



## EXECUTIVE SUMMARY

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


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

## Summary

Women living with HIV can encounter significant psychosocial challenges during pregnancy and early motherhood. The 4M project, funded by the MAC AIDS Fund and 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.

Between April and October 2016, the 4M project trained 46 women living with HIV to be 'Mentor Mothers', in eight UK regions. Feedback about the training has been positive from the 'Mentor Mothers', with many describing it as 'excellent'. Of the 46 'Mentor Mothers' trained, 57% confirmed that they would like to receive further training to become trainers themselves.

We believe we have built a sustainable network of 'Mentor Mothers' that can support women living with HIV through pregnancy and early motherhood. They represent an invaluable resource, complementing and working alongside existing clinical care.

 "The training was fantastic. I am glad I participated. I have come to understand that there is help out there. I don't have to suffer alone. I just have to know where to go and what to do."

**MENTOR MOTHER, LEICESTER**

### Who can train as a 'Mentor Mother'?

Almost all the women whom we train to become 'Mentor Mothers' are themselves living with HIV, who have also gone through pregnancy learning or knowing that they have HIV. (A few women who have been closely affected by these issues and who are also mothers, have been trained.) This 'peer mentor' model is known in other branches of healthcare such as mental health and cancer and is increasingly recognised as an invaluable addition to mainstream clinical services.

## Background

### HIV and pregnancy

Approximately 1,200 pregnancies are reported annually in the UK among women diagnosed with HIV.<sup>1</sup> Even though the UK rate of perinatal transmission<sup>i</sup> is currently less than 0.3% for women diagnosed with HIV, they may encounter significant psychosocial challenges in their journey to motherhood.<sup>2</sup> Some of these issues include:

- coping with a new diagnosis
- anxieties around starting antiretroviral therapy (ART)
- concerns about the side effects of ART
- fear of talking to or telling significant others about their HIV diagnosis
- intimate partner violence
- immigration, housing and financial concerns.

### Peer 'Mentor Mothers'

Peer support for people living with HIV means "those with this lifelong condition providing support through sharing knowledge and experiences and offering social, emotional and/or practical help".<sup>3</sup>

Peer support to women living with HIV during pregnancy has been widely adopted in sub-Saharan Africa. Examples include the introduction of the international mothers2 mothers (m2m)<sup>ii</sup> programme through clinics across seven countries, and community-led models developed by grassroots non-governmental organisations (NGOs) such as Mama's Club<sup>iii</sup> in Uganda. 'Mentor Mother' programmes have shown in evaluations and randomised controlled trials to have positive impacts on both maternal and infant outcomes, including improved psychosocial wellbeing, improved adherence to medical interventions, and greater capacity within mothers to tell others about their HIV status.<sup>4,5</sup>

i. Perinatal transmission refers to the transmission of HIV to a baby during pregnancy or labour, or after delivery as a result of breastfeeding. It is also known as vertical transmission.

ii See [www.m2m.org](http://www.m2m.org)

iii See <http://mamasclubonline.com>

Angelina Namiba, one of our team members, implemented the first grassroots NGO-led 'Mentor Mother' programme for women living with HIV in the UK. The London-based programme 'From Pregnancy to Baby and Beyond' (FPBB)<sup>iv</sup> was piloted in 2010–2011, then ran successfully until 2015 when funding ceased. A formal qualitative evaluation of FPBB demonstrated that it had a multi-dimensional positive impact on supported mothers' emotional wellbeing, whilst leading to personal growth among the 'Mentor Mothers' themselves.<sup>6</sup>

It is clear that there is a similar need among women living with HIV outside London. Approximately 65% of pregnancies in women living with HIV in the UK and Ireland are reported in women living outside London.<sup>2</sup> Women outside London may face particular challenges as a result of a lower concentration of local support organisations compared with those available in London. Building upon the successes of FPBB, we wanted to expand the 'Mentor Mother' programme across the UK, training women living with HIV to deliver this specialised support.

## Salamander Trust

The 4M project was delivered by Salamander Trust, a small, young charity with a global reach, led by a woman living with HIV. We aim to protect, promote and enhance the

health and rights of people (particularly but not exclusively) marginalised as a result of their, gender, HIV status or sexual and reproductive health. The core components of our work are training, global advocacy and research. In 2014 we conducted the largest global survey to date of the sexual and reproductive health and rights of women living with HIV for the World Health Organization (WHO). This was to inform WHO's forthcoming guidelines on this topic. We also coordinate support for *Stepping Stones*, the longest running community-based training programme in the world that is known to reduce gender-based violence in the context of HIV.

## About the project

### Project aims

We aimed to train 40 women living with HIV across eight UK regions, as 'Mentor Mothers' between January 2016 and January 2017 and in collaboration with HIV-specific third sector organisations.

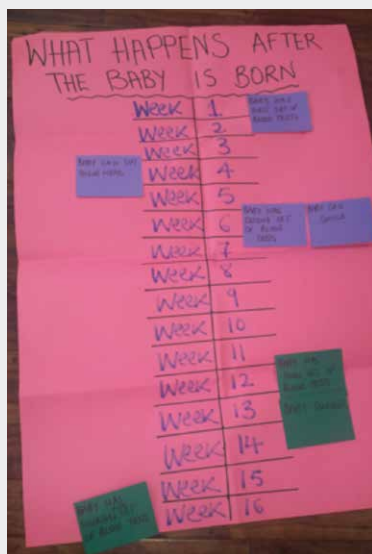
### Training programme

The 4M project was designed and delivered by the Project Coordinator, Angelina Namiba, a highly experienced trainer and peer support worker. Angelina is a woman living with

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Day 1 was delivered by Angelina and included information sessions, group discussions and interactive exercises. Overarching topics were:

- basics of HIV
- pre-conception planning
- safer conception
- preventing onward HIV transmission to sexual partners and the unborn child
- what happens during pregnancy
- national guidelines on prevention of vertical transmission
- delivery
- infant feeding
- strategies around talking to significant others about HIV
- staying engaged in health and social care, before during and after delivery.

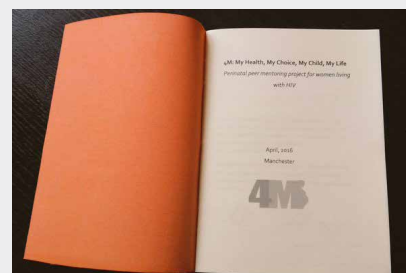


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Day 2 focused on peer mentoring, action planning and creative writing. We felt it was important to provide a safe space in which 'Mentor Mothers' could reflect upon their own journeys to motherhood, as well as gain skills and confidence to share this effectively with their peers.

Creative writing not only creates a record of participants' significant experiences and an opportunity for sharing, but also fulfils a human need for free individual expression. Like peer support networks, creative writing workshops have the potential to support sharing and reflection.

We used carefully supported writing exercises throughout the morning to stimulate imagination and build confidence. After each exercise 'Mentor Mothers' were invited to share their writing with the group to use as a springboard for further discussion and sharing.



TRAINING

iv. See <http://positivelyuk.org/pregnancy/>

HIV who has been through the pregnancy journey herself. Her co-trainer, Nell Osborne, led the creative writing element of the project. Nell, whilst not living with HIV herself, also has substantial experience of training and working with communities of women living with HIV in the UK and internationally.

Our innovative two-day training package comprised coaching on clinical and psychosocial aspects of pregnancy and HIV in combination with creative writing workshops. These components are designed to encourage trainees to reflect upon their own pregnancy journeys, and to gain the skills to support their peers to both navigate their pregnancy journeys and be in control of the 4M components – My health, My choice, My child, My life.

## Project management

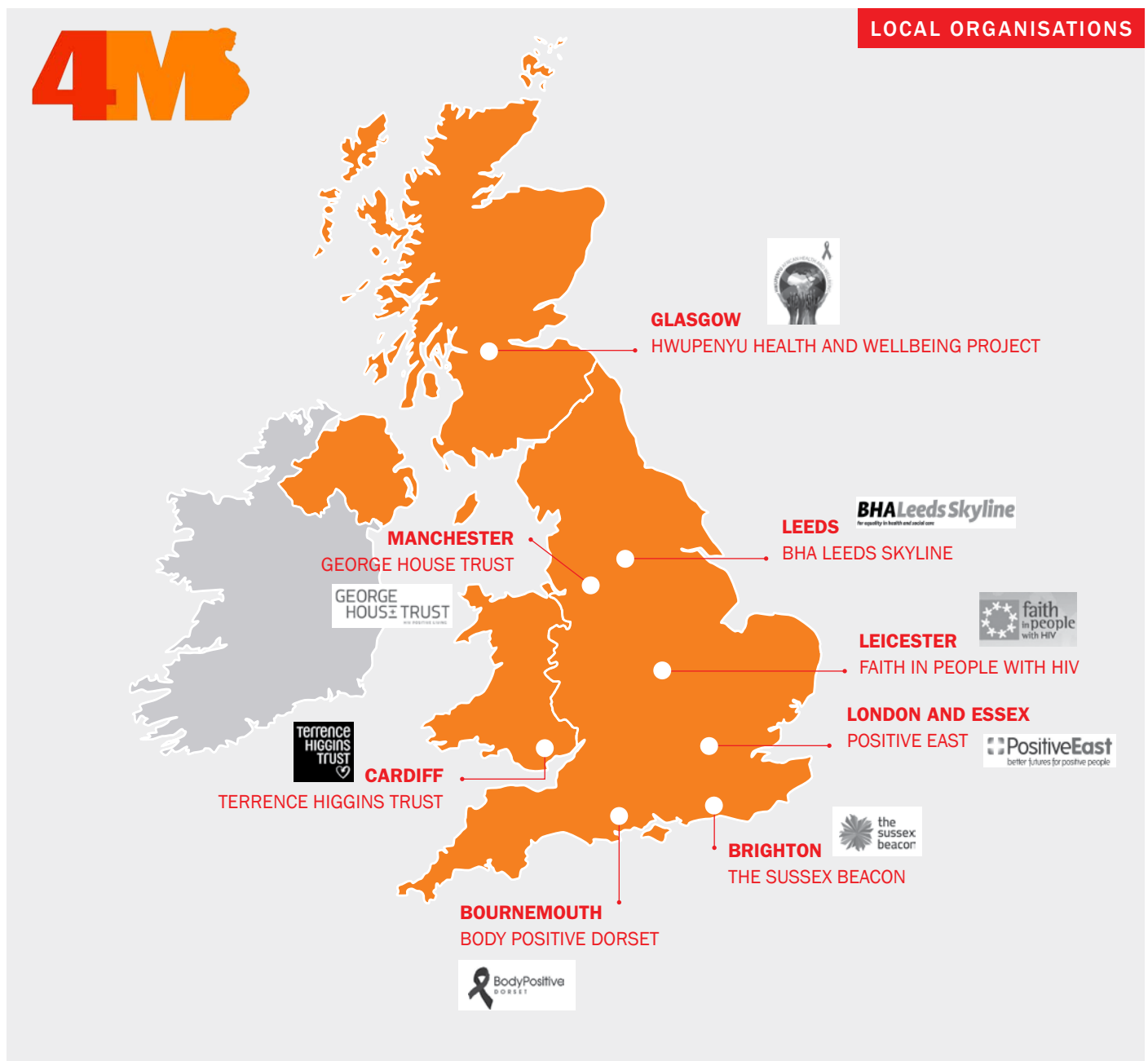
The project was directly managed by Angelina on behalf of the Salamander Trust. Oversight was provided by a Project

Steering Group comprising a wide range of stakeholders including clinicians, researchers, a specialist HIV midwife, and women living with HIV. The Steering Group met four times between January 2016 and January 2017. It provided feedback on project materials and outputs, as well as guidance on evaluation and project development.

## Collaborating organisations

Working in partnership with local HIV support organisations is central to this project. It is important that 'Mentor Mothers' are linked to local HIV support organisations in order to support and refer those who have more complex needs, as well as to receive ongoing support themselves.

We identified eight key geographical regions, ensuring good coverage across the UK, as well as delivering training in areas with both high and low HIV prevalence. This is because areas of low prevalence often have few HIV support services. We then approached organisations in these regions to



ascertain whether they would be interested in hosting the 4M training package. The eight host organisations we worked with were: BHA Leeds Skyline (Leeds), George House Trust (Manchester), Faith in People (Leicester), The Terrence Higgins Trust (Cardiff), The Sussex Beacon (Brighton), Body Positive Dorset (Bournemouth), Hwupenyu Health and Wellbeing Project (Glasgow) and Positive East (London and Essex).

## Project evaluation

A formal evaluation of the 4M project was conducted by a peer-researcher under the supervision of our Steering Group Chair, Dr Shema Tariq, a public health academic. We administered immediate pre- and post-training quantitative surveys to the 'Mentor Mothers' who had completed the training, to capture changes in knowledge, skills and confidence.

We intend to administer six-month post-training surveys (by telephone, email or post) to assess the longer term

impact of the training on 'Mentor Mothers'. This will be complemented by qualitative interviews with a proportion of 'Mentor Mothers', to explore the impact of training in further depth. We will also conduct surveys of host organisations to explore the impact of the training at an organisational level, and to identify key barriers and facilitators in sustaining the 'Mentor Mother' model of care.

## Training impact

We were funded to train 40 women as 'Mentor Mothers' across eight UK regions. We exceeded this number, training 46 women over 12 months. Over half of the trainees identified as 'Black African' (25), with 9 identifying as 'White British'. The age range was 22 to 67 years (see Table 1 for other characteristics). At the end of the project, each trained 'Mentor Mother' was ready to provide support to at least five other women living with HIV. Thus they were becoming an invaluable resource, complementing the clinical care of the management of HIV and pregnancy across the UK.

**Table 1: Characteristics of 46 women who completed 4M training**

| Educational status | Number | Region          | Number |
|--------------------|--------|-----------------|--------|
| University/College | 22     | Leeds           | 12     |
| Secondary          | 6      | Glasgow         | 8      |
| Primary            | 1      | Manchester      | 6      |
| Other              | 9      | London/Essex    | 5      |
|                    |        | Brighton/Sussex | 4      |
|                    |        | Bournemouth     | 4      |
|                    |        | Leicester       | 4      |
|                    |        | Cardiff         | 3      |

\* 8 did not answer

**Table 2: Participant feedback: overall**

|                  | Excellent (%) | Good (%) | No answer (%) |
|------------------|---------------|----------|---------------|
| Training         | 36 (78)       | 4 (9)    | 6 (13)        |
| Facilitation     | 35 (76)       | 4 (9)    | 7 (15)        |
| Creative writing | 38 (83)       | 2 (4)    | 6 (13)        |



"It is a very good experience ... made me realise how far I have come and how far I can go."

**MENTOR MOTHER, CARDIFF**

**Table 3: Participant feedback: improved knowledge and confidence**

|                   | Very much (%) | Quite a lot (%) | Moderately (%) | No answer (%) |
|-------------------|---------------|-----------------|----------------|---------------|
| HIV and pregnancy | 31 (67)       | 8 (17)          | 0              | 7 (15)        |
| Action planning   | 28 (61)       | 9 (20)          | 2 (4)          | 7 (15)        |
| Referrals         | 28 (61)       | 6 (13)          | 3 (6)          | 9 (20)        |

Overall feedback from the ‘Mentor Mothers’ who participated in the project was very positive, with the overwhelming majority rating the different components of the training as either ‘good’ or ‘excellent’ (see Table 2). We asked the ‘Mentor Mothers’ whether their knowledge about HIV and pregnancy, and confidence in action planning and making onward referrals, had improved as a result of the training. Again, nearly 90% reported that knowledge and confidence had improved either ‘quite a lot’ or ‘very much’ (see Table 3).

“We would like more of this training and support organised down here more often, thanks. It is very important that women get this type of training and get together more, for the large majority of women that are still in the dark about these issues.”

**MENTOR MOTHER, BOURNEMOUTH**



4M trainers, Nell Osborne and Angelina Namiba, with Hilda Achola, Social Care Support Worker at BHA Leeds Skyline.

## CREATIVE WRITING FEEDBACK

The creative writing element of the workshop was rated highly by ‘Mentor Mothers’. The writing sessions, particularly where ‘Mentor Mothers’ shared their own journeys of pregnancy, living with HIV and resilience, were particularly powerful. Many women reported that this had been the first opportunity they had to share their journeys in such a way in a safe space.

“The creative writing workshop brought a lot of memories that are useful on my journey keepsake but something that can help others [sic].

This is something powerful, yet without creative writing it is left hidden, forgotten, or never valued. It is like a hidden treasure.”

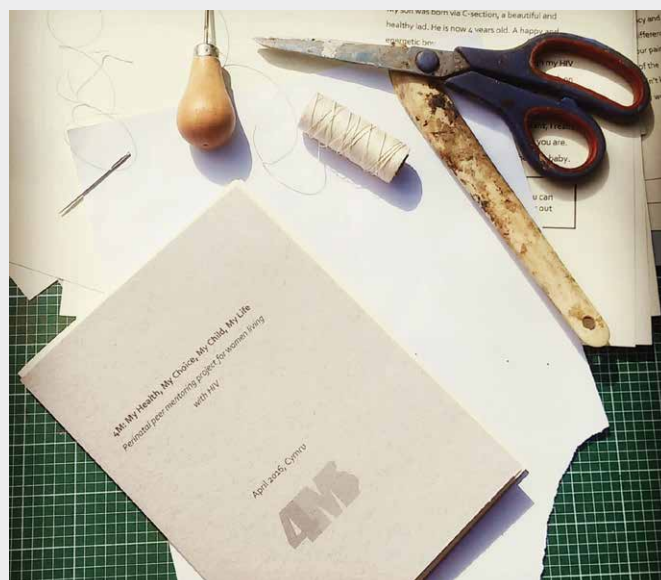
**PARTICIPANT, MANCHESTER**

## Challenges

Inevitably, we encountered challenges, which we actively sought to identify and address promptly. Key challenges included: recruitment and retention (often due to conflicting commitments); concerns about attending training delivered by strangers; and concerns about confidentiality. Most pertinently, given the pressures faced by many voluntary sector organisations, one training session was cancelled because of the closure of a host organisation through funding cuts.

In order to address some of these challenges we:

- created bespoke flyers for organisations to circulate to potential participants, in addition to other recruitment methods
- visited the organisation prior to the training in order to raise awareness of and to introduce our 4M concept and the training programme to potential participants
- used pro-active communication and rigorous follow-up (including reminder texts and emails) to and with booked participants
- met childcare costs where an HIV charity had funding constraints
- used social media (Twitter and Facebook) to raise further awareness of the project



## Outputs

We have endeavoured to disseminate the 4M project in a variety of ways in order to maximise impact:

1. **WHO case study submission:** Case Study: 'SRHR for women living with HIV' to accompany new WHO guidelines on this topic (awaiting response).
2. **Conference:** An oral presentation of our work, entitled, "4M: My health, My choice, My life, My child: developing a national network of 'Mentor Mothers' to support women living with HIV through pregnancy", was delivered at the Minding Mothers with Morbidities Conference<sup>v</sup> at Trinity College, Dublin.<sup>7</sup>
3. **Booklets:** Stories produced by the 'Mentor Mothers' during the workshops were edited and compiled into a handmade booklet. At the end of each story, the author parts with a small piece of advice (see the example below). Copies of these were returned to each workshop participant and the host organisation. We hope they will become invaluable resources for women going through similar experiences. We will also share these stories with healthcare professionals to facilitate understanding of the complexities women living with HIV may encounter during pregnancy and early motherhood.
4. **Social media:** We have made use of social media to publicise the project. This includes setting up a new twitter account, @4MProject, and use of existing Salamander Trust and personal Facebook accounts.
5. **Website:** The Salamander website describes the project and provides a list of workshop venues.<sup>vi</sup> Stories from the booklets will be made available on the project website as an online resource.
6. **Event:** The project will be presented at the Royal College of Obstetricians and Gynaecologists in early February 2017. The event will also be an opportunity to celebrate 'Mentor Mothers'.

Julia

### Having a Baby

I was diagnosed in 2009. A few months later I had to start medication. There was no choice for me because my viral load was very high. I had always struggled with taking tablets anyway. If I had a headache, I would have just dealt with the pain and struggled on. This was different. My choice was taken away. When I was diagnosed, I didn't feel unwell, so when I was told to take 4 tablets a day (the size of bullets!) I found it very hard. I couldn't enjoy dinner. All I could think about was these damn tablets. Then I couldn't swallow them. They got stuck in my throat and I would be sick. The medication made me feel very unwell so I kind of felt that I was okay and that the tablets themselves were giving me HIV. I questioned my sanity and the doctors around me.

My partner and I had planned to have a baby before my diagnosis so we continued on this journey. In some ways that took my mind off HIV. I knew I had to be fit and well for my child. As time went on the medication got much easier. I found a routine that worked for me and the side effects I got from my medication settled down. With the help of other women living with HIV who had been through similar situations I began to feel 'normal' again.

My dreams continued and I've gone on to have two beautiful, HIV negative children who are my world. Today I know without a doubt that those bullets of medication saved, and are still saving, my life. My hopes and dreams for the future will continue.

Julia's advice: My diagnosis did not take away my dream of becoming a mother.

v. See <http://trinityhirc.com/page/137/minding-mothers-with-morbidities-conference-programme/>

vi See <http://salamandertrust.net/project/4m-health-choice-child-life-perinatal-peer-mentoring-project-women-living-hiv/>

## Key successes

As the project draws to a close we have identified the following as key successes:

- We exceeded our planned number of 'Mentor Mothers' to train.
- We held supplementary HIV and pregnancy journey workshops with healthcare professionals at the invitation of local hospital trusts and universities. These included two workshops with a total of 63 student midwives at Hertfordshire University, and another with 25 midwives, student midwives and nursing staff at St. Richards' Hospital in Chichester, Sussex.
- We established an innovative training package that received positive feedback from participants.
- We developed a sustainable model of care to support women living with HIV during pregnancy and early motherhood.

## Going forward

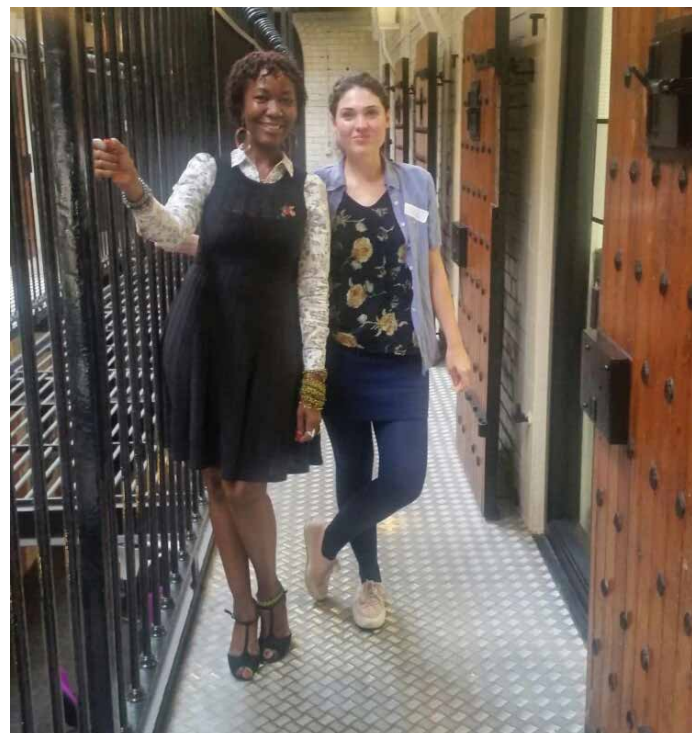
In our initial evaluation, twenty-six (57%) of 'Mentor Mothers' expressed an interest in being trained as trainers to deliver 'Mentor Mother' training themselves. Our immediate priority is therefore to secure further funding to hold a training-of-trainers workshop with 'Mentor Mothers' to further build capacity across the country.

We have also received a grant from MAC AIDS Fund to take this grassroots-led project beyond the UK to work with our partners, PIPE in Kenya and the Uganda Network of Young People Living with HIV/AIDS (UNYPA).

Finally, although for this project we trained 'Mentor Mothers' living with HIV, this grassroots-led model of work is easily replicable and may benefit other marginalised women across the UK (and elsewhere) during pregnancy and early motherhood. These could include women experiencing mental health issues, women who use drugs, women living with other chronic conditions and migrant women. We are keen to identify opportunities to develop this community-led work beyond the field of HIV.



Rebecca Mbewe, Mentor Mother and Co-trainer, with Angelina Namiba at The Sussex Beacon in Brighton.



Angelina Namiba and Nell Osborne deliver 4M training at Orkney Street Enterprise Centre (a former police station) in Glasgow.

## Thanks and acknowledgements

Huge thanks to:

- MAC AIDS Fund for funding this project
- the awesome Steering Group who guided us with such passion and enthusiasm, especially the Chair, Dr Shema Tariq
- all the great organisations across the UK who kindly organised and hosted the workshops for us
- and especially, the amazing women who came to the training workshops and who are now using their experience and new-found skills to support other women living with HIV on their own pregnancy journeys.

It has been a great privilege to work with you all.

### 4M 'Mentor Mothers' Project Team:

**Project Design and Coordination:** Angelina Namiba

**Creative Writing Coordinator:** Nell Osborne

**Evaluation Coordinator:** Longret Kwardem

**Steering Group Members:** Dr Shema Tariq (Chair); Professor Jane Anderson; Professor Susan Bewley; Dr Rageshri Dhairyawan; Kay Francis: Gill Gordon; Longret Kwardem; Rebecca Mbewe; Angelina Namiba: Nell Osborne; Dr Pat Tookey; Alice Welbourn; Professor Alison Wright.

<http://salamandertrust.net/project/4m-health-choice-child-life-perinatal-peer-mentoring-project-women-living-hiv/>

Twitter @4Mproject

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Funded by:



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TRANSFORMING THE WAY WE THINK ABOUT HIV



Participating local organisations:

