The Pennsylvania HIV Planning Group (HPG) welcomes participation from individual and organizational stakeholders. This participation is essential to furthering Pennsylvania's statewide HIV planning process. As HPG meetings are open to the public, participation likewise helps the public better understand how Pennsylvania is responding to the HIV pandemic.

To maximize this public benefit, and to help ensure HPG meetings are safe, welcoming spaces, this guide sets forth key principles to support our work.

Social Justice Grounding

For starters, we recognize that people living with HIV, as well as those living in communities with higher HIV incidence rates, already face stigmatization and social devaluation. HPG meetings should help liberate attendees from their marginalizing experiences, not add to them. This includes subtle forms of marginalization that may arise as unintended consequences of our words or actions.

Still, we are equally aware that developing our social justice capacities is a lifelong journey. As there is always much to learn, it is better to think of ourselves as beginners rather than experts. In this spirit, just as we challenge ourselves to grow, so we must give each other room to grow. To extend grace, to extend it generously, is an essential part of our ethical practice.

With these points in mind, we offer the following principles and advice.

Part 1: Help with choosing words wisely

Language both reflects reality and constructs it. In this vein, just as our words and phrases can flow from society's long-standing social inequalities, they can also reinforce them. We therefore ask all HPG participants to think critically about their words and phrases, paying special attention to those that are habitually used to describe or categorize others. What to one person may appear to be a harmless word or phrase may be experienced as hurtful by someone else.

Here are some tips to consider:

1) **Retire words that center privileged identities:** For instance, using male pronouns to refer to persons of unknown gender, along with other broad, male-identifying words such as “mankind” and “manpower,” put men and masculinity at the center of the social sphere. They also reflect the internalization of a sexist worldview in which women and femininity exist at the margins. By the same token, particular words and phrases may center whiteness, heterosexual orientation, dominant cultural affiliations, and other identities that have traditionally been privileged in our society.

2) **Use “person-first” language:** When referring to identities, adjectives are generally better than nouns. Adjectives, used respectfully, can help describe a shared base of experience or a shared sense of identity. The noun forms of adjectives, on the other hand, can objectify people, reducing them to the confines of our perception. For example, referring to someone descriptively as “gay” or “same-gender loving” can be an appropriate acknowledgement of an important part of that individual’s identity, whereas referring to “the gays” reduces multifaceted people to a single-sided perception of them. Even when one is intentionally commenting on another’s shortcoming, such as when someone makes a patently offensive comment, it is better to describe the behavior with an adjective, such as “racist,” than to classify that person as “a racist.”

3) **Echo others’ identity markers:** People who have been marginalized will often mention specific identity markers that are important to them. For example, a person who identifies as transgender may ask whether one’s organization tailors services to the unique needs of the transgender community. Responding with something like “we try to serve everybody,” tacitly signals discomfort with transgender people because the word “transgender” is avoided. Conversely, if one honestly answers, “I think we need to do a better job serving transgender people and a starting point is for us to learn more about the needs of transgender people” then that response not only models honesty and humility, it affirms an important part of that person’s identity.

4) **When in doubt, ask:** Sometimes the most liberating thing we can do is to humbly ask others for terminological assistance. Do they refer to themselves as Native Americans, Indians, or either? How do they feel about Hispanic versus Latino/a versus Latinx? Are the words Black and African-American interchangeable for them? Does it work to say "LGBT plus," or are other letters of the alphabet needed for others to feel included?

5) **Leverage others' experiences:** Because we fear offending others, sometimes we avoid discussing identity issues. But when we ask others to share their experiences, and to name words or phrases they have found hurtful, it signals our willingness to be vulnerable, and our willingness to listen. For people who have been marginalized, being heard, and feeling heard, can be very healing. Asking them to share their lived experiences also stimulates their participation.

6) **Offer apologies generously, defenses sparingly**: Because none of us perfectly practice our highest aspirations, misstatements happen. Whether we ourselves recognize our wrong turns, or they are pointed out for us, others are best served when we state our commitments to improve. Defensive reactions can deepen another person's sense of alienation, and rather than stimulate dialogue, shut it down. Finally, consistent with the preceding discussion about grace, it is quite acceptable to accompany a genuine apology with a genuine request for grace. Doing so models the idea that everyone in the room is on a journey and that we can walk in nonjudgmental companionship with each other as we pursue our respective developmental goals.

7) **Be mindful of jargon:** Jargon is the word set unique to a trade, profession, or group of people. Jargon is learned over time and not naturally intuitive to the public. Unfortunately, this means it often excludes those who are unfamiliar with it, and this exclusion can be experienced as marginalization. When possible, it is best to eliminate jargon, or to pause and define words and acronyms that are not readily understood by the public.

Part 2: Additional considerations for the HPG audience

Please be aware that our audience is quite diverse, and while this is not an exhaustive list, our audience typically includes: A) individuals who are living with HIV and those who are not, B) individuals who are new to HIV-related issues and those who have been exposed to them for decades, and C) individuals who do not identify with traditional heteronormative labels and those who do. Accordingly, here are pointers especially geared to our audience:

1) **Know that people living with HIV use a variety of self-referential terms:** In the early 1980s, after the discovery of the Human Immunodeficiency Virus, followed by the development of tests to detect the presence of HIV antibodies, an individual with a reactive test result was commonly referred to as "HIV+." In some circles, the word "poz" came into vogue, especially among people who constructively embraced living with HIV. While these terms are still in use, some people now consider them to be stigmatizing. We therefore offer two recommendations:

   A) **Again, use person-first language:** In general, use the terms "person living with HIV" and "people living with HIV," either of which may be abbreviated as PLWH or PLHIV once the basis of the abbreviation has been established.

   B) **Respect how people living with HIV choose to self-identify:** Respect those who use the terms "HIV+" or "poz" to refer to themselves, or to refer to people they consider to be peers. For some, these terms are not stigmatizing, they are badges of honor.

2) **Use "acquired" and "transmitted" instead of "infected:"** Although HIV is correctly classified as an infectious virus, there has been a shift in recent years away from describing people as "HIV infected," since this implies that those living with HIV are infectious. In fact, the virus in many people living with HIV is now so well-controlled that they cannot transmit it to others. Additionally, continually referring to someone as "infected" emphasizes their clinical status, rather than their lived experience. Thus it is now preferrable to refer to people as having "acquired HIV" instead of being

"HIV infected," and to refer to the virus as having been "acquired" or "transmitted" instead of an individual having been "infected" with it.

3) **Use "incidence" instead of "risk:"** Epidemiological data shows that HIV is not uniformly present across demographic groups. Therefore, it is sometimes necessary to discuss demographic distinctions. When referring to demographic groups in which HIV is more prevalent, refer to these as "higher incidence" groups rather than "at-risk" groups. HIV incidence rates are expressions of fact, whereas risk assessments are subjective, and when applied to a class of people, subtly disparaging. Similarly, no individual should ever be labeled "at-risk."

4) **Use updated terms to describe the virus and the disease:** In the early years of the pandemic, HIV was considered a terminal disease. It was generally assumed that HIV would destroy an individual's immune system and that this destructive process would inevitably lead to Acquired Immune Deficiency Syndrome (AIDS). It was believed that an individual who met the diagnostic criteria of AIDS would typically die of AIDS-related causes within 24 months. Unfortunately, AIDS phobia resulted in stigmatizing language that still circulates today. Some terms, such as "AIDS victim," or "dying of AIDS," are now clearly out of bounds and must be scrubbed from our vocabulary. Other terms more subtly ascribe negative connotations. For example, it is still common to find references to "HIV/AIDS," which not only conflates the virus with a particular diagnosis, it extends the perception that people exposed to HIV are doomed to what was once commonly called "full-blown AIDS." We recommend using "HIV" only when referring to the virus, and "HIV disease" only when referring to the medical condition that stems from acquiring the virus. It is best to limit the term "AIDS" to the limited circumstances in which it is necessary to differentiate that diagnosis from the broader HIV disease spectrum.

5) **Be attentive to how PLWH experience surviving and/or thriving:** Because it was once assumed that HIV exposure inevitably led to death, those who lived for many years after receiving an HIV-related diagnosis began to be called "long-term survivors." In the early 1990s, long-term survivorship was generally considered to be ten or more years. As treatment of HIV disease noticeably improved starting in the mid-1990s, however, the number of

long-term survivors increased, as did the life expectancy of those living with HIV. While the phrase “long-term survivor” is still an important part of the HIV-related vocabulary, there is now less emphasis on the exact number of years one has lived with HIV; there is instead more emphasis on the experiences accumulated along one’s survivorship journey. For instance, people who were diagnosed with HIV disease before the wide adoption of combination antiretroviral therapy are often considered to have a base of experience that is distinct from those who were diagnosed in later decades. Moreover, those who have lived with HIV for long periods, particularly those who have regained health after prior struggles, often intentionally shift their self-description from “surviving” HIV to “thriving with HIV.” Still, one must exercise caution; many long-term survivors face significant co-morbidities, some of which may relate to the very medications that helped them live for decades. Some long-term survivors consider themselves to be “disabled,” and due to ongoing health concerns, resent HIV disease being dismissed as readily manageable. However, others reject disability-related terms as stigmatizing. In the upshot, because we cannot assume anything about how those living with HIV perceive their diagnosis, regardless how many years may have elapsed since receiving it, we encourage sensitivity to the breadth of self-perceptions and self-descriptions among those living with HIV.

6) **Remember the allies:** Not everyone whose lives have been affected by HIV are themselves living with HIV. For example, some individuals who have never themselves acquired HIV grieve the loss of close friends or family members who died of HIV-related causes. Others may be presently partnered with someone living with HIV. Others still may have devoted their careers to serving people living with, or affected by, HIV. When speaking with HPG audiences, we recommend an approach that recognizes and values the contributions and experiences of everyone whose lives have been touched by HIV.

Part 3: Special advice for presenters

Just as we encourage all to consider *what* they say, we ask meeting presenters to consider *how* they say it. Here are some suggestions:

1) **PowerPoint:** We kindly ask every presenter to develop a PowerPoint presentation and send it to the HPG contact person well in advance. This helps ensure the presentation will be ready to go at the scheduled time.

2) **Create a PDF to accompany the PowerPoint file**: PowerPoint includes a feature that facilitates easy conversion of PowerPoint slides to a printable PDF. The HPG meeting planners will print paper copies of this PDF and make them available to onsite meeting attendees. Please create a PDF that places two slides on each page.

3) **Visibility:** To maximize visibility, both on screen and in print, we recommend creating PowerPoint slides that use dark content against light backgrounds. For headings we recommend a minimum font size of 24 points; for bulleted information and paragraphs we recommend a minimum of 22 points. Generally, plain san-serif fonts work best.

4) **Simplicity:** Please remember the adage, “less is more.” While long paragraphs, detailed tables, and complex graphs may work in documents, they rarely work in PowerPoint. Granted, visual variety can enliven what may otherwise be a run-of-the-mill presentation. But PowerPoint slides that succinctly summarize a few key points are strongly preferable to a clutter of detail no matter how artfully the clutter is presented.

5) **Remember the virtual audience, too:** Please keep in mind that HPG meetings are open to offsite audiences that use a variety of technological devices and connections to support their attendance. Hence, it is often more difficult for virtual attendees to hear and see a presentation as compared to those in the physical meeting space. For this reason, we ask presenters to speak more slowly, more clearly, and at a greater volume than they otherwise might. A quick side remark made without a microphone may be picked up by people within earshot, but it will probably be lost on others.

6) **Fielding questions:** HPG audiences typically display a high degree of investment and enthusiasm, and therefore may ask numerous questions. We recommend presenters determine how they prefer to field questions, and then communicate this to their audience up front. Some presenters prefer to field questions as they arise; others prefer questions at the end.

7) **Practicing Social Justice:** Finally, please keep in mind that creating accessibility is also an ethical social justice practice. Putting in the time and effort to create an accessible presentation helps ensure no audience member feels marginalized by a presenter. We want to maximize the potential for all audience members—of all identities—to feel valued.

Closing Thought

The HIV Planning Group is committed to the dignity of all. Please call or email us with any questions or concerns.

Further Reading

This guide was written to reflect key points raised at HPG meetings. It also reflects these resources, which we recommend for further reading:

National Institute of Allergy and Infectious Diseases (NIAID) (2020). NIAID HIV language guide. https://www.niaid.nih.gov/sites/default/files/NIAID%20HIV%20Language%20Guide%20071520%20revised_%20updated.pdf

The Well Project (2022). Why language matters: Facing HIV stigma in our own words. https://www.thewellproject.org/hiv-information/why-language-matters-facing-hiv-stigma-our-own-words