Strategies and Models for Community-Based Participatory Research

West Virginia School of Osteopathic Medicine
Center for Rural and Community Health
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Objectives

- Better understand community-based and participatory research and how it differs from traditional research.

- Learn more about the importance of community-building and engagement as preparatory and foundational to research.

- Learn how to build capacity and infrastructure for community-based research and engagement.

Agenda

- Introduction
  - WVSOM's Center for Rural and Community Health

- Community-Based Participatory Research (CBPR)
- Rural Response Grant
  - Community building as preparatory to research

- Greenbrier County Health Alliance (GCHA)
  - Community engagement strategies, impacts & foundations for research

- Patient-Centered Outcomes Research (PCOR) & Next steps

WVSOM - CRCH

OUR MISSION

The WVSOM Center for Rural and Community Health (CRCH) supports the osteopathic medical education focus on team-based and patient-centered care and the integration of prevention and population health to improve quality and efficiency of health care delivery.

OUR VISION

To develop program, collaborations, and resources that promote health, support research, and provide education and outreach to rural communities, students, providers, and practices across West Virginia.

OUR VALUES

Teamwork

Dependability

Trust

Integrity

Respect

Collaboration

Community Service

Creativity

Innovation
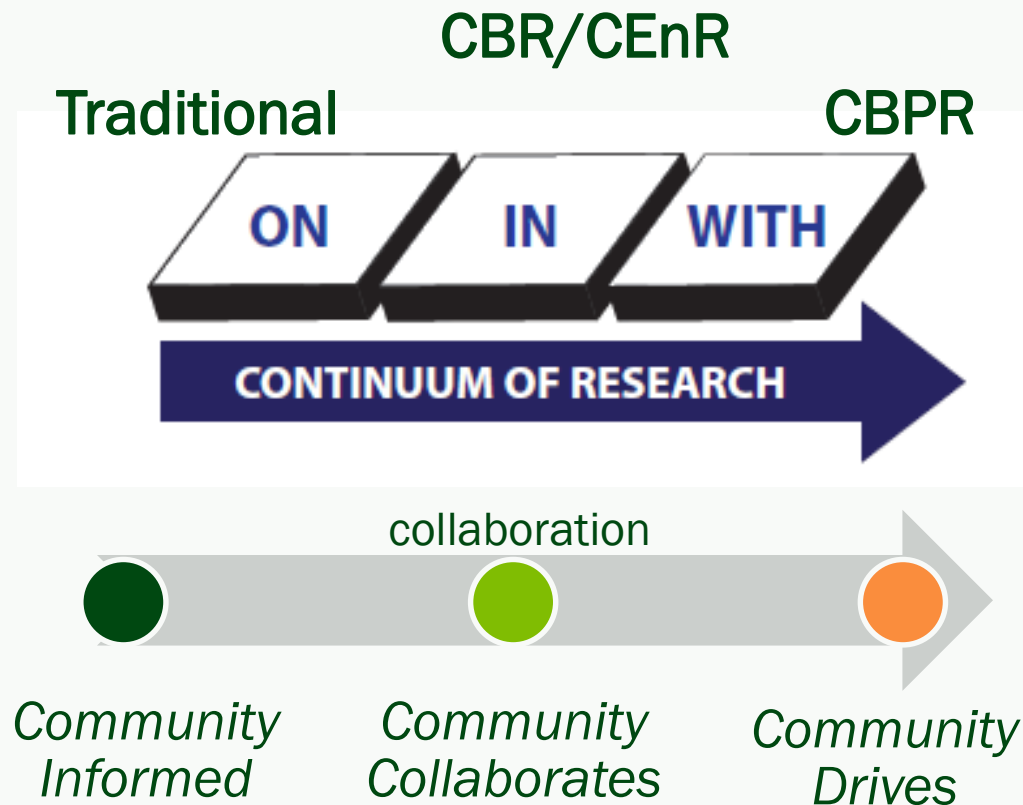
Responsiveness

Commitment to Excellence

Community-Based Participatory Research (CBPR)

- A collaborative approach to research that equitably involves all partners in the research process, sharing decision-making and responsibility and recognizing the unique strengths and expertise that each contributes. CBPR begins with a research topic of importance to the community and aims to combine knowledge with action to achieve social change to improve health outcomes and eliminate health disparities. *(paraphrased: W.K. Kellogg Foundation/Israel et al, 1998)*

- A transformative research paradigm giving underserved communities a genuine voice to bridge the gap between science and practice through community engagement and social action to increase the likelihood of interventional and translational success. *(paraphrased: Wallerstein and Duran, 2010)*

Community Research Continuum

CBR/CEnR

Traditional   CBPR

ON   IN   WITH

CONTINUUM OF RESEARCH

collaboration

Community Informed   *Community Collaborates*   *Community Drives*

Nothing about us without us.

Research Approach

	Traditional Research	Community-engaged Research	
		Research with Community	Community-based Participatory Research
Research Objective	Researchers define the issues based on epidemiologic data and funding priorities	Community participates in defining research questions that are relevant to their local needs and experience	Community identifies research issues or works with researchers to define and prioritize research goals (increased focus on community strengths) and are involve as part of the funding process
Study Design	Researchers base design on scientific rigor and feasibility	Researchers work with community to develop culturally appropriate and feasible study design	Researchers communicate the need for specific study design approaches and work closely with the community to design acceptable approaches that will be feasible and provide quality information including type (qualitative or quantitative methods)
Recruitment and Retention	Based on scientific issues and "best guesses" regarding how to best reach community members	Research consults community representatives on strategies to recruit and retain participants	Community representatives provide guidance on best way to reach intended study participants and keep them involved in the study
Instrument Design	Instruments are adopted and adapted from other studies based on psychometric analytic measures	Community members involved in some aspects of data collection	Community members contribute to instrument design including development and pilot testing prior to beginning formal research, increasing likelihood of validity and reliability

Research Approach (continued)

	Traditional Research	Community-engaged Research	
		Research with Community	Community-based Participatory Research
Data Collection	Conducted by academic researchers who have no connection to the community	Community members involved in some aspects of data collection	Conducted BY members of the community, to the extent possible based on available skill sets. Researchers and community members work together to help build community capacity
Analysis and Interpretation	Researchers "own" the data, control the analytic process, resources, and data interpretation	Researchers retain primary "ownership" of the data and analysis, but rely on community members to assist with interpretation	Data ownership is shared. Community and research partners work together to interpret results
Dissemination	Results published in peer-reviewed academic journals and presented at professional conferences by researchers	Results jointly disseminated in community and academic venues and may contribute to publications and presentations	Community member help researchers to decide appropriate venues and mediums to disseminate results in a timely manner, and are included as co-authors

Principles of CBPR

Recognizes community as a unit of identity

Builds on strengths and resources within the community

Facilitates collaborative partnerships in all phases of the research

Integrates knowledge and action for mutual benefit of all partners

Promotes a co-learning and empowering process that attends to social inequalities

Involves a cyclical and incremental process

Addresses health from both positive and ecological perspectives

Disseminates findings and knowledge gained to all partners

Involves a long-term commitment

Values = TRUST, respect, self-determination, sovereignty, empowerment, reciprocity
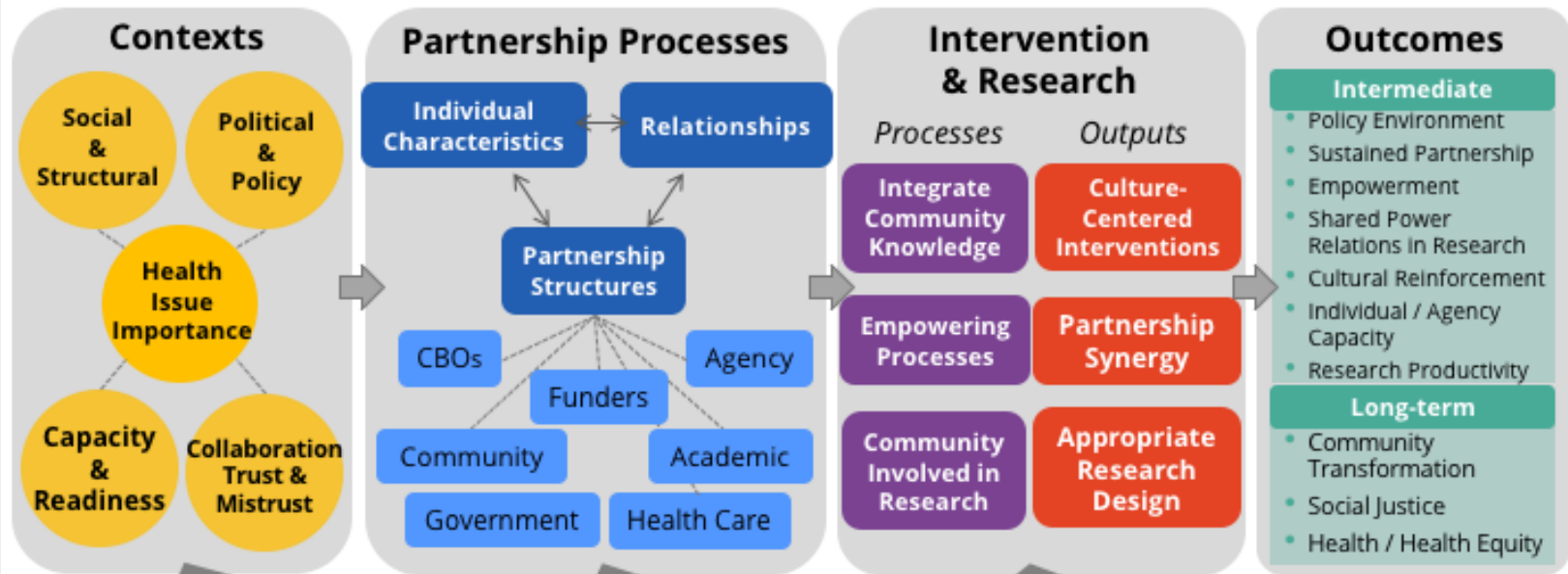
(Principles should also be partnership-defined!)

Principles of CBPR

CBPR Conceptual Model (2017)

CBPR Conceptual Model

Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2010, https://cpr.unm.edu/research-projects/cbpr-project/cbpr-model.html

Contexts
- Social & Structural
- Political & Policy
- Health Issue Importance
- Capacity & Readiness
- Collaboration Trust & Mistrust

Partnership Processes
- Individual Characteristics
- Relationships
- Partnership Structures
- CBOs
- Agency
- Funders
- Community
- Academic
- Government
- Health Care

Intervention & Research

Processes
- Integrate Community Knowledge
- Empowering Processes
- Community Involved in Research

Outputs
- Culture-Centered Interventions
- Partnership Synergy
- Appropriate Research Design

Outcomes

Intermediate
- Policy Environment
- Sustained Partnership
- Empowerment
- Shared Power Relations in Research
- Cultural Reinforcement
- Individual / Agency Capacity
- Research Productivity

Long-term
- Community Transformation
- Social Justice
- Health / Health Equity

Visual from amoshealth.org 2017
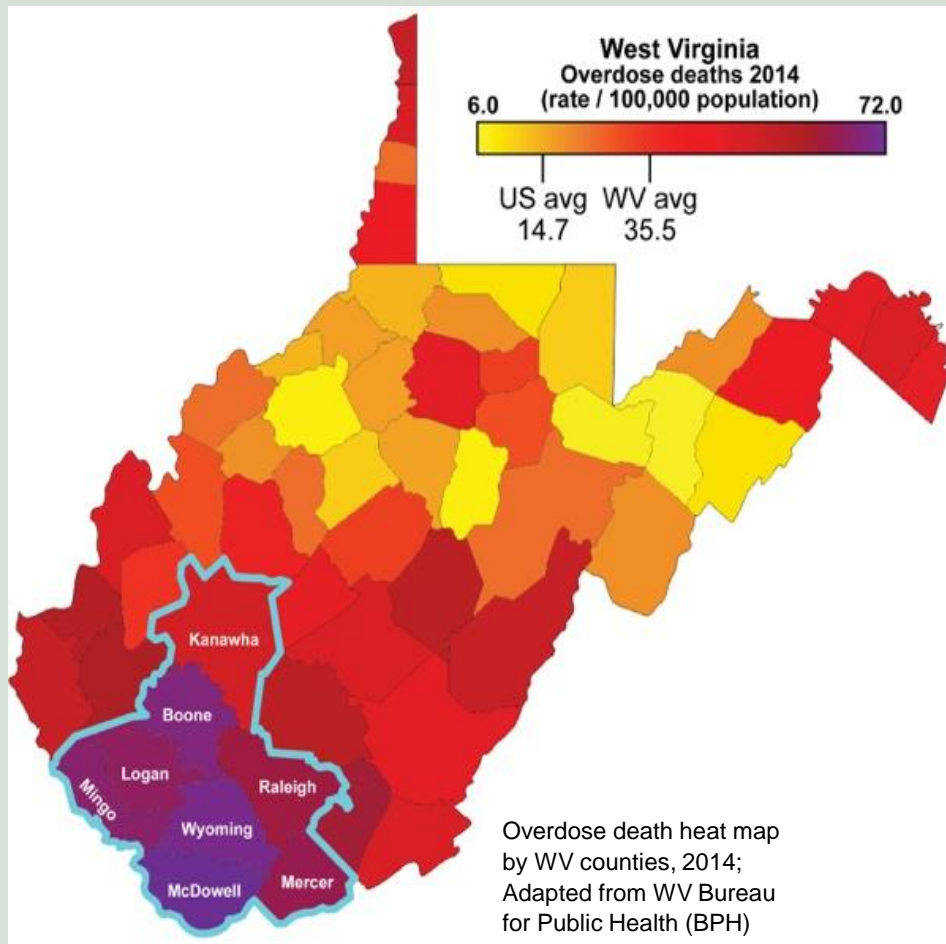
CBPR – so what?

- Pros
  - Subjectivity!
  - Community priority
  - Research relevance, application,
  - Enrich quality, validity, sensitivity
  - Diverse expertise for complex problems
  - Utilize existing systems and resources
  - Overcome distrust, bridge divides
  - Enhance agency, capacity, health & wellbeing

- Cons
  - Subjectivity!
  - Community self-defined
  - IRB issues
  - Macro approach & Global outcomes
  - Deficient assessment & evaluation
  - Accountability
  - Ends vs. means
  - Time!

Example - Opioid Related NIH/NIDA Partnership Grant

West Virginia
Overdose deaths 2014
(rate / 100,000 population)
6.0 ———————————————— 72.0

US avg WV avg
14.7   35.5

Overdose death heat map by WV counties, 2014; Adapted from WV Bureau for Public Health (BPH)

Table 1. Eight WV Counties		
Southern WV County	**CDC Rank**	**2014 Pop.**
McDowell	2	20,448
Mingo	7	25,716
Wyoming	16	22,598
Raleigh	18	78,241
Logan	20	35,348
Boone	22	23,714
Mercer	147	61,785
Kanawha	209	190,223

Engage the Community - Community Forums

Organize the Community - Community Workgroups

Trust Community Members' Ideas

FREE Family Fun Day

Sponsored by:
- Amazing Grace Fellowship
- Aversons Auto Repair
- Mountaineer Drug Pharmacy
- Water Valve Services
- Brent Wells
- Community Connections

Create Sustainable Programs
Boone Opioid Network

https://www.facebook.com/booneopioidnetwork/

Recovery Coach Academy©
SOLD OUT
Transformed People...

Boone Recovery Coach Academy

by David Sanders

📅 DATE AND TIME

Mon, Mar 26, 2018, 8:30 AM –
Fri, Mar 30, 2018, 4:30 PM EDT

📍 LOCATION

Madison Baptist Church
426 2nd St
Madison, WV 25130

LOGANBANNER.COM
Recovery Roads: Woman celebrates 18 months clean

RECOVERY PEERS

THURSDAYS 6pm WHARTON COMMUNITY CENTER

BLACK BALLOON DAY 2018
March 6, 2016

Raise Awareness
Reduce Stigma
Families are Affected Too
Entire Communities Affected

2nd Annual #BLACKBALLOONDAY
Raising Awareness
to the effects of
DRUG ADDICTION
#BooneHEARTS

Community Engagement Creates Potential for Community Research

http://www.greenbriercountyhealthalliance.org/

Partnership for Community Engagement

- West Virginia School of Osteopathic Medicine/Center for Rural and Community Health

- WVCTSI Community Engagement and Outreach Core

- Greenbrier County local service providers
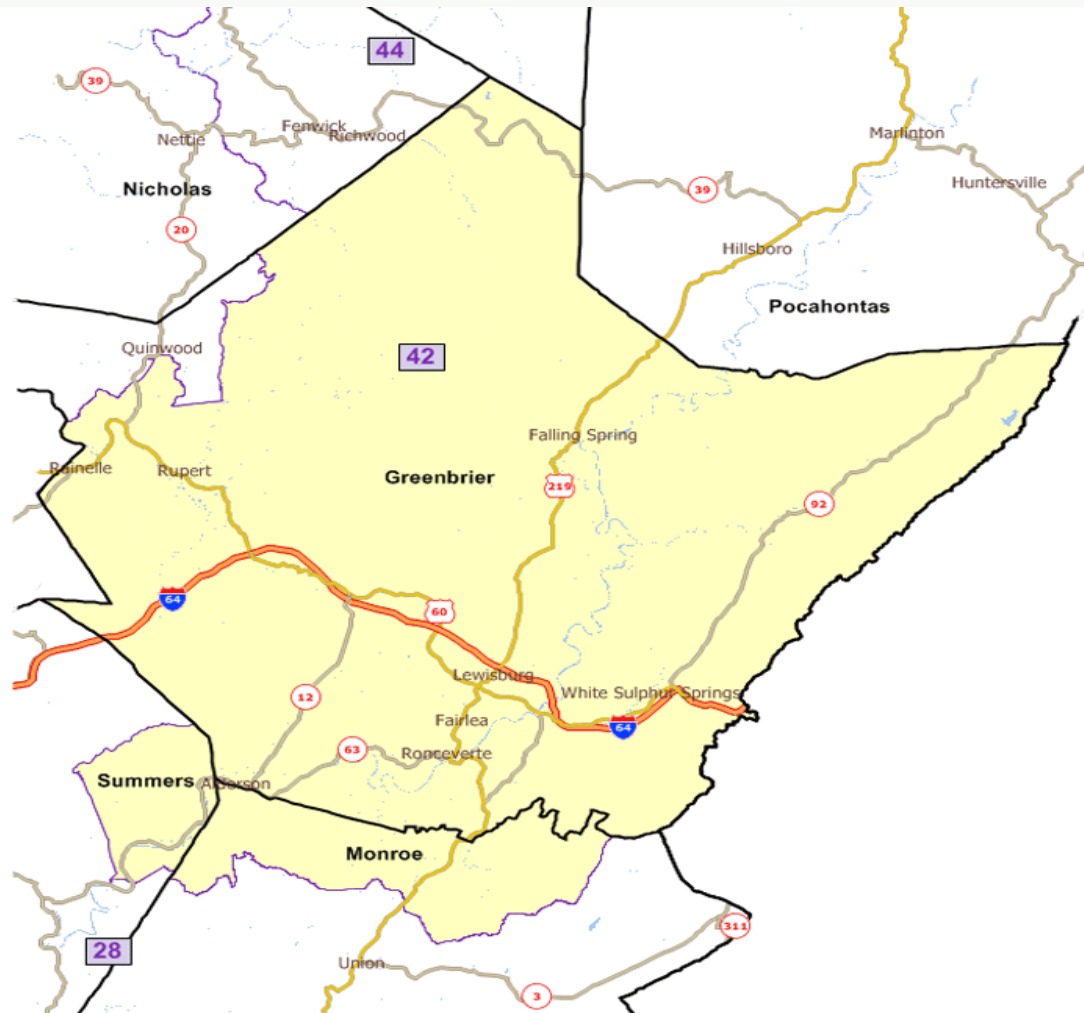
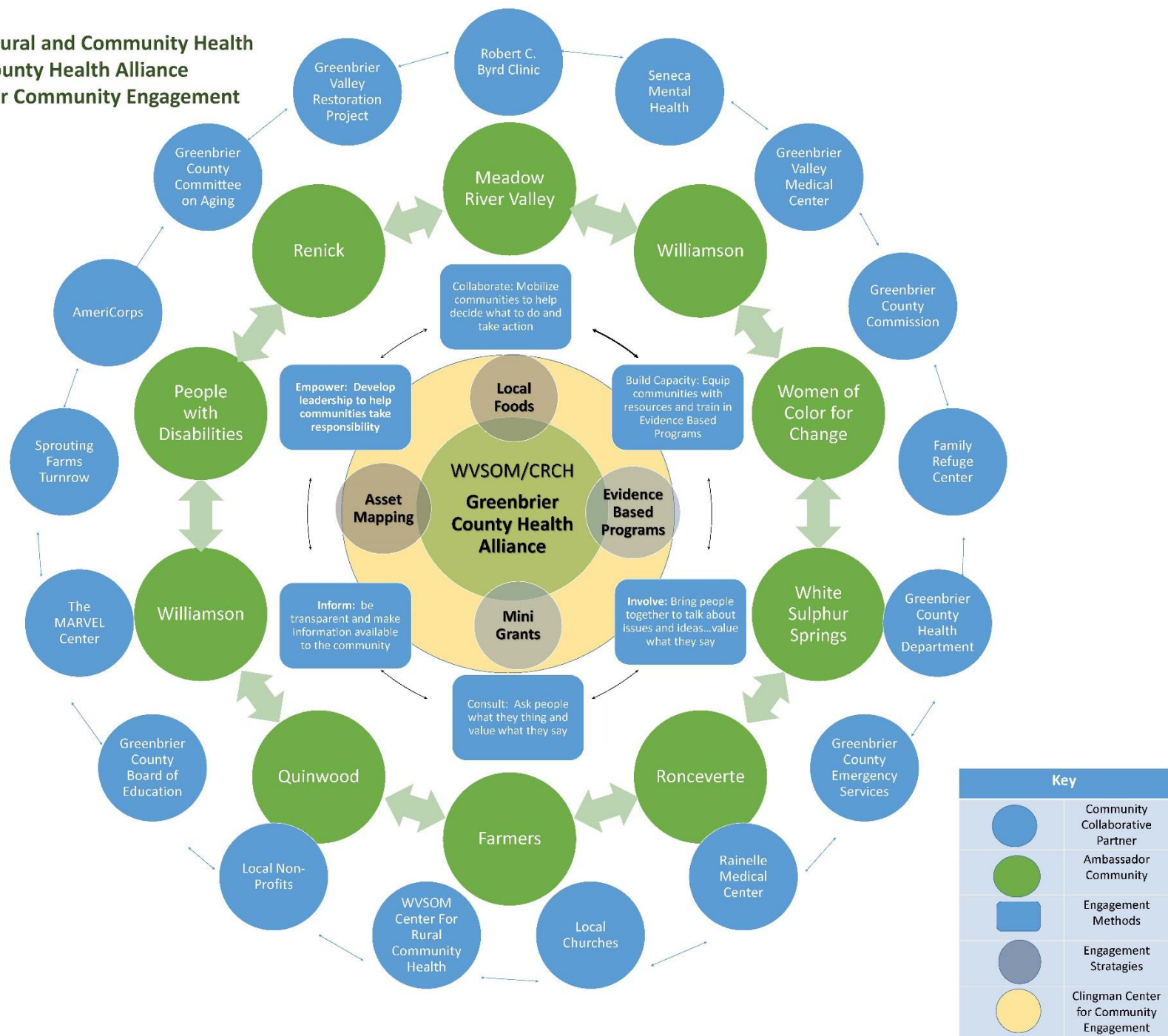- Grassroots community leaders

Maintain Focus on 4 Community Engagement Strategies

- Community Ambassadors

- Mapping of Assets

- Evidence Based Programs

- Local Foods to Meet Local Need

What has happened...?

WVSOM Center for Rural and Community Health
Greenbrier County Health Alliance
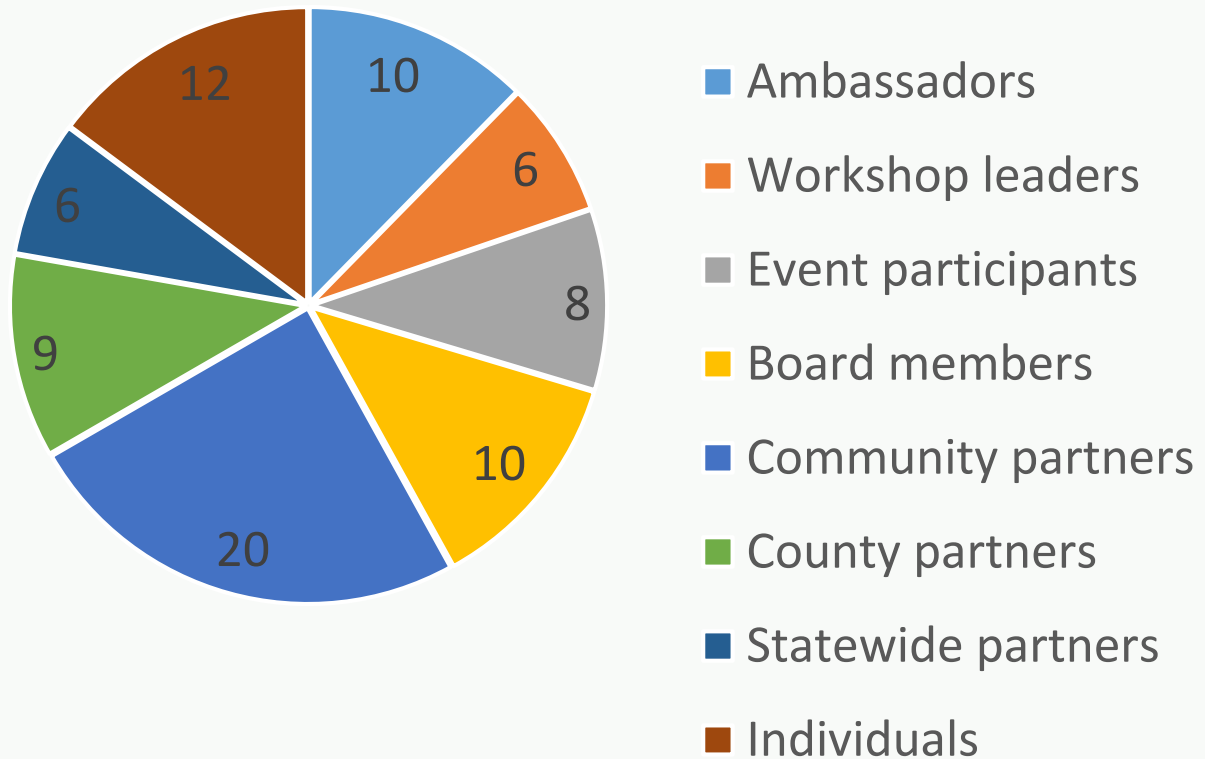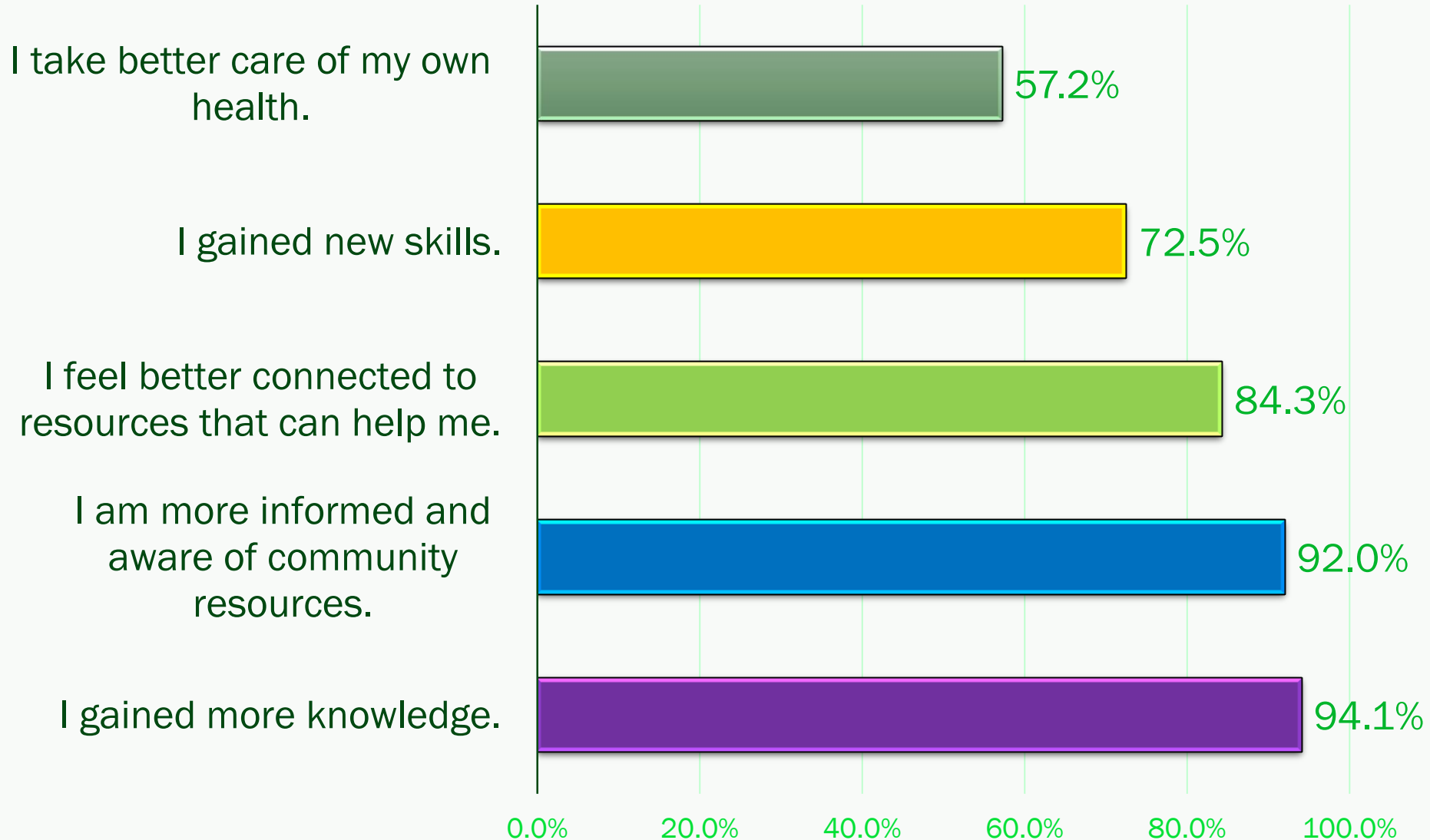**Clingman Center For Community Engagement**

Robert C. Byrd Clinic

Greenbrier Valley Restoration Project

Seneca Mental Health

Greenbrier County Committee on Aging

Greenbrier Valley Medical Center

Meadow River Valley

Renick

Williamson

AmeriCorps

Greenbrier County Commission

People with Disabilities

Collaborate: Mobilize communities to help decide what to do and take action

Build Capacity: Equip communities with resources and train in Evidence Based Programs

Women of Color for Change

Sprouting Farms Turnrow

Empower: Develop leadership to help communities take responsibility

Local Foods

Family Refuge Center

The MARVEL Center

Williamson

WVSOM/CRCH
Greenbrier County Health Alliance

Asset Mapping

Evidence Based Programs

White Sulphur Springs

Inform: be transparent and make information available to the community

Mini Grants

Involve: Bring people together to talk about issues and ideas...value what they say

Greenbrier County Health Department

Greenbrier County Board of Education

Consult: Ask people what they thing and value what they say

Greenbrier County Emergency Services

Quinwood

Ronceverte

Local Non-Profits

Farmers

WVSOM Center For Rural Community Health

Local Churches

Rainelle Medical Center

Key

Community Collaborative Partner

Ambassador Community

Engagement Methods

Engagement Stratagies

Clingman Center for Community Engagement

Partnerships have created trust...

GCHA Engagement Survey (summer 2018)

Survey Participants
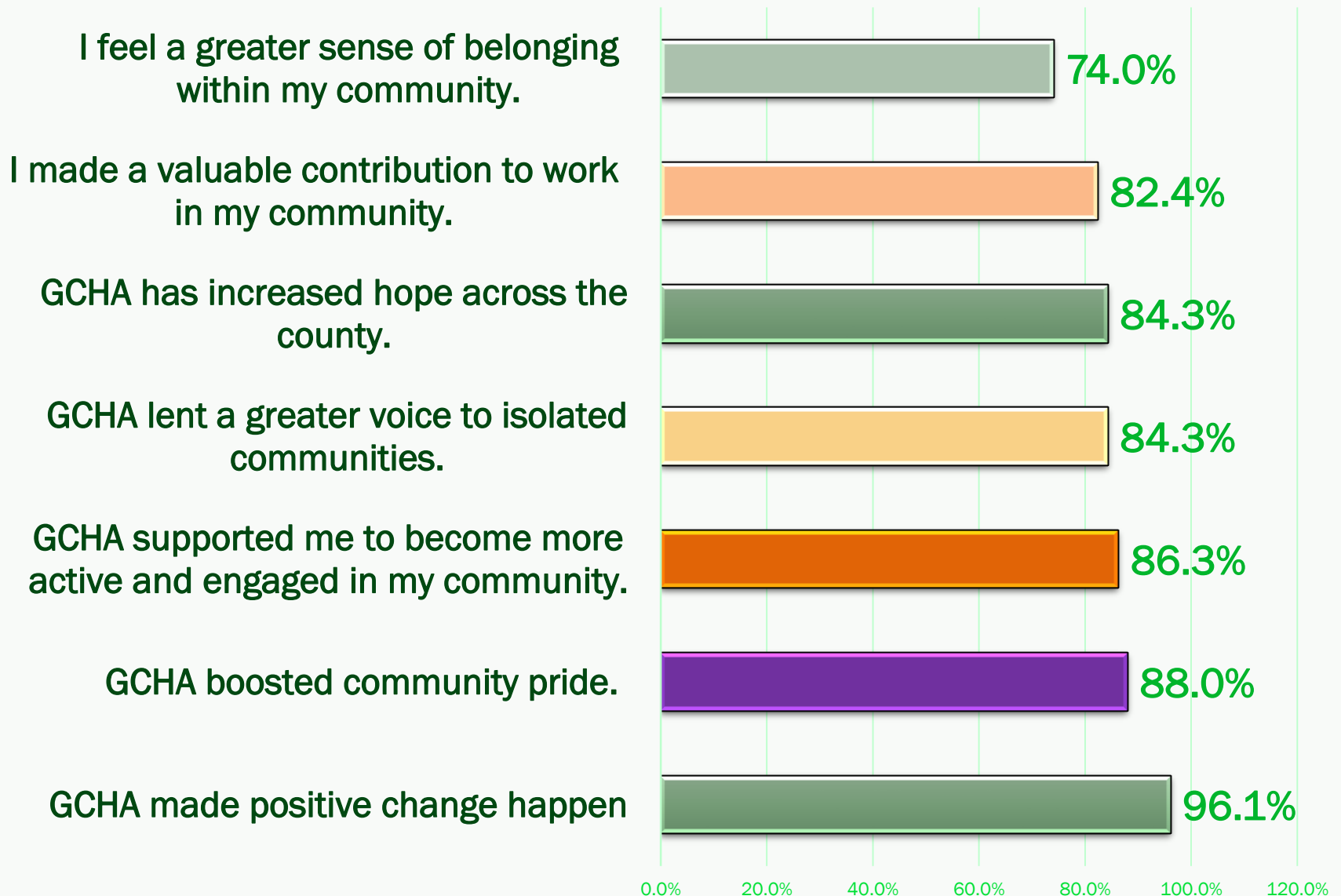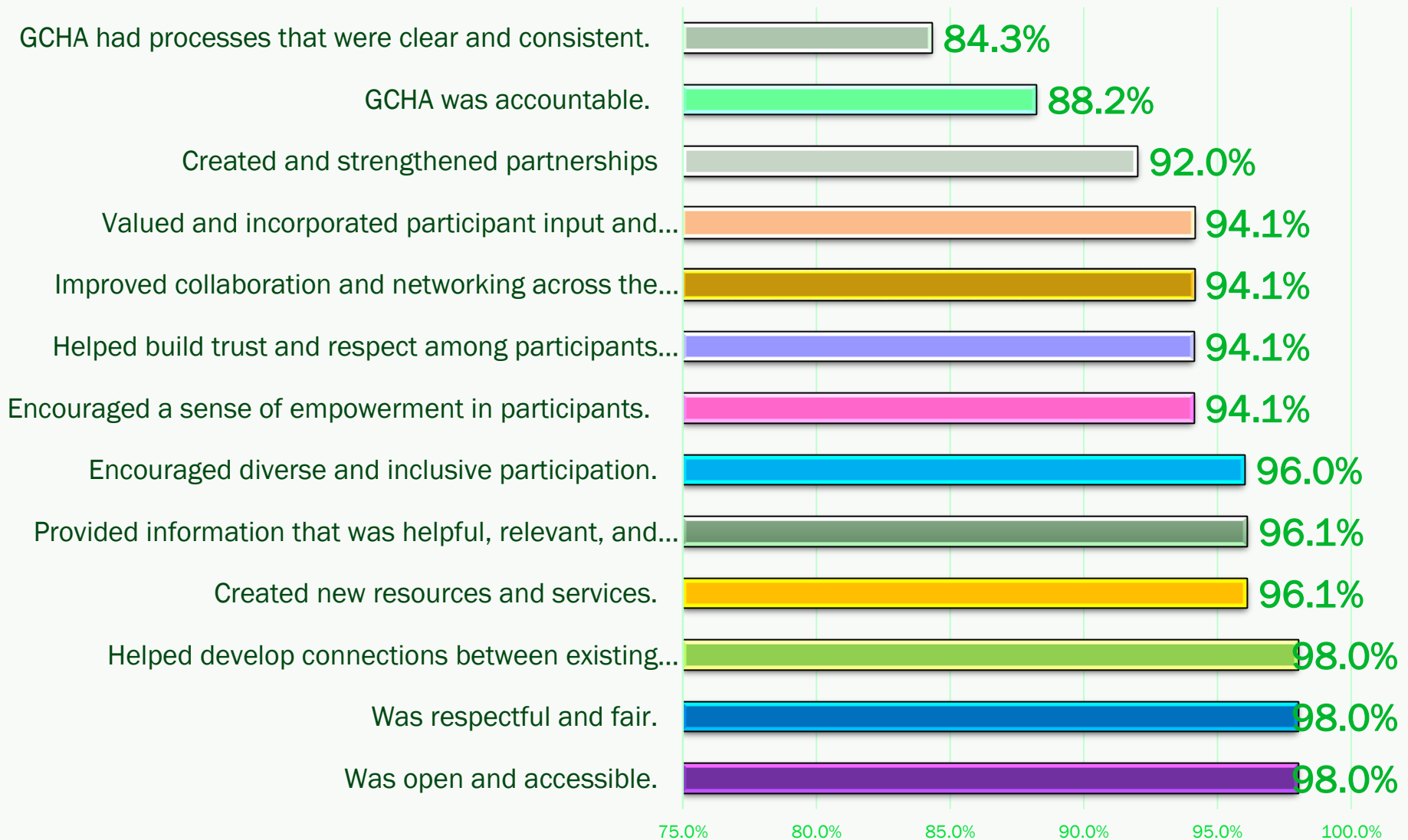

Pie chart values: 10, 6, 8, 10, 20, 9, 6, 12

Legend:
- Ambassadors
- Workshop leaders
- Event participants
- Board members
- Community partners
- County partners
- Statewide partners
- Individuals

Participation in GCHA contributed to:
(% Agree or Strongly Agree)

- I take better care of my own health. — 57.2%
- I gained new skills. — 72.5%
- I feel better connected to resources that can help me. — 84.3%
- I am more informed and aware of community resources. — 92.0%
- I gained more knowledge. — 94.1%

0.0%   20.0%   40.0%   60.0%   80.0%   100.0%

Participation in GCHA contributed to:
(% Agree or Strongly Agree)

Statement	Percentage
I feel a greater sense of belonging within my community.	74.0%
I made a valuable contribution to work in my community.	82.4%
GCHA has increased hope across the county.	84.3%
GCHA lent a greater voice to isolated communities.	84.3%
GCHA supported me to become more active and engaged in my community.	86.3%
GCHA boosted community pride.	88.0%
GCHA made positive change happen	96.1%

0.0% 20.0% 40.0% 60.0% 80.0% 100.0% 120.0%

GCHA:
(% Agree or Strongly Agree)

Statement	Percentage
GCHA had processes that were clear and consistent.	84.3%
GCHA was accountable.	88.2%
Created and strengthened partnerships	92.0%
Valued and incorporated participant input and...	94.1%
Improved collaboration and networking across the...	94.1%
Helped build trust and respect among participants...	94.1%
Encouraged a sense of empowerment in participants.	94.1%
Encouraged diverse and inclusive participation.	96.0%
Provided information that was helpful, relevant, and...	96.1%
Created new resources and services.	96.1%
Helped develop connections between existing...	98.0%
Was respectful and fair.	98.0%
Was open and accessible.	98.0%

75.0%   80.0%   85.0%   90.0%   95.0%   100.0%

Engagement process results

- GCHA was open and accessible. *98.0% of participants surveyed.*
- GCHA was respectful and fair. *98.0%*
- GCHA helped develop connections between existing resources. *98.0%*
- GCHA created new resources and services. *96.1%*
- GCHA provided information that was helpful, relevant, and understandable. *96.1%*
- GCHA made positive change happen. *96.1%*
- GCHA encouraged diverse and inclusive participation. *96.0%*
- GCHA encouraged a sense of empowerment in participants. *94.1%*
- GCHA helped build trust and respect among participants and partners. *94.1%*
- GCHA improved collaboration and networking across the county. *94.1%*
- GCHA valued and incorporated participant input and feedback into processes. *94.1%*
- GCHA created and strengthened partnerships. *92.0%*

Building skills, confidence, and capacity

"I have seen our community come together in many ways because of the influence of GCHA. I've also seen growth and improvements in individuals as they've learned ways of self-managing their health. On a personal level, my husband has lost weight and gained control of his diabetes with the support and information made available through the GCHA resources and teachings. We will be forever grateful to GCHA for the impact seen."

Interest in research

Questions:

- What data to collect, when to collect it, tools for collection?

- How to schedule time and resources for data collection?

- How to reflect on what's working and not working, and use information for further planning?

- What are my health options?

- How can we address health issues?

GCHA Potential for Research

- Facilitate community-focused and action-oriented discussions on health disparities, priorities, research, and solutions

- Educate community members, researchers, and healthcare stakeholders on community and patient-centered research process

- Develop a community research network with research capacity and tools to support research in Greenbrier Valley to adapt and disseminate throughout WV and Appalachia.

Clingman Community Engagement Center:
Engaging Patients and Providers in PCOR Training & Partnership

- Eugene Washington PCORI Engagement Award: Capacity Building – build community capacity & infrastructure for PCOR

- Dynamic hub for community-based initiatives and programming, evidence-based training, workforce development, culinary outreach, local foods justice.

- Strengthen trust, rapport, partnership, opportunity

- Build knowledge, competencies, abilities of stakeholders as partners with meaningful roles in research

- Discussion, priority, and agenda setting, training, skill-building, workshops, partnership and collaboration, advisory & evaluation panels, shared dissemination & sustainability plans

Perspectives

Health System

Patient

Payers

Culture/Society

Family

Health System

Patients

Health Outcome

Society & Culture

Community

Family

Health System

Parent/Caregiver
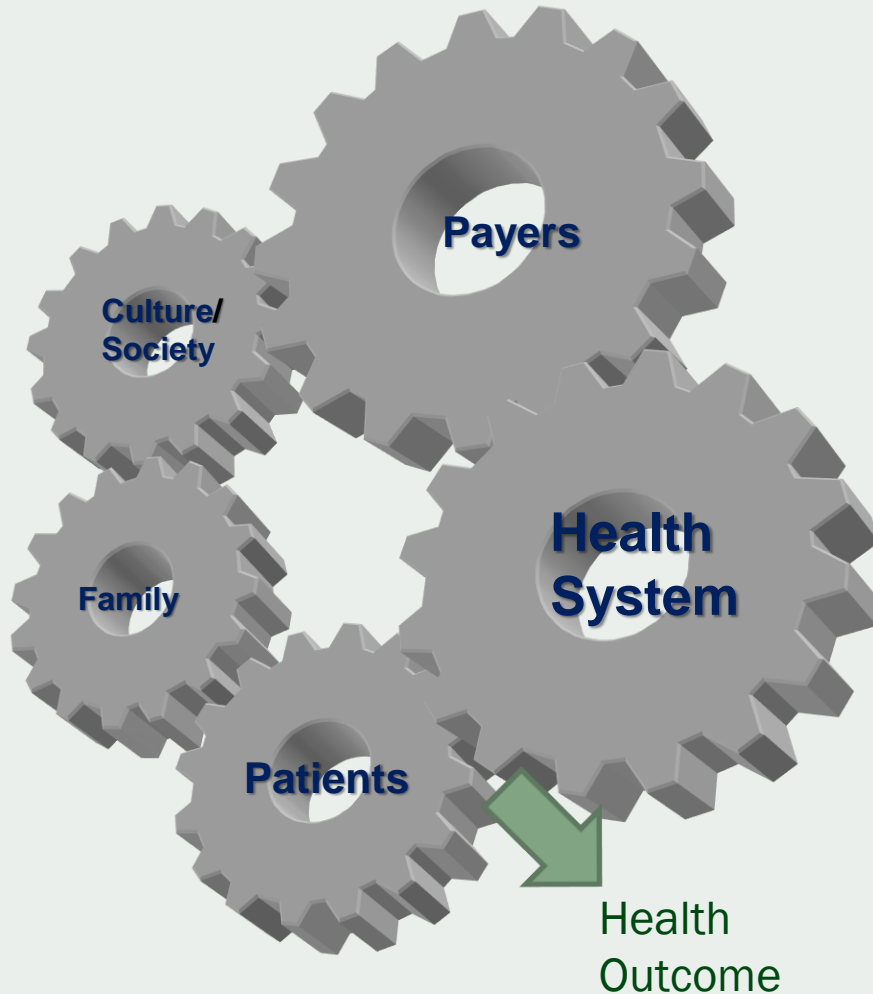
Child/Patient
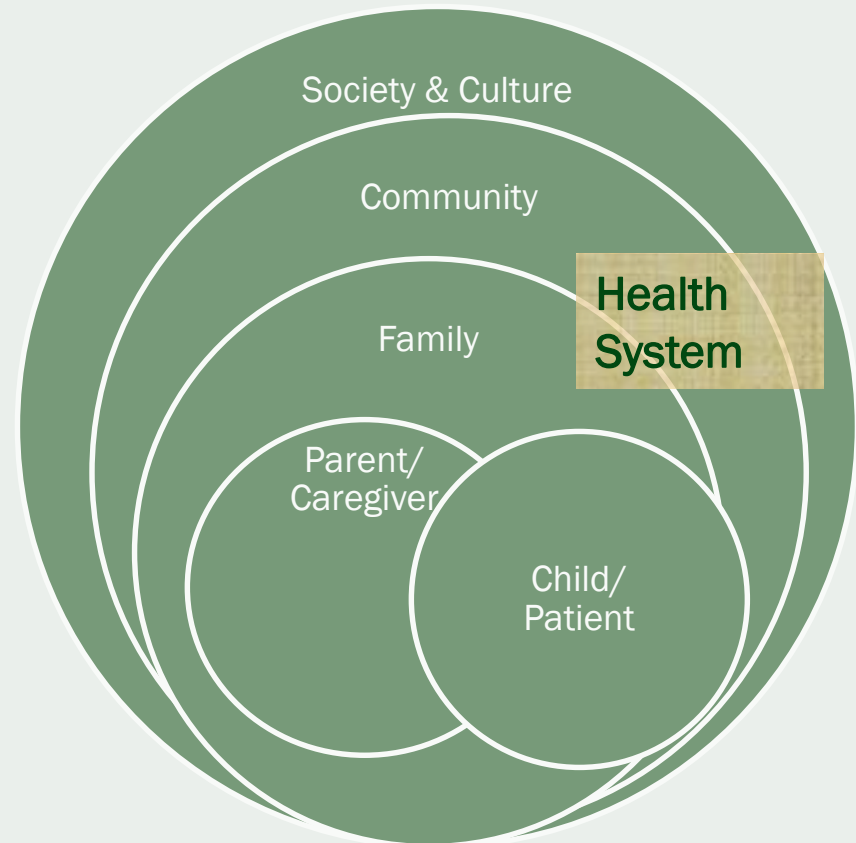
Health happens outside of the treatment setting.

Patient-Centered Outcomes Research (PCOR)

- Helps people and caregivers communicate and make informed health care decisions, allowing voices to be heard in assessing the value of health care options
- Actively engages patients and users of research in all steps of research process to meet stated goals and improve health outcomes
- Evaluates outcomes that are most important to patients
- Addresses implementation of research findings in clinical care environments
- Subset of CER

- **Comparative Effectiveness Research (CER):**
  - The generation and synthesis of evidence that **compares** the benefits and harms of alternative methods to prevent, diagnose, treat, and monitor a clinical condition or to improve the delivery of care. The purpose of CER is to assist consumers, clinicians, purchasers, and policy makers to make informed decisions that will improve health care at individual and population levels (IOM/PCORI)

If we asked better questions, there would be better evidence.

PCOR Engagement

- Stakeholders
  - **Patients & clinicians**
  - Caregivers, healthcare purchasers, payers, policymakers
  - Reps from hospitals, health systems, industry, advocacy and training, orgs

- Process priorities
  - Knowledge, experience, judgment, and values are desireable
  - Values: trust, respect, fairness
  - Outcomes: shared understanding & decision-making that is viewed as actionable and credible to all

- Approaches
  - **Research co-investigators & team partners**
  - **Advisory boards &** Community experts
  - Surveys, interviews, opinion polls

PCOR Study Engagement

- Understanding patient/stakeholder needs
  - Share personal & pro perspectives
  - Best approaches for addressing needs and priorities
- Research topics & questions
- Interventions
- Outcomes & measurement
- Recruitment & retention
  - Finding & recruiting participants
  - Training research staff
- Data collection
  - interviews, focus groups, surveys, tracking
- Data analysis and review
- Dissemination & application
  - Co-presenting, manuscript and newsletters, determining outlets, media interviews, meeting with officials

PCOR Framework
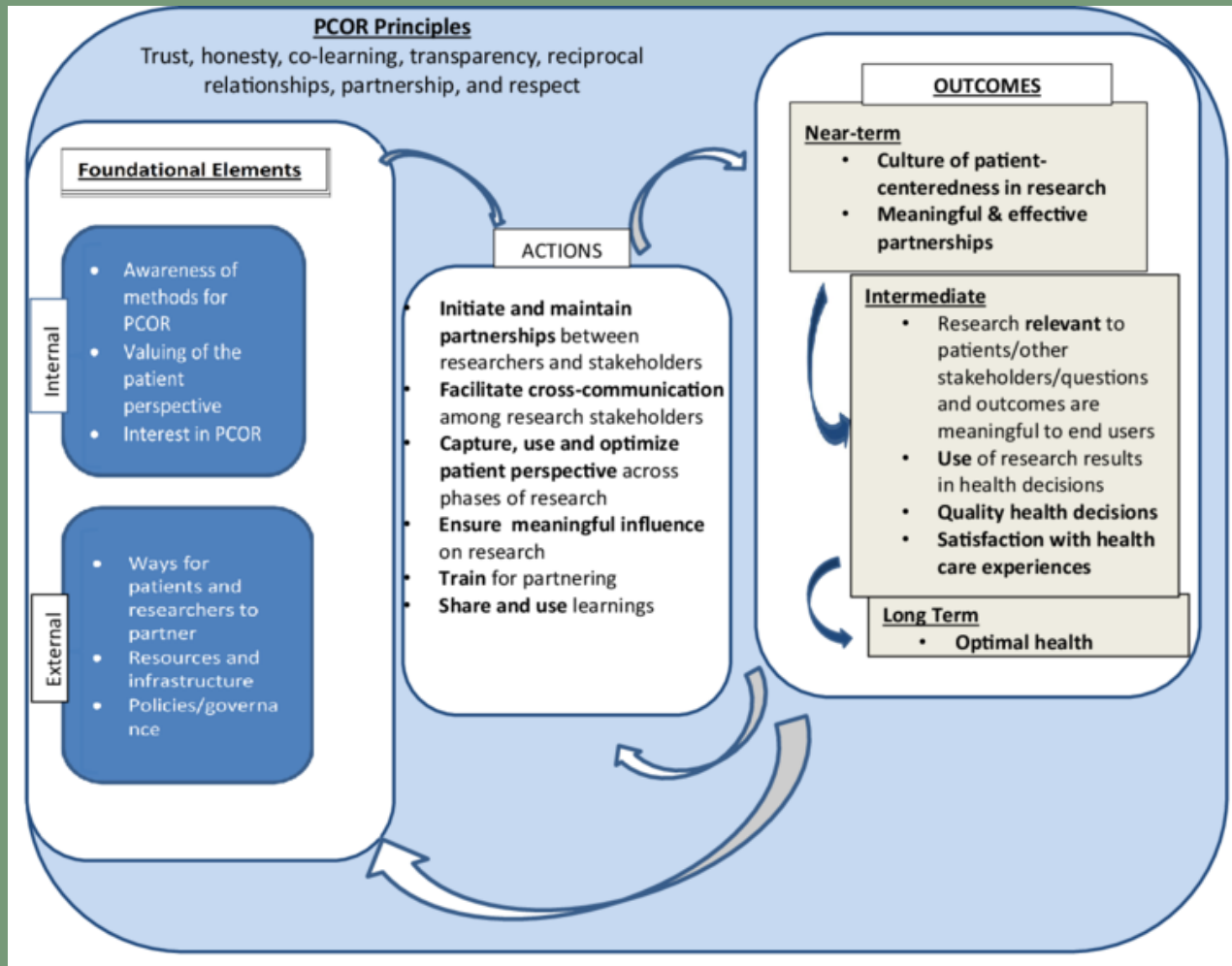
Limitations

- Lack shared understanding of effective stakeholder engagement in research
- Limited evidence base, data and evaluation
- Extensive training needs for all partners
- Partner selection bias/diversity & inclusivity
- Budget & cost concerns for project
- Time!
- Subjectivity

Findings

- Enhanced patient-centeredness/relevance of study processes and outcomes.
  - Reiterated significance of research being pursued.
  - Increased sensitivity and fit of interventions, materials, data collection
  - Decreased participation burden
  - Outcomes and measures of importance to participants

- Enhanced study design, conduct, and/or efficiency.
  - Recruitment, retention, follow-up, data collection
  - Expanded audience
  - Improved communication
  - Increased credibility of findings

Community Engagement Exhibit

2019 WVCTSI Annual Meeting
optional visit to Montwell Commons

Tour the Clingman Center Barn
April 3
1:00 - 3:00

We hope you can join us!

Greenbrier County
Health Alliance

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Thank you!

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