NOTHING ABOUT US WITHOUT US

BUILDING PATIENT-CENTERED OUTCOMES RESEARCH CAPACITY IN A NATIONAL CONSORTIUM OF LGBTQ+ HEALTH CENTERS

National Convening Report

written by

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FEBRUARY 2022

CALLEN-LORDE

Howard Brown Health

LEGACY COMMUNITY HEALTH

LYON MARTIN COMMUNITY HEALTH

WHITMAN-WALKER

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SUMMARY

Nothing about us without us: Building PCOR/CER capacity in a consortium of LGBTQ+ health centers was a PCORI Engagement Award (EACC#18813) that convened a diverse set of stakeholders representing five of the leading LGBTQ+ community health centers (CHCs) from across the United States. Our project was designed to foster partnership among diverse groups of LGBTQ+ health stakeholders to develop a shared agenda for PCOR/CER that is relevant, responsive, and useful to community health centers and the communities they serve. From September 2020 through August 2021, we engaged in a multi-stage collaborative process that included over 350 diverse stakeholders (over 50% of whom were patients) representing five community health centers. The project culminated in a 4-day virtual convening in which representatives from all five health centers came together to discuss: a) research priorities that are shared among patients and stakeholder groups; b) strategies for building research capacity within each CHC; c) strategies for increasing training opportunities and representation of LGBTQ+ individuals in all aspects of the research process, and d) opportunities for cross-center collaboration on a coordinated PCOR/CER agenda. This White Paper is designed to serve as a first step in the development of a stakeholder-driven, multi-pronged agenda for PCOR/CER to advance health equity goals for LGBTQ+ communities. Based on our collaborative process over the past twelve months, we present integrated and actionable information in three areas:

SHARED COMMITMENTS

This section presents the beliefs, principles, and aspirations for high-quality, equitable, patient-centered, and community-engaged LGBTQ+ research that emerged out of this Collaborative Convening. These shared commitments articulate a vision for future research work that was identified and affirmed by stakeholders over the course of the convening process.

PRIORITY RESEARCH AREAS

The priority research areas focus on research topics and specific research questions identified by stakeholders as most important to them and the communities they serve. Within each area, we present examples of stakeholder-identified projects that could be undertaken at a specific LGBTQ+ community health center or those envisioned as collaborative research across two or more health centers.

STRATEGIES AND RECOMMENDATIONS

The White Paper ends with a set of specific strategies and recommendations identified by stakeholders as the way forward toward an equitable LGBTQ+ research agenda, including actions that can be taken within individual health centers, across a consortium of health centers, by academic and other research partners seeking to do collaborative work with health centers, and by public and private funders seeking to make a difference in this field.

INTRODUCTION

The landscape of patient-centered outcomes research and comparative effectiveness research (PCOR/CER) focused on LGBTQ+ individuals has been historically limited by a number of factors.

1. Research with LGBTQ+ individuals has predominantly focused on pathology[1], specifically, HIV infection [2-5], psychiatric diagnosis [6-8], and trauma [9-11]. While documentation of these health issues is important to advance understanding of LGBTQ+ health, it does not explain *why and how* many LGBTQ+ people achieve and maintain good health despite adversity or identify the multilevel factors that influence the continuum of LGBTQ+ health over the life course [4,12,13].

2. Much of the research with LGBTQ+ populations has been conducted using a "top-down" approach, wherein research priorities are identified by funders or researchers, rather than the community [4]. The lack of explicit inclusion of patient stakeholders raises concerns that research conducted under LGBTQ+-focused funding announcements have little incentive to include patient stakeholder perspectives in the development, execution, and dissemination of LGBTQ+ health research.

3. There is a dearth of representation in scientific circles of LGBTQ+ individuals, and a lack of institutional commitment to environments that support LGBTQ+ professional development. This scarcity may be attributed to a lack of support for or recognition of LGBTQ+ health scholarship within academic institutions, a paucity of concordant mentors for early-stage investigators, limited LGBTQ+ professional networking opportunities, and/or campus climates hostile to LGBTQ+ people [14-17].

At the same time, there is a wealth of knowledge and expertise among a number of community health centers (CHCs) across the country specifically serving the needs of LGBTQ+ individuals. LGBTQ+ health services in the US have been available since the 1970s [5,18]. These community health centers have been at the forefront of LGBTQ+ healthcare service provision and advocacy for close to five decades and possess a wealth of knowledge and experience with the health concerns and priorities of their LGBTQ+ patient population. As trusted allies and resources for their patients and community stakeholders, these community health centers are uniquely poised to lead an LGBTQ+ patient-centered outcomes research agenda.While many researchers have sought to understand LGBTQ+ patients' experiences accessing healthcare services and preferences for care, the majority of these studies have focused on the general healthcare landscape, with limited consideration of LGBTQ+-focused health services and spaces [5,19–21]. It is imperative that researchers explore the provision and receipt of health services within LGBTQ+-serving CHCs to identify and test the components of LGBTQ+ health services that are associated with positive health outcomes throughout the lifespan.

By understanding these "active ingredients," we can create an evidence base for ensuring that all LGBTQ+ people have access to health services that are safe, affirming, and high-quality. In order to truly advance the field, representatives from these community health centers must not only be engaged in developing a LGBTQ+ research agenda but their established relationships with their patient populations and community partners must be harnessed to drive patient and stakeholder engagement in research question development, study design, data collection, data analysis, results interpretation and dissemination of findings. To date, many community health centers have lacked a formal infrastructure within which to convene to set such priorities for an LGBTQ+-focused PCOR/CER agenda and develop "in-house" research knowledge, expertise, and large-scale grant support. CHCs are increasingly recruited to participate in research, yet are often denied the resources or capacity to meaningfully engage as research partners [22,23]. At the same time, academic health researchers have become more aware of the importance of creating research partnerships with CHCs, but many lack the knowledge and experience necessary to build strong, equitable partnerships. An essential step towards developing an LGBTQ+-focused PCOR/CER agenda is the creation of a collaborative research infrastructure that leverages stakeholders' strengths and expertise to build research capacity within and across community health centers. Furthermore, because the majority of staff at LGBTQ+-serving CHCs are themselves members of the LGBTQ+ population, PCOR capacity-building at CHCs will facilitate supportive professional development and inclusion of LGBTQ+ members of the healthcare workforce.

> THIS WHITE PAPER PRESENTS CONCRETE, ACTIONABLE STEPS FOR DEVELOPING A MULTI-STAKEHOLDER DRIVEN, COMPREHENSIVE EVIDENCE BASE FOR LGBTQ+ HEALTH THAT IS IMPERATIVE TO THE OVERALL HEALTH AND WELLBEING OF THE LGBTQ+ COMMUNITIES.

PROJECT PARTNERS

The idea for this Engagement and Convening Project emerged out of a long-standing collaboration between Callen-Lorde Community Health Center and the Hunter Alliance for Research & Translation (HART) at Hunter College (CUNY). Callen-Lorde and HART have been collaborating on community-driven research for the last 10 years, including large-scale NIH demonstration projects, community needs assessments in support of Callen-Lorde's strategic planning, and training and capacity-building programs at the health center. In conceiving this project, the team chose specific health center partners based on a set of intentionally considered characteristics. **First,** health centers were chosen to represent geographic diversity – New York, San Francisco, Chicago, Houston, and Washington, DC – as well as racial/ethnic and gender diversity in the patient populations that they serve. **Second,** all health centers are large-scale providers that are recognized nationally as leaders in LGBTQ+ health. **Third,** all health centers are Federally Qualified Health Centers (FQHCs) that serve predominantly lower-income populations and focus heavily on serving the needs of LGBTQ+ patients of color, subpopulations who may face additional barriers to obtaining affirming and high-quality care. **Fourth,** although the health centers selected have varying experience in participating in or conducting research, each has identified the specific need for capacity-building assistance in order to be able to drive their own research agenda, rather than simply recruiting participants for external researchers. And **fifth**, all health centers expressed a desire to work collaboratively on a comprehensive LGBTQ+ PCOR/CER agenda that could tap into each center's individual strengths while benefiting from their collective resources and abilities.

Project partners are listed and described briefly below (in alphabetical order).

CALLEN-LORDE **CALLEN-LORDE COMMUNITY HEALTH CENTER, NEW YORK, NY** has been providing culturally sensitive services to the LGBTQ+ community for over 30 years and is the only healthcare facility in New York City and State with the expressed mission to serve LGBTQ+ communities. Using a harm-reduction and trauma-informed approach, Callen-Lorde provides medical, mental health/social work, psychiatry, patient navigation, and nursing services to over 17,000 patients per year. In addition to providing high-quality, culturally competent healthcare and supportive services targeted to LGBTQ+ communities and people living with HIV/AIDS, Callen-Lorde also serves as a center of excellence – helping to train the future leaders in LGBTQ+ health while blazing new trails in LGBTQ+ research and strategic partnerships.

HART Hunter Alliance for Research & Translation The **HUNTER ALLIANCE FOR RESEARCH & TRANSLATION, NEW YORK, NY** is an academic research laboratory in one of the largest public universities in the country, the City University of New York. HART resides within Hunter College, one of CUNY's flagship colleges, serving a diverse undergraduate and graduate population. HART's mission is to translate research findings into practical implications for service and advocacy organizations and to develop training and technical assistance tools that accelerate the pace of empirically-based practice. HART partners extensively with local, national, and international collaborators, applying psychological theories and research methods to develop innovative strategies that improve health equity and access. HART's research and capacity building efforts promote the provision of affirming and inclusive care, studying and developing intervention models that support individuals, families, and communities. HART is dedicated to research, advocacy, and service that can improve the lives of LGBTQIA+ communities in all their diversity.

HOWARD BROWN HEALTH, CHICAGO, IL was founded in 1974 and is one of the nation's largest lesbian, gay, bisexual, transgender, and queer (LGBTQ) organizations. Howard Brown Health serves over 35,000 adults and youth annually across multiple clinical and social service sites throughout the greater Chicago area. Their mission is to eliminate disparities in healthcare experienced by LGBTQ individuals through research, education, and the provision of services that promote health and wellness. In 2015, Howard Brown Health was designated an FQHC – the only FQHC in Illinois focused on the health needs of the LGBTQ population. Additionally, the Howard Brown Center for Education, Research, and Advocacy was established to collaborate on clinical research studies and behavioral interventions that address LGBTQ community priorities. Howard Brown Health also facilitates several Community Advisory Boards, which meet monthly to provide input on programs and services.

LEGACY COMMUNITY HEALTH, HOUSTON, TX is a full-service, FQHC that identifies unmet needs and gaps in health-related services and develops client-centered programs to address those needs. Legacy serves almost 170,000 community members annually, across 34 locations in Baytown, Beaumont, Deer Park, and Houston. Their mission is to drive health change in their communities. Legacy has been serving the LGBTQ community since 1978 and is a nationally recognized leader in HIV/AIDS primary care, prevention, and treatment, as well as providing comprehensive services to meet the unique needs of all their LGBTQ patients.

LYON MARTIN COMMUNITY HEALTH, SAN FRANCISCO, CA is a non-profit community clinic in San Francisco providing a patient-centered, integrated model of primary care and behavioral health services to women, lesbians, and transgender people since 1979. Their mission is to provide high-quality, compassionate, and innovative care, believing that good health means caring for both the body and mind. Lyon-Martin Health Services sees over 2,000 patients annually. In addition to their medical and mental health services, Lyon-Martin partners with the Transgender Law Center to run Project Health (Harnessing Education, Advocacy & Leadership for Transgender Health), which seeks to improve access to transgender healthcare by educating healthcare workers and students, advocating for systemic change through policy and legislation, and training local activists to become leaders in their communities.

WHITMAN WALKER HEALTH, WASHINGTON, D.C. was founded as an affirming health center for the gay and lesbian community in 1978 and has expanded to serve the growing needs of Washington DC's LGBTQ+ population. Their mission is to offer affirming community-based health and wellness services to all with special expertise in LGBTQ+ and HIV care. Whitman Walker became an FQHC in 2007 and provides medical, dental, mental health, specialty care, and pharmacy services at four locations throughout the DC area, including a specific youth services center that combines mental health; youth and family support; and comprehensive prevention, health, and wellness services. In 2019, the organization established the Whitman-Walker Institute to further its education, policy, and research, including the establishment of a Community Advisory Board.

METHODOLOGY

The work of this engagement process occurred in several iterative phases.

PHASE 1 : SEP 2020 – OCT 2020 | LISTENING SESSION DEVELOPMENT

In Phase 1, we met with each of the five health centers collectively and individually to develop both the content and format of community "listening sessions." These pre-convening listening sessions were designed to provide opportunities for meaningful involvement of a large group of stakeholders at multiple levels to guide the development of the Collaborative Convening agenda and content.

LISTENING SESSION GOALS

1. Gather input from a variety of stakeholders about patient-centered research priorities and values;

2. Include voices and perspectives from a wider group of stakeholders than would be able to participate in the Collaborative Convening; and

3. Identify key themes and issues across sites to inform and enhance the agenda, materials, and discussion for the Collaborative Convening.

To help frame the listening sessions and guide our initial discussions, we posed two questions to our collaborators. First, we asked, "What would it mean for community health centers to use research to achieve their own goals, instead of being used by outside researchers?" And second, "How can we harness research methods and funding to help address issues around healthcare equity, access, and patient-centered care?" We then asked each health center three questions to help them decide who should be included in the listening sessions: (1) who are your most important stakeholder groups?; (2) within these stakeholder groups, what type of diversity is present and needs to be adequately represented (e.g., age, race/ethnicity, LGBTQ+ identity, ability, socioeconomic status)?; and (3) whose voices have already been "heard" or "included" vs. whose voices should be lifted up and prioritized? Based on these meetings, we developed a comprehensive list of both open-ended and multiple-choice questions encompassing the following topic areas: (1) patient health concerns and patient-centered health outcomes; (2) research participation; and (3) research gaps and topics. A majority of the questions asked were similar across the health centers, but each health center could choose to customize certain questions to their particular needs or context.

> "WHAT WOULD IT MEAN FOR COMMUNITY HEALTH CENTERS TO USE RESEARCH TO ACHIEVE THEIR OWN GOALS, INSTEAD OF BEING USED BY OUTSIDE RESEARCHERS?"

PHASE 2: NOV 2020 – FEB 2021 | LISTENING SESSION IMPLEMENTATION

In Phase 2, we worked with each of the CHCs on the implementation of the listening sessions. Given the constraints of the COVID-19 pandemic, CHCs chose different innovative strategies to gather data and promote the inclusion of community stakeholders. Some CHCs used online surveys that were distributed to patients and staff; others conducted virtual focus groups with invited stakeholders; others utilized time at existing staff meetings or community advisory board meetings; others conducted individual sessions with community partners. All in all, we collected feedback from over 300 stakeholders, including patients (53%), clinicians/direct care providers (26%), healthcare administrators (10%), and health center researchers (11%).

OVER 300
STAKEHOLDERS PARTICIPATED

53%	26%	10%	11%
Patients	Clinicians/Direct Care Providers	Health Center Administrators	HC Research Staff

PHASE 3: MAR 2021 – MAY 2021 | COLLABORATIVE CONVENING DEVELOPMENT

In Phase 3, we developed the Collaborative Convening agenda, materials, and format, based on information gathered during the listening sessions and feedback from our partners. We organized the convening into four thematic sessions: (1) Identifying Shared Research Priorities, (2) Building PCOR Research Capacity, (3) Increasing LGBTQ+ Inclusion & Engagement in Research, and (4) Opportunities for Cross-Center Collaboration. To ensure that patients had a protected space to share their perspective, a fifth patient-only session was added. To disseminate session information, we created a website that included a series of short videos and handouts that corresponded with each convening session and was designed to enhance stakeholders' experience.

> "HOW CAN WE HARNESS RESEARCH METHODS AND FUNDING TO HELP ADDRESS ISSUES AROUND HEALTHCARE EQUITY, ACCESS, AND PATIENT-CENTERED CARE?"

PHASE 4: JUNE 2021 | COLLABORATIVE CONVENING

In Phase 4, we conducted the Collaborative Convening. Since the Collaborative Convening took place in a virtual format, we constructed the agenda and session content to encourage conversation and connection and limit "Zoom fatigue." Sessions took place over four days, and participants could sign up to attend as many as they wished. Participants were asked to prepare for each session by viewing videos and handouts that provided background material from the pre-convening listening sessions and included a set of questions that would be discussed during the live session. Sessions were a combination of large-group discussion and smaller break-out sections, which allowed for a more in-depth conversation. Additionally, to show our appreciation and acknowledge all the work stakeholders had done to help make the Collaborative Convening happen during an incredibly challenging year, each participant received two "goodie" boxes from an LGBTQ-owned business. The boxes focused on self-care and included activities specifically designed to foster connection in virtual environments, which were used as ice-breakers during the online sessions. A total of 49 stakeholders (approximately ten stakeholders from each health center) attended the Collaborative Convening. Patient stakeholders represented almost half of the total number of all participants (20 patient stakeholders, approximately four from each health center). The remaining 29 stakeholders represented clinicians, administrators/leadership, researchers, and other patient care staff.

PHASE 5: JUL 2021 – AUG 2021 | CONVENING REPORT DEVELOPMENT

In Phase 5, we developed the Convening Report and White Paper. The final two months of the project were spent digesting the content and discussions that emerged from the Collaborative Convening and synthesizing findings into two documents. First, we prepared a Convening Report, which presented the information collected in both the listening sessions and Collaborative Convening in narrative form. Second, we prepared this White Paper, to summarize the shared commitment, priority research topics, and recommendations that emerged from our year-long engagement project. As noted above, this White Paper is designed to provide integrated and actionable information to inform the development of a large-scale stakeholder-driven, multi-pronged agenda for PCOR/CER to advance health equity goals for LGBTQ+ communities.

A TOTAL OF
49
STAKEHOLDERS
PARTICIPATED
IN THE CONVENING
(~ 10 FROM EACH CHC)

SHARED COMMITMENTS

In this section, we present the beliefs, principles, and aspirations for high-quality, equitable, patient-centered, and community-engaged LGBTQ+ research that emerged out of this Collaborative Convening. The Shared Commitments articulates a vision for future research work that was identified and affirmed by stakeholders over the course of the convening process.

CENTERING HEALTH EQUITY OVER DEFICITS OR DISPARITIES

Prior LGBTQ+ research has placed tremendous emphasis on high rates of morbidity and mortality among LGBTQ+ communities, documenting the health disparities experienced in healthcare access and utilization. While evidence of existing health disparities can be an important advocacy tool, research that focuses on the description in the absence of action is not advancing patient-centered research outcomes or goals. Any truly patient-centered and community-engaged and LGBTQ+ health research agenda must move away from merely documenting health disparities and toward (1) identifying specific dynamics and mechanisms that perpetuate inequity; and (2) developing and evaluating real-world strategies that mitigate against inequity in healthcare access, utilization, and treatment.

> 66 **Many studies do not represent the people we serve**...I believe in order **to create better services and understanding** of our patients, we must **know more** about our patients, **beyond sensationalizing** their experience with documented evidence that continues to speak and elevate the areas to focus. 99 (DIRECT PATIENT CARE STAFF SUPERVISOR)

> 66 A lot of studies I participate in are **very similar**, are **very "copy/paste"**...[the research] is **not positive**, it's not tracking the **actual positive development** of the life-span of a transgender woman. **Bring me some information I can actually use.** 99 (PATIENT)

ELEVATING INTERSECTIONAL IDENTITIES

LGBTQ+ health research has often overlooked or under-represented LGBTQ+ persons with multiple and intersecting identities, including communities of color; disabled individuals; elder communities; houseless/homeless individuals; low-income individuals; and immigrant communities. To create an LGBTQ+ PCOR/CER agenda that centers health equity, it is critical to recognize and elevate intersectionality as a determinant of health, a potential source of stigma and discrimination, and an enduring source of resilience and strength. In addition, although not always conceptualized in terms of intersectionality, an integrated mind-body approach to health and illness is crucial to an intersectional understanding of individuals' experiences in the healthcare system. In order to fully address the health impacts of discrimination, it is critical to acknowledge the reciprocal relationships between psychological, biological, and social processes in determining wellbeing.

> *[We need research on] how **intersectionality** (having more than one oppressed identity) **impacts healthcare** & **how to make it better.*** [PATIENT]

> *Research is needed on how a **lack of consistent health insurance impacts** the **body** and **mental health**.* [PATIENT]

> ***Black and brown communities**, especially **poor and houseless communities**. These patients **have the least access to care** already and **because of federal and state funding guidelines**, I feel we sacrifice these patients in order to grow bigger and better and serve more patients at a higher socio-economic level. We **need** to start **breaking down barriers** for these patients that come from **lack of documentation**, **lack of access to basic health and hygiene needs**, and **access to supportive care coordination** for other basic needs like **food** and **housing stability**. I feel that **without access to these supports, our LGBTQ patients** in these populations are mostly ignored and **never have** a chance to **access** the care we are offering.* [CLINICIAN]

PRIORITIZING RESEARCH THAT IMPROVES THE LIVES OF PATIENTS AND SOLVES PROBLEMS WITHIN A HEALTH CENTER

In addition to responding to research requests from funders or outside partners, it is critical that LGBTQ+ community health centers conduct research that evaluates and informs the care they are already providing in alignment with their agency's mission. In contrast to research agendas that are dictated by outside researchers or funders, a patient-centered and community-engaged agenda is defined by its responsiveness to the immediate interests and needs of LGBTQ+ community health centers and their patients, staff, and the larger community. Research topic selection should be driven by what patients and providers need to know to improve health and wellbeing.

"The community that we're doing research around, it's often the communities that are marginalized... When we think about resources, folks mostly engage in research because they actually need the money. This is something that I can support me with, and I'm giving my information. And there is almost a sense of manipulation, if I didn't really need the money, would I be engaged with this research? **Because the question is, what does this research do for me and my community?** *And me being vulnerable in this already vulnerable state. What does that do for me?* **What does that help me? What does that improve? What problems will it solve?** *Or is it just to see me as a spectacle?"*

(PUBLIC POLICY COORDINATOR)

"If you're a **clinician** *and you're* **concerned about** *the* **person** *immediately* **in front of you** *and* **making sure** *that their* **care** *is* **comprehensive** *and* **meets their needs***, you* **don't want** *to be* **involved** *with* **research** *if you feel like that* **takes away** *from* **your connection,** *your patient provider relationship. It's really essential to be very* **clear** *and* **deliberate** *about saying* **how something is going to actually improve someone's care***, how it's going to* **improve their immediate lives** *and how it's going to* **do it in a timely fashion***. ...***one of the problems** *we've really had is* **explaining** *and* **translating** *how a* **specific practice** *is going to* **make that impact***, and* **how** *it's going to do it in a way that's going to* **clearly benefit that patient beyond** *getting an* **incentive** *or* **being involved***. I think what's really challenging is that* **we don't** *really* **have that explanation***, we don't even* **have that conversation.***"* (RESEARCH COORDINATOR)

ALIGNING RESEARCH ACTIVITIES AND PROTOCOLS WITH CLINICAL CARE

Relatedly, research that is responsive to the health center's overall mission must be designed and implemented in a manner that does not place an undue burden on patients, providers, and other health center staff. Research activities should not be disruptive to the provision of the highest quality clinical care. By definition, individuals who are engaged in research in clinical settings are both patients and participants. But too often, research projects prioritize the participant role and neglect the higher purpose of ensuring that patients are served and cared for by the setting. Equitable LGBTQ+ PCOR/CER emphasizes the extent to which the human being (i.e., patient) takes precedence over the research (i.e., participant). Inclusion/exclusion criteria, visit schedules, and other aspects of research protocols should be developed to ensure that as many patients have access to participation as possible, even if it means more work on the data analysis end.

66*The **federal community health center system** (of which we're a part) is **woefully underfunded** and **built around volume-of-care models**, making it **difficult to integrate research** into our work. **Research** seems like a **luxury** if there's **any time and resources left**.* 99

(SENIOR LEVEL MANAGEMENT & CLINICIAN)

66*One thing that I see a lot of is **prioritization** of these **best practices** coming in **conflict** with each other. I'm on the quality improvement group at [health center name]. We always have so **many things** that **we're trying** to work on to **improve** our **practice** that may be **research related**. I'm a part of our mental health team that's **working to improve results** among **suicidal patients** and follow up to care. That's **not part** of our **quality improvement measures**, and so therefore **not prioritized** as much. Even when we're **doing research**, a **competing priority** is our **ability** to **implement [research]** into our **actual practice** because we have **too many** things we're **trying to implement at once**.* 99

(BEHAVIORAL HEALTH CLINICIAN)

DESIGNING RESEARCH THAT CREATES OPPORTUNITIES FOR PATIENTS AND STAFF

Research studies are most often conceptualized as a means to an end – the research process itself may not be useful to participants or collaborators, but it will generate findings that will enhance care at some point in the future. In contrast to this model, community health centers should prioritize research that provides benefits to patients and staff during the research process; for example, by developing new programs, providing new funding, or enhancing access to treatments and services that might not otherwise be available in the health center. In this vein, it is vital that all research projects include a sustainability plan, to ensure that new services offered as part of a research study can be sustained after the research is completed (assuming that the services are deemed effective or useful for patients). Researchers should also consider providing opportunities for research participants that go beyond just financial incentives (or the ubiquitous pizza party). For example, participation in research can be an opportunity for forging connections among patients with shared experiences and interests, and researchers should consider innovative ways to provide these much-needed opportunities for social support and community building. Research conducted at health centers is also an opportunity to provide professional development for staff at all levels. External researchers who partner with CHCs should be required to provide these opportunities, ranging from training and mentorship to direct participation in research activities, including publication and presentation.

❝A discussion we've had on our community advisory board was about **how compensation doesn't necessarily only have to be monetarily,** it can also be a book about therapy or peer to peer conversations, or just like finding some way to be way more intentional about how we compensate and also support patients for participating in research. **How we can advocate for funding for intentional support and compensation.**❞ [RESEARCH MANAGER]

❝What came to my mind is having **different** types of **co-leads**. The **co-lead** would be an **investigator,** that is a **researcher** and a **community person**. And it's an **equal role** with **training involved**, and folks [community person] are **helping** and **being there** to also **translate**. They're **translating** for the **researcher**. They're **translating** for the **community,** and **at the same time** we're **creating opportunities** for folks **paid** internship programs. Because the **researchers are the researchers** and **maybe some** are **LGBTQ** people. But then there's also the issue of **are those LGBTQ people with the community** [they're studying] or are they just up there in that echelon of researchers.❞ [PATIENT]

ENSURING THAT RESEARCH METHODS ARE TRAUMA-INFORMED AND ACTIVELY DE-STIGMATIZING

The overemphasis on research documenting LGBTQ+ health disparities and deficits may recreate or trigger the very traumatic or stigmatizing experiences it is trying to understand. Stigma and minority stress scales often include items that are themselves stigmatizing or ask participants to relive stigmatizing experiences to document (yet again) the fact that stigmatizing experiences have negative impacts on mental health. To move toward a strengths-based health equity framework, it is incumbent on researchers to consider the reasons why they are asking certain questions, and whether the usefulness of these questions outweigh the potential harm to study participants. Truly patient-centered, community-engaged LGBTQ+ health research: 1) focuses on resiliency, strength, and joy, not only on documenting disparities and deficits; 2) ensures that study language is person-centered and non-stigmatizing, and 3) builds in support mechanisms (beyond resource lists) for individuals enrolled in studies dealing with stigma and trauma.

PILLARS of PATIENT-CENTERED LGBTQ+ HEALTH RESEARCH

FOCUSES ON RESILIENCY, STRENGTH, & JOY

66 *I think there **needs to be a pairing of the positive**, the **resilience and the stigma**? It seems like you if **you're going to ask what's difficult**, it would be awesome to also **ask what helps**. So what **makes you strong**?* 99 [PATIENT]

ENSURES THAT STUDY LANGUAGE IS PERSON-CENTERED AND NON-STIGMATIZING

66 ***Participants talk to me*** *about the fact that **they are very uncomfortable** with the ways that the **surveys are worded**… and from my **own experience** as a **transgender woman** it is **very uncomfortable** to even **read [the study materials]** to my **participants**.* 99 [RESEARCH ASSISTANT]

BUILDS IN SUPPORT MECHANISMS FOR INDIVIDUALS ENROLLED IN STUDIES DEALING WITH STIGMA & TRAUMA

66 *Include **peer support groups in the research process** where **people** are **able to support each other**… [offer] **behavioral health providers** as **part of a research study** -- not necessarily doing the research, but being available **if folks are experiencing trauma triggers**…[provide] people who **have already been identified** that they've been connected to along the way **[that participants] can go talk to.*** 99
[BEHAVIORAL HEALTH CLINICIAN]

RECONCEPTUALIZING DISSEMINATION ACTIVITIES ACROSS TIME, AUDIENCE, AND MODALITY

Conceptualizing dissemination as a process that begins at the inception of a research project and continues throughout implementation is key to conducting patient-centered outcomes research that is both timely and useful to patients and health centers. The overall goal of the dissemination process is to provide ongoing, clear communication about the study purpose, design, and potential impact. Dissemination activities and protocols should be developed with and implemented by patients, clinicians, and programmatic staff to 1) build trust around and enhance the applicability of findings; 2) create standardized "report-back" protocols for timely and ongoing dissemination of study information and findings; 3) facilitate real-time feedback, questions, and concerns from study participants and health center staff; and 4) ensure study information and findings reach beyond academic and scientific communities. As part of this commitment, researchers should strive to do research that is "flexible and nimble." The length of time between a study's inception and its ability to impact practice has been widely documented, and patient-centered, community-engaged research demands an accelerated time frame for impact. A "flexible and nimble" research approach is responsive to the immediate and shifting needs of patients and health centers and recognizes that these stakeholders cannot wait years to learn whether a particular strategy, intervention, or treatment is effective.

> 66 *I'm wondering if **part of dissemination** is **providing education** to the **community**, whether that's patients or health center staff, **about what's already been done**, and **what's already known** about this topic, and what additional piece this project will add.* 99 [RESEARCH ASSISTANT]

> 66 *One communication strategy I'm picking up has to do with **making sure** that the **research** that we're doing **originates within the communities** that we're studying. I think a lot about the ways that **communication happens in a community organizing** environment, where it's about **identifying community leaders**, having them **disseminate** what's going on **to their community**. And oftentimes, that **happens** through **word of mouth**, and through **one-on-one engagement** with people. I think there are ways that we could **use** those **similar strategies** in a **research context**.* 99 [CLINICIAN]

EMPHASIZING THE UNIQUE STRENGTHS OF LGBTQ+ COMMUNITY HEALTH CENTERS AS RESEARCH PRACTITIONERS AND PARTNERS

Community health centers provide a wealth of expertise and skills in the provision of equitable and affirming healthcare to LGBTQ+ communities who are historically underserved and underrepresented in research. However, researchers and funders often focus only on health centers' ability to provide access to their patient populations and have traditionally overlooked the value of the very care and services provided that directly improve the overall health and wellbeing of LGBTQ+ patients. Many community health centers have been providing care to their community for decades, allowing them to build credibility, connections, and trust. Community health centers attract staff who build ethical, non-judgmental, and respectful rapport with patients, which can be a tremendous facilitator of research participation. The majority of health center staff also represent the same LGBTQ+ communities that it is their mission to serve. And the co-location of research within a health center allows CHCs to both answer research questions and put research findings into action, providing an opportunity to build a rigorous evidence base for effective practice-based strategies/interventions. These strengths bring value to a research project equal to (or even greater than) value associated with research knowledge or grant writing experience. To move LGBTQ+ health research towards a health equity framework, it is imperative for funders and researchers to value and prioritize research that actively engages LGBTQ+ health center staff as research leaders.

"Having **research embedded** in a **FQHC** is a way to **help patients believe** in the **science** that is being done- if they **know the providers involved**, they are **more likely** to **trust** it." [CLINICIAN]

"We have a very **strong relationship** with our **patients** and the **transgender community**, and we would be **able to do research** that **involves patients in every step of the process** and is **based on trust and knowledge-sharing** (rather than being exploitative and for academic prestige) by making sure **we (and our patients)** are part of the **decision-making process** for what **studies** should be **conducted**, as well as **how to best conduct them**." [CASE MANAGER]

"We have a **large number of staff members who are part of the LGBTQ community** and therefore are more **sensitive** to the **impacts** and **consequences of research on vulnerable populations**."

[SENIOR LEVEL MANAGEMENT]

CONTESTING POWER DYNAMICS

Health centers have historically lacked the infrastructure and power to generate and conduct their own research. This has often created a contentious and fraught-filled relationship between researchers, academic institutions, and health centers. Health centers are inherently at a disadvantage when receiving research requests from outside researchers, particularly those at large academic research institutions due to their financial and legal power. Furthermore, institutions that fund LGBTQ+ health research perpetuate this power dynamic by not requiring researchers to actively consider, engage with, or address the research needs of health centers and their patients, disincentivizing researchers to conduct patient-centered, community-engaged research. To shift the power from academic institutions/researchers to health centers, funders must play an active role in 1) creating funding opportunities that allow health centers to develop and sustain a research infrastructure and model to design, implement, and disseminate their own research; 2) requiring a formal research engagement plan for all grant proposals (e.g., similar to PCORI's patient/stakeholder engagement plan) that concretely outlines the ways in which patients and health centers will participate at all stages of the research process; and 3) creating scientific review boards that include patient and provider stakeholders to ensure that the proposed research is beneficial to patients and health centers. Health centers themselves can contest these power dynamics by developing a set of shared standards for a collaborative partnership to which outside partners are required to adhere. Such standards might include guidelines for equitable budgeting, genuine partnership, and planning for sustainability.

> **"**We have **affiliations** with [university name] and other **universities** close by, but **they're always** the ones **coming into our clinic** and **telling us** what **they want** to do. We mostly **serve trans populations** and we always have **cis people** coming **from the outside** and **dictating** what they want to **learn about trans** [people].**"**
>
> (SENIOR LEVEL MANAGEMENT)

> **"**I think the **biggest issue here is power**. If **you're not in the position of power** to **turn down research requests** because you have research **staff that need** to be **funded to continue their jobs,** you can make as many standards as you want. But **if you don't have the power** to follow those standards, and really back them up it's going to be an impossible situation to be in. **We [health centers]** are **automatically** at a **disadvantage** when **receiving requests for research** from **academic institutions,** they have a **lot of power legally, financially**, and the **researchers** themselves, **are not incentivized to think about the needs of others**.**"** (RESEARCH DIRECTOR)

STRENGTHENING CAPACITY WITHIN LGBTQ+ COMMUNITY HEALTH CENTERS TO CONDUCT "HOME-GROWN" RESEARCH PROJECTS

Health centers' ability to generate and lead research shifts the focus of LGBTQ+ health research away from documenting disparities and deficits to a health equity framework committed to improving the lives of and care provided to LGBTQ+ communities. As discussed above, collectively, health centers have a tremendous amount of shared knowledge, skills, and experience providing patient-centered, affirming, and trauma-informed care that is currently underutilized, under-researched, and underfunded. Strengthening capacity to conduct "homegrown" research projects will provide health centers with the opportunity to: 1) develop a collaborative intra- and inter-agency research infrastructure and model that shifts the power of research design, implementation, and dissemination to patients and health centers; 2) create a shared set of research standards for academic institutions and individual researchers wishing to conduct research at any or all health centers; 3) actively produce evidence to support and expand new and existing services; and 4) advocate for local, state, and federal policies to increase funding for health centers.

> 66 *[Bringing in]* **funding** *that will* **allow us** *[health centers] to* **do our own research**, *which will* **give us the ability** *to* **enhance** *our data capacity and build an* **infrastructure** *to* **integrate [research] with clinical care**. 99
>
> [SENIOR LEVEL MANAGEMENT]

> 66 *I feel like* **we do have some power** *and* **part of that power** *is that* **our clinic** *is the* **hub** *for a lot of* **referrals to specialists, for gender affirming surgeries**. *Lots of different* **patients** *of ours* **go to different institutions**. *And if we were to say,* **we're going to study your surgical outcomes** *comparatively,* **based on our patient population,** *I think that would really ruffle some feathers. Because most of the time,* **they [surgeons] do research in their own silos**. *And because we* **serve a large diverse population** *we have some* **power to leverage** *and say, we're gonna do this* **research project, you come to us,** *and* **you can be part** *of the* **study design** *if you want to*, *but we're* **gonna do this on our terms,** *because these are* **patients in our community**. **We** *have the* **ability** *to* **work more fluidly** *without the same barriers that a large academic institution has.* **We're not incentivized to remain in our silos**, *just like our communities,* **we rely on community support** *to do our work.* 99 [CLINICIAN]

PRIORITY RESEARCH AREAS

The Priority Research Areas section includes research topics and specific research questions identified by stakeholders during the Collaborative Convening as most important to them and the communities they serve. Within each area, we present examples of projects that could be undertaken at a specific LGBTQ+ community health center or could be envisioned as collaborative research across two or more health centers.

RESEARCH AREA 1

DEVELOPING AND TESTING STRATEGIES FOR ADDRESSING THE MENTAL HEALTH NEEDS OF LGBTQ+ PATIENTS AND POPULATIONS

Despite consistent research documenting higher rates of mental health-related issues among LGBTQ+ individuals, there is a lack of tested interventions and implementation strategies focused on alleviating mental health symptoms in this population. There are several barriers that impact access to and uptake of mental health services for LGBTQ+ patients, including long waiting lists, a shortage of LGBTQ+ affirming and competent mental health providers, lack of vetting process for provider referrals, and lack of effectiveness research on new or existing mental health strategies/interventions for LGBTQ+ communities. The following are potential research topic areas identified as most important to address current gaps in mental healthcare for LGBTQ+ communities.

RESEARCH TOPIC 1A — IDENTIFY, ADAPT, AND TEST PEER SUPPORT MENTAL HEALTH STRATEGIES AND INTERVENTIONS

Peer support refers to an approach for supporting mental health recovery that is led by and for individuals who have lived experience with mental health and have navigated the mental health system as a member of the LGBTQ+ community. An extensive body of literature outside of LGBTQ+ health has suggested that peer support interventions that train peers to provide support in addition to existing services are associated with reduced hospitalization and symptom severity, as well as increasing levels of hope, empowerment, and quality-of-life. But there have been few, if any studies examining the efficacy of such interventions with LGBTQ+ communities, despite existing research highlighting the importance of peer and community support among LGBTQ+ individuals.

RESEARCH TOPIC 1B   DEVELOP AND TEST AN LGBTQ+ SPECIFIC MENTAL HEALTH PROVIDER TRAINING PROGRAM

Currently, there is a lack of evidence on strategies to increase LGBTQ+ competence among mental health providers. Most existing LGBTQ+ competency training and practice guidelines are non-empirical and based on clinicians' individual experiences providing care to LGBTQ+ communities, and focus on teaching cultural competency rather than evidence-based strategies/interventions that improve the mental health of LGBTQ+ individuals. As discussed above, LGBTQ+ community health centers have decades of experience providing ethical, non-judgmental, and affirming care. Further investigation might identify and test specific strategies used within each health center that can be adapted and implemented in different settings to increase the LGBTQ+ competency of mental health providers.

RESEARCH TOPIC 1C   DEVELOP AND TEST AN INTEGRATED MENTAL HEALTH CARE MODEL THAT TRAINS MEDICAL PROVIDERS TO PROVIDE "STOP-GAP" CARE WHILE PATIENTS WAIT TO BE CONNECTED TO LONGER-TERM MENTAL HEALTH SERVICES

The number of people seeking mental health services at each health center outweighs the number of available providers both within and outside health centers. Of great concern to both patients and providers are the lack of resources or interim support available to patients as they wait to receive services. There is an urgent need to develop and test strategies that utilize health centers' existing integrated models of care to increase medical providers ability to assess for and support patients' mental health.

RESEARCH TOPIC 1D   COMPARE DIFFERENT MODELS OF MENTAL HEALTHCARE PROVISION CURRENTLY BEING IMPLEMENTED AT LGTBQ+ HEALTH CENTERS TO IDENTIFY WHICH WORK BETTER AND WHY (AND WITH WHICH POPULATIONS)

To adequately address the gaps in and barriers to mental healthcare, health centers need effectiveness research to determine which mental health treatment strategies and interventions work best for LGBTQ+ communities and why. In the absence of such evidence, health centers' ability to advocate and pay for additional staff and services is limited. Furthermore, increasing access to services is intrinsically linked to reimbursement and stable financial standing for community health centers. LGBTQ+ community health centers are uniquely positioned to lead this field of research by identifying and examining existing models of mental healthcare currently being implemented within each health center.

RESEARCH AREA 2

UNDERSTANDING THE IMPACT OF LGBTQ+ SPECIFIC AND COMPETENT HEALTHCARE ON THE WELLBEING OF PATIENTS AND POPULATIONS

Historically, LGBTQ+ specific and competent healthcare has been associated with two main areas: 1) HIV prevention, care, & treatment and 2) cultural competency trainings aimed at increasing provider awareness of and comfort with LGBTQ+ patients. Little attention has been paid to understanding the mechanisms and factors that define LGBTQ+ competent healthcare and have the greatest impact on the health and wellbeing of LGBTQ+ individuals. While several examples of clinical best practice guidelines for working with LGBTQ+ communities exist, there is currently a lack of evidence base to support the implementation and use of these strategies. In the absence of an evidence-based model of LGBTQ+ healthcare, LGBTQ+ individuals will continue to experience tremendous barriers to accessing healthcare. The following are potential research topic areas identified as most important to address current gaps in our understanding of the meaning and impact of affirming healthcare for LGBTQ+ communities.

RESEARCH TOPIC 2A   DEFINE AND OPERATIONALIZE LGBTQ+ COMPETENT CARE

Before research can better understand the health impacts of LGBTQ+ specific and competent care, it is first necessary to define and operationalize what LGBTQ+ specific and competent care means to patients, clinicians, and other healthcare stakeholders. To some, LGBTQ+ competence may mean having a poster or health information materials specific to or inclusive of LGBTQ+ communities posted in waiting or exam rooms. For others, it may require a provider who is knowledgeable about LGBTQ+ sexual health and comfortable having sexual health conversations that are sex positive. For still others, it might mean having a provider that identifies as LGBTQ+ and/or advocates for the LGBTQ+ community. Relatedly, the concept of LGBTQ+ competence often presents the LGBTQ+ community as homogenous, and emphasizes the health needs and experiences of cisgender White, gay men. LGBTQ+ specific and competent care must address the whole LGBTQ+ community by identifying and testing strategies that directly address racism, sexism, ableism, and ageism within healthcare settings, provider interactions, and the LGBTQ+ community overall.

RESEARCH TOPIC 2B   EXAMINE WHY AND HOW (I.E., THROUGH WHAT MECHANISMS) LGTBQ+ –SPECIFIC HEALTH CENTERS AND PROVIDERS IMPACT THE HEALTH AND WELLBEING OF LGBTQ+ PATIENTS

There is little to no research on why and how LGBTQ+-specific health centers and LGBTQ+-identified providers impact the health and wellbeing of their LGBTQ+ patients. Potential mechanisms include: increased knowledge, potential for identification, safety cues, a less judgmental approach, decreased stress, buffering social support, and a willingness on the part of patients to more fully engage in their healthcare. Given the extensive research on the stigma, discrimination, and structural barriers LGBTQ+

people must navigate in order to receive healthcare, it is necessary for research to investigate the ways in which LGBTQ+-specific health centers and providers impact the health and wellbeing of LGBTQ+ patients in order to identify strategies that can be adapted and implemented within other healthcare settings.

RESEARCH TOPIC 2C COMPARE DIFFERENT LGBTQ+ CARE MODELS, DESCRIBE THEIR COMPONENTS, AND EXAMINE THEIR ASSOCIATION WITH PATIENT OUTCOMES.

As leaders in the field of LGBTQ+ health, community health centers play an important role in being able to develop and disseminate an evidence base for LGBTQ+ health best practices by identifying and evaluating the real-world strategies and services they are already providing that positively impact patient outcomes. Current standards of care guidelines for providing care to LGBTQ+ patients lack a clear scientific evidence base, which directly impacts health center's ability to obtain funding to expand existing and create new services based on patient need. By providing evidence for real-world strategies and interventions that can be adapted and implemented in a variety of settings, health centers have the potential to impact and shift the ways in which LGBTQ+ healthcare is provided overall.

RESEARCH AREA 3

ENHANCING EVIDENCE-BASED
GENDER AFFIRMING CARE

Over the past two decades, awareness of and research on the healthcare needs and experiences of transgender, non-binary, and gender diverse individuals has grown exponentially. Relatedly, access to and use of gender-affirming medical interventions, such as hormones and/or surgery (e.g., top surgery, vaginoplasty, phalloplasty) have also increased due to federal, state, and local policies requiring healthcare payers to reimburse for this care. But despite the rapid increase in studies on transgender, non-binary, and gender diverse individuals, little evidence exists on the effectiveness of specific gender-affirming strategies and intervention; patient's goals, expectations, and motivations for medical/surgical intervention; and the impact of gender-affirming care on patients' overall health and wellbeing. The following are potential research topic areas identified as most important to address current gaps in research on gender-affirming care for transgender, non-binary, and gender diverse patients.

RESEARCH TOPIC 3A — DEFINE AND STANDARDIZE THE "COMPONENTS" OF GENDER AFFIRMING CARE

Past research on gender-affirming healthcare and practice has predominately included relatively homogenous, mostly White, well-educated patients from high socioeconomic backgrounds who either receive care in specific gender clinics (in Europe) or large academic medical centers (in the United States). The experiences of these participants are not widely applicable to the majority of patients and/or care provided by our collaborative partners. In the existing transgender health literature, definitions of gender-affirming care are often synonymous with medical treatment, such as hormones, surgery, mental healthcare practices, and/or gatekeeping measures (e.g., informed consent models, or hormone and surgery letters). However, gender-affirming care strategies and interventions identified by patients and implemented by clinicians demonstrate a collaborative patient-centered approach to care that focuses on the ways in which providers and other health center staff interact with and provide care for transgender, non-binary, and gender diverse patients. To develop evidence for gender-affirming care that is both widely inclusive and broadly applicable, there is a need to define and operationalize gender-affirming healthcare from the perspective of the patients and community health centers that provide care to them.

RESEARCH TOPIC 3B — DEVELOP A BETTER UNDERSTANDING OF PATIENT GOALS, EXPECTATIONS, AND MOTIVATIONS FOR MEDICAL AND/OR SURGICAL INTERVENTION, AND HOW TO MEASURE THEM IN A CLINICAL SETTING

Little research has focused on patient goals, expectations, and motivations for accessing gender-affirming hormones and/or surgical intervention. Clinical care guidelines set forth by the World Professional Association for Transgender Health (WPATH) do not take into account patient centered outcomes for initiating or sustaining gender affirming medical or surgical treatment, outside of a persistent sense of gender incongruence or gender dysphoria. In the US, access to gender-affirming treatment is further complicated by a patient's ability to pay for their care, whether via health insurance or out of pocket. This requires providers to determine who is most "deserving" based on level and duration of discomfort with sex assigned at birth and the ability to pay for treatment. This process undermines the patient-provider relationship by creating a power dynamic whereby patients must prove their deservingness rather than engage in a collaborative relationship around meeting their healthcare goals. The lack of research and clinical focus on patient-centered outcomes for gender-affirming medical and/or surgical intervention directly impacts the care that health centers provide. Research is needed to equip patients and providers with concrete information and strategies to help with both the identification of goals, expectations, and motivations for medical and/or surgical interventions and the process of deciding which treatment is most appropriate to meet patients' health goals.

RESEARCH TOPIC 3C DEVELOP AND TEST MEASURES OF QUALITY-OF-LIFE OUTCOMES ASSOCIATED WITH RECEIVING GENDER AFFIRMING CARE

Relatedly, current measures of quality-of-life outcomes associated with receiving gender-affirming care focus on assessing satisfaction with surgical outcomes (e.g., contour of chest) and relief of gender dysphoria symptoms (e.g., I am comfortable taking my shirt off), not on patient-centered quality-of-life outcomes. The emphasis on measuring patient satisfaction with medical treatment and whether treatment has relieved symptoms of gender dysphoria highlight the ways in which current standards of care are designed to validate providers' decisions to provide care, rather than understand whether the care patients are receiving is aligned with and meeting their health and quality-of-life goals. There is an urgent need for patient-centered quality-of-life outcomes research to assist patients and providers in determining the factors associated with receiving gender affirming care that impact the health and wellbeing of transgender, non-binary, and gender diverse patients.

RESEARCH TOPIC 3D IDENTIFY HEALTH CARE NEEDS AND BARRIERS FOR NON-BINARY INDIVIDUALS

There is a lack of clinical guidance and health research addressing the health care needs of non-binary individuals. The erasure of non-binary individuals directly impacts their health and wellbeing and the care that is provided to them. LGTBQ+ community health centers are at the forefront of providing gender-affirming care to non-binary individuals and as such, are uniquely positioned to conduct research designed to develop an evidence base that identifies and addresses the healthcare needs of non-binary individuals.

STRATEGIES AND RECOMMENDATIONS

To complement the set of Shared Commitments and High Priority Research Areas, stakeholders identified a series of specific strategies and recommendations that could be adopted by health centers and other key stakeholders to advance an equitable and community-driven research agenda. We view these as a starting point for both conversation and collaboration.

INDIVIDUAL LGBTQ+ COMMUNITY HEALTH CENTERS

RECOMMENDATIONS

- Ensure that community members are actively, authentically, and meaningfully involved in all aspects of the research process.

- Prioritize research that "creates opportunities" (see Commitment #5, above) for patients, staff, and the health center as a whole.

- Identify benefits to research participants other than monetary incentives.

- Actively review hiring and training practices to ensure that they are equitable and do not include unnecessary requirements for hiring. Value lived experiences over academic qualifications for relevant research jobs. Support staff in a way that sets them up for success.

IMMEDIATE NEXT STEPS

- Identify specific practice areas, programmatic strengths, or service gaps that are ripe for research inquiry.

- If applicable, review existing Community Advisory Boards or other advisory bodies to make sure they have a genuine voice. Ensure that there are structures in place to act on their recommendations for change.

- Identify aspects of research implementation or strategies for research engagement within your health center that are particularly successful and could be shared with other health centers.

- Create a Working Group to discuss the health center's priorities and needs for research engagement, and greater participation in an integrated LGBTQ+ PCOR/CER agenda.

CONSORTIUM OF LGBTQ+ HEALTH CENTERS

RECOMMENDATIONS

- Identify and enact shared collective power to demand/advocate for, develop, conduct and disseminate meaningful patient-centered research.

- Create a collective partnership body to share resources and support.

- Develop, disseminate, and adhere to a set of shared standards for ethical research collaboration with outside partners.

- Build shared resources to increase data capacity, including the creation of shared data collection systems and tools.

- Develop a more formalized collaborative research infrastructure that can support and sustain the integration of research into clinical care, including 1) engaging patients and health center staff in all stages of the research process, 2) developing standardized research integration protocols by department, and 3) designing new or enhancing existing data systems.

- Develop and adhere to shared standards for research dissemination at every stage of the research process, from conceptualization to participant recruitment to data analysis.

IMMEDIATE NEXT STEPS

- Initiate a cross-health center patient network to bring patients interested in LGBTQ+ research together.

- Identify opportunities and resources for cross-center collaboration on shared research topics and interests.

- Produce an "elements of style" guide to de-stigmatize language used in recruitment materials, study protocols, consent forms, surveys, and interviews/focus group.

- Circulate any health-center specific guidelines about ethical research collaboration standards and convene a cross health center working group to draft a set of shared standards.

- Identify specific quality/practice improvement measures that could be developed into research projects or data collection.

ACADEMIC AND OTHER RESEARCH PARTNERS

RECOMMENDATIONS

- Commit to ethical practice standards for community-based research collaboration, including equitable budgeting, partnership in the development of both research agenda and methods, integration of research activities into the ongoing work of the clinical site, ensuring community-focused dissemination.

- Plan for sustainability in any collaborative research project, making sure that any new programs or services developed as part of the research can be maintained to benefit health center patients at the conclusion of the study.

- Create Co-Lead or Co-PI research investigator positions to share roles and expertise between community representatives and researchers. Under this strategy, it is critical that Co-Leads share genuine power and responsibility for the work, and that the community representatives' opinions, contributions, and expertise are valued.

- Actively build in research training and professional development activities for health center staff into the activities of the research project. This might include providing project- or topic-specific in-services for staff, providing opportunities for attending scientific conferences or other trainings, and engaging health center staff in regular research team meetings and discussions.

- Make sure that community-based partners are provided with opportunities for authorship (both on scientific publications and public reports), and the ability to present their own research findings.

PUBLIC AND PRIVATE FUNDERS

RECOMMENDATIONS

- Require researchers to adhere to ethical practice standards with community-based partners in order to receive funding.

- Promote and disseminate these standards, including providing funding to community-based health centers to train researchers on their application in different settings.

- Provide support for research capacity-building activities within community health centers that strengthen their ability to conduct and lead home-grown research projects.

- Provide support for collaborative models that enable community health centers to learn from each other and build collective capacity and expertise.

- Create funding opportunities that are designed explicitly to be led by CHCs who may be asked to find an academic partner, as opposed to the other way around.

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