

Stigma and poor mental wellbeing: A global community approach to identifying and addressing common barriers to living well with HIV



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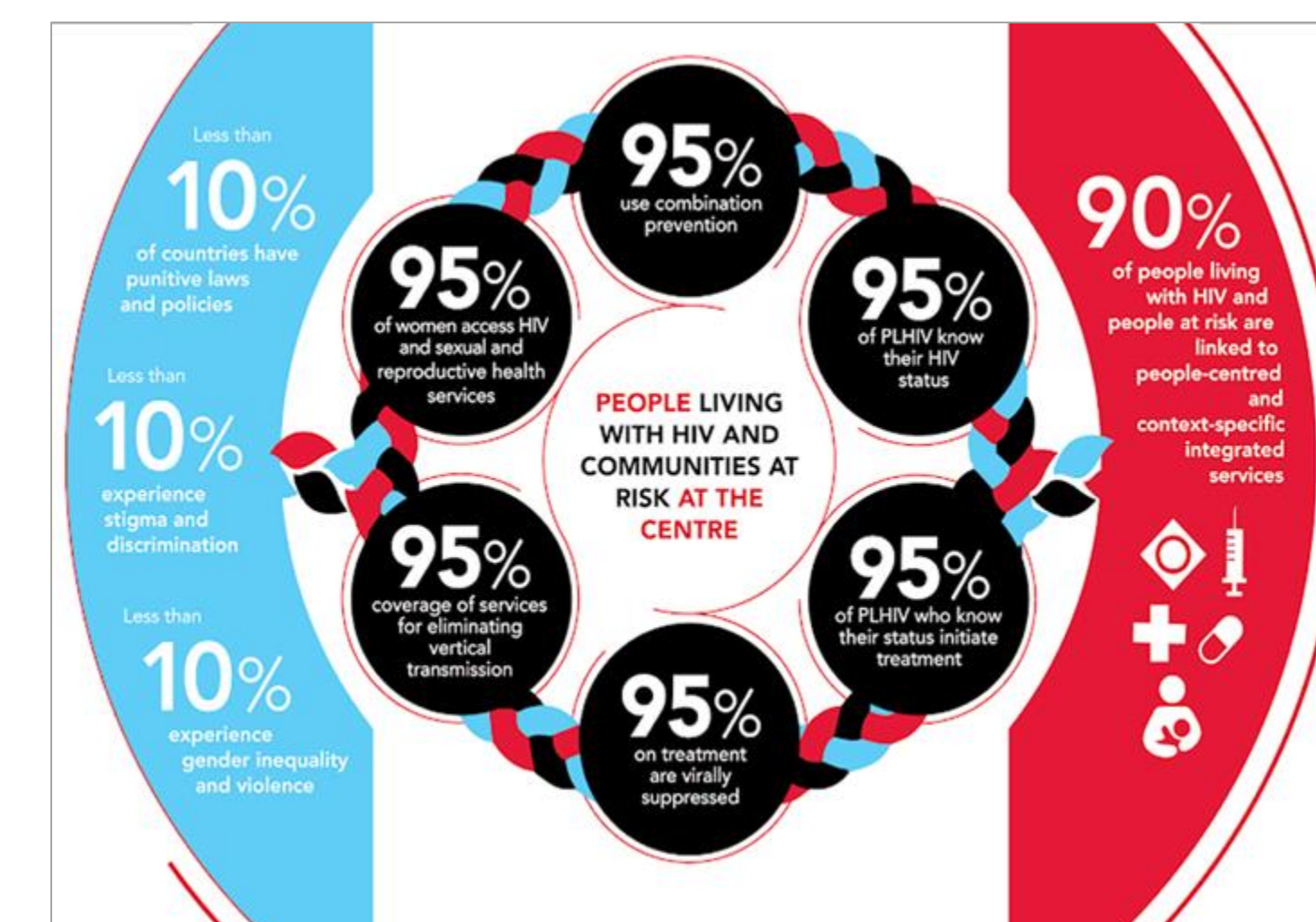
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Background

- Inequities in socially marginalized and disenfranchised communities continue to drive disparities in HIV transmission rates, testing, and linkage and retention to care.^{1,2}
- People and their communities are the focal point of the UNAIDS Global 2025 targets (Figure 1), reflecting the need to break down the social, political, and structural barriers and deliver services that respond to the specific needs of those that continue to sit on the outer margins of care.
- Previously described expert-led, long-term success (LTS) framework identified the importance of person-centric approaches to address the multifaceted needs of all individuals and to support the LTS vision of 'every person living with HIV being able to live their best life'⁴.
- Communities have the power to mobilize the demand for services, support health systems, influence social attitudes and norms, and facilitate a more enabling environment for equitable access to HIV care.
- Ten community leaders representing diverse, key populations and global regions were brought together to identify and prioritize the collective barriers to living well with HIV and inform potential solutions in this Gilead Sciences, Inc sponsored initiative.

Figure 1. UNAIDS top-line targets for 2025³



Description

- The HCC program included a dynamic, stepwise process of planning, discussion and prioritization over three meetings. Outputs from the first two meetings are presented here (Figures 2 and 3).
- Regional and community-level experience informed a combination of pre-work, deep discussion, live polling, and consensus agreement across the meetings.
- A literature review, reporting the prevalence and impact of HIV-related stigma and poor mental wellbeing and interventions to address them, informed the pre-work and contributed to the discussion and prioritization of potential solutions to overcome the global challenges within the communities represented.
- The HCC program was sponsored by Gilead Sciences, Inc.

Figure 2. Overview and objectives of the HIV Community Council series

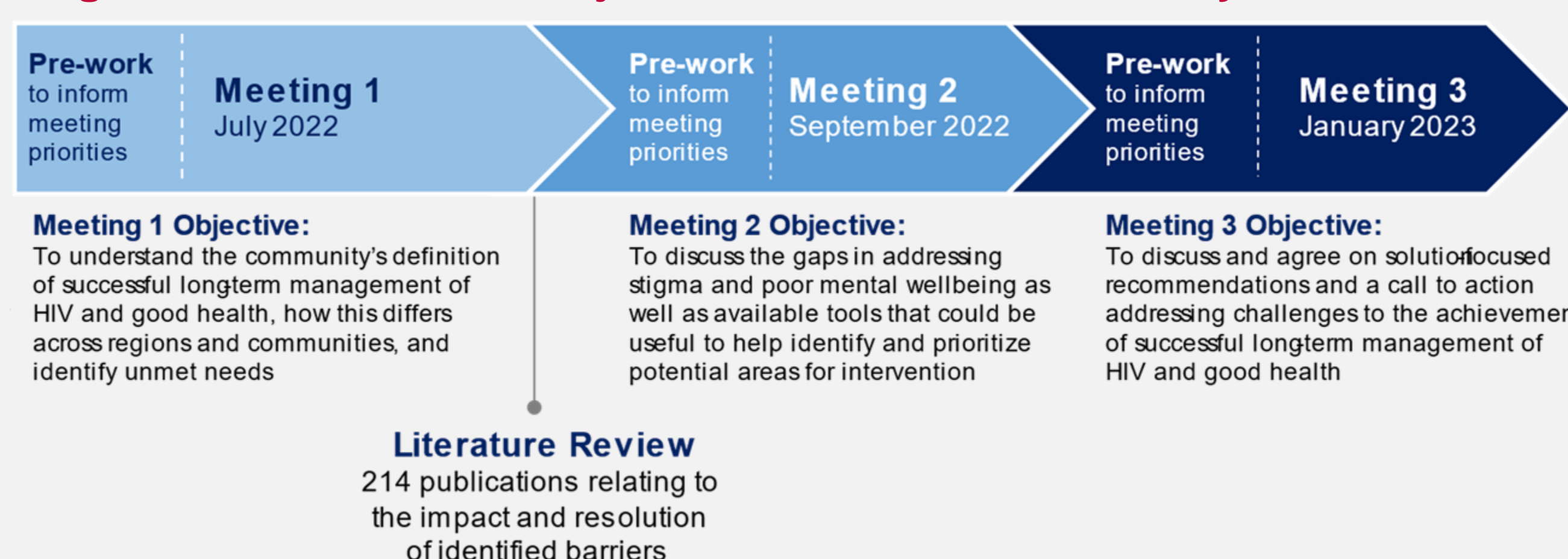
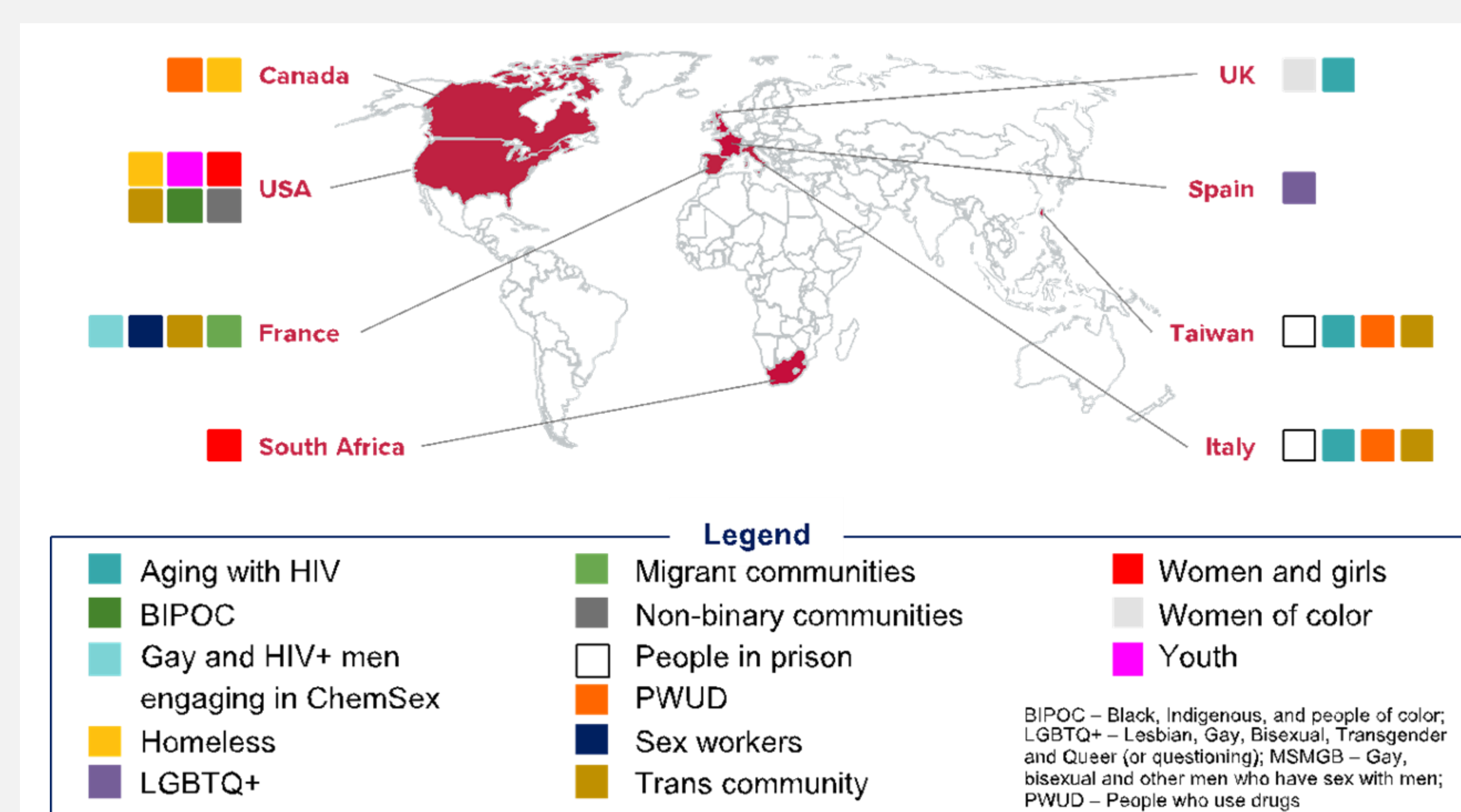


Figure 3. The HIV Community Council comprised ten community experts representing key populations across the globe



Lessons learned

- In recognition of the fact that living well with HIV can mean something different to everybody and in acknowledgement of the LTS framework,⁴ the Council prioritized four elements that enable people to live well with HIV through a series of discussion, pre-work and poll (Figure 4).
- Based on the agreed definition of living well with HIV, HCC members identified seven global barriers to living well with HIV through a process of shared personal/community experience, prioritization and consensus.

Figure 4. Four fundamental elements to living well with HIV from a community lens

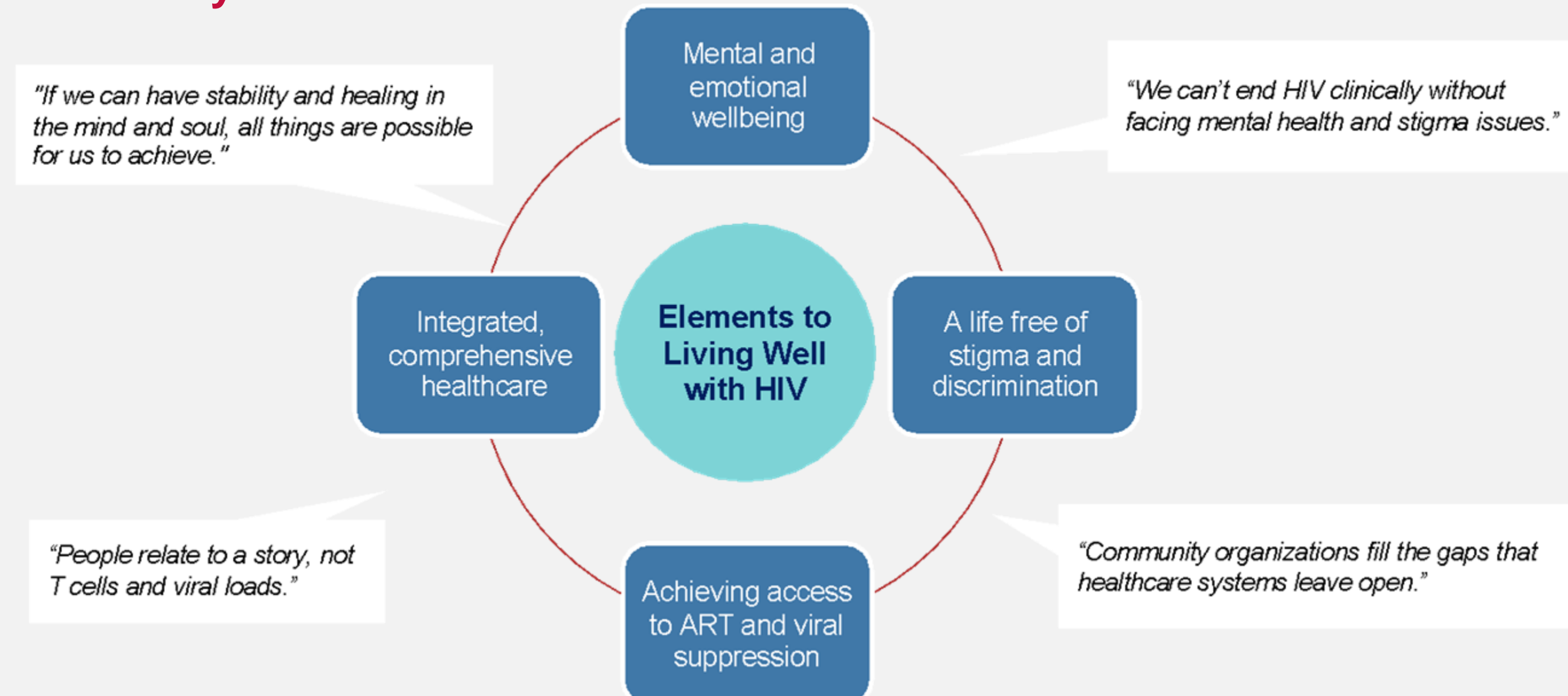
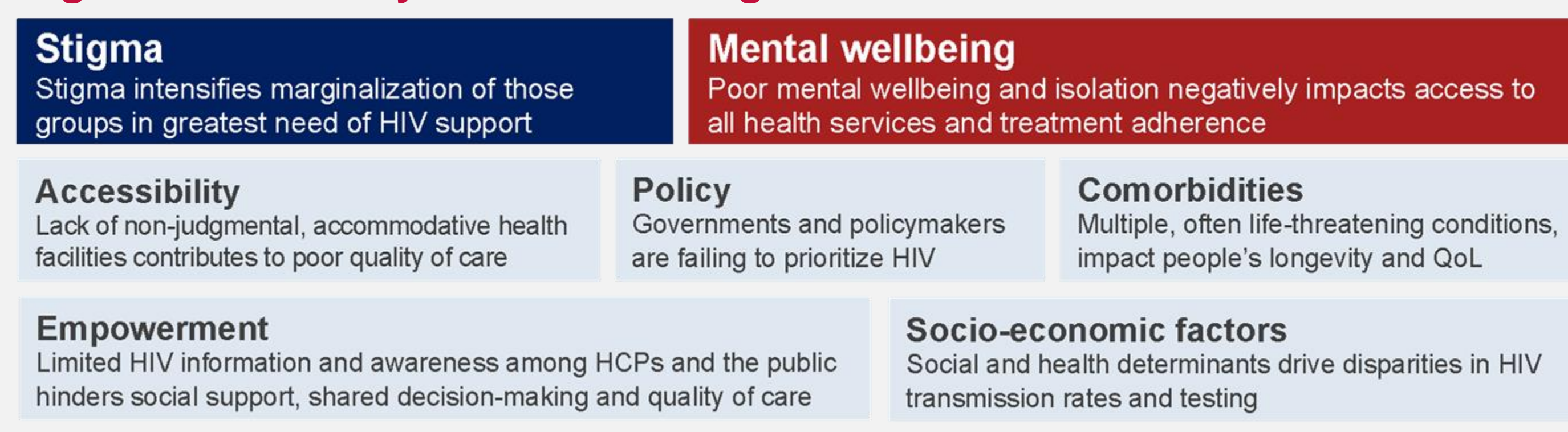
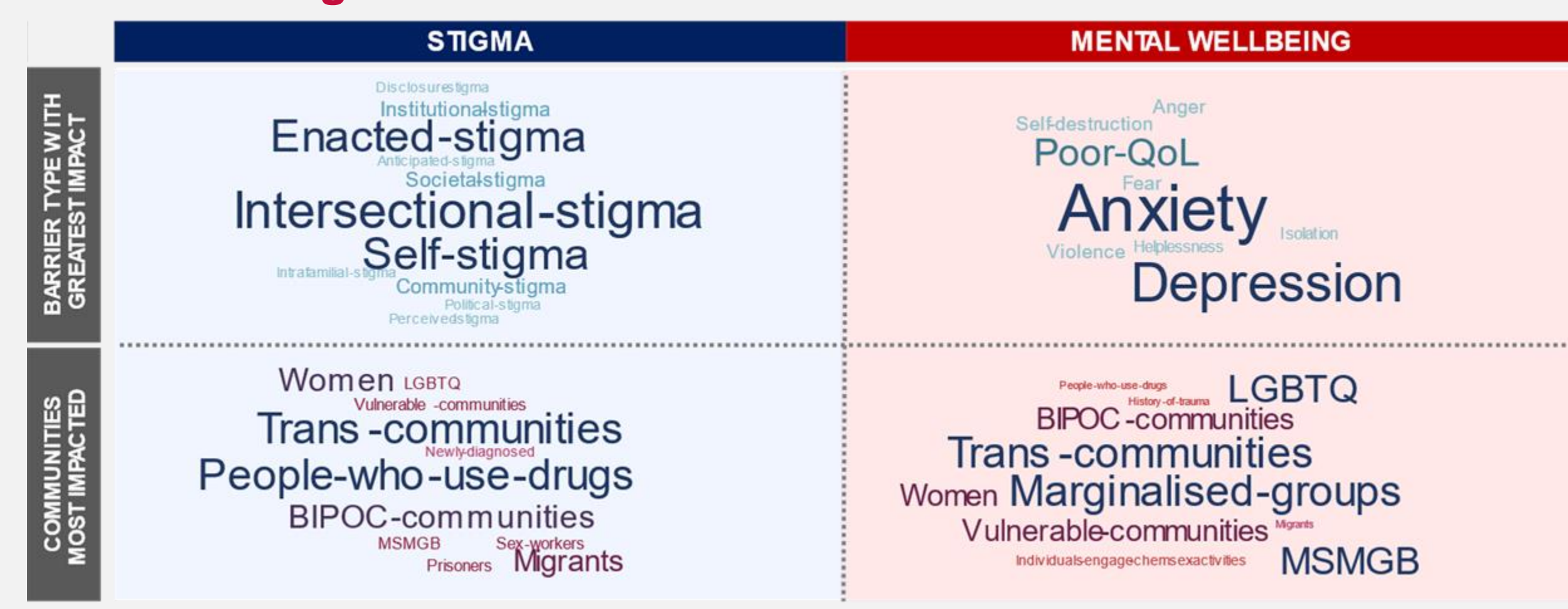


Figure 5. Seven key barriers to living well with HIV



- The HCC was asked to identify which types of stigma and poor mental wellbeing most impact their community and region, and free-text answers were captured through a pre-meeting survey. Larger font size shows the most common response, and smaller text showing less frequent answers.

Figure 6. Barrier types and groups most affected by stigma and poor mental wellbeing



- These results informed the second HCC discussion, during which members shared their experiences of tools and interventions to address HIV-related stigma and poor mental wellbeing that could have the greatest, positive impact on those communities most affected.

- The second meeting focused on the co-creation of solution-based statements that the community can consider to facilitate improvements in HIV-related stigma and mental wellbeing.
- These statements reflected global, regional and community-specific priorities and were accompanied by examples of existing or theoretical tools and interventions that the HCC believed could inform development and implementation.

Figure 7. Six solution-based statements to address HIV-related stigma and poor mental wellbeing



Conclusion and Next steps

- This project explores the collective and regional- and community-specific barriers facing marginalized and disenfranchised communities living with HIV to identify potential solutions by which they can be addressed.
- As advocates for those disproportionately affected by HIV, the HCC members were uniquely placed to share their insights, experiences and priorities and elevate the community voice and agreed that stigma and poor mental wellbeing are the greatest barriers to living well with HIV across the cross-sectional communities that they represent.
- The HCC has since held a final meeting to develop the six solution statements into a set of actionable recommendations that facilitate access to care and make it possible for everyone, everywhere, to live well with HIV.

References: 1. Pellowski JA, et al. A pandemic of the poor: social disadvantage and the U.S. HIV epidemic. Am Psychol 2013;68(4):197-209. 2. Ransome Y, et al. Structural inequalities drive late HIV diagnosis: The role of black racial concentration, income inequality, socioeconomic deprivation, and HIV testing. Health Place 2016;42:148-158. 3. UNAIDS 2020. World AIDS Day Report: Prevailing against pandemics by putting people at the centre. 4. Lazarus, JV et al. Long-term success for people living with HIV: A framework to guide practice. HIV Med 2023;24(Suppl. 2):8-19. doi:10.1111/hiv.13460.

Acknowledgements

This project was funded by Gilead Sciences. Ellie Collins and Lynn Hamilton from Synthesis Health provided medical writing support.

