

# Salamander Trust

Annual Report 2017-2018



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# Salamander Trust

## 1: Our Training Programmes

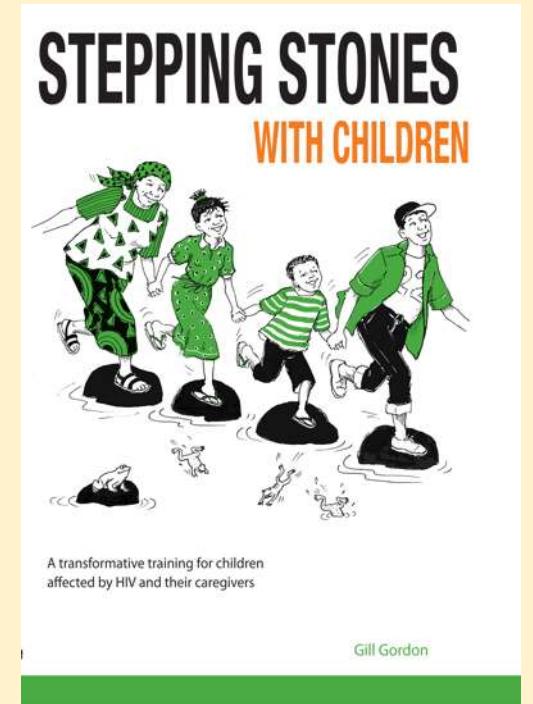


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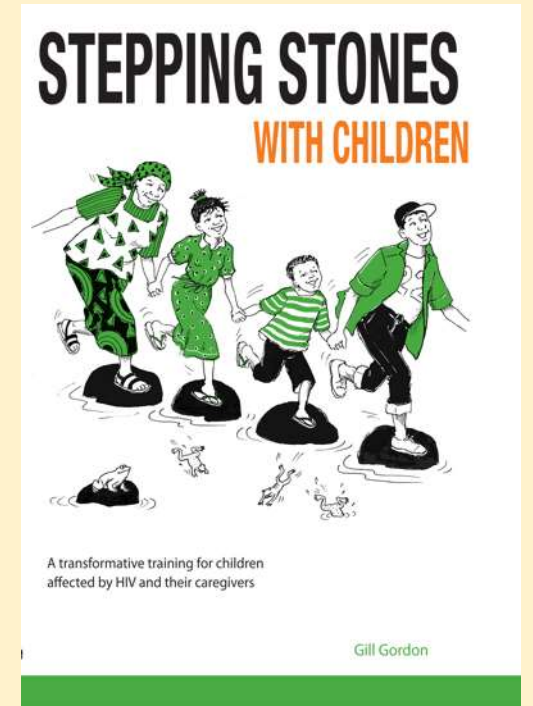
# *Stepping Stones with Children*

- We had our article about the impact of StStwCh accepted for publication by the Health Education Journal.
- We wrote and published our Impact Brief, in order to share the project's process and effects with donors and prospective users in an accessible way.
- We researched possible sources of funding, ruling out around 90 and sharing 17 with our partners.
- We kept in contact with our partners through webinars and email, and assisted them with their funding applications.



# *Stepping Stones with Children continued*

- We responded to enquiries for free materials, and distributed 327 English manuals and 144 in Swahili.
- We made and shared 5 posters about *StStwC* for World AIDS Day.
- We submitted 2 abstracts about *StStwC* to AIDS 2018; one was accepted as a poster presentation.
- We supported PASADA's process (funded by UNAIDS) of adapting the manual in order to receive the Tanzanian government's accreditation, including Alice Welbourn attending their adaptation workshop.
- We supported 2 Masters students from Liverpool School of Tropical Medicine to set up research related to *StStwC* with PASADA.



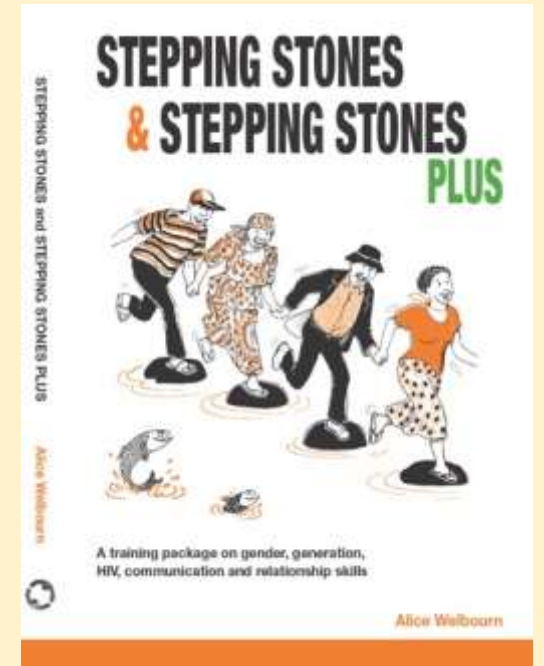






# Stepping Stones & Stepping Stones Plus

- We finalised the revision of the *Stepping Stones & Stepping Stones Plus* adaptation guidelines.
- Alice made a presentation to YouthPower in the USA about how the *Stepping Stones* process fits their evidence-based framework for effective programming with young people.
- We produced three newsletters for our International *Stepping Stones* Community of Practice members, covering diverse issues, including: highlighting our various publications; the language we choose to use; and our 4M project.



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Martha Tholanah

"I often challenge negative language right there with the person who's saying it. We need to continually push the Ministry of Health for issues around language to be part of the curriculum and provide continuous in-service training so people don't forget."

I work with the International Community of Women living with HIV (ICW) in Zimbabwe in Harare. We mainly work with girls and women who are living with HIV within their communities about access issues to healthcare services for their HIV treatment, access to safe water, safe shelter, safety and security around home, regarding violence against women and girls, GBV, working around issues of poverty and stigma and discrimination. We also use the experiences we pick up from what members experience in their day-to-day realities, take it up with different authorities eg the local clinic.



## Guidelines for adapting Stepping Stones

2017 VERSION



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We are delighted to share with you what has happened in recent months. In this edition of the newsletter, we focus on the recently published documents.

1. Our use of language: The power of positive language we use on a daily basis can make a difference.
2. Stepping Stones with Children Results: The effectiveness of Stepping Stones with children in social norms change.
3. Stepping Stones and Young People: Lessons from a systematic review of holistic approaches to make a presentation in the context of social norms change.
4. New Stepping Stones Adaptation Guide: A new guide to meet the needs of different contexts.



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Welcome to our first Stepping Stones newsletter of 2018!

In this edition we look more closely at the power of language and how we can adapt the words we use to create more positive outlooks.

Contents:

## Stepping Stones and young people: seeking cross-sectoral positive outcomes in social norms change lessons from around the world

With thanks to all those involved in Stepping Stones around the world, especially, for this presentation:

Ellen Bajenja  
Salamander Trust

Martin Opondo Obwor  
IPH Kenya

Dr Matthew Shaw  
Formerly MRC The Gambia

Alice Welbourn PhD FRCOG (Hon)

Positive Youth Development | Webinar | 7 September 2017



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Warm greetings on International Women's Day, 8<sup>th</sup> March 2018.

for mother programmes

elements from two other training programmes. They both relate to women living with HIV in grassroots programmes, created and led by a woman who has gone through the pregnancy journey. The first (4M+ Project) is based with the second (PIPE) in Kenya.



UNYPA



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# *4M: My health, My choice, My child, My life*

- With funding from ViiV, we conducted a 3 day national training of trainers workshop in Manchester for 14 Mentor Mothers. The training graduates formed the 4MNet National Network of Mentor Mothers, with a WhatsApp group to share updates and requests for their services.
- We used funding from the MAC AIDS Fund to run a series of webinars, to start to develop a national standard training manual, and to provide supervision and support sessions for 4MNet members.
- Two 4MNet members started to work with our Monitoring and Evaluation Associate to ensure meaningful involvement of the group in ongoing research around the project.





# 4M continued

- Salamander Associates and 4MNet members did a lot of public speaking! This included: to some MSPs in the Scottish parliament; to the HIV nurses network, to university student midwives, and to medical students; at the EACS and THET conferences; at the UK STOPAIDS AGM; at a NHS event about breastfeeding; at the International Women and HIV Conference in Boston; and running a workshop with 12-17 year-olds living with HIV.
- Team member Longret worked with a Masters' student from the London School of Hygiene and Tropical Medicine to conduct qualitative research about 4M. The resulting research poster won the 2018 Award for Community Research at the British HIV Association conference.





MY HEALTH, MY CHOICE, MY CHILD, MY LIFE

Challenges Facing Marginalised Groups. How Women Living with HIV can be Disproportionately Affected

**THET National Conference**  
From National to Universal. The UK Contribution to Global Health.  
23-25 October 2017

4M: My  
Mentori

Angelina  
Salamander



4M 'my health, my choice, my child, my life':  
Developing a national network of 'Mentor Mothers' to support women living with HIV through pregnancy – A 6 month evaluation



L. Kwaridemi<sup>1</sup>, A. Namiba<sup>2</sup>, N. Osborne<sup>3</sup>, J. Anderson<sup>4</sup>, R. Dhairiyawan<sup>5</sup>, S. Tariq<sup>6</sup>, P. Tooley<sup>7</sup>, A. Welbourn<sup>8</sup>  
<sup>1</sup>Salamander Trust, London, United Kingdom; <sup>2</sup>Homerton University Hospital, London, United Kingdom; <sup>3</sup>Barts Health NHS Trust, London, United Kingdom; <sup>4</sup>University College, London, United Kingdom; <sup>5</sup>PUCL, Institute of Child Health, London, United Kingdom

<http://tinyurl.com/4MProject>

## Background

Despite biomedical advances in the prevention of vertical transmission, pregnancy for women with HIV is a particularly challenging time. Complex, HIV associated psychosocial problems are common and compromise maternal, infant and family wellbeing. In 2016, the 4M project trained 46 women living with HIV in 8 UK regions to become 'Mentor Mothers' (MM), using an innovative community-led programme with a focus on psychosocial support, to promote grassroots ownership and sustainability. We now report on the 6 month post programme evaluation of the training programme

## Objective

To evaluate MMs' and host organisations' experiences of the 4M training programme and its potential for long-term impact on them.

## Methods

An online survey was designed and delivered to: (i) 46 women who had undergone the MM training programme and (ii) 8 HIV voluntary sector programme host organisations. Free text was analysed thematically.

The training made [me] feel comfortable around other people with the same condition. I have been hiding away try to avoid those I knew were in the same situation. Simply because I am shy and

## Results

### Mentor Mothers

- Almost half (22) of MMs responded; 12 (54%) completed the whole survey and 10 partially completed.
- Of the 21 who responded to the question, all reported that the 4M training programme had significantly improved their knowledge of HIV, pregnancy and action planning.
- Additional self-reported impacts included improved self-confidence, reduced sense of isolation and a greater sense of community.
- 20 of 21 (95%) reported improved confidence in using creative writing to support other women living with HIV.
- Nearly three quarters (8/11) said they would benefit from refresher sessions six months (4), nine months (1) and one year (3) after initial MM training.
- 8 of 11 (73%) also expressed interest in becoming trainers.

For me the training was just perfect as we were all able to talk openly without fear or judgement. It was wonderful, they were amazing (MM3)

### PROGRAMME HOST ORGANISATIONS



### Host Organisations

- Of the 8 host organisations approached, 4 responded and all the programme managers (PMs) reported the training as valuable, engaging and relevant.
- They described the programme as opening up an empowering dialogue between women.
- Key challenges included limited training time, participants' changing circumstances, volunteer retention, limited referrals from services and clinics, suitable timing and person-centred ongoing training for MMs.

## Conclusion

Evaluation of the training programme was positive at an individual and at an organisational level 6 months after completion of training. Developing a community-based network of trained MMs provides an invaluable sustainable resource to provide psychosocial support and complement clinical care of pregnant women living with HIV across the UK. A training of trainers' workshop will be conducted before the end of 2017.

We would be interested in doing further training with you in the future, should there be an opportunity. The biggest challenge is working with the mentors to offer them the type of mentoring they would like to do and at suitable times whilst working within our limited resources (PM4)

Most of the African women we approached were very enthusiastic and understood well the aims of the project. They didn't quite grasp the concept



4M:  
My health,  
My choice,  
My child,  
My life

Developing a national network of Mentor Mothers to support women living with HIV through pregnancy

## Songs of Experience

Experience-based research

### What is the 4M Project?

Women living with HIV can encounter significant psychosocial challenges during pregnancy and early motherhood. The 4M project, delivered by Salamander Trust, is an innovative training package that aims to build a network of women living with HIV as 'Mentor Mothers' to support women living with HIV across the UK during this time.

### 4M ToT Workshop, October 2017

During October 2017 we ran a Training of Trainers workshop, funded by ViiV Healthcare, with fourteen of the trained 'mentor mothers' from across the UK. This included a creative writing workshop designed to provide a safe and creative space in which to explore, share and reflect upon their experiences of living with HIV. The following stories were written by participants, based on their own experiences, in response to the question 'What helped you to cope with your HIV diagnosis?'



**HIV Nurses Network**  
Living with HIV in 2017: Issues for Healthcare

**Stigma and Language**

11<sup>th</sup> April 2017

Angelina Namiba  
Associate, Salamander Trust  
anamiba15@gmail.com



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# 4M+: *My health, My choice, My child, My life*

- With funding from the MAC AIDS Foundation, we conducted two workshops (one rural, one urban) in Kenya and two more in Uganda, with our respective partners, PIPE and UNYPA.






During the workshops, the participants learned how to create their own books based on the workshop exercises, their own experiences, and their recommendations to healthcare providers and advice to others. In total 65 women participated.

- We ran a 6 month review with each group, and used the findings to produce an Advocacy Brief about 4M+.



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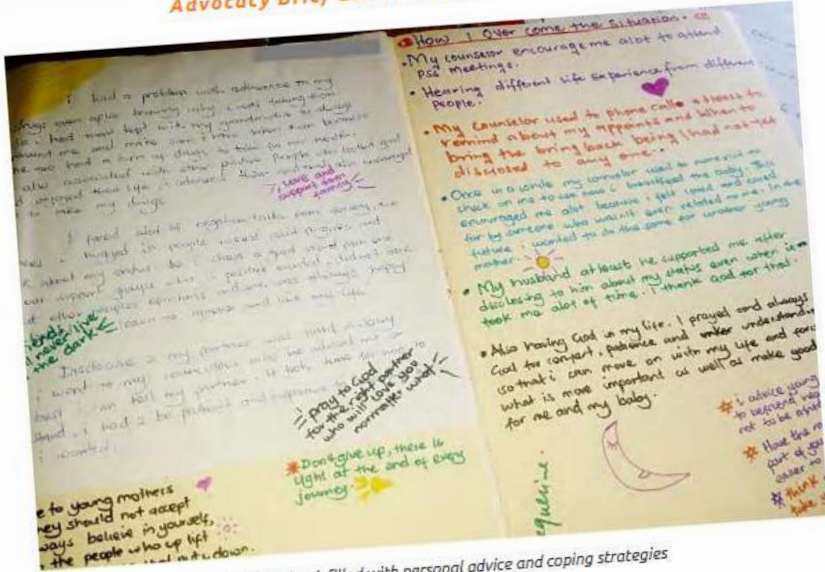




**4M+**


# 4M+: PERINATAL PEER MENTORING PROGRAMME FOR WOMEN LIVING WITH HIV

4M STANDS FOR MY HEALTH, MY CHOICE, MY CHILD, MY LIFE

## Advocacy Brief about the 4M+ Programme



Handmade book filled with personal advice and coping strategies

### BACKGROUND

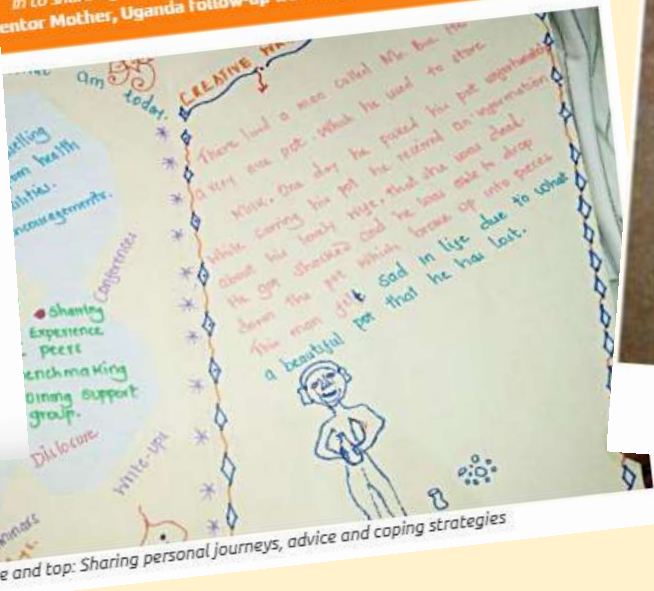
During 2017, Salamander Trust, in collaboration with PIPE Kenya and UNYPA Uganda, implemented a Peri-Natal Peer Mentoring programme with young women living with HIV, with funding from the MAC AIDS Foundation.

The programme aimed to empower young women with knowledge on safe motherhood and HIV, primarily to uphold the young women's own sexual and

reproductive health and rights and, in so doing, to reduce chances of vertical transmission. The programme also focused on skilling the young mothers to support their peers in similar ways through their pregnancy journeys. The programme provides safe spaces for women to share, connect and support each other.



During my pregnancy, I met a mother aged 23 years at the ANC clinic. She was HIV positive and she was out, she found herself HIV positive while her husband was negative. She was very sad and she was not able to share her life experience with them. I was called in to share my life experience with them.



Above and top: Sharing personal journeys, advice and coping strategies



Sharifa, Resty, (both from UNYPA), Ellen (Salamander Trust), Jacqui (UNYPA), Angelina and Nell (both from Salamander Trust)



A participant charts her own pregnancy journey



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# Community for Understanding Scale Up



- Salamander Trust is a founding member of the CUSP. Its nine member organisations draw on experiences of their social norms change initiatives to share lessons about working effectively.



- During 2017/18 we held monthly calls and produced a Policy Brief setting out our insights and advice regarding taking social norms programming to scale. Alice Welbourn, funded by Raising Voices, joined with CUSP colleagues to present the findings at the Sexual Violence Research Institute Conference in Rio.

 Raising Voices



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## 2: Our Research Programmes



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# WHO Guideline on SRHR of women living with HIV

- Alice co-authored two peer reviewed journal articles about the Guideline; one was its journal's third most-downloaded article in 2017.
- Salamander organised a well-attended European launch of the Guideline, hosted by the Royal College of Obstetricians and Gynaecologists.
- Alice made presentations about the Guideline to the Global Fund on AIDS, TB and Malaria, to WHO, and to the International Federation of Medical Students Associations. The WHO Director General stated *'the process followed for the development of this guideline was an approach that we hope can be replicated elsewhere as a best practice for the Organization.'*
- In early 2018, Salamander received a small grant from WHO to develop a generic checklist for implementation of the Guideline at national level, by women living with HIV.



# Non-specialist psychosocial support interventions for women living with HIV: A systematic review

Laura K. Beres<sup>a</sup>, Manjula Narasimhan<sup>b</sup>, Jennifer Robinson<sup>a</sup>, Alice Welbourn<sup>c</sup> and Caitlin E. Kennedy<sup>a</sup>

<sup>a</sup>Department of International Health, Johns Hopkins University, Baltimore, MD, USA; <sup>b</sup>Department of International Health, Johns Hopkins University, Baltimore, MD, USA; <sup>c</sup>Department of International Health, Johns Hopkins University, Baltimore, MD, USA



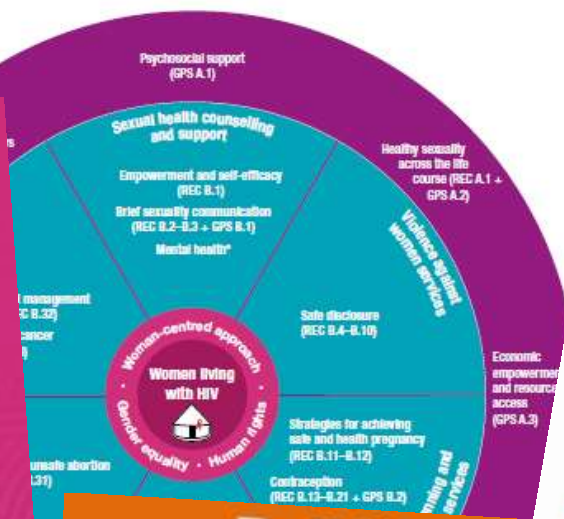
## Consolidated guideline on sexual and reproductive health and rights of women living with HIV

### Introduction

Living with HIV impacts physical and psychological aspects of a person's health and well-being. WHO estimates that 1.1 million people living with HIV and anxiety than the general population. The reported higher prevalence in women living with HIV is a negative impact of psychological life (Lowther et al., 2016; Niu, Xiao, 2016; Vo et al., 2016). A large body of evidence shows that for women living with HIV, reproductive health and rights are important. Women reported depressive symptoms, experiencing rejection (Orza et al., 2016), and experiences, including social exclusion and rights violations, challenged their sexual and reproductive health and ability to exercise their rights (Orza et al., 2016).

**CONTACT** Laura K. Beres [laura.beres@jhu.edu](mailto:laura.beres@jhu.edu)  
North Wolfe Street, Baltimore, MD 21205, USA  
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Figure 2.1: Framework of WHO recommendations and good practice statements to advance the sexual and reproductive health and rights of women living with HIV



## Building a safe house on firm ground

**Core Team Members:** Luisa Orza, Alice Welbourn, Susan Bewley, E. Tyler Crone, Marijo Vazquez

**GRG members:** Nukshinarao Ao, Cecilia Chung, Sophie Dilmitis, Calorine Kenkem, Svetlana Moroz, Suzette Moses-Burton, Hajjarah Nagadya, Angelina Namiba, L'Orangelis Thomas Negrón, Gracia Violeta Ross, Sophie Strachan, Martha Tholanah, Patricia Ukoli, Rita Wahab.

**WHO:** Manjula Narasimhan



# Using GRADE as a framework to guide research on the sexual and reproductive health and rights (SRHR) of women living with HIV – methodological opportunities and challenges

Nandi Siegfried<sup>a</sup>, Manjula Narasimhan<sup>b</sup>, Caitlin E. Kennedy<sup>c</sup>, Alice Welbourn<sup>d</sup> and Anand Yuvraj<sup>e</sup>

<sup>a</sup>Independent Clinical Epidemiologist, Cape Town, South Africa; <sup>b</sup>Department of Reproductive Health and Research, World Health Organization, Geneva, Switzerland; <sup>c</sup>Department of International Health, Johns Hopkins University Bloomberg School of Public Health, Baltimore, USA; <sup>d</sup>Salamander Trust, London, UK; <sup>e</sup>Independent Community Consultant, India

### ABSTRACT

In March 2016, WHO reviewed evidence to develop global recommendations on the sexual and reproductive health and rights (SRHR) of women living with HIV. Systematic reviews and a global survey of women living with HIV informed the guideline development decision-making process. New recommendations covered abortion, Caesarean section, safe disclosure, and empowerment and self-efficacy interventions. Identification of key research gaps is part of the WHO guidelines development process, but consistent methods to do so are lacking. Our method aimed to ensure consistency and comprised the systematic application of a framework based on GRADE (Grading of Recommendations, Assessment, Development and Evaluation) to the process. The framework incorporates the strength and quality rating of recommendations and the priorities reported by women in the survey to inform research prioritisation. For each gap, we also articulated: (1) the most appropriate and robust study design to answer the question; (2) alternative pragmatic designs if the ideal design is not feasible; and (3) the methodological challenges facing researchers through identifying potential biases. We found 12 research gaps and identified five appropriate study designs to address the related questions: (1) Cross-sectional surveys; (2) Qualitative interview-driven studies; (3) Registries; (4) Randomised controlled trials; and (5) Medical record audit. Methodological challenges included selection, recruitment, misclassification, measurement and contextual biases, and confounding. In conclusion, a framework based on GRADE can provide a systematic approach to identifying research gaps from a WHO guideline. Incorporation of the priorities of women living with HIV into the framework systematically ensures that women living with HIV can shape future policy decisions affecting their lives. Implementation science and participatory research are appropriate over-arching approaches to enhance uptake of interventions and to ensure inclusion of women living with HIV at all stages of the research process.

**ARTICLE HISTORY**  
Received 2 November 2016  
Accepted 21 March 2017

**KEYWORDS**  
HIV; GRADE; sexual and reproductive health and rights; research gaps; WHO

free-day meeting in March 2016, WHO formulated evidence-based recommendations on sexual and reproductive health and rights (SRHR) of women living with the human immunodeficiency virus (HIV). The consolidated guideline brings together relevant recommendations from WHO guidelines, and new recommendations that were developed as part of a Guideline Development Group (GDG) including people living with HIV. The GDG drew evidence from systematic reviews in order to develop new consensus-based clinical recommendations and good practice statements (World Health Organization, 2016).



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# UNAIDS ALIV[H]E Framework

- We and 6 partners completed our research concerning the evidence base for reducing violence against women in the context of HIV.
- We held a webinar to launch the Framework with UNAIDS and its partners.
- We used a grant from UNAIDS to research, write and submit an academic article about the ALIV[H]E Framework.
- This was complemented by producing powerpoint presentations, to explain the relevance and usefulness of the ALIV[H]E Framework.
- Alice Welbourn joined the advisory board for research using the Framework by the South African MRC and partners in Botswana, about issues facing women living with disabilities.





# ALIV[H]E

Action Linking Initiatives on Violence Against Women and HIV Everywhere

## framework



Figure 1: ALIV[H]E Framework structure and timeline

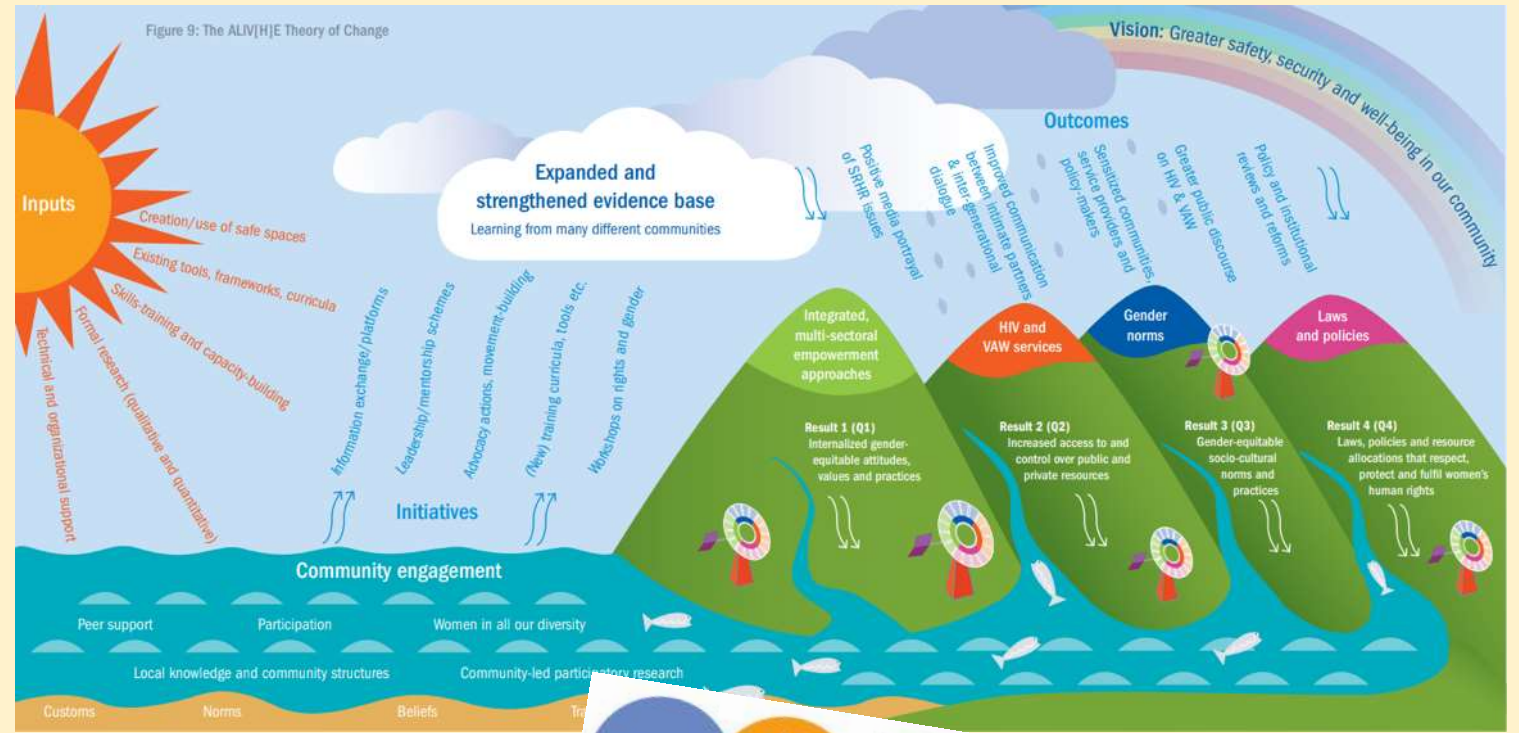
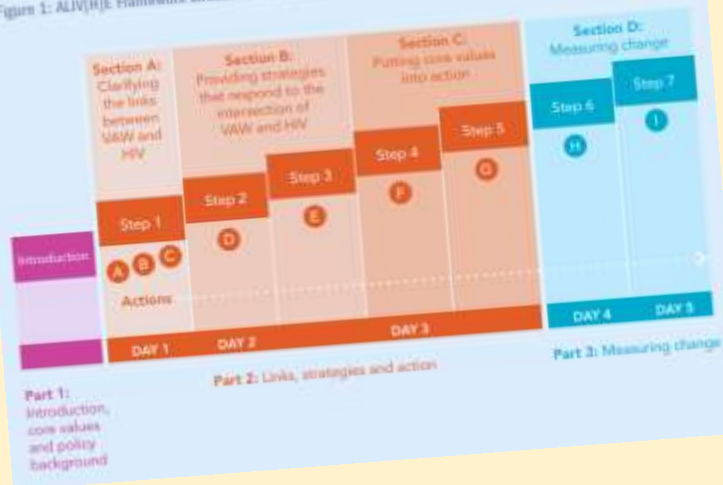


Figure 5: The change matrix



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# UN Women Global Treatment Access Review

- We finished our review, conducted with AVAC and ATHENA, which confirmed high levels of violence against women, at home (from partners and relatives), in communities and in healthcare settings. This significantly affects women's ability to access their treatment for HIV.

- UNWomen published the full report on its website.

- We wrote, submitted and successfully published an article about the review in the Harvard Journal of Health and Human Rights.



# *ICW Latina & Hivos violence against women research*

- We won a bid to deliver this regional research project, working in partnership with Development Connections, and commissioned by ICW Latina and Hivos. (No funds received this year, but we began the work).
- We first conducted a desk review regarding violence against women living with HIV in Latin America and the Caribbean.
- We also prepared for the next stage of the research, providing training to ICW contacts and peer researchers to carry out the research. It will focus on the experiences of young women, Indigenous women, women of African descent, and Garifuna women in Guatemala, Honduras, Paraguay, Peru, Bolivia, Colombia and the Dominican Republic.





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## 3: Our Advocacy Work



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## *Other advocacy activities*

Our main advocacy activities were inherent in our training and research work, as already described.

In addition, we are often asked to contribute to various fora. In 2017-18 this included:

- a [presentation](#) at the SWIFT research consortium about violence against women in the context of HIV;
- a [blog](#) and [podcast](#) for the British Medical Journal;
- a [blog](#) on World AIDS Day for STOPAIDS about violence against women.

We also used our [twitter](#) and [Facebook](#) accounts, and our websites, to reach out about issues. For example, we created a '[storify](#)' about our 4M Training of Trainers workshop in Manchester.





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## 4: Our Accounts



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# Accounts: 1 April 2017 to 31 March 2018

<b>Funds as at start of year, 1 April 2017</b>	<b>£165,407</b>
Unrestricted	£129,422
Restricted	£35,985

<b>Income during the year</b>	<b>£70,767</b>
Comic Relief grant	£3,099
MAC AIDS Fund grant	£27,150
UNAIDS grant	£11,349
ViiV Healthcare grant	£20,000
WHO grant	£5,201
Donations	£2,613
Bank interest	£1,355

<b>Expenditure during the year</b>	<b>£109,444</b>
Training	£76,813
Research	£14,541
Advocacy	£14,056
Governance & core running costs	£4,034

<b>Funds as at end of year, 31 March 2018</b>	<b>£126,730</b>
Unrestricted	£96,377
Restricted	£30,353

To view our full accounts please click [here](#)



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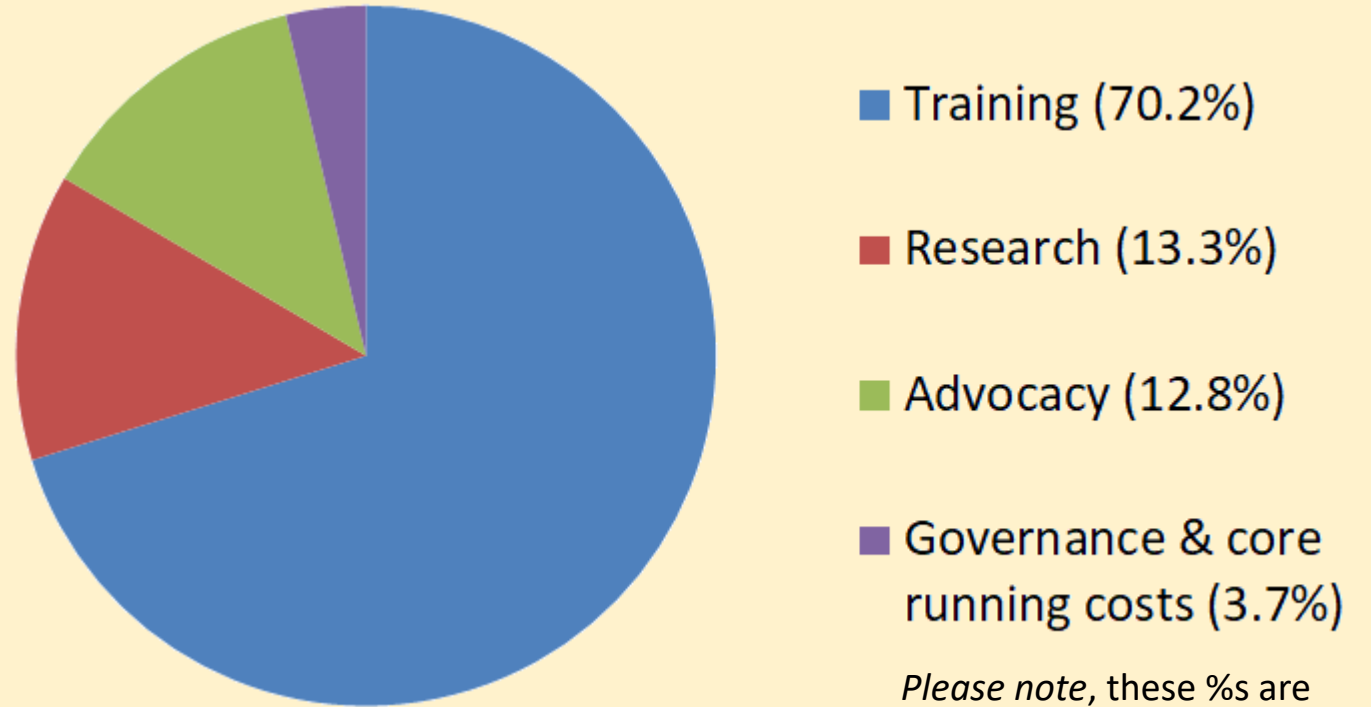
# Expenditure: 1 April 2017 to 31 March 2018

As this chart shows, the majority of our expenditure was on training, with equal spending on research and advocacy.

Our governance & core running costs are very low because all Salamander Associates work from their homes, so the Trust has no office overheads.

Furthermore, as Chair of the Trustees, our Director Alice Welbourn works for the Trust without payment, with only her Trust-related expenses covered.

The Trust's Treasurer, Nigel Padfield, also carries out his role on a voluntary basis.



*Please note, these %s are approximate.*



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## 5: Our Supporters



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*Warm thanks to all our funders this year!*



# *Huge thanks also to all our wonderful colleagues:*

## **Salamander Trust Associates:**

- Emma Bell
- Ellen Bajenja
- Sophie Dilmitis
- Gill Gordon
- Fiona Hale
- Sue Holden
- Longret Kwardem
- Rebecca Mbewe
- Angelina Namiba
- Nell Osborne
- Laura Pulteney
- Marijo Vazquez

## **Associates by Project:**

4M: Angelina, Longret, Nell, Rebecca

4M+: Angelina, Ellen, Nell

ALIV[H]E: Andy, Luisa

Guideline checklist: Sophie

ICW Latina: Dinys, Emma, Fiona, Marijo, Martin

StStWC: Ellen, Gill, Laura, Sue

## **Main Partners:**

- Tyler Crone & Luisa Orza, ATHENA Network
- Dinys Luciano, Martin Negrete, Development Connections
- Andy Gibbs, HEARD / University of Kwa-Zulu Natal
- Namibia Women's Health Network, Namibia
- PASADA
- PIPE Kenya
- Silvia Petretti, Positively UK
- Practical Action Publishing
- Lori Michau, Leah Goldmann Raising Voices
- Hege Wagan, UNAIDS
- UNYPA Uganda
- Dr Manjulaa Narasimhan, WHO



# *And our gratitude to our great 4M Steering Group members:*

Dr Rageshri Dhairyawan (Chair)

Dr Shema Tariq

Professor Jane Anderson

Professor Susan Bewley

Gill Gordon

Longret Kwardem (Project M&E Coordinator)

Rebecca Mbewe

Angelina Namiba (Project Coordinator)

Nell Osborne (Project Co-Trainer)

Dr Pat Tookey

Alice Welbourn

Professor Alison Wright



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# *And heartfelt thanks to the Salamander Trust Trustees:*

Jenifer Gatsi

Jill Lewis

Jane Tewson

*Treasurer:*

Nigel Padfield

*Chair and Founding Director:*

Alice Welbourn



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# Contact details

You can find more detailed information about our activities and publications at

[www.salamandertrust.net](http://www.salamandertrust.net) and [www.steppingstonesfeedback.org](http://www.steppingstonesfeedback.org)

## Salamander Trust:

Registered UK Charity No. 1143381

Registered Company No. 06734362

ECOSOC Status

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**Twitter accounts:** [@SalamanderTrust](https://twitter.com/SalamanderTrust) [@StStFeedback](https://twitter.com/StStFeedback) [@4Mproject](https://twitter.com/4Mproject)



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