

## SHORT REPORT

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# Building Trustworthiness in Health Care and Research: Disrupting Traditional Practices Through Authentic Community Engagement—Project ENTRUST

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### Abstract

**Introduction:** Project ENTRUST is a mixed-method, community-collaborative, and community-grounded initiative at Duke Health aimed at co-creating a model for equity-driven engagement and trust-building in health care and research.

**Methods:** Community members, Duke Health, and university leaders developed the 7-phase ENTRUST Model—a structured roadmap for trust-building through collaborative survey development, town halls, and recommendations for institutional change.

**Results:** The ENTRUST process engaged 6167 survey respondents, over 300 community members and organizations across 6 town halls, and 3 focus groups.

**Conclusions:** The ENTRUST Model offers a replicable framework for health care systems and research institutions seeking to build trust within communities.

**Keywords:** community engagement; health care; health equity; medical research; trust; trustworthiness

### Introduction

Trust, defined as the “willingness to be vulnerable under conditions of risk and interdependence,”<sup>1</sup> is foundational to health. Trustworthiness, defined as the belief

that a relationship with an individual or organization is reliable, truthful, and benevolent in situations that involve risk,<sup>2</sup> must be earned through the actions of that individual or organization. Health systems and

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research institutions have a clear role in dismantling mistrust<sup>a</sup> and earning trust from the communities they serve.<sup>3</sup> Rather than focusing on the community as the cause of lack of trust, systems-level change requires centering community perspectives and lived experiences of racism, discrimination, and inequities that drive mistrust. When community perspectives are excluded, improvement efforts can remain disconnected from the people they intend to serve.<sup>4</sup> Meaningful systems-level change toward equitable, trustworthy, and anti-racist health care and research requires authentic and sustained collaborations with the community throughout each step of the process.<sup>5,6</sup>

This project was guided by two foundational frameworks: the Truth, Racial Healing, & Transformation (TRHT) framework,<sup>7</sup> and Community-Based Participatory Research (CBPR) principles.<sup>8</sup> The TRHT is a comprehensive, community-driven approach designed to address the historical and contemporary impacts of racism by challenging the entrenched belief in a hierarchy of human value by race. It seeks to foster racial healing and systemic transformation through narrative change, relationship building, and structural reform. Complementing this, CBPR principles emphasize equitable collaboration between academic institutions and communities throughout the research process. These principles prioritize shared decision-making, mutual respect, and the co-creation of knowledge to ensure that research is both culturally responsive and action oriented. Together, these frameworks informed the design and implementation of Project ENTRUST, guiding its commitment to trust-building, transparency, and equity in health care and research.

### The Project ENTRUST Model

In 2019, a diverse group of local leaders representing the community of Durham, North Carolina, and the surrounding areas approached leaders at Duke Health with concerns about the community's lack of trust in the Duke Health health care and research system. Longstanding relationships between these community leaders and trusted partners within Duke Health played an important role in facilitating this initial meeting and establishing the basis for this community-collaborative

project. In response to the community insights and concerns, Duke Health sought to understand the issues impacting trust of the institution by the community and identify ways to become a more trustworthy provider of health care and partner in research. Project ENTRUST was created in 2021 to work with the community and patients at Duke Health to develop innovative and transformative systems-level change practices that lead to improved trust in Duke Health. In this project, community refers to a wide array of individuals residing in and/or serving residents of Durham, North Carolina, a majority-minority city, and its surrounding counties. This includes representatives from community-based organizations (CBOs), faith-based organizations, community advisory boards and councils, and community leaders. These community partners represent the voices and needs of the populations they serve and are actively engaged in co-developing strategies to build trustworthiness in health care and research; they play a central role in shaping health care and research practices through lived experience, cultural insight, and trusted relationships. Their involvement ensures that solutions are grounded in authentic community perspectives and are responsive to local needs.

Here, we outline the ENTRUST Model: A Community Collaborative Model for Assessing and Building Trustworthy Health Care Systems and Research (hereafter ENTRUST Model, Fig. 1) and the process through which this model was created. The ENTRUST model fully integrates and centers the community, as critical experts, collaborators, and partners with a focus on improving trustworthiness, health outcomes, and health equity. The seven-phase ENTRUST Model illustrates the interconnectedness between health systems and communities and provides a critical and necessary foundation for Duke Health and other health care systems to examine trust through community engagement that leads to systems change.

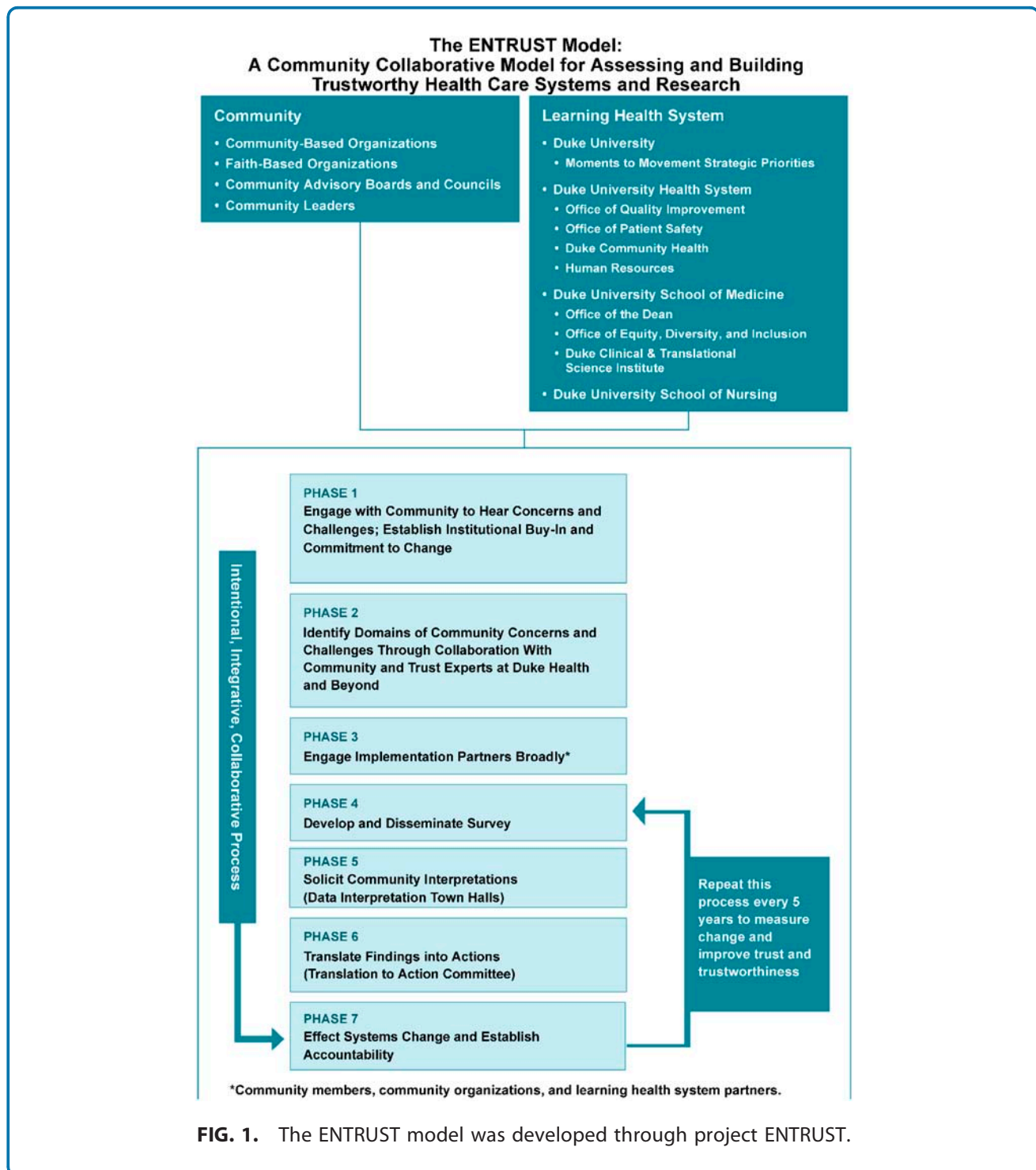
### ENTRUST Model Phases

#### Phase 1: Engage with Community to Hear Concerns and Challenges; Establish Institutional Buy-in and Commitment to Change

In the spring of 2021, while the Black and Latinx communities were experiencing disproportionate harms from the COVID-19 pandemic coupled with an increase in anti-racist activism, a Duke Health collaborative community consultation studio (CCS), a forum to directly solicit feedback from community members, partners,

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<sup>a</sup>We recognize that distrust and mistrust are related concepts, differing in that distrust refers to first-hand lived experiences, whereas mistrust refers to more generalized perceptions. Throughout, we use the broader term mistrust to encompass the general perceptions of the community while recognizing that distrust also exists within this context.



**FIG. 1.** The ENTRUST model was developed through project ENTRUST.

and experts, yielded valuable insights into trust and trustworthiness. Participants shared negative experiences they had faced when partnering with Duke Health, seeking health care, and engaging in research. A Project ENTRUST Core team (see Acknowledgments for a list

of team members and partners) was developed from individuals involved with the broader Duke University Research Equity and Diversity Initiative (READI),<sup>9</sup> a community-partnered research initiative dedicated to advancing equity in research practices, and included

faculty leadership, evaluation experts, and an operations team responsible for project management with collective expertise in health disparities, community engagement, and data collection methodologies. READI served as a base for Project ENTRUST to implement this effort.

The Project ENTRUST Core team oversaw design, and methodology, and monitored ongoing project advancement. Engaging community groups as colleagues ensured this work reflected community concerns and recognized community expertise; for example, input was received via engagement with members of a Community Engaged Research Initiative (CERI) Community Advisory Council, a CCS, and engagement with a local county public health department. This input informed the identification of domains of community concern, discussed below, as well as later phases (e.g., more detailed aspects of survey design; town hall interpretation).

#### Phase 2: Identify Domains of Community Concerns and Challenges through Collaboration with Community and Trust Experts at Duke Health and Beyond

Collaboration between Duke Health, community partners, and other invested groups laid the foundation for understanding the dynamics of trust in health care systems and developing a community-centered survey to assess trust and trustworthiness. The ENTRUST Core team utilized innovative anti-racist and equity-focused community engagement methods to identify systems-level factors that create and sustain mistrust in health care systems and research institutions. Community partnerships and engagement efforts provided crucial input into the conceptualization of trust and trustworthiness, particularly the need to focus on experiences of discrimination, racism, and bias. Additionally, the ENTRUST Core team gathered input from scholars in the fields of clinical care, health inequities, research, restorative justice, and systemic racism.

#### Phase 3: Engage Implementation Partners Broadly

Through existing and robust community and academic partnerships, this program engaged community partners and community advisory board and councils (CABs/CACs) through CCSs. The Duke Clinical and Translational Science Institute-Community Engaged Research Initiative CAB, which consists of over 20 community members, engaged numerous Durham and Triangle region CBOs in CCS forums. The Project ENTRUST CCS focused on the lived experience

of patients, providers, community members, and groups by soliciting their insight on recruitment materials, data collection procedures, and instruments.

#### Phase 4: Develop and Disseminate the ENTRUST Survey

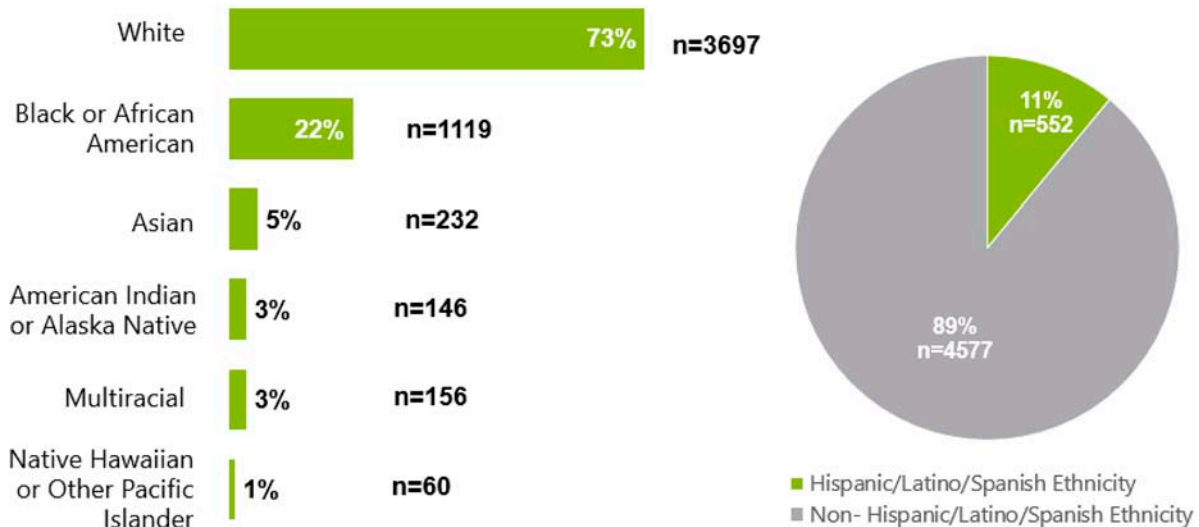
Phase 4 involved community partnership in the ENTRUST Survey (see Supplementary Data) development to disrupt traditional research processes. Relevant frameworks and measures/scales were reviewed in existing literature. Survey items were included from well-validated tools designed to quantify medical mistrust, as well as novel items co-developed with community input and adapted to the unique experiences of community members.<sup>10,11</sup> Key domains focused on trust in health care, research, and community partnerships. Specific items examined included barriers to care, views on the research enterprise, attitudes toward trustworthiness, clinical interactions, experiences of discrimination, and organizational trust. The survey prioritized 4 constituent groups: patients, employees, community members (residents of the greater Durham area), and CBOs serving Durham. The final survey was designed to be completed in 15 min. The Duke Health Institutional Review Board approved this study (Pro00110562) with a waiver of signed informed consent.

The survey was offered online in English and Spanish via Qualtrics with access through emailed promotions or the Duke Health MyChart application, an electronic medical record portal for patients. Other dissemination efforts involved robust outreach plans with community partnerships for snowball sampling; collaboration with community organizations and media channels (social media, newsletters, flyers); and sharing of the survey URL link or QR code by community outreach mechanisms. In 9.5 weeks from May 5, 2023, to July 10, 2023, 6167 participants responded to the survey. Participant race and ethnicity data are presented in Figure 2.

#### Phase 5: Solicit Community Interpretations (Data Interpretation Town Halls)

Unique and essential to the Project ENTRUST process, community interpretation of research findings essentially disrupts the traditional research process, which prioritizes the interpretation of findings by researchers. In phase 5 of Project ENTRUST, a CCS was held with community members to present data visualizations of the initial findings and ensure these visualizations were clear and suitable to present at

## Race & Ethnicity



**FIG. 2.** Information about race and ethnicity was solicited in 2 separate survey questions. Not all survey respondents answered these questions. Some survey respondents answered only one of these questions. Of the 6167 respondents, 5036 responded to the question regarding race and 5129 responded to the question regarding ethnicity. Additionally, the survey question regarding race allowed respondents to select multiple races, and respondents who selected multiple races were counted in all selected groups. The demographic data are representative of the Triangle region, but not Durham county. Durham County is 35% African American and 14% Latino based on recent census data. U.S. Census Bureau. Census data. Accessed June 1, 2024. <https://www.census.gov/en.html>.

data interpretation town halls. Project ENTRUST data interpretation town halls consisted of a 30-min presentation of the data, a 45-min co-led community member and health care system staff dyad breakout session, and a 15-min report back to hear community voices. We worked with the community to train health care staff and community leaders who co-led these breakout sessions. In total, 6 data interpretation town halls comprising over 300 patients, community members, employees, and CBOs, along with 3 focus groups involving LATIN-19, Duke Cancer Institute, and Duke Primary Care Patient and Family Advisory Council, shared initial results with the community and solicited their interpretation. These community data interpretation town halls provided actionable recommendations, as highlighted by community members and key constituent groups, to build more trustworthy health care and research at Duke Health.

### Phase 6: Translate Findings into Actions (Translational to Action Committee)

In phase 6 of the ENTRUST Model, Translation to Action Committees will be established with key leadership members and community partners to review and implement the actionable recommendations developed during the survey and data interpretation town halls. These committees will focus on community outreach and engagement, patient engagement and education, health care provider training and support, implementation and integration, and transparent dissemination.

### Phase 7: Effect Systems-Level Change and Establish Accountability

The Translation to Action Committees will implement systems-level change in phase 7. The Project ENTRUST community recommendations will be embedded in the culture, strategic priorities, and policies across the health

care system and research institution. Every 5 years, the program will repeat phase 4 through phase 7 of the ENTRUST Model to measure changes in trust and trustworthiness and explore systems and organizational change. Forthcoming manuscripts will publish Project ENTRUST findings, including ENTRUST survey results, programs and systems changes enacted, and the impact these changes have on trust in Duke Health.

## Discussion

Trust plays a central role in all medical relationships and is an important contributor to positive therapeutic outcomes. Lack of patient trust is associated with fewer doctor-patient interactions, poor clinical relationships that exhibit less continuity, reduced likelihood of following medical advice, worse self-reported health, reduced utilization of health care services, and lower clinical research participation; thus contributing to health disparities, particularly among minoritized and marginalized populations.<sup>12</sup> Project ENTRUST developed a model process that assesses trust and trustworthiness with the goal of remedying factors contributing to mistrust and lack of trustworthiness in health care and medical research at Duke Health.

Success for Project ENTRUST is defined through a combination of quantitative benchmarks, qualitative indicators, and meaningful community engagement outcomes. A key achievement was the co-development and dissemination of the ENTRUST Survey, which surpassed its original goal of 3500 responses, ultimately engaging 6167 participants. The survey included six open-ended items exploring perspectives of trust, distrust, and recommendations in and for Duke Health. Notably, over 50% ( $n = 3209$ ) of respondents provided a response to these items, indicating a high level of engagement and the value of providing an opportunity for qualitative community input in the survey.

The ENTRUST Model also facilitated 6 town hall meetings and 3 focus groups with over 300 attendees, followed by a post-event survey completed by 121 participants. Analysis of post-event survey responses indicated strong community approval of the Project ENTRUST model process with high average ratings (mean > 4.6 on a 5-point scale) across items measuring satisfaction, perceived trustworthiness, and degree of meaningful engagement. This model has the potential to catalyze systems-level change. The Translation to Action Committee, currently being organized, will address commonly shared concerns and

recommendations identified through comprehensive analysis of survey data and townhall discussions. Themes emerging from community feedback have guided short-term action items, some of which have been prioritized for immediate implementation. The ENTRUST Model's collaborative design is a transformative framework for advancing trust, equity, and accountability in health care. While early successes are evident, the Project ENTRUST team recognizes that building trust is a long-term endeavor. As such, the sustainability plan includes repeating the ENTRUST Model Phases 4–7 every 5 years to ensure continued impact. The ENTRUST Model establishes a roadmap for other health care systems and medical research institutions to earn the trust of the communities they serve through engagement and systems-level change. From this foundation, we can assess the impact of systems-level change efforts over time and continually identify opportunities to enhance, expand, or course correct to promote equity in health care and research. Broad dissemination of the ENTRUST Model to other health care systems and research institutions contributes to the advancement of trust and trustworthiness research already underway nationally.

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**ENTRUST Core team members:** Community Engagement Research Initiative (CERI), Center for Equity in Research [EIR], Office of Evaluation and Applied Research Partnership [O-EARP]), Duke Clinical and Translational Science Institute (CTSI), Duke Office of Community Health.

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### Authors' Contributions

A.T.: Data curation, investigation, project administration, resources, software, supervision, validation, visualization, writing—original draft, writing—review and editing; C.C.D.: Project administration, writing—original draft, writing—review and editing; D.C.J.: Resources, writing—review and editing; D.M.: Conceptualization, methodology, writing—review and editing; J.S.: Conceptualization, data curation, investigation, methodology, project administration, supervision, writing—review and editing; K.L.B.E.: Project administration, supervision, writing—review and editing; L.E.B.: Conceptualization, funding acquisition, investigation, project administration, resources, supervision, writing—review and editing; M.L.: Conceptualization, project administration, supervision, writing—review and editing; N.J.B.: Conceptualization, investigation, methodology, project administration, resources, supervision, writing—original draft, writing—review and editing; P.B.M.: Data curation, formal analysis, validation, writing—review and editing; R.P.S.: Resources, writing—review and editing; S.E.: Conceptualization, data curation, investigation, project administration, resources, supervision, writing—original draft, writing—review and editing; S.N.: Funding acquisition, resources, writing—review and editing; S.Q.: Data curation, formal analysis, visualization, writing—review and editing; S.T.: Project administration, writing—review and editing; W.B.: Project administration, writing—review and editing.

### Human Participant Protection

This study was approved by the Duke Health Institutional Review Board (Pro110562). The study was granted a waiver of signed informed consent.

### Author Disclosure Statement

No competing financial interests exist.

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### Supplementary Material

Supplementary Data

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### Abbreviations Used

- CAB = Community advisory board
- CAC = Community advisory council
- CBO = Community-based organization
- CBPR = Community-Based Participatory Research
- CCS = Community consultation studio
- CERI = Community Engaged Research Initiative
- ENTRUST Model = ENTRUST Model: A Community Collaborative Model for Assessing and Building Trustworthy Health Care Systems and Research
- REDI = Research Equity and Diversity Initiative
- TRHT = Truth, Racial Healing, & Transformation