

Engaging Diverse Stakeholders: Strategies from the Environmental influences on Child Health Outcomes (ECHO) Program

CLOSER Conference Preparing for the future III: Tackling key challenges facing longitudinal population studies in a post-COVID world 20 January 2022

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The ECHO Program



ECHO'S MISSION:

To enhance the health of children for generations to come.

ECHO'S PROGRAM OBJECTIVES:

- Improve the health of children and adolescents by conducting observational and intervention research that will inform high-impact programs, policies, and practices.
- Institute best practices for conducting Team Science in the 21st century, giving researchers the tools to work collaboratively to improve child health.

ECHO'S OVERARCHING SCIENTIFIC GOAL:

 Answer crucial questions about the effects of a BROAD range of EARLY environmental influences on child health and development

Broad range of early environmental exposures

Health outcomes throughout childhood and adolescence

PRE-, PERI- UPPER AND AND **POSTNATAL**

LOWER **AIRWAY**

OBESITY

NEURO-DEVELOPMENT



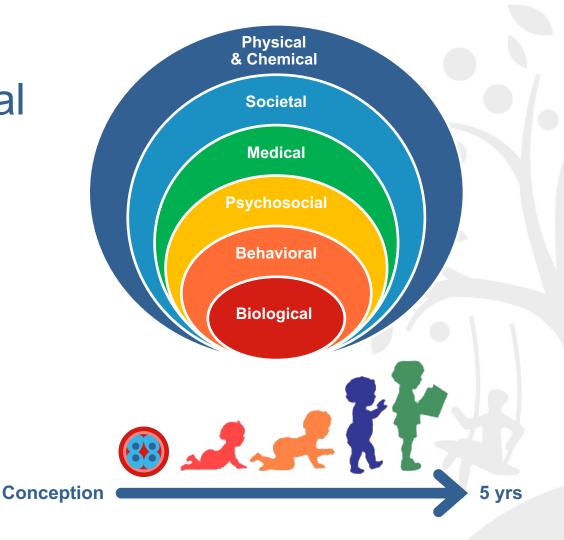






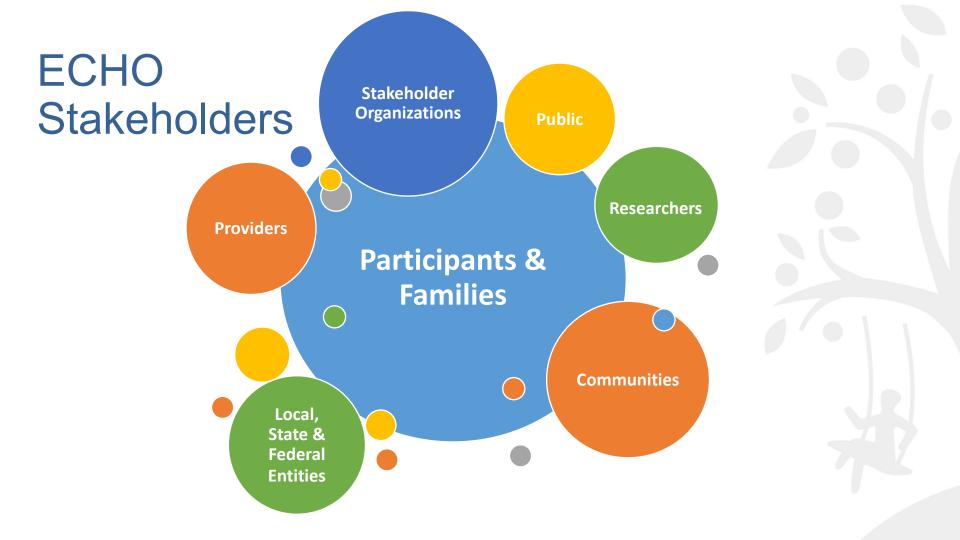






ECHO-wide Cohort Data Platform

- Data from ~97,000 participants from 72 cohort studies
 - -59,000 children
 - 27,000 active follow up (growing)
 - -42,000 biospecimens
- Diversity in age, SES, geography, race/ethnicity
 - -26% Hispanic, 43% White, 12% Black, 4% Asian, 3% Al/AN, 4% More than one race, 8% Unknown/not reported/other
- Becoming nation-wide research resource
 - -Harmonized existing measures & standardized new measures
 - Common data collection protocol



Participant Engagement

- Participant Experience Survey
- Participant Representatives (Advisory Board and Return of Results Task Force members)
 - Co-created policies related to returning results to participants
 - Informed participant-facing materials (website, comms materials, etc.)
 - Supported publication lay summaries
- Cohort-led engagement







Research-driven Engagement



POTENTIAL END-USER STAKEHOLDER RESEARCH PRIORITIES



OBESITY

End-User Stakeholder (source document)

Bill and Melinda Gates Foundation

American Association for the Advancement of Science Speech by Bill Gates

(https://www.gatesfoundation.org/ideas/ speeches/2020/02/bill-gates-americanassociation-for-the-advancement-ofscience)

Robert Wood Johnson Foundation - Health Eating Research

State of Childhood Obesity: Prioritizing Children's Health During the Pandemic

(https://media.stateofobesity.org/wpcontent/uploads/2020/10/13205332/ State-of-Childhood-Obesity-10-14-20-Final-WEB.pdf)

Knowledge Gaps and Research Priorities

- There is evidence that children in wealthy countries who grow up in super-hygienic environments (with an abundance of processed foods and antibiotics) have poor gut health that may make them more susceptible to obesity, diabetes, allergies, and maybe even autoimmune disease. There's still a lot we don't know about the microbiome—including which bacterial species are most critical for health and whether augmenting these species can reduce mainurition.
- The dispartities in the groups being hit hardest by COVID-19 and those at increased risk of obesity show real parallels. While obesity
 hits every racial and ethnic group and every income level, it doesn't affect each group equally. And we see a similar trend with
 COVID-19. There are a number of different factors that may be involved. Some of the disparity has to do with exposure, but much of it
 has to do with opportunities to make healthy choices. Who has the opportunity for healthy eating, healthy activities, and other types of
 behaviors that reduce obesity risk?
- Before the COVID-19 pandemic hit, 51 percent of all students nationwide qualified for free or reduced-price school meals. That's
 millions of students from low-income families who rely on school meals as a critical source of daily nutrition. What happens when that
 source of food is jeopardized because schools are forced to close?

US Preventive Services Task Force

Trials evaluating the direct benefits and harms of screening for obesity in children and adolescents are needed

ECHO Strategic Planning Task Force in early 2019

- End-user stakeholder organization outstanding research gaps
- Environmental scan with the Outcome Working Groups
- Multiple rounds of discussion

End-user Stakeholder Gaps documents

- Shared with Outcome Working Groups
- Encouraged to review, discuss, and address knowledge gaps with ECHO-wide analyses

ECHO sessions and presentations and stakeholder conferences

National Stakeholder Organizations

The NIH ECHO Program Office leads outreach to national professional and advocacy groups through tactics including:

- Individual and group meetings
- External newsletter, the ECHO Connector, sent bimonthly to all organizations
- Webinars for all organizations, held 1-2 times a year.
- Web content and materials development to address needs identified by stakeholder organizations
- Personalized outreach to share publications and activities on topics of interest to specific organizations
- Participation in stakeholder organization conferences

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News You Can Use

ECHO Publication Explores Disparities in Vitamin and Mineral Intake in Pregnant Women

A mother's intake of key nutrients during pregnancy can have long-lasting consequences for her child's health. Previous research suggests that a significant number of pregnant women aren't meeting recommended doses of key nutrients.



Katherine Sauder, PhD

Prior studies do not tell us what groups are at the most risk for poor nutrition during pregnancy, making it more difficult for doctors and public health workers to help them manage their nutrition. To find out who is most at risk, Katherine Sauder, PhD of the University of Colorado Anschutz led her team and collected data from nearly 10,000 women in 15 ECHO cohorts across 14 states. The investigators looked at the intake of 19 key vitamins and minerals among pregnant women in different sociodemographic and physical subgroups.

The study found that more than one in five pregnant women did not get enough of vitamins D, E, K, and choline and minerals magnesium and potassium, even when taking dietary supplements. Women age 14-18, those who were Hispanic or Black, those who had less than a high school education, and those with obesity were at the highest risk for undernutrition during pregnancy. On the other hand, non-Hispanic women were the most likely to get too much folic acid, potentially putting their child at an increased risk for chronic illness.

"This study shows that the dietary supplements women use today do not help them get all the nutrients they need in the right amounts," said Dr. Sauder. "Personalized approaches for dietary counseling and dietary supplement recommendations are needed."

The <u>article</u>, titled "Disparities in risks of inadequate and excessive intake of micronutrients during pregnancy," is published in The Journal of Nutrition.

ECHO Researchers Investigate the Effects of Phthalate Exposure on the Placenta

Phthalates are a group of chemicals used in plastics and household products, including some personal care products like perfurmes, nail polishes, soaps, and hair sprays. Little is known about how these man-made chemicals may affect pregnant women and the health of their developing babies. To investigate the potential effect of pithalates on an infant's health, Alison

Lessons Learned

- Build awareness and capacity early
- Provide infrastructure and support for engagement
 - E.g. IDeA States Pediatric Clinical Trials Network
- One size does not fit all
 - Different strategies, different media, different messages for different stakeholder groups

Next Steps/Future Directions

Within the final years of ECHO

- ECHO-wide Program Annual Evaluation
 - Now measure engagement as a program indicator
 - Dissemination to relevant stakeholders supported and tracked
- Stakeholder Engagement Working Group
 - Early in development of new analyses
 - Ongoing capacity building with investigators
- Coordinating Center Communications team
 - Ongoing development of new media and templates for different groups
 - Twitter handle @ECHOChildHealth

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