



Community Engagement in Research and Design of a Transgender Health Information Resource

Brad Morse¹ Marvyn Allen² Lisa M. Schilling¹ Andrey Soares¹ Kristen DeSanto³
Brooke Dorsey Holliman⁴ Rita S. Lee⁵ Bethany M. Kwan⁶

¹Division of General Internal Medicine, Data Science to Patient Value Initiative, University of Colorado Anschutz Medical Campus, Aurora, Colorado, United States

²One Colorado, Denver, Colorado, United States

³Strauss Health Sciences Library, University of Colorado Anschutz Medical Campus, Aurora, Colorado, United States

⁴Department of Family Medicine, Adult and Child Center for Outcomes Research and Delivery Science, University of Colorado Anschutz Medical Campus, Aurora, Colorado, United States

⁵Division of General Internal Medicine, University of Colorado Anschutz Medical Campus, Aurora, Colorado, United States

⁶Department of Emergency Medicine, Adult and Child Center for Outcomes Research and Delivery Science, Data Science to Patient Value Initiative, University of Colorado Anschutz Medical Campus, Aurora, Colorado, United States

Address for correspondence Brad Morse, PhD, MA, University of Colorado Anschutz Medical Campus, School of Medicine, 1890 N Revere Ct Ste: P12-3221, Aurora, CO 80045, United States (e-mail: brad.morse@cuanschutz.edu).

Appl Clin Inform 2023;14:263–272.

Abstract

Background Access to credible and relevant health care information is an unmet need for the transgender and gender-diverse (TGD) community. This paper describes the community engagement methods and resulting community priorities as part of a codesign process for the development of a Transgender Health Information Resource (TGHIR) application.

Methods A lesbian, gay, bisexual, transgender, and queer advocacy organization and an academic health sciences team partnered to establish a community advisory board (CAB) of TGD individuals, parents of TGD individuals, and clinicians with expertise in transgender health to inform the project. The analytic-deliberative model and group facilitation strategies based on Liberating Structures guided procedures. Affinity grouping was used to synthesize insights from CAB meeting notes regarding roles and perspectives on the design of the TGHIR application. We used the Patient Engagement in Research Scale (PEIRS) to evaluate CAB members' experience with the project.

Results The CAB emphasized the importance of designing the application with and for the TGD community, including prioritizing intersectionality and diversity. CAB engagement processes benefited from setting clear expectations, staying focused on goals, synchronous and asynchronous work, and appreciating CAB member expertise. TGHIR application scope and priorities included a single source to access relevant, credible health information, the ability to use the app discreetly, and preserving privacy

Keywords

- ▶ library science
- ▶ mobile app
- ▶ health care informatics
- ▶ human-centered design
- ▶ patients

received
September 15, 2022
accepted after revision
December 20, 2022

DOI <https://doi.org/10.1055/s-0043-1763290>.
ISSN 1869-0327.

© 2023. The Author(s).

This is an open access article published by Thieme under the terms of the Creative Commons Attribution-NonDerivative-NonCommercial-License, permitting copying and reproduction so long as the original work is given appropriate credit. Contents may not be used for commercial purposes, or adapted, remixed, transformed or built upon. (<https://creativecommons.org/licenses/by-nc-nd/4.0/>)
Georg Thieme Verlag KG, Rüdigerstraße 14, 70469 Stuttgart, Germany

(i.e., safe use). An out-of-scope CAB need was the ability to identify both culturally and clinically competent TGD health care providers. PEIRS results showed CAB members experienced moderate to high levels of meaningful engagement ($M[\text{standard deviation}] = 84.7[12]$ out of 100).

Conclusion A CAB model was useful for informing TGHIR application priority features. In-person and virtual methods were useful for engagement. The CAB continues to be engaged in application development, dissemination, and evaluation. The TGHIR application may complement, but will not replace, the need for both culturally and clinically competent health care for TGD people.

Background and Significance

Transgender and gender-diverse (TGD) individuals experience a multitude of health disparities attributable to stigma, discrimination, marginalization, and transphobia, leading to stress, poor social support, and poor health care access and quality.^{1–3} In 2015, the American College of Physicians recommended policies for improving health equity among the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community—urging more research on best practices for equitable health care.⁴ One factor in health disparities for people who are TGD is lack of access to relevant and credible health information to guide health decision-making and access to health care.^{5–7} For this work, credible health information was defined in partnership with our community advisory board (CAB) as content created by reputable organizations, like Trevor Project,⁸ that were knowledgeable about care specific to the needs of TGD individuals, or MedlinePlus.⁹

Previous studies using both qualitative and quantitative methods have shown that health information needs and information-seeking behavior^{10–12} among the TGD community include health care access (e.g., finding competent specialists),¹³ medical care (e.g., hormone therapy),¹⁴ strategies for communication with care providers,¹⁵ legal and policy issues (e.g., health insurance benefits^{16,17} and discrimination¹⁸), strategies and services for counseling,¹⁹ and social support.²⁰ While there are multiple existing resources for accessing TGD health information online (e.g., Point of Pride,²¹ Human Rights Campaign²²), it can be overwhelming to determine which resources are credible, accessible, or most relevant to a given individual. The purpose of this project was to curate existing credible resources and allow someone to find the most relevant information. A mobile application (app) was selected as the modality for this project. We sought to codesign an app in partnership between academic researchers and TGD community members to optimize value and appropriateness for the TGD community. Community engagement in research is especially important to ensure that the products of research are sensitive to the TGD community's needs, perspectives, and social context.^{23–26}

Community engagement in health research with the TGD community has shown methods such as steering committees using facilitated discussion formats (e.g., World Cafes, Town Halls) are useful for identifying barriers to health care

access.^{23,24} Participatory methods are encouraged in the prioritization and conduct of research that addresses health inequities in the TGD community.²⁷ This project is built upon this literature on TGD community engagement and codesign of digital health tools²⁵ in the context of the design of a health information resource app.

Objective

This project aimed to design a Transgender Health Information Resource (TGHIR) app, a mobile app that would facilitate searching for credible, relevant TGD health information. The project relied upon three methods of engagement that integrated participatory methods with human-centered design²⁸ (→ Fig. 1): (1) we engaged a TGD CAB in establishing priorities and iteratively codesigning the tool, (2) with CAB input, we conducted focus groups with people who are TGD, or parents of TGD adolescents, to understand health information needs, and (3) we held design sessions with research participants to determine desired mobile app features and functionality to access credible health information resources. Specifically, the purpose of the CAB was to ensure the overall design process for the TGHIR app reflected the needs, preferences, and priorities of the TGD community. This paper focuses on methods and experiences engaging the CAB throughout the design process, including the interpretation of focus group findings and iterative review of prototypes emerging from the design sessions. Additional details on the focus groups, design sessions, and design of the TGHIR app are described elsewhere.^{29,30}

Methods

Overall Design

We followed community-engaged research principles and methods to orient the project to the health needs of the TGD community, identify key audiences and relevant policies, codesign research data collection instruments, protocols, and recruitment strategies (i.e., focus group guides and design session protocols), and develop a dissemination strategy and plans for pilot testing the resulting TGHIR app.³¹ We did this work with the CAB. Recognizing and prioritizing the expertise of those who identify as transgender was the foundation of this work.³² By partnering with and engaging individuals who identify as TGD, we expected to more

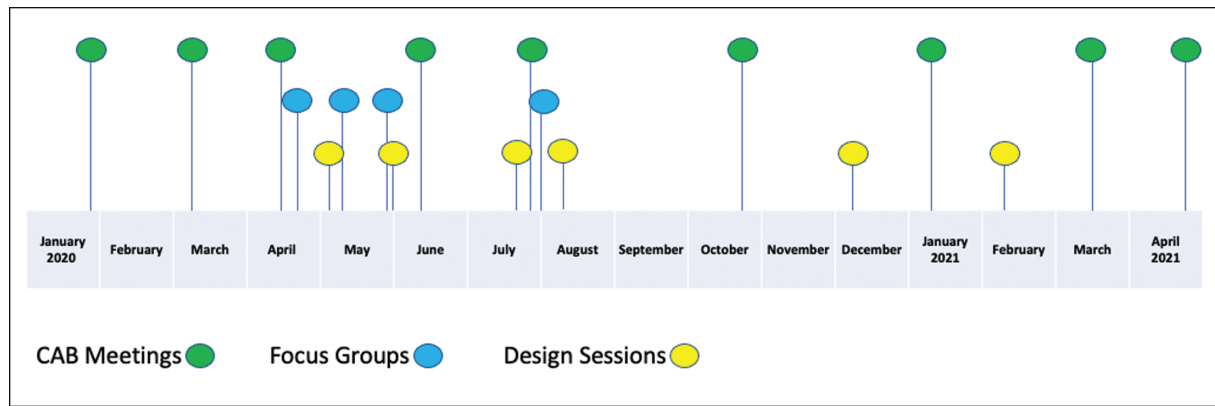


Fig. 1 TGHIR CAB, focus group, design session timeline. CAB, community advisory board; TGHIR, Transgender Health Information Resource.

authentically represent the needs and perspectives of the TGD community in this research. The university's institutional review board deemed engagement activities "not human subjects research."

Setting, Team, and Partners

The academic setting was the University of Colorado Anschutz Medical Campus and the Strauss Health Sciences Library. Partnering organizations included representatives from One Colorado—an advocacy organization dedicated to advancing equality for LGBTQ people and their families—and the UHealth Integrated Transgender Health Program. The research team consisted of eight individuals, including five white, one Asian, one black, and one Hispanic individual(s); one member of the team identifies as gender diverse and another member identifies as part of the LGBTQ community. Research team members brought expertise in library science, qualitative methods, user-centered design, user experience, software development, health care informatics, community engagement, dissemination and implementation science, health services research, LGBTQ health, and internal medicine. To ground our work, the research team received a "cultural-responsiveness training" focused on TGD terminology and concepts from a research team member with expertise in transgender health.

Establishing a Transgender and Gender-Diverse Community Advisory Board

The planned membership of the TGHIR CAB included people who identify as transgender, nonbinary or genderqueer,

LGBTQ advocacy organization representatives, clinicians who care for the TGD community, and parents of TGD adolescents. The CAB also included the university-based research team.³¹ The research team and community partners initially determined the desired composition (number and types of individuals), selection strategy, role in decision-making, and name of the group. CAB members were selected based on the process described in [Table 1](#). CAB members were paid \$50 per meeting.

Engagement Framework and Methods

The engagement framework was the analytic-deliberative model (ADM) of stakeholder engagement.³¹ According to the ADM, effective engagement focuses on the importance of both data collection and the decision-making process, or deliberation, by the engaged partners and communicating informed recommendations.³¹ We convened the CAB in a series of meetings ([Fig. 1](#)) to inform decision-making. At each CAB meeting, the research team began by gathering inputs (ADM step 1), including evidence from research professionals and community experience. Then, the research team synthesized the evidence and input from the CAB members (ADM step 2) to identify common versus unique needs and perspectives. Next, the research team made decisions (ADM step 3) based on the combined evidence and aligned stakeholder perspectives. The CAB was engaged throughout the project in all aspects of design, conduct, and interpretation. We used group facilitation methods based on Liberating Structures,³³ a series of structured group activities that invite broad thinking and diverse participation.

Table 1 Community advisory board member nomination and selection process

Step	CAB member selection activity
1	Work with partners to develop criteria for CAB membership and creation of a flyer and an interest form
2	Potential CAB members nominated by TGHIR partners
3	CAB informational flyer with a link to an online interest form were sent to nominees. Upon receipt of completed interest forms, the project manager contacted those meeting criteria for follow-up
4	CAB member interviews were conducted to discuss the nature of the work ensure fit with the candidate's goals and motivation to participate

Abbreviations: CAB, community advisory board; TGHIR, Transgender Health Information Resource.

Table 2 Community advisory board meeting topics and attendance

CAB meeting date, location, and duration	CAB meeting agenda topic	Meeting attendance (CAB–research team)
January 31, 2020 In-person, 4 h	<ul style="list-style-type: none"> • Project introduction • Purpose-to-practice exercise • CAB input on focus group guide and recruitment strategies 	12–5
March 6, 2020 Zoom, 1 h	<ul style="list-style-type: none"> • Exploration of the concept of “credibility of health information resources” 	10–6
April 15, 2020 Zoom, 1 h	<ul style="list-style-type: none"> • Workstreams for asynchronous work 	11–7
June 12, 2020 Zoom, 1 h	<ul style="list-style-type: none"> • Standing in solidarity with Black Lives Matter • Review of existing health care Provider resources and websites 	12–7
July 29, 2020 Zoom, 1 h	<ul style="list-style-type: none"> • Discussion on focus group and design session data collection 	8–7
October 26, 2020 Zoom, 1 h	<ul style="list-style-type: none"> • Health information resource tool demo and stakeholder-centered outcomes discussion 	3–8
January 13, 2021 Zoom, 1 h	<ul style="list-style-type: none"> • Tag creation and discussion on the results of usability testing 	8–7
March 16, 2021 Zoom, 1 h	<ul style="list-style-type: none"> • Health information resource tool demo, new grant announcement, plans for continued engagement 	10–5
April 26, 2021 Zoom, 1 h	<ul style="list-style-type: none"> • Celebration of grant completion 	10–6

Abbreviations: CAB, community advisory board.

In January 2020, the CAB met for an initial in-person half-day kickoff in the community-based facility often utilized by the partnering LGBTQ organization. We used the Liberating Structures Purpose-to-Practice (P2P) exercise to define how the CAB would collaborate with the research team.³⁴ The P2P exercise allowed the CAB, including the research team, to shape the group’s subsequent interactions and decision-making processes. The P2P exercise involves a facilitated discussion to engage a group in defining five elements (purpose, principles, participants, structures, and practices) underlying a collaborative effort. Over the course of approximately 2 hours during the CAB kick-off meeting, one research team member, BK, experienced in engagement-facilitated discussions used the 1-2-4-All³⁵ technique to elicit CAB perspectives on each P2P element. 1-2-4-All entails 1-minute solo brainstorming to a prompt, 2 minutes in pairs, 4 minutes in groups of four, and then full group sharing. The kick-off was followed by eight virtual 1-hour meetings, held every 6 to 8 weeks through April 2021 (→ **Table 2**). Attendance records were kept for each meeting. Following each meeting, the research team met to discuss the evidence and input from the CAB to make decisions about the conduct of research and/or design of the TGHIR app. The research team prepared a one to two-page synthesis of each CAB meeting with implications for the research and returned it via e-mail to the CAB members for review.

Analysis of the Engagement Process and Community Advisory Board Design Priorities

To synthesize insights from CAB and research team discussions and decisions, the research team analyzed notes and reflections from the CAB meeting synthesis documents and

notes from the research team meetings. The method of analysis consisted of an affinity grouping³⁶ exercise conducted in Mural,³⁷ an online collaboration software app. The affinity grouping exercise was conducted by two research team members who facilitated the CAB meetings and served as multiple principal investigator and project manager, B.K. and B.M., respectively. One person reviewed the research meeting notes B.K. and one reviewed the CAB synthesis documents B.M.; for each document, one to two phrase summaries were generated (e.g., the group was supportive of welcoming new CAB members) of important discussion points, decisions made, or results of CAB engagement. Summary phrases were typed on Mural’s “sticky notes” and mapped together based on similarities in relation to four categories about interactions between community partner CAB members and research team members who were also CAB members. The four categories were as follows: (1) What went well in this engagement type and what is the evidence? (2) What was missing in this engagement type or did not go as well and what CAB goals were not accomplished? (3) How did the CAB members engage around the design of the app? (4) How did the CAB members engage around the conduct of research? The groupings facilitated the synthesis of how the CAB shaped the project.

Community Advisory Board Member Experience Evaluation

The Patient Engagement in Research Scale³⁸ (PEIRS) is a validated 22-item survey³⁹ that measures the quality of engagement from the participant’s perspective. The PEIRS includes seven themes of meaningful engagement of participants in research; items are answered on a five-point Likert

Table 3 Asynchronous CAB tasks

Asynchronous task	Task description
Health resources spreadsheet	CAB members reviewed and provided insight on a list of health information resources, specifically focusing on credibility and competence, curated by the team’s health sciences librarian
Working group sign-ups	During the kickoff meeting, CAB members voiced enthusiasm for working asynchronously in smaller working groups focused on particular topics or project goals. CAB members completed a form to assess expertise and set up working groups around different interests and expertise
Design session preparation	CAB members helped test a training plan for preparing research participants to collaborate in a web-based space
Tagging exercise	CAB members were asked to identify potential “tags” that could be used to label each of the health information resources housed in the TGHIR tool to allow filtering

Abbreviation: CAB, community advisory board; TGHIR, Transgender Health Information Resource.

scale and are summed to produce a score between 0 and 100. A PEIRS score under 70 is interpreted as a low-to-moderate level of meaningful engagement and above 92 indicates extremely high meaningful engagement. The survey takes approximately 10 to 15 minutes to complete. After the final CAB meeting for the project, all active CAB members were invited to complete the PEIRS survey electronically in the REDCap electronic data capture tool.⁴⁰

Results

Community Advisory Board Membership and Participation

All those nominated were invited to join the CAB and all accepted; all but one completed the 1-year commitment. A new member was nominated to replace the person who resigned. The CAB included 20 individuals: 13 community

members and 8 research team members; 1 individual belonged to both the CAB and research team. CAB members included eight persons who identified as TGD, four parents of TGD adolescents, and three clinicians with expertise in TGD health care, including primary care, surgery, and mental health. At the kick-off meeting, the CAB members indicated that they would like to work both synchronously during CAB meetings (→Table 2, CAB meeting agenda topics and attendance) and asynchronously (→Table 3, Asynchronous CAB Tasks).

Purpose-to-Practice Exercise Insights

The P2P exercise outputs are shown in →Fig. 2. Overall, the P2P organized CAB communication and decision-making processes and informed initial priorities for the design of the TGHIR app. The purpose was articulated as making reliable health information accessible to the transgender

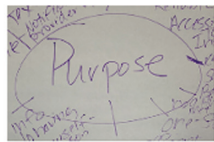
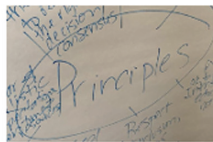

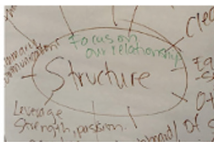
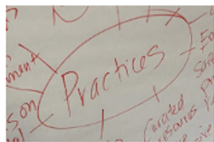
Purpose-to-Practice (P2P)				
Purpose: Why is the work (i.e., connecting people who are transgender to health resources & the TGHIR app) important to you and the larger community?	Principles: What rules must we obey as we work together as a community advisory board in pursuit of our purpose?	Participants: Who must be included in the design and testing of the TGHIR app? Who are we missing on the CAB?	Structure: How will we organize to distribute the work and make progress in a timely, efficient, & productive manner?	Practices: What are we going to do to achieve our purpose? What will we offer to the users/community?
				
<ul style="list-style-type: none"> • Access to relevant care & resources • To ensure basic health needs are met • Reliable source of medical health information 	<ul style="list-style-type: none"> • Remain vulnerable, extend grace • Stay focused on our purpose • Respect & inclusion • Listen for understanding & learning 	<ul style="list-style-type: none"> • Mental health clinicians • Parents, siblings, & family • Trans people of color • Diversity in all dimensions 	<ul style="list-style-type: none"> • Summary communications • Leverage strengths & passions • Clear timeline & deadlines • Small asynchronous workgroups 	<ul style="list-style-type: none"> • Focus on mental health • Curated resources that are responsive to language • Distinguish between cultural & clinical competence

Fig. 2 TGHIR CAB kick-off purpose-to-practice exercise insights. CAB, community advisory board; TGHIR, Transgender Health Information Resource.

community. The CAB agreed mutual respect, focus on goals, setting appropriate expectations, and reaching consensus would be guiding principles. We established each person should diligently fulfill their roles and responsibilities and would speak from experience and domains of expertise, such as clinicians or members of different racial backgrounds.

The project operationalized CAB priorities in several ways. For example, in the P2P “structure” round, it was recommended that the CAB work both synchronously and asynchronously. CAB members endorsed the use of familiar asynchronous technologies to collaborate, such as Google Drive and email. The CAB completed several asynchronous tasks (see [Table 3](#)), although a broader “workstream” concept (tasks completed by smaller workgroups) was challenging to implement and sustain.

P2P insights guided TGHIR app design in several ways. For instance, during the P2P “Purpose” round, CAB members emphasized ensuring TGHIR app users’ safety by protecting their identities as a TGD individual. Safety was operationalized by not collecting any user data other than an email when the user created an account and allowing for discreet use of the app, such as an app icon that did not explicitly signify TGD purpose. Not all CAB member insights were implementable in the scope of TGHIR version 1.0. For instance, CAB members recommended translating the app into Spanish, but this was outside the scope of the project timeline and budget. As a result, some CAB members expressed dissatisfaction that the features important to minority communities were not prioritized.

Community Advisory Board Engagement Process Affinity Grouping Insights

The affinity grouping activity revealed CAB engagement process, outputs, and overall experience insights ([Table 4](#)).

Community Advisory Board Social Justice Orientation

The CAB was highly attuned to issues of social justice relevant to the TGD community and other marginalized communities with whom they identified. For instance, intersectionality

was a top priority for the CAB from the outset. While much of this project occurred in the context of social unrest during the coronavirus disease 2019 (COVID-19) pandemic, Black Lives Matter protests following the death of George Floyd, and the 2020 U.S. Presidential election, social justice has long been a priority for the TGD community.^{41,42} Both the historical and contemporary sociopolitical climate and experience of the TGD community oriented the project to social justice priorities. For instance, the CAB emphasized increased diversity among those participating in the TGHIR research and design activities.

Community Advisory Board Asynchronous Work

Specific, time-bound tasks with clear instructions were most likely to be completed by CAB members outside of CAB meetings. Completing tasks outside of the regularly scheduled CAB meetings was difficult, perhaps due to the CAB member’s competing life priorities and lack of financial incentives. There was no budget for additional compensation for CAB members outside of meeting times, as we had not anticipated this type of additional work when writing the grant.

Community Advisory Board Priorities for Transgender Health Information Resource App Design Features

Members of the CAB provided rich insights on the content and organization of the TGHIR app, including categories of health and medical information to be included. These included, but were not limited to, health insurance, hormone therapy, and legal resources. These insights guided the work of the project’s health sciences librarian to begin identifying information resources. CAB members helped ensure appropriate sensitivity and consideration of language, labels, accessibility, and inclusivity.

Upon seeing an initial demo of the app, the CAB expressed concern about the resource filter functionality. Originally, based on design session data, the filter was set up to have a top-level sorting category labeled “audience.” In this filter, the user could select their audience as

Table 4 CAB and research meeting synthesis affinity grouping themes

Affinity grouping prompt	Research meeting insights	CAB meeting insights
1. What went well in these interactions and what is the evidence?	Productive discussions on how to interact with CAB on topics that were out of scope for the grant; thoughtful reflections on group process	Social aspects of relationship building included “what’s new” on the agenda and reflecting upon current events. The CAB bonded well
2. What was missing, or did not go as well, what goals were not accomplished?	Dissemination efforts were routinely discussed; we had multiple presentations, but manuscripts were slow to emerge	The CAB observed multiple diverse perspectives were missing from the group. Future research proposals should focus on enhanced diversity
3. How did the stakeholders engage around the design of the tool?	CAB input was not always prioritized over what was learned in focus groups or design sessions	The CAB provided community-based insight on design decisions and what resources were needed in the TGD community
4. How did the stakeholders engage around the conduct of research?	All research team participants were engaged and routinely came to the meetings	The CAB emphasized the need for a diverse and intersectional research sample. The CAB informed selection of outcomes and measures for future research

Abbreviations: CAB, community advisory board; TGD, transgender and gender-diverse.

“transgender men,” “transgender women,” or “transgender and gender nonconforming” and recommended resources would be filtered by relevance to a particular gender identity. A majority of the CAB felt an adequately diverse spectrum of gender identities was not captured with this labeling. They debated between relabeling this filter or removing the “audience” filter entirely and ultimately voted democratically for the latter. Instead, users were first asked to sort by category, a process driven by the user’s interests instead of personal labels. The CAB endorsed this approach as friendlier and nonexclusionary.

Challenges Operationalizing Community Advisory Board Input in Transgender Health Information Resource App Design

There were several aspects of CAB input that could not be feasibly incorporated into the TGHIR app design. The CAB’s initial top priority feature was for the TGHIR app to facilitate finding trusted health care providers and services that were both culturally competent (i.e., “trans-friendly”) and clinically competent (i.e., well versed in evidence-based health care for people who are TGD). Although the TGHIR app was able to include existing resources for searching for care providers for TGD people (e.g., OutCare: find an LGBTQ competent health care provider),⁴³ the CAB was disappointed that the TGHIR app could not include its own curated care provider catalog.

Another CAB priority feature was a social peer-to-peer information-sharing component, which was also out of the scope for version 1.0. Even consideration of existing tools and resources that had been developed to accomplish peer-to-peer goals as a component of the TGHIR app was not satisfactory. Finally, the results of the tagging exercise also proved infeasible to implement in version 1.0. Six CAB members identified “tags” for each information resource that they perceived as likely search terms for people who might be searching for information provided by that resource. Integrating a “free text” search functionality using these tags was added to the list of desired features for the next release of the TGHIR app.

CAB Influence on the Conduct of Transgender Health Information Resource Research and Codesign

CAB members were consulted on the conduct of research, and the codesign methods used to develop the TGHIR app. CAB members edited a focus group guide (ensuring appropriate terminology) and recruitment strategies during the kick-off and contributed to the interpretation of focus group findings at subsequent CAB meetings. The CAB stated that it would be valuable to include topics related to race and insurance barriers in the focus group guide. CAB input on the dissemination of future research planning was also beneficial. The CAB advocated that our research team build a national network among additional LGBTQ advocacy organizations to aid the recruitment of more diverse participants for future research. The CAB strongly advocated for testing the TGHIR 1.0 in an intersectional and diverse sample. The research team subsequently secured funding to conduct a

pilot study to test methods to recruit TGD people of color and other diverse community perspectives such as neurodiversity.

Patient Engagement in Research Scale Findings

Eight out of thirteen community members (61%) and six out of seven research members (85%) completed the PEIRS survey at the end of the project. Survey respondents ranged in age from 18 to over 55; self-described gender was reported as follows: eight cis women, two cis men, one non-binary person, two trans women, two trans men, one gender nonconforming person, and two unspecified; race/ethnicity was self-described as follows: one Black person, one Asian person, one Native American person, three Hispanic people, six white people, and two other/unspecified people. The mean PEIRS score for the CAB was 84.7 out of 100 (standard deviation = 12.07; range: 53.33–98.89), classified as moderate to high levels of “meaningful engagement.”³⁸

Discussion

As a research team composed of seven cisgender individuals and one gender-diverse individual, we could not develop this app alone, we partnered with TGD community representatives. The project’s CAB represented one component of a human-centered design and community-engaged research process.²⁹ The TGHIR research and development team iterated TGHIR app design with the integration of insights from the literature, CAB priorities, and formal data collection from focus groups and design sessions with TGD individuals.

Overall, the ADM³¹ combined with group facilitation using Liberating Structures effectively guided the process of gathering inputs, combining evidence, aligning perspectives, and making decisions about the TGHIR app design. The CAB members’ level of engagement was evident through regular meeting attendance, willingness to share values and highly personal experiences, comfort pushing back on the research team around design decisions, and moderate to high self-rated PEIRS scores.

Several aspects of the engagement approach were notable for their apparent impact on both trust and relationships. First, the half-day in-person CAB kick-off meeting (held in January 2020) guided by the P2P exercise was important for building rapport, setting the tone for the project, establishing a shared language, and quickly orienting the research team to design priorities. Shorter, more frequent video conference calls following the kick-off included agendas and materials (e.g., TGHIR app mock-ups, health information resource lists) shared in advance were also effective for iteratively informing design decisions. The research and development team made progress between calls, shared work products, gathered CAB input, pivoted as necessary, and proceeded to the next development stage. This process mirrors several aspects of the Boot Camp Translation⁴⁴ approach (initial kick-off, expert presentations, subsequent conference calls, and iterative design) to engaging community members in the design of dissemination strategies for health campaigns, adapted for the digital health space.

Although we had planned to hold at least some CAB meetings virtually, the COVID-19 pandemic made it necessary. The CAB also expressed a preference for asynchronous engagement through online collaborative platforms (i.e., Google Drive for document sharing, email communication), although this was seldom used. Wilton and colleagues reported a combined in-person and online engagement approach was preferred for their public engagement initiative, as participants indicate less positive experiences with online engagement approaches.⁴⁵ Similarly, Thayer et al reported that best practices for virtual engagement included the use of multiple platforms for both synchronous and asynchronous work goals.⁴⁶ Thus, our hybrid approach was likely beneficial.

There were lessons learned about the process of engaging the TGD community in the design of the TGHIR app. In addition to TGHIR design features, the CAB informed focus group and design session consent processes and recruitment strategies focused on generating diverse community perspectives (racial/ethnic diversity, mental health, and neurodiversity⁴⁷), and outcomes and measures for a pilot study. While not all priority features could be included in TGHIR v1.0 precisely as the CAB envisioned (peer-to-peer sharing, competent clinician locator, and Spanish language resources) the team had honest, open conversations about what was possible. At every stage of the project, we discussed what was in scope for the current version and committed to seeking funding for future versions that would integrate more desired features. Explicit expectations for long-term engagement were important for showing the CAB that this work was not going to be “helicopter” or “parachute” research.^{48,49} This is especially important when collaborating with stigmatized and marginalized communities such as those who are TGD as a way to build trust and rapport.⁵⁰ Addressing intersectionality²⁷ (a top CAB priority) as an element of social justice in engaging the TGD community in health research requires “naming intersecting power relations, disrupting the status quo, and centering embodied knowledge.” A CAB engagement strategy can be useful for operationalizing these principles, but power imbalance when researchers engage advisory boards is a known challenge.⁵¹⁻⁵³ Our strategies for balancing power dynamics with the CAB were to plan for open discussion time (ideally more than half the time) during CAB meeting agendas and for the facilitator to actively encourage CAB members to share their perspectives both during meetings and privately through email or phone conversations. Other community-based participatory methods may be more effective for balancing power dynamics when engaging the TGD community⁵⁴; research on comparative engagement could investigate this question.

Ultimately, the TGHIR app may address an unmet need for access to high-quality health information to inform health decision-making for the TGD community. While the TGHIR app does include the ability to search for existing resources for finding clinicians that self-report providing health care to TGD individuals, it cannot directly address one of the CAB’s most urgently identified needs—access to culturally and clinically competent care.⁵⁵ For the CAB, this refers not

only to health care related to gender affirmation but also to the whole-person care needs that all people have, such as preventive care and chronic disease management, areas in which TGD people experience health inequities.⁵⁶⁻⁶⁰ Clinician education strategies and addressing clinician transphobia are also needed.^{61,62}

Conclusion

Lessons learned from this project included the value of a CAB approach as part of a codesign process for establishing a shared language, setting initial priorities to guide the work of the research and development team, interpretation of data and the evidence, and future research planning. Engaging the CAB yielded an informed network of community members who collectively endorsed the project and cocreated the work process through shared decision-making on how design decisions are made to ensure that the TGHIR app was appropriate to support the TGD community. Further research is needed to evaluate the effectiveness of the TGHIR app for improving TGD engagement in care, health outcomes, and equity.

Clinical Relevance Statement

To empower TGD patients and families in shared decision-making and to be fully engaged advocates in their own health care, they need to be informed. It is not possible for any health care system, set of clinicians, and ancillary staff to serve the information needs of every person. Health care and community resources are also concentrated in urban settings, with rural settings having less access to health care and other forms of support. Creating an app designed by and for the TGD community may allow patients access to the information they need to advocate for their health and better partner with their health care team.

Multiple-Choice Questions

1. How were credible health information resources defined for this project?
 - a. From a definition provided by the CDC
 - b. In partnership with the Community Advisory Board (CAB)
 - c. To include resources that were created by reputable sources such as The Trevor Project
 - d. B and C
 - e. All of the above

Correct Answer: The correct answer is option d. Researchers worked with the CAB to define what we would consider credible health information resources for inclusion in the TGHIR, such as the content from the Trevor Project

2. Why did the research team follow community-engaged research principles and methods to orient the project to the health needs of the TGD community?

- a. To identify key audiences and relevant policies
- b. To co-create research data collection instruments, protocols, and recruitment strategies
- c. To develop a dissemination strategy
- d. To develop plans for pilot testing the TGHIR app
- e. All of the above

Correct Answer: The correct answer is option e. We followed community-engaged research principles and methods to orient the project to the health needs of the TGD community, and relevant policies, cocreate research data collection instruments, protocols, and recruitment strategies, and develop a dissemination strategy and plans for pilot testing the resulting TGHIR app.

Protection of Human and Animal Subjects

This work was determined “not human subjects research” according to the Colorado Multiple Institutional Review Board (Protocol no.: 19-1562).

Conflict of Interest

None declared.

Acknowledgments

This work would not be possible without the partnership of our dedicated CAB members. We also acknowledge all of our partners, including One Colorado, the University of Colorado Strauss Health Sciences Library, and the UHealth Integrated Transgender Health Program.

References

- 1 Walch A, Davidge-Pitts C, Safer JD, Lopez X, Tangpricha V, Iwamoto SJ. Proper care of transgender and gender diverse persons in the setting of proposed discrimination: a policy perspective. *J Clin Endocrinol Metab* 2021;106(02):305–308
- 2 Heng A, Heal C, Banks J, Preston R. Transgender peoples' experiences and perspectives about general healthcare: a systematic review. *Int J Transgenderism* 2018;19(04):359–378
- 3 Baldwin A, Dodge B, Schick VR, et al. Transgender and gender-queer individuals' experiences with health care providers: what's working, what's not, and where do we go from here? *J Health Care Poor Underserved* 2018;29(04):1300–1318
- 4 Daniel H, Butkus RHealth and Public Policy Committee of American College of Physicians. Lesbian, gay, bisexual, and transgender health disparities: executive summary of a policy position paper from the American college of physicians. *Ann Intern Med* 2015; 163(02):135–137
- 5 Augustaitis L, Merrill LA, Gamarel KE, Haimson OL. Online transgender health information seeking: facilitators, barriers, and future directions. In: *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems* [Internet]. Yokohama Japan: ACM; 2021. 1–14. Accessed February 2, 2023 at: <https://dl.acm.org/doi/10.1145/3411764.3445091>
- 6 Flores AR, Brown TNT, Herman JL. Race and Ethnicity of Adults Who Identify as Transgender In the United States. The Williams Institute; 2016
- 7 Pho AT, Bakken S, Lunn MR, et al. Online health information seeking, health literacy, and human papillomavirus vaccination among transgender and gender-diverse people. *J Am Med Inform Assoc* 2021;29(02):285–295
- 8 The Trevor Project | For Young LGBTQ Lives [Internet]. The Trevor Project. [cited 2021 Nov 18]. Accessed February 2, 2023 at: <https://www.thetrevorproject.org/>
- 9 MedlinePlus Information about MedlinePlus for Developers [Internet]. [cited 2022 Aug 28]. Accessed February 2, 2023 at: <https://medlineplus.gov/about/developers/>
- 10 McKay B. Lesbian, gay, bisexual, and transgender health issues, disparities, and information resources. *Med Ref Serv Q* 2011;30(04):393–401
- 11 Morris M, Roberto KR. Information-seeking behaviour and information needs of LGBTQ health professionals: a follow-up study. *Health Info Libr J* 2016;33(03):204–221
- 12 Drake AA, Bielefield A. Equitable access: information seeking behavior, information needs, and necessary library accommodations for transgender patrons. *Libr Inf Sci Res* 2017;39(03):160–168
- 13 Beiriger A, Jackson RM. An assessment of the information needs of transgender communities in Portland, Oregon. *Public Libr Q* 2007; 26(1–2):45–60
- 14 Clark BA, Marshall SK, Saewyc EM. Hormone therapy decision-making processes: Transgender youth and parents. *J Adolesc* 2020;79:136–147
- 15 Redfern J, Sinclair B. Improving health care encounters and communication with transgender patients. *J Commun Healthcare* 2014;7(01):25–40
- 16 Bakko M, Kattari SK. Transgender-related insurance denials as barriers to transgender healthcare: differences in experience by insurance type. *J Gen Intern Med* 2020;35(06):1693–1700
- 17 Dowshen NL, Christensen J, Gruschow SM. Health insurance coverage of recommended gender-affirming health care services for transgender youth: shopping online for coverage information. *Transgend Health* 2019;4(01):131–135
- 18 Reisner SL, Hughto JMW, Dunham EE, et al. Legal protections in public accommodations settings: a critical public health issue for transgender and gender-nonconforming people. *Milbank Q* 2015; 93(03):484–515
- 19 Fraser L. Depth psychotherapy with transgender people. *Sex Relationship Ther* 2009;24:126–142
- 20 Budge SL, Adelson JL, Howard KAS. Anxiety and depression in transgender individuals: the roles of transition status, loss, social support, and coping. *J Consult Clin Psychol* 2013;81(03):545–557
- 21 Point of Pride | Life-changing healthcare access for trans folks [Internet]. [cited 2022 Nov 21]. Accessed February 2, 2023 at: <https://www.pointofpride.org>
- 22 Transforming words into action. - HRC [Internet]. Human Rights Campaign. [cited 2022 Nov 21]. Accessed February 2, 2023 at: <https://www.hrc.org/about>
- 23 Noonan EJ, Sawning S, Combs R, et al. Engaging the transgender community to improve medical education and prioritize healthcare initiatives. *Teach Learn Med* 2018;30(02):119–132
- 24 Thompson HM, Clement AM, Ortiz R, et al. Community engagement to improve access to healthcare: a comparative case study to advance implementation science for transgender health equity. *Int J Equity Health* 2022;21(01):104
- 25 Lunn MR, Lubensky M, Hunt C, et al. A digital health research platform for community engagement, recruitment, and retention of sexual and gender minority adults in a national longitudinal cohort study—The PRIDE Study. *J Am Med Inform Assoc* 2019;26(8-9):737–748
- 26 Clements-Nolle K, Bachrach A. Community based participatory research with a hidden population: The Transgender Community Health Project. In: *Community Based Participatory Research For Health*. Hoboken, NJ: Jossey-Bass/Wiley; 2003:332–343
- 27 Wesp LM, Malcoe LH, Elliott A, Poteat T. Intersectionality research for transgender health justice: a theory-driven conceptual framework for structural analysis of transgender health inequities. *Transgend Health* 2019;4(01):287–296
- 28 Chen E, Leos C, Kowitt SD, Moracco KE. Enhancing community-based participatory research through human-centered design strategies. *Health Promot Pract* 2020;21(01):37–48
- 29 Morse B, Soares A, Ytell K, et al. Co-design of the transgender health information resource: virtual participatory design. *J Particip Med* 2022 (e-pub ahead of print). Doi: 10.2196/38078

- 30 Developing a transgender health information resource mobile app: participatory design and agile development [JMIR Preprints. [cited 2022 Nov 18]. Accessed February 2, 2023 at: <https://preprints.jmir.org/preprint/42382>
- 31 Deverka PA, Lavalley DC, Desai PJ, et al. Stakeholder participation in comparative effectiveness research: defining a framework for effective engagement. *J Comp Eff Res* 2012;1(02):181–194
- 32 Wright L, Grimm C, Retrum JH, et al. B3–4: establishing an aging-in-place model for the lesbian, gay, bisexual, and transgender (LGBT) community: lessons learned from a community-research partnership. *Clin Med Res* 2014;12(1–2):106–106
- 33 Kimball L. Liberating structures: a new pattern language for engagement. *Syst Thinker* 2012;23(01):5
- 34 Lipmanowicz KM Henri. Liberating Structures - 33. Purpose-To-Practice (P2P) [Internet]. [cited 2022 Aug 12]. Accessed February 2, 2023 at: <https://www.liberatingstructures.com/33-purpose-to-practice-p2p/>
- 35 Lipmanowicz KM Henri. Liberating Structures - 1. 1–2–4-All [Internet]. [cited 2022 Aug 13]. Accessed February 2, 2023 at: <https://www.liberatingstructures.com/1-1-2-4-all/>
- 36 What Is Affinity Grouping? Definition, Common Challenges, & FAQ [Internet]. [cited 2022 Aug 12]. Accessed February 2, 2023 at: <https://airfocus.com/glossary/what-is-affinity-grouping/>
- 37 MURAL is a digital workspace for visual collaboration [Internet]. [cited 2021 Jul 9]. Accessed February 2, 2023 at: <https://www.mural.co/>
- 38 Hamilton CB, Hoens AM, McQuitty S, et al. Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. *PLoS One* 2018;13(11):e0206588
- 39 Patient Engagement In Research Scale (PEIRS) [Internet]. Arthritis Research Canada. [cited 2022 Dec 6]. Accessed February 2, 2023 at: <https://www.arthritisresearch.ca/peirs/>
- 40 REDCap [Internet]. [cited 2021 Jul 9]. Accessed February 2, 2023 at: <https://www.project-redcap.org/>
- 41 Cashore C, Tuason MaTG. Negotiating the binary: identity and social justice for bisexual and transgender individuals. *J Gay Lesbian Soc Serv* 2009;21(04):374–401
- 42 Hagen WB, Hoover SM, Morrow SL. A grounded theory of sexual minority women and transgender individuals' social justice activism. *J Homosex* 2018;65(07):833–859
- 43 OutCare Health - LGBTQ+ Healthcare Resources & Providers [Internet]. OutCare. [cited 2022 Aug 22]. Accessed February 2, 2023 at: <https://www.outcarehealth.org/>
- 44 Thompson JH, Davis MM, Michaels L, et al. Patient-refined messaging for a mailed colorectal cancer screening program: application of boot camp translation in a latino-based community health center. *J Am Board Fam Med* 2019;32(03):307–317
- 45 Wilton P, Neville D, Audas R, Brown H, Chafe R. An evaluation of in-person and online engagement in Central Newfoundland. *Healthc Policy* 2015;11(02):72–85
- 46 Thayer EK, Pam M, Al Achkar M, et al. Best practices for virtual engagement of patient-centered outcomes research teams during and after the COVID-19 pandemic: qualitative study. *J Particip Med* 2021;13(01):e24966
- 47 Strang JF, Klomp SE, Caplan R, et al. Community-based participatory design for research that impacts the lives of transgender and/or gender-diverse autistic and/or neurodiverse people. *Clin Pract Pediatr Psychol* 2019;7(04):396–404
- 48 Haelewaters D, Hofmann TA, Romero-Olivares AL. Ten simple rules for Global North researchers to stop perpetuating helicopter research in the Global South. *PLOS Comput Biol* 2021;17(08):e1009277
- 49 Fohner AE, Volk KG, Woodahl EL. Democratizing precision medicine through community engagement. *Clin Pharmacol Ther* 2019;106(03):488–490
- 50 Vincent BW. Studying trans: recommendations for ethical recruitment and collaboration with transgender participants in academic research. *PsycholSexuality* 2018;9(02):102–116
- 51 Brown KM, Walker L, Kaminstein DS. Building an effective and empowered community advisory board for veterans. *J Humanist Psychol* 2020. Doi: 10.1177/002216782097603
- 52 Kelly G, Wang SY, Lucas G, Fraenkel L, Gross CP. Facilitating meaningful engagement on community advisory committees in patient-centered outcome research. *Prog Community Health Partnersh* 2017;11(03):243–251
- 53 Simwanga M, Porter J, Bond V. Who is answerable to whom? Exploring the complex relationship between researchers, community and Community Advisory Board (CAB) members in two research studies in Zambia. *Crit Public Health* 2018;28(03):318–328
- 54 Katz-Wise SL, Pullen Sansfaçon A, Bogart LM, et al. Lessons from a community-based participatory research study with transgender and gender nonconforming youth and their families. *Action Res* 2019;17(02):186–207
- 55 Kreines FM, Quinn GP, Cardamone S, et al. Training clinicians in culturally relevant care: a curriculum to improve knowledge and comfort with the transgender and gender diverse population. *J Assist Reprod Genet* 2022;39(12):2755–2766
- 56 Meyer IH, Brown TNT, Herman JL, Reisner SL, Bockting WO. Demographic Characteristics and Health Status of Transgender Adults in Select US Regions: Behavioral Risk Factor Surveillance System, 2014. *Am J Public Health* 2017;107(04):582–589
- 57 Winter S, Diamond M, Green J, et al. Transgender people: health at the margins of society. *Lancet* 2016;388(10042):390–400
- 58 Feldman JL, Luhur WE, Herman JL, Poteat T, Meyer IH. Health and health care access in the US transgender population health (TransPop) survey. *Andrology* 2021;9(06):1707–1718
- 59 Cotaina M, Péraire M, Boscá M, Echeverria I, Benito A, Haro G. Substance use in the transgender population: a meta-analysis. *Brain Sci* 2022;12(03):366
- 60 Rodriguez-Wallberg K, Obedin-Maliver J, Taylor B, Van Mello N, Tilleman K, Nahata L. Reproductive health in transgender and gender diverse individuals: a narrative review to guide clinical care and international guidelines. *Int J Transgender Health* 2022;0(00):1–19
- 61 Transphobia rather than education predicts provider knowledge of transgender health care - Stroumsa - 2019 - Medical Education - Wiley Online Library [Internet]. [cited 2022 Nov 21]. Accessed February 2, 2023 at: <https://onlinelibrary.wiley.com/doi/full/10.1111/medu.13796>
- 62 Lacombe-Duncan A, Logie CH, Persad Y, et al. Implementation and evaluation of the 'Transgender Education for Affirmative and Competent HIV and Healthcare (TEACHH)' provider education pilot. *BMC Med Educ* 2021;21(01):561