



Participatory Health Research: Challenges and Approaches

April 8, 2020



Welcome!

Participatory Health Research: Challenges and Approaches



We'll get started in just a couple of minutes.

Please be advised that there is no dial-in for this webinar; all audio is provided directly through the Adobe Connect platform.

Welcome!

Participatory Health Research: Challenges and Approaches



Dr. Andrea Robles
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Office of Research and Evaluation,
CNCS*

Introductory Remarks

Participatory Health Research: Challenges and Approaches



Dr. Mary Hyde
*Director, Office of Research
and Evaluation, CNCS*



INVOLVING COMMUNITIES, PATIENTS AND STAKEHOLDERS IN RESEARCH

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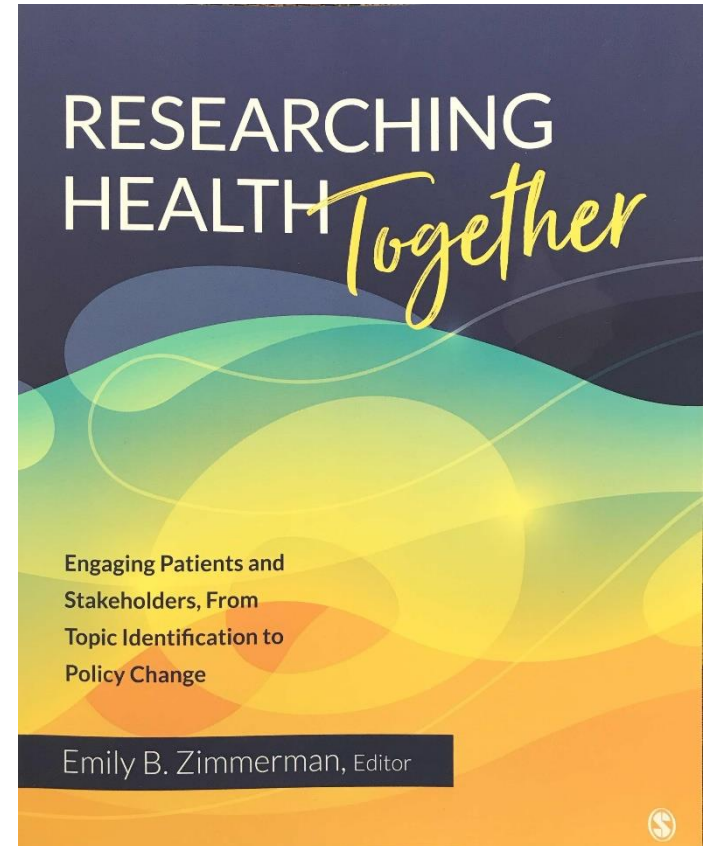


FOCUS ON APPROACHES TO COMMUNITY ENGAGED RESEARCH

*Researching Health Together:
Engaging Patients and Stakeholders, From
Topic Identification to Policy Change*

Edited by: Emily B. Zimmerman

March 2020 | 496 pages | SAGE Publications, Inc.





WHY STAKEHOLDER ENGAGEMENT?

Reduce health disparities

Increase accountability and transparency

Improve

- research relevance
- quality of research and interventions
- sustainability of initiatives
- dissemination of results

Translate research evidence into practice

Increasing research funder emphasis on collaboration

PRINCIPLES OF ENGAGEMENT



A key starting point is committing to principles of community engagement

- Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011.
- Israel, B. A., Eng, E., Schulz, A. J., & Parker, E. A., eds. (2012). *Methods in Community-Based Participatory Research for Health, 2nd Ed.* San Francisco, CA: Jossey-Bass.
- <https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>.



CHALLENGES

Relationship building

- Low levels of trust
- Poor historical relations
- Tokenism
- Representation
- Power differentials

Implementation

- Cultural differences
- Geographic separation
- Deadlines
- Participant retention
- Time and resource demands

Infrastructure

- Equity (e.g., sharing resources)
- Providing evidence of impact
- Financial sustainability
- Ongoing infrastructure support

PROJECT GOALS

Develop

- Identify community concerns and research priorities
- Develop and prioritize research questions/topics
- Identify outcomes and metrics (patient-centered outcomes)

Implement

- Improve understanding of health and health care
- Investigate and address social determinants of health
- Develop and test interventions and technologies
- Implement programs

Share

- Translate health messages/guidelines (e.g., Boot Camp Translation)
- Promote policy change
- Evaluation

PARTNERS

Individuals

- University faculty, students
- Community members
- Patients and caregivers
- Local leaders
- Professionals/ service providers
- Policymakers

Organizations

- Health practices
- Community organizations
- Advocacy organizations
- National associations
- Research centers

Systems

- Health systems and payors
- Public agencies

APPROACHES

Team approaches

- Community-based participatory research (CBPR)
- Shared leadership (research co-PIs and co-investigators)
- Committees (leadership, executive, steering)
- Advisory groups, boards, councils
- Project workgroups
- Expert (or national) advisory committees

Network/coalition approaches

- Research networks (e.g., patient-powered research networks)
- Practice-based research networks (PBRNs)
- Collective Impact initiatives

WAYS TO ENGAGE STAKEHOLDERS

Sharing ideas

- In-home meetings
- Town halls and forums
- Community events

Gathering data

- Community-led data collection
- Focus groups, interviews
- Photovoice
- Mapping/sharing data
- Digital storytelling

Developing strategies

- Deliberative methods
- Group model building and participatory modeling
- Community engagement studios, community review boards

CAPACITY BUILDING



Opportunities to learn about the community history and culture

Research training

Board member development

Training in specific skills (e.g., facilitation)

Advocacy training

Learning collaboratives



FACILITATORS

People

- Diverse participants
- Multi-stakeholder engagement
- Boundary spanner or 'navigator' to connect partners
- Employing community members

Processes

- Managing power differences (e.g., creating groups)
- Facilitation
- Stakeholder governance
- Aligning missions across stakeholder groups

Infrastructure

- Community review (e.g., community engagement studio)
- Engage long-term coalitions/backbone organizations
- Engage community-based fiscal sponsor
- Institutional support

LESSONS LEARNED

Relationships

- Develop more relationships
- Engage a well-known, trusted community lead
- Obtain input from stakeholders as early as possible
- Learn more about the local community

Processes

- Address history and trauma
- Commit to sharing resources and power
- Set realistic expectations
- Provide opportunities for co-learning
- Regular meetings, 'check-ins' and updates

Sustainability

- Shift leadership for sustainability, focus on leadership development
- Support is needed for administrative infrastructure



SEED METHOD FOR QUESTION DEVELOPMENT AND PRIORITIZATION

A multi-stakeholder engagement method that combines participatory concept modeling and question development to address a health issue of significance to the community

Brings together diverse local stakeholders to:

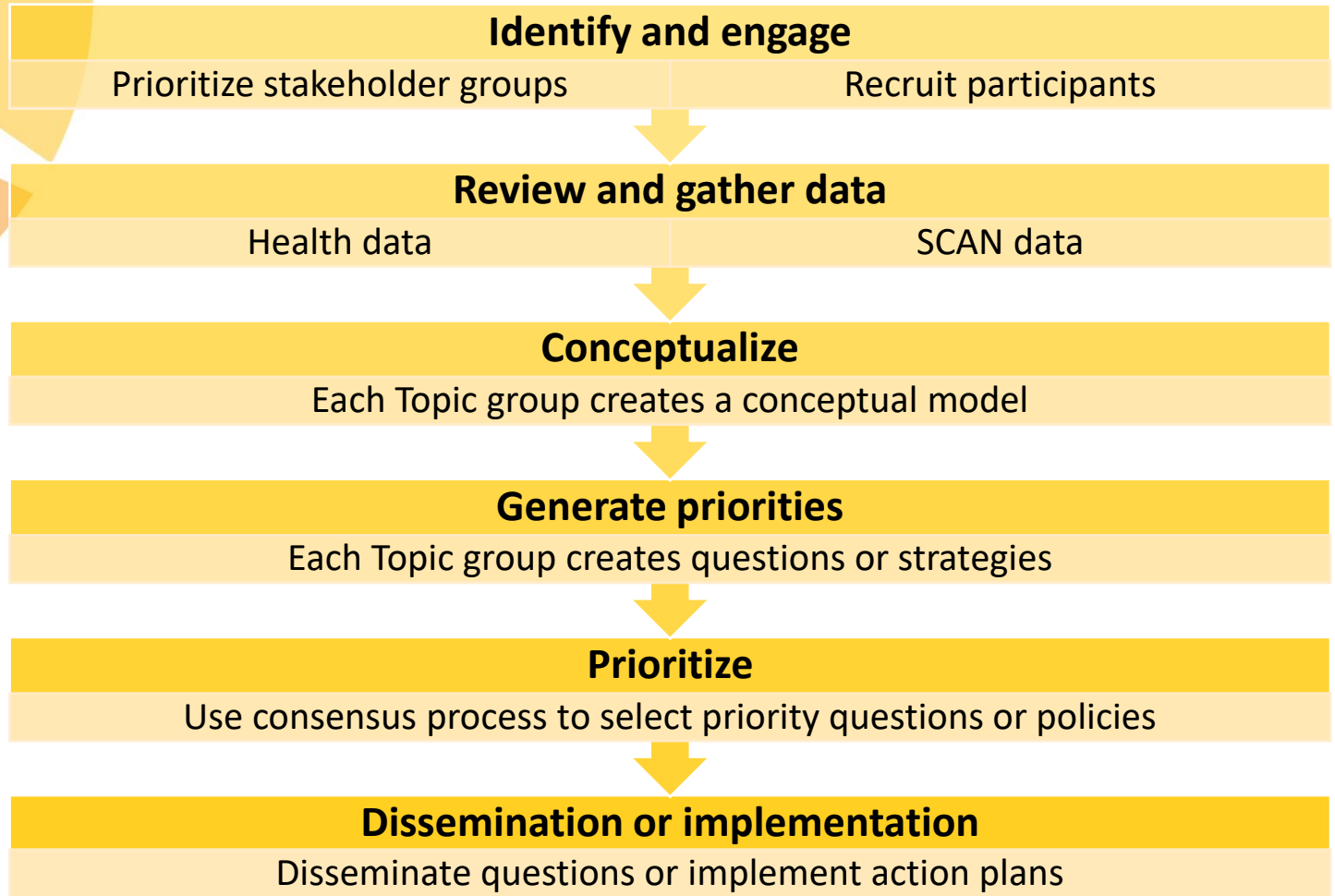
Explore potential causal factors

Develop and prioritize research questions or action planning strategies

Types of Engagement in the SEED Method

Type	Level of engagement	Description	Example: Richmond demonstration on diabetes and hypertension
Research team	Collaborative	CBPR team that leads the project	Community and academic partners on research team
Topic groups	Consensus	Diverse stakeholders engaged based on experience and knowledge. Create conceptual models, and research questions	3 Topic groups (seniors, adults with low health care access, service providers). Created 91 research questions in all, prioritized 19
SCAN	Consulting	Provide additional perspective through focus groups/interviews	5 focus groups and 11 interviews

SEED METHOD STEPS



SEED METHOD TOOLS

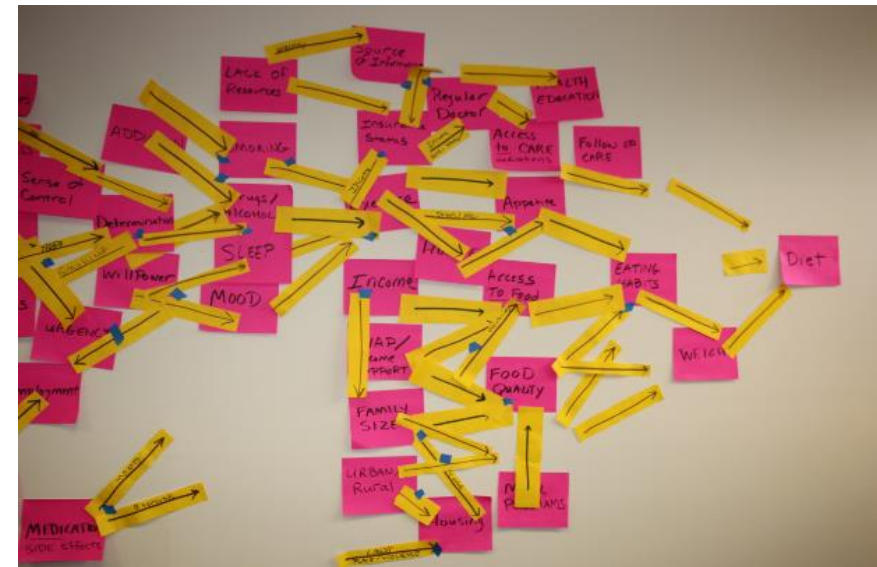
Matrices to identify stakeholders for Topic groups

Facilitation guides for Topic group activities:

- Participatory conceptual modeling
- Question development
- Prioritization

Toolkit

<https://societyhealth.vcu.edu/work/the-projects/the-seed-method-for-stakeholder-engagement.html>



SEED EXAMPLE: OPIOID PROJECT

CNCS 2018 Community Conversations Research Grantee
Virginia Tech and VCU

- 2-year shared experience between community partners and stakeholders to address the opioid crisis in a rural area with one of the highest opioid prescription rates in the U.S.
- Generate stakeholder priorities, including questions, strategies, and policies.
- Facilitate development of action plans and support implementation

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 **VirginiaTech**
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OPIOID PROJECT: STAKEHOLDER PARTICIPANTS

Participatory Research team

- 2 faculty
- 1 graduate assistant
- 6 community members

Topic groups

- Community
- Service providers
- Health providers

SCAN participants

- 4 focus groups (community, policy, treatment, recovery)

OPIOID PROJECT: RESULTS

STRATEGIES

- 68 proposed strategies
- 15 prioritized strategies

COMMUNITY STAKEHOLDER MEETINGS

- 2 Community stakeholder meetings
- Selected 5 high priority strategies

WORK GROUPS

- 4 work groups
 - Establish drug court
 - Establish detox center
 - Raise awareness
 - Prevention education

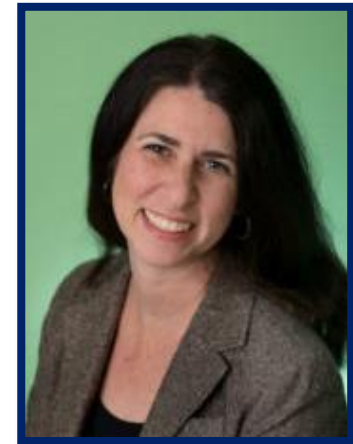
The background of the slide is a vibrant yellow color. Overlaid on this background is a network diagram consisting of several yellow circles of varying sizes connected by thin yellow lines. The circles are arranged in a way that suggests a complex, interconnected network or social structure. The lines connect the circles in a non-linear fashion, creating a web-like pattern.

Thank you!

Sí Texas Partnership-Centered Evaluation



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Lisa Wolff, ScD,
Vice President,
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Sí Texas: Social Innovation for a Healthy South Texas



Health Resources in Action
Advancing Public Health and Medical Research

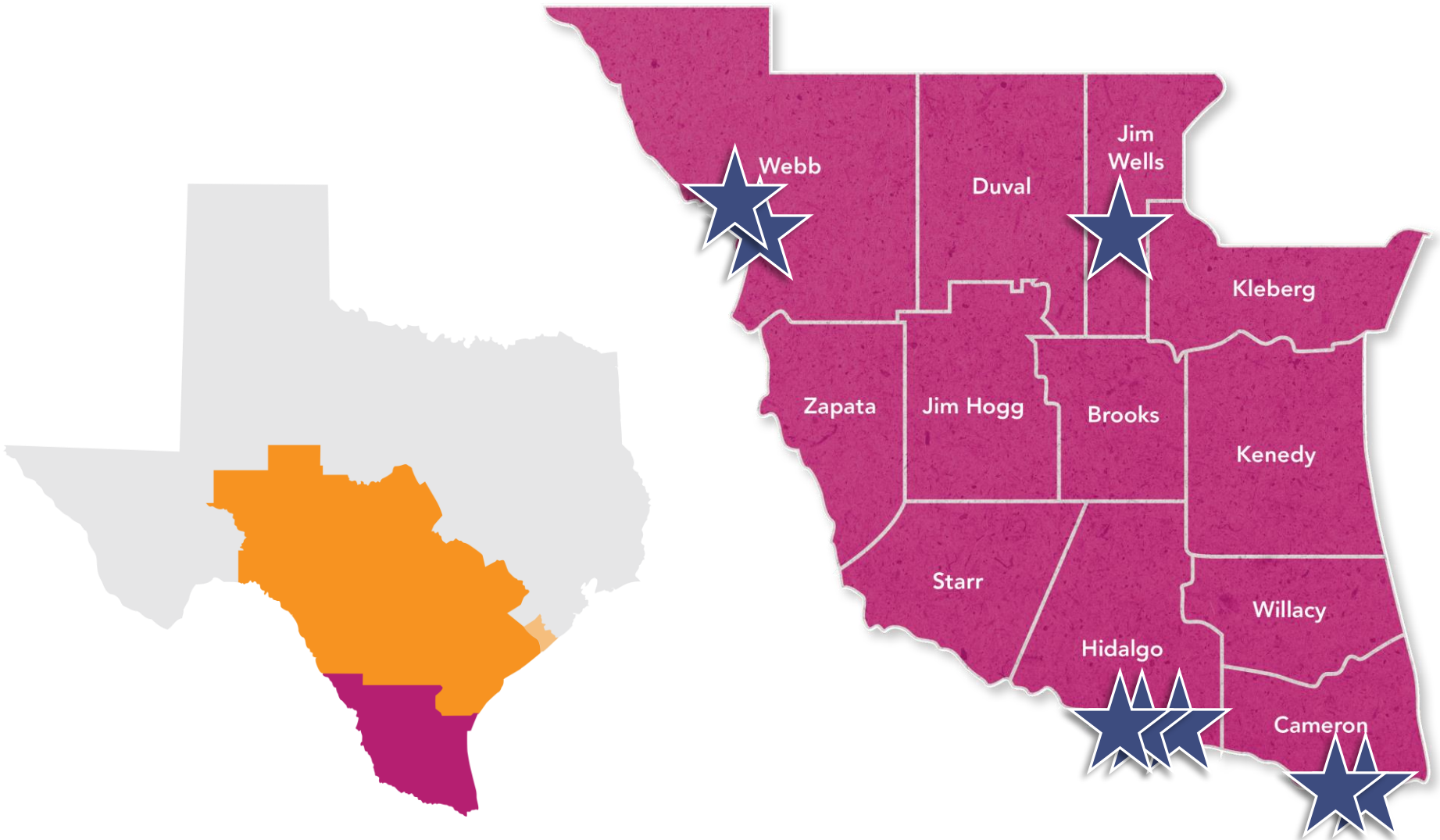


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Sí Texas Focus Area



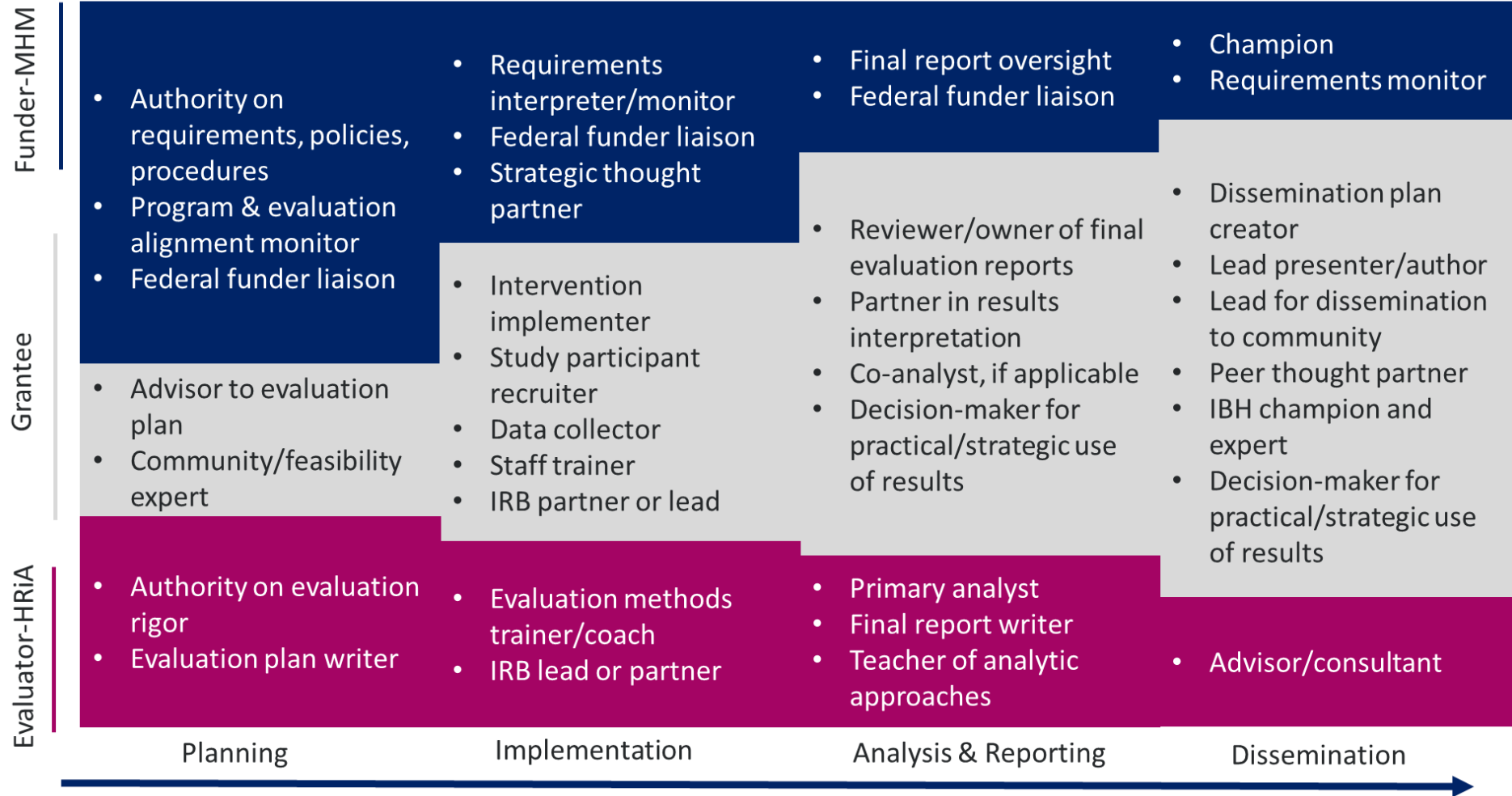
Evaluation Overview

8 Distinct Grantee-Level Evaluation Studies

- 4 randomized control trials, 4 quasi-experimental designs

1 Overall Portfolio-Level Evaluation Study

Sí Texas Partnership-Centered Approach to Evaluation*



*Brodesky M.K., Errichetti K., Ramirez M.M., Martinez-Gomez S.J.V., Tapia S., Wolff L., Davis M.V. (2020). Collaborating to evaluate: The Sí Texas partnership-centered evaluation model. In E. B. Zimmerman (Ed.), *Researching health together: Engaging patients and stakeholders in health research from topic identification to policy change*. Thousand Oaks, CA: SAGE Publishing.

Evaluation Consideration: Standardization versus Customization

Consistent across grantee evaluations:

- 5 common outcomes
(identified through consensus building session among grantees)
- Level of rigor (RCT or QED)
- Type of analysis

What was customized:

- Participant eligibility criteria
- Protocols for data collection
- Patient characteristic information collected
- Additional outcome measures (e.g., anxiety, cholesterol)

Evaluation Consideration: Capacity Building

- Intensive multi-year Evaluation Learning Collaborative & Technical Assistance
 - Quarterly in-person full-day evaluation training sessions for full cohort
 - Virtual and in-person topical “mini-courses” with small groups
 - Individualized TA with evaluator team across project period
- Range of methods
 - Peer sharing & coaching, didactic, role-playing, hands-on activities, games, small group work, etc.



Lessons Learned

- **Navigating dynamics** is complex and constantly fluid. Consider ways to build trust early on.
- Clear and regular **communication** is essential and should be tailored, but **consistency in messaging** is critical.
- Important to **recognize what we don't know** and that there is **expertise** among all involved.
- **Capacity-building** can provide the foundation for collaboration and can happen in all directions. We need to embrace the end goal of trying to work our way out of a job.

Thank you!

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To learn more about Sí Texas: www.mhm.org/sitexas

Evaluation Reports: [CNCS Evidence Exchange](#)

HRiA: www.hria.org

Closing Remarks

Participatory Health Research: Challenges and Approaches



Dr. Kayla Cranston
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Director of Conservation Psychology
Strategy and Integration at Antioch University*

Q&A

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Questions?

Dr. Melissa Gouge
*Research Analyst, Office of
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