Implementation Strategies involving End Users to End the HIV Epidemic: Consumer Voice Tools

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February 2024

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Disclosures

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- VA Center for Mental Healthcare and Outcomes Research
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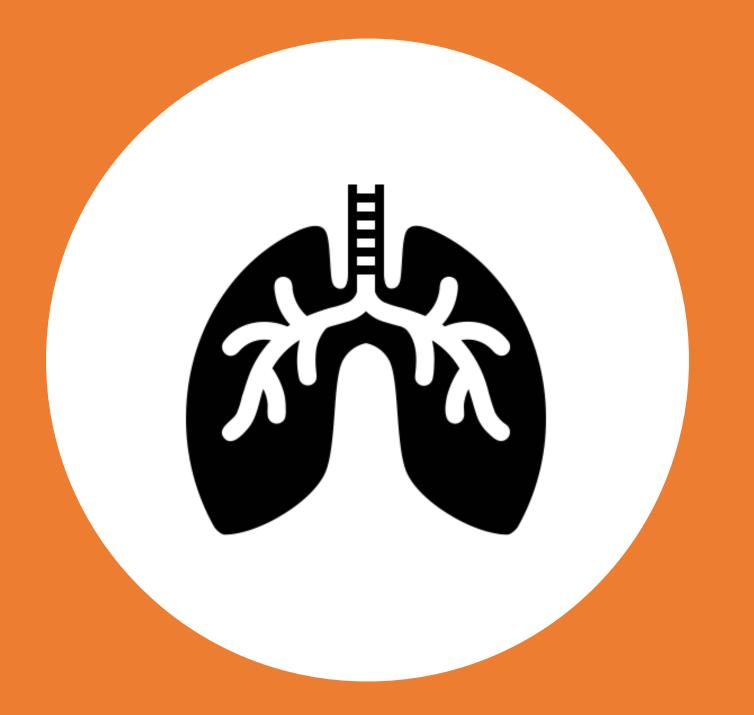- ViiV Healthcare, Inc.

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- U.S. Department of Veterans Affairs,
- United States Government, or
- the University of Arkansas for Medical Sciences.

For equitable and just implementation of innovations, we must embrace complexity and realize these are career-long, life-long endeavors.

What is the most elegant next step (for you)?*

*adrienne maree brown, Emergent Strategy

Let's get present

Sometimes, people who need quality care most are least likely to receive it

Dr. Ana Baumann, 2021 presentation
National Healthcare Quality and Disparities Reports, 2003-2021

In my field, I am aware of health care disparities in:

a. structural access to innovation (it's out there, but people have few chances to even get in line for it)

b. receipt of innovation (people are less likely to be offered it)

c. quality of innovation (people are receiving it, but with worse fidelity or patient-centeredness)

d. outcomes of innovation (people are receiving it, but not benefitting as much as others)

Brief overview of implementation practice (which is part of every implementation trial)

The paradigms of implementation science and health care disparities research follow similar steps to detect, understand, and reduce gaps

Detecting research-to-practice gap and disparities

Understanding the gap and why disparities exist

And, implementation practice is determined by what we learn here

Reducing the gap and disparities

Implementation practice is what happens here

There are multiple clusters of implementation strategies

🟩 Engage consumers		🟩 Develop stakeholder interrelationships	
🟥 Use evaluative & iterative strategies		🟪 Utilize financial strategies	
🟦 Change infrastructure		🟧 Support clinicians	
🟩 Adapt & tailor to the context		🟨 Provide interactive assistance	
		🟪 Train & educate stakeholders	

Waltz et al. 2015

Giving everyone the same implementation strategy is not equitable (although it can be easier).

Equality

Equity

Tailoring implementation strategies appears important for uptake

- Tailoring: assessing relevant determinants and designing/changing the strategy to address those determinants and needs of all people involved in a specific context

- Increasing evidence that tailoring implementation strategies may be more effective than one-size-fits-all approaches[1]

Baker et al., 2015; Kilbourne et al., 2014; Kirchner et al., 2017; Lewis et al., 2015; Powell et al., 2017

Engaging end users or "recipients" affected by the health problem is gold standard in health disparities research and probably should be in implementation science, too.

Ramanadhan et al., 2015;
Chambers & Holt, 2017 special issue

Preliminary studies suggest engaging end-users in implementation leads to:

1. Better intervention fit for patients[1]
2. Systems redesign that is more patient centered [2]
3. Greater use of effective healthcare interventions in many settings[3]
4. Improved patient health behaviors and outcomes [4]

1. Nápoles AM, Stewart AL. 2018. Transcreation: an implementation science framework for community-engaged…
2. Lopatina E, Miller JL, et al. 2019. The voice of patients in system redesign…
3. Hero, Goodrich, Ernecoff, et al. 2023. Implementation Strategies for Evidence Based Practice in Health and Health Care: A Review of the Evidence, PCORI report.
4. Wells KB, Jones L, Gilmore J, et al. 2013. Community-Partnered Cluster-Randomized Comparative Effectiveness Trial…

Because groups of people have been caring for themselves for generations, they can and must care for the research in their communities.

"Information, data, and research about our peoples—collected about us, with us, or by us—belong to us and must be cared for by us."

-Liz La quen náay Kat Saas Medicine Crow

Revisit 9 clusters of implementation strategies[1]

🟩 Engage consumers		🟩 Develop stakeholder interrelationships	
🟥 Use evaluative & iterative strategies		🟪 Utilize financial strategies	
🟦 Change infrastructure		🟧 Support clinicians	
🟩 Adapt & tailor to the context		🟨 Provide interactive assistance	
		🟪 Train & educate stakeholders	

1. Mass media
2. Involve patients in uptake/adherence
3. Involve patients/ consumers and families
4. Prepare patients/consumers to be active participants
5. Increase demand

"Engaging consumers" strategies does not have enough specificity to be actionable

has some of strongest evidence compared to other strategies[2]

1. Waltz et al. 2015
2. Hero, Goodrich, Ernecoff, et al. 2023. Implementation Strategies for Evidence Based Practice in Health and Health Care: A Review of the Evidence, PCORI report.
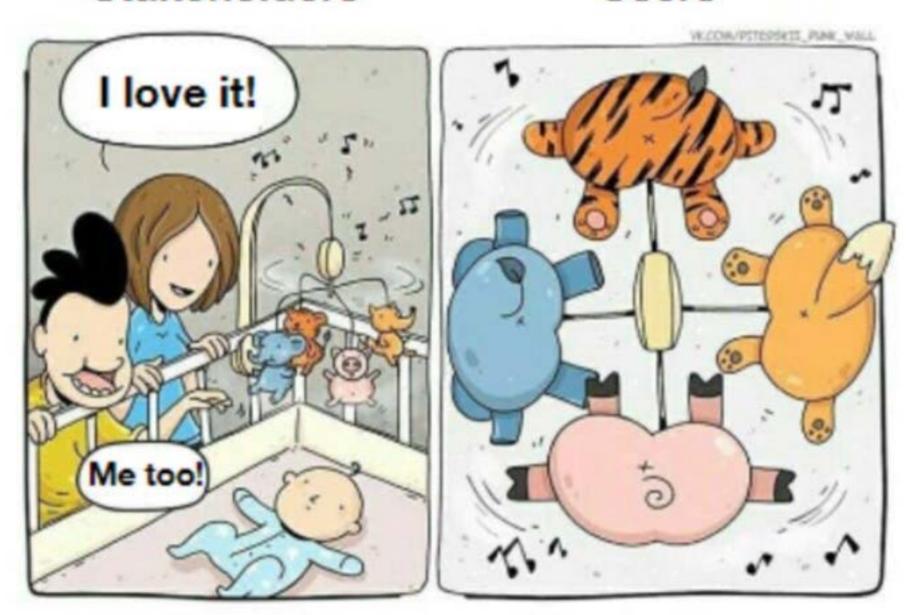
We developed tools for implementation practice on how to engage consumers, especially those who experience marginalization.

"We would love to engage patients in implementing new services, but we don't know how…" – Hospital middle manager

Consumer Voice is generalizable and free

- Tools are not specific to suicide or to Veterans
- Generalizable to other service users – schools, community settings, criminal justice systems
- Google Drive – available by clicking here
- VA users: Consumer Voice - Home (sharepoint.com)

Consumer Voice

Design team made decisions

Eva Woodward, PhD
Psychologist, Lead Research
Investigator

Rajinder (Sonia) Singh, PhD
Psychologist, Research
Investigator

Celia Scanlon
Veteran Consultant, Former
Seaman, U.S Navy & Retired
Medical Support Assistant, South
Texas VA

Cathleen Willging, PhD
Anthropologist, Research
Investigator

Damon N. Cluck, JD
Veteran Consultant, Retired
Colonel, U.S Army and National
Guard

Irenia Ball, BS
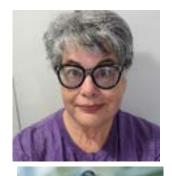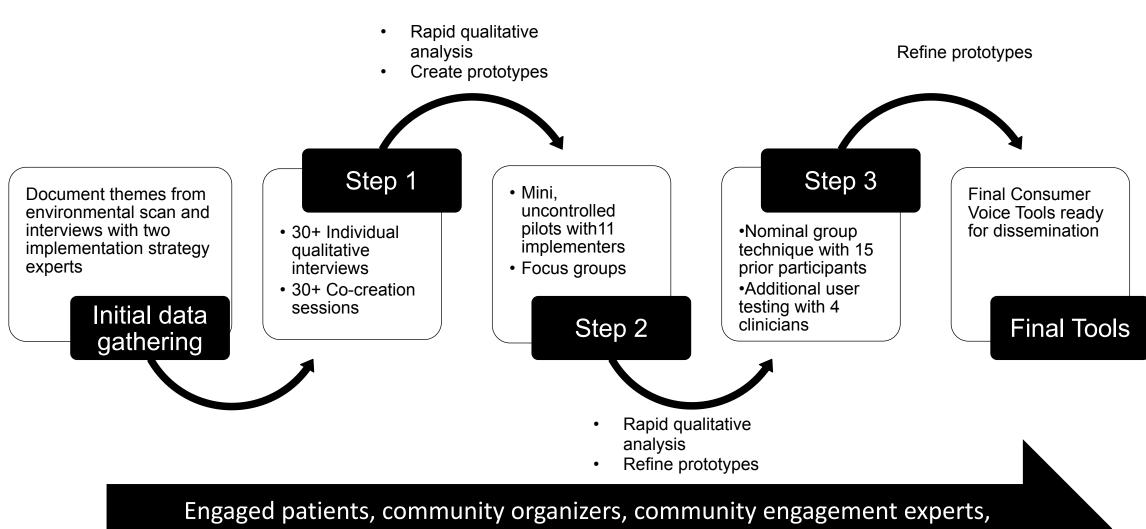Research Assistant

JoAnn Kirchner, MD
Psychiatrist, Research Investigator

We used human centered design to develop Consumer Voice

- Rapid qualitative analysis
- Create prototypes

Refine prototypes

Step 1

Step 3

Document themes from environmental scan and interviews with two implementation strategy experts

Initial data gathering

- 30+ Individual qualitative interviews
- 30+ Co-creation sessions

- Mini, uncontrolled pilots with 11 implementers
- Focus groups

Step 2

- Nominal group technique with 15 prior participants
- Additional user testing with 4 clinicians

Final Consumer Voice Tools ready for dissemination

Final Tools

- Rapid qualitative analysis
- Refine prototypes

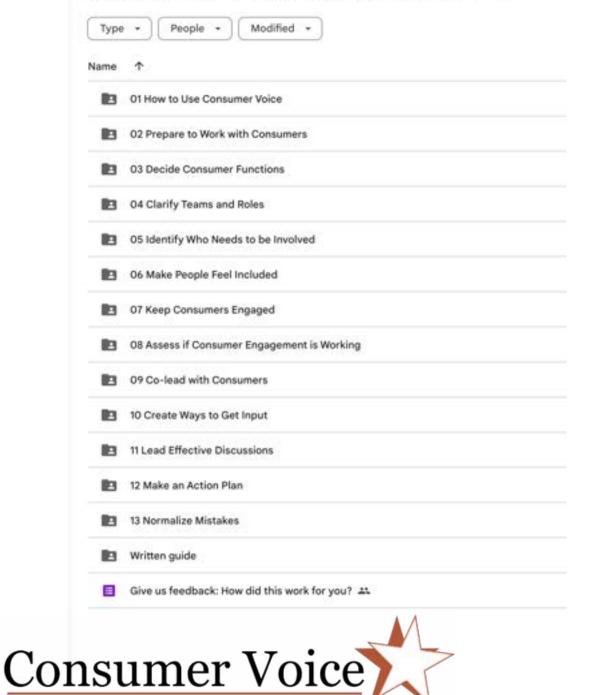Engaged patients, community organizers, community engagement experts, implementation experts, clinical leaders over 18 months

5 Core Principles for Engaging Consumers in Implementation Practice

1. Really listen to others, especially consumers and community members (People in positions of power need to prepare to do this).

2. There are several ways to recruit and engage consumers - use multiple.

3. Work with diverse groups of people involved in the problem.

4. Set clear expectations, roles, orient people, and clarify how work will get done.

5. Repeatedly show how consumer and community contributions are valuable.

Consumer Voice

Name ↑

📂 01 How to Use Consumer Voice

📂 02 Prepare to Work with Consumers

📂 03 Decide Consumer Functions

📂 04 Clarify Teams and Roles

📂 05 Identify Who Needs to be Involved

📂 06 Make People Feel Included

📂 07 Keep Consumers Engaged

📂 08 Assess if Consumer Engagement is Working

📂 09 Co-lead with Consumers

📂 10 Create Ways to Get Input

📂 11 Lead Effective Discussions

📂 12 Make an Action Plan

📂 13 Normalize Mistakes

📂 Written guide

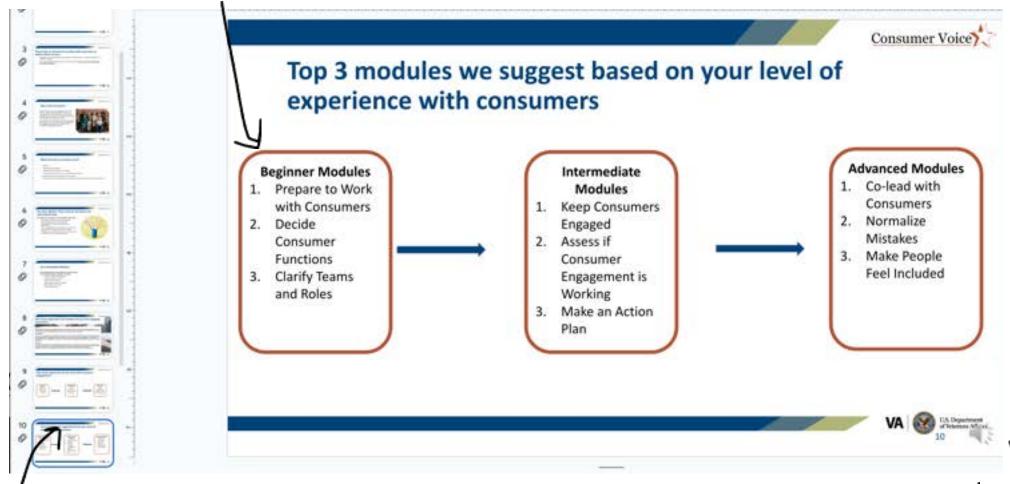📋 Give us feedback: How did this work for you? 👥

Consumer Voice

- Slides with audio voice overs: Example click here

- Cheat sheet to Get Started Quickly

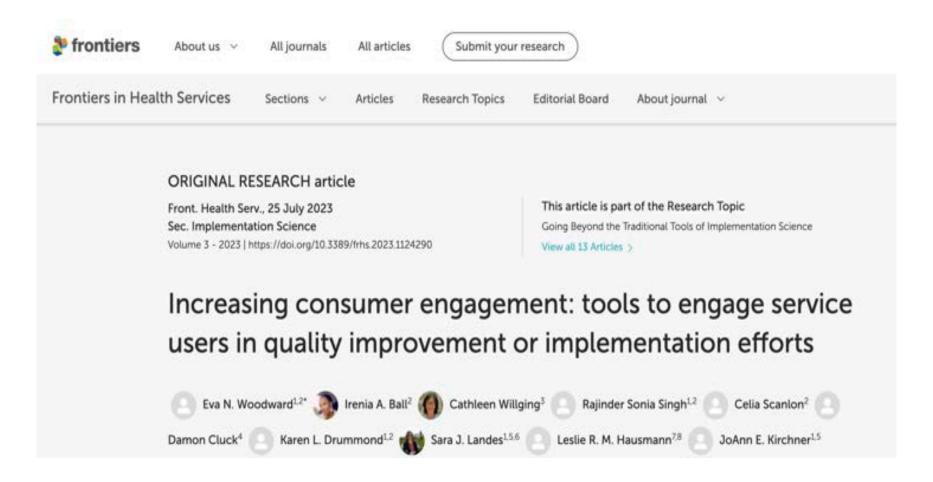- Supporting documents – templates, extra reading, talking points

Type ▾   People ▾   Modified ▾

Name

📁 Supporting Documents

🄿 Create ways to get input. Listening Time = 14 mins 👥

📄 Get Started Quickly_Create Ways to Get Input (VA edit 508).pdf 👥

Consumer Voice ⭐

read

Work ahead

listen

Top 3 modules we suggest based on your level of experience with consumers

Beginner Modules
1. Prepare to Work with Consumers
2. Decide Consumer Functions
3. Clarify Teams and Roles

Intermediate Modules
1. Keep Consumers Engaged
2. Assess if Consumer Engagement is Working
3. Make an Action Plan

Advanced Modules
1. Co-lead with Consumers
2. Normalize Mistakes
3. Make People Feel Included

Consumer Voice

VA — U.S. Department of Veterans Affairs

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You can read more about development of Consumer Voice

Examples of Consumer Voice in HIV implementation science
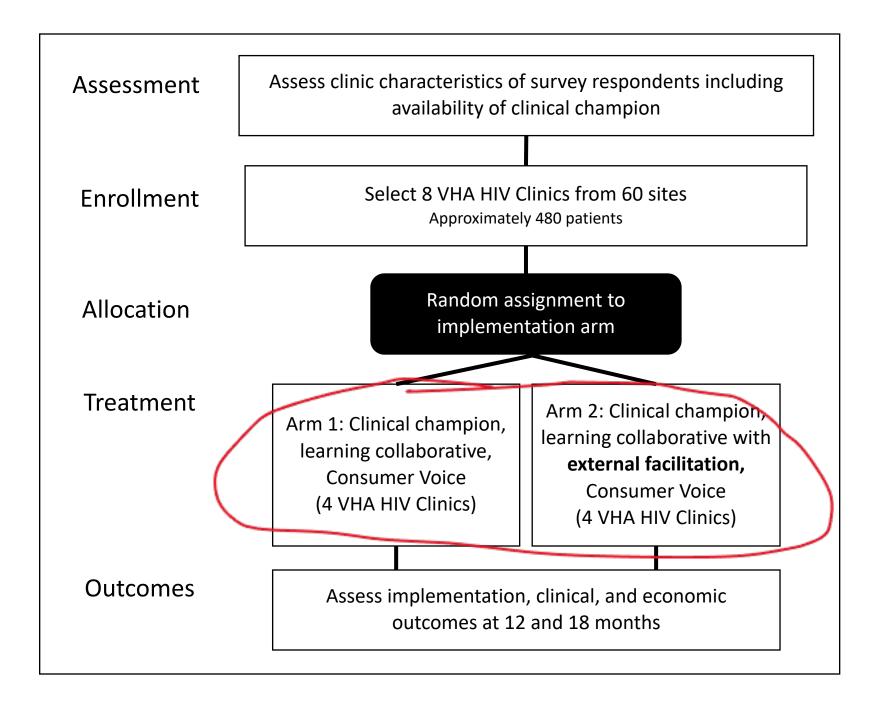
Consumer Voice

Example 1 - real

Hybrid 3 study on implementing depression care in HIV clinics for Veterans of the U.S. military

Principal Investigators: Jacob Painter and Eva Woodward

R01-level grant - VA Health Systems Research (1I01HX002759-01A1)

Just starting

Specific Aims of a Hybrid III trial over 4 years

1. (Implementation) Determine, through a cluster-randomized controlled trial among VA HIV clinics, the effect of adding external facilitation to implementation strategies consisting of a site-level clinical champion and learning collaborative.

2. (Effectiveness) Determine the impact of a nurse care manager on depression and suicidal ideation among Veterans living with HIV receiving the intervention.

3. (Economic) Estimate budget impact of implementation strategies by calculating cost of Consumer Voice, clinical champions, learning collaborative, and external facilitation.

Assessment	Assess clinic characteristics of survey respondents including availability of clinical champion
Enrollment	Select 8 VHA HIV Clinics from 60 sites Approximately 480 patients
Allocation	Random assignment to implementation arm
Treatment	Arm 1: Clinical champion, learning collaborative, Consumer Voice (4 VHA HIV Clinics) · Arm 2: Clinical champion, learning collaborative with **external facilitation,** Consumer Voice (4 VHA HIV Clinics)
Outcomes	Assess implementation, clinical, and economic outcomes at 12 and 18 months

Process evaluation will answer:
1. What will clinical champions do with Consumer Voice?
2. What will facilitators do with Consumer Voice?
3. How will patients engage differently between arms?

Potential results

Implementation strategies that interface with end users

- Media designed with and for Veterans living with HIV and depression on waiting rooms TV, mass e-mails from health care system, and physical mail
- Phone waiting messages describing benefits of treating depression

Implementation strategies that interface with clinicians or managers designed with end users

- Workflow changes to screen for depression and discuss positive screens that are more patient-centered
- Sustained community of practice for other innovations with clinicians, leaders, and Veterans living with HIV
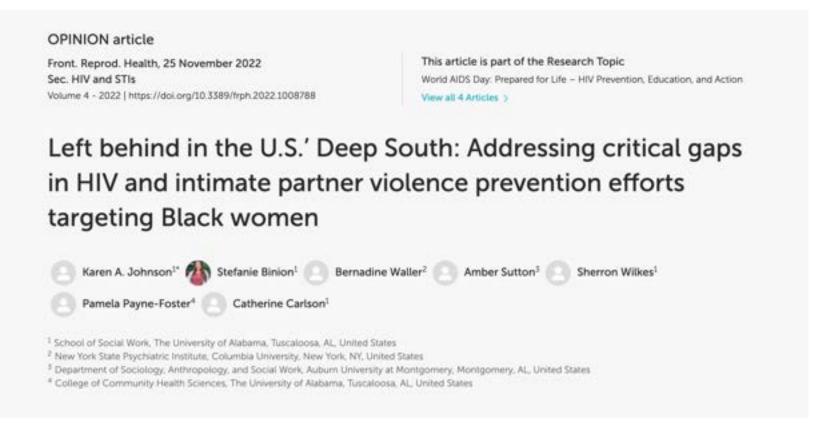
Example 2 – made up but based on some true things

Interventions to prevent HIV among Black women in the Deep South (United States):

- Two 4-hour group sessions
- 4 telephone calls over a 12-month period
- Focused on personal, relational, sociocultural, and structural factors associated with adolescents' HIV risk
- Vouchers for male partners' HIV testing and treatment
- Adapted to also include component to address intimate partner violence

Diclemente et al., 2009

What scientists know

OPINION article

Front. Reprod. Health, 25 November 2022
Sec. HIV and STIs
Volume 4 - 2022 | https://doi.org/10.3389/frph.2022.1008788

This article is part of the Research Topic
World AIDS Day: Prepared for Life – HIV Prevention, Education, and Action
View all 4 Articles >

Left behind in the U.S.' Deep South: Addressing critical gaps in HIV and intimate partner violence prevention efforts targeting Black women

Karen A. Johnson[1*]   Stefanie Binion[1]   Bernadine Waller[2]   Amber Sutton[3]   Sherron Wilkes[1]
Pamela Payne-Foster[4]   Catherine Carlson[1]

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HIV protective factors:
1. Spirituality or religiosity
2. Living with a partner
3. Social support

Unknown

What are best implementation strategies to enhance uptake and spread of the HIV + intimate partner violence intervention among Black girls and young women?

Johnson, Binion, et al., 2022.

Formative evaluation over 9 months

Research Team

- Use Consumer Voice to help them create and meaningfully assist an implementation research team with:
  - Black adult women in the Deep South who have experienced intimate partner violence
  - School administrators
  - Black girls and young women who are current students
  - Implementation practitioners
  - Implementation scientists
  - Department of Health HIV liaison

Methods to identify barriers and facilitators to uptake

- Walking or windshield survey at the school and nearby area
- Group interviews with current students
- Surveys of adult caregivers of current students
- Group interviews with staff
- Group interviews with administrators
- Based on analysis, implementation mapping process to identify and design strategies.

Potential results

Implementation strategies that interface with end users

- Financial incentives for completing group sessions from Department of Health

- Educational text messages about intimate partner violence and free local resources

- Student liaisons who create social media posts about the intervention and spread in their own peer networks

- Brochures about intervention in nurse's office

Implementation strategies that interface with administrators or educators designed with end users

- Develop an implementation guide that can be piloted at 1-2 schools and refined to be a key document at other schools for spread.

- Revise workflow so nurse can host a "private check-in" hour daily during lunch

- Create a coalition between multiple schools, city leaders, health department leaders, and an equal number of Black girls and young women in schools

- Set up a data monitoring plan on intervention uptake, reach, and quality that is collected by school and analyzed by local researchers – data collection methods are designed with student collaboration

- Education for teachers on recognizing signs of intimate partner violence and how to refer students to intervention

We are piloting Consumer Voice⭐ right now

Eva N Woodward,[1,2] Cathleen Willging [ID],[3] Sara J Landes,[2,4,5]
Leslie R M Hausmann,[6,7] Karen L Drummond,[1,2] Songthip Ounpraseuth,[8]
Irenia A Ball [ID],[1] JoAnn E Kirchner[2,4]

…and renaming it, too! (taking suggestions)

End user implementation strategies probably need to be used <u>if</u> context could benefit.

What we did before

- Focus on single implementation strategies only.

- Compare single to multi-faceted implementation strategies.

What we might do now

- Build more situated, relational and organizational capability to support implementation.

- Include a wider range of research perspectives in studies.

- Diversify methods to include approaches such as realist evaluations to explore context in which strategies are used.

Boaz, A., Baeza, J., Fraser, A. *et al*. 'It depends': what 86 systematic reviews tell us about what strategies to use to support the use of research in clinical practice. *(2024)*

Still, there is limited research to answer questions about end user involvement in strategies for equity:

1. Which strategies are most impactful to promote equity?
2. What is the impact of adding end user engagement in implementation to "standard" strategies on equity outcomes?
3. Does tailoring implementation strategies with end user input reduce health care disparities?
4. Which tailoring approaches with end users are cost effective for disparity problems?

For equitable and just implementation of innovations, we must embrace complexity and realize these are career-long, life-long endeavors.

What is the most elegant next step (for you)?*

*adrienne maree brown, Emergent Strategy

Thank you! Let's continue the conversation.

X: @EvaWoodwardPhD
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We are recruiting postdoctoral fellows!

- 2 years, VA funded, 75% research, 25% clinical
- Health equity, community engagement
- Implementation Science Certificate Program
- Suicide prevention, primary care, HIV, PTSD

SCAN ME

There are existing ways to document changes to implementation plans or strategies that may differ for different groups.

Great tool for tracking strategies used

Great tool for tracking when strategies were tailored, by who, when, and why

Integrating implementation science in clinical research to maximize public health impact: a call for the reporting and alignment of implementation strategy use with implementation outcomes in clinical research

Brittany N. Rudd ✉, Molly Davis & Rinad S. Beidas

The FRAME-IS: a framework for documenting modifications to implementation strategies in healthcare

Christopher J. Miller ✉, Miya L. Barnett, Ana A. Baumann, Cassidy A. Gutner & Shannon Wiltsey-Stirman

Implementation strategies involve many aspects

- Action – what is done?
- Actor – who did this?
- Context – physical location, emotional context, social setting
- Dose – how much, how often
- Action target - what is this thought to change?
- Temporality – when did this occur?
- Implementation outcome – how will this impact things?
- Justification – why use this?

Rudd et al., 2020

Think upstream about what is causing inequities or disparities.

1. Partner outside health sectors to implement[1]

2. Use systems science and agent-based modeling approaches to capture multilevel cause and effect[2]

3. Design research questions, data collection, analysis, and interpretation that account for upstream factors – consider Health Equity Implementation Framework and or theories of structural violence, intersectionality, policy and governance [3, 4]

4. Link social determinants of health and other upstream contributors to moderators or health outcomes[1]

1. Brownson RC, Kumanyika SK, et al. Implementation science should give higher priority to health equity. Implementation Sci. 2021;16:28.
2. McNulty M, Smith JD, et al. Implementation Research Methodologies for Achieving Scientific Equity and Health Equity. Ethn Dis. 2019;29:83–92.
3. Woodward EN, Singh, RS, et al. A More Practical Guide to Incorporating Health Equity Domains in Implementation Determinant Frameworks. Implementation Science Communications. 2021.
4. Snell-Rood, C., Trott Haramillo, E., Hamilton, A. B., Raskin, S. E., Nicosia, F. M., Willging, C. Advancing health equity through a theoretically critical implementation science. Translational Behavioral Medicine. 2021.

Acknowledge and plan for uneven power, privilege, and oppression of yourself, your team, and communities you work for

Our process of knowledge production is influenced by our lived experiences, systems in place before us, and thus, our and their biases.

Questions asked / problems of focus

Potential solutions

Implementation methods, theories, strategies, data, analysis

Mechanisms of change

Inequitable and unjust outcomes

Dr. Cory Bradley, Presentation 2022

There are many ways to critically self-reflect

- Self-assessments about cultures, identities, experiences, certain populations, interventions
- Readings, blog posts, infographics
- Consultation
- Reflective writing
- Culturally immersive experiences
- Audio or videotaping your interactions with feedback

privately

with a peer

small groups

supervisor or role model

Just published: "Learning to practice reflexivity engaging communities in implementation science" by Eva Woodward and Irenia Ball