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

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?

- **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	✓ **Thoroughly vetted resources to inform everyday practice**
X "Political Correctness," "Woke"	✓ **Scientific integrity, basic respect**
X Achieving righteousness	✓ **Practicing humility**
X An act of mastery	✓ **An ongoing practice of learning & adapting**
X Replacing Word A with Word B	✓ **Listening & evolving**

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Thank you!

Any Questions?

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