methods used to qualitatively explore the impact of PPI in the study
5b: Quantitative evidence of impact	If applicable, report the methods used to quantitatively measure or assess the impact of PPI
5c: Robustness of measure	If applicable, report the rigour of the method used to capture or measure the impact of PPI
Section 6: Economic assessment	
6: Economic assessment	If applicable, report the method used for an economic assessment of PPI
Section 7: Study results	
7a: Outcomes of PPI	Report the results of PPI in the study, including both positive and negative outcomes
7b: Impacts of PPI	Report the positive and negative impacts that PPI has had on the research, the individuals involved (including patients and researchers), and wider impacts
7c: Context of PPI	Report the influence of any contextual factors that enabled or hindered the process or impact of PPI
7d: Process of PPI	Report the influence of any process factors, that enabled or hindered the impact of PPI
7ei: Theory development	Report any conceptual or theoretical development in PPI that have emerged
7eii: Theory development	Report evaluation of theoretical models, if any
7f: Measurement	If applicable, report all aspects of instrument development and testing (eg, validity, reliability, feasibility, acceptability, responsiveness, interpretability, appropriateness, precision)
7 g: Economic assessment	Report any information on the costs or benefit of PPI
Section 8: Discussion and conclusions	
8a: Outcomes	Comment on how PPI influenced the study overall. Describe positive and negative effects
8b: Impacts	Comment on the different impacts of PPI identified in this study and how they contribute to new knowledge
8c: Definition	Comment on the definition of PPI used (reported in the Background section) and whether or not you would suggest any changes
8d: Theoretical underpinnings	Comment on any way your study adds to the theoretical development of PPI
8e: Context	Comment on how context factors influenced PPI in the study
8f: Process	Comment on how process factors influenced PPI in the study
8 g: Measurement and capture of PPI impact	If applicable, comment on how well PPI impact was evaluated or measured in the study
8 h: Economic assessment	If applicable, discuss any aspects of the economic cost or benefit of PPI, particularly any suggestions for future economic modelling.
8i: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so that others can learn from this study

Courtesy of Angie Smith, MD (University of North Carolina – Chapel Hill)

Successfully Engaging Marginalized Communities

CLEARLY DEFINE…

Partner and stakeholder population(s)

Purpose or goal(s)

Compensation

Jones L and Wells K, JAMA, 2007

Things *you* should do?

Recognize Community Experts

Create Engagement Structure

INVITE YOUR PATIENTS TO PARTICIPATE

Invest Time in Educating

Engage at Early in Project

Create shared vision/mission

PAY YOUR PARTNERS

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