

# Fund what works: fund community-led women's rights organisations for an effective, ethical and sustainable response to HIV

## Introduction

The WHAVE is a podcast series by and for women living with HIV around the world, talking about our sexual and reproductive health and rights. This is the 1st of four briefs based on this series.

### 1. This brief

In this brief, we focus on the challenging issue of funding for women's rights organisations. Longret Kwardem of the 4M Mentor Mothers Network features a lot in the quotes in this brief because she decided to speak specifically about it for episode 12 of The WHAVE. However, funding challenges have been reported by the contributors to all episodes, without exception, as a constant and chronic worry and drain on their mental resources. Their experiences reflect the findings of research into funding for women's rights work, including a study for UN Women on financing for equality in the HIV response (Nilo, 2019),<sup>1</sup> the foreword of which captures the issue:

*'Although strong United Nations policies and frameworks aimed at gender equality and women's empowerment exist, when it comes to HIV and AIDS response, there is increasing 'lip service' and rhetoric around commitments.'* Alessandra Nilo<sup>1</sup>.

<sup>1</sup> Financing Women's Organizations & Mobilization for Gender Equality: One of the Keys to Ending AIDS' – Nilo, A. Background Paper for the Expert Group Meeting on Financing for Gender Equality in the HIV Response/ UN Women; 2019. (forthcoming)

## 2. Key message: Funding is a huge challenge for networks and organisations of women living with HIV

Funding for women living with HIV is vital to implement WHO's Consolidated Guideline on Sexual and Reproductive Health and Rights of Women living with HIV (WHO, 2017<sup>2</sup>). This is recognised in the Checklist for community engagement (WHO, 2019<sup>3</sup>), which calls on key donor partners to 'support organisations and networks of women living with HIV, especially those from key affected populations, who are struggling to access funding for the important work we are doing.'

However, it is clear from the experiences of the women who contributed to The WHAVE that funding is a huge challenge for organisations of women and girls living with HIV. In every episode of Series 1, women talk about the importance of funding for collectives and organisations of women and girls living with HIV, and the impact of the current lack of funding on their work.

*'Funding has just been such a huge frustration to be honest. We spend hours applying for funding every year, every year it's a struggle, and it's enough funding only to achieve the barest minimum.'* (Longret Kwardem, UK)

Contributors from countries as diverse as Argentina, Cameroon, Kenya, Puerto Rico, Spain, Uganda, UK, and Zimbabwe, underscore the current scarcity of funds for organisations and networks of people living with HIV and the peer support, treatment literacy and advocacy they engage in.

*'In our context, funding is scarce, funding is like the tears of dogs, we do*

*not even find it. It is important to give us enough funding. Our deepest wish is to really make funding available to enable these women to do what they want to do.'* (Francine Nganhale, Cameroon)

The WHAVE contributors describe how they and their organisations are affected by the funding 'starvation cycle'<sup>4</sup>. This phrase refers to how funders focus on short-term, project-based granting, often with limited or no provision for overhead or core costs. Civil society organisations often find themselves reliant on only one or two supportive funding sources. They feel pressure to finish reporting on one grant before applying for the next (if repeat funding is even available), thereby conforming to these unrealistic expectations and leaving themselves with a funding gap. They often underbudget for overheads, staffing, equipment, training, proposal and report writing and so on, and may also under-report the costs. This further fuels unrealistic donor expectations of how much money it takes to run an organisation. Lack of continuity of funding exacerbates this further.

*'The funding we have had so far has been project funding, and it's usually year on year, so every year we have to apply for new funding and that's the challenge. Because it's project-based work and we haven't got any core funding to make sure we are sustaining ourselves.'* (Longret Kwardem, UK)

The WHAVE contributors raise the following important points about funding.

2 World Health Organisation, 2017, Consolidated guideline on sexual and reproductive health and rights of women living with HIV. [https://www.who.int/reproductivehealth/publications/gender\\_rights/Ex-Summ-srhr-women-hiv/en/](https://www.who.int/reproductivehealth/publications/gender_rights/Ex-Summ-srhr-women-hiv/en/)

3 WHO, 2019, Translating Community Research Into Global Policy Reform For National Action: A Checklist For Community Engagement To Implement The WHO Consolidated Guideline On The Sexual And Reproductive Health And Rights Of Women Living With HIV. <https://www.who.int/reproductivehealth/publications/srhr-women-hiv-implementation/en/>

4 Salway, M. and Walker, E. 2015. Preventing death by starvation. Charity Finance, June 2015. [https://www.cass.city.ac.uk/\\_data/assets/pdf\\_file/0016/344113/Charity-Finance-Preventing-death-by-starvation-Salway-and-Walker-June-2015.pdf](https://www.cass.city.ac.uk/_data/assets/pdf_file/0016/344113/Charity-Finance-Preventing-death-by-starvation-Salway-and-Walker-June-2015.pdf)

## 2.1 Donors commonly focus on larger organisations, but should ensure that more funding reaches smaller and community-led organisations

Women contributors to The WHAVE talk about the fact that many funders believe that formal, structured organisations can more effectively use and account for funds than smaller grassroots organisations. Yet it is grassroots, smaller organisations that are often more representative of - and better connected to - women, young people, and other communities living with or affected by HIV. Contributors highlight the structural and societal challenges their organisations may face, including inequalities related to gender, age and other aspects of identity.

*'There is a perception of hierarchy, that because one group has a structure that they are more credible, it's easier for them to receive funding. There is the element of who has access and the privilege of being able to formalise their structures. There are certain aspects such as age, gender, sexuality that may limit the ability of a group to formalise. How formal or informal a group is should not be the main indicator of how credible or impactful their work is. There is a real onus on HIV organisations, the ones with the big, established structures, to go more to grass roots and support the capacity of women-led organisations, young people-led organisations, because there are structural barriers to them receiving funding.'* (Bakita Kasadha, UK)

Often global organisations - international development organisations or NGOs - are funded by donors to manage funds that are ultimately intended to support regional and national organisations and efforts. However, sometimes little of the funding actually reaches those regional and national organisations. This 'fund-management' architecture has a detrimental knock-on effect, affecting the entire response to women and HIV, and its growth and evolution.

*'I believe that the regions can manage our funds, do our own studies, make our reports with our regional networks and our regional cultures. So I think we have to break the logic of global studies, global financing, and especially if we are talking about northern funders providing funding to the south, as that is super colonising. There is also the issue that sometimes the southern organisations who are sub-contracted do not benefit at all politically or economically.'*

(Mariana Iacono, Argentina)

Fundraising itself has a cost, so unfunded or underfunded organisations of women living with HIV are investing voluntary time in writing grant proposals.

*'We haven't got funding in place to be able to fundraise, because fundraising takes time. So you either find that we have a fundraising proposal that is not good enough, or we have to get people to work with us pro-bono to support us to do the fundraising work, and the funders chose to give the funding to big organisations with less [specific] expertise than what we have. It's so frustrating.'* (Longret Kwardem, UK)

For small community-led organisations, it is extremely important that funding opportunities and guidelines are transparent and easy to understand, and that guidance accurately conveys the expectations of the funder and the kind of terminology the funder expects to see in proposals. Funders and others must reduce the bureaucracy involved in applying for funding (particularly anything more than seed funding), and build the fundraising capacity of community-led organisations. But these are not the only things which are off-putting - seed funding is often only for project activities, and rarely covers core costs, and the jump between seed funding and bigger project funding is often a big barrier.

*'So it scares me to apply for bigger funding because I feel like I don't have it, because I am doing direct work, I go direct to the beneficiaries. When I get money, I reach out to my ladies, and I'm like let's do this, and that's all. To hire auditors, you need to have this big organisation, I can't afford it. At the grass roots, most [organisations] are registered, but they don't have these documents, a workplan, they don't even know how to write, but they are helping each other. And this is the thing that needs to come out. For big organisations that have everything, they can win these funds. If you look at grassroots ladies they know each other, they reach each other, they are always available 24-7, they never close doors, they help each other. It's very important – very, very important.'*  
**(Resty Nalwanga, Uganda)**

## **2.2 Donors and fund-management organisations should support the kind of activities women living with HIV prioritise, and the ways women choose to organise**

Contributors to The WHAVE often describe work which they consider essential as women living with HIV. Yet they have seen its funding cut, or it is considered ineligible for funding, despite responding directly to the priorities of women living with HIV.

*'It's important that we have funders listening to what we are saying our priorities are. Because we talk about what we want, and then we go out to look for the funding to do the work, and that's not what the funders want to fund.'* **(Longret Kwardem, UK)**

Globally, funding for women's rights organisations, especially grassroots organisations, is extremely scarce,<sup>5</sup> and the experiences of The WHAVE contributors reflect that.

*'I would say all funding and services should be approached from a gender equity lens. Until you do that, it's very easy for women to end up having nothing because of gender inequality. By default, we always end up with less than we require. What percentage of funding goes to women? Very small.'*  
**(Longret Kwardem, UK)**

In some cases, work that has been previously funded and showed good results is scaled back when there is a reduction in funding available. MariJo Vázquez of Spain talks about a drop in funding resulting in scaling down of successful training provided by women living with HIV, which had been supporting nursing students to understand the importance of non-discriminatory, patient-centred care.

Sometimes whole regions experience challenges, as in the case of Latin America, where there has been a huge reduction in donor funding in countries classed as Middle Income Countries. As Mariana Iacono of Argentina points out, this does not take into account the political challenges and huge economic inequalities experienced in the region, and their disproportionate impact on women and girls. This significantly affects the work of regional and national networks of women living with HIV, including the work of the International Community of Women living with HIV (ICW) across Latin America and the Caribbean, and within countries such as Argentina.

In other cases, it may be because the type of work carried out is not visible to others, by its very nature of being specifically run by and exclusively for women living with HIV. It can therefore seem as being of dubious value, and can feel threatening to health workers or other pro-

<sup>5</sup> Association of Women in Development (AWID) 2019. Toward a feminist funding ecosystem. [https://www.awid.org/sites/default/files/atoms/files/awid\\_funding\\_ecosystem\\_2019\\_final\\_eng.pdf](https://www.awid.org/sites/default/files/atoms/files/awid_funding_ecosystem_2019_final_eng.pdf)



professionals, who may have never experienced the power of peer support in their own lives. The work can thus not be seen as eligible by policy makers and donors, who can often doubt its potential impact.

*‘Sadly, we don’t receive enough funding for this. People think theatre is nothing much, no impact. But they are wrong.’*  
**(Rahayu Rahmat, Malaysia)**

Contributors would like donors and fund-management organisations to recognise the importance of different kinds of initiatives. One example is participatory workshops on sexuality and sexual pleasure run by and for women living with HIV in Puerto Rico.

*‘I think it would be good to be able to fund initiatives that are different, that are grassroots, in communities, carried out by women living with HIV, who have a better idea of what the needs are, what the implications are. Ways that are not so bureaucratic. I think it would be important to look for other ways to fund grassroots initiatives that work with art. I believe these initiatives have been important and transformative for women. They are focused on and thought up by women for women living with HIV, based on evidence generated by women.’*  
**(L’Orangelis Thomas, Puerto Rico)**

Many of the contributors work on a voluntary basis with their peers at community level. All of them want their work to be better resourced, supported and acknowledged. However, they do not all have, or want to have, an organisational set-up through which to do this. Even where the women are part of an organisation of women living with HIV, these may not have audited accounts, or even be formally constituted. And not all community women’s organisations or networks wish to become professionalised, formal, structured organisations with all that entails. Yet this means that even when these women, their networks and organisations are doing extremely valuable work

with people in places, or in ways, that other organisations are unable to cover, they are not seen as having the level of accountability or structure familiar to or needed by donors and are not supported by donors, or fund-management organisations to engage on their own terms.

## **2.3 Resourcing and support should be prioritised for the advocacy, organising and peer support work of women living with HIV**

Contributors feel strongly that the work they do is a priority for women living with HIV and should be recognised as such – and that their passion and energy should be valued as integral to the global response to HIV. The kind of work they are doing is often not done by other types of organisation.

*‘I do all this because I believe in it, because I think it’s important, and because nobody else is doing it here. I am not an organisation, it’s just me doing this. There is not much funding – if we have some, we can provide refreshments, more art supplies, or sometimes we can buy specula or menstrual cups for all the participants. But many times I just do it with what I have.’*  
**(L’Orangelis Thomas, Puerto Rico)**

*‘A lot of us run these organisations because we are passionate, and we have a need, and we know how important it is to our quality of life – it was started by us because that’s our priority, and those are the things we need to live well. [...] There is funding there but the funders don’t want to give us the funding, because our priority is not theirs. And funders assume that because we have been volunteering, we are going to carry on volunteering, but it’s not sustainable.’*  
**(Longret Kwardem, UK)**

When funding is scarce or simply not available, contributors talk about doing what they can with the resources available to them.

In Argentina, the national chapter of the International Community of Women Living with HIV mobilised women living with HIV with very little funding.

*'We had a whole two-year process to revitalise the Argentina national chapter which had been put on hold a bit and was inactive. [...] We had activities throughout the country, from the north in the province of Jujuy, Santiago del Este, in Patagonia, in the center, and all under our own steam with very little funding, We managed to have capacity building, assemblies, training workshops for women with HIV - and for other people not just women with HIV. We were also following up the whole national issue with the government.'*

**(Mariana Iacono, Argentina)**

In the UK, 4M Mentor Mothers has used technology where funding was not sufficient for face to face meetings.

*'We are a UK-wide network. Women would like to meet up regularly, but we haven't got the money to do that. The WhatsApp group was supposed to be a cheaper way of making sure we are 'meeting' each other.'*

**(Longret Kwardem, UK)**

Contributors in different countries describe various ways of self-funding their work. For some, their grassroots organisations - including Positive Young Women Voices in Kenya and Tendo's World in Uganda - raise money through income-generating activities such as handicrafts, or making and selling reusable sanitary pads. In Malaysia, Rahayu Rahmat has authored a book about her life, *'Be careful of this woman: my journey to freedom'*. Profits from the book help

to fund her work as the founder of Sinar Sofia, an organisation providing a safe haven support for women living with HIV, sex workers and women who use drugs. She is not paid at all for this work.

*'In 2017, we set up our own small shelter, it's very small, nothing fancy, using our own money to place these women. I just want them to have a safe place. I'm not being supported by anyone. Sometimes I will do crowd funding to maintain and sustain it and of course I wrote my own book, and whatever proceeds of my book go to maintaining our shelter.'*

**(Rahayu Rahmat, Malaysia)**

## **2.4 Current funding priorities lead to activist burn-out, and this must be addressed**

Many contributors talk about self-funding their community work by finding full-time paid employment to earn money. Reflecting gender inequality and the gender pay gap, this is often low-paid work which can fit around the gendered demands of unpaid caring responsibilities. They then use any free time they have to do their advocacy, organising and peer support work. The balancing of unpaid community, peer support and advocacy work with the need to secure an income is a common challenge.

*'A lot of us do the 4M Mentor Mother work on a volunteering basis mainly. I am a full time worker in mental health, because I have bills to pay. And I do 4M Mentor Mother work on top of that. So I struggle with the time, because I have to do my full time job first, because that's what pays my bills.'*

**(Longret Kwardem, UK)**

This can often lead to burnout for women, which is exacerbated when the peer support that can re-energise activists is not valued and funded.

*'[Getting a paid job] leads to serious burnout because both are full time – you are doing two full time jobs, that's what it's like, except one you are not getting paid, and the other maybe you get paid for one to survive. [...] Peer support, treatment literacy and advocacy is still highly highly relevant although it seems the focus has shifted from that and it doesn't seem that anyone wants to support that and also when activists get burnout what happens – people say oh just look after yourself, but how do you look after yourself when you are now known as an advocate and an activist, it's like you are on call 24 hours a day. I know people deal with burnout differently, but getting together with others helps, debriefing, doing something together so you re-energise and get back into the system to provide that advocacy and activism.'*

**(Martha Tholanah, Zimbabwe)**

## **2.5 Current funding models also limit women's participation and involvement in advocacy, organising and peer support work**

Women described the difficulty of combining advocacy and community work with often full-time paid work when funding for additional activities is virtually non-existent. For some women, involvement in peer support, which helps their personal and professional growth and self-confidence, enables them to get back into the world of paid work. However, this can then also affect the quality of peer support they are able to provide.

*'With a lot of the women who volunteer to do the mentoring, when they started off maybe they weren't working, and now they are starting to work and it's becoming difficult, not because they don't want to, but now they have a full-time job. Even if they want to be part of the group they are*

*not having that much time to be able to engage with us any more. A lot of them say it would be great if we could get the funding to be able to employ them to do this mentoring – because it is a job. We are volunteering, but it's an expertise.'*

**(Longret Kwardem, UK)**

For others, it limits their ability to advocate effectively, and the degree to which they are able to keep up to date with key discussions that influence national priorities. This makes it very hard for them adequately to represent their constituencies, or to create effective consultation and feedback to contribute to key evidence; or to influence policies and debates.

*'At the moment, one has to try as much as possible to be connected to the community, to continue giving that support, while taking also, if you can, another job, where you earn some money so you can feed yourself. But then it means how much can you put into that unpaid work in terms of keeping up with information, with the new evidence that is being generated, the new trends, the new guidelines, new information, new good practice that are coming up from others, how much can you keep up, and I'm just finding that for a lot of us in Zimbabwe, we have the passion but without the financial and material support, and we no longer have that system where we give each other, as activists, sessions and make sure we are updating each other, informing each other about new trends.'*

**(Martha Tholanah, Zimbabwe)**

When women's need to engage in paid work undermines their ability to engage in unpaid advocacy work, their absence is often used to undermine a larger agenda around sexual and reproductive health and rights of women living with HIV.

*'Many of ICW's members, for example,*

*work during the day, from 8am to 8pm, or from 8am to 6pm. So, for example, there are all kinds of activities in the National Congress, or with the United Nations Population Fund, UNAIDS, or whoever, but sometimes our members cannot attend because of work. Many of them work for a daily wage. So, of course, one can say, “oh ICW is not present”, or “they say they are involved but they are nowhere to be seen”.’*

**(Mariana Iacono, Argentina)**

## **2.6 Funding should be available to enable women living with HIV to do the work that really makes a difference to them**

Contributors describe the unstinting support they give other women and girls living with HIV in all areas of their lives. In particular they offer peer support, and support for women and girls' economic lives, mental and physical health, sexual and reproductive health, housing and shelter. Through their activism, some of the women

have brought about changes in policy and practice that have far-reaching consequences for the lives of people living with HIV, such as lifting the ban on the antiretroviral drug Dolutegravir (or DTG) in Kenya, described by Lucy Wanjiku Njenga of Positive Young Women Voices.

Resty Nalwanga of Uganda describes the possibilities that a grant of \$1500 afforded her and the importance of the application requirements being simple.

*‘If we are funded, people will live, people will do things, people will tap into their passion and dreams and they will feel like there is someone caring for them.’*

**(Resty Nalwanga, Uganda)**

Francine Nghanhale of Cameroon says that support for women's associations encourages women to come together to share their experiences, support each other and learn to live without fear. She emphasises the importance of building the platform provided by the International Community of Women living with HIV in the sub-region of Central Africa.

### **Investing in women and girls living with HIV must be more than tokenistic. Yet The WHAVE contributors are still asking the same questions posed in 2011 (Salamander Trust<sup>6</sup>):**

- Why is it that women living with HIV continue to beg for the smallest crumbs of occasional funds for our advocacy work?
- Why do we continue to have to fight for our voices to be heard in places where decisions that so deeply affect our lives are being made?
- Why is it that international organisations systematically exclude us while claiming to prioritise the rights and needs of women and girls living with HIV and proclaiming their commitment to our meaningful involvement in decisions which affect our lives?
- Why do we not have access to funds to sustain our self-help and social justice networks?

6 Salamander Trust, 2011, Put your money where your mouth is: Invest in women and girls living with HIV. 2011 – time for change! [https://salamandertrust.net/wp-content/uploads/2019/02/ICW\\_WECARE\\_Policy-briefing\\_ENG\\_July2011.pdf](https://salamandertrust.net/wp-content/uploads/2019/02/ICW_WECARE_Policy-briefing_ENG_July2011.pdf)



### 3. The WHAVE contributors call for the following solutions:

Donors and international organisations:

- **Please listen to women<sup>6</sup>**, reconsider the effectiveness of your funding strategies, explore approaches to redistribution (such as Universal Basic Income<sup>7</sup>, cash transfers or other redistribution approaches) that would support women living with HIV to continue to do their vital peer support, community and advocacy work; and invest in the priorities of women and girls living with HIV.
- **Make more funding** available to grassroots and community-based organisations of women living with HIV.
- **Recognise** that many women's organisations cannot meet requirements such as three years' existence and audited accounts before being able to apply for funds, or even requirements to have a bank account (many women's organisations are challenged by restrictions on opening accounts). Work with women's organisations to ensure funding is accessible to them, and appropriate for their needs.
- **Establish a step-wise approach** to funding, to address the current gap between the very small pots of money which may be accessible to some grassroots organisations, and the much bigger grant funding available to larger, established and formalised organisations.
- **Fund what we want to prioritise:** this includes recognition of the impact of participatory community-led activities including, peer support, theatre and arts-based approaches.
- **Simplify funding processes**, which prioritise small organisations and networks of women living with HIV.
- **Include core funding in every grant, support organisational overheads, and address the funding starvation cycle:**

this will reduce burn-out and provide more continuity between projects;

- Recognise our expertise through our personal experiences: treat us as partners instead of sub-grantees: **provide support to us and build our capacity** as smaller community organising groups.

*'And then the crème de la crème [of the ladder of meaningful participation] is that women themselves are able to actually organise that for themselves, so they might be able to secure funding, they are autonomous, that's the ideal.'*  
(Bakita Kasadha, UK)

As COVID-19 overwhelms us all globally, it is all the more important that women living with HIV have funding so that we can be meaningfully involved in all the decisions made around our SRHR. We are learning daily of increased intimate partner violence facing women in communities in lock down, of limited access to contraceptive goods and services, including condoms, of reduced access to abortion (with concomitant future increases in maternal morbidity and mortality). ARV stockouts will also no doubt ensue. We are also yet to learn about the effects of COVID-19 on women living with HIV across the life span, including during pregnancy, as well as the effects on the baby in-utero or post-partum. Peer support in these times is more important than ever to reinforce collective resilience to the many and complex challenges involved. One thing that more than three decades of global community HIV activism has taught us, as well as the women's rights movement, is that there will be no ethical, effective, sustainable response without meaningful community engagement to respond effectively to all that COVID-19 has in store for us.

7 Ruckert, A., Huynh, C. and Labonté, R., 2018. Reducing health inequities: is universal basic income the way forward?. Journal of Public Health, 40(1), pp.3-7. <https://academic.oup.com/jpubhealth/article/40/1/3/2966187>

## In addition to the material already cited, here is some additional suggested reading, in chronological order:

- Htun M, Weldon SL. The civic origins of progressive policy change: Combating violence against women in global perspective, 1975–2005. *American Political Science Review*. 2012 Aug;106(3):548-69. <https://pdfs.semanticscholar.org/4bbc/e68659522a085d2665426b98663ae49c02ff.pdf?ga=2.25174333.10204540.1585565286-1049780565.1585565286>
- Welbourn, A. The gender politics of funding women human rights defenders. December 2012. *Open Democracy*. <https://www.opendemocracy.net/en/5050/gender-politics-of-funding-women-human-rights-defenders/>
- Porter, F., Ralph-Bowman, M., & Wallace, T. (Eds.). (2013). *Aid, NGOs and the realities of women's lives: a perfect storm*. Bourton-on-Dunsmore, Rugby: Practical Action Publishing. <https://developmentbookshop.com/aid-ngos-and-the-realities-of-women-s-lives>
- ICW East Africa. Are women organisations accessing funding for HIV/AIDS? October 2014. <http://www.icwea.org/download/2210/>
- Duran LA. 20 Years of Shamefully Scarce Funding for Feminists and Women's Rights Movements. 2015. <https://www.awid.org/news-and-analysis/20-years-shamefully-scarce-funding-feminists-and-womens-rights-movements>
- Stevenson, J. All the Things We Could Do, If We Had a Little Money: The Costs of funding Women's Rights Work. May 2015. *Huffington Post*. [https://www.huffingtonpost.co.uk/jacquistevenson/womens-rights-funding\\_b\\_7449852.html](https://www.huffingtonpost.co.uk/jacquistevenson/womens-rights-funding_b_7449852.html)
- Hickel J. *The divide: a brief guide to global inequality and its solutions*. New York: Random House; 2017. <https://www.jasonhickel.org/the-divide>
- Goldmann L, Lundgren R, Welbourn A, Gillespie D, Bajenja E, Muvhango L, Michau L. On the CUSP: the politics and prospects of scaling social norms change programming. *Sexual and Reproductive Health Matters*. 2019 May 31;27(2):51-63. <https://www.tandfonline.com/doi/full/10.1080/26410397.2019.1599654>
- Oxfam GB. A leap of faith. Conversations with funders of women's organizations. 2019. <https://policy-practice.oxfam.org.uk/publications/a-leap-of-faith-conversations-with-funders-of-womens-organizations-620823>
- Gender and Development Network. Solution – or part of the problem? Reflections on the role of INGOs in women's rights work. 2019. <https://static1.squarespace.com/static/536c4ee8e4b0b60bc6ca7c74/t/5dc95a72913dc6206eea1f52/1573476982054/Briefing+Nov+2019+-+Solution+or+part+of+the+problem.pdf>
- UNAIDS. Communities Make the Difference. World AIDS Day 2019. [https://www.unaids.org/sites/default/files/media\\_asset/world-aids-day-2019-communities-make-the-difference\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/world-aids-day-2019-communities-make-the-difference_en.pdf)
- Salamander Trust. *From Surviving to Thriving: Women's Rights and Resilience*. Film. 2020. <https://vimeo.com/387293394>
- African Philanthropy Network et al. 2020. An open letter to International NGOs who are looking to 'localise' their operations. <https://www.opendemocracy.net/en/transformation/an-open-letter-to-international-ngos-who-are-looking-to-localise-their-operations/>
- Financing Women's Organizations & Mobilization for Gender Equality: One of the Keys to Ending AIDS' – Nilo, A. Background Paper for the Expert Group Meeting on Financing for Gender Equality in the HIV Response/ UN Women; 2019. (forthcoming)

## More information on The WHAVE, Women living with HIV, Advocates, Voice, Empowered.

<https://podcasts.apple.com/gb/podcast/salamander-trust-the-whave-podcasts/id1453316451>

The WHAVE is a series of podcasts by and for women living with HIV, talking about our sexual and reproductive health and rights.

- In English: The WHAVE <https://salamandertrust.net/project/podcasts/>
- In Spanish: La Ola <https://salamandertrust.net/project/salamander-trust-podcasts-en-espanol/>
- In French: La Vague <https://salamandertrust.net/project/salamander-trust-podcasts-en-francais/>

### Salamander Trust (2019-2020)

- #1 (English) Lucy Wanjiku Njenga, Kenya. Why restrict access to the antiretroviral drug Dolutegravir for women of reproductive age?
- #2 (French) Francine Nghanhale, Cameroon. The importance of peer support for women living with HIV in the Democratic Republic of Congo.
- #3 (Spanish) L'Orangelis Thomas, Puerto Rico. Women living with HIV, sexual health and pleasure.
- #4 (Spanish) MariJo Vázquez, Spain. Learning from women living with HIV: training for medical students.
- #5 (English) Resty Nalwanga, Uganda. Peer mentoring for young mothers living with HIV.
- #6 (English) Martha Tholanah, Zimbabwe. 'Why am I even being screened if I have no recourse if I need further treatment?' Cervical cancer and women living with HIV.
- #7 (English) Bakita Kasadha, UK. Research with us, not about us: meaningful involvement of people living with HIV.
- #8 (English) Bakita Kasadha, UK. Undetectable = Untransmittable: transforming the way we feel about ourselves as women living with HIV.
- #9 (English) Lucy Wanjiku Njenga, Kenya. A success story for collective campaigning: overturning the 'restriction' on Dolutegravir for women of reproductive age.
- #10 (English) Rahayu Rahmat, Malaysia. Women living with HIV, sex workers and women who use drugs: challenges in accessing sexual and reproductive health and rights.
- #11 (Spanish) Mariana Iacono, Argentina. Women living with HIV in Argentina, our priorities.
- #12 (English) Longret Kwardem, UK. 4M Mentor Mothers: where is the funding?
- #13 (English) Longret Kwardem, UK. Peer research and meaningful involvement of women living with HIV, an ongoing challenge.

## BACKGROUND ON THIS PAPER

Podcasts are increasingly popular, can be produced and edited with basic equipment, and are accessible to people around the world with a smartphone or computer. In each episode of Series 1 of The WHAVE, a contributor tells a story of advocacy, organising, or peer support work by and for women living with HIV. In this way, contributors from Africa, Asia, Latin America and Europe share their perspectives, expertise and current priorities, in episodes in English, French and Spanish.

Some issues come up time and again in different episodes. These are now brought together in this collection of thematic papers to support the dissemination of key messages arising from The WHAVE podcast:

- **Paper #1:** Funding for organisations of women living with HIV
- **Paper #2:** Access to sexual and reproductive health and rights and HIV services for women and girls living with HIV
- **Paper #3:** Equal partners: recognising the expertise of women living with HIV

We expect these papers to be of interest to relevant teams in UNAIDS, WHO and other technical partners, Ministries of Health, NGOs, networks and associations of people living with HIV, and others involved in addressing HIV and/or sexual and reproductive health and rights of women and girls living with HIV.

A fourth paper is for women living with HIV who are interested in recording a podcast:

- **Paper #4:** A how-to guide to making a podcast for women living with HIV

To access all the briefs, please click [here](#).

Suggested Citation: Salamander Trust et al (2020) The WHAVE Podcast Paper #1. ***Fund what works: fund community-led women's rights organisations for an effective, ethical and sustainable response to HIV***

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