



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

ADVOCACY BRIEF, JUNE 2020

From elimination of MTCT to ensuring SRHR Main Document

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PART 1: The Background

In 2012, Angelina Namiba created the Mentor Mother Project 'From Pregnancy to Baby and Beyond' funded by Janssen and MAC AIDS Fund and supported by Positively UK. She developed a London-based training programme for women living with HIV to train as Mentor Mothers to provide peer support to other women in London¹.

In 2016, Angelina and Salamander Trust acquired funding to expand the programme to make it UK-wide. The 4M Programme, 'My Health, My Choice, My Child, My Life', is an innovative peer-led project training women living with HIV across the UK to provide their peers with psychosocial support in their pregnancy journey and beyond. As a result of this work, Mentor Mother peer support is now promoted as good practice in the British HIV Association (BHIVA) National Pregnancy Guidelines², in line with the National Standards of Peer Support in HIV³.

Since then, 4M has developed into a UK-wide and international community network of women living with HIV. Through establishing safe community spaces and grassroots ownership, 4M specifically addresses the challenges women living with HIV experience as they navigate the perinatal journey. It continues to grow organically in varied ways.

In 2019, we secured funding from the mental health charity, MIND, to include a specific focus on perinatal mental health support through the 4M for Mental Health project (4M4MH). We also registered the 4M Mentor Mothers Network as a Community Interest Company (4MNet CIC), with Angelina Namiba, Longret Kwardem and Rebecca Mbeve as the CIC's Directors, and an advisory steering group which includes Mentor Mothers, clinicians, academics and researchers.

- 1 Knudsen-Strong in partnership with Positively UK (2011) From Pregnancy to Baby and Beyond: Preliminary Findings from an Evaluation of the Pilot Programme. [online] Available at: <http://positivelyuk.org/wp-content/uploads/2014/11/Pos-UK-Pregnancy-Project-Evaluation-Report-Aug11.pdf> [Accessed 20 May 2020].
- 2 BHIVA (2018) British HIV Association guidelines for the management of HIV in pregnancy and postpartum 2018 (2019 second interim update) [online] Available at: <https://www.bhiva.org/pregnancy-guidelines> [Accessed 15 May 2020].
- 3 Positively UK, Steering Group (2016) National Standards of Peer Support in HIV. [online] Available at: <https://hivpeersupport.com> [Accessed 15 May 2020].

Part 2: A timeline: From Pregnancy to Baby and Beyond to 4M Mentor Mothers Network CIC

(For details, refer to Annex 1, 'A year by year account of our work' either later in this file or in a separate document on this website)

2012-2015

Angelina, based at Positively UK, develops London-based programme From Pregnancy to Baby and Beyond, with a multi-disciplinary Steering Group training women as Mentor Mothers.

2016

The UK-wide 4M programme starts under Salamander Trust, with Mentor Mother training workshops across the UK in partnership with HIV organisations, and a slightly revised Steering Group.

2017

4M goes international (4M+), delivering workshops with PIPE Trust (Kenya) and Uganda Network of Young People living with HIV (UNYPA).

4M holds a UK national Training of Trainers (ToT) workshop for Mentor Mothers in October; launches the 4M WhatsApp group for Mentor Mothers for mutual support (4MNet); and presents its work in posters at the British HIV Association Conference (winning a commendation) and the European AIDS Clinical Society Conference.

2018

4M and 4M+ Advocacy briefs launched. 4M and 4M+ present joint panel at AIDS2018; regular UK supervision/support sessions with MMs start; webinars start; talks across the UK start; BHIVA conference community research award; authorship of a book chapter about 4M for a book about midwifery by the University of Hertfordshire Midwifery Department, for international readership (publication due in 2020).

2019

4MNet CIC registered with UK Companies House; 4MNet WhatsApp group extended to other UK-based members and 4M+ colleagues; launch of 4M Mentor Mothers ToT manual; new webinars produced; 4M4MH perinatal mental health project conducted, producing a mental health annex to the ToT manual and a concertina leaflet with contact details for mental health resources and organisations; poster presented at AIDS IMPACT Conference on our participatory evaluation of WhatsApp for digital peer support.

2020

4MNet CIC bank account opened; 4MNet CIC receives first grant in its own right for '4M on Fire' work to respond to Covid-19; Annex to manual on mental health developed; peer reviewed article on perinatal digital peer support published in AIDS Care Journal.

Part 3: Our current priorities

Supporting Mentor Mothers' priority needs during COVID-19

Virtual social connections and peer support

- Providing platforms for Mentor Mothers to meet virtually, increase our mental well-being, and share experiences of COVID-19 from our different locations including positive news, encouragement, support service information, self-care tips.
- Regular one-to-one check-ins to see how people are getting on and where they may need support.
- Regular updates on staying healthy during the COVID-19 pandemic.
- Filtering information shared to ensure it is relevant, useful and limits negative information.

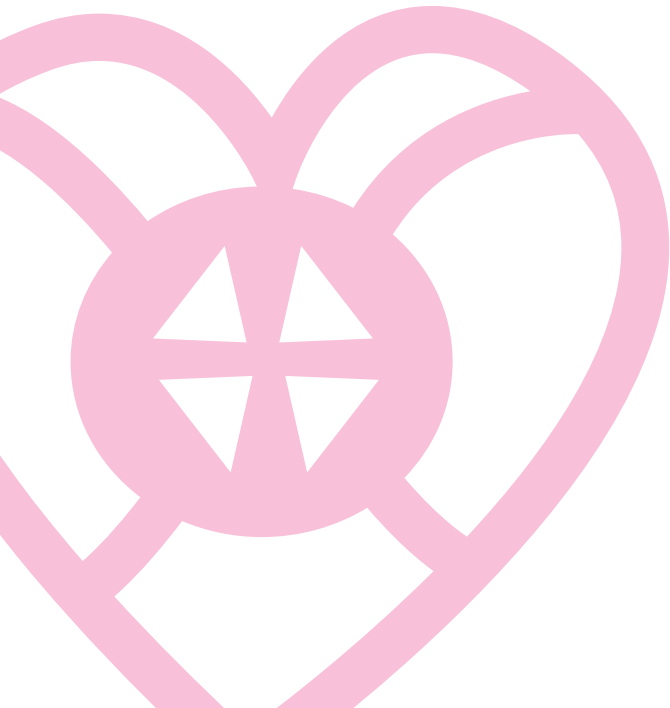
Research

- Collection of evidence about how COVID-19 is affecting us and impacting on our sexual

and reproductive health and rights, including evidence from our lived experiences.

Expanding our reach

- Reaching out to women living in rural areas to provide them with a safe space (even a virtual one) where they can access support and tools.
- Ensuring all clinics in rural areas are aware of the Mentor Mother service and can refer to a peer led support pathway.
- Working towards this model to be available and accessible to women of all ages (shaped to their unique needs i.e. pregnancy journey, accessing healthcare or the menopause).
- Raising awareness of GPs so they have knowledge of this care pathway.
- Translation of 4M materials into other languages to be accessible to more women.



Part 4:

Next steps for 4M

Our next steps include the consolidation and development of our network, our CIC, and our reach. Depending on the funding we are able to obtain, our ideas for the future development of 4MNet CIC include the following:

Raise awareness and advocate

- Work to increase HIV awareness and knowledge amongst health care providers, police, social services, and other service providers, especially about U=U (Undetectable=Untransmittable).
- Establish links with organisations that support women through the birthing process.
- Carry out social justice advocacy for equality in access to medication, education and housing.

Address violence against women

- Organise seminars and workshops to empower women to create safe spaces for dialogue about violence and to seek help.
- Use case work for discussions and education on how violence manifests in women's lives, their rights, forms of redress and where they can seek support.

Use our creativity

- Have more creative spaces for Mentor Mothers.
- Enable creation of a calendar with 4M women to raise funds for further workshops and meetings.

Increase training and facilitation skills-building

- Run the 4M Mentor Mothers training course more regularly (ideally every 3 months). Where appropriate, extend it to cover more than two days.
- Given constraints related to COVID-19 and on-going funding challenges, organise workshops for Mentor Mothers in delivering virtual

training and online facilitation skills.

- Where possible given COVID-19 restrictions, actively involve 4M ToT-trained Mentor Mothers in facilitating workshops in their local areas.
- Pair less experienced Mentor Mothers with more experienced ones.

Expand our scope and reach out to more women

- Increase national and international networking and have a wider reach with more Mentor Mothers trained and membership expanded.
- Improve links for Mentor Mothers with clinics and mentees.
- Collect different Mentor Mother peer support models from around the country for shared learning.
- Increase 4M's profile and representation at events and conferences, and organise an open day.

More peer research

- Continue to provide a platform for peer research, collect best practice and work collaboratively, with opportunities for wider involvement in writing, reviewing and publishing articles.

Develop our digital capacity

- Increase Mentor Mother access to digital platforms and IT, including through subscriptions to communications platforms and one-to-one IT and social media support for Mentor Mothers.

Professional development and support for Mentor Mothers

- Where possible, provide more face-to-face group peer support, skills sharing and resilience-building meetings for Mentor Mothers, where we can catch up with and learn from each other.

- Keep Mentor Mothers informed about opportunities including placements and job links.
- Source paid work for Mentor Mothers, and pay Mentor Mothers to support the 4M messages.
- Provide Mentor Mothers with continuous support and guidance.
- Increase support for conference applications for Mentor Mothers.
- Increase one-to-one support for Mentor Mothers.

"There is breath, pain, moments of sleep – so deep -
waking to the urge to push
the cycle repeats over and over again
culminating
Birthing is imminent
That opened my eyes wide
into the gaze of my sister
I'm broken open
I am now the we; Mother & Child
That makes me whole"

Story written by Janine

Part 5: Our successes

Our current priorities and plans for next steps are based on our experiences so far, and are intended to build on our successes and address some of the challenges we have faced. In this section, we share 4M's many successes, which have been achieved thanks to our women-centred, holistic and trauma-informed principles, our collective organising, our peer-led approach, and a considerable amount of passion and dedication on the part of the core team, Mentor Mothers, and advisory steering group.

Strong peer-led governance and guidance

- Led by Black African migrant women living with HIV, run in full collaboration with Mentor Mothers, and guided by a multidisciplinary steering group of some of the UK's leading experts in perinatal care and HIV, including Mentor Mothers living with HIV, obstetricians, HIV clinicians, academic and peer researchers.

Strong principles

- Innovative, ethical, gendered, rights-based, women-centred, grassroots, holistic, collaborative, progressive and trauma-informed.
- Rooted in the WHO 2017 Consolidated Guideline on Sexual and Reproductive Health and Rights of women living with HIV.

Strong relationships of trust

- Created, led and run by us as peers who share experiences, which offers Mentor Mothers and the women they mentor a level of trust and confidence in 4M that is hard to match.
- A collectively formed, consistent group since October 2017 has meant sustainable and lasting connections within the network.
- Trusting relationships between the project team and Mentor Mothers, working in partnership to agree suitable ways of working that are unique to each Mentor Mother, so that each may receive and provide peer support in the most convenient and effective way.

Peer support for the supporters (Mentor Mothers)

- Well-being support through regular one-to-one supervisions from the project team. Mentor

Mothers share personal or mentoring issues and the project team works with them to resolve those.

- Being peers, the project team understands that sometimes Mentor Mothers may need time off and the team is flexible enough to adjust, so that Mentor Mothers can focus on themselves when required, while still receiving support from the network.
- 4MNet and Mentor Mothers have established a wide range of networks. Some Mentor Mothers are linked to HIV clinics and others volunteer independently, to provide perinatal peer support for women in their local areas.
- Mentor Mothers receive peer support through the 4MNet WhatsApp group, which enables them to both receive peer support for themselves and offer it to one another. It helps them to feel supported enough to provide peer support to their mentees.
- The project team also receive peer support from the project coordinator who, in turn, receives support from a pro-bono psychologist. In addition, from July 2020 onwards, each project team member will receive her own pro-bono support from a psychologist.

Working holistically/collaboratively with multiple partners for mutual learning

- 4MNet are keen advocates of working collaboratively and holistically across multiple sectors eg training student midwives, developing guidance with the National HIV Nurses Association (NHIVNA), the British HIV Association (BHIVA).
- 4MNet creates awareness among multisectoral services to better understand and utilise Mentor Mother services and has made links with non-HIV-related organisations working with and

around pregnancy, women's health and women's rights. These include MumsNet, Doctors of the World, MIND, Inclusion Healthcare Brixton, Praxis, Refugee Action, Refugee Council, Right to Remain, Agenda Alliance for women and girls at risk, Take her Hand, Birth Companions, Maternity Action, City of Sanctuary, Survivor's Voices, Women for Refugee Women, Southall Black Sisters, Greater Manchester Women's Support Alliance and Women in Prison.

- 4M For Mental Health (4M4MH) perinatal mental health workshops were held at Positive East London, George House Trust Manchester, Brunswick House Hull, Hillingdon AIDS Response Trust (HART), Africa Advocacy Foundation (AAF) London, NAZ London. We have run some groups face-to-face in partnership with local HIV organisations. Talks on the subject were given at the British HIV Association (BHIVA) Annual Conference, National HIV Nurses Association Annual Conference, UK Community Advisory Board (UKCAB) Quarterly Meeting and the STOPAIDS Annual Members Meeting.

Peer and collaborative research

- 4MNet promotes peer research and active involvement of women living with HIV as equal partners. It has engaged in collaborative participatory research with University College London (UCL), London School of Hygiene and Tropical Medicine (LSHTM) and University of Northumbria with abstracts presented at conferences such as: European AIDS Conference Society October 2017; Boston International Conference 2018; BHIVA spring conference 2017 (highly commended poster) and 2018 (community award for best community research); International AIDS Society July 2018 Global Village: The HIV Howler Transmitting Art and Activism Newspaper; AIDS Impact Conference 2019 (details on the Salamander Trust website⁴). Longret Kwardem has been invited to make a presentation about 4M at the International AIDS Conference in July 2020 (AIDS 2020).



Preparing for a workshop about 4M and mentor mothers at George House Trust in Manchester, 2019

⁴ <https://salamandertrust.net/project/4m-health-choice-child-life-perinatal-peer-mentoring-project-women-living-hiv/> [online] Available at: [Accessed 20 May 2020].

Education and sharing our experiences

- 4MNet runs a webinar series, and now has 12 on issues identified by the 4MNet members. Topics include the BHIVA guidelines; immigration; quality of life; talking to others about HIV; perinatal mental health; HIV trauma-informed care; living with HIV, sexual and reproductive health and rights and violence against women; and women; HIV and the menopause. They are recorded and available to access freely from our dedicated vimeo platform⁵.
- 4MNet improves knowledge and confidence of Mentor Mothers through training and networking to provide quality perinatal support to mentees.

Leadership/practical mentoring

- 4MNet members have opportunities to be involved in giving presentations about 4M, co-facilitating workshops, attending learning events, presenting in webinars, and contributing to development of 4M resources. Mentor Mothers report feeling empowered to be involved within the HIV community, and increased confidence in pursuing other activities outside the HIV sector, as a direct result of the training and engagement with 4M: a testimony to 4M's role in developing their leadership skills.
- The project team also supports the Mentor Mothers with mentoring on practical skills like preparing for public speaking at conferences, job applications, developing presentations, encouragement to get involved with more activities for their well-being and other forms of support in their local areas, unique to each woman. 4M mentors Mentor Mothers with practical skills for their well-being, unique to each woman. Although some issues women face may not directly relate to HIV, they affect their ability to manage and live well with HIV⁶.

Organisational working systems/Communication platforms

- 4MNet communicates and provides support using a variety of platforms including telephone, Skype, Zoom, WhatsApp and/or mobile phone

text. We recognise that not all women have access to internet or IT and that they have varied needs and different levels of digital and other literacy, English language skills etc. Therefore women are sometimes seen face-to face.

- 4MNet has an active twitter account and our activities are also posted on The Salamander Trust Facebook page and website, with our supporters and allies tagged and encouraged to share. Webinars, websites and social media are wide reaching. Our active 4MNet WhatsApp group uses include: information sharing and updates; mutual support; announcements about job opportunities events, meetings and opportunities to join advisory boards and steering groups; upcoming webinars and sharing recorded webinars; sharing achievements; requests for information to inform individual presentations.
- 4MNet CIC is in the process of developing its brand-new website.

Training the trainers

- Publication of the 4M Mentor Mothers Training of Trainers Manual in 2019 to train other women living with HIV to become Mentor Mothers. This was described by Professor Chloe Orkin, immediate past Chair of the British HIV Association, as 'world class'. It has also been endorsed by leading UK charities and 4M Mentor Mothers themselves and is being accessed globally.

Advocacy

- 4MNet has been pivotal in influencing leadership by producing statements, taking up speaking and oral and poster presentation opportunities at conferences and All-Party Parliamentary Group (APPGs) meetings in Westminster.
- 4MNet members joined SWIFT (Supporting Women with HIV Information Network). This is a UK and Ireland Knowledge Network, bringing together healthcare providers, researchers, activists and advocates interested in research on HIV and women. 4 members of 4MNet (2

5 Salamander Trust webinars <https://vimeo.com/407122621> [Accessed 12 May 2020].

6 Sophia Forum and Terence Higgins Trust, Women and HIV- Invisible No Longer, A national Study of women's' experiences of HIV. (2018) <https://sophiaforum.net/index.php/hiv-and-women-invisible-no-longer/> [Accessed 12 May 2020].



Rebecca introducing the Mayor of London at the Fast Track Cities launch, 2019



Longret and Angelina representing 4M at the National HIV Nurses' Association, 2019.

Mentor Mothers, the Peer Research Manager and the Project Manager) chaired sessions at the SWIFT Symposium on living well with HIV and getting involved in research, in September 2018. One Mentor Mother and two members of the project team are members of SWIFT's Steering Group.

- Development of an Advocacy Brief⁷ with the Mentor Mothers in 2018 which included some 'asks'.

Respect for diversity

- The 4M programme considers the different needs and priorities of women living with HIV in all our diversity and all are welcome. All experiences of women living with HIV are respected. We tailor our work and training to the priorities of the service users and their circumstances, for example delivery within an already established support group, availability of space, and literacy and levels of understanding of attendees.

Importance of language

- We are passionate about language. Language influences how we feel, think, act and react. We use and advocate the use of positive, affirming, solution-focused, forward-thinking language, which builds on the active agency of those involved. Our Project Team lead co-authored a policy brief on the importance of "the language of HIV" for the National HIV Nurses Association⁸ and talks on the topic regularly at conferences and other venues. 4MNet's solution-focused approach validates experiences and uses positive language and approaches to enable agency and proactiveness among the members.

Peer led and participatory mixed methods monitoring and evaluation approach

- 4MNet is a completely participatory, peer-led initiative. As the UNAIDS-commissioned ALIV[H]E framework explains, a participatory approach means that those most affected by an issue are meaningfully involved in designing, implementing, monitoring and evaluating the initiative designed to address it. A participatory approach hands the power over from an academic researcher researching 'on' or 'in' women, to research instead 'with' women participants, who are often community members⁹.

Membership expansion

- 4MNet has increased membership from 18 to 34 (28 in the UK, 6 in East Africa). With additional funding and capacity we could expand this further.

Influencing policy through our lived realities

- The impact of 4MNet's work on the sexual and reproductive rights of women living with HIV going through the pregnancy journey has been profound. The programme has shifted understanding of pregnancy from a largely biomedical disease-prevention event, focusing primarily on "PMTCT" or "eMTCT" ("prevention or elimination of mother-to-child-transmission") to a largely psychosocial life-creating journey of perinatal care, respect and support, to uphold the sexual and reproductive health, well-being and rights of women living with HIV, in line with the WHO 2017 Consolidated Guideline on this issue.

4M evaluations show that pregnant women with HIV benefit hugely from peer support. This influenced the updated UK BHIVA 2019 pregnancy guidelines to explicitly recommend peer support perinatally as a valuable component of care for a woman living with HIV.

7 4M Advocacy Brief – May 2018, (2018), Salamander Trust, <http://salamandertrust.net/wp-content/uploads/2016/04/SalamanderTrust4MAdvocacyBriefFINALJune2018lowres.pdf> [online] Available at: [Accessed 20 May 2020].

8 <https://www.nhivna.org/NHIVNA-Best-Practice>

9 ALIV(H)E (Action Linking Initiatives on Violence Against Women and HIV Everywhere) framework. 2017. Salamander Trust, Athena, UNAIDS, AIDS Legal Network, Project Empower, HEARD, University of KwaZulu-Natal, [online] Available at: https://www.unaids.org/en/resources/documents/2017/ALIVHE_Framework [Accessed 15 May 2020].

Part 6: Our challenges

We have of course faced challenges including personal, professional and collective challenges, and barriers arising from structural and systemic inequality

- Personal and professional challenges and responsibilities sometimes prevent the Mentor Mothers from being as involved as they would like.
- Providing peer support can affect / trigger personal issues. However, involvement is also reported as a coping mechanism / support system.
- Over-involvement is also a challenge for some. Ongoing supervision enables women to talk through the different issues.
- Our aim is for Mentor Mothers to be integrated within clinic multi-disciplinary teams (MDT) but we have faced challenges and obstacles with this.
- There is a challenge around awareness of the Mentor Mother service and referral pathways within other community and social services.
- Much of our existing 4M work is done on a voluntary basis; this can lead to exhaustion, lack of capacity and burn-out.
- As migrant women living with HIV ourselves, we feel a close connection with the Mentor Mothers we work with. We know that this work takes huge time and effort, including a lot of volunteer time, to build trust and confidence between us as a group. This is a long-term process to build ethical, effective, and sustainable change.
- Funding for our work, as indeed for any grassroots women's rights-based organisation, is extremely hard to source. We are currently looking at new potential funding sources, which is challenging.
- The project team all work as part-time self-employed consultants to the project. 4M work takes a significant amount of our unpaid time and effort. Although we feel positive about our progress to date, being self-employed, we find ourselves having to compensate with other work.
- There is no core funding for the programme. A lot of unpaid time is dedicated to writing funding proposals and fulfilling funders' reporting obligations.
- As Mentor Mothers become more confident and get other jobs (because we can't afford to pay them), they have less time to volunteer their time supporting pregnant women
- Whilst it is a great success that MMs gain the confidence to seek employment opportunities elsewhere, this can also be a challenge. Because we are not able to provide paid opportunities, we as a network lose out on their valuable expertise. A possible solution would be to collaborate with other organisations that have the capacity to have Mentor Mothers 'placed' within their organisations so women can have the flexibility to work and earn in their role as Mentor Mothers.
- We have registered the CIC and are its directors. We have received our first funding award as a fully independent entity. There is still a lot of organisational structural set-up required, which needs funding. This is a huge challenge, as the recent Salamander funding brief describes¹¹.

Ideally we want to be training new Mentor Mothers who can take the place of current Mentor Mothers as they move on or develop, whilst also advocating for more funding within the sector to grow the movement sideways. This means that 4M need not necessarily expand, but that other projects develop, as a "mushrooming effect".

Part 7: Help us build our movement

We invite you to help us build our movement!

Volunteer

- We are seeking a volunteer treasurer to join our board of directors to support 4M Net with its accounting and compliance. Please do get in touch if you know of anyone who might have the right skill set and a couple of hours a week available.

Funding

- We warmly welcome any suggestions of new funding streams to support us – particularly flexible, long-term, unrestricted and core funding that is based on trust relationships.

Collaborations

- We want to increase working collaboratively with HIV organisations and organisations addressing housing justice, mental health, domestic violence, etc, to meet the increasing intersectional and multidimensional needs women have. Get in touch with us if you would like to explore collaborations.

How else can you support us?

If you are a healthcare provider: if you would like to connect with trained 4M Mentor Mothers near you, please contact us at the email below, for learning and knowledge exchange.

If you are a voluntary organisation: you can contact us at the email below to explore a collaboration with us, find out who is trained in your area, or to organise a training of more 4M Mentor Mothers.

If you advertise paid jobs in HIV, health, women's rights or covering other relevant themes in the voluntary and community sector: please add us to your circulation lists so we can share job adverts with Mentor Mothers. Or if you can offer a paid internship or placement to a Mentor Mother, please contact us.

If you are a researcher: contact us for collaborative participatory research.

If you are a donor: we welcome your partnership and support at the email below.

If you are a woman living with HIV who has had a baby: do contact us about possible training opportunities, as well as how to join the 4MNetwork.

If you would like to be kept in touch about our progress: we can put you on an email list for further updates.

If you are passionate about the sexual and reproductive health and rights of women living with HIV, follow us on social media and share our work.

Twitter: @SalamanderTrust; @4Mproject

Facebook: Salamander Trust ; 4M Mentor Mothers Network CIC

4MNet CIC is keen to hear from women and organisations across the globe who might want to develop something similar to our model. The training manual is available freely to download.

Part 8: Acknowledgements

We wish to acknowledge the inspiring 4MNet members for their passion and commitment, selflessly sharing their lives and expertise through the years to create a safe space for all of us, a sisterhood and a better community.

We also acknowledge the ongoing support of 4M's incredible Steering Group members: Jane Anderson; Susan Bewley; Laura Byrne; Rageshri Dhairyawan (Chair); Gill Gordon; Fiona Hale; Vicky Johnson; Longret Kwardem; Rebecca Mbewe; Angelina Namiba; Shema Tariq; Pat Tookey; Alice Welbourn; and Alison Wright.

A massive thanks to our funders – MAC AIDS Fund, ViiV Healthcare, MIND and our Anonymous donor who enabled all of this to happen.

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Finally, we acknowledge our amazing research partners, training partners, allies and collaborators for complementing our work.

4M Mentor Mothers Programme Team:

Programme Design and Coordination: UK: Angelina Namiba;

Evaluation Coordinator: Longret Kwardem; Peer Trainer Coordinator Rebecca Mbewe;

East Africa Co-trainer: Ellen Bajenja

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Additional UK session trainer: Silvia Petretti, Positively UK

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4M Network
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