

**EDITORIAL**

# Language matters: The importance of person-first language and an introduction to the People First Charter

One year ago, *HIV Medicine* endorsed the People First Charter and adopted its terminology guidance for authors and reviewers; this piece outlines the background to the creation of the Charter and why the language we use is so important.

Thanks to the incredible progress in HIV treatment and care over the last 40 years, most people living with HIV who are on suppressive antiretroviral therapy (ART) have a normal life expectancy and can be confident that they have zero risk of passing HIV on to their HIV-negative sexual partners [1]. Yet people living with HIV continue to experience unacceptable levels of stigma and discrimination. The Positive Voices survey revealed that 1 in 6 people with HIV worried about being treated differently in healthcare settings due to their HIV status, 1 in 10 avoided seeking healthcare when needed due to fears of stigma, and 1 in 20 felt they had been refused or delayed healthcare because of their HIV status [2]. Fears and experiences of stigma and discrimination were higher amongst women and those in the north of England.

Stigma can be a barrier to HIV testing, accessing HIV care and adherence to ART [3, 4]. Stigma is challenging to measure, and its impact on people may vary depending on the type of stigma and the setting in which it is anticipated or experienced. For example, internalized stigma predicts outcomes related to mood and self-esteem, anticipated stigma impacts health behaviours and outcomes (such as medication adherence), and anticipated or experienced stigma from healthcare workers may be particularly harmful in terms of quality of life and ART adherence [5]. Getting language right, and constantly reviewing the language we use as acceptable terminology evolves, is a critical part of addressing stigma. Using the wrong words can inadvertently undermine people, perpetuate disparities, confer judgment and create barriers to accessing care or sharing relevant information. Conversely, the right words can empower people, encourage them to access care and actually improve the care itself. A randomized case study showed that neutral language in the medical notes improved offers of analgesia to a hypothetical person with sickle cell disease, as compared with

stigmatizing language [6]. Examples of negative language in medical notes include those that question credibility, express disapproval, stereotype people by race or social class, portray patients as difficult and convey a paternalistic tone [7].

The person-first language movement is far from new; it started during a self-advocacy conference in the US in 1974 [8], has slowly gained traction since, and has played a key role in reducing stigma in clinical communication [9]. Condition areas at the forefront of person-first advocacy include diabetes care [10], obesity care [11] and mental health [12]. NHS England has produced guidance on language and diabetes [13] and on making language accessible to people with learning difficulties [14]. The King's Fund has highlighted that the restructuring of NHS care in England should be seen as an opportunity to reappraise the words we use [15]. Many have called for less stigmatizing language in HIV care; UNAIDS developed terminology guidance in 2011 (which was updated in 2015 [16]) and other organizations have developed material promoting appropriate language, including the National HIV Nurses Association [17], The Salamander Trust [18] and The BodyPro [19]. Despite this, stigmatizing language in the field of HIV remains rife. It is for this reason that the People First Charter was created.

Some of the language we use is undoubtedly influenced by the language used to describe the evidence that subsequently informs guidelines, policies and practice. It is hard to promote inclusive language in routine care when conferences and journals, particularly speciality journals, continue to accept stigmatizing language. It was the frequent use of phrases such as 'HIV-infected people' in abstracts presented at the International AIDS Society Conference in 2021 that triggered the creation of the People First Charter website, a single-issue site promoting person-first language in HIV research and care [20]. Whilst the website has been well received by many, particularly the community of people living with HIV, there have been examples of defensive responses to promoting the language guidance. People tend to over-interpret the advice when questioning its use; for example, we do not object to the use of 'infection' in the context

of epidemiology or when referring to ‘HIV-infected cells’ in the context of basic science. Another theme has been ‘we always encourage the use of UNAIDS guidance’, yet those very organizations and journals continue to publish materials that contradict those assertions. It is hard to stop using terminology that has been embedded in one’s daily parlance for years, particularly when presenting in a language that is not your first language. For that reason, our initial focus is on written materials, with the intention that spoken language will soon follow.

Since its inception, the People First Charter has been endorsed by several organizations and other journals alongside *HIV Medicine*. We very much hope that all medical and scientific journals will follow suit in the immediate future and that clinical services will swiftly follow. The advent of people being able to access entries in their primary care record [21] may be just the lever we need to routinely embed person-first language across all elements of healthcare. Stopping to think about the language we use offers an opportunity to pause and reflect on the impact of that language on people living with the issue in question, and that can only be a good thing.

Persistent exposure to language that dehumanizes or disempowers people living with HIV risks normalizing it, encouraging stigmatizing language to persist in healthcare settings and mainstream media. That *HIV Medicine* has embraced and embedded the call to use person-first language is something of which we are very proud. We call on all journals to follow the lead of this one and embed inclusive, person-first language in their publications.

## KEYWORDS

HIV, language, people-first, person-first, stigma

Laura Waters<sup>1</sup> 

Matthew Hodson<sup>2</sup>

Jo Josh<sup>3</sup>

<sup>1</sup>Consultant Physician in HIV & Sexual Health Central & North West London Trust, London, UK

<sup>2</sup>NAM Aidsmap, London, UK

<sup>3</sup>British HIV Association; Steering Group UK-Community Advisory Board, London, UK

## Correspondence

Laura Waters, Consultant Physician in HIV & Sexual Health Central & North West London Trust, London, UK.

Email: [lwaters@nhs.net](mailto:lwaters@nhs.net)

## ORCID

Laura Waters  <https://orcid.org/0000-0002-1379-1775>

## REFERENCES

- BHIVA guidelines on antiretroviral treatment for adults living with HIV-1 2022. Accessed 27 October 2022. <https://www.bhiva.org/file/63513a1745ea9/BHIVA-guidelines-on-antiretroviral-treatment-for-adults-living-with-HIV-1-2022.pdf>.
- Kall M, Kelly C, Auzenbergs M, Delpech V. *Positive Voices: the National Survey of People Living with HIV—Findings from the 2017 Survey*. Public Health England; 2020.
- Iott BE, Loveluck J, Benton A, et al. The impact of stigma on HIV testing decisions for gay, bisexual, queer and other men who have sex with men: a qualitative study. *BMC Public Health*. 2022;22:471. doi:10.1186/s12889-022-12761-5
- Spence AB, Wang C, Michel K, et al. HIV related stigma among healthcare providers: opportunities for education and training. *J Int Assoc Provid AIDS Care*. 2022;21. doi:10.1177/23259582221114797
- Turan B, Hatcher AM, Weiser SD, Johnson MO, Rice WS, Turan JM. Framing mechanisms linking HIV-related stigma, adherence to treatment, and health outcomes. *Am J Public Health*. 2017;107(6):863-869. doi:10.2105/AJPH.2017.303744
- Goddu PA, O’Conor KJ, Lanzkron S, et al. Do words matter? Stigmatizing language and the transmission of bias in the medical record. *J Gen Intern Med*. 2018;33(5):685-691. doi:10.1007/s11606-017-4289-2
- Park J, Saha S, Chee B, Taylor J, Beach MC. Physician use of stigmatizing language in patient medical records. *JAMA Netw Open*. 2021;4(7):e2117052. doi:10.1001/jamanetworkopen.2021.17052
- Wehmeyer M, Bersani HJ, Gagne R. Riding the third wave: self-determination and self-advocacy in the 21st century. *Focus Autism Other Dev Disabl*. 2000;15(2):106-115.
- Healy M, Richard A, Kidia K. How to reduce stigma and bias in clinical communication: a narrative review. *J Gen Intern Med*. 2022;37(10):2533-2540. doi:10.1007/s11606-022-07609-y
- Dickinson JK, Maryniuk MD. Building therapeutic relationships: choosing words that put people first. *Clin Diabetes*. 2017; 35(1):51-54. doi:10.2337/cd16-0014
- Weight Bias: People-First Language. Accessed 3 October 2022. <https://www.obesityaction.org/action-through-advocacy/weight-bias/people-first-language/>
- Use Person-First Language to Reduce Stigma. Accessed 3 October 2022. <https://www.mentalhealthfirstaid.org/2022/04/use-person-first-language-to-reduce-stigma/>
- Language Matters: Language and Diabetes. Accessed 3 October 2022. <https://www.england.nhs.uk/wp-content/uploads/2018/06/language-matters.pdf>
- Making information and the words we use accessible. Accessed 3 October 2022. <https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-information-and-the-words-we-use-accessible/>
- Inclusive language in health and care: why the words we use matter. Accessed 3 October 2022. <https://www.kingsfund.org.uk/blog/2021/08/inclusive-language-health-and-care>
- UNAIDS Terminology Guidelines. Accessed 3 October 2022. [https://www.unaids.org/sites/default/files/media\\_asset/2015\\_terminology\\_guidelines\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/2015_terminology_guidelines_en.pdf)

17. Watson S, Namiba A, Lynn V. The language of HIV: a guide for nurses. *HIV. Nursing*. 2019;19(2):BP1-BP4.
18. The power of language. Accessed 3 October 2022. <https://salamandertrust.net/project/the-power-of-language/>
19. People-First Language in HIV medicine: A critical component of your hiv care toolkit a guide for medical professionals who treat people living with HIV. Accessed 3 October 2022. <https://www.thebodypro.com/article/hiv-medicine-clinical-language-terminology>
20. People First Charter. Accessed 3 October 2022. [www.peoplefirstcharter.org](http://www.peoplefirstcharter.org)
21. Access to patient records through the NHS App. Accessed 3 October 2022. <https://digital.nhs.uk/services/nhs-app/nhs-app-guidance-for-gp-practices/guidance-on-nhs-app-features/accelerating-patient-access-to-their-record>