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Partnering to Accelerate Research into Action

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HEAL CONNECTIONS
SHARING SESSION

Communicating Your Research with Plain Language Materials

December 7 | 1PM EST

Alexandra Collins, PhD
(she/her)
Assistant Professor, Brown University School of Public Health

Claire Macon
(she/her)
Research Assistant, People, Place, and Health Collective

Julia Vail, MA
(she/her)
Communications Project Manager, Duke Clinical Research Institute

Maya Ragavan, MD, MPH, MS
(she/her)
Assistant Professor, University of Pittsburgh School of Medicine

Joseph Amodei, MFA
(they/them)
Assistant Professor, Lehigh University

HEAL CONNECTIONS
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Communicating Your Research with Plain Language Materials

TODAY'S AGENDA

1:07 to 1:15 p.m.
Lay Summary Development: Best Practices and Findings from Pediatric Trials Network Formative Research with Julia Vail

1:15 to 1:35 p.m.
The Community Vitality Collaborative + Knowledge Translation Strategies with Maya Ragavan & Joseph Amodei

1:35 to 1:55 p.m.
testRI: Developing a community-driven drug supply surveillance system in Rhode Island

1:55 to 2:00 p.m.
HEAL Connections process, meeting evaluation

2:00 to 2:25 p.m.
Q&A, peer-to-peer engagement, workshop your materials

What You Will Learn

1. The best practices for translating your research, choosing the best format for dissemination, navigating common pitfalls, and tailoring materials to your specific audience.

2. The importance of engaging community partners and people with lived experience in the research and content development process to improve your final product and foster bi-directional communication throughout the life of your study.

3. How to partner with HEAL Connections and receive support for your creation of plain language materials.

Lay Summary Development: Best Practices and Findings from Pediatric Trials Network (PTN) Formative Research

December 7, 2023

Duke Clinical Research Institute | FROM THOUGHT LEADERSHIP TO CLINICAL PRACTICE

What is a lay summary?

- Plain-language summary provided after the close of a study to inform participants, stakeholders, and the public on what was learned
- Why provide one?
  - Disseminate findings to a broader audience
  - Honor participants as active partners in research
  - Give participants a sense of closure
  - Have the potential to enhance recruitment and retention
  - Inspire greater public trust in clinical research

Developing lay summaries: Process

- Budget ~30 hours for the development of a lay summary.
- Start with the Clinical Study Report (CSR) or the primary results manuscript.
- Use language that is fair, balanced, factual, and non-promotional.

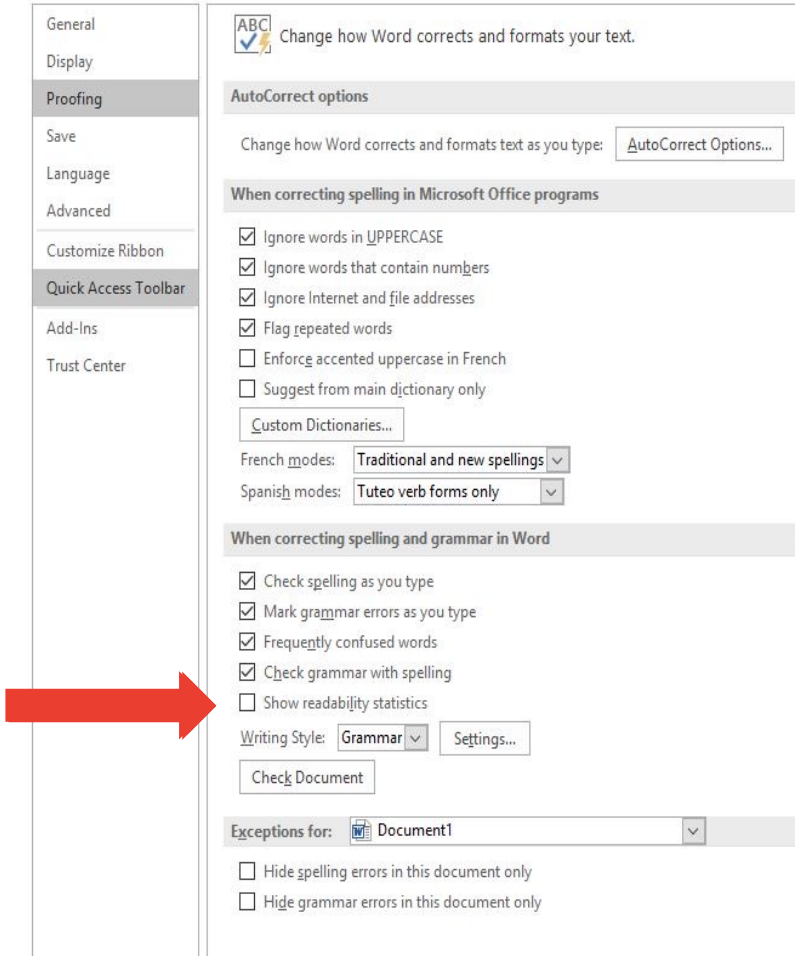
Developing lay summaries: Content

Be sure to include:

- Results of the primary endpoint
- Drug-related adverse events
- Impact of the results to patients and clinicians
- Future research plans
- An opportunity to learn more, such as:
  - Link to published manuscript
  - Link to ClinicalTrials.gov with the study identifier
  - Study website, study team contact information
- Date when summary was completed, a statement that results are from one study and that other studies may have different results

Developing lay summaries: Content

- Avoid jargon and acronyms.
- Write in clear, short sentences.
- Use readability resources and tools, such as Flesch Reading Ease and Grade level tools in MS Word:
  - Under “Review” tab, go to “Language” and pull down to “Language Preferences.”
  - Under “Proofing,” check the box that says, “Show readability statistics.”
  - When you go to “Spelling and Grammar,” the readability score will appear.



Developing lay summaries: Design

- Use bold headings (Q&A format can aid in understanding)
- Make use of bullet lists when possible to avoid long paragraphs of text
- Break up text with white space when possible
- Use infographics, models, or diagrams to include more visual content and explain findings

THE AMPICILLIN IN INFANTS STUDY

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WHAT WERE THE STUDY RESULTS?
Most of the infants responded best to a dose that was based on:
- Their age
- How far along in the pregnancy their mothers were when they were born

Based on these findings, researchers were able to suggest a dose of ampicillin that was both safe and effective for newborns.

WHAT SIDE EFFECTS DID NEWBORNS HAVE?
None of the newborns had any side effects from taking the medicine.

142 BLOOD SAMPLES

WHAT HAPPENED DURING THE STUDY?
Over a three-month time period, a total of 142 blood samples were taken from 73 newborns (about 2 samples per newborn). These samples were taken as part of the newborns' regular medical care, so only a few extra needle sticks were needed.

WHAT KIND OF STUDY WAS THIS?
The study enrolled 73 newborns at nine sites who were already taking ampicillin to treat an infection. It was an open-label study, meaning that both the researchers and families knew that the infants were taking the drug. After the dose of ampicillin was given, researchers checked the levels of ampicillin in the infants' bodies over time to find out what dose was safest and most effective.

WHERE CAN I LEARN MORE ABOUT THIS CLINICAL TRIAL?
A summary of the results can be found online at **pediatrictrials.org**. If you have additional questions, please speak with the doctor or staff at your study site.

73 NEWBORNS

9 RESEARCH SITES

WHO CONDUCTED THE STUDY?
The study was conducted by the Pediatric Trials Network (PTN), a group of more than 100 research sites around the world that are working to find the safest and most effective doses of commonly used medicines for infants and children. Children aren't just little adults. Their bodies are growing and changing, meaning that they process medicines differently than adults do. The PTN works to make sure doctors and families have the information they need to give children the right dose: one that will get them well and keep them safe.

The study was made possible with support from the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

WHAT HAPPENS NEXT?
The results of this study will be sent to the U.S. Food and Drug Administration (FDA), a government agency that approves drugs and devices used to treat patients. Our findings may be used to change this medicine's "label," or the printed information that is included along with the drug. The findings will also be published in scientific journals. Both the label and publications can provide doctors with information to help them give the safest, most effective dose of this medicine to children.

** This summary was completed on [month/year]. Newer information since this summary was written may now exist. This summary includes only results from one single study. Other studies may find different results.*

PEDIATRIC TRIALS NETWORK
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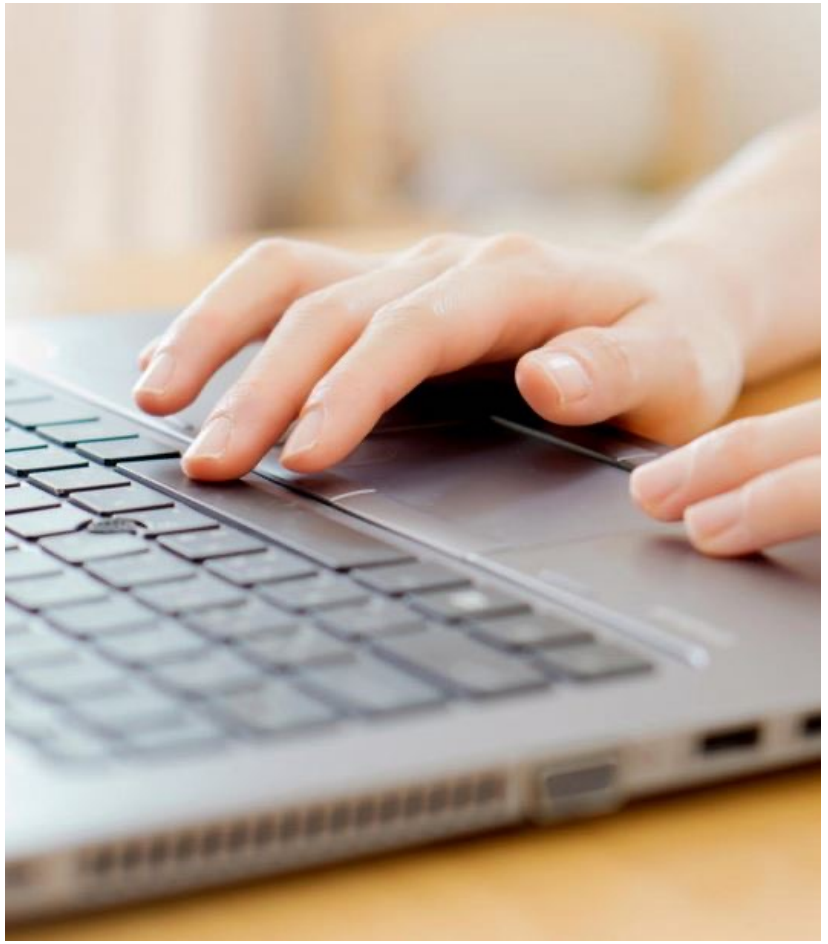
Developing lay summaries: Dissemination

- Provide thank-you note during the last study visit, including details for accessing lay summaries when available.
- If research sites are expected to distribute hard copies, this must be specified in the site agreement.
- We typically distribute via the study website:
  - Gives participants the choice to access/read it
  - Allows them to easily share with a third party
  - Make sure it does not appear as promotional



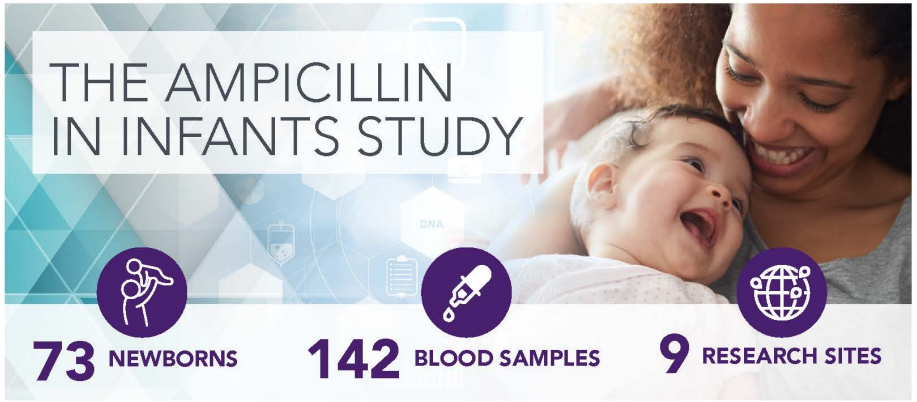
Developing lay summaries: Other considerations

- Update consent language template to include the intent to provide lay summaries. Do not provide too much detail.
- Make sure study budget accounts for development of lay summaries.
- Make sure to get IRB approval of summary and distribution plan
- Ensure lay summaries are translated into the same languages in which the ICF was provided

Formative research with adolescents and caregivers

- Conducted by the Pediatric Trials Network (PTN) in partnership with DCRI Communications and the Duke BASE Lab.
- Purpose was to determine how, when, where, and what to provide in summaries of research results.
- Qualitative study using one-on-one, in-depth interviews with 27 people representing a diverse cohort (24 caregivers and 3 adolescent study participants).
- Assessed comprehension, attractiveness, acceptability, relevance, persuasiveness, and credibility of two versions of the same lay summary.

THE AMPICILLIN IN INFANTS STUDY



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WHAT SIDE EFFECTS DID NEWBORNS HAVE?

None of the newborns had any side effects from taking the medicine.

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WHERE CAN I LEARN MORE ABOUT THIS CLINICAL TRIAL?

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Findings: Attractiveness

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Good:

- Overall look and feel, particularly the picture of mom and baby.
- "Clean" look of the summary.
- Flow of information. Participants said they could read the summary in logical order and knew what to focus on next.

Needs improvement:

- Icons were not positioned by the relevant text. You have to read entire summary to get context on the numbers.
- One participant noted she would not like a picture of a happy, healthy baby and mom if her child was in the NICU.

Findings: Attractiveness

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Good:

- Boxed text sections helped with organization.
- One participant said she liked the inclusiveness of the graphic (adult could be mother or father).

Needs improvement:

- Boxed text sections led to no coherent flow – participants did not know where to read next.
- The website link in the middle of the page compared at the end of the document.
- Purple color too dark, not appealing.

Findings: Relevance

- Most caregivers felt the information shared in the summary was written specifically for them as caregivers.
- However, they differed on whether it would be appropriate for adolescents.

  Some participants suggested that PTN provide children ages 12-14 an easier-to-read summary that was lighter on details (results only).

  They also suggested making the design elements more child-friendly for this audience.
- Some participants thought it may be more appropriate to only give a lay summary to the caregiver and allow them to share what they feel is suitable with their child.

Findings: Persuasiveness

Nearly all participants thought the summaries would encourage participants to:

- Take action, such as learn more and/or get involved in PTN research.
- Visit the PTN website.
- Share information from the summary with family, friends, or doctor.

After reading the summary, most participants:

- Believed they learned about the safety of the drug when used in newborns.
- Said they understood where to find additional information about the study.
- Said they understood that the PTN study was the first step in the FDA process of providing new information about drugs to health care providers.

Putting Knowledge into Practice: ECHO

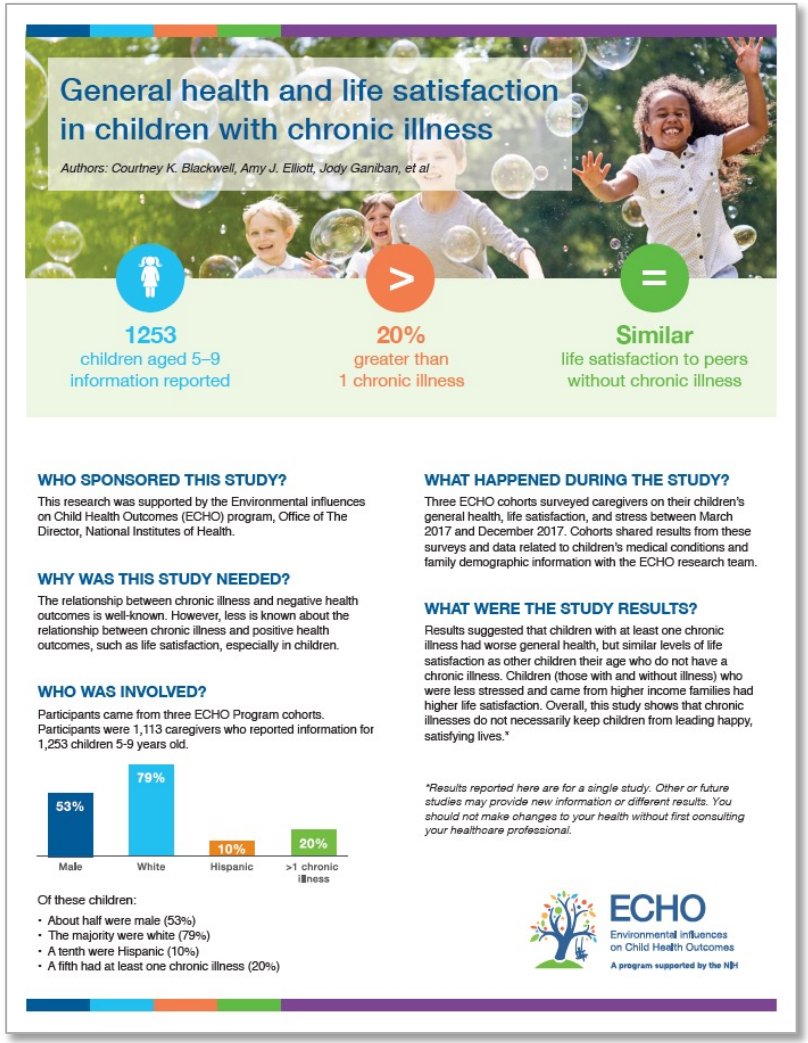
– Reach out to author teams at journal submission with lay summary request form.

– Form includes questions like:

- What are main takeaways?
- What were study results?
- Who was involved?
- When did study take place?
- What happened during the study?
- Why was the study needed?

– Ask them to make as lay friendly as possible, but realize you will likely have to do some revisions yourself.

– Consider other formats, like flash talks, to accommodate different learning styles and preferences.



The Community Vitality Collaborative
+
Knowledge Translation Strategies

Mobilizing and Organizing in a Community to Promote Vaccine Equity

Maya Ragavan, MD, MPH, MS
Assistant Professor of Pediatrics

Joseph Amodei (they/them), MFA
Assistant Professor of Media Design

Acknowledgements

- Urbankind Institute, Urban League of Greater Pittsburgh, Casa San Jose, Neighborhood Resilience Project, community co-leads of the CVC
- Elizabeth Miller, MD, PhD; co-founder of CVC
- Mylynda Massart, MD, PhD; Ken Ho, MD research co-leads of the CVC
- All members of the Community Vitality Collaborative with whom we have had the immense privilege of partnering
- Elizabeth Lusardi, Finley Keeler, Olivia Migliori and Erin Mickievicz who have created many of the infographics we are showing
- University of Pittsburgh Momentum Funds, Allegheny County Health Department, and Judy Martin, MD for providing funding

Land Gratitude

We live and work on the ancestral lands of the Osage, Lenape, and Shawnee people

We pay tribute and respect to their past, present, and future people, community, and culture

Community Vitality Collaborative (CVC)

A **partnership** among community-based organizations, community members, researchers, health systems leaders, and leaders from public health agencies

Mission focused on dismantling COVID-19 related health inequities through promoting vaccine equity

Why we convened

Pittsburgh was a site for the COVID-19 vaccine trials and the trial site PIs wanted to put together an advisory committee

Team came together to try to do something different and reimagine community-partnered research

Intentionality about our name

Advisory: “having the power to make recommendations but not take action enforcing them”

Community partnered principles

- Ability to anticipate and resolve problems
- Committed partnerships
- Sustainability
- Authentic, effective, and transparent communication
- Mutually respectful and reciprocal relationships

Scott et al., 2021

The CVC is led by community-based organizations

PROUD HAVEN
a place to be home

UrbanKind
INSTITUTE

Urban League of
Greater Pittsburgh

UPMC
LIFE CHANGING MEDICINE

ADVOCACY STRATEGIES

Group meetings

- Have met weekly from 3 to 4 PM on Wednesday since July 2020
- Attendance ranges from 20 to 40
- Mix of updates, conversations, community announcements, research presentations, reflections

COVID-19 vaccine clinical trials

'I Won't Be Used as a Guinea Pig for White People'

Mistrust of vaccines runs deep in African-American communities. Against formidable odds, Father Paul Abernathy and his teams are trying to convince residents of Pittsburgh's historic Black neighborhoods to volunteer for trials testing a Covid-19 shot.

Community-partnered vaccine clinics

Inclusion of community health workers as Phase 1A during initial vaccine roll out

Community led clinics at community-based sites

Schools, outdoor spaces, community-based organizations

Vaccine community-based townhalls

Vaccine celebrations!

Trustworthiness workgroup activities

Open agenda time to reflect, heal, and build relationships

Co-created research

- Source of trustworthy COVID-19 information or Black and Latine adults in Pittsburgh
- Researcher perspectives about how to build trustworthiness in research

"If it's difficult to identify participants from Black communities and if it's difficult to get members of those communities to trust me, then the easiest thing is just not to include them… the exclusion from research is not traumatic in the easily or usually defined sense, but it perpetuates injustice and **it perpetuates a scientific self-delusion** in the sense that we think that our results apply to all individuals, but we haven't included all individuals in our research."

Supporting **language access** during vaccine distribution

BCAP

Casa San Jose

APALA
ASIAN PACIFIC AMERICAN LABOR ALLIANCE, AFL-CIO
PITTSBURGH
APALANET.ORG

JFCS PITTSBURGH

ADVOCATE
PITTSBURGH

Infographics as a knowledge translation strategy

Why infographics?

- Easy to make
- Visual and ideal for co-creation
- Easy to share with others
- Visually tailored to the needs of the Medi Ecosystem you are working in
- Can include QR codes for people to access more information
- Can be used to share research results, information more broadly, or for any other type of knowledge translation!
- Aligned with a language justice approach

Research infographic

Research infographic: Instagram Panels

LAS PERSPECTIVAS Y EXPERIENCIAS DE LOS INMIGRANTES Y REFUGIADOS CON LA VACUNA CONTRA CORONAVIRUS

Un estudio de investigación

CIRCLE LAB
COMMUNITY INTEGRATED RESEARCH FOR CARE AND LANGUAGE EQUITY

¿RECUERDA TODA LA CONFUSIÓN CUANDO SE APROBARON LAS PRIMERAS VACUNAS CONTRA EL CORONAVIRUS?

¿Cómo fueron las experiencias de las personas viviendo en un lugar en dónde no hablaban el idioma principal y fue difícil agendar una cita médica ,aún antes del inicio de la pandemia?

¿QUÉ QUEREMOS APRENDER?

La meta de este esudio de investigación fue colaborar con líderes de la comunidad para explorar las perspectivas de las comunidades inmigrantes y de refugiados que no hablan inglés respecto a las vacunas contra el coronavirus y sus experiencias con la vacuna.

¿A QUIÉN INCLUIMOS?

Los participantes fueron de cuatro grupos prominentes de inmigrantes y refugiados en Pittsburgh, Pensilvania. Los participantes no hablaban inglés (es decir, inglés no fue su idioma principal ni lo entienden bien).

- Latine o Hispano (español)
- Butanés (nepalí)
- Congolés (francés)
- Chino o Taiwanés (mandarín)

66 INDIVIDUOS PARTICIPARON
85% DE ELLOS FUERON VACUNADOS

¿CÓMO LO HICIMOS?

Los líderes de la comunidad facilitaron **entrevistas en grupos** con los miembros de la comunidad en su idioma preferido.

Los grupos fueron organizados por la **preferencia del idioma y por el estado de vacunación** de los participantes.

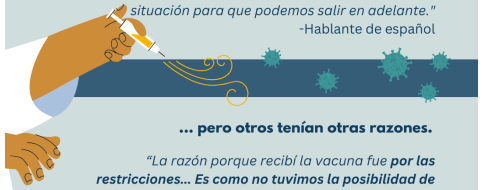
LO QUÉ ENCONTRAMOS

1. MUCHAS VECES LA EXPERIENCIA DE RECIBIR LA VACUNA FUE POSITIVA
2. LOS PARTICIPANTES SE ENFRENTARON BARRERAS DEL IDIOMA Y A MENUDO DEPENDÍA DE LOS MIEMBROS DE LA FAMILIA PARA LA INTERPRETACIÓN
3. LAS ORGANIZACIONES COMUNITARIAS AYUDARON A CONECTAR A LOS PARTICIPANTES CON LAS VACUNAS
4. LOS PARTICIPANTES NO VACUNADOS COMPARTIERON MIEDO DE LOS EFECTOS SEGUNDARIOS Y LA CREENCIA EN LA INMUNIDAD NATURAL

1 EN GENERAL, LA VACUNA FUE VISTA COMO CONFIABLE Y LAS EXPERIENCIAS DE RECIBIRLA FUERON POSITIVAS

La mayoría de los participantes recibieron la vacuna porque tenían confianza en su efectividad...

"Para mí, confío en la ciencia. Hay muchas personas unidas trabajando para mejorar la situación para que podemos salir en adelante."
-Hablante de español



... pero otros tenían otras razones.

*"La razón porque recibí la vacuna fue **por las restricciones... Es como no tuvimos la posibilidad de elección.** Nos estaban obligando a vacunarnos si queríamos viajar."*
-Hablante de francés

2 NO TODO FUE FÁCIL

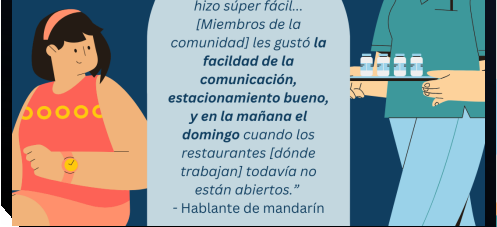
Los participantes dijeron que el idioma, la transportación, el registro complicado y solicitudes para documentos fueron las partes más difíciles de la experiencia.

*"La persona que conocí hizo todo lo posible para asegurar que la entendía. Fue una experiencia maravillosa, pero cuando regresé **para el segundo dosis, era de la otra manera.**"*
-Hablante de francés

*"No entiendo inglés muy bien... **Mi hijo hizo el papel del intérprete allí.**"*
-Hablante de nepalí

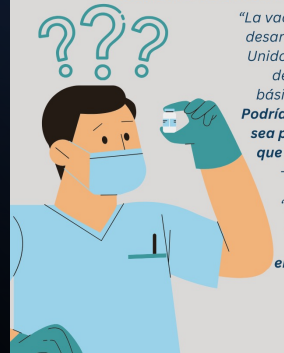
3 LAS ORGANIZACIONES COMUNITARIAS JUGARON UN PAPEL GRANDE

Las organizaciones comunitarias que sirven a los inmigrantes y refugiados contectaron a los participantes con las vacunas y llevaron a cabo algunas clínicas de vacunas que quitaron barerras culturales y de idioma.



*"La clínica asiática lo hizo súper fácil... [Miembros de la comunidad] les gustó **la facilidad de la comunicación, estacionamiento bueno, y en la mañana el domingo** cuando los restaurantes [dónde trabajan] todavía no están abiertos."*
- Hablante de mandarín

4 LOS PARTICIPANTES NO VACUNADOS COMPARTIERON MIEDO DE LOS EFECTOS SEGUNDARIOS Y LA CREENCIA EN LA INMUNIDAD NATURAL



*"La vacuna fue investigada y desarrollada en los Estados Unidos entonces los sujetos del investigación fueron básicamente caucásicos... **Podría ser que la protección sea peor para los asiáticos que para los caucásicos.**"*
-Hablante de mandarín

*"Estoy pensando en mi mismo, **todavía no he tenido un hijo, entonces no quiero que esto sea afectada,** todavía estoy jóven."*
-Hablante de francés

PODEMOS MEJORAR

Los participantes ofrecieron sugerencias para los proveedores médicos para mejorar el acceso a las vacunas y la confianza y el acceso en las comunidades que no hablan inglés.

- Proveer información sobre las vacunas que sea más clara y accesible
- El acceso del idioma es ESENCIAL (personal bilingües o servicios de interpretación)
- Permitir la vacunación en casa o sin cita
- Ofrecer las vacunas en las oficinas médicas y en los lugares del empleo

INVESTIGACIONES FUTURAS PUEDEN ACLARAR ALGUNOS DETALLES

Investigaciones futuras deben explorar las diferencias en las experiencias sobre el coronavirus entre los grupos inmigrantes y refugiados y por dónde viven...

... y deben estudiar el trabajo de las organizaciones comunitarias en los esfuerzos para vacunar a sus comunidades.

NUESTROS PRÓXIMOS PASOS

El equipo del estudio sigue construyendo colaboraciones en las comunidades y en las investigaciones con participación de la comunidad.

NUESTROS ASOCIADOS

Asian Pacific American Labor Alliance of Pittsburgh + Bhutanese Community Association of Pittsburgh + Casa San José + Congolese Union of Pittsburgh + Jewish Family and Community Services + Organization of Chinese Americans

Para mas información sobre este estudio y para ver otros proyectos visítenos

RAGAVANCIRCLE.COM

CIRCLE LAB
COMMUNITY INTEGRATED RESEARCH FOR CARE AND LANGUAGE EQUITY

EL ESTUDIO FUE REALIZADO EN EL VERANO DE 2021

Research infographic: Instagram Panels

IMMIGRANT AND REFUGEE PERSPECTIVES AND EXPERIENCES WITH THE COVID-19 VACCINE

A Research Study

CIRCLE LAB
COMMUNITY INTEGRATED RESEARCH FOR CARE AND LANGUAGE EQUITY

REMEMBER HOW CONFUSING IT WAS WHEN THE COVID-19 VACCINES FIRST CAME OUT?

What would it have been like if you were living in a place where you didn't speak the language and had a hard time making doctor's appointments even before the pandemic?

WE WANTED TO FIND OUT

The goal of this study was to work with community partners to explore the perspectives of non-English speaking immigrant and refugee communities on COVID-19 vaccines and on their vaccination experiences.

WHO DID WE INCLUDE?

Participants were from four major immigrant and refugee groups in Pittsburgh, Pennsylvania. Participants were non-English speaking (English was not their first language and they don't understand it well).

Latine or Hispanic (Spanish)	Bhutanese (Nepali)
Congolese (French)	Chinese or Taiwanese (Mandarin)

66 INDIVIDUALS PARTICIPATED
85% WERE VACCINATED

HOW DID WE DO IT?

Our community partners hosted **group interviews** with community members in their preferred language.

Groups were organized by the participants' **language preference** and **vaccination status**.

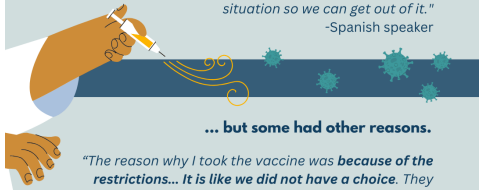
MAIN FINDINGS

1. THE VACCINATION EXPERIENCE WAS OFTEN POSITIVE
2. PARTICIPANTS FACED LANGUAGE BARRIERS AND OFTEN RELIED ON FAMILY MEMBERS FOR INTERPRETATION
3. COMMUNITY ORGANIZATIONS HELPED CONNECT PARTICIPANTS TO VACCINES
4. UNVACCINATED PARTICIPANTS SHARED FEARS OF SIDE EFFECTS AND BELIEF IN NATURAL IMMUNITY

1 OVERALL, THE VACCINE WAS SEEN AS TRUSTWORTHY AND VACCINATION EXPERIENCES WERE POSITIVE

Most participants got the vaccine because they trusted in its effectiveness...

*"Personally, **I believe in science**. There are many people united in working to improve the situation so we can get out of it."*
-Spanish speaker



... but some had other reasons.

*"The reason why I took the vaccine was **because of the restrictions... It is like we did not have a choice**. They were forcing us to be vaccinated if we wanted to travel."*
-French speaker

2 IT WASN'T ALL EASY

Participants said that language, transportation, and complicated registration and documentation requests were some of the most difficult parts of the experience.

*"The person I met did everything to make sure that I was understanding her. It was a wonderful experience but when I went back **for my second dose, it was the other way around.**"*
-French speaker

*"I don't really understand English... **My child played the role of interpreter there.**"*
-Nepali speaker

3 COMMUNITY ORGANIZATIONS PLAYED A BIG ROLE

Community organizations that serve immigrants and refugees connected participants with vaccines and held vaccine clinics that helped remove some language and cultural barriers.

*"The Asian clinic made it really easy! ... [Community members] really liked the **ease of communication, good parking, and on a Sunday morning** when restaurants [their work places] are not yet open."*
- Mandarin speaker

4 UNVACCINATED PARTICIPANTS SHARED FEARS OF SIDE EFFECTS AND BELIEF IN NATURAL IMMUNITY

*"The vaccine was researched and developed in the United States so research subjects were basically Caucasians... **It could be that the protection is worse for Asians than that for Caucasians.**"*
-Mandarin speaker

*"I'm thinking about myself, **I haven't had a child yet so I just don't want that to be affected**, I'm still young."*
-French speaker.

WE CAN DO BETTER

Participants offered suggestions to providers for improvements to vaccine access and trust and access in non-English speaking communities.

FUTURE RESEARCH CAN CLEAR UP SOME DETAILS

Future research should explore the differences in COVID-19 experiences between immigrant and refugee groups and by where they live...

... and should look into the work of community organizations on vaccination efforts.

OUR PARTNERS

Asian Pacific American Labor Alliance of Pittsburgh + Bhutanese Community Association of Pittsburgh + Casa San José + Congolese Union of Pittsburgh + Jewish Family and Community Services + Organization of Chinese Americans

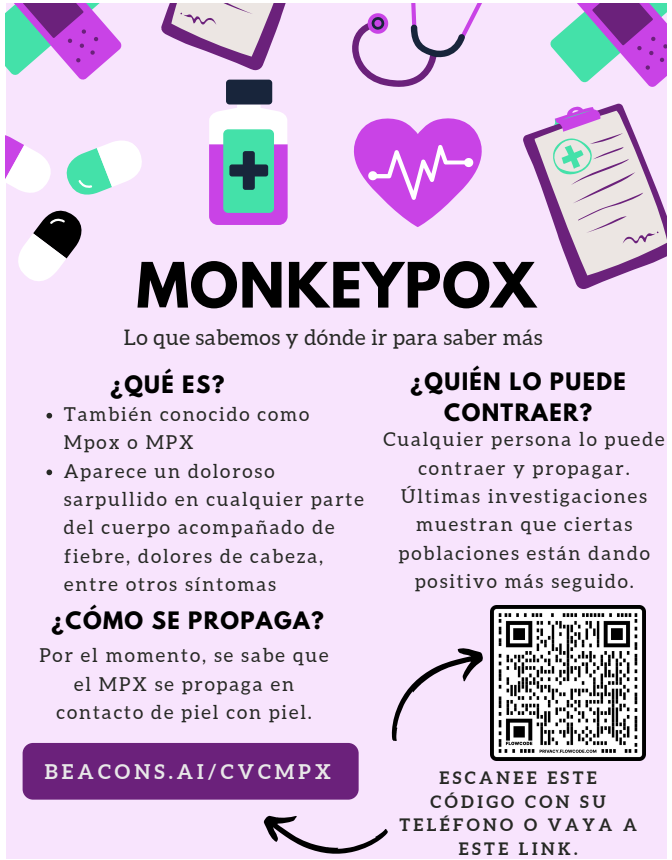
For more information about this study and to see other projects, find us at

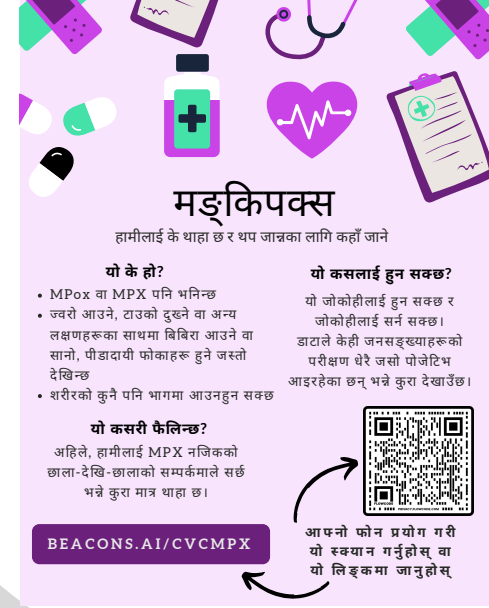
RAGAVANCIRCLE.COM

CIRCLE LAB
COMMUNITY INTEGRATED RESEARCH FOR CARE AND LANGUAGE EQUITY

STUDY CONDUCTED IN SUMMER 2021

Informational infographic



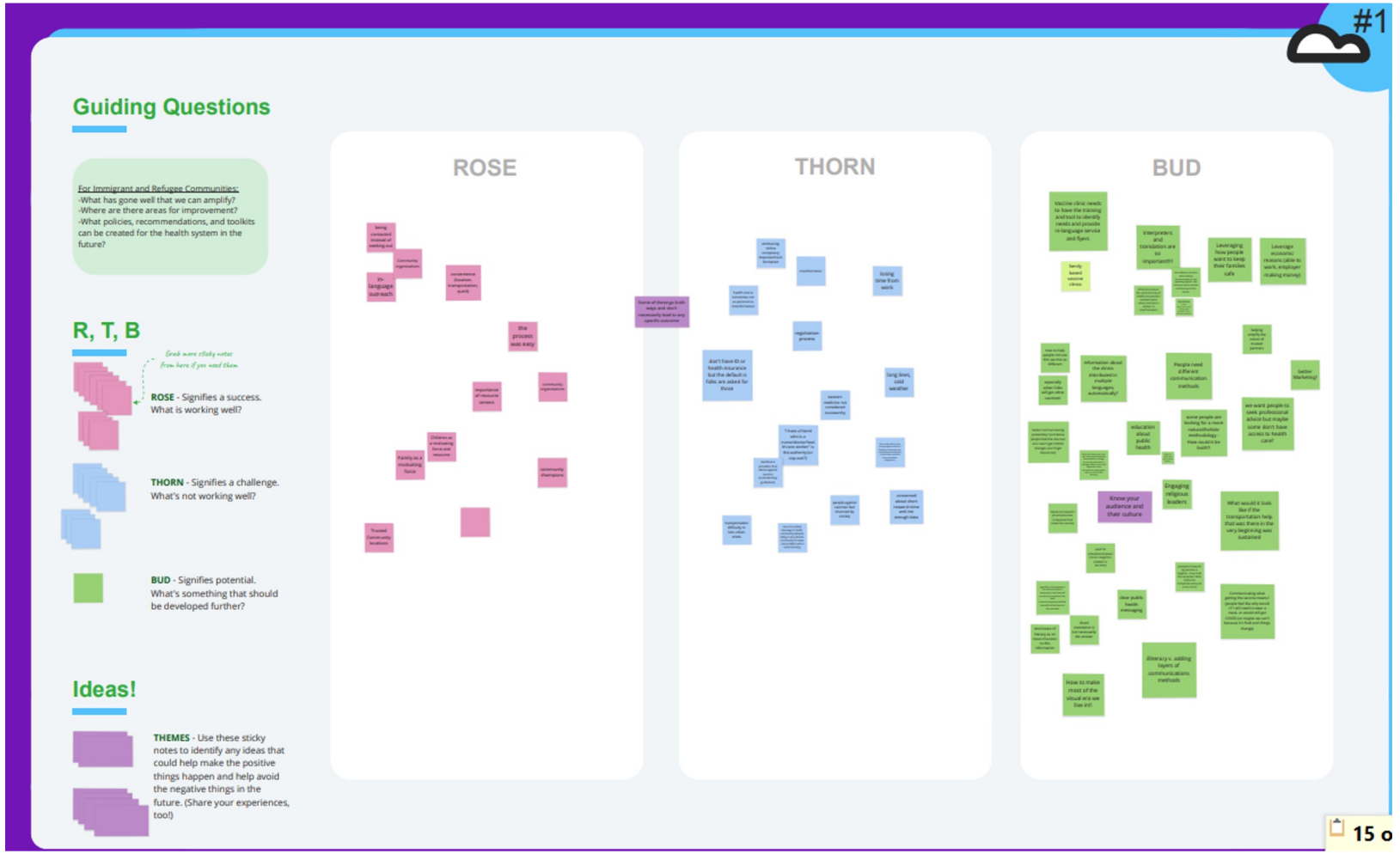


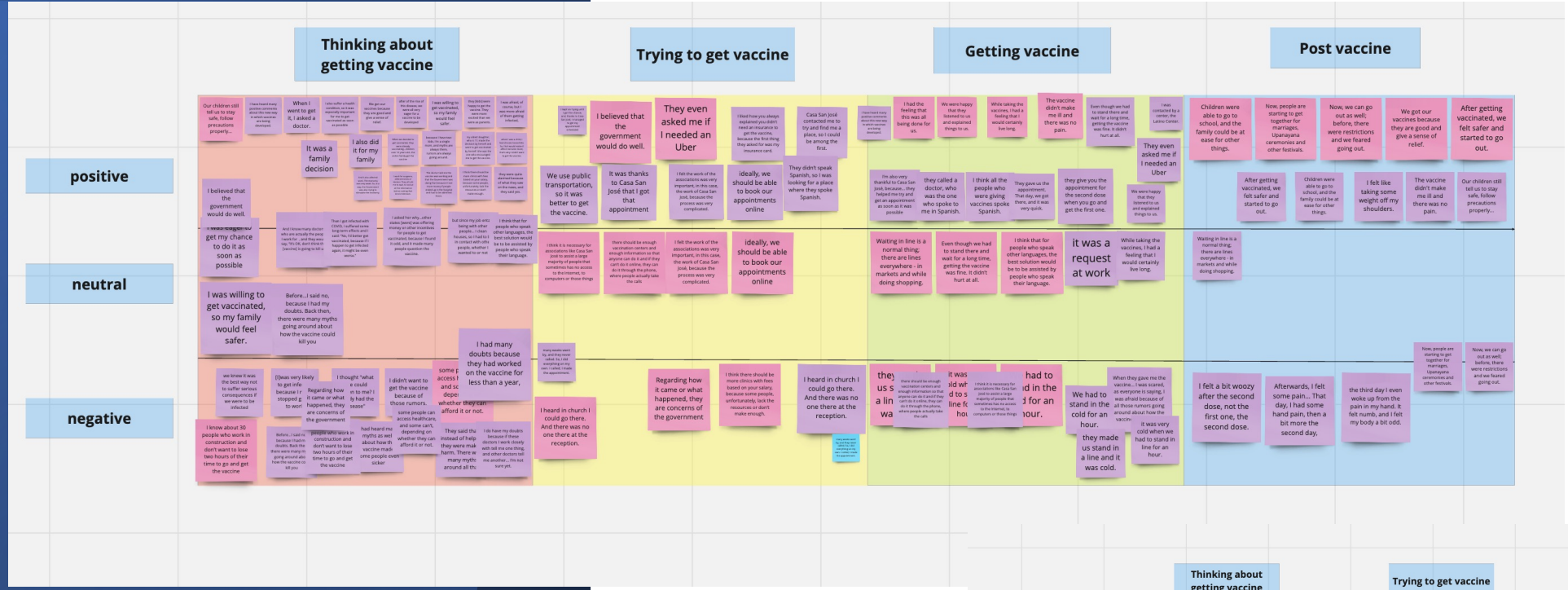
Translated into many languages!

Pashto, Arabic, Chinese, Dari, Nepali, Spanish, English, Urdu

Flexibility with infographics

Use of human-centered design for community engaged data analysis



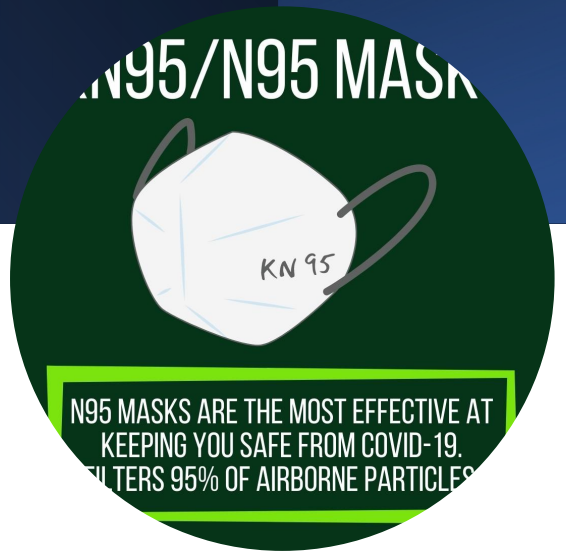


Use of human-centered design for community engaged data analysis

Next steps

- Goal: for every research study there is an accompanying infographic
- Dissemination plan to ensure reaches intended audience
- Knowing the media ecosystem of the intended audience
- Metrics to see how infographics are spread (e.g., tracking QR codes)
- Comprehensive evaluation of infographics
- Funding specifically for developing infographics (as well as institutions valuing this as an important part of research dissemination and promotion for researchers)
- Support for community-academic collaborations in developing and disseminating infographics

Looking forward to hearing your questions and reflections!



Maya Ragavan
ragavanm@chp.edu

Joseph Amodei
joa222@lehigh.edu

testRI: Developing a community-driven drug supply surveillance system in Rhode Island

Claire Macon, BA
Research Assistant, Brown University School of Public Health

Alexandra Collins, PhD
Assistant Professor, Brown University School of Public Health

HEAL Connections | December 7, 2023

toxicological and ethnographic drug surveillance testing in Rhode Island

Disclosures

This work is funded by the Foundations for Opioid Response Efforts (FORE)

No conflicts to declare

testRI overview

Two-year community-based study that launched in May 2022

- Oversight and input from a community advisory board

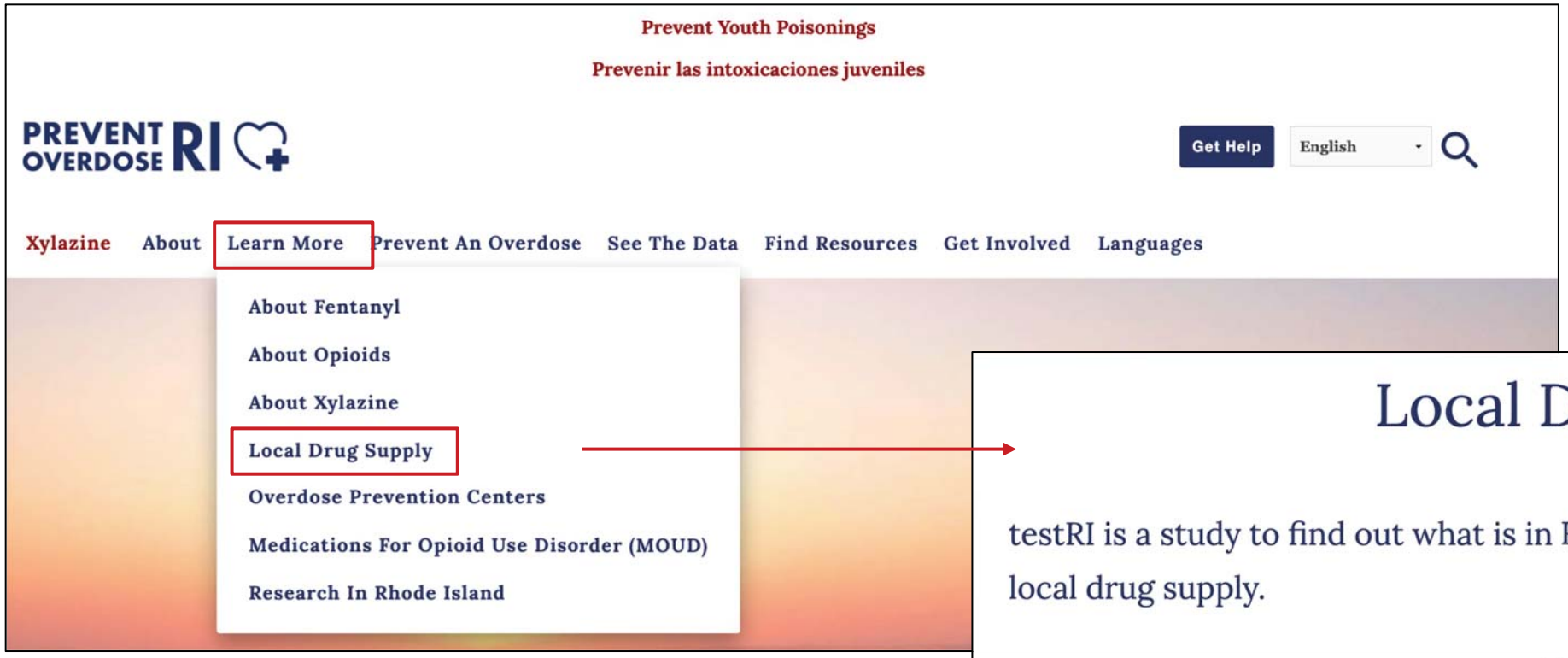
Methods:

- In-depth interviews with people who use drugs at baseline (n=50) and 6-month follow-up (n=25)
- Observational fieldwork
- Toxicology testing of donated samples
- Toxicology and dissemination feedback surveys

Project goals

1. Assess how **individual-level** use practices are impacted by the drug supply
2. Track **street-level** drug supply changes
3. Rapidly **disseminate findings** to inform overdose prevention efforts at individual, community, and state levels

Dissemination approaches



In 2023, we have had over 2,500 visitors to the page with an average of 465 visits per month. Users spend an average of one minute on the page.

People who visited the page spent an average of 2:30 visiting other pages and media on the website

https://preventoverdoseri.org/local-drug-supply/

What have we tested?

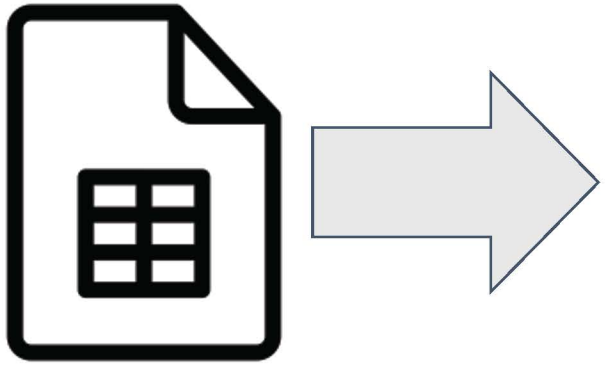
Below is a list of all the samples we have tested. We show where we collected samples and what substances we found in each sample. We also show the substance the person thought they were using under the "sold as" column.

Legend:

O = Opioids; **S** = Stimulants; **B** = Benzos; **C** = cannabinoids; **A** = Other active cut; **M** = Starting materials/byproducts;
H = hallucinogen/dissociative; * indicated substances that make up most of a sample

testRI
Toxicological and Ethnographic Drug Surveillance Testing RI

Search:



Sample	Month	City/Town	What was tested	Sold as	Substances found
182	2023-09	Providence	powder (tan)	Heroin	**Xylazine* (A)** **Fentanyl* (O)** Starting material and/or byproducts in fentanyl(s) production: 4-ANPP, Phenethyl-4ANPP, 4-anilinopiperidine (M)
181	2023-09	Providence	crystal (white)	Crystal meth	**Methamphetamine (S)***
180	2023-08	Providence	Pipe (white powder, black char)	Crystal meth	**Methamphetamine (S)*** Cocaine (S) Fentanyl (O) Amphetamine (S) Gabapentin (A) N-ethylamphetamine (S) N-propylamphetamine (S) Pholedrine (S) Starting material and/or byproducts in fentanyl(s) production: 4-ANPP, Phenethyl-4ANPP (M) Breakdown products/metabolites/intermediates of cocaine found: Benzoylecgonine, Norcocaine, Ecgonine methyl ester (M)
179	2023-08	Providence	Cooker (white powder)	Fentanyl	**Fentanyl* (O)** **Methamphetamine (S)*** Acetylfentanyl (O) Acrylfentanyl (O) Beta-hydroxyfentanyl (O) Starting material and/or byproducts in fentanyl(s) production: 4-ANPP*, Phenethyl-4ANPP, 4-anilinopiperidine
178	2023-08	Providence	White powder	Fentanyl	**Fentanyl* (O)** Acetylfentanyl (O) Beta-hydroxyfentanyl (O) Starting material and/or byproducts in fentanyl(s) production: 4-ANPP*, Phenethyl-4ANPP, 4-anilinopiperidine (M)
177	2023-08	Providence	Pipe (brown crystal)	Crystal meth	**Methamphetamine (S)*** Fentanyl (O) Pholedrine (S) N-ethylamphetamine (S) Ephedrine (S) Methcathinone (S) Acetylfentanyl (S) N-propylamphetamine (S) Starting material and/or byproducts in fentanyl(s) production: 4-ANPP, Phenethyl-4ANPP (M)
176	2023-08	Providence	Cooker (black flecks)	Methamphetamine	**Methamphetamine (S)*** Cocaine (S) Fentanyl (O) Xylazine (A) Starting material and/or byproducts in fentanyl(s) production: 4-ANPP (M) Breakdown products/metabolites/intermediates of cocaine found: Benzoylecgonine (M)
175	2023-08	Providence	Rubber glove	Fentanyl	**Xylazine* (A)** **Fentanyl* (O)** Acetylfentanyl (O)

What do the substances mean?

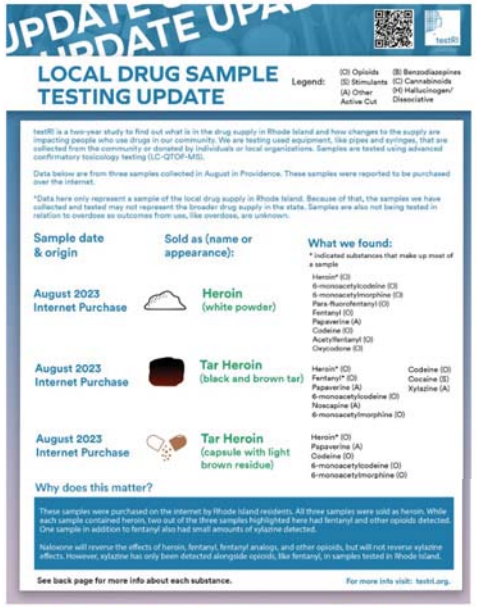
testRI
Toxicological and Ethnographic Drug Surveillance Testing RI

You can learn more about the substances we found during our study in this glossary.

Show 50 entries Search:

Substance	Description
2-phenethylamine	**Phenethylamine** is a naturally occurring substance in humans and can also be made synthetically. It can be purchased as a dietary supplement. It has stimulant properties.
4/N-ethylamphetamine	**4-ethylamphetamine** and **N-ethylamphetamine** are designer drugs with similar structure to amphetamine and have amphetamine-like effects and risk.
6-monoacetylcodeine	**6-monoacetylcodeine** is an impurity sometimes seen in heroin.
6-monoacetylmorphine (6-MAM)	**6-monoacetylmorphine (6-MAM or 6-AM)** is an active heroin breakdown product.
Acetaminophen (Tylenol)	**Acetaminophen (Tylenol)** is a pain medication frequently added to drugs as an active cut. At standard doses it is safe, but in very high doses it can cause liver injury or failure.
Acetylfentanyl (or desmethyl fentanyl)	**Acetylfentanyl (or desmethyl fentanyl)** is a fentanyl analog. Acetylfentanyl can also be a byproduct in fentanyl synthesis. Based on studies in mice, acetylfentanyl is less potent than fentanyl. Acetylfentanyl has not been approved for pharmaceutical use and there have been no studies in humans on safety of use. Over the last decade acetylfentanyl has been reported in the drug supply and in fatal overdoses. In overdose, acetylfentanyl can cause sedation and decreased or stopped breathing. Naloxone will work to reverse overdose due to fentanyl and fentanyl analogues.
Acrylfentanyl (or acryloylfentanyl)	**Acrylfentanyl (or acryloylfentanyl)** is a fentanyl analog. Based on limited non-human data, its potency is reported similar to fentanyl. Acrylfentanyl has been reported in the drug supply over the last few years and since 2016, it has been involved in overdose deaths in Europe and the US. In overdose, acrylfentanyl can cause sedation and decreased or stopped breathing. Naloxone will work to reverse overdose due to fentanyl and fentanyl analogues. Because of its toxicity, lack of familiarity, inconsistent dose, and mixing into drugs which often already include fentanyl, overdose risk is high.
Alprazolam (Xanax)	**Alprazolam (Xanax)** is a short-acting benzodiazepine often used to treat anxiety. In overdose it can cause heavy sedation, slowed or stopped breathing or unresponsiveness. The risk is higher if used with other sedating substances like opioids or alcohol.
Aminophenazone	**Aminophenazone** is a pain medication no longer available for use in the US due to approximately 1% risk of skin rash and changes in blood cell lines, both of which can potentially be fatal.
Aminorex	**Aminorex** is a metabolite of levamisole with similar effects to amphetamines. Previously it was marketed as a stimulant/weight loss agent, but was removed from the market by the FDA due to concerns it caused high blood pressure in the lung (pulmonary hypertension).
Aripiprazole	**Aripiprazole** is an antipsychotic medication.
Benzoylecgonine	**Benzoylecgonine** is an inactive major breakdown product of cocaine.
Benzylfentanyl	**Benzylfentanyl** is a fentanyl analog with limited pharmacologic activity. It is used as a starting product to manufacture non-pharmaceutical fentanyl(s).
Beta-hydroxyfentanyl	**Beta-hydroxyfentanyl** is an active fentanyl analog and metabolite of fentanyl. The data on clinical effects in humans is very limited. Potency is unknown.
Bromazolam	**Bromazolam** is a designer benzodiazepine in the triazolobenzodiazepine class structurally related to alprazolam (Xanax), replacing the chlorine with a bromine. It has never been approved for medical use and data on pharmacology and toxicity is limited. Bromazolam has been identified in post-mortem toxicology in both Europe and the US. Drugs in the benzodiazepine class generally carry risk of tolerance and dependence with regular risk. Overdose can cause sedation and problems breathing, especially if combined with other sedating substances.

Local Drug Supply Updates



Click to download our latest drug supply update from August, 2023.

How do supply updates work?

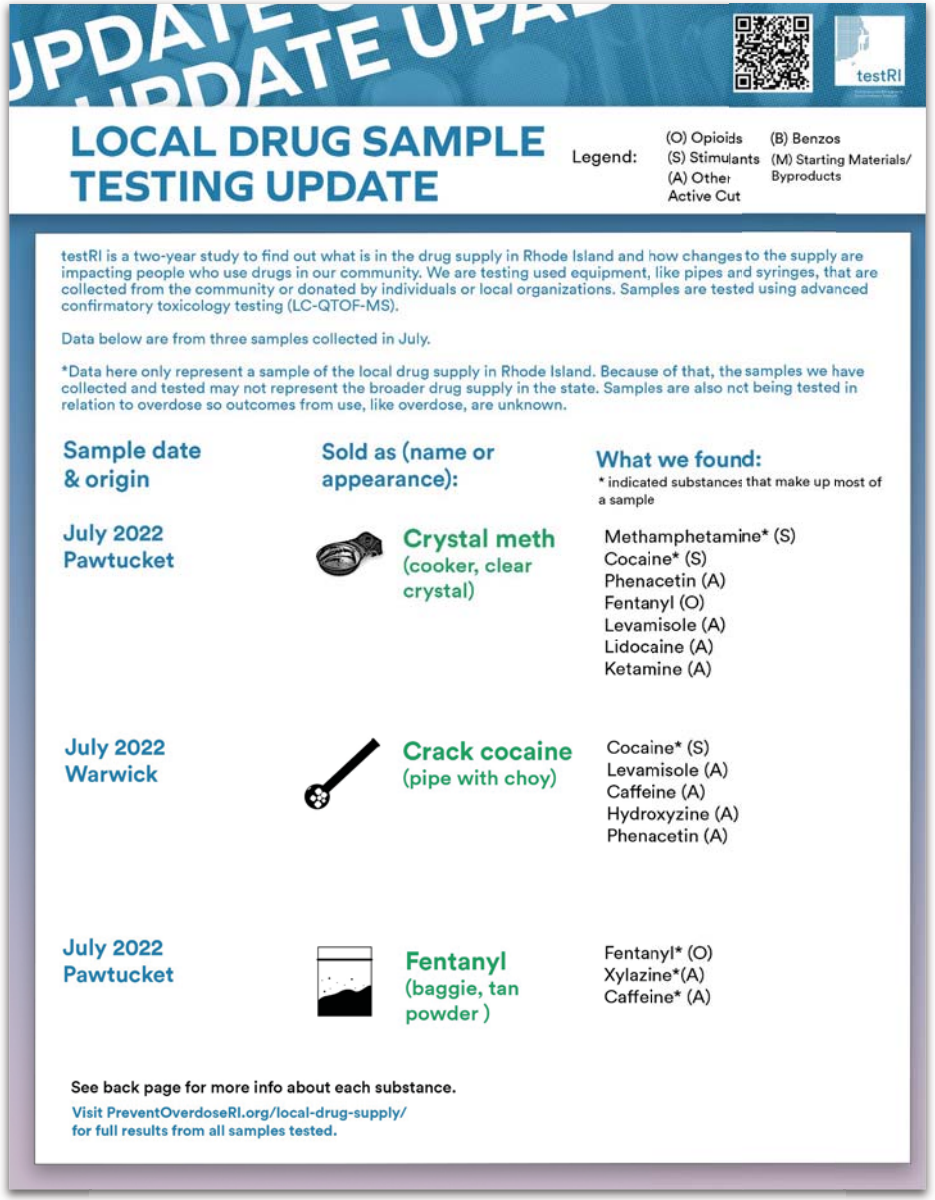
One of the study's main goals is to see how drug supply changes impact people who use drugs in our community. This study tests used equipment, like pipes and syringes. We collect equipment from the community and donations from individuals or local organizations. We test samples using advanced confirmatory toxicology testing (LC-QTOF-MS). All testing takes place at the Rhode Island Hospital toxicology laboratory.

What do these results mean?

Our results show that local drug supplies are volatile and change often. But it is important to know that the samples we collect and test only show us a small part of the drug supply in Rhode Island. These results may not represent the broader drug supply in the state. We also don't know whether what we tested led to an overdose.

Want to see more updates?

We will update this page every month with our latest findings. You can also **visit our Local Supply Update Archive to view all past updates.**



Substance Spotlights

The samples we test contain a lot of different substances. Below are spotlights on a few substances we have found. Click on an image for more information.

testRI Local Sample Testing SPOTLIGHT

Nitazenes Found in Samples from the Local Rhode Island Drug Supply

testRI is a two-year study to find out what is in the drug supply in Rhode Island and how changes to the supply are impacting people who use drugs in our community. We are testing used equipment, like pipes and syringes, that are collected from the community or donated by individuals or local organizations. Samples are tested using advanced confirmatory toxicology testing (LC-QTOF-MS).

Data from all samples tested in the study can be found on https://preventoverdoseri.org/local-drug-supply/

*Samples we have collected and tested only represent a small part of the local drug supply in Rhode Island and may not represent the broader drug supply in the state. Samples are also not being tested in relation to overdose so outcomes from use, like overdose, are unknown.

Background:

Recently, nitazenes (isotonitaze, metonitazene, and protonitazene) – a dangerous class of synthetic opioids– were detected in drug samples sold as fentanyl or 'dope' in Rhode Island.

Nitazenes are a novel class of synthetic opioids with varying potency that can be less potent to up to 40 times more potent than fentanyl. Nitazenes have never been approved for medical use in the United States.

Nitazenes have recently been reported in the drug supplies throughout the US including in Philadelphia, Washington DC, Ohio, and Chicago. In these locations, nitazenes have been detected in various forms including powder, solid, and liquids.
.

Why does this matter?

Nitazenes are present in the drug supply with and without knowledge of people who use drugs.

The high potency of nitazenes combined with inexperience with dosing, lack of awareness of nitazene presence, and mixing into drugs that already contain fentanyl increases overdose risk.

Human clinical data on nitazenes including risk for dependence, tolerance, and withdrawal with chronic use is limited.

Nitazenes have a different structure than other opioid classes and are not detected using standard urine drug testing or fentanyl test strips.

Health Effects:

The three nitazenes–isotonitazene, metonitazene, and protonitazene–found in samples from Rhode Island are reported to have similar or higher potency than fentanyl.

In all drug samples, a nitazene was found in combination with fentanyl, fentanyl analogs, and xylazine.

These findings are consistent with findings in drug samples across the country where nitazenes have been detected and mixed with fentanyl.

Nitazenes cause opioid effects, and risk of overdose from nitazene exposure is high.

Naloxone (Narcan) is effective in treating nitazene-related opioid overdose.

RIDOH Provider Advisory

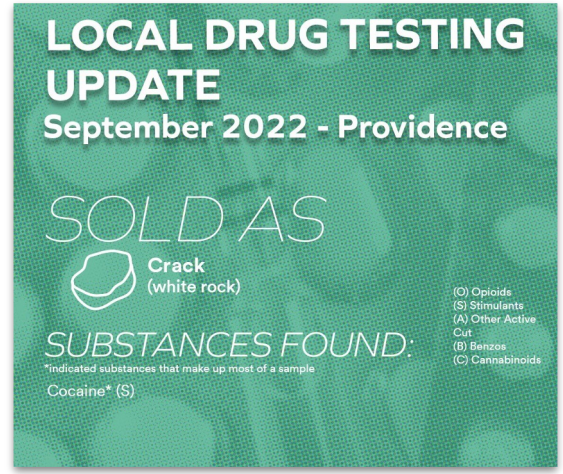
July 15, 2022

Introducing testRI - A New Resource for Understanding Rhode Island's Local Drug Supply

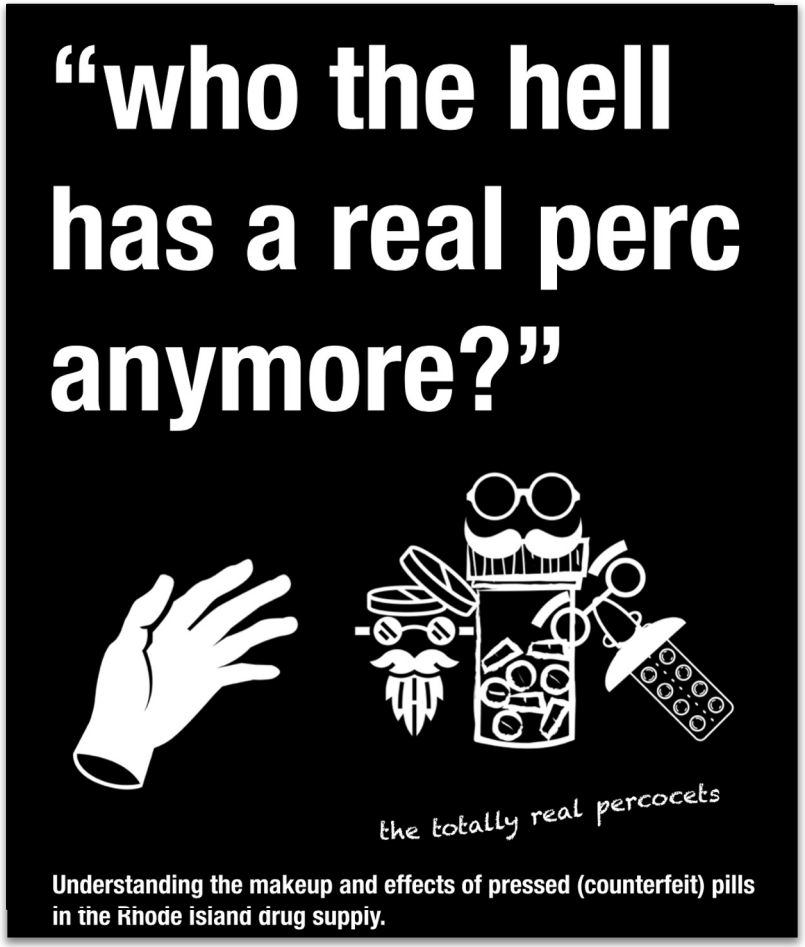
The Rhode Island Department of Health (RIDOH), in partnership with Brown University School of Public Health, would like to introduce testRI, a two-year research study to find out what is in the local drug supply in Rhode Island and how changes to the supply are impacting people who use drugs in our communities.

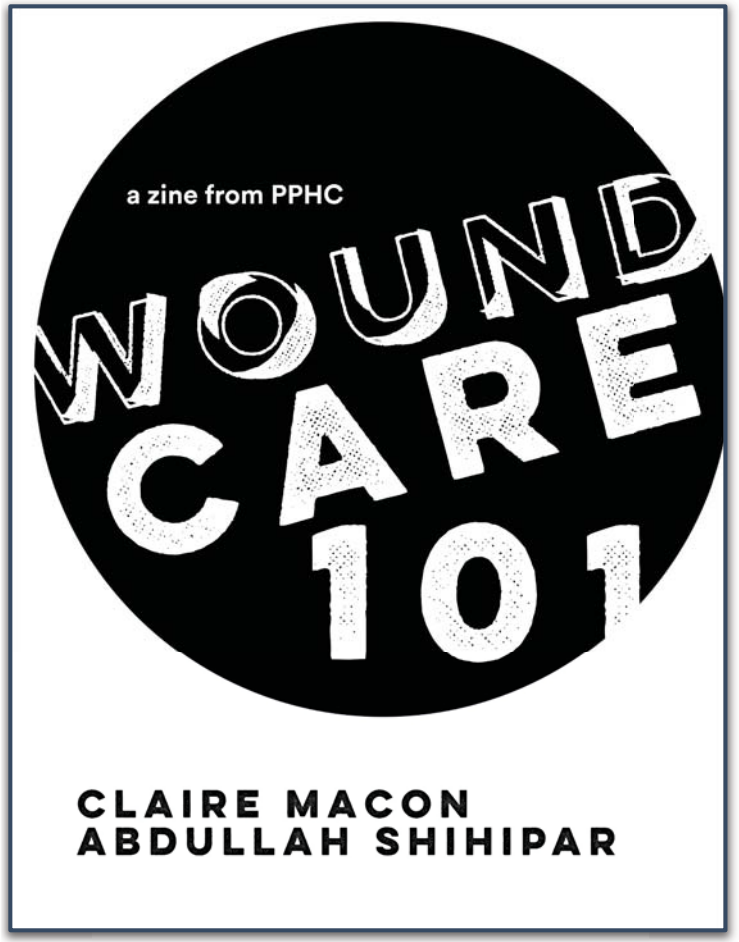
How does testRI research work?

The testRI research team tests used equipment, like pipes and syringes, that are collected from the community or donated by individuals or local organizations. Samples are tested using advanced confirmatory toxicology testing (LC-QTOF-MS). Data from all samples tested in the study can be found on Rhode Island's overdose information website and data dashboard, PreventOverdoseRI.org.



Zines





Zines are available for download from: https://medium.com/pphc/zines/home

Implications

- Facilitated conversations about xylazine and other novel psychoactive substances being found locally (e.g., nitazines)
- Focused attention on the presence of xylazine in local drug supplies
    - Dedicated page on the state's overdose data dashboard
    - Community information dissemination via outreach workers and front line service providers
    - Distribution of wound care kits
- Increased dissemination and education on pressed pills, polysubstance use, and other substances at state and local levels
- Launch of community drug checking program by a partner organization

Opportunities

1. Enhancing state-level drug supply surveillance information and sharing information in near-real-time
    a. *These efforts need to be developed and implemented alongside community organizations

1. Legalizing drug checking services across US jurisdictions and increase accessibility of these programs

1. Co-create public health messaging about the overdose crisis and drug supply with communities impacted
    a. Will allow for tailored and accessible messaging that is grounded in needs of diverse communities

Appreciations and gratitudes

- All of our study participants for their countless contributions to the research
- Partners, staff, and advocates at our community partner organizations including: VICTA; Project Weber/RENEW; House of Hope; AIDS Care Ocean State; Parent Support Network; Community Care Alliance; the Rhode Island Department of Health; and Dr. Adina Badea at Rhode Island Hospital
- Administrative and study staff at the Brown University School of Public Health & the People Place and Health Collective in particular:
    - Abdullah Shihipar on creating testRI dissemination outputs and social media posts
    - Max Krieger and Todd Hampson for their work on the creation and maintenance of our data dashboard on PreventOverdoseRI.org
- mPI Dr. Rachel Wightman

Thank you!

alexandra_collins1@brown.edu

HEAL's Vision is to Make Research Results Useful for Communities

Understand community needs

Help HEAL researchers work with communities

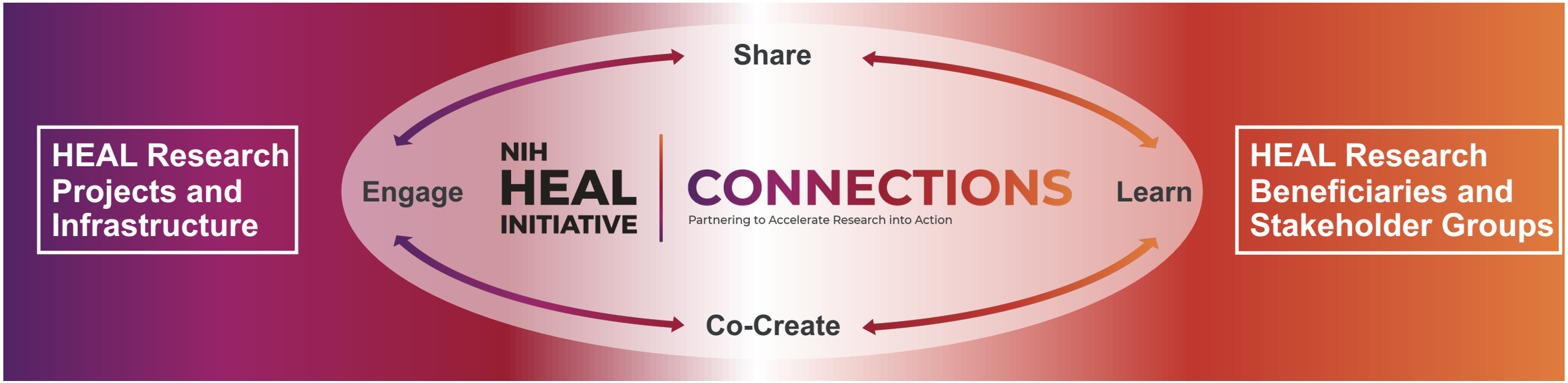
Build partnerships with communities who can benefit from HEAL research

Make research findings user-friendly to broaden their reach and impact

Introducing a new center to accelerate research into action by:

Creating pathways to **further build and sustain community partnerships**

Supporting HEAL researchers to **meaningfully share research results**

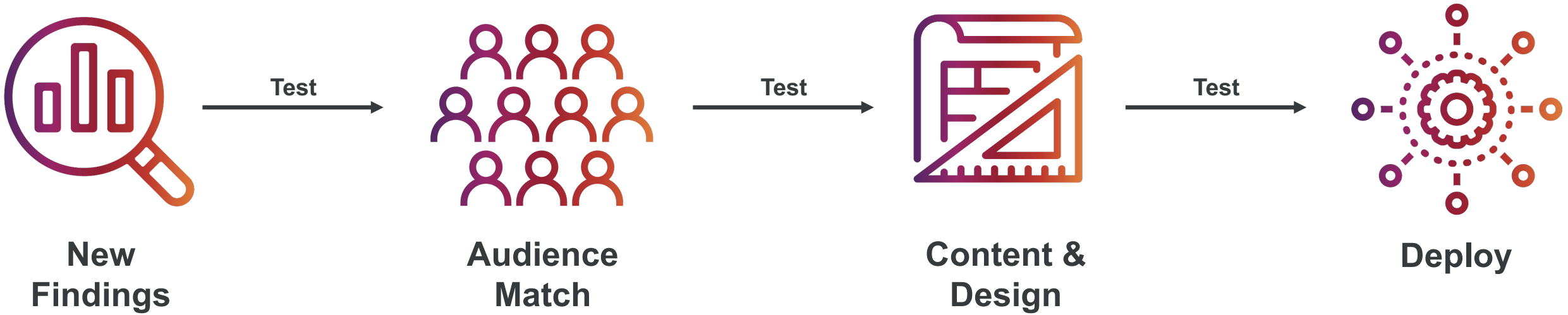


HEAL Connections Process

The HEAL Connections process includes a Stakeholder Feedback Team to ensure products resonate with people from a variety of backgrounds.

Team members represent diverse ethnic backgrounds, educational experiences, and geographic locations.

They review research findings, identify beneficiaries and audiences, provide feedback on content, graphics, and dissemination strategies.



Connect with HEAL Connections

Participate in Sharing Sessions like this one to learn from your peers, share your experiences, and consult with our in-house team and your peers on dissemination issues and opportunities facing your project.

As your HEAL project team plans for and nears results dissemination, consider reaching out to us at **HEAL-Connections@duke.edu** to set up a one-hour consultation.

Visit https://heal.nih.gov/data/connections

Other Resources

- **NIH Communications Support:** For researchers funded through NIH, alert your program officer to any upcoming publications.

- **The Community Engagement Alliance Consultative Resource (CEACR)**: Request consultation on all things community engaged research. Learn more here.

- **Community Campus Partnerships for Health:** Offers consultation to support community engagement needs and challenges. Learn more here.

- **Multi-Regional Clinical Trials Center:** Explore resources around return of results, health literacy, engaging patients, and more. Explore here.

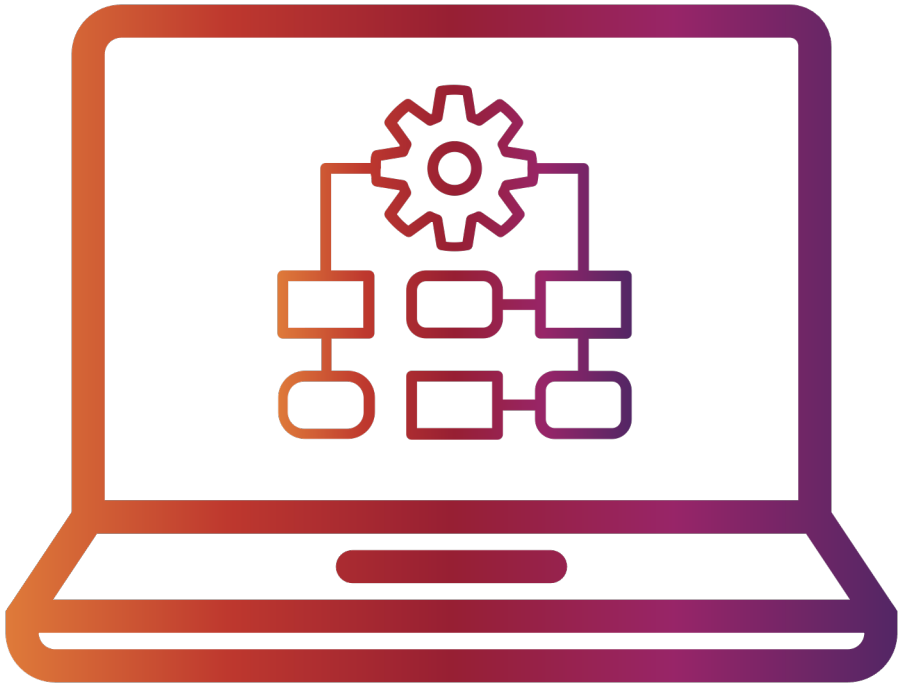
Meeting Evaluation

To help design, contribute to, and improve our programming, please complete the evaluation survey at https://bit.ly/PlainLanguageSSeval

Office Hours

Stay tuned for post-event follow-up emails with:

- Within one day: Evaluation survey
- Within a week: Recording, slides, list of resource



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