Language matters when communicating about HIV. Survey of 100 PLH at the monthly updates hosted by the San Diego HIV Consortium (SDHIVConsortium.org)

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Background

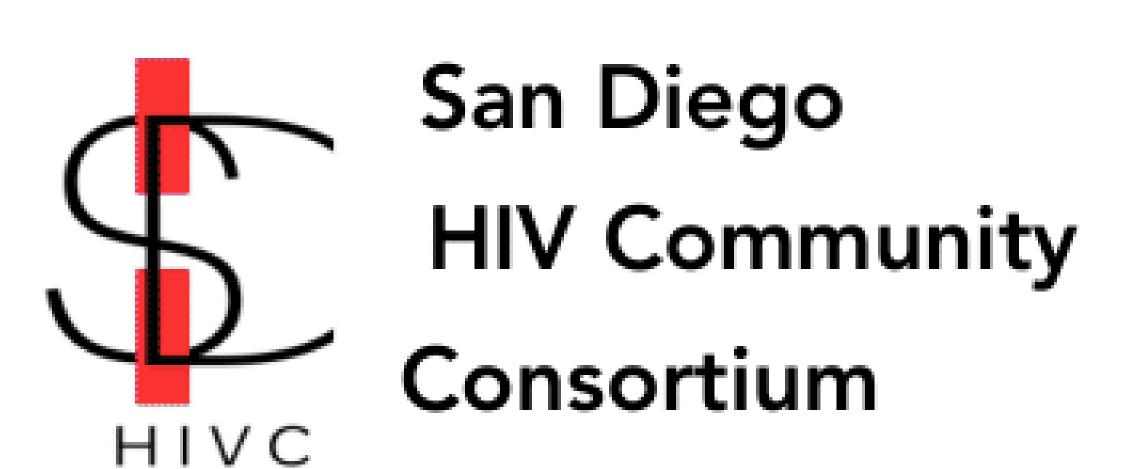
Language in HIV care influences stigma, trust, and treatment engagement. Despite established guidelines (e.g., Denver Principles, UNAIDS), harmful terms like "HIV-infected" persist. Community input is vital to ensure respectful communication and affirming care.

Objective

To identify preferred and stigmatizing HIV-related terms among PLH and support language that promotes dignity and inclusion in care settings.

Methods

From Jan–Apr 2024, 100 PLH and 12 healthcare providers (MDs, DOs, NPs, PAs) completed an anonymous, convenience-based survey. The survey included multiple-choice and open-ended questions. Responses were analyzed descriptively to assess language preferences and identify stigmatizing terms.





STIGMATIZING TERMS

- HIV-infected
- Full-blown AIDS
- HIVer
- Person/patient with HIV
- Died of AIDS

PREFERRED LANGUAGE

- Person living with HIV
- PLWH
- PLH
- PLHIV
- PLWHA
- WLWHA

Results

When asked how they preferred to be addressed:

- Only 25% of PLH were comfortable with the term "patient"
- 8% expressed discomfort with the label "client"
- All 12 medical providers surveyed (6 MDs, 1 DO, 3 NPs, 2 PAs) reported using "patient" exclusively, with only one accepting "client" as an alternative

Despite existing terminology guidelines, medical providers did not report using people-first alternatives. This disconnect highlights the need for continued provider education and patient-centered dialogue.

Conclusions

Open dialogue about language preferences fosters better communication and more affirming care within the HIV community. We urge providers to ask PLH how they prefer to be addressed and to revisit the Denver Principles — "We are People With AIDS." As one participant shared, "Words hurt." Language remains a powerful factor influencing HIV testing, stigma, treatment engagement, and overall trust in care. Following the UNAIDS Terminology Guidelines and the People First Charter is as critical today in 2025 as it was in 1983.

