Gaining Trust Through Local Partnerships and Programs Webinar Summary







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Building Trust is Essential for Health Equity Programs

On June 28, 2023, more than 120 advocates from 80 organizations joined with Sanofi for the Health Equity Acceleration Community of Practice (CoP) webinar on "Gaining Trust through Local Partnerships and Programs." Three patient advocacy leaders shared insights about successful approaches their organizations are using to build trust. Breakout discussions further identified insights and practical advice. This report summarizes key takeaways from CoP participants as well as useful resources to help US advocacy groups deepen trust and accelerate the impact of their health equity programs.

Why It Matters

Building trust enables successful health equity programs because it helps:



Engage the community in tailored interventions to meet specific challenges and make decisions that align with local needs and preferences.



Overcome historical barriers such as discrimination, past injustices, and mistrust of institutions, and pave the way for meaningful collaboration and healing.



Improve health literacy and comprehension by delivering information in a relevant, culturally sensitive manner with input from local community members.



Sustain solutions through enduring relationships with partners and ongoing involvement of community leaders.



Empower communities to take an active role in their own health outcomes by being involved in the planning, implementation, and evaluation of heath equity programs.

The Bottom Line - 10 Actions to Build Trust

Key Takeaways to Build Trust and Improve Impact of Advocacy Health Equity Programs

Act with Cultural Humility

- Engage in critical self-reflection and self-critique to identify your own organizational and personal biases and assumptions about culture that may influence interactions.
- Authentically listen, understand, and engage patients/communities as experts in their own lives and respect their perspectives, fostering trust over time.
- Avoid pre-supposing you fully understand people's circumstances and that you already know the best solution.

Embrace the Principles of Trustworthiness

- Recognize community expertise, maintain ongoing communications, build feedback loops, and show commitment to the community.
- Understand the community and its history with other organizations.
- Create spaces for community input and feedback, including (but not limited to) cultural advisory boards and diverse representation on boards of directors.

Find & Address Power Imbalances

- Know that patients perceive subtle cues, such as how different patients were described by the HCP and a lack of diversity among healthcare staff, which affects their trust of offered services.
- Be aware of inequalities and implicit biases within healthcare systems.

Collaborate Locally

- Engage in honest conversations to find trusted stakeholders who will help identify gaps and understand the needs of the community.
- Collaborate with organizations that have already established trust in the community.
- Partner with existing community resources and organizations.
 Avoid duplication of efforts.
- Keep stakeholders, partners, patients, and the community informed about the program's progress, changes, and the reasons behind iterations.



Be Willing to Rethink Approaches

- Adapt based on community needs, input, and choices. The landscape and needs of the community may change over time, so it is important to stay updated.
- Regularly re-evaluate and adjust plans based on insights gained from genuine community engagement.

Get Insights from Diverse Advisory Boards

- Intentionally include voices that are typically underrepresented and from various backgrounds. Get referrals from community members and include local people who reflect diversity of the community.
- Engage the board to gain insights, set goals, define metrics, develop action plans, assess progress, and make adjustments.
- Establish routine touch points and engagement with advisory board members to maintain their involvement and leadership.

Empower All Advisors Equally

- Ensure all advisory board members feel their voices are valued and have an equal say, regardless of their background or expertise.
- Create separate spaces for different groups to express their perspectives, then bring them together for collective discussions.

Build Local Community Networks

- Ask advisors to help make connections in the community.
- Leverage the connections of local partners and your advisory board members to create a more powerful network throughout the community you are serving.

Define Success & Articulate Value

- Define what success means for different stakeholders including patients and their support networks, partners, and the community.
- Build your health equity program value proposition with community input so it reflects what matters to them.
- Demonstrate your value proposition through actions and measures.

Shift from Measuring Numbers to Showing Impact

- Prioritize long-term community impact, not just program attendance. Focus on outcomes measurements.
- Get input to identify metrics for engagement, quality of life, symptom control, and other indicators of program effectiveness.
- Collect data regularly to assess impact and continuously inform program improvements and decision making.
- Incorporate data into program communications to show the impact and how you are learning and adapting.

Understand the Communities You Want to Reach

Eucharia Borden

6 Family Reach

How Family Reach Is Doing It

Family Reach provides non-medical financial support to more than 23,000 families each year. Through their Cancer Equity Initiative, they are focused on building trust and addressing the needs of Black and Hispanic/Latino patients disproportionately affected by cancer and poverty. It consists of community partnerships and an onsite program. Cities are identified that have high cancer incidences paired with a significant number of economically disadvantaged patients. By first concentrating efforts on specific communities, Family Reach aims to develop impactful programs that can be replicated in other areas.

Family Reach emphasizes the significance of understanding the community by referencing the <u>Principles of Trustworthiness</u>, developed by the Association of American Medical Colleges. This approach recognizes the expertise and knowledge already present within communities. They gain trust by taking time to truly get to know the community, what the community needs, and how their services fit into the community.

"The Principles of Trustworthiness research is so good because it bottom lines the actions needed. It doesn't make it complicated or intellectual. If you're going to do it, take your time, and do it right. This is the straight talk that people really need."

Family Reach also partners with established, trusted organizations already embedded within the target communities. Collaborating with organizations in seven communities nationwide, focused on reaching and serving Black and/or Hispanic/Latino patients, allows Family Reach to provide direct support through a trusted network. They ensure transparency about their actions and clearly communicate benefits to the local community.

Gain Insights to Guide Trusted Solutions

Amanda Montague







Multiple Sclerosis Association of America (MSAA) improves lives through vital services and support for the MS community. As part of this mission, MSAA focuses on specific underrepresented communities including African Americans and Hispanics facing disparities and people in rural locations.

MSAA gains insights to guide their solutions through advisory boards comprising people living with MS, care partners, and healthcare professionals who represent these specific

"If you want an advisory board that has actionable items, communities need to feel like they are leading the way and involved in the process."

communities. MSAA has African American and Latinx/Hispanic Latino Advisory Boards that guide its programs for each of these communities. These boards engage in honest conversations to understand the needs and gaps of the communities and develop meaningful support solutions that resonate with those being served.

Additionally, MSAA created a program called "Developing your own comprehensive MS center" for rural populations. Since many rural patients receive MS care from general practitioners or community neurologists, this program helps them identify different professionals and resources in their local area and assists patients in creating a comprehensive MS care approach that meets their unique needs.

Earn Trust Through Value & Measurement

Lynda Mitchell

How Allergy & Asthma Network Is Doing It

<u>Allergy & Asthma Network (AAN)</u> raises awareness



and promotes research for severe asthma. The <u>Not One More Life Trusted Messengers</u> program was developed in response to the adverse effects of the pandemic on the Hispanic Latino and Black communities. The program originated as a local initiative called Not One More Life, providing asthma screenings and education in churches. It evolved into the Trusted Messengers program to address challenges of the pandemic and regain trust.

To implement the Trusted Messengers program, AAN partnered with churches, health professionals working in under resourced communities, fraternities and sororities and other respected individuals to hold events at churches to screen people for asthma and offer COVID testing and vaccinations. Collectively, these "trusted messengers" helped AAN develop value propositions, relevant metrics, and provided insights to tailor program components to the specific needs and preferences of the target communities.



Their involvement established diversity and representativeness in patient advisory groups and helped establish program credibility.

Language and cultural considerations were incorporated by providing materials and webinars in Spanish, using bilingual interpreters, and accommodating different dialects for effective communication and inclusivity.

"The program that we are implementing in 2023 is very different than the pilot we started in 2020. It is based on looking at the data, iterating, and improving our program. We keep everyone informed about what we are doing so they can see why we are changing and need to have their help in a different way than maybe we did initially."

Conclusions

Underserved patients face disparities in access to healthcare and resources, causing negative impacts on health outcomes. Many US patient advocacy groups are determined to help address health equity gaps by bringing programs into communities and working with local partners. For solutions to be effective and deliver sustainable results, it is essential to build trust with the communities these programs are intended to serve.

Building trust is a multifaceted endeavor that takes time and commitment. The CoP discussions underscored the significance of acting with cultural humility, embracing the Principles of Trustworthiness, forming and empowering diverse advisory boards, continuously adapting and iterating to meet the needs of the communities being served, articulating meaningful value, and committing to measuring impact.

These best practices and listings are provided as a resource only and do not constitute an endorsement by Sanofi of any particular organization or its programming. Additional resources on this topic may be available and should be investigated. Sanofi does not review or control the content of non-Sanofi websites.



Useful Resources

Throughout the webinar, advocates in the Community of Practice highlighted publicly available resources they found helpful for their health equity programs and for building trust in particular. These resources are listed below, in alphabetical order, for your information.

Disparities Impact Statement (cms.gov)

 Disparities Impact Statement is a tool that can be used by all healthcare stakeholders to achieve health equity for racial and ethnic minorities, people with disabilities, sexual and gender minorities, individuals with limited English proficiency, and rural populations.

Nueva Vida - Never Give Up. (nueva-vida.org)

- Inform, support, and empower Latinas whose lives are affected by cancer, and to advocate for and facilitate the timely access to state-of-the-art cancer care.
- Founded under the belief that no physical, financial, or structural barrier should block the care of any person.

Patients Rising

- Resources to help patients and their allies connect people with transportation, lodging, financial assistance, medical records help, etc.
- Patient Helpline 800-685-2654 or <u>HELP@PatientsRising.org</u> provides direct, personalized access to information, and a network of public and nonprofit programs and resources.

PCs for People - Technology for Individuals, Families, and Nonprofits

 Working to get low-cost quality computers and internet into the homes of individuals, families, and nonprofits with low income.

Principles of Trustworthiness | Center for Health Justice (aamchealthjustice.org)

- The Principles of Trustworthiness Community Video
- The Principles of Trustworthiness
- The Principles of Trustworthiness Toolkit
- The Principles of Trustworthiness Workshops

ResearcherToolkit2018.pdf (acceleratedcure.org)

 Minority Engagement in MS Research Patient Recruitment Toolkit for research professionals.

