

Sharing research results with study participants and partners: examples from the HEALing Communities Study

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Learning Objectives

- By the end of the seminar, participants will be able to:
 - Explain why it is important to share study results with participants.
 - Identify key components of the HEALing Communities Study's activities around results sharing.
 - Develop a plan to share study results with participants.

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All medical research subjects should be given the option of being informed about the general outcome and results of the study.

World Medical Association. World Medical Association declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA* 2013; 310: 2191–2194. <https://pubmed.ncbi.nlm.nih.gov/24141714/>

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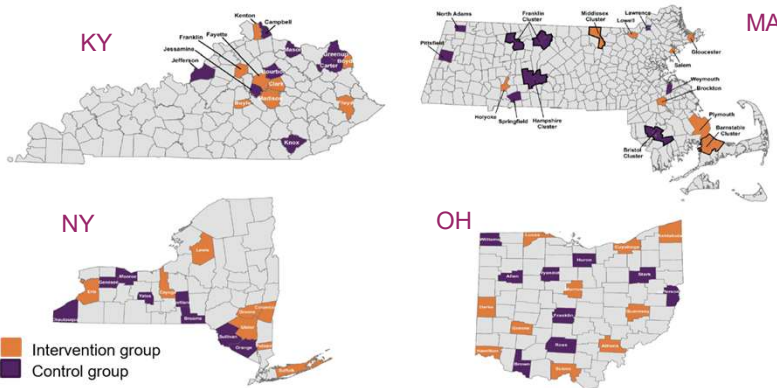
Why share study results with participants?

- Show your appreciation for their participation
- Explain results in layperson terms
- Get their perspectives on results
- Explore next steps
- Research staff satisfaction

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HEALing Communities Study

April 2019 – NIH and SAMHSA funded MA, NY, OH, KY to work with 67 highly affected rural and urban communities to reduce opioid overdose (OD) deaths by implementing a community engaged process to deliver evidence-based practices in healthcare, behavioral health, criminal legal settings



- Communities were the unit of analysis in the RCT
- Each with a high baseline annual opioid overdose rate ($\geq 25/100,000$ adults)
- At least 30% rural
- Total >10 million people

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Communities that HEAL (CTH) Intervention

3 Components



Community Engagement

Diverse coalition expertise >
Enhance EBP selection,
relevance, and
implementation



The Opioid Reduction Continuum of Care Approach (ORCCA)

A menu of strategies to
support EBP
implementation



Community-Based Health Communications Campaigns

Reduce stigma, increase
awareness and adoption of
EBPs



Increase awareness and adoption of evidence-based practices to

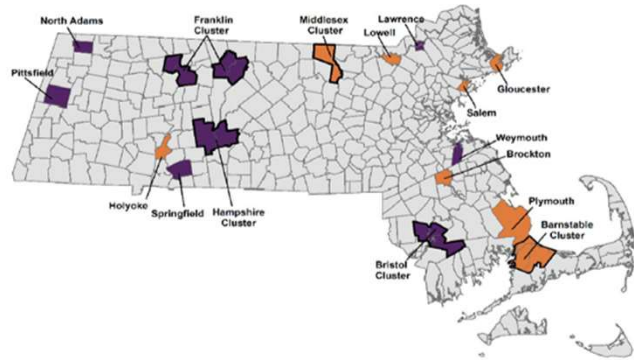
save lives!



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HCS-MA Results Sharing Activities

- Monthly Newsletter
- Community Presentations
- HCS-MA Paper Forum



Monthly Newsletter

Monthly Newsletter

- Aimed at community coalition members, starting sending it broader audience this fall
- Shares information on publications, resources, funding opportunities, successes of community members, job postings
- Sent via constant contact
- Distribution 500+ people



Community Presentations

Goal of Community Presentations

- Share study results
- Discuss how strategies have been sustained
- Introduce resources
- Show our appreciation for their participation

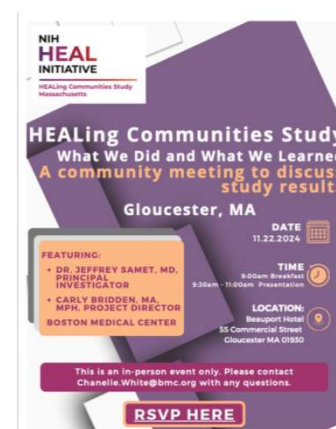
Objectives for today

- Brief review of HCS goals and procedures
- HCS RCT Results
 - Main outcome
 - Secondary outcomes
 - Other study outcomes
- Community data
- HCS dissemination products
- Community discussion on sustainability

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Community Presentation Logistics

- Worked with local community member
- Emailed invitation with PDF of publication
- Google form for registration
- In-person preferred, hybrid or zoom option if requested
- Held in community partner building or hotel
- 90-120 minutes
- Refreshments
- Some tailoring of presentation for each community



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Community Site Visits

Status

- 11/16 completed Sept – Nov 2024 (8-40 attendees)
- 2 scheduled November 2024
- 3 planned early 2025



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Paper Forum

- A presentation series for HCS investigators to present a wide range of study outcomes and discuss implications
- Open to all, aim to have academic and community audience
- Once or twice a month, 1 hour (~20 minute presentation with Q&A discussion)

HCS-MA PAPER FORUM

Mobile treatment for opioid use disorders: Implementation of community-based assessment, medication access interventions

With **DR. AVIKE CHATTERJEE & DR. ALLYSON PARKER**

Date: 11 Dec 2024 Time: 11:00 am EST

[REGISTER NOW](#)

For more information: Avikar@hhs.gov

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HCS- MA Paper Forum Logistics

- Identify papers/topics of interest
- Reach out to authors to schedule
- Advertise (e.g., newsletter, email, LinkedIn)
- Zoom registration form
- Have not been paying presenters

Status

- 4 sessions hosted as of 11/15 (10-15 ppl)
- 3 sessions scheduled before end of 2024
- Sessions will be hosted throughout 2025

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Things to consider

- Budget
 - Include plans and expenses in grant proposal
 - Refreshments & room rental/AV
 - Travel
 - Marketing, printing & supplies
- Staffing resources – scheduling, creating slides & newsletter
- Invitations – keep up to date contact information
- Don't wait too late
- Staff/investigators for presentations
- Participant burden – explore multiple options

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Successes and Challenges

Successes	Challenges
<ul style="list-style-type: none">- People appreciate the team returning and sharing results- Communities are proud of their participation and continued success beyond HEAL- Opportunity for community members to get together again- Research team gains insight on what worked and didn't- Discussion of "what's next"	<ul style="list-style-type: none">- Losing contact with people- Small audiences- Prioritizing data and other information for dissemination- Retaining research staff- Inability to stand up an MA-HCS website- Advertising with enough advance notice

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Your Experience

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Resources

- <https://mrctcenter.org/project/aggregate-results/>
- <https://mrctcenter.org/project/return-of-individual-results/>
- <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-transparency/informing-participants/communicating-study-findings-participants-guidance/#communicate>
- <https://www.google.com/search?q=sharing+results+with+research+participants&ie=UTF-8&oe=UTF-8&hl=en-us&client=safari>