

INTRODUCING

OAC's Lived Experience Research Collaborative

by Hannah Hayes, MPH, BSN, RN



A New Way to Do Research

The Obesity Action Coalition (OAC) is launching an exciting new initiative called the Lived Experience Research Collaborative. Through this effort, the OAC aims to transform how obesity research is conducted by involving the community every step of the way. The goal is to make sure research reflects what matters most to people living with obesity and is guided by their voices so it is fair, practical and useful. This work will help generate new knowledge and allow us to apply what is learned to improve care, influence policy and create positive change.

Community Matters

To support this work, OAC is developing a research plan centered on community engagement and health equity. Community engagement involves working alongside people to address issues that matter to them. Health equity means everyone has a fair and just opportunity to be as healthy as possible.

To move this work forward, OAC will build the skills, tools and support needed to conduct community-engaged research. Above all, the organization wants to learn directly from people living with obesity to guide research grounded in evidence, real-life experience and meaningful action.



" The OAC aims to transform how obesity research is conducted by involving the community every step of the way. "

Research is a way to discover new knowledge. Obesity is one of the most studied health conditions. However, much of the existing obesity research has relied on quantitative methods to examine health risks and measure how treatments work. These findings are often shared through numbers that show patterns and trends.

Qualitative research has been used less often in obesity research. This approach explores the “why” behind people’s behaviors and health outcomes. It also looks at how experiences and choices are shaped by the conditions in which people live, learn, work and play.

In the past, researchers often decided what to study without asking the people most impacted by an issue about what mattered most to them. Rather than being partners, people living with obesity were often left out of research and policy decisions that directly affected their health.

Learning From Lived Experience

In recent years, there has been growing recognition of the importance of including people with lived experience in research. Lived experience is knowledge that comes from a person’s experiences, identity, and point of view, not just from their education or job.



When lived experience is used and valued in research, the results are more likely to reflect what communities truly need. That also makes it easier to apply research findings in the real world. This improves the likelihood that treatment will be effective and leads to better health outcomes.

Including lived experience in research aligns closely with OAC’s mission to give a voice to individuals affected by obesity and empower them throughout their health journey. OAC sees lived experience as an important and valuable form of knowledge. By partnering with the community, OAC aims to support research that informs programs and advocacy and helps guide decisions based on both data and the priorities of those most affected.

Our Approach

Community engagement means making sure people are involved and heard in discussions about issues that affect them. It means valuing people’s ideas and experiences to identify ways to address problems. It requires honest, responsible collaboration to pursue fair solutions.

Community engagement is not a one-time event. It is an ongoing process that takes time, flexibility and commitment to build trust and strong relationships. Studies show that effective community engagement has the potential to strengthen health systems and advance health equity.

Community-Based Participatory Action Research is a research approach grounded in these principles. Community-based means the work is centered on a community’s needs, challenges and strategies. Participatory means community members and their

Platinum

Amgen
Boehringer Ingelheim
Eli Lilly and Company

Gold

American Society for Metabolic & Bariatric Surgery
Genentech
Novo Nordisk
Pfizer
Potomac Currents

Silver

AstraZeneca
DEXCOM
Fractyl Health
Intuitive Surgical
Kailera Therapeutics
Metsera
Novartis
Regeneron
Seca Medical Body Composition
Structure Therapeutics Inc
Wave Life Sciences
Zealand Pharma

Bronze

American Association of Clinical Endocrinology
Biohaven Pharmaceuticals
Boston Scientific
Curax Pharmaceuticals
Geisinger Healthcare System
KVK Tech
Madrigal Pharmaceuticals
Obesity Medicine Association
Parexel International, LLC
Rhythm Pharmaceuticals
Wondr Health
Worldwide Clinical Trials

Patron

AmBari Nutrition
Bariatric Advantage
Billings Clinic
Bloom Science
ConscienHealth
Fay Nutrition
FlyteHealth
Gainesville Medical Obesity Specialty Clinic
Healthy Interactions
ProCare Health
ProSiento
The Obesity Society
Weight Watchers
Woman's Hospital

Platinum:	\$100,000 and up	Bronze:	\$5,000 - \$9,999
Gold:	\$50,000 - \$99,999	Patron:	\$1,000 - \$4,999
Silver:	\$10,000 - \$49,999		

List as of 3/20/2026

knowledge are included throughout the research process. Action-based means the research is meant to inform strategic action and drive change.

In this type of research, community members are partners. They help decide on research questions, collect data, analyze results and share findings. This approach helps ensure research is relevant and useful to the people it is intended to serve.

Making It Happen

As OAC moves forward with the Lived Experience Research Collaborative, it is inspired by the National Bleeding Disorders Foundation. This organization works to find cures and prevent complications from blood disorders through research, education and advocacy. The National Bleeding Disorders Foundation recognized that people with rare disorders and those in underserved communities often experienced gaps in care. To help close those gaps, the organization created a research collaborative that engages the community to guide research that matters to them.

Using the National Bleeding Disorders Foundation as a model, OAC is taking a phased approach to building a research collaborative centered on the lived experience of people affected by obesity.

- **Phase 1** will focus on learning about community needs and priorities. This will include listening sessions, surveys and input from people with lived experience and experts in the field.
- **Phase 2** will focus on developing a research plan. This will include forming committees and working with partners to turn what is learned into action steps.
- **Phase 3** will focus on building research skills and support. This includes identifying funding opportunities and fully integrating leaders with lived experience into the research process.



How You Can Participate

OAC is kicking off this project this summer with community listening sessions. During these sessions, the OAC wants to hear what matters most to people in obesity research. The sessions will be offered online and in person at the *Your Weight Matters* National Convention in Orlando, Florida. Learn more about the Convention at: YWMConvention.com

A group of OAC leaders will help plan, facilitate and analyze the sessions. To share power in the research process, a group of OAC community members will also help interpret findings, develop recommendations and share what is learned.

If you would like to help shape research that affects you, OAC invites you to join a listening session this summer. The organization wants to hear from people with diverse backgrounds and experiences so many voices are represented. These discussions will help identify what matters most to the community and highlight possible research priorities for the future.

Stay tuned! More information is coming soon. If you are an OAC member and would like to get involved or have questions, email: research@obesityaction.org.

Note: This article draws on published research and community-engaged practice guidelines. A full reference list is available upon request.

About the Author:

Hannah Hayes, MPH, BSN, RN, is a nurse and public health professional with experience in community health and translating evidence into practice. She is consulting with the Obesity Action Coalition to support research initiatives centered on the needs and voices of the community.



ABOUT THE OBESITY ACTION COALITION (OAC)

The Obesity Action Coalition (OAC) is a National non-profit organization dedicated to giving a voice to individuals affected by obesity and helping them along their journey toward better health. Our core focuses are to elevate the conversation of weight and its impact on health, improve access to obesity care, provide science-based education on obesity and its treatments, and fight to eliminate weight bias and discrimination.



VIBRANT COMMUNITY



NATIONAL AWARENESS CAMPAIGNS



ANNUAL CONVENTION



ADVOCACY



PUBLIC EDUCATION

LEARN, CONNECT, ENGAGE

The OAC knows that the journey with weight can be challenging but we also know that great things happen when we learn, connect and engage. That is why the OAC Community exists. Our Community is designed to provide quality education, ongoing support programs, an opportunity to connect, and a place to take action on important issues.

Through the OAC Community, you can get access to:

- Weight & Health Education • Community Blogs
 - Community Discussion Forum
 - Ongoing Support • Meaningful Connections
- AND MUCH MORE**



JOIN TODAY: GO TO OBESITYACTION.ORG/JOIN

info@obesityaction.org

(800) 717-3117 | (813) 872-7835 | Fax: (813) 873-7838



@ObesityActionCoalition

@ObesityAction