

The HIV Collective
Kick-off meeting report

**Working together to
end the HIV epidemic**

For everyone, everywhere

HIV Collective kick-off meeting report

Meeting overview

On 12th July 2022, Gilead Sciences hosted the inaugural *HIV Collective* kick-off meeting with 37 community representatives, as an opportunity to discuss the evolving HIV landscape, the impact this is having on patient organisations and what we need to do to achieve our common vision of ending new HIV transmissions for everyone, everywhere across the UK.

Meeting objectives

- To discuss challenges and opportunities to end new HIV transmissions by 2030 and agree actions needed to move forward
- To facilitate the sharing of knowledge and best practice around how we can collectively reach these target
- To reinforce Gilead's commitment to supporting the community through the *HIV Collective* programme

Executive summary

The meeting featured interactive community presentations, workshop sessions and Q&A. It provided opportunities for attendees to listen, reflect and discuss the core challenges and opportunities in reaching the target of ending new HIV transmissions by 2030 (as set by UK Governments). Throughout the meeting four key themes emerged as areas of priority that, as a collective, we need to address as we strive towards this target.

Firstly, it was agreed that there needs to be better definition of the 2030 targets and what we mean by 'ending' transmissions. It was agreed that there needs to be greater awareness and understanding of where the ultimate accountability and responsibility lies in achieving this target and the role of community-based organisations.

There is also a need to recognise and respond to the needs of all underserved communities affected by HIV and ensure that they are not 'left behind' in the efforts to reach the 2030 target. Groups such as women, older people, migrants and the transgender community continue to be overlooked by many HIV services and initiatives.

Another key theme identified was the need to focus on the language that we use. It has become commonplace to use exclusionary terms such as 'lost to follow-up' and 'hard to reach' both within, and beyond the HIV community. This focus on language also needs to apply to how we talk about the 2030 targets – the ideas of 'elimination' and 'getting to zero' overlook those already living with HIV and the support that they will need beyond 2030.

The final theme that emerged from the meeting is that "HIV isn't done". In the uncertain funding and political landscape, it is vital to ensure that national and local commissioners don't lose focus on HIV so that across the UK all those living with, or at risk of acquiring HIV, remain front of mind. To do this we need to reinvigorate activism in HIV, reminding ourselves of what has worked in the past but also looking at new ways of doing things such as collaborations beyond the HIV sector, looking at new pathways and services, and investing in younger generations of HIV advocates.



Achieving 2030 targets: Voices of the community

What are the barriers?

Discussion around what could stop us achieving the 2030 targets centred around three key areas:

1. Structural and social inequality

- Societal stigma and attitudes towards those living with HIV continue to be a barrier i.e. because of race, gender, sexuality, immigration status, age
- Digital exclusion and the move towards more online/digital services increasing the disadvantage among marginalised groups
- Lack of information on HIV that resonates with young people and the public, limiting a broad understanding of what HIV looks like today
- Lack of trust in the healthcare system, particularly among the underserved groups who are considered 'hard to reach'
- Ability to reach the economically disadvantaged e.g. those living in poverty or who are homeless
- Regional differences, including a lack of focus on supporting and listening to those outside of cities and a limited understanding of intersectionality of HIV in local/rural areas

2. The language we use

- Language used around 2030 targets (i.e. 'elimination' and 'getting to zero') isn't always inclusive; people living with HIV will still exist beyond 2030 and need continuing support particularly around quality of life

- Language used to describe certain individuals (i.e. 'lost to care' and 'hard to reach') can be exclusionary and exacerbate their lack of engagement
- U=U is a complex message that isn't widely understood; there are nuances of how this translates for different communities and age groups
- Quality of life needs to be better defined and, building on the great work already underway in the sector, have consensus on how it should be measured

3. The current environment in the UK

- Ongoing health service reforms could impact access to prevention, treatment, and support services
- The evolving political landscape is creating uncertainties, particularly in regard to prioritisation of and commitment to the 2030 target, longer-term financial commitment to and prioritisation of funding for HIV services, and prevention methods
- Challenging financial environment in the UK resulting in overall funding cuts including for HIV services
- London-centric modelling is excluding those living in regional or rural settings



Where are the opportunities?

Discussion around the opportunities that will help us strive towards the 2030 targets focused on four areas:

1. Consensus and collective action

- Defining what the 2030 targets mean for the voluntary sector and the wider HIV community and agreement on the strategic areas of priority will enable powerful collective action
- A consensus on the definition of 'quality of life' will enable more aligned communications on how it can be supported/improved across the HIV community

2. Public education and awareness

- Finding ways to 'normalise' HIV e.g. through sharing individual stories and experiences of a wide range of people living with HIV, in particular:
 - Overcoming misperceptions about HIV that perpetuate stigma
 - Challenging the 'HIV doesn't apply to me' message to support more people accessing prevention services
- Continuing to invest in services beyond the NHS, such as community-based services, to help overcome current challenges within the healthcare environment (i.e., funding, staffing, backlog of services) – this could include greater awareness of the value of community-based services

3. Funding and sustainability

- As a sector we need to strive for more open and honest conversations about funding, encourage a review of funding models and advocate for adequate/sustainable funding including core/unrestricted funding
- Community organisations should consider implementing robust and effective monitoring and evaluation of programmes to secure long-term funding and take learnings from the 'scaling up' approach to ensure that a long-term, sustainable solutions are established from the start

4. New pathways and collaborations

- Creating collaborations and partnerships beyond the HIV sector – identifying key issues to be addressed (i.e., from the strategic priorities identified above) and looking for common priorities and audiences, in turn create a wider network of HIV health advocates
- Focus on the next generation of advocates and healthcare professionals (HCPs, e.g., GPs and primary care professionals) who will continue to drive progress for HIV in the future



Key actions to take forward

During discussions at the meeting, we heard consensus on the following actions that will be revisited in future sessions so that learnings and solutions can be shared:

- Review the actions that sit behind the 2030 targets and provide a consensus on what this means for community organisations
 - Include a review of the language being used – refrain from using terms such as ‘lost to care’ and ‘getting to zero’, and focus on all those affected by HIV from communities at risk to those living with HIV
 - Gain clarity on how progress towards 2030 will be measured and ensure accountability at a local level
- Share positive stories and lived experiences of different people living with HIV to:
 - Support better representation of communities affected by HIV and in turn generate greater empowerment of those affected
 - Break down negative connotations of living with HIV and tackle stigma
- Advocate for change for the most marginalised within the community such as:
 - Through the creation of community-based ‘brave spaces’ for people to access information and support
 - Allowing more choice in how services are accessed e.g., digital vs in person
- Work with the HIV Action Plan implementation group (and similar groups across the UK) to maintain efforts towards engaging a wider network of HCPs to educate and upskill them to be able to talk about HIV to overcome stigma and lack of trust within broader healthcare settings
- Strengthen and build more HIV advocates across the HIV sector, particularly:
 - Focussing on training and mentoring a new generation of HCPs to better understand the needs of people living with HIV today
 - Engaging younger people living with HIV to continue to drive progress to 2030 and beyond
- Strive for more open and honest conversations about funding, including:
 - Continuing to advocate for a review of funding models and adequate/sustainable funding
 - Implementing robust evaluation methods to provide an evidence-based approach to long-term funding
 - Seeking collaboration and expertise from outside the HIV community e.g., charitable organisations from other sectors, organisations such as Spring Impact, to support broader, more sustainable funding solutions



Key learnings for Gilead and the wider life science sector

The meeting provided a valuable opportunity for Gilead to listen directly from the community and take learnings to inform future planning, such as:

- Review of Gilead's grant funding process to ensure clarity of process
- Consider how industry-developed programmes such as the [HIV Collective](#) and [Find Your Four](#) can add value to work being done by community organisations
- Better sector engagement to inform future initiatives – for example, Gilead's *Find Your Four* campaign could benefit from considering the following:
 - Revising language used in website copy and campaign materials to update the reference to U=U and be more inclusive of younger people
 - Being clearer on what the campaign is asking people living with HIV to do
 - How the campaign is supporting people who are no longer engaged in care
 - How to ensure the campaign is set up to reach a broader group of individuals, beyond those who are already engaged
 - How to ensure the campaign supports those living in areas where there are no voluntary support services
 - Alignment to migrant projects to reach these audiences
 - How to reach those not digitally literate or don't have access to online resources

Conclusion

In a challenging and evolving public health landscape, the meeting provided a moment of reflection for the HIV community.

The engaging discussions and working groups challenged our collective understanding of the 2030 targets and what this truly means for people living with or at risk of acquiring HIV. It raised questions around the language we use and the importance of this as we seek to reinvigorate efforts towards further progress in HIV prevention and care. It also rallied the community around the message that 'HIV isn't done' and a need for renewed activism in the face of funding restrictions and a shift in political and local commissioning priorities.

Importantly it was recognised that this meeting was just the first step in the process. The insights gathered as part of the meeting are being shared with all those involved to help fuel future discussions and programmes.

Moving forwards, as part of the *HIV Collective* Gilead will continue to listen, facilitate conversations, and drive collaboration so that as a community, we can address challenges and leverage opportunities to continue progress towards the 2030 target and beyond.



Useful links

Please note that some of these links contain content that is not owned or controlled by Gilead Sciences, and Gilead Sciences is therefore not responsible for your interactions with the websites or the information they contain.

HIV Action Plan: <https://www.gov.uk/government/publications/towards-zero-the-hiv-action-plan-for-england-2022-to-2025/towards-zero-an-action-plan-towards-ending-hiv-transmission-aids-and-hiv-related-deaths-in-england-2022-to-2025>

National Government reports on HIV testing, diagnosis and care in the UK: <https://www.gov.uk/government/publications/hiv-in-the-united-kingdom>

People First Charter: <https://peoplefirstcharter.org/>

HIV Collective website: <https://www.hivcollective.co.uk>

Find Your Four website: <https://www.hivfindyourfour.co.uk/>

Spring Impact resources: <https://toolkit.springimpact.org/home>