



**Office of Clinical Research**  
**First Friday**

**The Value of Engagement:  
Seeing Patients/Caregivers as Critical  
Research Experts**

**Friday, October 7<sup>th</sup>, 2022**

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lives  
here**



## **Learning Objectives:**

- 1) Describe the value of patient/caregiver engagement in supporting research**
- 2) Describe how partnership can broadly improve study recruitment and retention**
- 3) Identify ways to engage with patients and/or caregivers without slowing your study's progress**

## **Target Audience:**

**Clinical Research Professionals (CRPs) at UC/H and Cincinnati Children's Hospital Medical Center (CCHMC): including Principal Investigators (PIs), Research Nurses (RNs), Critical Care Unit Nurses (RNs), Pharmacy Technicians and Regulatory Specialists.**

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### Learner Assurance Statement

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### Accreditation Statement for Directly Sponsored Activity

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The University of Cincinnati designates this live activity for a maximum of 1 *AMA PRA Category 1 Credit*<sup>™</sup>. Participants should claim only the credit commensurate with the extent of their participation in the activity.

\*\*CRPs, NPs, PAs, and RNs can count activities certified for *AMA PRA Category 1 credit*<sup>™</sup> for professional credit reporting purposes. Other healthcare professionals should inquire with their certifying or licensing boards.\*\*

### Disclaimer Statement

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## **Planning Committee Members:**

- Maria Stivers, MS, CIP; Course Director – No Relevant Relationships
- Nathaniel L. Harris, BS, Course Coordinator – No Relevant Relationships
- Zachary Johnson, BS – No Relevant Relationships
- Heather Muskopf, CME Program Manager – No Relevant Relationships

## **Speaker:**

**Melinda Butsch Kovacic, MPH, PhD**

Professor and Associate Dean of Research

UC College of Allied Health Sciences

*No Relevant Relationships*

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# October 2022 Study of the Month

## Does Your Child Have Bipolar Disorder?

### Bipolar Disorder Study

#### What

The purpose of this clinical research study is to evaluate the safety, tolerability, and pharmacokinetics of olanzapine and samidorphan in children with bipolar I disorder.

#### Who

Children 10-12 years of age who are affected by bipolar disorder and are still experiencing symptoms.

#### Pay

Participants will receive compensation for their transportation and/or time for study visits. All study visits, tests, procedures, and medications will be provided at no cost to participants.

#### Details

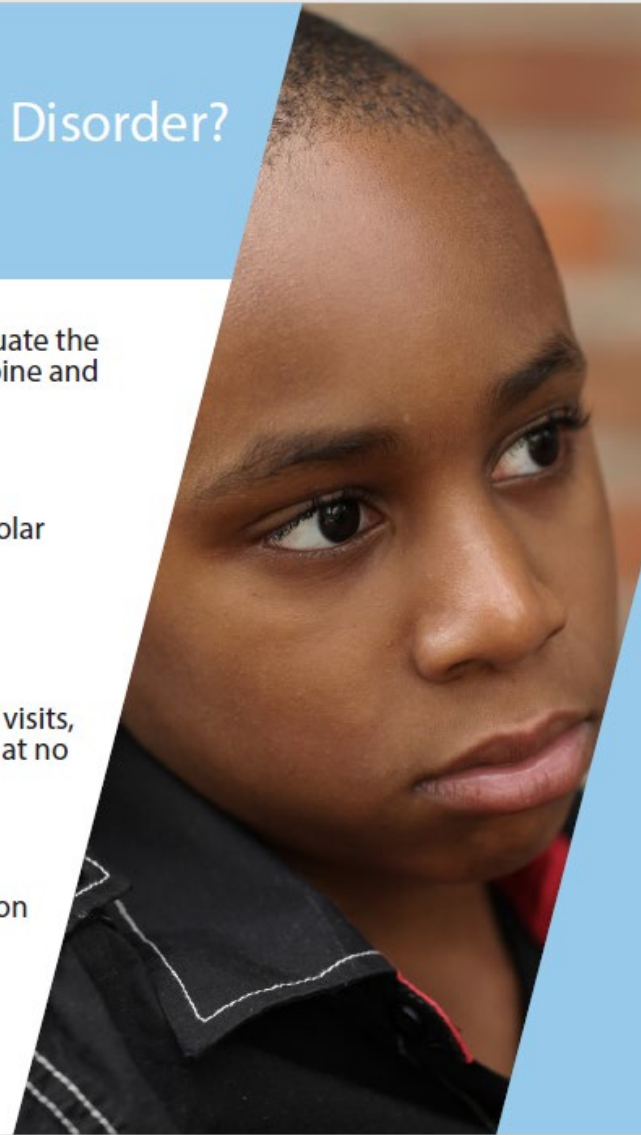
For more information, contact Emily Baltes-Thompson at 513-558-3952 or [baltesec@ucmail.uc.edu](mailto:baltesec@ucmail.uc.edu).

  
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24-22 IRB # 2021-0485

 Health.

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# UC Health Annual Flu Campaign

**The UCH annual flu campaign starts the week of October 3<sup>rd</sup>, 2022.**

The flu vaccine is a mandatory requirement and of utmost importance this year with the continued challenge of COVID-19.

UC Health Employee Health will be providing the flu vaccine, free of charge, to employees and affiliates but also willingly accept documentation of the vaccine received elsewhere.

If you are a UCH Employee, or a UCP employee hired prior to April 1, 2022, the survey (consent form) will be in Readysat. ***This survey must be filled out prior to receiving your vaccine, and also if you receive the vaccine elsewhere.***

**All UC Health employees and clinicians are required to receive an annual flu vaccination by Friday, Nov. 11, at 5 p.m**

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**Please contact UCH Employee Health for any questions**

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# Office of Clinical Research Lunch & Learn

Thursday, October 20<sup>th</sup>, 2022, 12:00noon - 1:00pm  
Virtual Presentation

## IDS (Investigational Pharmacy) – A Great Drug Interaction

Please join us for a look into the world of Investigational Drug Services and its relationship to other research areas. Discover the innovations propelling the growth of IDS and refresh pharmacy tips and tricks for IDS requests.

**Mary Burns, PharmD, Rph**  
University of Cincinnati Medical  
Center

UC Health Investigational Pharmacy

**Dorice Smith, BA, CPhT**  
University of Cincinnati Medical  
Center

UC Health Investigational Pharmacy

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## Today's Presentation:

# **The Value of Engagement: Seeing Patients/Caregivers as Critical Research Experts**

Research has great potential to impact people's lives IF participating patients and their caregivers understand their roles in its success. If CRPs engage their participants and help them see themselves as expert stakeholders, their study's recruitment and retention will benefit.

**Melinda Butsch Kovacic, MPH, PhD**

**Professor and Associate Dean of Research**

**UC College of Allied Health Sciences**

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# **The Value of Engagement: Seeing Patients/Caregivers as Critical Research Experts**

*Melinda Butsch Kovacic, MPH, PhD*

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[butschms@ucmail.uc.edu](mailto:butschms@ucmail.uc.edu)

*text me at 859-757-6808*



# Learning Objectives

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- Describe the value of patient/caregiver engagement in supporting research
- Describe how partnership can broadly improve study recruitment and retention
- Identify ways to engage with patients and/or caregivers without slowing your study's progress



# My Journey

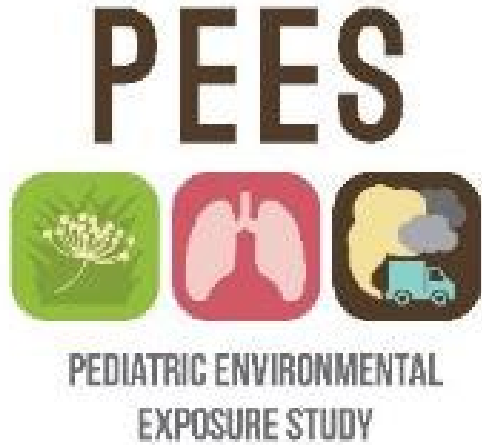
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# Positions/Roles

- **Cincinnati Children's Hospital Medical Center Research - 2006**
  - Asthma Research – genetics, biomarkers, environmental exposures
  - Cancer/Fanconi Anemia Research – oral HPV and Head and Neck Cancer
  - Community Research/Citizen Science – We Engage 4 Health
  
- **University of Cincinnati (UC) College of Allied Health Sciences - 2014**
  - Associate Dean of Research
    - Faculty Mentor
    - Research program development
    - Represent college on UC committees
  
- **University of Cincinnati Cancer Center - 2022**
  - Associate Director of Community Outreach and Engagement (COE)
    - Evaluate and monitor 10 county catchment area data
    - Provide education to faculty to support THEIR engagement in COE
    - Outreach to community to encourage cancer education, screening
  - Director, Cancer Research Scholars Program
    - 22 undergraduate summer research scholars in cancer research groups

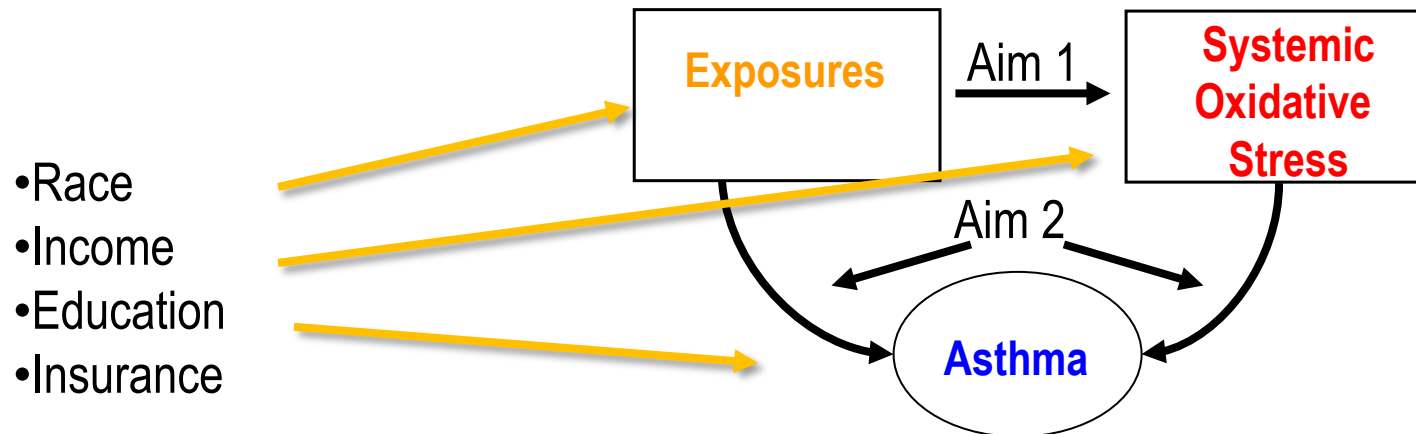


# Early Asthma Research – R21 and KL2



**Aim 1.** Does the environment impact markers of stress?

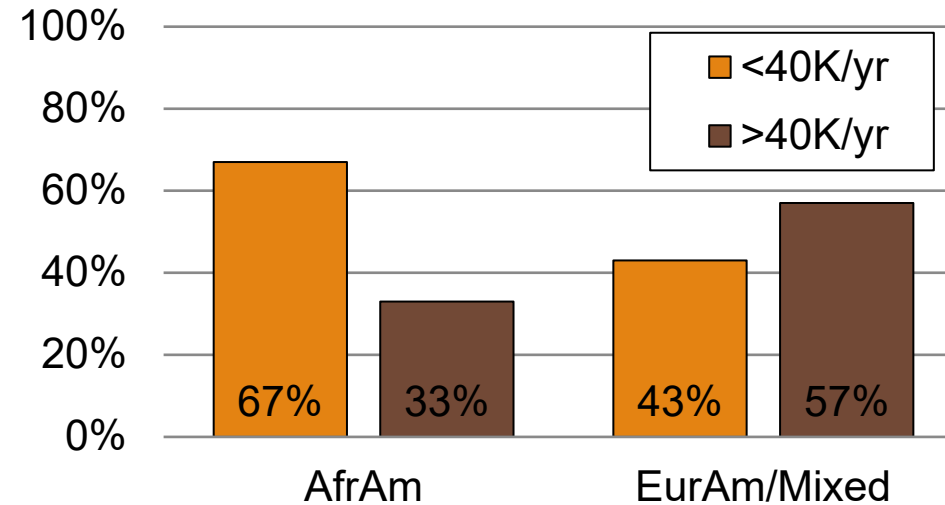
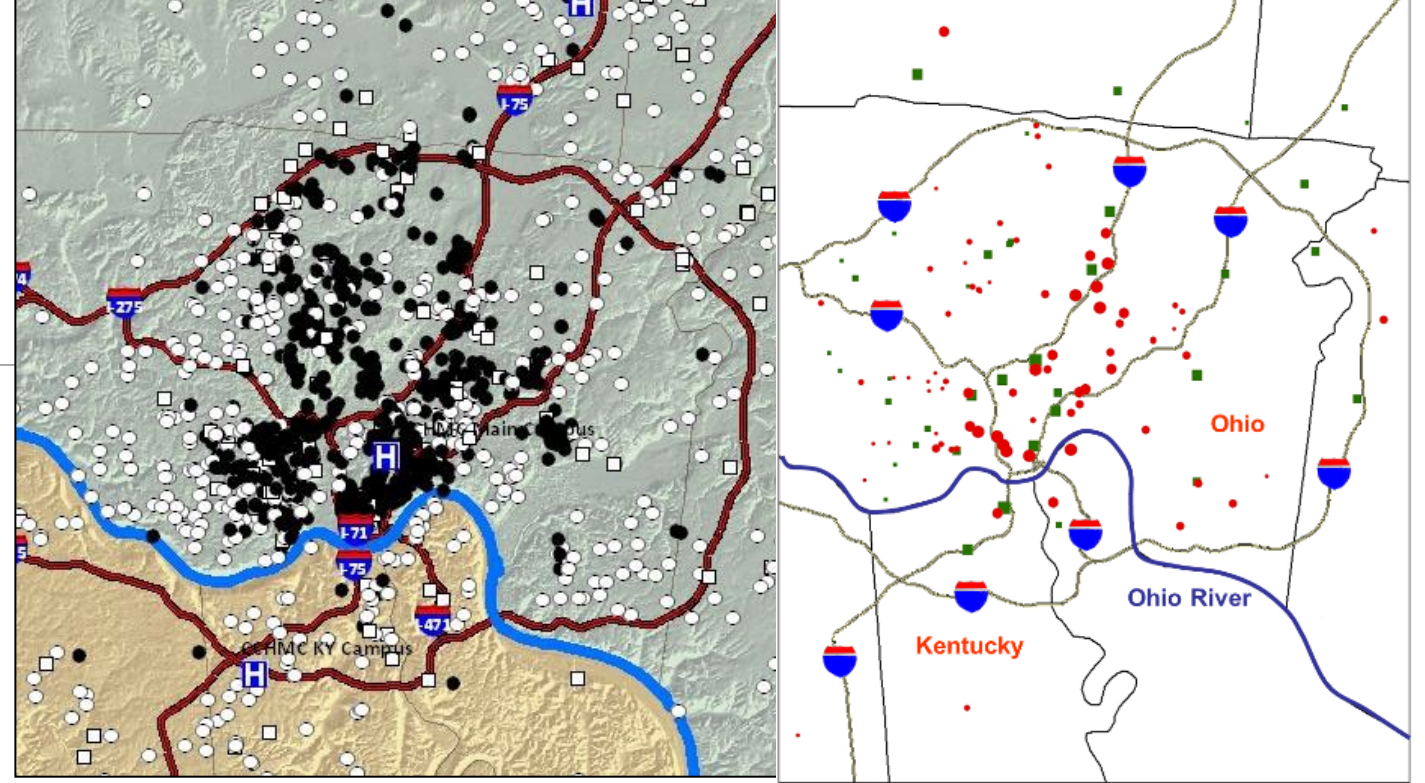
**Aim 2.** Is measurement of stress **a better predictor** of risk of childhood asthma than parent reported exposures (captured via surveys)?





# Associations with Race and Income

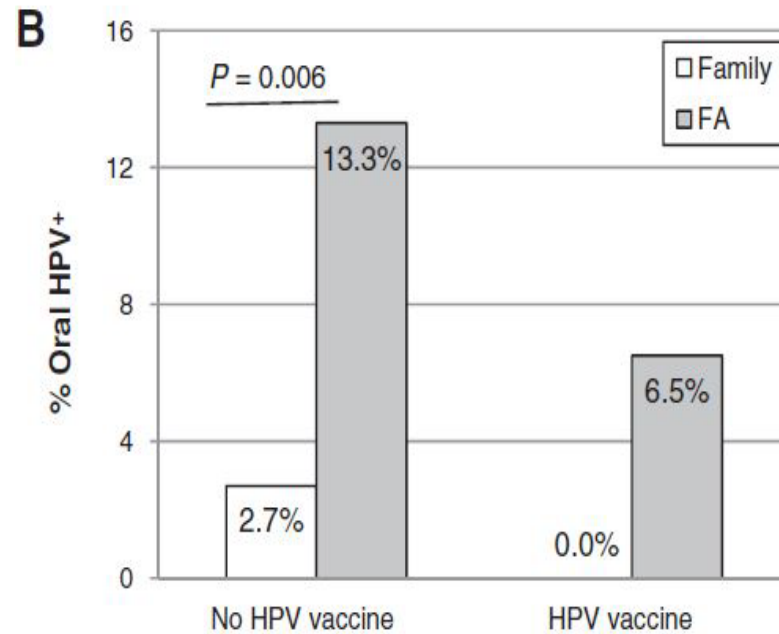
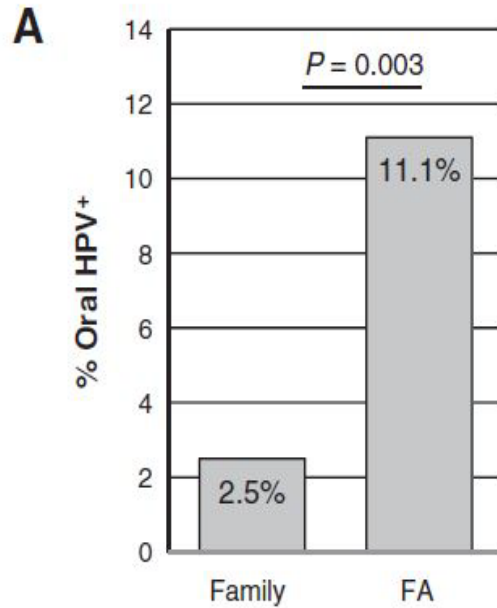
- We observed higher levels of truck related air pollution (aka Diesel Exhaust Particle or DEP) exposure in African Americans
- More secondhand smoke exposure and DEP exposure as well as markers of stress in children with lower family incomes
- Lower income was significantly associated with more frequent asthma symptoms & poorer asthma control too



# R01-funded Longitudinal Study Examining Oral HPV in FA

We sought to better understand the 1,000-fold amplified risk of HNSCC in individuals with Fanconi Anemia (FA) by characterizing the *epidemiology* of oral HPV infection and *host immunological responses*.

With over 500 participants, we found that oral HPV was all too common compared to family members; their immune profiles also differed



# The FA Study was only possible ....

Fanconi Anemia Research Fund (FARF)  
Pilot grant funding prior to R01

Recruitment at:

- Annual Family Meetings
- Biannual Adult Meetings

Willingness of families to participate  
= *ideal research community*







# I Realized That I Loved Partnering with Families and Communities

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## Questions I asked myself:

- How can I better **educate** potential participants, so they feel more comfortable becoming research participants in my studies?
- How can I best **partner** so that families and communities can positively impact MY research, and they encourage others to participate?
- What do I **need to learn** from THEM to be a good partner to THEM?



# I Realized That I Loved Partnering with Families and Communities

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## Questions I asked myself:

- How can I **leverage** the experts in the communities to encourage community-academic partnerships?
- How can I use all that I have learned to **encourage other academics and their research groups** to partner with families and communities in a mutually beneficial way?
- How can I **informally teach** faculty and staff the skills needed to be good partners and see their patients/caregivers as experts?



# Addressing Health Promotion Challenges in Cincinnati's West End – *Since 2011*

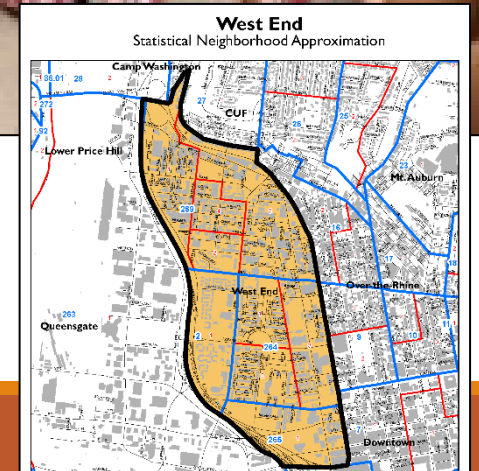
## Learned about differences:

- Educational differences
- Health literacy levels
- Differing learning styles
- Socio-cultural differences
- Age-related differences
- Differences in life experiences
- Psychological/emotional differences



## Plus....

- Mistrust of healthcare providers
- Mistrust of research





# NIGMS-R25 Funded “We Engage 4 Health (WE4H)”

An interdisciplinary  
community-academic partnership

- 5 Faculty
- 4 Staff
- 1 High School Interns
- 5 Undergraduate Interns
- 6 Community Members
- 3 Evaluation Services

Focuses on promoting community  
health and citizen science

Foundation: community co-designed  
graphic-stories and hands-on learning  
experiences.



**SEPA** SCIENCE EDUCATION  
PARTNERSHIP AWARD

Supported by a National Institute of General Medical Sciences  
Co-PI's: M Butsch Kovacic and S. Hershberger (Miami U)  
Original Community Partner: Cincinnati's West End



# Reasons to Engage

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# Goal of ALL Human Subjects Research

To provide evidence and insights that can be used to improve health outcomes

Description

Prediction

Explanation/understanding

Control

Application







# Ethics of Human Subjects Research ([HSR](#))

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Social and clinical value

Scientific validity

Fair subject selection

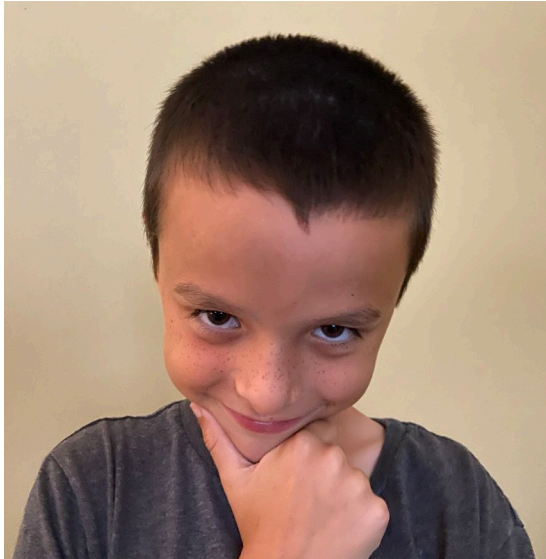
Favorable risk-benefit ratio

Independent review

Informed consent

Respect for potential and enrolled  
participants

# Value of Participant Perspective



Researchers' priorities differ from patients and study participants; research therefore lack pragmatism and patient centeredness. I know how it feels to be a research participant and a parent of one....

Engagement via consultation, collaboration and/or publicly led efforts to better understand their perspectives can help researchers reduce research participant burden and improve participation and retention of more diverse groups, particularly in clinical trials, by tailoring or targeting their studies

It can also ensure our research reflects the needs of diverse populations

# Greater diversity in research participation is critical to ensuring health equity for all

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Participants in research should reflect the diversity of our culture and conditions, considering race, ethnicity, gender, age, abilities, etc.

The lack of diversity among research participants has serious ethical and research consequences.

This includes impeding our ability to generalize study results, make medical advancements of effective therapies, and it prevents some populations from experiencing the benefits of research innovations and receipt of high-quality care.

- Community engagement is a method to improve diversity and be more inclusive in research.





# Ways to Engage

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# Ideas for Easier Ways to Engage with Patient/Caregiver Experts

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- Give and collect a participant feedback survey and ask them about ideas they have to improve their experience AND then use responses to inform study optimization
- Create/provide TARGETED education to participants about the *disease topic* – work WITH participants to co-create this if possible
- Create/provide TARGETED education about your *research study* - work WITH participants to co-create this if possible
- For longitudinal studies, provide a quarterly newsletter that can be texted, emailed and mailed – ask participants how they want to receive updates from the baseline visit (ask how not if) - work WITH participants to co-create this if possible
- Consider having a study website where you post updates, education, etc. to engage participants; update it regularly

# More Ideas for Easier Ways to Engage with Patient/Caregiver Experts

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- Consider holding online or in-person learning sessions sharing information about your study PRIOR to enrollment so people can learn/ask questions
- Encourage participant REFERRALS – highlight how many referral received via the website, newsletter, etc.
- Invite and pay someone familiar with the study in the community to make referrals; attend HEALTH FAIRS and other events to share education and extend study invitations.
- Be willing to GO TO the community talk about your active research – make it easy to understand by all and lead to meaningful discussion – invite participation at the end of the talk – the talk should include education AND not solely be a marketing tactic
- Consider sharing with individual participants meaningful PERSONAL data



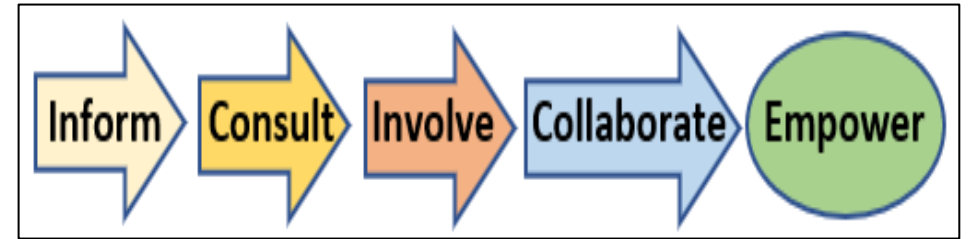
# Consider a Community – Academic Partnership (CAP)

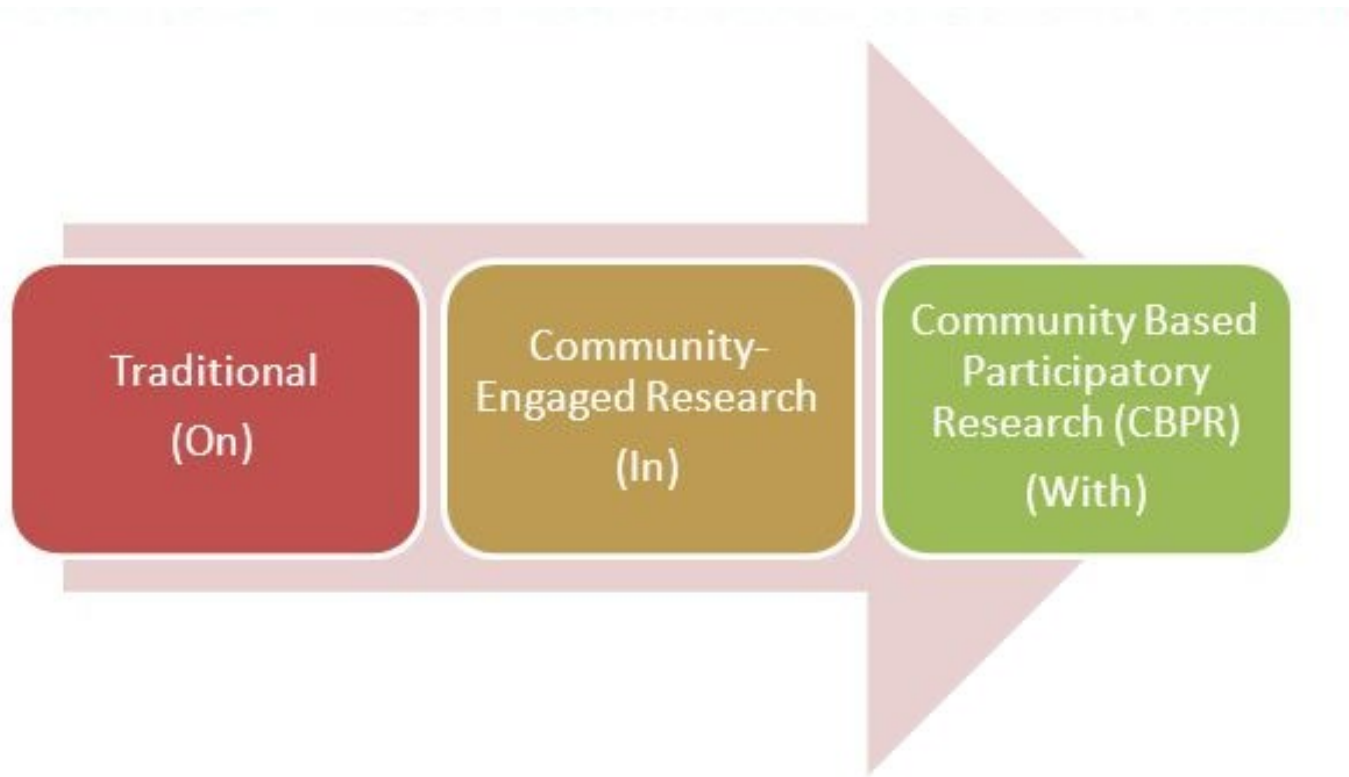
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Do you want: outreach, engagement or partnership opportunities that are available over time?

Consider increasing levels of engagement :

- Teach them something
- Ask them to **inform** a process via experience sharing
- Ask them to **consult** via idea sharing
- **Involve** them – ask them to co-design a survey or educational materials – but realize doing so takes time!
- Ask them to **collaborate** by supporting survey collection as a citizen scientist
- **Empower** them to take the lead and you follow





# Developing a CAP

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- Partner WITH individuals, groups, organizations over time in a mutually beneficial way
- Up front time in developing relationships and trust
- Having the “right” personality and being flexible, patient and resilient is key
- Co-creating a Partnership Agreement or Charter to share expectations is helpful
- Making the Agreement about people and not a specific grant is best

# Don't Try to Create a CAP Alone!!!



## Leverage COE institutional resources:

- UC Cancer Center Community Outreach and Engagement – Melinda Butsch Kovacic
- CCTST Community Engagement – Lori Crosby
- UC Community Change Collaborative – Farrah Jacquez, Kathie Maynard & Jess Kropzcynski
- UC Center for Environmental Genetics Community Engagement Core – Nick Newman
- UC Center for Public Engagement with Science (PEWS) - Angela Potochnik
- UC Ethics Center – Andrew Cullison
- The Cincinnati Project - Michael Griffin
- CCHMC Community Outreach – Monica Mitchell
- UC Urban Health Pathway – Dena Cranley
- UC Urban Futures - Kathie Maynard
- UC Public Health Programs – Regan Johnson
- UC Experiential Learning – Michael Sharp



# Start with Participant – Engaged Design

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In a meta-analysis of the effectiveness of health interventions, low community engagement in both design and delivery result in substantially less effectiveness (O'Mara-Eves et al., 2015).

# Common Ways Community Can Inform Research

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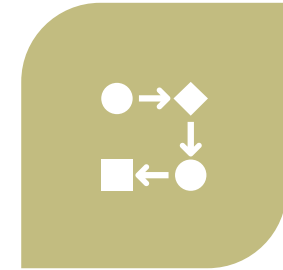
FEEDBACK  
SURVEYS



FOCUS GROUPS



INTERVIEWS



AN ITERATIVE CO-  
DESIGN PROCESS

# Other Fields Use It

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*The corporate world uses it to create better products, design better spaces, and optimize methods.*

## Take lessons from the design field:

**Recruit participants.** These can be people with relevant experience or background in the design space, business stakeholders or anyone else playing a part in the project.

**Conduct workshops.** Plan activities to encourage participation from everyone. There can be different levels of participation from people —they could just share their experiences and stories, brainstorm ideas and make mind maps, or create prototypes. It depends entirely on the context of your project and your participants.

**Record sessions and take notes.** As always, observe everything, record conversations with participants and take notes about the outcomes of your workshops.





# WITH Study Participants

The process of developing resources along with community members is called co-development, co-creation, or co-design

The authors of “Co-Design of Health Interventions With Children and Young People” (Thabrew et al., 2018) describe co-design as active collaboration between researchers, designers, developers, and users as “experts of their experiences” as they jointly explore and articulate needs and jointly explore and make solutions.”



# What Can Be Co-designed With Community?

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Consent forms  
and information  
brochures

Study design and  
study approach  
plans

Marketing and  
study recruitment  
plans & materials

Surveys, focus  
group scripts,  
interview guides

Training and  
intervention  
materials

Research  
educational  
materials

Individual reports  
to give to study  
participants

Study-related  
newsletters and  
websites

# *Simple Actions to Support Mutual Respect*

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1

Make sure you train your co-designers or ask them specific questions to answer so they know exactly what you need and can authentically help you; no rubber stamps!

2

Be respectful of their time, be open to their ideas and perspectives without getting defensive; carefully consider any ethical concerns they may have and allow them to give feedback at multiple stages


3

Thank them publicly (via publication authorship or acknowledgement); provide them financial incentives if you are able

4

Make sure your co-designers see the final product(s) of their efforts! Celebrate your successes together!

# Research co-design in health: a rapid overview of reviews

Peter Slattery\* , Alexander K. Saeri and Peter Bragge



## Abstract

**Background:** Billions of dollars are lost annually in health research that fails to create meaningful benefits for patients. Engaging in research co-design – the meaningful involvement of end-users in research – may help address this research waste. This rapid overview of reviews addressed three related questions, namely (1) what approaches to research co-design exist in health settings? (2) What activities do these research co-design approaches involve? (3) What do we know about the effectiveness of existing research co-design approaches? The review focused on the study planning phase of research, defined as the point up to which the research question and study design are finalised.

**Methods:** Reviews of research co-design were systematically identified using a rapid overview of reviews approach (PROSPERO: CRD42019123034). The search strategy encompassed three academic databases, three grey literature databases, and a hand-search of the journal *Research Involvement and Engagement*. Two reviewers independently conducted the screening and data extraction and resolved disagreements through discussion. Disputes were resolved through discussion with a senior author (PB). One reviewer performed quality assessment. The results were narratively synthesised.

**Results:** A total of 26 records (reporting on 23 reviews) met the inclusion criteria. Reviews varied widely in their application of ‘research co-design’ and their application contexts, scope and theoretical foci. The research co-design approaches identified involved interactions with end-users outside of study planning, such as recruitment and dissemination. Activities involved in research co-design included focus groups, interviews and surveys. The effectiveness of research co-design has rarely been evaluated empirically or experimentally; however, qualitative exploration has described the positive and negative outcomes associated with co-design. The research provided many recommendations for conducting research co-design, including training participating end-users in research skills, having regular communication between researchers and end-users, setting clear end-user expectations, and assigning set roles to all parties involved in co-design.

**Conclusions:** Research co-design appears to be widely used but seldom described or evaluated in detail. Though it has rarely been tested empirically or experimentally, existing research suggests that it can benefit researchers, practitioners, research processes and research outcomes. Realising the potential of research co-design may require the development of clearer and more consistent terminology, better reporting of the activities involved and better evaluation.

**Keywords:** Research co-design, patient and public involvement, research engagement, community-academic partnership, participatory research

\* Correspondence: [peter.slattery@monash.edu](mailto:peter.slattery@monash.edu)  
BehaviourWorks Australia, Monash Sustainable Development Institute,  
Monash University, Melbourne, Australia



# Evaluate the Co-design Process in YOUR Hands

Most researchers that use co-design fail to evaluate their co-design process (see Slattery et al. Health Research Policy and Systems, 2020)

Co-design is becoming increasingly valued and is often a positive in grants

Ask your co-designers about their experience working with you AND about how their contributions were valued and included in whatever they were co-designing with you



# My Personal Examples

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# CCTST West End Community Research Advisory Board

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Listens to many researchers talking about their research both in-person and online

Some give a science talk; some SPEAK to them.

Come share your work with them – they are happy to give you feedback!

# Advisory Boards

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“...studies increasingly show that when health care administrators, providers, patients, and families work in partnership, the quality and safety of health care rise, costs decrease, and provider and patient satisfaction increase”

Willis, R., Krichten, A.,  
Eldredge, K., & Carney, D.  
(2013). Creating a patient and  
family advisory council at a  
level 1 trauma center. *Journal  
of Trauma Nursing*, 20(2), 86-  
88.







# OUR STORY-BASED STRUCTURE

“Stories help people to better understand and make sense of the world.”

Stories have been used to share knowledge from generation to generation for thousands of years and are important ways to connect with audiences. Rather than a long list of dry facts, stories include enough emotional detail so that listeners better and much more vividly remember even ideas and concepts and are more likely to use and share what is learned.

For health promotion stories see [www.WeEngage4Health.life](http://www.WeEngage4Health.life)



Our programs are anchored by graphic-style stories for grade 5 through adults!

These stories are read aloud by participants to create engagement, ownership, and common ground.

The stories model science thinking and investigation that's followed up by related hands-on experiences.

Our stories and hands-on experiences are co-designed with Cincinnati area communities.

Co-design with communities helps us meet the needs and interests of diverse audiences!



# Uniqueness of WE4H Graphic Style Stories

Shared ownership  
with co-designers

Fun, engaging, and  
motivating

Locally and culturally  
relevant

Quickly create  
shared experiences

Understood &  
enjoyed by people of  
all ages and literacy  
levels

Lead to meaningful  
discussions and  
personal  
connections

Explains “why”  
rather than simply  
telling people “what”  
to do

Focuses on only 3  
big ideas that are  
memorable and  
actionable

Useful in informal  
programming, health  
education events &  
more!

# Consider Literacy and Health Literacy Levels

**Q: Why should participants of all backgrounds participate? How might participating in this study help others with those diseases/in their local community/African Americans?**

A: Reference populations for genetic research have historically been overrepresented by participants who identify as White or have European ancestry. Increasing the racial and ethnic diversity of participants in genetic research will help researchers and healthcare providers to better understand genetic risk factors for diseases seen in the whole population and genetic risk factors for people with these traits. Increasing African Americans' participation in genetic research will help researchers to understand the genetic factors contributing to disease burden in this population and will increase the potential for their healthcare providers to recommend increased health surveillance and lifestyle changes to prevent or manage diseases with genetic risk factors.

**Q: Why is this research important to people of all backgrounds?**

A: Prior research has shown that there are many genetic differences between races. Varying living environments and lifestyles also impact genetic risk factors. Differences in values and ideals influence how people make decisions too. To create useful decision tools, genetic research studies need participants of all backgrounds. To date, most studies have had far too few African American and non-white participants. Greater diversity in our study will lead to better decision-making tools for everyone.

**Hemingway**  
*Editor*

**Readability**

**Grade 12**

OK. Aim for 9.

Words: 872

Show More ▾

**5** adverbs, meeting the goal of 9 or fewer.

**12** uses of passive voice. Cut to 11 or fewer.

**4** phrases have simpler alternatives.

**7** of 53 sentences are hard to read.

**20** of 53 sentences are very hard to read.

**Hemingway**  
*Editor*

**Readability**

**Grade 8**

Good

Words: 611

Show More ▾

**0** adverbs. Well done.

**3** uses of passive voice, meeting the goal of 11 or fewer.

**0** phrases have simpler alternatives.

**0** of 55 sentences are hard to read.

**0** of 55 sentences are very hard to read.

- [Hemingway app](#) is a great tool to help ensure your research communications are readable, understandable, and actionable by ALL literacy levels - No acronyms!

# Our Cast of Characters are Community Co-designed Too!

## OUR CAST OF CHARACTERS





Does health research improve the health of my community?

Will I be safe when participating in health research?

# RESEARCH READY

A GRAPHIC-STYLE STORY ABOUT HEALTH RESEARCH FOR GRADE 5 THROUGH ADULTS

WE ENGAGE 4 HEALTH IS FUNDED BY A GRANT FROM THE NATIONAL INSTITUTES OF HEALTH SCIENCE EDUCATION PARTNERSHIP AWARDS.



## RESEARCH REVIEW



We'll give you info on some research projects to look at...

See which of the questions below you can answer.

### TIPS FOR CONSIDERING PARTICIPATION IN A RESEARCH STUDY...

#### HISTORY AND RELEVANCE

WHAT PRIOR RESEARCH HAS BEEN DONE?  
HOW IS THE RESEARCH RELEVANT TO ME AND MY FAMILY?  
AM I ELIGIBLE? (DO THEY MEET INCLUSION AND EXCLUSION CRITERIA?)

#### RISK AND BENEFIT

WHAT IS A POTENTIAL POSITIVE IMPACT TO ME, MY FAMILY OR OTHERS, NOW OR IN THE FUTURE?  
WHAT, IF ANY, POTENTIAL RISKS OR SIDE EFFECTS EXIST?  
IS THERE ANY COST TO ME FOR PARTICIPATING?  
WILL I GET PAID OR HAVE OTHER FINANCIAL BENEFITS?

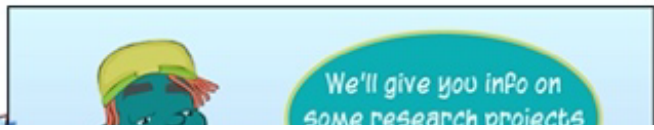
#### AM I WILLING TO

...GIVE BIOLOGICAL SAMPLES SUCH AS BLOOD OR SALIVA (SPIT) IF REQUIRED?  
...BE GIVEN MEDICAL TESTS IF REQUIRED?  
...COMPLETE SURVEYS IF REQUIRED?  
...TAKE MEDICATIONS OR USE A MEDICAL DEVICE IF REQUIRED?  
...COMPLETE MEDICAL FORMS THAT MIGHT GO INTO MY PERSONAL HEALTH RECORD?

#### DO I FEEL COMFORTABLE WITH

...THE LEVEL OF CONFIDENTIALITY?  
...THE NUMBER OF STUDY VISITS OR THEIR LENGTH?  
...SHARING MY PERSONAL PERSPECTIVES WITH THE STUDY TEAM?





Being “Research Ready” means understanding the 3 P’s.

**Purpose:** What is the purpose of health research?

**Protection:** How are people kept safe when they participate in health research?

**Participation:** Why should people participate in health research?



CRAs are community volunteers who help their friends and neighbors BECOME “**Research Ready.**”

CRAs schedule and conduct **Research Ready Discussions** for teens through adults in their communities.

CRAs follow the **Research Ready Discussion Plan** to conduct Research Ready Discussions using the “Research Ready” story.

CRAs work in teams of two to provide support to each other and benefit from each person’s strengths.



WE ENGAGE 4 HEALTH IS FUNDED BY A GRANT FROM THE NATIONAL INSTITUTES OF HEALTH SCIENCE EDUCATION PARTNERSHIP AWARDS.

...THE LEVEL OF CONFIDENTIALITY?  
 ...THE NUMBER OF STUDY VISITS OR THEIR LENGTH?  
 ...SHARING MY PERSONAL PERSPECTIVES WITH THE STUDY TEAM?  
 ...THE RECORD?

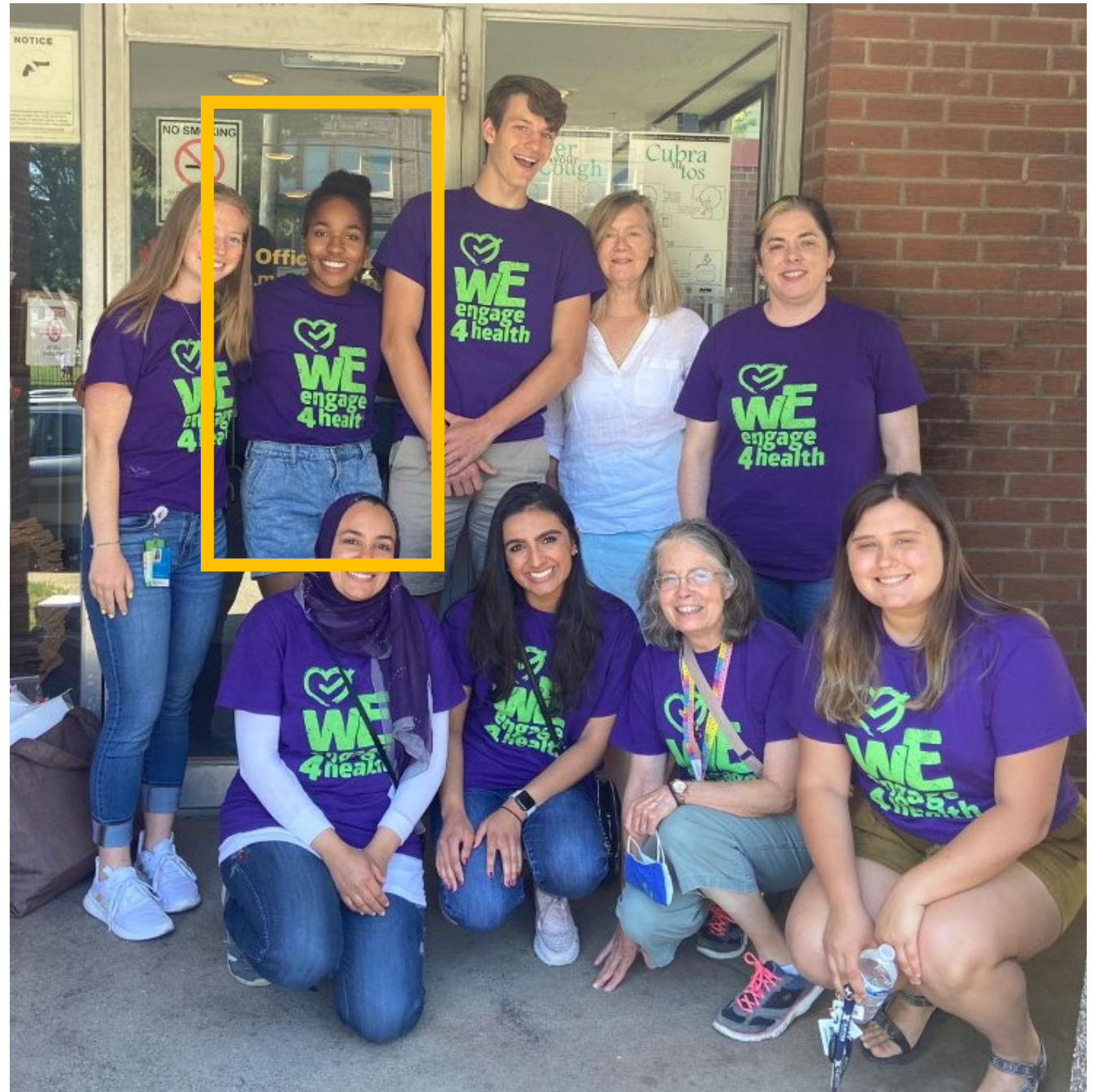


**WE** engage  
4 health



**M-PAACH**

Mechanisms of Progression of  
Atopic Dermatitis to Asthma in Children





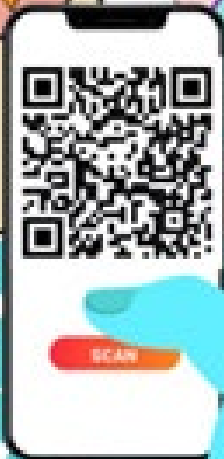
# \*ECZEMA STUDY UPDATE

#STUDY IS CALLED M-PAACH



Your child's next eczema study visit at Children's Hospital is due soon!

Read our \*story for a refresher about the goals of the M-PAACH study and what testing involves!



SCAN QR CODE TO OPEN STORY

\*Graphic-style story is for grade 5 through adults



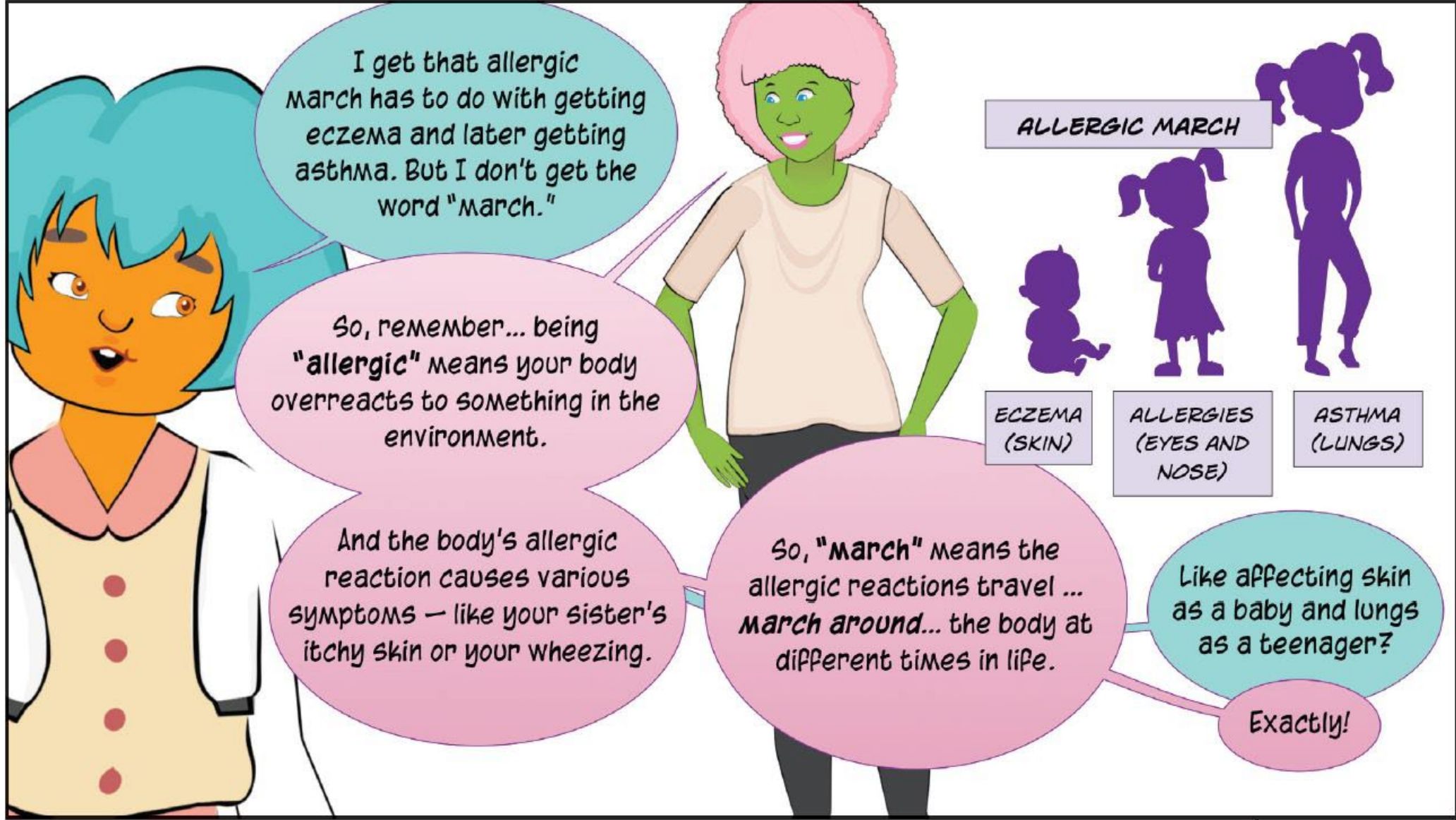
I'm glad we learned so much about the M-PAACH study!

Me too! Now we know exactly what your little sister will be doing as a research subject!



[HTTPS://WEENGAGE4HEALTH.LIFE/MPAACH/](https://weengage4health.life/mpaach/)

# Define Concepts





# How the study works



# Explain the science of the study

Maybe you learned that people can have a gene with a different recipe than most people. We call it a **gene variation**.

Gene variations make proteins that are a bit different than the original and may not work as well.

Certain gene variations may lead to babies having eczema.

So my baby sister Addie might have one of those variations!

She might! Addie would need genetic testing to find out.

**TYPICAL GENE "RECIPE"**

**ORIGINAL PROTEIN BEING MADE**

**GENE VARIATION "RECIPE"**

**DIFFERENT PROTEIN BEING MADE**

GENE DIFFERENCE

PROTEIN DIFFERENCE



# How the samples taken will be used – why their important

The M-PAACH scientists are looking for eczema-related gene variations. They use the blood samples taken at visits.

They want to find out if babies who get asthma when older have different gene variations than babies who never get asthma.

So that's why the blood samples are so important! The blood helps scientists understand how genetics plays a role in the allergic march.

I think it's worth a bit of fussing from the poke!

BABY A GOES ON TO HAVE ALLERGIC MARCH (HAS ASTHMA WHEN OLDER)

BABY B DOES NOT HAVE ALLERGIC MARCH (NO ASTHMA WHEN OLDER)

M-PAACH RESEARCH QUESTION:  
DOES BABY A HAVE DIFFERENT ECZEMA GENE VARIANTS THAN BABY B?

# Why participants need to return annually

You can see that all the samples and information are important to helping the M-PAACH scientists understand the allergic march!

When babies come back each year for all 5 years, the data is much more **comprehensive**.

Comprehensive?  
Meaning, like, complete?  
I think their data is like a story! When people do not come back, pieces of the story are missing.

A story with missing pieces is no fun to read! We want to know what happens!

YEAR 1  
DATA COMPLETE

YEAR 2  
DATA COMPLETE

YEAR 3  
NO DATA

YEAR 4  
NO DATA

YEAR 5  
FINAL DATA COMPLETE

★  
EVEN IF OTHER YEARS HAVE BEEN MISSED, COMING BACK FOR YEAR 5 IS STILL EXTREMELY VALUABLE!



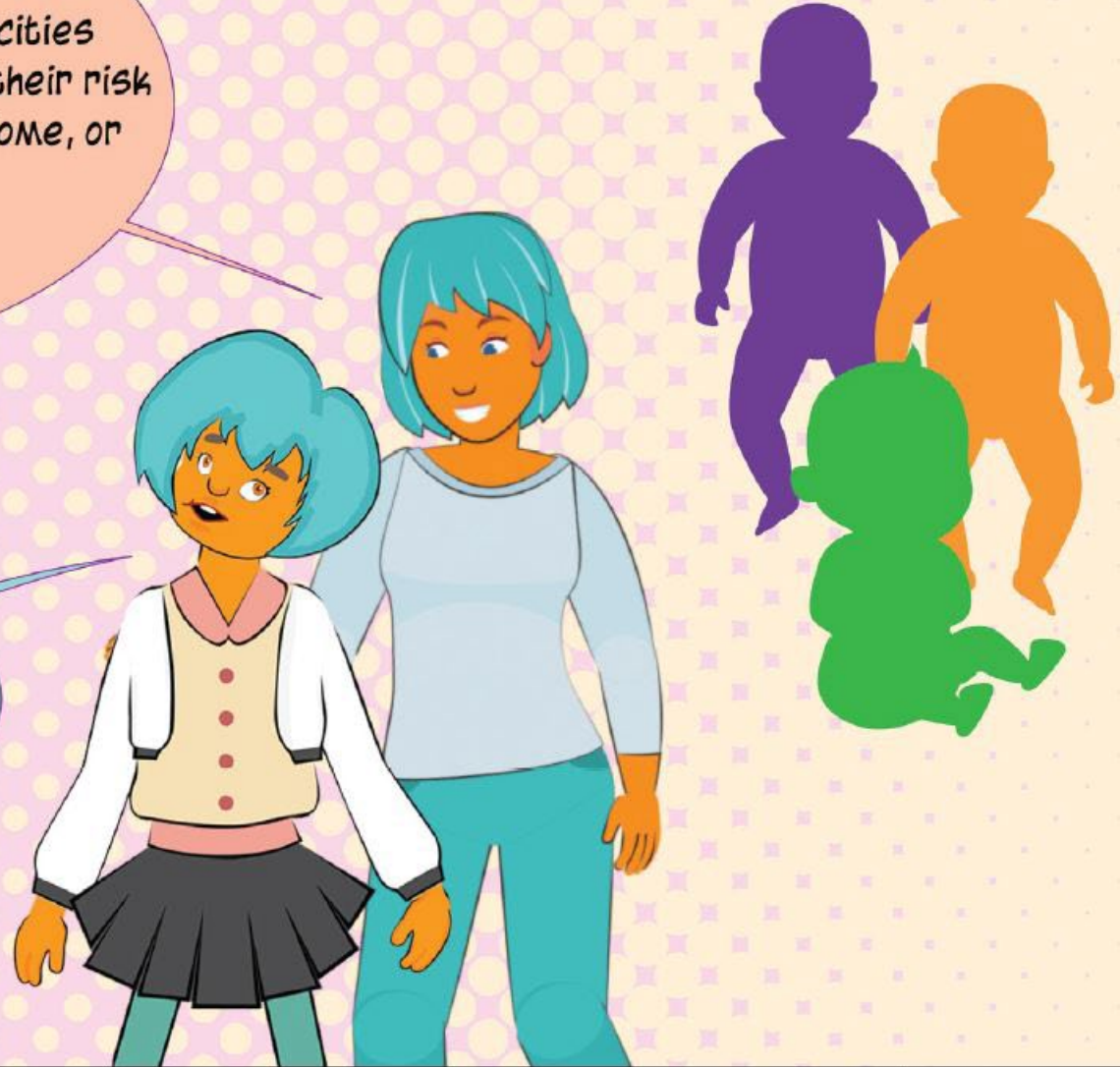
# Encouraging Diversity

People from different races and ethnicities may have gene variations that influence their risk for getting diseases, how sick they become, or how well treatments work.

If a research study includes only one group, the results may not apply to other groups.

Oh, so that must be why M-PAACH encourages people from all backgrounds to join!

exactly!



# Helping people to make a good decision about participation

## TOP POINTS ABOUT M-PAACH RESEARCH STUDY

### M-PAACH STUDY PURPOSE

THE GOAL OF THE M-PAACH STUDY IS TO UNDERSTAND WHY SOME CHILDREN HAVE AN "ALLERGIC MARCH" FROM ECZEMA TO ALLERGIES TO ASTHMA AND SOME DO NOT.

### STUDY TESTS

- BLOOD SAMPLE FOR GENE TESTING
- SKIN SAMPLE TO LOOK AT GENES AND BACTERIA
- SKIN PRICK TEST TO LOOK FOR ALLERGIES
- LUNG FUNCTION TEST TO LOOK FOR ASTHMA
- DUST SAMPLE TO LOOK AT ENVIRONMENT
- PLUS... SALIVA, STOOL AND NASAL SAMPLES

BABIES  
LIKE ME NEED  
YOU!

RETURN FOR YOUR M-PAACH  
STUDY VISITS TO HELP  
SCIENTISTS HELP  
CHILDREN!



### RISK AND BENEFIT

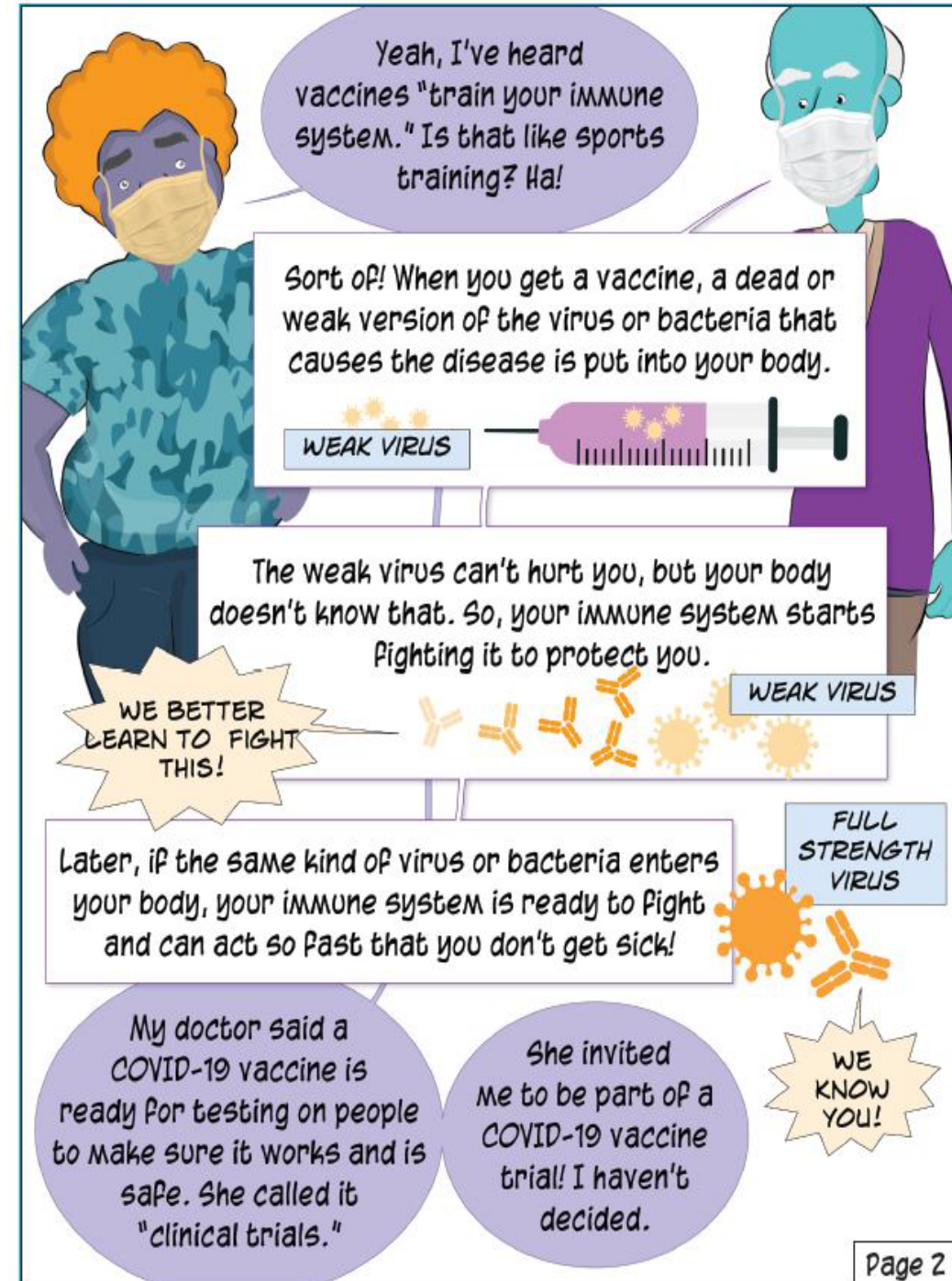
- YOUR CHILD'S RISK IS TEMPORARY DISCOMFORT FROM SOME TESTS.
- YOUR BENEFIT IS KNOWING IF YOUR CHILD HAS ALLERGIES OR ASTHMA. YOU'LL ALSO HAVE THE SATISFACTION OF HELPING FUTURE CHILDREN THROUGH WHAT IS LEARNED.

### VALUE OF RETURNING VISITS

- YOUR RETURNING VISITS GIVE RESEARCHERS THE COMPLETE STORY ABOUT WHETHER YOUR CHILD IS "MARCHING" FROM ECZEMA, TO ALLERGIES, TO ASTHMA.
- THIS GIVES YOU MORE KNOWLEDGE ABOUT YOUR CHILD'S HEALTH AND GIVES RESEARCHERS MORE INFORMATION TO USE AS THEY WORK TO HELP FUTURE CHILDREN.



# 3-panel stories







## CHALLENGES TO HEALTH

- 1 FOR LIFE TO GET BACK TO NORMAL, WE NEED THE PROTECTION FROM COVID-19 THAT A VACCINE OFFERS.
- 2 SOME PEOPLE THINK VACCINES FOR DISEASES LIKE MEASLES AREN'T NEEDED ANYMORE BECAUSE THEY DON'T INFECT LOTS OF PEOPLE. BUT IF PEOPLE STOP GETTING VACCINES, MEASLES AND OTHER DISEASES WILL MAKE MANY PEOPLE SICK AGAIN.
- 3 SOME PEOPLE ARE SCARED TO GET VACCINES. THEY WORRY ABOUT VACCINE INGREDIENTS OR THE CHANCE OF A BAD REACTION.

## HEALTHY ACTIONS

- 1 VACCINES WORK AND ARE SAFE. TAKING THE VACCINES YOUR DOCTOR RECOMMENDS HELPS KEEP YOU AND THE PEOPLE AROUND YOU HEALTHY.
- 2 PARTICIPATING IN CLINICAL VACCINE TRIALS HELPS MAKE SURE THE VACCINE WORKS WELL FOR ALL KINDS OF PEOPLE.
- 3 HELP YOUR IMMUNE SYSTEM PROTECT YOU FROM DISEASE. SLEEPING ENOUGH, EATING COLORFUL FRUITS AND VEGETABLES, AND EXERCISING BOOST YOUR IMMUNE SYSTEM.

### DID YOU ENJOY THIS STORY?

Learn more about COVID-19 and vaccines in our longer story at [www.WE4H.life/vaccine](http://www.WE4H.life/vaccine)

THIS STORY WAS DEVELOPED AS A COLLABORATION OF COMMUNITY REPRESENTATIVES OF THE WEST END NEIGHBORHOOD IN CINCINNATI, OHIO AND WE ENGAGE 4 HEALTH PROGRAM MEMBERS.





  
**THERE'S A LOT TO LOVE ABOUT**  
**LICK RUN GREENWAY**



On the surface, the Lick Run Greenway looks like a park with a stream running through it.







And it is!

But this urban green space was actually designed to keep rainwater from causing sewer overflows.





Rainwater collects in the Lick Run Greenway from a wide area. The Lick Run stream carries the rain water to Mill Creek.



## WATER CHALLENGES

-  MUCH of the Cincinnati area has sewers that carry both sewage and rain water in the same pipe.
-  WHEN they fill up with rain water during heavy storms, our sewers are designed to overflow into local streams and rivers. This puts a mix of rainwater and raw sewage into our waterways.
-  WHEN our sewers were first built, overflow to streams and rivers was considered OK, but it's not OK anymore.
-  WHEN most land was undeveloped, lots of rain water soaked into the ground. Now, much of the land surface is built on or paved. Plus, extreme storms have become more frequent and more intense. So, much more rain water enters the sewer system. Overflows happen more often. Sewage backups into homes also happen more often.
-  SEWER overflows and backups cause a mess and smell bad. The worst part is that overflows and backups can make you sick.
-  OVERFLOWS put E. coli bacteria and other germs into streams and rivers. If you swallow water with high levels of E. coli, you can become ill. After big storms, cities may declare it unsafe to swim, canoe, or kayak in lakes and rivers. Wet basements from sewage backups are a source of mold that can cause illness.

## WATER SOLUTIONS

-  URBAN greenways like Lick Run provide a big unpaved area for rain water to be absorbed instead of going into the sewer system. The plants in the greenway help to filter the water naturally too!
-  LICK Run Stream takes this rain water out to Mill Creek. Mill Creek goes to the Ohio River.
-  THE sewer system does not overflow or back up as much. Our water is cleaner and we are healthier!
-  CINCINNATI residents are trained as "citizen scientists" to do weekly water tests to measure the impact of Lick Run!

# Easy Ways to Engage

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- **Community Outreach Discussions** – a science talk with the goal of discussion
- **Event Attendance** - health fairs, volunteer or celebration dinners, road races and rides, and fundraisers – and more!





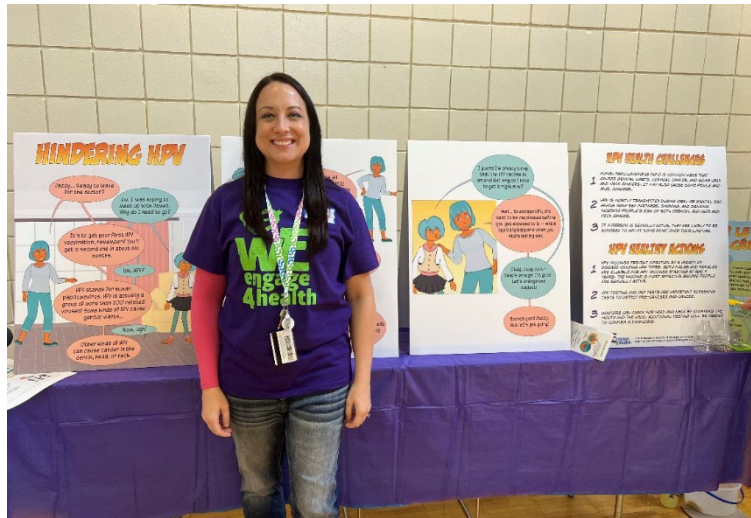


## Tell Your Research's Story

- **Problem** - conflict or knowledge gap being addressed
- **Action** - steps taken to solve the problem
- **Resolution** - impact of action



# Community Health Fairs





# Health Screening Results Form (version 1)

Name \_\_\_\_\_

Date of Birth \_\_\_\_\_

Sex \_\_\_\_\_

Thank you for participating in our study. Included are your test results. If you have questions or concerns, please ask your doctor.

Measure	Value
Date of Screening: _____	
Height	____ feet ____ inches
Weight	____ pounds
Body Mass Index	____ kg/m <sup>2</sup> ____ %
Blood Pressure	Systolic: _____ mmHg ____ %
	Diastolic: _____ mmHg ____ %
Status	
Cholesterol	Total: _____ mg/dL _____
	LDL: _____ mg/dL _____
	HDL: _____ mg/dL _____
	Trigs: _____ mg/dL _____

**Body Mass Index (BMI)** is a number calculated from your height and weight. BMI is a reliable indicator of body fatness. BMI percentile (%) considers your BMI along with your sex and age.

Weight Status	Body Mass Index Percentile (%)
Underweight	< 5th%
Healthy weight	5th% - 85th%
Overweight	85th - 95th%
Obese	≥ than the 95th%



**You can maintain a healthy weight by:**

- Eating healthy foods & drinks (water is best!)
- Being physically active on most days
- Getting adequate sleep (≥8 hours/night)
- Limiting television time (≤2 hours/day)



**High blood pressure** (also called hypertension) is an important health issue in children because it is considered a risk factor and has been linked to heart disease and stroke in adulthood. Children can lower their risk by maintaining a healthy weight, eating nutritious foods and exercising often.



**A systolic and/or diastolic blood pressure (BP) %**  
 ≥ 95th% = High BP  
 90th - 95th% = elevated/borderline BP  
 120/80 mm Hg = elevated/borderline BP

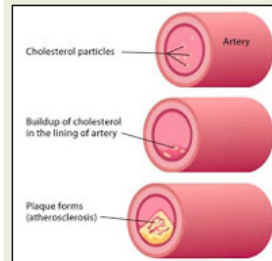
**Triglycerides (Trigs)** are other types of fats. If you eat carbohydrates, including sugars, that aren't used right away to make energy, your body turns them into triglycerides and moves them into fat cells for storage. As you require energy to move and play, the fat cells release triglycerides. Over your lifetime, too many triglycerides in the blood results in hardened arteries and higher risk of heart attack and stroke in adulthood.

	Boys	Girls
Normal	34-137	37-145



CCHMC IRB Protocol # 2014-0119  
 Study PI: Melinda Butsch Kovacic  
 Co-Investigators: Lisa Vaughn, Farrah Jacquez  
 Contact: 513-803-0130

**Cholesterol** is a type of fat in the blood. Everyone needs to have some cholesterol in their blood to be healthy, especially good cholesterol or high-density lipoproteins (HDL). However, kids who have higher-than-normal levels of total cholesterol and low-density lipoproteins (LDL) have a higher risk of developing clogged or narrowed blood vessels



that carry blood to their heart muscles. Reducing your total and LDL cholesterol levels with proper diet and exercise is believed to give kids like you a better chance of having lower cholesterol and risk of heart disease when you become adults. To raise HDL and lower LDL cholesterol, don't smoke or be around smoke maintain a healthy weight, and exercise often!

	Total*	LDL (bad)*	HDL (good)*
Normal	<170	<120	>60
Borderline	170-199	120-144	40-60
Abnormal	≥200	≥145	<40

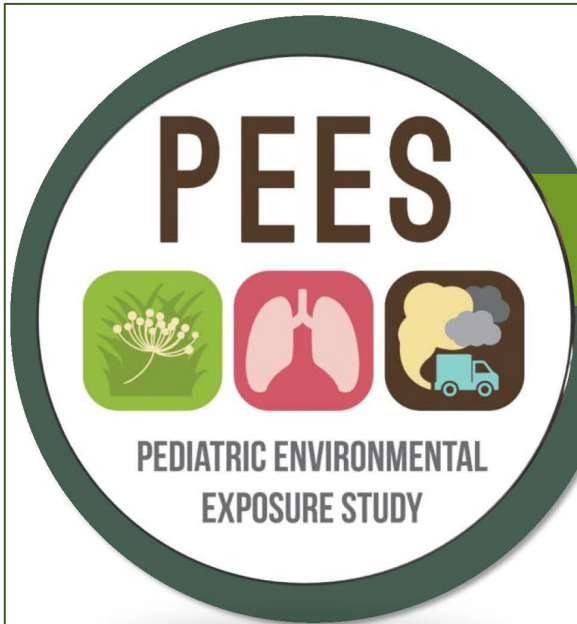
# Sharing Personal Data with Participants

- Consider sharing clinically relevant individual results, where appropriate
- May increase participation particularly with blood draws
- Likely will support good will, repeat research participation
- Make sure you provide education to accompany results





# Newsletters



**THANK YOU!  
OUR STUDY PARTICIPANTS  
MAKE A DIFFERENCE!**

Our study's enrollment to date is:  
Phase 1 – 294 children with asthma  
Phase 2 – 282 children with asthma  
Plus more than 115 children without asthma

Since 2008, our purpose has been 1) to examine how the environment (e.g. air pollution and smoking) and genetics influence levels of stress and inflammation in individuals with asthma and allergies and 2) to better understand how stress and inflammation modulates severity of asthma and allergy symptoms. Notably, our study has examined cytokines such as Interleukin 13 (IL-13) and Interleukin 17 (IL-17) in children with asthma. These cytokines interact with cells of the immune system in order to regulate the body's response to disease and infection, as well as mediate normal cellular processes in the body. While researchers have known the importance of IL-13 in asthma for some time, only recently have we begin to understand the role(s) of IL-17 in asthma and to observe how the environment modifies these cytokines. Thank you for helping us!

We publish our research findings in peer reviewed journals. Peer review ensures that our work is effectively subjected to the scrutiny of other experts in our field and encourages researchers to strive to produce high quality research that will advance the field. Below are representatives of our work. To view our work, hit the hyperlinks below or do a search at <https://www.ncbi.nlm.nih.gov/pubmed/>

IL-17A enhances IL-13 activity by enhancing IL-13-induced signal transducer & activator of transcription 6 activation.  
[Journal of Allergy Clinical Immunology](#)  
2017 Feb; 139(2):462-471

Diesel exhaust particle induction of IL-17A contributes to severe asthma.  
[Journal of Allergy Clinical Immunology](#) 2013  
Nov;132(5):1194-1204

Early maternal smoking & age contribute to epithelial cell IL-13 responsiveness in a pediatric asthma population.  
[Allergy](#). 2019 May 18  
doi: 10.1111/all.13876

Produced by the Research Team of Dr. Melinda Butsch Kovacic MPH, PhD [Melinda.Butsch.Kovacic@cchmc.org](mailto:Melinda.Butsch.Kovacic@cchmc.org)

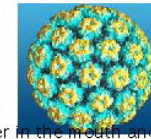
## Oral Human Papillomavirus



### Oral HPV Infection

#### What is Human Papillomavirus (HPV)?

- Human papillomavirus (HPV) is a virus from the papillomavirus family that affects membranes that line the body in areas such as the throat, mouth, anus, and cervix, among others.<sup>1</sup>
- There are 100+ types of HPV including 40 HPV types that can affect the genital area.<sup>1</sup> At least 17 types can cause cancer in the mouth and genital areas (high risk types). Some evidence suggests that HPV may have a role in skin cancer.<sup>4</sup>
- HPV-16 is the most common cancer causing or high-risk type, causing 50% of HPV-related cancers, mostly squamous cell cancers. HPV-18 is the second most common cancer causing type, causing 20% of cancers, mostly adenocarcinomas.<sup>2</sup> Other types of low-risk HPV cause warts including genital warts.
- HPV is very common in sexually active teens and adults. Most types of HPV cause no symptoms, particularly in people with a healthy immune system. A healthy immune system suppresses the spread of the virus before causing health issues.
- In the general population, annual Papanicolaou (Pap) testing is performed in younger women to detect changes resulting from HPV infection in the cervix. Pap and HPV testing are performed together in women 30+ years to screen for HPV.



#### What is an Oral HPV infection?

- HPV of any type that is found in the mouth and throat is called "oral HPV."<sup>2</sup> There are no screening guidelines for oral HPV at this time although some dentists are now offering testing.
- Some high risk types of oral HPV can increase the risk of cancers of the head and neck.<sup>2</sup> Other low risk types of oral HPV can cause warts in the mouth and throat.<sup>2</sup>

#### The HPV Vaccine

- Two HPV vaccines are available in the US. Quadrivalent HPV (HPV4) vaccine (Gardasil, Merck) was approved by the Food and Drug Administration (FDA) in June, 2006, and bivalent HPV (HPV2) vaccine (Cervarix, GlaxoSmithKline) was approved by the FDA in October, 2009. For both vaccines, it is important to have all 3 doses over 6 months to be protected against the HPV types in the vaccine. The timings of the shots may also influence protection.
- HPV vaccines do not protect against all HPV types. Additionally, if an HPV infection occurred prior to vaccination, the vaccination will not treat the infection. Studies have shown that people with FA respond to the vaccine, although it is unclear if the immune levels produced are protective or if immune decline modifies protection offered by the vaccines.

HPV4 (Gardasil)	HPV2 (Cervarix)
<ul style="list-style-type: none"> <li>Protects against HPV types 16 and 18 (high risk) and types 6 and 11 (low risk wart causing)<sup>3</sup></li> <li>Approved for females and males 9-26 years of age<sup>5</sup></li> </ul>	<ul style="list-style-type: none"> <li>Protects against HPV 16 and 18 (high risk)<sup>6</sup></li> <li>Approved for females 9-25 years of age<sup>6</sup></li> </ul>





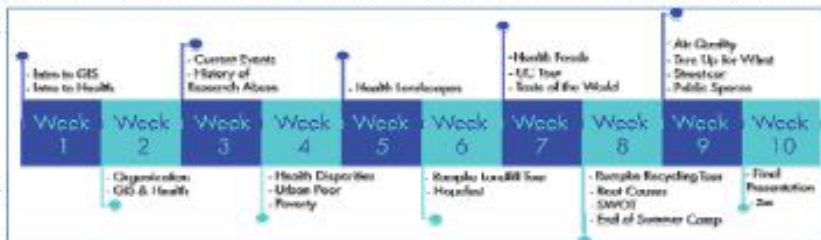
# Partners in Health

## Community Youth Scientists (CYS)



**BREAKING THROUGH**

Dr. Melinda Butsch Kovacic, MPH, PhD, Associate Professor (right inset) at Cincinnati Children's Hospital Medical Center (CCHMC) and the 7 Hills Neighborhood Houses Findlay Street Center received a 2014 Community Health Grant from the Center for Clinical and Translational Science and Training (CCTST) - a partnership between CCHMC, the University of Cincinnati (UC), and the Cincinnati VA Medical Center. The **CYS Program** was in part based on Dr. Butsch Kovacic's 'Coaching On Achieving Community Health' (COACH) Program which provided health education, drug prevention and leadership training to 5 West End teenagers over the summer of 2013. With the 2014 grant, 12 West End teen workers studied the **7 Habits of Highly Effective Teens** book, as well as learned about environmental health, community advocacy, research methodology, and urban planning and mapping using Geographic Information System software. Ken Woodson, MPH, CHES, a UC Health Education student, lead the program. Over the summer, there were a number of speakers and several field trips including to UC, the Rumpke Landfill and Recycling Plants, and the Cincinnati Zoo. In November, 5 **CYS** went to see the 'A Revealing the Light Within' art exhibition at Miami University and toured campus.



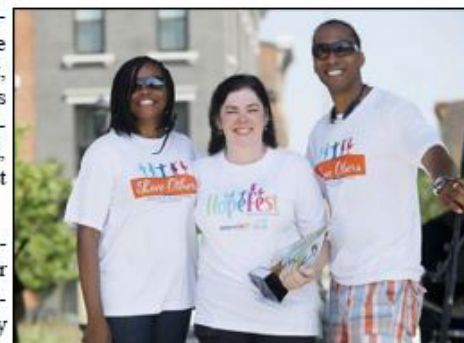
**Thank you to our summer speakers!**

- ▶ Catherine Ramstetter, PhD, CHES, Assistant Professor & Associate Dean at the Christ College of Nursing and Health Sciences
- ▶ Peachy Seiden, MS, RD, Licensed and Registered Dietitian with a private nutrition consulting practice, Peachy Health Smart
- ▶ Kelly Rawe, MEd & Josh R. Stout, BA, Undergraduate Academic Advising – Health Promotion & Education Program at UC
- ▶ Michael Topmiller, PhD, GIS Data Specialist at Health Landscape, LLC.
- ▶ Sara Cullin, Senior Corporate Communications Coordinator at Rumpke Landfill
- ▶ Anne K. Gray, Education Specialist, Rumpke Waste & Recycling
- ▶ Patrick H. Ryan, PhD, Environmental Health Epidemiologist and Associate Professor at CCHMC



### The HopeFest Health Passport

HopeFest is a health screening and education festival that also gives Cincinnati kids a chance to have some fun! In past years, face painting, balloon art, games, and music helped to spice up the event. Reds mascots and Batman are known to stop by. Kids always walk away with all kinds of goodies. Still, HopeFest is so much more, because of the HopeFest Health Passport.



**2015 HopeFest Humanitarian Award Winner Melinda Butsch Kovacic with HopeFest Founders Sherman and Sadell Bradley**

One of the challenges for community-led health programs is the lack of data to identify priorities for health programs, support their funding and implementation. Indeed, health statistics are commonly reported from hospitals or social service agencies and therefore may not represent a portion of the population at the greatest need who do not utilize these services. While several free health screenings are offered each year in Cincinnati, organizers often miss a great opportunity to collect health-related data to utilize in future community-led endeavors. The HopeFest Health Passport provides the chance to simultaneously target education, screenings and collect data from some of the neediest children living in Cincinnati. Dr. Melinda Butsch Kovacic, MPH, PhD developed the Health Passport to support Hopefest events and to help Consider the Poor's Sherman Bradley to sustainably change health and education outcomes for children living in poverty across Cincinnati. Dr. Butsch Kovacic, an Associate Professor at the University of Cincinnati and Cincinnati Children's Hospital Medical Center used her training and experiences in epidemiology and community research to first evaluate the success of HopeFest. Later, she saw the festival as an opportunity to engage screeners so that the Passport served their needs better as well as the needs of attendees and their broader communities.



With each subsequent year, additional clinical screens and education topics were added. Feedback from attendees, screeners and volunteers alike led to the refinement of the Passport and the data collection process and to its greater capacity to uniquely identify areas of greatest community need. Further, the inclusion of community partners and university students and faculty members now supports the development of inclusive clinical professionals to better serve diverse families living in the inner city. Undoubtedly, the Health Passport is a much needed sustainable model for health data collection by community organizations doing health screenings festivals. For this reason, Dr. Butsch Kovacic was one of two recipients of the 2015 HopeFest Humanitarian Award.



ISSUE

02

A Quarterly Update

March 2021

# WE4H Times

## Coming soon!

WE4H participants will soon be able to earn virtual badges to show their accomplishments!



## See us at CitSciVirtual 2021!

By Madison Biddle



**Power of Stories Workshop:** WE4H creates and offers stories in various formats as part of our citizen science projects. Attendees will learn what makes a good story and get support to begin stories for their own citizen science projects. A "Power of Stories How-To Guide" will help them continue developing their stories.

**Data Interpretation Workshop:** The success of citizen science activities is often judged on the data captured. In this workshop, attendees will learn how to effectively organize, evaluate, and use data and consider ways of sharing data through stories.

**Eyewitness Community Survey (ECS) Poster:** A poster presentation will introduce the ECS project. ECS is a citizen science research project that focuses on how environmental factors might impact health in a community. ECS features an online survey tool that community members use to gather data. Data collected during pilot testing of the ECS tool will be shared.

**Citizen Science (CS) RAP Poster:** A poster presentation will introduce the CS RAP program. CS RAP is a series of sessions (online or in person) featuring stories, discussions, and hands-on activities on topics that include understanding citizen science, ethics of research, and collecting, analyzing, and interpreting data.

## Issue Highlights

See us at CitSciVirtual 2021 P.1

ECS Winter Pilot P.2

Power of Stories Research Update P.3

Facilitator Training Pilot a Success! P.4

New CRA Research Ready Program P.5

CCTST COVID-19 Critical Community Challenge Project P.6

WE4H will be joining presenters from around the world at the **Citizen Science Association May 2021 conference CitSciVirtual: Local, Global, Connected**. As described at [citizenscience.org](http://citizenscience.org), conference organizers "... want to hear about the current state of citizen science, as well as what you've learned that is going to shape the face of citizen science in the future." WE4H will be participating with two workshops and two posters. Workshops will include live, synchronous material as well as asynchronous material that will be accessed via the CitSciVirtual web platform.



## What is We Engage 4 Health?

We Engage 4 Health (WE4H) is a community health project supported by the Science Education Partnership Award (SEPA) Program of the National Institute of General Medical Sciences (NIGMS). WE4H is a partnership between the University of Cincinnati, Cincinnati Children's Hospital, Miami University, and Cincinnati-area community partners.

The goals of We Engage 4 Health are to

- Improve health and science knowledge in the community
- Reduce chronic disease in communities where it occurs most
- Increase citizens' involvement in their own and community's health
- Strengthen science competencies and encourage STEM careers in youth

## How to get involved...

- Learn about doing health outreach in your community!
- Learn about hosting free community health outreach programs for your organization!
- Learn about free WE4H programs that you and your family can attend!

## OUR STORY-BASED STRUCTURE



- ★ Humans are wired for stories.
- ★ Stories speak to the part of the brain where decisions are made.
- ★ Stories make it easier for people to remember.
- ★ Reading out loud can help people to feel ownership of the information.



# Consider Engagement – It Is Really Fun!





# Community Outreach & Engagement Dialogue Circles



**To help UC/CCHMC faculty better understand the value of COE, this Summer, the COE hosted 4 Community Dialogue Circles on the following topics:**

- *The Value of COE to Busy Basic Science, Clinical & Population Health Researchers*
- *Best Practices for Giving Research Talks to Spur Community Outreach Discussions*
- *Collaborative Design for Mutual Researcher-Community Benefit*
- *Critical COE Skills for the Newly Engaged*



**Each presentation was followed by a discussion.**

- *A one-page “notes” page with key takeaways and resources was provided to all attendees.*
- *All were video recorded and a link to all 4 of these recordings will be offered soon!*



Questions?