Valuing Voice for
Advancing Healthy Lifestyles in Communities
Learning Series Session 2

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Session Objectives

01
Understand the importance of valuing voice in community research

02
Review precedents, benefits and challenges

03
Look at examples of tools that can support research in communities

A question for you

Why and How We Do Community Research: A Look at Models Over Time

Benefits and Challenges of Valuing Voice to Advance Healthy Lifestyles

Techniques and Approaches for Valuing Voice

Your thoughts and questions

Today's Agenda

A question for you: I'll ask this at the end of our session!

- Where and how do *you* think the practice of Valuing Voice can be most useful to advancing healthy lifestyles?

Why we conduct community research

For community improvement

- learn about and build theories of cause, effect and change that reflect the context
- lead to knowledge and change: from what is to what can or should be
- consider replicability of the solution to other contexts

For measurement

- Developing a conceptual or program framework
- Developing surveys or instruments to assess actions, change, or impact
- Assessing the utility or relevance of a program

For improvement of research

- Documenting burden and unmet needs of populations
- Identifying ways to share information for uptake, and change

Why community engagement for healthy lifestyles

- With thanks to Dr. Odoms-Young for reminding us

- Inequities exacerbated by recent events

- Systems structured to convey "less than" messages

- Patterns of violence

- "underrepresented" is an understatement

Community Research to Advance Healthy Lifestyles: Some Examples

- The effects of isolation on health (COVID)

- Identifying influences for well-being in elder care environments

- Looking at health and wellbeing characteristics for people who have physically limiting conditions

How we make community change: Prioritizing Voice

We ask the **More Knowledgeable Others** (MKOs)

Those who experience, observe, describe, explore or affect a situation or context

Those who can describe factors, gaps, desires, needs, current state

Those who will be affected by the outcome

The More Knowledgeable Other

- Ultimately, documenting **authentic lived experiences of people** is critical to understanding and assessing facts, needs, truths and possibilities

- **Knowledge in context is key.**

Valuing Voice: Three Antecedents

Stakeholder Engagement

Community Based Participatory Research (CBPR)

"Nothing About Us Without Us"

Stakeholder Engagement

- The umbrella term

- Initially corporate social responsibility

- Informs dialog and leads to sustainable shareholder value

- Models abound in social science research too

Values:

Seeks **reactions, feedback** on opinions of those likely to benefit from, be affected by an issue

Benefits:

Can create greater transparency, **justifiable decisions**

Limits:

Often "top-down", seeking feedback on **already answered questions**, power gatekeepers

Uses:

Broadly in social research and corporate strategy development

Jeffery, Neil (2009). "Stakeholder Engagement: A Road Map to Meaningful Engagement" (PDF). The Doughty Centre for Corporate Responsibility, Cranfield School of Management.

Community Based Participatory Research

- CBPR (CAPR, COPR, CCPR)

- Lewin: late 1940's action research, suggested by field theory's potential in social organization research

- Evolved with Action Research and Appreciative Inquiry

Values:

Collaboration in and of communities

Potentially higher uptake for community change

Benefits:

Greater **commitment to results**

Limits:

Power sharing

"Translation" of content **by outsiders**

Unbalanced representation

Needs **long term commitment** to reach impact

Uses:

Health and public health, environmental justice, social and environmental issues

Viswanathan M, Ammerman A, Eng E, et al. *Community-Based Participatory Research: Assessing the Evidence*. Summary, Evidence Report/Technology Assessment: Number 99. AHRQ Publication Number 04-E022-1, August 2004. Agency for Healthcare Research and Quality, Rockville, MD.
http://www.ahrq.gov/clinic/epcsums/cbprsum.htm

Nothing About Us Without Us

- Asserts **critical role of persons** to participate in creating, approving, designing and evaluating research

- "Anti-research"

- Combats the hierarchical paradigm that creates the "other"—the subject

- Seeks to support healing

Values:

Negotiates for values, **control, ownership**.

Establishes primacy of the population, for **equity**

Benefits:

Attempts to redress **historical bias** and hierarchy of knowledge and power in a system.

Can lead to greater more **effective change**

Limits:

Generalizability of results for uptake.

Resource intensive

Uses:

Indigenous cultures, people who have disabilities, those who experience mental or emotional health conditions, aging

For example: Tuhiwai-Smith, Linda. Decolonizing Methodologies: Research and Indigenous People. 2nd edition, 2012. London: Zed Books.

STAKEHOLDER ENGAGEMENT

COMMUNITY BASED
PARTICIPATORY
RESEARCH
(CBPR)

CCPR
CAPR
COPR
PAR
Appreciative Inquiry

NOTHING ABOUT
US WITHOUT US

1947   1973   1993

Valuing Voice

- Defines individuals as **assets**

- **Produces community** from individual positions

- Seeks, embraces **knowledge of individuals** to inform a big issue that affects many

- Leads to **group wisdom**

Values:

Assumes individual as a **reliable unit of knowledge** for building a response to the issue or create change

Benefits:

Mitigates hierarchical approach to social change research

Reduces reliance on appointed advocates as source

Supports greater **uptake** of results

Limits:

Design challenges in capturing voice most efficiently and appropriately
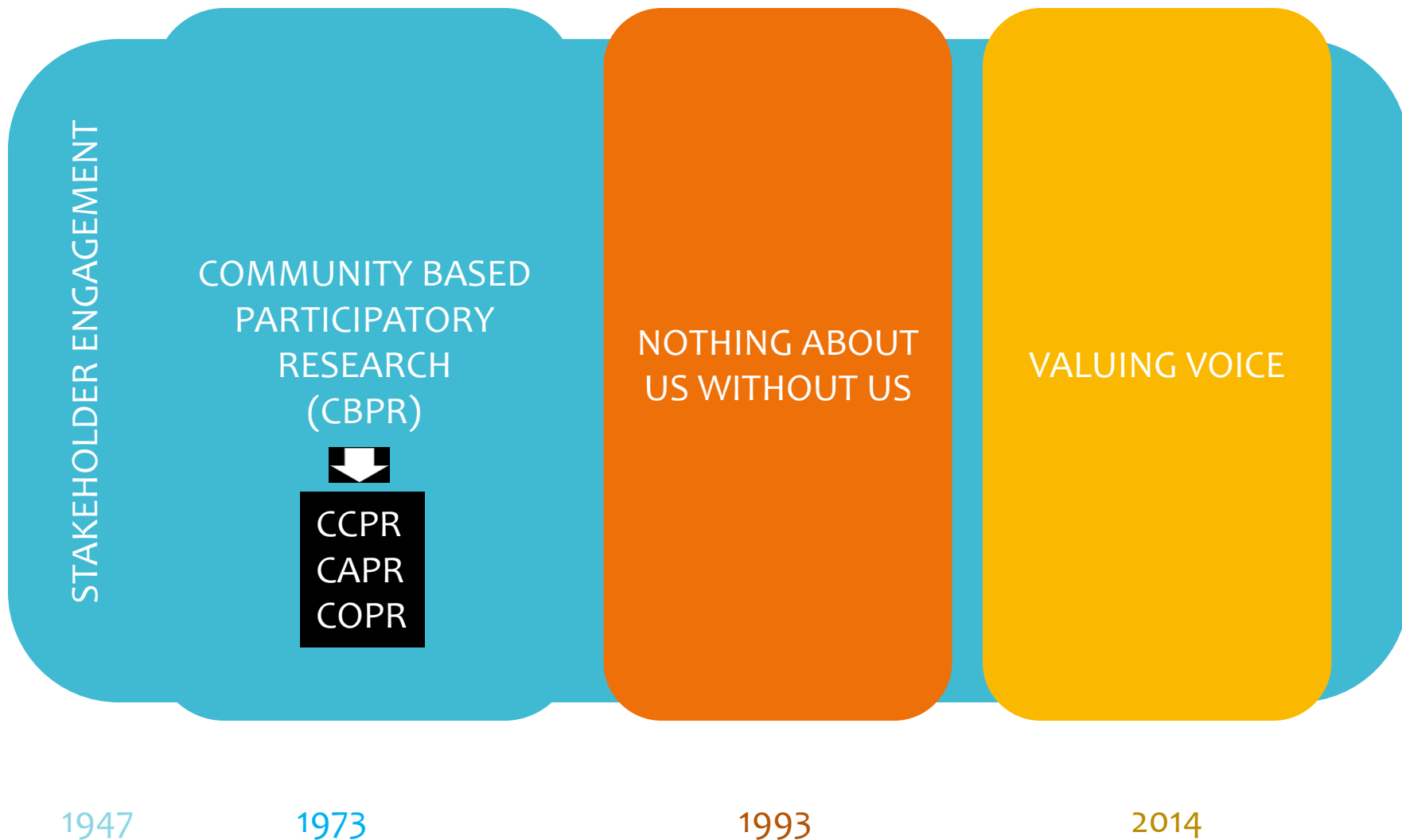
Obstacles to active participation are many

Uses:

Public health, mental and emotional health, people who have disabilities, aging/isolated populations,
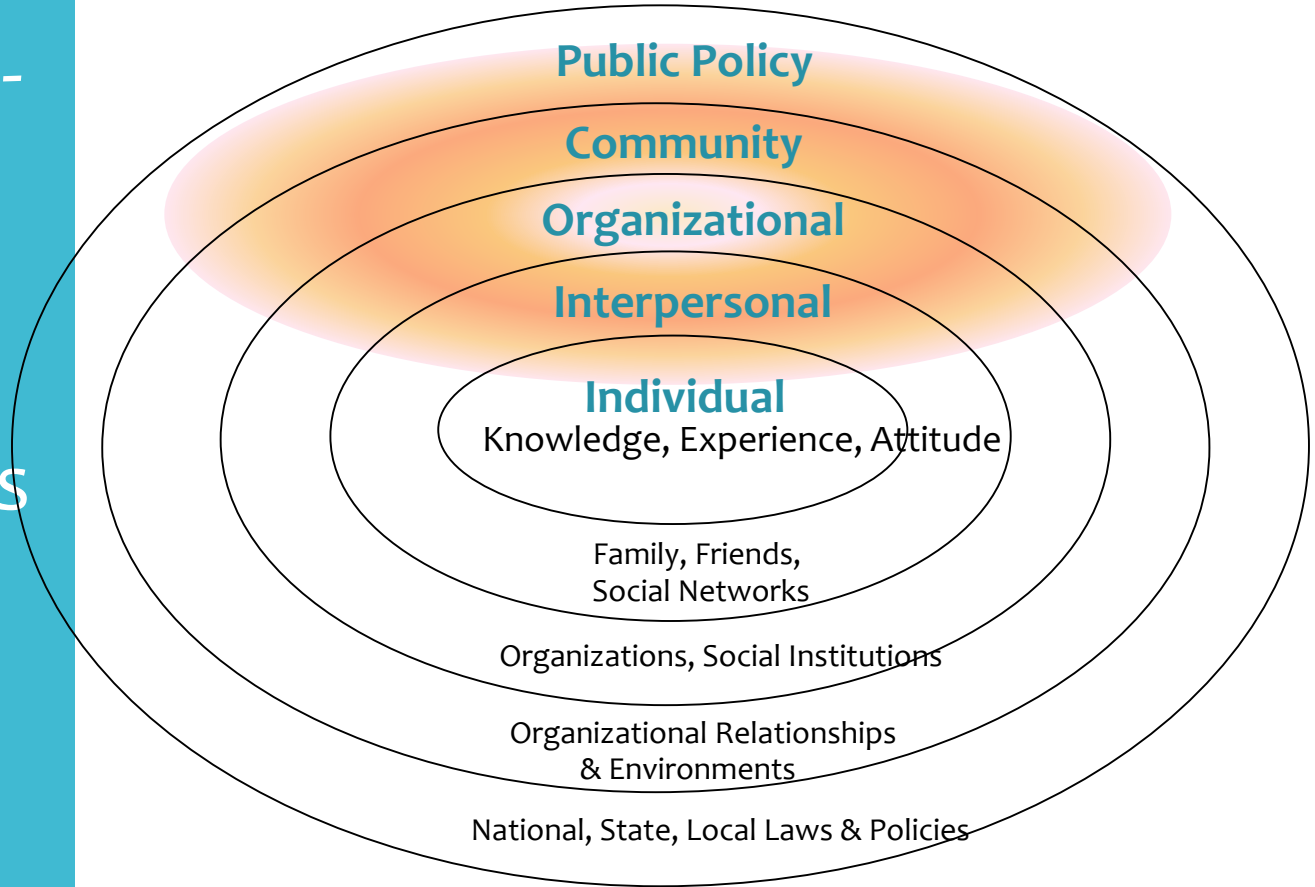
Any group that should be part of their own solution

STAKEHOLDER ENGAGEMENT

COMMUNITY BASED PARTICIPATORY RESEARCH (CBPR)

CCPR
CAPR
COPR

NOTHING ABOUT US WITHOUT US

VALUING VOICE

1947   1973   1993   2014

Standard Community-based Research: Agencies and Systems as Proxy

Public Policy

Community

Organizational

Interpersonal

Individual
Knowledge, Experience, Attitude

Family, Friends,
Social Networks

Organizations, Social Institutions

Organizational Relationships
& Environments

National, State, Local Laws & Policies

Valuing Voice in Context: Person as Primary Resource

Public Policy

Community

Organizational

Interpersonal

Individual
Knowledge, Experience, Attitude

Family, Friends, Social Networks

Organizations, Social Institutions

Organizational Relationships & Environments

National, State, Local Laws & Policies
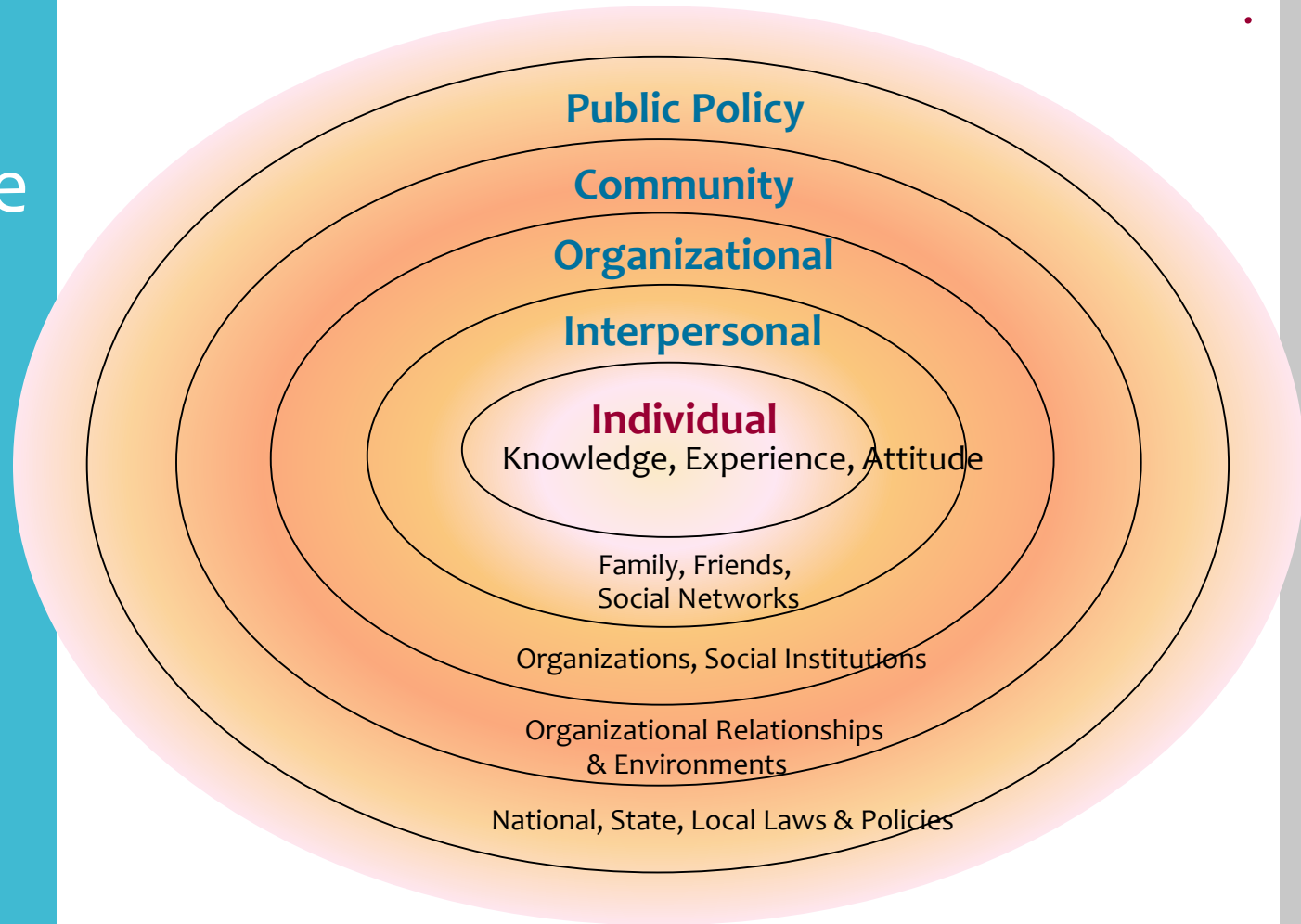
How do we seek and capture knowledge?

Goals:
Recruitment
Participation
Ownership

Thinking of your work

How do you know if you are valuing the voices of the individuals and communities to inform your programs?

What are some challenges you have had to engaging people to participate?

What design or engagement approaches have you used successfully to learn the opinions of those for whom the program is intended?

The Objectives: Voice in both Process and Outcome

Beyond answering a predetermined (research or planning) question

Creating an environment for *readiness, willingness* to *speak, contribute, risk*

In the end, the community's ownership, ability to direct decisions and affect results

Means:
Respect
Humility
Capacity

- Respect
  - A building process
  - Allies are critical

- Humility
  - Know what you don't know
  - Allies are critical

- Capacity
  - Research to prepare
  - Skills to encourage, support, focus
  - Applying best designs to the question and the context

Characteristics of Valuing Voice

Mitigating Power Challenges

First-hand knowledge

Language and understanding

Community Authorship

The benefit of process

Adapting to the context; making the process relevant

Valuing Voice benefits

For the person in the community	Validation of knowledge/lived experience as having value Recognition of the right of the person to contribute to the community Awareness of making a contribution to improve
For the community	Authority is vested in the community's members Trust and rapport improves among community members and with the project Summative knowledge and recognition of capacity Process leads to system improvement
For the project	Breadth, depth, quality and currency of opinion and knowledge on the topic Perspectives that will allow the project greater impact

Ultimately, who has control of the research

Often, **subjects in conventional research studies are simply seen as data sources and don't have a voice in the data's interpretation or use. ...** This **"research on"** design can reduce the likelihood that the results will be accepted or used.

The **very groups who are often targets of research**—marginalized, disenfranchised, and less powerful constituencies—**are those whose first-hand knowledge and experience are most relevant to an issue**.

Kane and Rosas, 2017

The project plan should link the objectives and the knowledge holders

Individual voices and perspectives captured
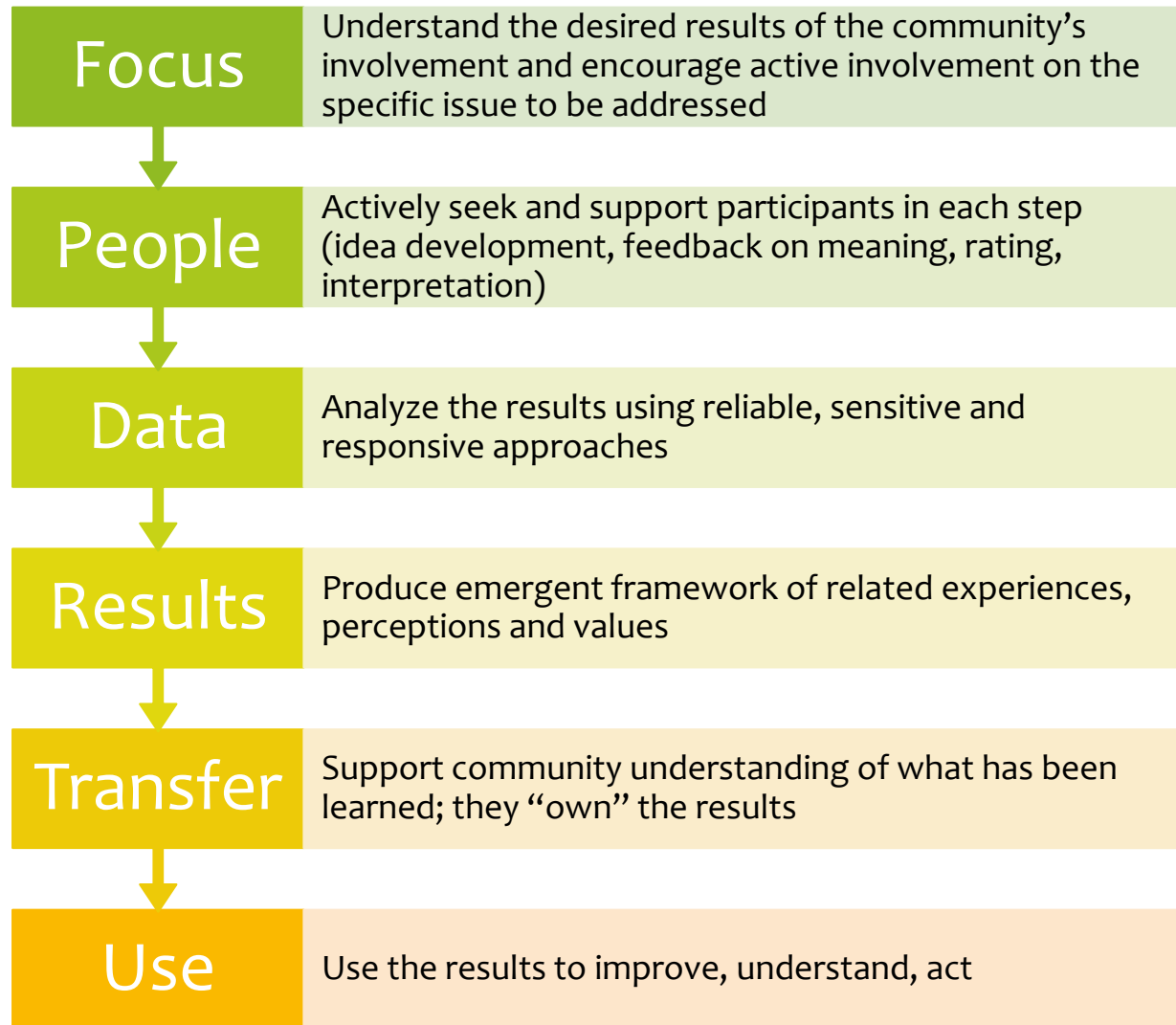
Choosing the right tools

Setting the stage for ownership

Leading to acceptance and use of the resulting framework

Simple Rules: Researchers and Program Managers

Focus	Understand the desired results of the community's involvement and encourage active involvement on the specific issue to be addressed
People	Actively seek and support participants in each step (idea development, feedback on meaning, rating, interpretation)
Data	Analyze the results using reliable, sensitive and responsive approaches
Results	Produce emergent framework of related experiences, perceptions and values
Transfer	Support community understanding of what has been learned; they "own" the results
Use	Use the results to improve, understand, act

Simple Rules: People as Knowledge Source

Contribute — Contribute what each person thinks, knows, observes, feels, experiences, recalls, requires

Organize — Contribute to the community's understanding of the surfaced issues and how they are related, building a system of community thought

Value — Contribute individual perceptions of value or priority, based on each individual's perceptions and experiences

Challenges to Valuing Voice

Power and authority

- Who controls the research plan and process
- Gatekeepers to support the project, or not
- Messages in the social systems

Recruitment and participation

- Seeking and connecting people in their own context
- Capacity limits: time, access to information
- Structural, community factors that inhibit involvement
- Complicated project design

Language and communication

- Literal and cultural communication requirements
- Clarity, consistency

Some Techniques for Community Research

Technique	Characteristic
Anonymous Drop Box	"Pulse" opinion capture
Brainstorming, Brainwriting	Point in time opinion
Charrettes	Structured, pre-loaded outcome
Committee, Task Forces	For planning
Community, Town Hall Forums	Open opportunity, group input=community result
Delphi, NGT	Structured, iterative
Focus Groups, Interviews	Interpersonal, scripted
Questionnaires, Surveys	Designed by researcher, responsive input from individuals
World Café	Scripted questions, open opportunity for every participant

Some Techniques for Valuing Voice

Technique	Characteristic
Appreciative Inquiry	Person-Centered systematic response development
Assistant supported participation	Enables those with limitations to partiacipate
Body mapping	For patient outcomes self-reporting
Community map reflection	Considers assets and issues in the cultural and environmental landscape
Group Concept Mapping	Open, prioritizes individual input at three stages = community owned result
Moment in time, reflection over time	Journaling for self-reporting on conditions, personal or contextual
Mood mapping	Supports self-reflection for mental health, wellbeing
Participatory Action Research	Prioritizes action from engagement
Purposeful presence	Coaching and support for individual contributions and group decisions
Photovoice, pictographic input	Translates visual content into frameworks for group consideration; context rich

An Example

Specific Aims

- Seek the wisdom of the community to activate older members with existing health conditions in advancing their own healthy lifestyle
- To help lead to new programs, greater connection, capacity to sustain

Focus

- *When I think about ways to feel better more often, a thing that would help me might be…*

Contributors

- Older community members, their family members, people who support older community members with social or medical services
- Others…

What Have We Learned: The "Yes, but…" Issues

Philosophical: We believe in and advocate for voice. But..

Practical: We have greater capacity to include people in their own futures than ever before, but…

Political: We have the mandate to create social change, but…

Personal: We have a stake in improving the lives of our fellow (residents, countrymen, humans), but…

Programmatic: We support programs that are intended to create lasting change, but…

A question for you

- Where and how do *you* think the practice of Valuing Voice can be most useful to advancing healthy lifestyles?

Thank you!

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