



WHAT IS #GENENDIT?

#GenEndit is the culmination of this belief: united, we can grow attention, conversation, action and momentum to end AIDS as a public health threat. Together, we are the Generation-to-End-It. #GenEndIt.

#GenEndit is a partnership of individuals, organisations, initiatives and movements working together to find solutions whose collective efforts and investments fuel and sustain the #GenEndIt movement.

#GenEndit is a unifying message to inspire collective attention and ownership to end AIDS.

#GenEndit is a hashtag that virtually connects our common passion.

#GenEndit is a mantra that empowers and inspires.

#GenEndit is a global call to action.

HOW DOES #GENENDIT WORK?

- We create a #GenEndIt global community.
- We show our common commitment to ending AIDS through collaboration, conversation, awareness, youth engagement, public support and by raising up the work of each other.
- We campaign together on AIDS issues young people care about, issues like HIV testing and prevention education, more funding to respond to the AIDS epidemic, an end to all forms of discrimination.

Intro to toolkit

This toolkit aims to support young people worldwide to join the #GenEndIt movement and take action, creating individual and collective campaigns to drive attention to the issues young people care about in the HIV response. In this guide, you will find an introduction to campaigning with and for #GenEndIt and how you can get involved. We're here to support you, and this step-by-step toolkit includes practical information on how to take action, be an inclusive campaigner and organise impactful events. This, plus some helpful and actionable tips for practising self-care and addressing power dynamics.

We hope you find this toolkit to be exactly that: a useful set of tools and guidance to help you develop your skills and expertise as a campaigner and, most importantly, join us to drive change and end AIDS by 2030.

Foreword(s)

My desire to campaign started in early 2019 when I was in rural Uganda delivering a project on SRHR education in secondary schools. Uganda is a country with high rates of gender inequality, disparities in socioeconomics and high HIV prevalence, as of 2021, 1.4 million people were living with HIV.

During my time on the project I came to learn that within education settings in Uganda it is only legal to teach and promote abstinence. The lack of adequate, age appropriate education for young people meant that young people were unable to make informed decisions about their health. It also resulted in many young people having inaccurate, sometimes harmful beliefs about HIV and people living with HIV.

This experience motivated me to do more to raise awareness about the importance of adequate education, to lobby governments to provide adequate funding for access to medicine and delivery of local projects, but more importantly to dispel myths about HIV and people living with HIV.

After I returned to the UK I joined Youth Stop Aids as a campaigner, and last year became the chair of the #GenEndIT Youth Steering Group. My experience as a chair has been wonderful. It has been a privilege to work and collaborate with such talented young women. A lot of great work has been done to tackle HIV/AIDS as a public health threat, but there is still more to do and we need to ensure we don't become complacent in making it a priority.

I am excited for this toolkit as it's the first one ever for campaigners connecting them to the wider network and movement of #GenEndIT. It's also great for #GenEndIT to reflect on the amazing work that we have done so far and look to the future of things we would like to achieve. I think this tool kit will be very useful for campaigners because it's been designed with the needs of young people in mind. We have created a toolkit that can be utilised by campaigners who are beginners or ones who are well experienced, ultimately supporting them to make change the way they want big or small. We have also included ways campaigners can keep themselves safe, practice self-care whilst doing work they are passionate about. - Sally Hamilton, Steering Group Chair



Being young, I find myself at the intersection of vulnerability when it comes to HIV. Taking action and engaging in advocacy are not merely choices; they are essential steps towards safeguarding my health and the health of countless others in similar circumstances. By involving myself in youth-focused HIV organisations and movements like #GenEndIt, I joined a collective effort and voices dedicated to addressing the unique challenges young people face in the HIV response. #GenEndIt has always empowered me with knowledge, support, and a platform to raise the voices, effect change, and work towards a world where HIV is not a barrier to a fulfilling life.

"Engaging in the youth-focused HIV movement is not a choice but a drive of hope, empowering young people like us to illuminate a brighter, healthier future for all."

Karon Lama, Steering Group Member.

Terminologies

Preferred/Key HIV Terminology	Description
HIV	Human Immunodeficiency Virus - A retroVirus that attacks the white blood cells within the immune system.
AIDS	Acquired Immunodeficiency Syndrome - Umbrella term for the illnesses that occur from untreated HIV, at the point of AIDS the immune system is severely compromised and unable to fight off infections.
Person/people living with HIV	A person who is HIV positive (avoid referring to people as an abbreviation, such as PLHIV, as this can be dehumanising.)
Undetectable Viral Load	Reduction in the amount of the virus in the blood to undetectable levels and slowing the progress of HIV disease
U = U/Undetectable = Untransmittable	A term used to explain that people living with HIV who are on treatment and have a fully suppressed viral load cannot transmit HIV.

Viral Load	The amount of virus in a person living with HIV's blood
PrEP	Pre-exposure prophylaxis - refers to antiretroviral medicines prescribed before exposure (or possible exposure) to HIV. Several studies have demonstrated that a daily oral dose of appropriate antiretroviral medicines is effective in both men and women for reducing the risk of acquiring HIV infection through sexual or injection transmission (from sex by about 99% and from injection drug use by at least 74%).
Key populations	Populations or communities disproportionately impacted by HIV. Gay, bisexual, and other men who have sex with men sex workers and their clients, transgender people, people who inject drugs prisoners and other incarcerated people These populations often suffer from punitive laws or stigmatising policies, and they are among the most likely to be exposed to HIV. Their engagement is critical to a successful HIV response everywhere—they are key to the epidemic and key to the response. Countries define the specific populations that are key to their epidemic and response based on the epidemiological and social context. Avoid referring to high(er)- risk groups or vulnerable groups.
Stigma and discrimination	Stigma can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others, such as when certain attributes are seized upon within particular cultures or settings and defined as discreditable or unworthy. When stigma is acted upon, the result is discrimination. Discrimination refers to any form of arbitrary distinction, exclusion or restriction affecting a person, usually (but not only) because of an inherent personal characteristic or perceived membership of a particular group. It is a human rights violation. In the context of HIV, this can be a person's confirmed or suspected HIV-positive status or key populations, irrespective of whether or not there is any justification for these measures.
Youth-led responses	Interventions, actions, and strategies that seek to improve the health and wellbeing from a human rights-based approach, of young people (under 30 years old) living with and affected by HIV, and are specifically informed and implemented by and for young people (under 30 years old) living with and

	affected by HIV, and the organizations, groups, and networks (both formal and informal) led by them. A youth-led response can be implemented by a youth-led chapter/branch/network within a larger organization or network that is not youth-led, so long as the youth-led chapter/branch/network has decision-making power over the activities and budget, where it exists. If there is funding it must be managed by the youth-led chapter.
Youth-led organisations in the context of the HIV response	Youth-led organisations are defined as groups and networks in the HIV response, whether formally or informally organised, that are led, informed, and organised by young people (under 30 years old) living with and affected by HIV, for young people living with and affected by HIV, and address young people's issues, and which at least 80% of the governance, leadership, staff, spokespeople, membership, and volunteers are made up of young people under 30 years old, and represent the perspectives and voices of their constituents, and who have transparent mechanisms of accountability. Youth-led organisations are characterised by horizontal decision-making processes that engage young people in all their diversity in the decisions being made, and are led by representatives of the youth communities that they serve.

For further references please visit UNAIDS Terminology Guidelines - 2015 | UNAIDS

Chapter 1 - Join the movement

#GenEndIt was launched in 2016 at the International AIDS Conference in Durban, South Africa, and is currently steered by the 10 global AIDS organisations (Charlize Theron Africa Outreach Project, Elizabeth Taylor AIDS Foundation, Grassroots Soccer, Sentebale, Elizabeth Glaser Pediatric AIDS Foundation, MTV Staying Alive Foundation, Elton John AIDS Foundation, The PACT, Avert & UNAIDS).

- Anyone is welcome to join
- This toolkit will serve as a practical guide for the young campaigners on how they can be better involved in the #GenEndIt movement and use the #GenEndIt hashtag, tagging UNAIDs and #GenEndIt and other partners would also help amplify their work.
- To join the GenEndIt movement use

Chapter 2 - Take action / what change you want to make

This is an inspirational section illustrating different kinds of actions you can take as part of HIV advocacy and awareness campaigns. It aims to emphasise that campaigns can be of any size, big or small and still make a difference.



Any campaign's success depends on how we communicate about it and what strategies we adapt. One of the main thing to focus and take action on is:

Developing Key Messages: key messages tell the world what you want to change! They are concise and compelling statements that communicate your issue succinctly. The general format of a key message is: We want A to do B because it will improve C. Key messages should be used consistently across all of your activities and communications.

Developing a message framework can help you create key messages tailored to specific audiences. A good message framework consists of a primary message that speaks in specific terms about the advocacy campaign's overall goal. Secondary messages support your primary message, providing further facts and explaining how your vision can be achieved. The secondary messages should be targeted to your different audiences.

Examples of HIV campaigns:

A video on overcoming stigma associated with HIV AIDS- story of Livey Van Wyk, supported by UNICEF as a pregnant HIV-positive teenager, who at aged 17 found out she was both pregnant and HIV positive. She was ostracised by the community and removed from the school she loved. She tells of how important UNICEF were to her, and how they helped her as a child to develop to a point where she could share her story. The town which had previously shunned her now elected her mayor; her child was born HIV negative. The story itself is empowering with Livey achieving her goal and living a happy, full life.¹

Another <u>initiative of Knit Together</u>; which aims at helping Young People access life-saving information on HIV AIDs. Knit Together Initiative brings young people together to review FLHE curriculum taught in secondary schools – and to advocate to make family life education better while addressing many obstacles, including the stigma around talking about young people and sex.

<u>I am a Work of ART</u> is a community-informed national campaign funded by the U.S. Department of Health and Human Services designed to encourage people with HIV who are not in care for HIV to seek care, stay in care, and achieve viral suppression by taking antiretroviral therapy (ART). And <u>this page</u> features ten success stories through this campaign.

<u>Doing It</u> – a bilingual campaign to encourage all adults to get tested for HIV and know their status. In addition to encouraging testing for all Americans, the campaign focuses on populations who are most at risk for HIV in the United States.

The <u>Play 4 SRHR project</u>, designed to provide essential support to young people in Malawi. The programme aims to provide intensive week-long training. The primary objective is to equip them with vital knowledge and life skills, helping them make informed decisions about their health and well-being, both now and in the future.



¹ Story information-https://social-change.co.uk/blog/2018-12-01-the-best-world-aids-day-campaigns-and-why-they-were-successful

Chapter 3 - Campaigner self care and safety

As a HIV campaigner it is important to prioritise your own well-being while advocating for others. Some ways in which you can do this are listed below

You can set boundaries

Clearly communicate your limits and needs to others, saying no when necessary, and prioritising self-care. It's important to establish boundaries to prevent burnout and maintain a healthy work-life balance.

Practising mindfulness

HIV campaigners can practise mindfulness by engaging in activities that promote present moment awareness, such as meditation, deep breathing exercises, or yoga. Taking time to focus on the present can help reduce stress by giving your mind a break and improve overall well-being.

Seeking support

You can seek support by connecting with other campaigners or joining support groups specifically for HIV advocacy. You can also reach out to friends, family, or mental health professionals for emotional support and guidance. Remember, you don't have to go through it alone!

Taking breaks

Working too hard and for too long can be draining and damaging to your mental health and wellbeing. Taking a break is a necessity for your productivity and focus. A few signs that you should take a break:

You feel fatigue setting in * * You're working too much on one single task * * You're neglecting your body's needs (physiological needs, postural hygiene, etc). * * You're feeling frustrated and need to clear your mind * * You find it hard to concentrate on anything * *

Aisha Moore's Journey to self-care

Here I have shared Aisha Moore's interview with Jamal Refuge about her self-care Journey as a HIV professional. Aisha talked about overworking herself, experiencing burnout and how she overcame these things, as well as some of the criticisms she faced and how she dealt with them.

Aisha stated that the fight to end the HIV epidemic is urgent, but not so urgent that she needed to lose sleep, stop eating regularly, or allow her body to break down in the process.

Keeping safe

Knowing how to stay safe is an important part of activism and campaigning

Recommendation to stay safe on Twitter



Chapter 4 - Power dynamics

Leadership is about shifting power, not holding it.

In the work that we do as campaigners, it is crucial that we think about power dynamics, systematic inequalities and how we overcome them, both in terms of how we design a theory of change and strategy for winning our campaigns but also in how we set up the campaigning work to start with.

As campaigners, we need to put understanding power dynamics at the heart of our thinking: who is designing a campaign? Who is making the decisions? Who is speaking? And who is missing from the conversation? What language are we communicating in? Are we speaking on behalf of others, rather than inviting them into the conversation and encouraging them to have their say? How do we make sure everyone feels safe to share their thoughts and to contribute confidently?

And in our campaigning strategy: who holds the power on the issue we are working to address? What will convince them to support our calls for change? What other types of power might be working in this area, either to help or hinder our campaign?

Shifting power in our work

Five top tips for understanding and understanding and thinking about power dynamics:

Put a set of principles in place so that everyone involved in your campaign centres power-shifting in their work. You could use this <u>Power Shifting Checklist</u> developed by Restless Development as a starting point.

Think about how you set up and facilitate meetings, brainstorms and events. If they are online, how are you ensuring that those who cannot join due to connectivity challenges are able to contribute? If you plan to use a platform like Zoom, can you use language functions within the platform to ensure that those who use a different language can follow the conversation and contribute? How are you facilitating conversations so that those who feel less confident can contribute (for example, using smaller break-out sessions or tools like Miro or Mural for people to add their thoughts). Have you given thought to how you will ensure that the meeting is accessible for those with additional needs, including disabilities, and that they can fully participate? How representative of marginalised groups and inclusive are your participants?

How are you making decisions? If you're working as part of a group, how are you setting up decision-making to ensure that everyone feels comfortable to contribute their viewpoint? If a smaller group of people have made a decision about the campaign, how are you communicating this back to other stakeholders in order to be transparent? Are you keeping stakeholders up-to-date with how your campaign is going and seeking their feedback?

It's my experience vs speaking on behalf of... Are you speaking about your own experiences or on behalf of someone else? If you're campaigning on an issue that you care about but is something that you don't have direct experience of or is an issue that occurs in a different country or region, consider how you're talking about the people involved. Are you using language that does not acknowledge the



agency of others, instead depicting them as victims or as powerless? Are you speaking in a way that emphasises a power dynamic of "them" and "us"? Instead, think about how you're sharing other people's stories - have you got a connection with that community and have you spoken with them about their experiences and how they would prefer those experiences to be shared? Have you given thought to the images you share? Do you have the permission of any individuals involved when it comes to sharing those images?

Who is missing? If you've organised a meeting or event, look around and think: who is missing? Is everyone in the room - or virtual room! - the "usual suspects", people you would expect to see, who might share the same perspectives on change-making and campaigning? This is not necessarily a bad thing as it may mean that you have a high-functioning team who have been working together from a range of different backgrounds. However, if you think you're missing the skills and expertise of others, particularly if the majority of participants are based in one region but campaigning on issues happening in an entirely different location, then you should consider how you bring others into the conversation.

Power Dynamics Reading:

If you may also want to refer to this helpful resource on understanding power:

→ All About Power by Srilatha Batliwala <u>Srilatha Batliwala's publication from CREA "ALL ABOUT POWER" (CREA 2019)</u>

Chapter 5 - Impactful events and storytelling

To develop a powerful campaign message, focus on a clear and compelling objective, understand your target audience, and use persuasive language and visuals. Make it memorable!

Share personal stories

Some of the reasons why sharing stories is important for an effective HIV campaign are:

- ★ Starting a conversation Get people talking about your campaign to generate interest and engagement
- ★ Educating A personal story can help people understand HIV from another point of view other than medical or Science based, they should learn things about HIV that they didn't know before.
- ★ Advocating Stories can connect people and build solidarity, fostering understanding and support for those affected by HIV.
- ★ Changing minds and creating empathy Stories humanise the issue and encourage open conversation that reduces stigma.

A good story is:

★ **Authentic** - this Involves the story being genuine, sharing real experiences and thoughts. The stories should be true to the individual in order to connect with others.



- ★ Inspires your audience when the audience is inspired it can motivate them to take action, create hope and show that change is possible. It can empower others to overcome challenges and make a positive impact.
- ★ Timely this is important because it relates to current events or issues, making it more relevant and impactful. It helps capture attention and encourages immediate action and reflection.
- ★ Unique the story will stand out and capture attention. Offering a fresh perspective, sparking curiosity and creating a lasting impression.

To create some impactful visuals you can use <u>The Greats</u>, it is a free vault with carefully curated socially engaged visual content open to anyone to use or adapt.

<u>Chapter 6 - Inclusive campaigning</u>

It is important when campaigning in the HIV space to be intentional about being inclusive! Understand the diversity of the society we live in, each person contributing their own uniqueness, and HIV affecting all these people in different ways.

In relation to HIV, inclusivity can be seen as ensuring that people, particularly the communities most affected by the epidemic, regardless of their background, gender identity, sexual orientation, age or ethnicity, are included and represented in HIV-related discussions, campaigns, and support services. It involves creating a safe and non-discriminatory environment where everyone affected by HIV feels respected, supported, and empowered.

Inclusive approaches promote equal access to prevention, testing, treatment, care, and support services for all individuals impacted by HIV.

Here are some ways to make your campaign Inclusive:

→ Ensure diverse representation in campaign materials.

If it's a digital HIV campaign that includes social media and e-actions, such as reels, videos and images make an effort to use people from different backgrounds and communities in the imagery.

→ Use inclusive language that avoids stigmatising or discriminatory terms.

Stigma and discrimination are prominent experiences for a lot of people living with and affected by HIV. Stigma can deter people from getting tested, and seeking treatment. Using the wrong language can perpetuate stigma and shame. The <u>People First Charter</u> is a helpful tool used to centre person first HIV language in your campaign. You can also refer to the <u>UNAIDS terminology Guidelines</u>.

→ Collaborate with diverse communities and organisations to amplify their voices.

Focus on allyship, including those with lived experience and underrepresented voices. The PACT is a good entry point for mapping the partners working on HIV and sexual reproductive health, specifically youth organisations working on these issues.



Make sure to include people with lived experiences' in blogs and storytelling, allowing them to share their stories. (Check the terminologies chapter for a list of groups disproportionately affected by HIV). Chapter 5 discusses storytelling in more detail.

→ Provide accessible information in multiple languages and formats

This might look like using clear text, using accessible venues with ramps and lifts, providing sponsorship or travel support where possible, sharing notes, including content warnings, considering what privileges may impact your campaigns and what barriers may prevent others from joining in campaigns.

For any campaign activities where there may be speakers or panellists you could provide a translator and sign language interpreters.

→ Address intersectionality by recognizing how HIV impacts different communities.

HIV disproportionately affects some demographics, such as gay men and sex workers (you can see the full list of key populations in the terminologies chapter).

Example: A campaign focusing on HIV prevention would need to consider that there are different means of acquiring HIV. Condom promotion alone may be appropriate for some groups (gay men, sex workers etc) however, people who inject drugs may need harm reduction interventions such as needle/syringe programmes.

Examples of Inclusive HIV campaigns:

A good example of a campaign that centres inclusion and diversity is the Women and HIV: Invisible No Longer campaign.

It was a one-year project led by Sophia Forum and Terrence Higgins Trust. It aimed to set out clear recommendations for policy and service development to ensure that greater focus is given to women affected by HIV.

They discovered they didn't have much information about what it means to be a woman in the UK living with or at risk of HIV. They didn't know what women's needs were or what interventions were in place to meet those needs.

They saw a lack of inclusion in the HIV space and they set up their campaign to fill that gap. The focus of the project was all women including trans women. Women of different sexualities and ethnicities, whether they do or don't have children, or are pregnant, were all included.

Remember, inclusivity is about embracing diversity and making everyone feel welcome and represented!

Chapter 7 - Tracking your impact

• Define a SMART goal. It is important to begin with a clear idea of the change you would like to see with your campaign. A good way to begin is to think through what would you like your community to think, feel and do at the end of the campaign. Broadly speaking, a goal describes what a campaign wants to achieve or influence and represents what the campaign



is trying to achieve or change, not what it does. A goal must be <u>SMART</u> i.e. Specific, Measurable, Attainable, Relevant and Time bound.

- **Define indicators**. Once you have identified the goal, think about what will help you identify whether the goal has been achieved. Indicators act as signals, signposting whether or not expectations of change are being met and form an important part of most approaches to measure impact. An indicator is something that helps provide evidence that a change has happened it is not the desired change itself.
- Indicators can be categorised in different ways. The simplest way is to differentiate between quantitative and qualitative indicators. Quantitative indicators are reported as numbers, such as units, prices, proportions, rates of change and ratios. Qualitative indicators are reported as words, in statements, paragraphs, case studies and reports. Note that it is not the way in which an indicator is worded that makes it quantitative or qualitative, but the way in which it is reported.
- Measuring the impact of your campaign depends on the type of campaign you are implementing, the context in which it is being implemented and the types of activities undertaken. A campaign conducted on-ground will have a different way of measuring impact as opposed to one that is conducted virtually. Collecting evidence of change against any indicator can be achieved by different methods or data collection tools.
- For a social media campaign, social media analytics are a useful tool to capture impact. Every social media channel has its own analytics tool built-in. These provide a great way to get some quick facts about how effective your efforts are on these channels and discover potential areas for improvement.
 - Likes on posts, videos; re-shares, comments, mentions, number of followers
 - Twitter Analytics
 - Instagram analytics tool
- Think about using tools such as <u>Zoom Polls</u>, <u>Mentimeter</u> and <u>Google forms</u> to gather insights on how the audience of your campaign is receiving the information and whether it is leading to any change. These are useful snapshot engagement tools that can be built into your campaign plans at different points.
- Stories of change are powerful ways to capture and demonstrate the impact of your campaign. <u>Most Significant Change</u> Approach
- Some points for reflection can also be built into campaign activities to collect evidence of change. Some ways to do this are institutionalising regular 'reflection sessions' with the campaign team.