NIAID HIV Language Guide: Advocating for Person-first Language in Research

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Key Messages

- Person-first language helps reduce stigma and discrimination
- Language may differ by community and region
- Using person-first language requires asking questions and listening to people
- Recognize that language evolves over time

What is Person-first Language?

- The individual is placed BEFORE the diagnosis
- It is the use of intentional word choices that puts the person-first, asserting that they are not defined by a condition or disease

Why is NIAID Prioritizing Person-first Language?

- Certain language is insensitive to people and their basic human dignity
- Offensive, inaccurate, and inappropriate language stigmatizes and alienates study participants and the communities in which we work
- Using person-first, inclusive, and respectful language emphasizes humanity, highlights autonomy
- It promotes the idea that someone's health and health determinants are only facets of their full life and identity
- The NIAID HIV Language Guide can be found at: https://www.niaid.nih.gov/research/hiv-language-guide

NIAID HIV Language Guide and Related Materials

Research > Resources for Researchers

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NIAID HIV Language Guide

NIAID is making every effort to eliminate the use of stigmatizing terminology and advance the use of person-first, inclusive, and respectful language. This updated HIV Language Guide (May 2024) is an important step toward that end. This resource is applicable to all communications, including but not limited to grant applications, contracts, publications, presentations, abstracts, and press materials.

It should be noted that the NIAID HIV Language Guide has relevance beyond HIV. It includes language related to other areas of research, diseases and conditions, gender and sexuality, general research terminology, and more. NIAID urges all staff, collaborating researchers, and stakeholders to review the Language Guide and make use of it for all written and oral communications.



Credit: NIAID

Download the NIAID HIV Language Guide

Supporting Materials

The following slide and invitation templates may be used to reiterate the importance of eliminating the use of stigmatizing terminology in NIAID-supported meetings, workshops, and conferences.

- HIV-specific Template Introductory Slide PDF (PowerPoint Version PPT)
- Generic Template Introductory Slide PDF (PowerPoint Version PPT)
- Meeting Invitation Template Language PDF (Word Version DOC)
- Speaker Invitation Template Language PDF (Word Version DOC)

Reflection

• Have you experienced stigma as the result of language?

• What have you heard in the clinical research and/or medical setting that you found offensive or hurtful, or simply made you feel uncomfortable?

Examples Highlighting Non-stigmatizing, Person-first Language in HIV Research

- Do not describe people by their disease, infection or condition
 - People with HIV rather than HIV-infected people
 - People who inject drugs rather than injection drug users
- Do not use "subjects" or "patients" to describe people enrolled in research studies or clinical trials
 - Participant or Volunteer
- Do not use "sex" and "gender" interchangeably
 - Sex (refers to sex assigned at birth)
 - Gender (refers to psychosocial or cultural identity)
 - Use cisgender for people whose gender matches their sex assigned at birth and transgender for people whose gender does not match their sex assigned at birth

Examples Highlighting Non-stigmatizing, Person-first Language in HIV Research

- Do not use "at risk" or "high-risk" person/population
 - Person/population with greater likelihood of HIV exposure
 - Population experiencing a disproportionate impact of HIV
 - High incidence population
 - Affected community
- Do not use "sterilizing" when referring to HIV cure
 - Eradication, Clearance

Examples Highlighting Non-stigmatizing, Person-first Language in HIV Research

- Do not use mother to child transmission
 - Perinatal transmission
 - Vertical transmission
- Do not use Verticals to describe people who acquired HIV in utero or at birth
 - Lifetime survivors
- Do not use infants at risk of HIV
 - Infants exposed to HIV (in utero, during labor, through breastfeeding/chestfeeding/nursing/lactation
 - Fetus exposed to HIV in utero
- Do not use "mother" unless you're certain that's how someone identifies
 - Birth parent
 - Pregnant people
 - Postpartum participant
 - Parent-infant pair

Change is Hard!

What terminology is hardest to change?

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What terminology is hardest to change?

(i) Start presenting to display the poll results on this slide.

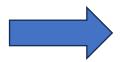
What Terminology is Hardest to Change?

Breastfeeding



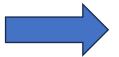
Chestfeeding, Nursing

Mother



Parent, Birth parent

Pregnant Woman



Pregnant Person, Pregnancy Potential

Stigmatizing Language is Ubiquitous

- The Representative Studies Rubric (RSR)
 - Age, ethnicity, gender, drug use, pregnancy, race, sex assigned at birth, language (agreement with the Guide)
- Protocol analysis (All 47 studies enrolling in Fall 2021)
- 100% of protocols contained at least 1 instance of stigmatizing language
 - HIV-infected / Infection / Infect (96%)
 - At-risk / High-risk (62%)
 - Target (57%)
 - Subjects (51%)

IMPAACT Protocols & Language

• Acceptable or Not?

 To establish, among young <u>HIV-uninfected women</u>, the plasma drug concentrations associated with daily directly observed oral pre-exposure prophylaxis (PrEP) during pregnancy and postpartum

• What could you say instead?

- Among young women who are not living with HIV
- Among young cisgender women without HIV
- Among cisgender women age X and younger living without HIV

IMPAACT Protocols & Language

• Acceptable or Not?

Women at risk for HIV infection

What could you say instead?

- Women who are disproportionately affected by HIV
- Women in high incidence areas
- Women who have a greater likelihood of acquiring HIV
- Women who have a greater likelihood of being exposed to HIV

IMPAACT Protocols & Language

- Acceptable or Not?
 - Women with HIV infection
- What could you say instead?
 - Women living with HIV
 - Women with HIV

Approaches for Correcting "oops"

- What to do when you observe, read, hear nonperson-first, stigmatizing language?
 - Be especially careful when using cut/paste from other (even recent) material
 - Correct written documents and send with a clarifying explanation
 - Indicate what your preference is

Stigmatizing Language Impacts All Facets of Medicine and Research

- The goal: End the use of stigmatizing language in all aspects of research
- Stigmatizing language has been ingrained into our everyday lives as well as our research culture
- Change will be slow and incremental
- We ask for your patience, support, and continued guidance as the research community tries to adopt more respectful language

"Language evolves as fluidly as our knowledge of the virus itself."

Dr. Marrazzo, Director NIAID

- **X** A universally sanctified rulebook
- X "Political Correctness," "Woke"
- **X** Achieving righteousness
- X An act of mastery
- X Replacing Word A with Word B

- ▼ Thoroughly vetted resources to inform everyday practice
- ✓ Scientific integrity, basic respect
- Practicing humility
- An ongoing practice of learning & adapting
- ✓ Listening & evolving

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Thank you!

Any Questions?

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