

INCLUSIVE HIV TERMINOLOGY/ CONSIDERATIONS FOR EXTERNAL AND INTERNAL COMMUNICATIONS - EATG SUGGESTIONS

EATG has prepared this brief document in order to improve the *external and internal communication* of the RBDCOV project in relation with the inclusion of the HIV community.

Some general recommendations and suggestions are:

- At EATG, as we are involved in many European projects, we always use **British English**, so would recommend that RBDCOV uses the same. If your preference is American English, we (and all partners in communications) should **be consistent with whichever is selected**.
- At EATG, we believe that **people should never be referred to as an abbreviation** (e.g. *PLHIV*), since this can be dehumanising. Instead, we highly recommend that **the name or identity of the group should be written out in full** (in this case, *people living with HIV*). Abbreviations for population groups can, however, **be used in charts or graphs** where brevity is required. If we have to abbreviate, EATG prefers *PLHIV* (and not *PLWHA* or similar...).
- We follow the principle of **referring to people first**, before their condition, this should be the same when referring to participants (e.g. *rather than "HIV participants": participants living with HIV, rather than "dialysis patients": people receiving dialysis* - "person/people with condition").
- When posting on social media, please make sure that words (**specifically medical conditions and other scientific terminology**) are spelled correctly in English, as this might have an impact on how external audience perceives the work of the project and the partners involved.
- For this type of project, where the participants are involved in a vaccine trial, participants should not be referred to as "patients", but instead as **"trial participants"** as in the trial they are not in a doctor-patient situation receiving diagnoses/treatment for their condition, but in a trial for a vaccine.
- We prefer to **avoid using the word "vulnerable/ vulnerable populations"**, this can be disempowering. Instead, we suggest indicating the population you are referring to.

Hereunder, you can find a table¹ that might be of help when you draft a message to be inclusive for the HIV community specifically.

Please avoid:	Alternatives
AIDS patient	Person with complications of advanced HIV; person with an AIDS-defining illness
AIDS test	HIV test
AIDS virus	HIV
Catch HIV	Acquire HIV
Contagious/infectious	Person with transmittable HIV or detectable viral load
Died of AIDS	Died from complications related to HIV <i>or</i> died of an AIDS-related illness
HIV-infected person, people, individual(s), populations	Person/people living with HIV

¹ Table adapted from: [PFC recommended HIV terminology - Laura Waters / NIAID HIV Language Guide](#).

Trial Subjects/ Patients	(Trial) participant, volunteer participant
Fight and other combatant language (e.g. struggle, battle, campaign or war)	Avoid such terms unless in a direct quotation or because of the specific context of the text. One rationale for this is to avoid transference from the fight against HIV to a fight against people living with HIV. We would recommend avoiding fight and other combatant language even in relation to SARS-CoV-2 and COVID-19 pandemic, for the same rationale as above. We recommend alternatives such as: response, management of, measures against, initiative, action, efforts and programme.
Consider avoiding:	Alternatives
Abbreviations	Avoid abbreviating e.g. people who inject drugs (PWID), women living with HIV (WLWH) if possible
Co-infected person or people	Person living with HIV and <additional condition> e.g. <i>person living with HIV and hepatitis B.</i> <i>Treating 'HIV/hepatitis co-infection' or living with HIV/HBV is acceptable, treating the 'HIV/hepatitis co-infected' is not.</i>
Detectable or viraemic patients	People with a detectable HIV-RNA or viral load, or people with viraemia
Ending HIV, ending AIDS	Ending HIV transmission, ending late HIV presentation or preventable HIV-related deaths
HIV exposed infant	Infant exposed to HIV
HIV exposed uninfected infant	HIV-negative infant exposed to HIV
High-risk people/population/group	Affected community/population or high-incidence population high-risk people/population/group
Hard to reach populations/individuals	hardly reached or unsuccessfully engaged populations/individuals
Intravenous drug user/IVDU; drug addict; drug abuser	People who use drugs; People who inject drugs
Spread, infect	Transmit, pass on
HIV deaths	HIV-related mortality or HIV-related deaths
Mother to child transmission	Vertical transmission, perinatally acquired HIV
People failing therapy; failing patients	People experiencing treatment failure, people on failing therapy
Poorly adherent	Person/people with poor adherence
Resistant patients	People with resistant virus
Vulnerable people	We suggest indicating which groups of population you are making a reference to.

Suggestions and implications for terminology for kidney health² for use in patient-facing contexts.

Consider Avoiding:	Alternatives
Renal/ nephro-	Use kidney (e.g. “kidney transplant” instead of renal transplant or Transplant nephrectomy) when referring to kidney disease and kidney function.
Dialysis patients	People receiving dialysis or People on dialysis.
Disease	The use of the term “disease” may need to be clarified and supported with education and counselling.
Stages	Group
End-stage kidney disease (ESKD)	“Kidney failure” with appropriate descriptions of presence or absence of symptoms, signs, and treatment as ESKD is not patient-sensitive and connotes stigma.

THE USE OF EMOJIS ON SOCIAL MEDIA

We would like to suggest the following recommendations:

- To avoid gendered emojis - 🧑 🧒
- To avoid any type of emojis that portray any type of human fluid (splashes, blood, etc.) - 🩸
- To avoid any emojis that look like “danger” - ⚠️ 🚫

² Suggestions based on [KDIGO Consensus Conference on Nomenclature for Kidney Function & Disease](#) and Tong, Allison et al. “[Patient and Caregiver Perspectives on Terms Used to Describe Kidney Health](#).” Clinical journal of the American Society of Nephrology : CJASN vol. 15,7 (2020): 937-948. doi:10.2215/CJN.00900120.