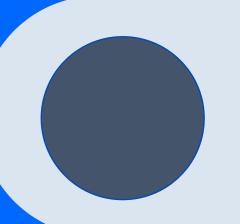
Engaging People with Lived Experience through Community Advisory Boards

Examples from the KyOSK Design Team and Harm Reduction Collaborative of Eastern Kentucky (HRCEKY)



April Young, PhD, MPH
University of Kentucky College of Public Health
June 17, 2025
2025 Kentucky Harm Reduction Summit

Outline

History of the Harm Reduction Collaborative of Eastern Kentucky

Board member recruitment

Board structure

Selected board accomplishments

Harm Reduction Kiosk

Barrier Relief Program

Lessons learned

Video: Board members' experience in their own words

Disclosure

I am named as an inventor on harm reduction vending machine technology for which the University of Kentucky owns the intellectual property.

History of HRCEKY



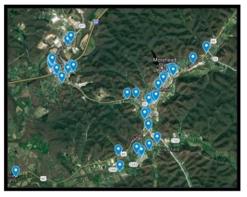


A Story















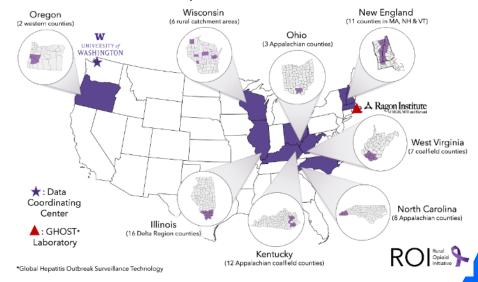


National Rural Opioid Initiative

Funded eight sites in August 2017

Co-funded by National Institute on Drug Abuse (NIDA), Centers for Disease Control and Prevention (CDC), Substance Abuse and Mental Health Services Administration (SAMHSA), and the Appalachian Regional Commission (ARC)

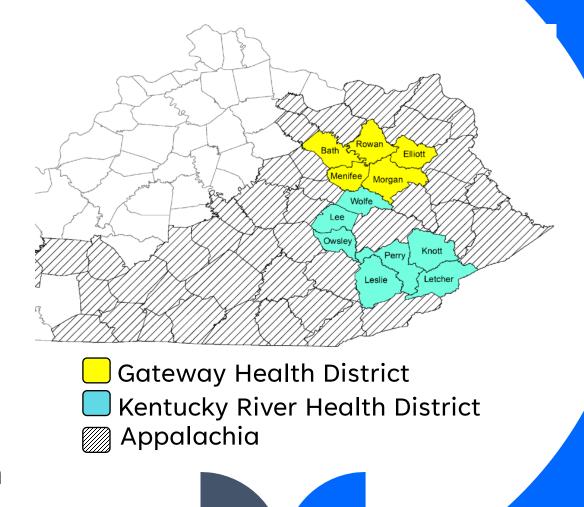
Rural Opioid Initiative Sites





CARE2HOPE

- Kentucky Communities and Researchers Engaging to Halt the Opioid Epidemic (CARE2HOPE)
- Co-led by University of Kentucky and Emory University, with many academic and state partners
- **Purpose:** To partner with residents of the 12 counties to build evidence-based, community-rooted public health responses to the epidemics of opioid misuse, overdoses, HCV, and HIV.



CARE2HOPE Components

Interviews with community leaders (n=82)

Interviews with people who use drugs (n=57)

Community
Academic
Partnerships &
Advisory Boards

Longitudinal surveys with people who use drugs followed over 30 months (n=338)

Community-level trial of intervention for people involved in criminal legal system (n=231)

CARE2HOPE Board

Board Structure

6 to 8 people who use drugs

Met approximately quarterly in person

Meetings lasted approximately 2 hours

Members were paid \$50 per meeting and Chairperson was paid \$75

Example Agenda Items

Challenges encountered accessing services or engaging in risk reduction

Emerging trends in drug market

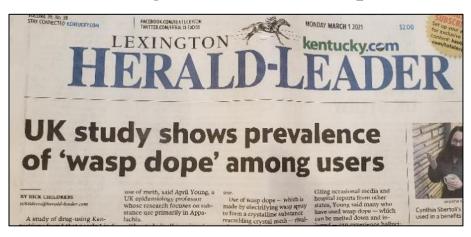
Suggestions related to study methods (i.e., recruitment, survey items)

Review of educational materials developed by study team

Requests for training or information



Projects Inspired by Advisory Board







UK study to test effectiveness of kiosk with harmreduction goods as way to increase access and fight the stigma felt by drug users

Fentanyl Test Strips

KORE

Know what's in your drugs, prevent overdose

Fentanyl test strips can tell you if your drugs contain a deadly opioid called fentanyl or one of its relatives, like carfentanil, Fentanyl is added to drugs like heroin, meth, cocaine, and pills. You should use fentanyl test strips on ALL drugs, not just heroin.

These strips are not perfect - for example, they may miss certain relatives of fentanyl. You could still overdose even if the strip says there is no fentanyl

How to use fentanyl test strips

- ▲ Step 1. Add sterile water (1/4 inch, about 5 ml or 10 drops) to your drug residue and mix well.
 - If injecting, draw your shot into your syringe leaving some residue in your cooker (e.g., spoon can, lid). Add the water (i.e., rinse water) to the cooker and mix well.
 - If snorting, leave some residue on the sides of the bag or surface you snort from if it can hold water. Add the water and mix well.
 - If using pills, break a piece off and crush it or crush the whole pill in a container (e.g., bag, can, cup). Add the water and mix well.
- Step 2. Test. Hold the strip by the blue end. Dip it into the mixture up to the wayy lines (%), but not deeper than the first blue line (-). Hold it there for 15 seconds.
- Step 3. Wait, Remove the strip from the mixture. Lav it on a clean surface. Wait one full minute (60 seconds) for it to process.
- Step 4. Results. If no line appears, something went wrong. Re-do the test. One red line (positive) = Fentanyl Two red lines (negative) = No fentanyl ("two thumbs up", "two is better than one")

How to reduce your overdose risk (from HarmReduction.org)

- . Always carry naloxone. Find where to get it at KyStopOverdoses.ky.gov or ask your local pharmacy.
- Be extra careful if using alone. Try to not use alone or have someone check on you so they can help if you overdose. If you are going to use by yourself, call 1-800-484-3731 (NeverUseAlone.com).
- Take it slow and use less. A little fentanyl goes a long way with fentanyl and overdoses can occur quickly You can always go up, but you can't go down
- Try snorting instead of injecting. Injecting carries the highest risk for overdose
- . Space out doses. Take time between doses because fentanyl acts fast and is different for everyone
- In a group? Take turns. Make sure someone is always alert and that someone has naloxone.
- . Know the signs of an overdose. Call 911 if you see someone overdose.
- Listen to your body. Health impacts overdose risk. Drink fluids, eat, and rest as much as possible

By using fentanyl test strips, you accept all responsibility for any injury or death that could occur, whether the drugs have been tested, or not tested, for fentanyl. Fentanyl test strips are drug paraphernalia.

Developed in consultation with the CARE2HOPE Advisory Board

Preparing to inject

Use a clean syringe, cooker, cotton, and water. If you have no other option but to re-use your or someone else's old syringe or cooker, clean it using water and diluted bleach. Shake the bleach solution around in it and let it sit for 2 minutes. Cleaning it will help but it won't kill all germs and viruses. Using Q-tip cotton to filter is safest; cigarette filters and tampons can contain chemicals and/or small pieces of glass. Do not re-use your cottons; it can cause an infection (i.e. 'cotton fever'). Use clean water to dissolve your drugs; do not use lemon juice.

Tying off

Elastic tourniquets should be used to make veins more accessible. A slip-knot (see figure) is ideal so it can be removed quickly if necessary. Remove the tourniquet once you see blood in the syringe.



Correct needle insertion

Needles should be inserted at a 15° to 35° angle with the bevel opening facing up (see figure). Always insert in the direction of the heart. You've hit a vein when dark red blood moves slowly into the syringe after pulling back the plunger. Avoid hitting an artery, never inject where you feel a pulse and don't go too deep.

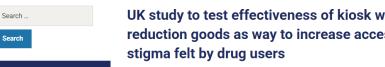
Safest injection location

The arm is the safest site for injecting (see figure for best choices). Be sure to clean the injection site with alcohol pads, soap and water, or hydrogen peroxide. Routine cleaning will reduce vour risk of endocarditis. Also, rotate vour injection sites to avoid a vein collapse. Remember, having caffeine or nicotine before you inject can make it harder to hit veins.



After injecting

Pull the needle out at the same angle it went in. Clean the site and any sites where you missed the vein with an antiseptic wipe or soap and clean water. If you notice a lump, you may have an abscess, Don't drain it yourself; go to a clinic. If you get fever, chills, pain, or a dark line near the lump, get to a clinic quickly because you could have a blood infection.



Development of a Regional Board

Awarded funding from Vital Strategies to:

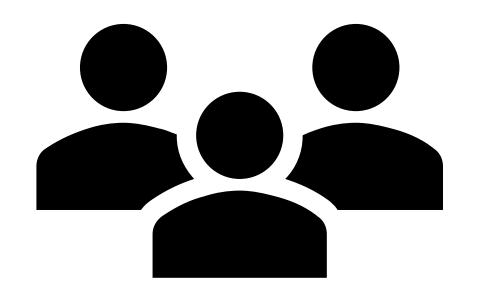
- 1) Sustain the board and expand their regional representation
- 2) Engage the board in advising on the design of a harm reduction vending machine
- 3) ???



Goals for HR-CEKY Funding

Awarded funding from Vital Strategies to:

- 1) Sustain the board and expand their regional representation
- 2) Engage the board in advising on the design of a harm reduction vending machine
 - Shared goal with KyOSK Design Team (to be explained)
- 3) 333



HR-CEKY

Harm Reduction Collaborative of Eastern Kentucky

Building the Board

Building the Board

- Focused on regional representation, with no more than two members per county (eventually abandoned county limits)
- Invited longstanding members of the CARE2HOPE Advisory Board and other boards
- Advertised through flyers at the local syringe service programs
- Reached out to members of studies who had consented to be contacted about future opportunities

Want to be a part of change?

Do you:

- Use Drugs?
- Live in Eastern KY?

You may be eligible.

- Apply today to serve on a harm reduction <u>Community</u> <u>Advisory Board!</u>
- Meetings are confidential
- Members are <u>paid \$50</u> for every 2 hour meeting (up to 6 per year)
- Meetings are <u>led by a</u> person who uses drugs



Visit www.tinyurl.com/UKCAB or scan

the QR code to apply today!





Application

Qualtrics survey collecting the following:

- County of residence
- Whether they used drugs in the past 6 months
- First name and last initial
- Contact info (phone number, email)
- Age
- Gender
- Sex

- Sexual orientation
- Race
- Ethnicity
- Why interested in joining the board
- Willingness to meet virtually, share expertise, and maintain confidentiality



Application Process

- 1. Advertisement through SSPs and research studies
- 2. Person applies through Qualtrics link
- 3. Staff contact person to discuss CAB and screen for inclusion criteria (e.g., drug use within last 6 months)
- 4. Person is invited to serve on board

23 applied online

18 screened by phone

17 attended at least one meeting

Membership



Current Membership

Average age – 39.5

Gender

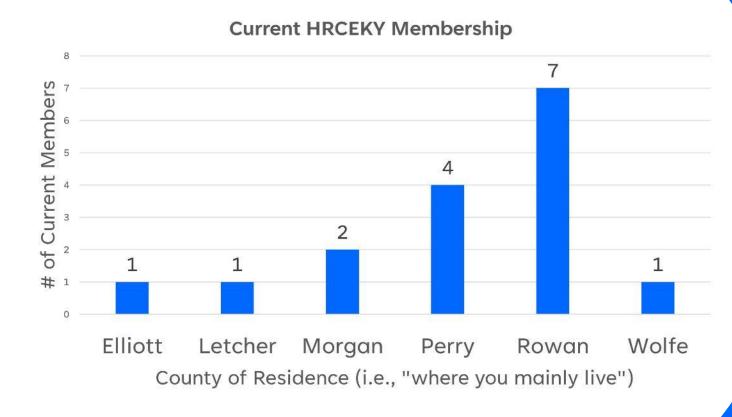
- Man
- Woman 10
- Non-binary 1

Sex

- Male 6
- Female 10

Race

- White 15
- More than 1 one race



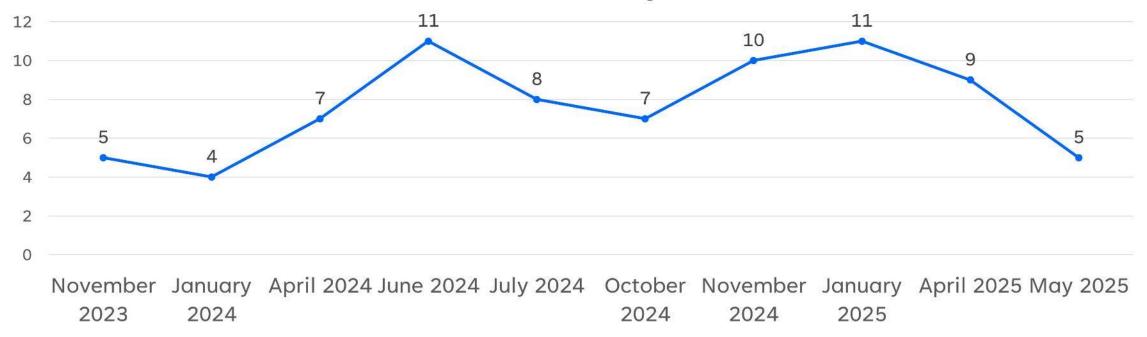


Board Structure

- Led by a four-person executive committee of founding members
 - Supported to attend the 2023 Harm Reduction International Conference
- Full board meets every other month and founding members meet in intervening months.
- All meetings are on Zoom for one hour on Monday afternoons.
- If visitors (e.g., researchers, collaborators, community agencies) request to attend the meeting, the board votes on whether they can attend.
- \$50 per meeting
- \$100 for co-chairs

Meeting Attendance





Name and Mission

Members chose the name and crafted the mission:

"The Harm Reduction Collaborative of Eastern Kentucky's (HCEKY) mission is to help our communities reduce harm, remove barriers, and provide stability for people with experience using substances in Eastern KY. The HRCEKY believes in evidence-based harm reduction practices and acknowledges that improving the health of people who use drugs improves the health of the whole community. We strive to lead all people who use drugs to health and safety regardless of their circumstances and lift others up so they can better themselves and the lives of others. The HRCEKY lends our expertise to community partners and those serving people who use drugs in Eastern KY."

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 - Shared goal with KyOSK Design Team (to be explained)
- 3) 333

Harm Reduction Kiosk (KyOSK)

Harm Reduction Kiosks

In our studies in rural Eastern Kentucky, ~50% of people who inject drugs are not going to the syringe service programs.

Reasons include fear of being discovered as a person who uses drugs, fear of law enforcement, knowing staff, stigma, lack of transportation.

Participants wanted a more discrete, accessible option for harm reduction service access.

Background

Harm reduction "vending machines" have been operating globally for more than **30** years and the first study on them was published **27** years ago.

Studies have found that they can expand access to supplies by expanding hours of service, offering increased privacy, and increasing geographic coverage of services.



KyOSK Study

Received funding in September 2022 to launch a study to design and test the effectiveness, implementation, and cost-effectiveness of a harm reduction kiosk **tailored to the local community** (e.g., a rural county in Eastern Kentucky).

The "KyOSK Design Team" of local and state partners and people with living experience with substance use was convened to guide the tailoring.



KyOSK Design Team

Eight people with living experience with substance use Four local health department / SSP partners Six state agency partners

Meetings are in-person in the local community, with a hybrid attendance option

Began meeting in April 2023

Eight meetings as of May 2025



Artist: Sarah Cooper



Features Decided by Design Team

- Machine type
- Access method
- Appearance and logo
- Installation location
- Supplies and supply packaging
- Supply limits
- Call-back menu

**Decisions guided by focus group and survey data, personal expertise, and local and state policy





HR-CEKY Votes

Extra features requested requiring board approval:

- Dispense a personal sharps container with each syringe vend
- Allowance for syringe type choice
- Detection mechanism when sharps bin is full
- Mechanism for preventing opening until valid code is entered



Harm Reduction Kiosks

Machine for other supplies and service call-back



Syringe exchange machine

Goals for HR-CEKY Funding

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- 3) ???

Launching programs

Cost savings resulted from the slow recruitment of board members.

Board members were asked what to do with the cost savings.

Board members were provided with ideas and asked to generate their own.

Board members were asked to choose one ambitious option and one that seemed feasible to accomplish quickly.

Discussions During Board Meetings

During June 2024 meeting, HRCEKY members discussed ideas for funds that would:

- Promote harm reduction
- Keep people going to harm reduction services
- Pay for basic needs like housing and transportation

- Reduce stigma in the community
- Raise awareness of harm reduction principles

Activities Considered by HR-CEKY

Choose 1 <u>more feasible</u> activity

- Naloxboxes
- Increasing SMART Meetings
- Overdose education and direct naloxone distribution

Choose 1 <u>more ambitious</u> activity

- Barrier relief program
- New vending machines (in addition to KyOSK)
- Drug checking service expansion

Activities Considered by HR-CEKY

Choose 1 <u>more feasible</u> activity

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Choose 1 more ambitious activity

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Barrier Relief Program

Purpose

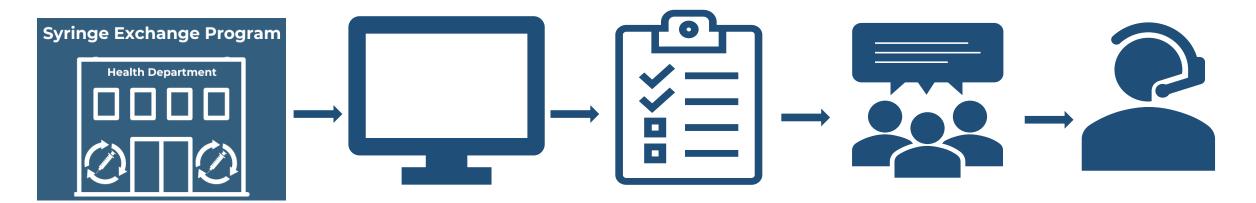
To alleviate barriers to engaging in harm reduction and/or to accessing harm reduction, treatment, and/or recovery services.

Timeline

- Board voted to launch barrier relief program in June 2024
- Team engaged Voices of Hope to assist in administering program
- Board set limit on administrative costs and deadline for launch
- Agreement was established with Voices of Hope to administer program in October 2024
- Program launched in December 2024



Application Process



Clients apply at SSP*

SSP staff help client complete short online application and upload documentation

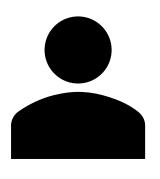
Board Liaison reviews and obtains additional information, if needed** Liaison or board approval (depending on size of request)

Voices of Hope administers the barrier relief

*Only available in the 12-county HR-CEKY region

Examples: Lease agreement for rental assistance, car repair quote for car repair assistance Note: SSP staff have gas cards available on site for distribution for applicants in need of gas cards

Barrier Relief By The Numbers



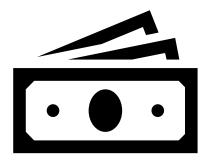
201

unique people served



331

requests approved



\$10,721

provided



*Data from December 17, 2024 through May 16, 2025

Barrier Relief Requests

Count	Type of Assistance
310	Gas card
7	Bicycle
5	Utility bill (including cell phone bill)
2	Laundry kit (laundry detergent pods, fabric softener, dryer sheets, hamper)
2	Rent or security deposit assistance
2	Tent
1	Other (e.g., drug testing fees, prescription medication, etc.)
1	Sleeping bag
1	Vehicle repair or maintenance

^{*}Data from December 17, 2024 through May 16, 2025



Lessons Learned

Harm Reduction Collaborative of Eastern Kentucky

Tips for Creating PWLE Advisory Boards

- 1) Liaison position is <u>crucial</u>.
 - If possible, find Liaison who has experience investigating/solving problems and can work with population to build trust.
- 2) Be <u>transparent</u> at every step of process with the board.
 - Members should set and understand the review process, compensation structure, member expectations, etc.
- 3) Establish leadership committee early in the process.



Tips for Creating PWLE Advisory Boards

- 4) Financial compensation is important.
 - Our members valued being compensated for their time and effort rather than provided with food or swag.
- 5) Virtual meetings can work with members in rural settings.
 - Despite broadband challenges in rural communities, virtual meetings overcome transportation barriers.
- 6) Establish program outcomes and hold regular progress reports.
- 7) In program implementation, anticipate board member needs.

First-hand Accounts of Board Experience

<u>Video</u>

Produced by Linda Kim from the University of Kentucky College of Public Health. Filmed on May 16 and May 22, 2025



Board Members

HRCEKY

Jason H

Ashley B

Marcus C

Elizabeth S

Larry S

Drake B

Glenda P

Natasha P

Rick S

Unnamed board members

KyOSK Design Team

Elizabeth S

Larry S

Shirley Candybar C

Magic Man

Paula S

Patty S

Kerri BK

Harold F

Pamela Wright

Scott Lockard

JoAnn Fraley

Jana Collins

Linwood Strenecky

Chase Barnes

Connie White

Van Ingram

Caitlyn Hood

Acknowledgments

HRCEKY

HRCEKY Members

Lisa Maybrier

Voices of Hope

Syringe service program staff

Kentucky River District Health

Department

Gateway District Health

Department

Dave Lucas (Vital Strategies)

KyOSK

KyOSK Design Team Members

KyOSK Study Staff

KyOSK Study Participants

KyOSK Co-investigators

Chelsi Cheatom

Susannah Stitzer

SUD Support, Education, & Destigmatization Student Organization

Kentucky Opioid Response

Effort (KORE)

KIRP / Target 4

Kentucky Harm Reduction

Coalition

Kentucky Department for Public

Health

Kentucky Office of Drug Control

Policy

Kentucky River District Health

Department

Gateway District Health

Department

Machine manufacturers

Funding

HRCEKY and machine development funding from Vital Strategies, Inc. (PI: Young, Moffitt)

The KYOSK Study is funded by the National Institute on Drug Abuse (R01 DA055872, PI: Young).

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health, Vital Strategies, or agency partners. The funding agencies and partners had no role in design; information collection, management, or interpretation; preparation of this presentation, or decision to present this content.





Thank you!

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