Guidelines for Conducting Health Research **WITH** LGBTQ+ Individuals and Communities in New Mexico

Although community-based participatory research (CBPR) is most often associated with community and academic research partnerships that aim to study and ameliorate health disparities experienced by racial and ethnic minority populations, its principles are essential for working with other groups rendered vulnerable due to social marginalization as well. In 2014, we helped initiate a CBPR process to address health inequities faced by lesbian, gay, bisexual, transgender, and queer (LGBTQ+[1]) people in urban and rural areas of New Mexico. Understanding that researchers and clinicians, as experts in their fields, occupy a position of power relative to research participants and patients, we sought to deepen our partnership with others in the LGBTQ+ community by collaboratively developing and submitting an application for a Patient-Centered Outcomes Research Institute Pipeline to Proposal Award. The purpose of this award was to connect extant organizations invested in LGBTQ+ health within New Mexico to pool expertise and resources to strengthen the ability of partners to undertake health services and intervention research to reduce and prevent LGBTQ+ health disparities across the state.

Once funded, we formalized this burgeoning community-academic partnership through the establishment of the New Mexico LGBTQ+ Health Collaborative (or "Collaborative" for short), a 15-person advisory board of healthcare advocates, patients, providers, and health services researchers from across the state (Figure 1). The Collaborative's agreed upon goal is to enhance knowledge of the experiences of gender and sexual minorities within health services in ethnically- and geographically-diverse communities in order to both plan and implement research that is necessary to improve quality of care for LGBTQ+ people.

Figure 1 – Organizations represented in the New Mexico LGBTQ+ Health Collaborative

With funding from the Community Engagement Core of the New Mexico Center for the Advancement of Research, Engagement and Science on Health Disparities (CEC NM CARES HD), the Collaborative also authored *Guidelines for Conducting Health Research with LGBTQ+ Individuals and Communities in New Mexico* as an online resource to inspire bi-directional communication and learning for health services researchers, research-involved healthcare staff and providers, community health advocates, policy specialists, state officials and others interested in working with non-heterosexual and gender non-conforming individuals to promote community-partnered research, innovative interventions, and better healthcare for LGBTQ+ persons and communities (Guidelines are available at http://hsc.unm.edu/programs/nmcareshd/cec.shtml#tabs1-toolkits).

COMMUNITY-BASED PARTICIPATORY RESEARCH

The Collaborative has adopted CBPR methodologies as a primary strategy for developing and carrying out a research agenda that is responsive to LGBTQ+ needs and concerns. Community-based participatory research has been defined as a "collaborative approach that involves communities and researchers equitably in all stages of the research process" with the goal of combining knowledge with action to pursue social change (Kellogg Foundation, 2001). The partners in the Collaborative have repeatedly emphasized the importance of ensuring that research must be done *with*, rather than in or on their communities. In this spirit, the Collaborative has agreed to adhere to the core principles of CBPR as outlined by Minkler and Wallerstein (2010):

1. Recognize community as a unit of identity;
2. Build on strengths and resources in the community;
3. Involve an empowering and power-sharing process that attends to social inequalities;
4. Promote co-learning between participants, researchers, and practitioners;
5. Integrate and achieve a balance between research and action for the benefit of all partners;
6. Emphasize public health problems of local relevance and also ecological perspectives that recognize and attend to the multiple determinants of health and disease;
7. Involve systems development through a cyclical and iterative process;
8. Disseminate findings and knowledge gained to all partners and involve all partners in the dissemination process; and
9. Require a long-term process and commitment to sustainability.

In sum, CBPR creates a framework for bi-directional information sharing, education and thinking to inspire a truly partnered and collaborative research process. The following pages offer a brief summary of the research efforts that led us to create to these guidelines, including our "Motivation and Approach," the developed "Guidelines for Conducting Health Research with LGBTQ+ Individuals and Communities," and a few "Concluding Thoughts."

MOVITIVATION AND APPROACH

Health Disparities in the LGBTQ+ Community – Compared to their heterosexual, cisgender[2] counterparts, LGBTQ+ people are more likely to suffer from mental health and substance abuse problems, eating and body-related disorders, sexually transmitted diseases, poor diet and insufficient exercise, and are less likely to benefit from standard preventative services (e.g., cancer screens) and treatment for comorbid conditions (e.g., cardiovascular disease and diabetes; Hembree et al., 2009; McNair and Hegarty, 2010). Guidelines promoting LGBTQ+ cultural competence across domains of service delivery, clinic environment, and institutional structure may enhance health services research generally and primary care research in particular (Ard and Makadon 2016). Yet recent reviews of existing guidelines highlight the insufficient research base and inclusion of LGBTQ+ patient and provider perspectives in both their design and implementation (McNair and Hegarty, 2010).

LGBTQ+ Distrust of Medicine and Health Research – Although health disparities warrant closer research, LGBTQ+ people, like members of many ethnic/racial/cultural minority populations, may experience discrimination at individual, community, and institutional levels to such extents that they distrust medical organizations and research enterprises. Such distrust stems from cultural stigma concerning sex and gender atypicality in medical systems (Dregar et al., 1998). Over the last fifty years, for example, LGBTQ+ people have experienced denial of treatment for Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS; Wright et al., 2013); invasive and damaging genital surgeries and hormone treatments to normalize sex and gender in babies with ambiguous genitalia (Kessler et al., 1998); and ongoing 'reparative therapies' promoted by healthcare providers who believe persons who are same-sex attracted can "become comfortable and fulfillingly heterosexual with psychotherapeutic treatment" (Berger, 1994). Such commonplace experiences

pathologize sexual and gender difference and alienate LGBTQ+ patients. These experiences are also shaped by institutional discrimination embedded in laws, policies, social norms, and care-giving practices. Health research, especially in terms of how it represents LGBTQ+ people, can reinforce institutional discrimination by promoting both erroneous assumptions about normative sexual and gendered behavior and negative societal stereotypes.

Developing LGBTQ+ Guidelines for Health Research – These guidelines were created to promote bi-directional learning, effective communication, and trust between members of the LGBTQ+ community, health advocates, LGBTQ+ community organizations, healthcare providers, and health services researchers to engage collectively in projects that can dispel stereotypes, inspire health equity and catalyze social change. The Collaborative began by deciding upon a qualitative interview approach to gather data for the guidelines. The Collaborative then developed a series of semi-structured interview questions to guide one-on-one discussions with Collaborative-identified LGBTQ+ individuals from New Mexico who were tapped to discuss the relational and participatory needs of sexual and gender minority research participants from rural and urban areas of the state.

Between June and October 2015, a contracted ethnographer interviewed 20 LGBTQ+ New Mexicans. Participants ranged in age from late twenties to sixties and occupied a range of gender, sexual, and ethnic/racial/cultural identities. Most participants resided in Albuquerque at the time of the interview, but many were originally from rural areas and tribal communities. Many had explicit interests in health research, as members of the healthcare provider community, with specialties ranging from nursing to mental healthcare to surgery. Other participants were students, advocates, activists, and self-described "regular" members of an LGBTQ+ community. Our broad participant base allowed us to highlight the ways in which LGBTQ+ New Mexicans from diverse social positions think about and experience healthcare, research and health policy.

Participants reviewed an Informed Consent script approved by the University of New Mexico Institutional Review Board, and provided verbal consent prior to each interview. Interviews included seven open-ended questions concerning health policy, health care seeking and health research experiences to elicit their ideas for research to improve LGBTQ+ health disparities. Participants also voluntarily offered personal vignettes and described their perceptions of common misunderstandings between LGBTQ+ research participants and researchers and/or patients and clinician researchers. Conversations averaged 30 minutes to an hour in length, though some participants contributed up to two hours of their time. Participants who could not meet in person completed the interviews via telephone. Participants were not compensated financially for their contribution.

Interview participants and members of the Collaborative cited examples of research and healthcare related encounters that were "homophobic," "transphobic," "biased," "discriminatory," and "insensitive." Many suggested that such encounters could be avoided if researchers and clinicians had greater exposure to LGBTQ+ communities, more explicit and accurate information about LGBTQ+ healthcare and research needs, and more effective training in inclusive communication practices. As many participants identified as Native American or Hispanic, issues of research misconduct were brought to the fore, as were calls to use CBPR when conducting research with any marginalized community. The following are community-driven guidelines to be used when convening, educating, and training members of a research team to undertake fully partnered health research with people who are LGBTQ+ and their communities.

GUIDELINE 1

Understand fluidity within and diversity of the LGBTQ+ community.
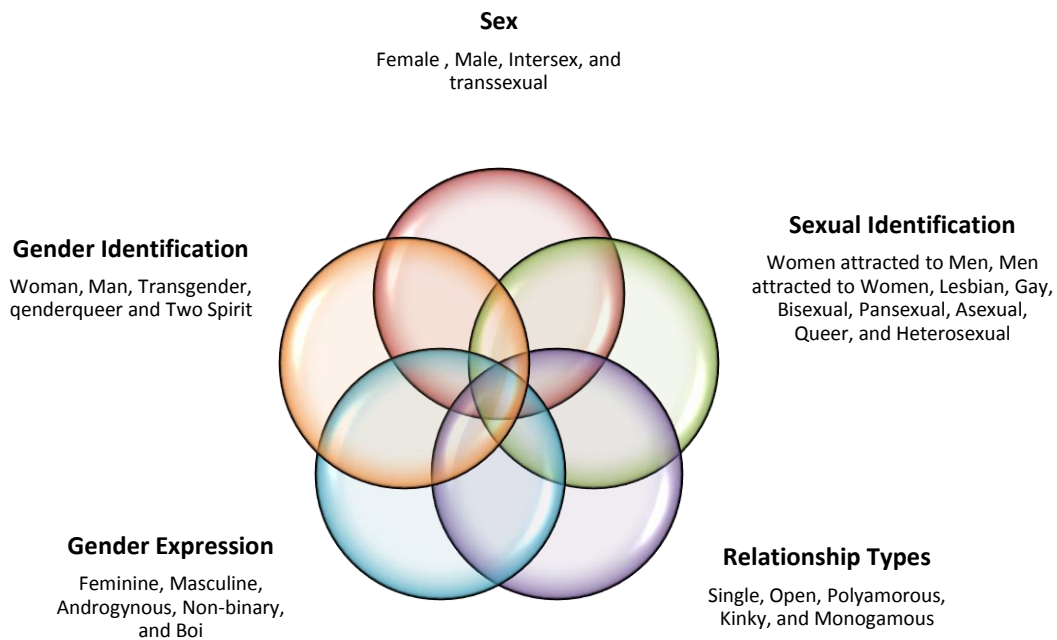
At the start of any research initiative involving sexual and gender minorities, the partners must recognize the tremendous variety of individuals we invoke when utilizing the umbrella term "LGBTQ+." An acronym created in the 1990s in an effort to be more inclusive of diverse groups, LGBTQ+ actually describes a multiplicity of people with distinct experiences and identities of sex, gender, and sexual orientation. LGBTQ+ individuals are positioned uniquely along broad spectrums. Some LGBTQ+ individuals may experience their genders and sexualities as stable, identifying with certain categories throughout their lives, while others will experience such categories with fluidity, occupying several different categories within these spectrums during their lifetime.

LGBTQ+ is often mistakenly used interchangeably with "gay and lesbian." Participants emphasized that this practice must be changed. An LGBTQ+ provider stated:

> "I worry about non-binary folks [i.e. not adhering to social standards of masculinity and femininity]. These folks get left behind more than anyone else; a lot times butch lesbians [and those with] non-normative gender presentations get the weirdest, most uncomfortable reactions from researchers and healthcare staff/providers."

"Sexual diversity means more than gay or straight," added one participant. "Poly and kinky people can sometimes still feel stigmatized or sensationalized and not free to speak about their sexual lives and relationships." Another participant addressed the "B" in LGBTQ+, clarifying that "bisexual people have traditionally been largely ignored and often feel marginalized and judged within both LGBTQ and heterosexual communities and in research." As these comments suggest, research initiatives in LGBTQ+ communities can be challenging due to the broad spectrum of its membership, as well as the unique health and healthcare needs of people linked by a common acronym and marginalized position relative to dominant gender and sexual norms. The complexity of these relations and potential identities is explored in Figure 1 below.

Figure 2 – Venn Diagram of Sex, Gender, Sexuality, and Relating

Sex
Female , Male, Intersex, and transsexual

Gender Identification
Woman, Man, Transgender, qenderqueer and Two Spirit

Sexual Identification
Women attracted to Men, Men attracted to Women, Lesbian, Gay, Bisexual, Pansexual, Asexual, Queer, and Heterosexual

Gender Expression
Feminine, Masculine, Androgynous, Non-binary, and Boi

Relationship Types
Single, Open, Polyamorous, Kinky, and Monogamous

GUIDELINE 2

Know the relationship between communities and your research institution prior to outreach and engagement as power dynamics are often longstanding between institutions and communities.

When forming research partnerships, understanding historical dynamics that drive relationships between institutions and communities, as well as those underlying relationships between partners in research initiatives, is key to creating transparent collaborations and building the trust necessary for joint efforts and long-term sustainment. For work with LGBTQ+ communities, this is a particularly salient point, as the "humanity" of LGBTQ+ people has been historically defined in opposition to sexual and gender roles considered "normal" by a dominant Western standard. Medicalization of those differences pathologizes non-heterosexual and gender non-conforming people and is institutionalized via reference sources such as the Diagnostic and Statistical Manual of Mental Disorders, research, routine practices (e.g., surgical "correction" of the genitals), and conversion therapy. Medical pathologization of LGBTQ+ people has contributed to gender and sexuality-based social trauma and violence, and medical researchers have directly and indirectly provided 'evidence' and 'expertise' to 'justify' instances of such pathologization deemed unacceptable by today's standards.

Collaborative members and participants were adamant that health and healthcare researchers be aware of such historical engagement between LGBTQ+ individuals and academic and medical institutions. One participant said, "You need to know the relationship between the community and the university: when working in Native communities for example, researchers need to know the histories of tribes with the university. This is just more complex when the individuals are LGBTQ." Another emphasized, "There has to be an authenticity and transparency to the research approach used in vulnerable communities. LGBTQ+ individuals and other minority communities have been so used and harmed that we sometimes feel like objects under a microscope."

GUIDELINE 3

Understand historical trauma as it relates to the LGBTQ+ community AND how this trauma interacts with other axes of oppression and individual trauma.

Similarly, the concept of historical trauma is useful for members of research partnerships to aid in their understandings of how past societal violence can be connected to personal trauma and contemporary health disparities. Historical trauma theories posit that past violence and assaults (e.g. the colonization of the Americas and slavery) against certain populations have undermined both physiological and psychological health among many of their members today. These theories also suggest that historical oppression has led to a "weak mainstream political will to ameliorate [these disparities]" (Chavez et al., 2008). Although theories of historical trauma have been developed particularly in reference to processes such as the colonization of indigenous peoples and internment and genocide of Jewish peoples, persons contributing to these guidelines understand clearly how concepts of historical trauma related specifically to past violence against and attempts to oppress LGBTQ+ populations. Although LGBTQ+ communities and their allies may be well aware of endured traumas that continue to contribute to or result from health disparities, one participant told us, "the roots are not widely understood by healthcare professionals and health researchers, and this lack of understanding must be rectified in order to develop positive academic/medical/community relationships and create meaningful and sustainable research inspired changes in healthcare delivery."

Others suggested that some LGBTQ+ community members have internalized trauma to such a degree that they have come to "accept and expect" anti-LGBTQ+ stigma and discrimination, as constant reinforcement of traumatic experiences can lead to internalized experiences of "minority stress" for LGBTQ+ individuals who may be excluded from benefits and protections offered to heterosexual and cisgender people (Meyer 2010). This minority stress—the cumulative and ongoing effects of stigma, discrimination, and other daily microaggressions—shaped healthcare seeking among the majority of the people we interviewed, many of whom disclosed situations in which internalized trauma led to the continual postponement of healthcare or avoidance of services altogether. "I just stopped seeking routine healthcare for a long time because I didn't want to deal with the trauma it brought up," said one participant.

A researcher and healthcare provider shared an experience to illuminate how one of her patient's feelings of not being 'heard' lead to miscommunication and stress during a therapeutic encounter. She explained that during a first-time gynecological exam, her patient, who openly identified as a lesbian, shut down when asked about contraception. Her patient assumed that the doctor was equating contraception with pregnancy prevention, and purposefully ignoring her assertion that she was lesbian. The situation was diffused once they had a more lengthy conversation about the benefits of contraception including hormone regulation, treatment of menstruation-related disorders, improving acne, and other benefits beyond the scope of pregnancy prevention. During our interview, the practitioner reflected, "I think our misunderstanding was that I didn't explain my philosophies on gender identities, sexual orientation, and behavior. I need to be clear about my role as a health practitioner [and explain that] it's not the same as my outlook on gender and sexuality." The same lesson, she contended, also applied to research endeavors involving LGBTQ+ people.

GUIDELINE 4

Form long-term relationships with leaders, advocates and community members in an advisory capacity prior to designing research projects to ensure that research questions respond to community-driven concerns, and research design and materials are culturally-sensitive and specific.

Participants suggested that researchers with an interest in undertaking LGBTQ+ studies partner with an array of (non-academic) community allies and leaders at every stage of the research process to disrupt engrained power differentials between "researcher and researched" in a visible and practical manner. Participants emphasized the need to find community allies with "solid" records in the community. They also indicated that research partners should consider the ability of potential allies to mediate conflict or maintain positive relations in his/her own community as a means of predicting their ability to work in a team, negotiate intra-team differences, and build toward common research goals.

While one-on-one communications are important with LGBTQ+ research participants, community perceptions of how research is conducted and communicated are equally important. Allies or liaisons in the communities within which research projects are taking root can be extremely helpful when identifying key partners, explaining community histories, and shaping relevant research. A participant explained, "Liaisons are very important – find someone within the group, because they're all different from one another. Get someone to work along with the researcher. It will facilitate more honest disclosures and conversations." According to participants, the best liaisons were people familiar, trusted, and considered dependable by local organizations that advocated for LGBTQ+ people, and were also knowledgeable and skilled in recognizing and negotiating varying stakeholder interests related to research, in order to ensure effective communications about research activities and their outcomes.

Participants called for research partnerships that were of a long-term rather than transient nature, calling on researchers in particular that want to be engaged with LGBTQ+ for the long haul. One participant underscored this point,

> "We would love to work with researchers on [LGBTQ+] issues, as long as the researcher will stick around, and give something back to the community. Some have come in to research the Trans community. They gather information and just disappear. How does that help our community? It just reinforces stigma, our sense of outsiderness, and negative feelings about research and privilege on the part of academics."

Participants suggested that regular communications of research findings to community groups, as well as clear and persistent communications about research timelines and expectations are fundamental methods for avoiding misperceptions regarding researcher distancing, avoidance or project completion.

GUIDELINE 5

Create research partnerships by conducting fully engaged community-based research with LGBTQ + community members.

For research to be successful in LGBTQ+ communities, outreach, recruitment, and data collection should include individuals along the sexual and gender minority continuum in as many phases of the research process as possible in order to have input from team members with varying intersecting identities and community memberships (Figure 3). Partnering with community leaders, advocates and LGBTQ+ persons allows researchers to understand the ways in which gender and sexuality intersect with race, economic position, regional and rural/urban locales, age, dis/ability, and other axes of difference within local contexts. For example, for some, residency in rural areas, economic disadvantage, and even tribal affiliation, can intersect to create isolation and compound disparities in health and access to community. Others, however, may find rural residency preferable, experiencing resilience through kinship networks and support from the local culture. Participants also made it clear that for research about LGBTQ+ people to make an impact on reducing longstanding disparities, it was important for both academic researchers and all other community-based research partners to integrate concerns for these types of intersections in standard research practices, starting with design of research questions to selection of methods to the act of gathering data to how the resulting data will be analyzed and reported.

Figure 3 – Axes of Intersectionality
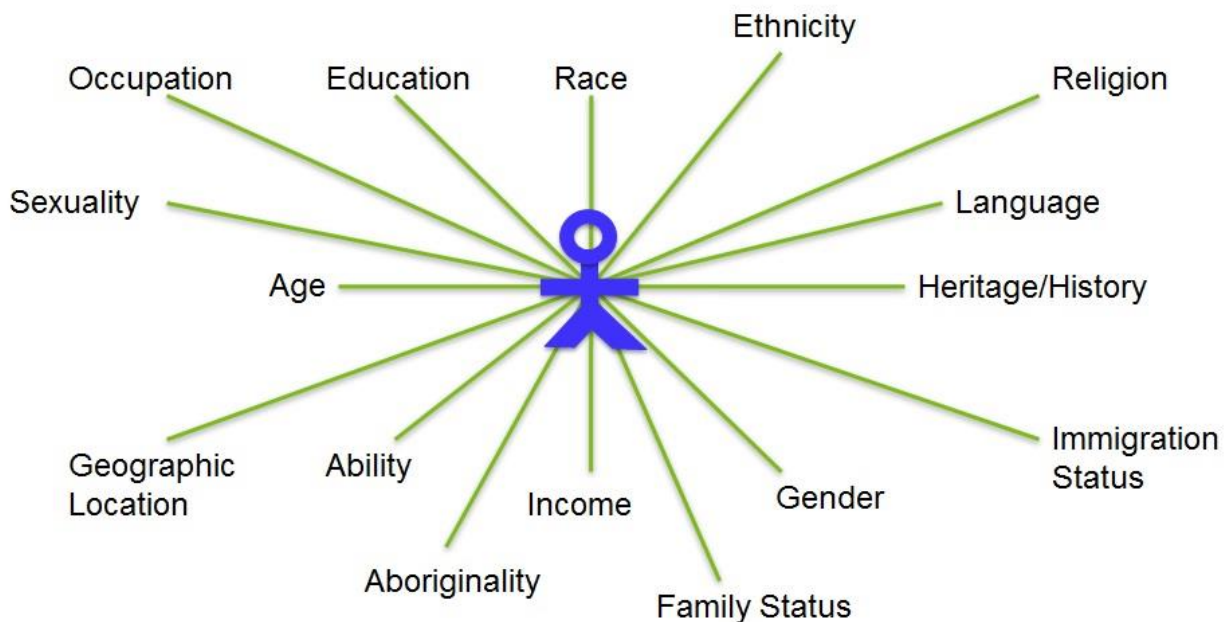
(From Claire's Passion Blog – Retrieved on August 10, 2016)

GUIDELINE 6

Incorporate inclusive, community-preferred language in all consent documents and research instruments including open-ended demographic forms. When possible, let the participants state their preferred name and pronoun, their label, if any, their behavior, what they call their relationships, and why.

For non-heterosexual and gender non-conforming people, sexualized and gendered labels and categories are not merely descriptive. They are deeply personal, social and political identities. Identity labels and pronouns are hotly debated within LGBTQ+ communities as well as in non-queer contexts. As one participant explained, "Researchers should probably be aware of the internal politics of the LGBT community and the internal tensions over gender, over lesbian and gay issues, over trans issues... In activist circles we pay great attention to language and pronouns." Another told us, "There are questions that I'm comfortable with because of my whiteness, status as cisgender, education level, etc., that other people who are located further away from the dominant power structure might not be. The way we phrase things—the language we use—we have to be more sensitive to the needs of those with whom we are working."

Furthermore, persons sharing the same gender identity, sexual attraction, and behavior may identify differently from each other, and individuals who vary in gender identity, sexual attraction, and behavior may use the same label. For example, a cisgender women who sleeps with other cisgender women may identify as a lesbian, while another may identify as queer. A transgender man who is in a relationship with a cisgender man may identify as gay, as do many cisgender men in relationships together. A transgender woman in a relationship with a cisgender man may also identify as gay. The key is to ask persons recruited for research to identify themselves, and to approach each situation in a respectful manner. Examples of acceptable pronouns may include they, them, their, themselves, ze, zhe, zir, hir, as well as her, him, hers, his, herself, and himself (Figure 4).

> **Figure 4 - Examples of pronouns**
>
> They, them, their, themself
> Ze, Zhe, zir, hir
> "just me," or "my name"
> her, him, hers, his, herself, himself

While some may experience mislabeling as disrespectful or impolite, gender non-conforming contributors to these guidelines cited mislabeling or misuse of pronouns as major sources of misunderstanding, miscommunication, and harm in interactions with researchers and healthcare providers. One participant used an example of seeking gynecological care to illustrate why it is important to be aware of pronoun use. Already uncomfortable as a Trans man and confronting past body and identity-related trauma, he had put off seeking such care until the situation became life threatening. At the appointment where he learned that he would need an emergency hysterectomy, nurses repeatedly referred to him as "Miss." He said, "It added more trauma to the experience." Participants unanimously agreed that a good rule of thumb is for researchers and health providers to talk to research partners, ask what they call themselves, and avoid assuming identifications based upon how they present themselves as a method to avoid miscommunication or perpetuating patterns of trauma for transgender research participants. These conversations should be noted so that all future researchers and healthcare staff/practitioners are aware of the individual's preference.

CONCLUDING THOUGHTS

For the Collaborative, CBPR in considered to be an effective means to cultivate positive, respectful, and long-term relationships with members of the LGBTQ+ community. The guidelines, in particular, represent an essential first step to developing the trust, transparency, and bi-directional participation necessary to ensure successful research partnerships. As we deepen our research partnerships overtime, the Collaborative intends to revisit and revise the guidelines as necessary, incorporating lessons learned as well as new thoughts and considerations about how we can all optimally work together to enhance the health and wellbeing of LGBTQ+ through research. The CBPR approach is also favored for providing a space for people with multiple intersecting identities to work together on research projects with potential to create sustainable and equitable healthcare experiences for LGBTQ+ people while simultaneously advancing the science of health disparities.

ENDNOTES

[1]LGBTQ+ acknowledges that people who identify with or are grouped within this category may identify in a variety ways beyond the designations of "lesbian," "gay," "bisexual," "transgender" and/or "queer."

[2]Cisgender refers to individuals whose sex assigned at birth aligns with their gender identity.

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