



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

ADVOCACY BRIEF, JUNE 2020

## From elimination of MTCT to ensuring SRHR Annex: A year-by-year account of our 4M work

© 2020 4M Mentor Mothers Network CIC

### 4M YEAR ONE (2016) Mentor Mothers Training

- With MAC AIDS FUND funding and in partnership with key HIV organisations, 46 women living with HIV in eight UK regions were trained to be Mentor Mothers (MMs).
- The two-day peer-led Mentor Mother training package ‘The Pregnancy journey and Beyond’ comprised coaching on clinical/psychosocial aspects of pregnancy and HIV and creative writing workshops. These diverse components were to encourage trainee reflection on their own pregnancy journey and also help them develop the skills to support other women in each of the 4M components – My health, My choice, My child, My life.

*“Personally, the training gave me more courage to be able to speak about my story*

*and secondly it gave me the courage to help another person. I didn’t feel like I was confident enough to help another person who is in the same situation as me but after the training I felt empowered, you know. I had the courage to face the people and I feel like I had the tools - not exactly everything, but at least I felt more confident to talk to someone else and tell them a piece of advice or just talk, you know have a chat with someone who’s going through the same situation. So I felt like I’ve been really empowered and ready to go to the next step.” (MM, training workshop)*

Immediate post training<sup>1</sup>, 6 months post-training<sup>2</sup> and one-year post-training evaluations<sup>3</sup> found that for most women it had exceeded

1 Namiba A, Kwardem L, et al, Developing a national network of ‘Mentor Mothers’ to support women living with HIV through pregnancy, (2017), BHIVA Conference poster, Salamander Trust. [online] Available at: [https://salamandertrust.net/wp-content/uploads/2016/04/SAIT\\_4M-BHIVA\\_poster2017\\_FINAL.pdf](https://salamandertrust.net/wp-content/uploads/2016/04/SAIT_4M-BHIVA_poster2017_FINAL.pdf) [Accessed 10 May 2020].

2 Kwardem L, Namiba A, et al, 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 (2017), EACS Conference Poster, Salamander Trust. [online] Available at: [https://salamandertrust.net/wp-content/uploads/2016/04/SalamanderTrust\\_4M\\_EACS\\_posterOct2017\\_FINAL.pdf](https://salamandertrust.net/wp-content/uploads/2016/04/SalamanderTrust_4M_EACS_posterOct2017_FINAL.pdf) [Accessed 20 May 2020].

3 Cameron A and Kwardem L (2017) 4M “My Health, My Choice, My Child, My Life”: a Qualitative Evaluation of a National Mentor Mother Training Project to Support Women Living with HIV through Pregnancy. Masters level: London School of Hygiene and Tropical Medicine

expectations and was empowering on an individual and community level. Women valued the medical information, and were using the creative writing techniques to support them in their mentoring.

*“The training had a huge positive impact on me. I feel more courageous and confident to talk about my experience and to support other mothers and women in the same kind of situations. I have mentored one expectant mother and one with children, so two in total so far. I am ready and happy to do more.” (MM 6 months post-training)*

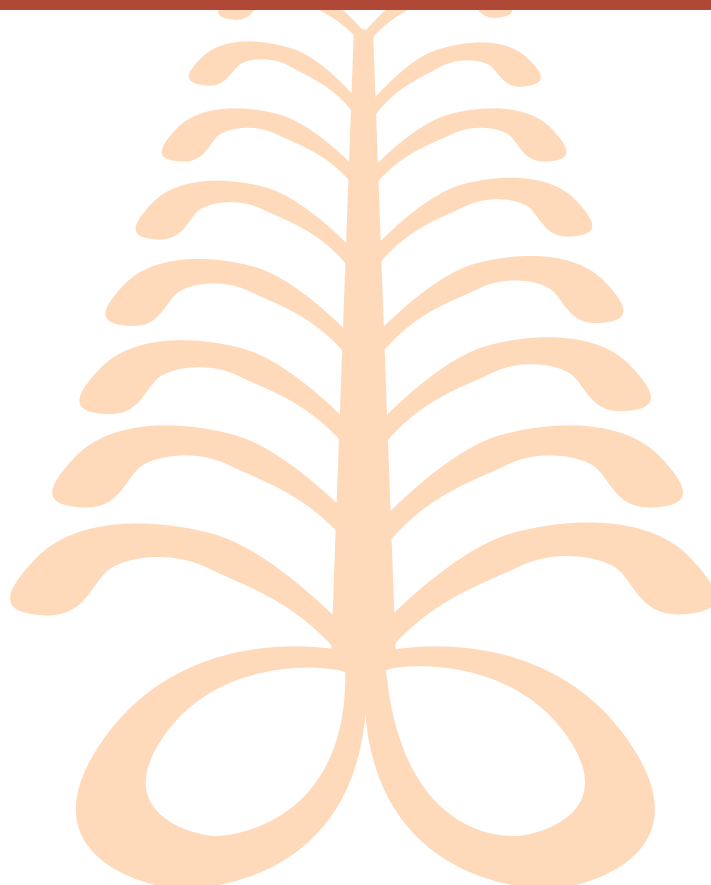
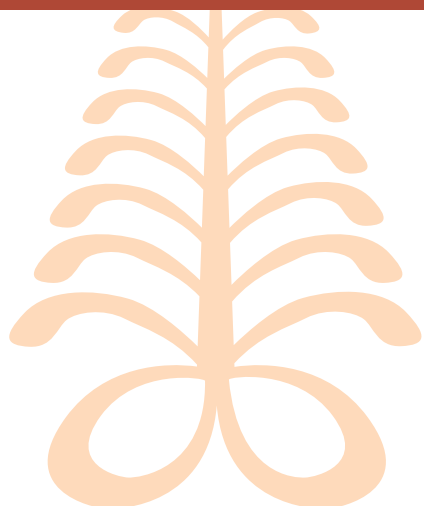
*“I have found that writing really helps to relax me when am stressed and mentoring a challenging person the creative writing and relaxation tips have been really helpful.” (MM 1 year post-training)*

- MMs also identified barriers to providing peer-support, including their own personal and social circumstances; health issues; being a migrant, language, literacy, culture, social isolation, stigma and inadequate links with local HIV clinics and support services.

*“It has made me more aware of what pregnant HIV positive women go through. I have not yet been able to support anyone as I feel I am not ready yet, but my time will come when I can do that.” (MM 6 months post-training)*

*“Yes, the training has helped me consolidate my understanding of guidelines and how they push us into a one size fits all which doesn’t fit our realities.” (MM 6 months post- training)*

The 4M network of trained Mentor Mothers is a valuable resource available to complement the clinical care and management of HIV and pregnancy in the UK.



## 4M YEAR TWO (2017)

### Residential Mentor Mothers Training of Trainers workshop

*“I don’t remember walking home after I received my HIV diagnosis. But I do remember my mum, how she looked at me and how soft her lap felt as I lay my head there. That love, the acceptance and realisation that I was still her daughter, regardless of this little virus in my blood, gave me the strength to know that, three months pregnant at the age of 23, everything was going to be fine.*

*My mum had a plan. She told my dad who told the pastor who then prayed for my long life. This further made me believe that I was going to be fine. I was lucky then, and I still am, to have family, friends and a community that loves and supports me. People have tried to stigmatise me but with this foundation I keep standing. I have gone on to have two beautiful children, 15 years and 8 years old. I have mentored countless mothers, won an Inspirational Person of the year award and I am a trustworthy member of my community; all thanks to this love and support.” Patricia, Mentor Mother<sup>4</sup>*

- In 2017, with ViiV Healthcare funding, 14 Mentor Mothers from across the UK attended a Training of Trainers (ToT) residential weekend in Manchester to build their capacity to be recognised as qualified trainers and to enable them to deliver the Pregnancy Journey training to their peers.
- The training was peer-led by 6 trainers and included group facilitation skills; linking peer mentoring to the National Standards of Peer Support; creative writing<sup>4</sup>; understanding and conceptualising sexual and reproductive health and rights; and an introduction to monitoring and evaluation.

*“So much experience and knowledge gained beyond the boundaries of the facilitated sessions. The worth and beauty of this training is the connections made.” (MM ToT training)*

*“People don’t realise how strong we are and we underestimate how strong we are. Even though we are vulnerable, we are still strong and when we have our own space like today, I think it’s beautiful. I*

*feel connected to everyone. I had goose bumps and said we actually need this because out there we don’t have that.” (MM ToT training)*

- Participants practised facilitation skills in pairs throughout and were assessed by at least 2 trainers to determine their skills, confidence, capacity to deliver a workshop independently, and whether they needed further support. Results indicated that most of the women were ready to run an introductory workshop with a co-facilitator.
- Workshop participants reported that getting together with peers over three days in a safe space enabled the sharing of experiences and creation of a community which generated feelings of normalisation:

*“The passion and love in this room is amazing, it made me feel normal, be myself. It is amazing what words can do, it brought a lot of emotions, It is something I am going to do to let my emotions out in writing.” (MM ToT training)*

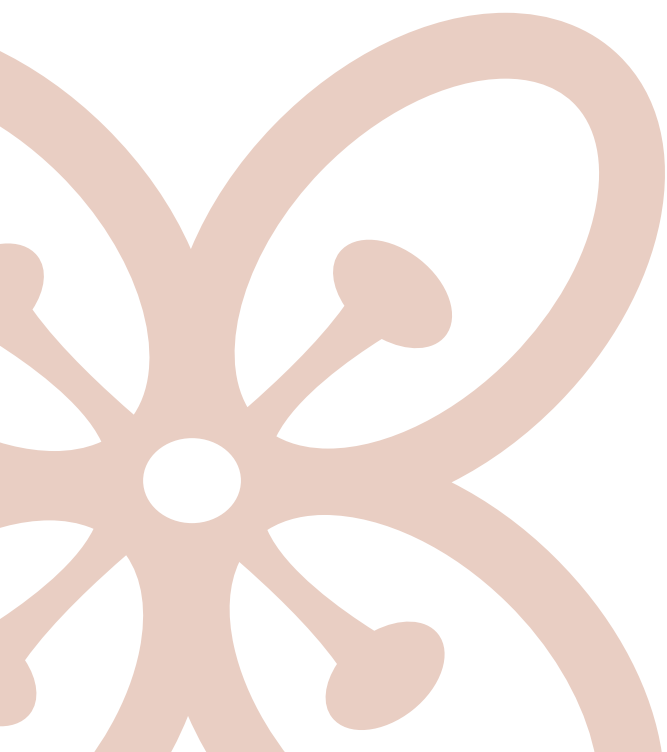
<sup>4</sup> Songs of experience: experience-based research (2018) Salamander Trust, [https://salamandertrust.net/wp-content/uploads/2020/07/4MNet\\_TOT\\_Manchester\\_CreativeWriting\\_Transcripts\\_Final\\_Feb2018.pdf](https://salamandertrust.net/wp-content/uploads/2020/07/4MNet_TOT_Manchester_CreativeWriting_Transcripts_Final_Feb2018.pdf)

- One outcome of the residential training was that the women decided they needed an ongoing safe space to connect; this resulted in the formation of the 4MNetwork. The chosen communication platform was WhatsApp as they felt it was an accessible and economical way to keep the safe space, trusting relationship, connection and bond formed during the residential training weekend.

*“I thought the focus on the practicalities, practising facilitation skills, was really a*

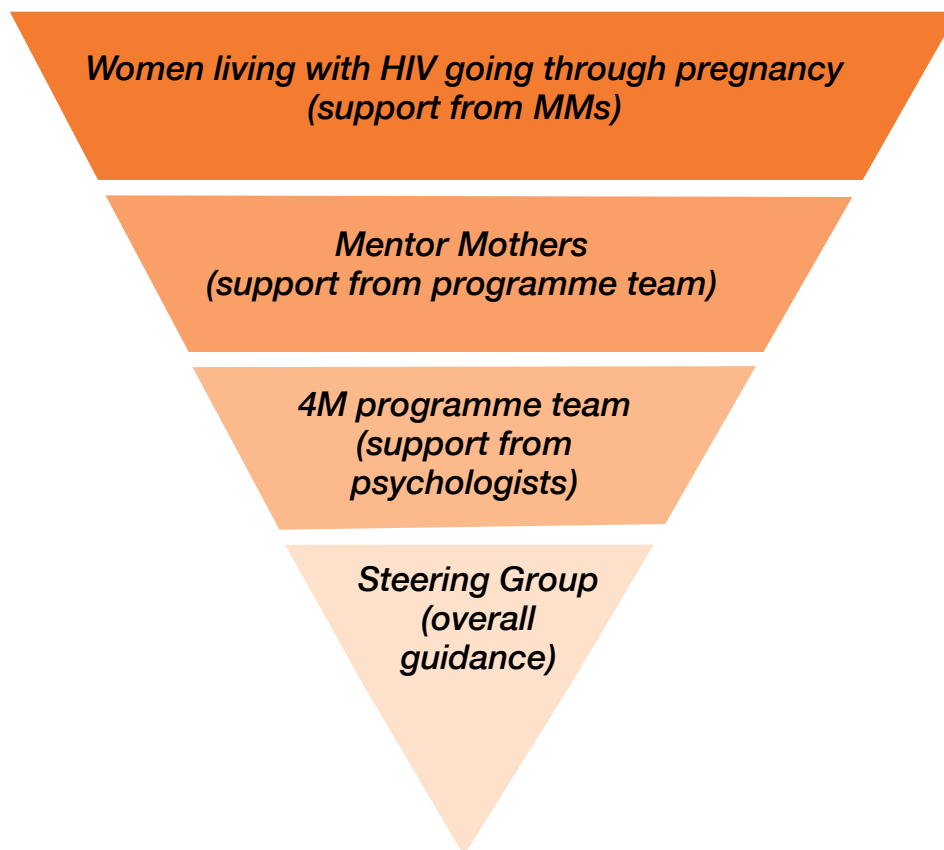
*very good idea. It made it clear that we are capable with support, more than we might think. Very much enjoyed the opportunities to relax from absorbing information with creative writing. Emphasis on expressing self. I enjoyed group sharing and even the moment of verbal conflict was able to be resolved with time to reflect and honouring the positivity of the group and the very great love and respect shared by all. Thank you.” (MM ToT training)*

The Mentor Mothers continue to develop immensely both personally and professionally. A better awareness of the service provided by Mentor Mothers, and uptake by health and social care professionals working in collaboration with Mentor Mothers in their local areas as equal partners and an integral part of the MDT team that provides care and support for women will better address the psychosocial issues women face in their perinatal journey and better utilise the MM service.



## 4M YEAR THREE (2018)

### Developing 4M National Network of Mentor Mothers (WhatsApp) Mothers Training of Trainers workshop



*“I am living better with HIV by being more empowered to question consultants within HIV specialism and in other departments being more open about status and sharing knowledge of u=u, also processing experiences of past abuse highlighted in the training means I am living better as a result of identifying and exploring past trauma.” (MM 6 months post-ToT)*

- In 2018, with funding from MAC AIDS Fund and ViiV Healthcare, the 4M Network was able to develop its activities, building on the bond created between the MMs at the 2017 residential training and consolidating the WhatsApp group. Topics for webinars were discussed in the Whatsapp group, and organised in partnership with other service providers and relevant experts.
- The project team began to provide regular one-to-one peer supervision and support to Mentor Mothers, to enable them to continue supporting mentees in their local areas and work.

*“4MNet training is full of ladies who celebrate their womanhood, have a zest for life and uplift each other.”  
(MM 1-year post TOT)*

- Qualitative evaluations were carried out 6 months and one year after the 2017 residential training to assess longer term outcomes of the workshop. Most Mentor Mothers reported feeling empowered by the 4M Network which provided peer support, improved confidence, information, knowledge exchange, personal/professional development, engagement in advocacy, taking control of services and a valued community.

*“I have supported several women during their pregnancy and post birth as part of my role as a peer navigator working at Homerton hospital. Approximately twice a month I am able to attend the maternity clinic for HIV positive women, working alongside the midwife, this allows for a very complete picture of the developmental stages of a pregnancy and the concerns, decisions the pregnant woman has to make on her pregnancy journey.” (6 months post-TOT)*

*“It has been a Positive result for me as I can take control of my life and get involved at any level.” (MM 1year post-TOT)*

- However, some personal and structural challenges, including ongoing trauma and residence status, were found to limit the capacity of some Mentor Mothers.

*“I haven’t been as active as I hoped I’d be due to work constraints. I have to do double shifts as my visa is about to run out. It has been hard to be involved in webinars, supervision or even just attending the workshops. The stress of not knowing where I’d get almost £10000 for visa renewal has affected not only my mentoring buy also my family life. I wish things were different and I could do more the way I used to.” (MM 6 months post-ToT)*

Personal, external, and structural challenges continue for Mentor Mothers, and they need ongoing support and supervision from 4MNet.



(c) 4M Mentor Mothers Net

## 4M YEAR FOUR (2019) Expansion, consolidation and sustainability

- With funding from MAC AIDS FUND, the 4MNetwork virtual platform was expanded and consolidated. 4M increased membership from 18, to 34. (5 MM from East Africa, 23 in the UK, 4 Project members and two trainers). Currently, 4M directly supports 34 volunteers across the UK and East Africa<sup>5</sup>.
- In July 2019, 4M Network CIC was registered as an independent UK community interested company. Although registered and thus independent, it still takes time for a new organisation to be fully functionally independent, owing to various challenges and hurdles<sup>6</sup>. An awayday was held in November to chart a path for the new CIC and in the coming years we will be developing the structures and strengthening governance and other organisational priorities while continuing to provide support to the Mentor Mothers and keeping abreast with all the other activities 4M has been involved with. In October 2019 the 4M Mentor Mothers training of trainers manual was e-published to enable the training of more Mentor Mothers, both in the UK and across the globe<sup>7</sup>.

*“The 4M training the trainers manual is a rich resource which will enable women with HIV who are interested in peer support to build up their confidence and skills as well increase the capacity of other women through becoming trainers. Peer support, sharing our lived experiences to encourage mutual learning and growth, is very effective in overcoming challenges such as receiving an HIV diagnosis during pregnancy. The 4M manual will make it easier to have a structured approach to peer support, which is fun, supportive, safe and respectful.”*  
**(Silvia Petretti, CEO, Positively UK.)<sup>8</sup>**

*“I personally feel there is space for mental health specific/focused work in HIV/pregnancy for the women I provide support for, because most women seem to be handling a lot in this period of time as most of them will have not long had their diagnosis. So dealing with the diagnosis, the pregnancy journey, the anxiety that comes with it, the uncertainties, relationship breakdown, domestic violence among others is always overwhelming for them. Most women seem to need lots of mental health support during this period.”* (MM MIND funding application rapid survey 2018)

- 4M delivered talks and perinatal mental health workshops with women’s rights and health organisations so that they can better understand and address perinatal mental health and HIV.

5 All volunteers are trained MMs and 14 have been through the Training of Trainers workshop. The East African MMs were trained in 2017 by Angelina, Ellen Bajenja and Nell Osborne in Kenya and Uganda, through partners PIPE Trust in Kenya and the Uganda Network of Young People living with HIV in Uganda. This “4M+” training was funded by MAC AIDS FUND (See previous 4M advocacy [brief](#); and information on 4M+ on Salamander Trust [website](#)).

6 Salamander Trust (2020) Fund what works: fund community-led women’s rights organisations for an effective, ethical and sustainable response to HIV, Podcast Paper #1. [online] Available at: [https://salamandertrust.net/wp-content/uploads/2019/02/20200331\\_The\\_WHAVE\\_paper1\\_Funding\\_Final.pdf](https://salamandertrust.net/wp-content/uploads/2019/02/20200331_The_WHAVE_paper1_Funding_Final.pdf) [Accessed 20 May 2020].

7 Salamander Trust (2019) 4M Mentor Mothers Training of Trainers Manual [online] Available at: [tinyurl.com/4MProject](http://tinyurl.com/4MProject) [Accessed 12 May 2020].

8 Salamander Trust (2019) 4M Mentor Mothers Training of Trainers Manual Endorsements Poster [online] Available at: <https://salamandertrust.net/wp-content/uploads/2016/04/4MManualendorsementsposterFINAL.pdf>

- 4M developed three new resources: a webinar on mental health during pregnancy and in the context of HIV<sup>9</sup>; a concertina contact information leaflet of mental health resource agencies<sup>10</sup>; and a perinatal mental health and HIV annex link to the 4M Mentor Mother Training Manual.

*“The benefits of being involved with 4M4MH is meeting people working in the mental health field who have helped me understand the complexities of mental health and implementation of interventions that have been proven to work.” (MM 4M4MH)*

- We conducted a qualitative evaluation of the use of digital technology by the 4MNet Network with a PhD student from the University of Northumbria<sup>11</sup>. This research found that Mentor Mothers primarily viewed the 4M Network as a professional community: a place for members to pursue the aims and goals of 4M by supporting each other and sharing personal and group achievements. Feelings of trust, respect, and community were established through an in-person group decision to use WhatsApp, and communal drafting of, and adherence to, group etiquette. Mentor Mothers found comfort participating in a national, accessible, and familiar forum, characterised by communal kindness and acceptance. Discussions often elicited positive feedback and empathy, providing support, and building community.

*“There are other... HIV support groups that I belong to... but it’s not the same at all. There you get a lot of ‘oh I have blessings for you’ and ‘these pictures’ and a lot of, I don’t want to say it’s rubbish but, you know, but it’s wasting my time to look at that. And I don’t know how they managed it with 4M, but no one does that; they managed to create some kind of magical boundary that no one wastes—nothing there is wasteful. I’ll get home and have a look and it will be like 84 messages and I’ll think ‘oh I can’t bother’, but if there’s two on 4M I will look because it’s like ‘oh what’s happening?’ You know, if there’s something then it’s going to be worthwhile.” (MM digital research participant)*

*“Within the staff team we use WhatsApp to manage the project and communicate about stuff, do our work plans, meetings basically. Does that make sense? We use it as a team tool.” (Project team digital research participant)*

- Despite some concerns, WhatsApp enabled Mentor Mothers to build a community and share knowledge. innovation. Our research was presented as a poster at the 2019 AIDS IMPACT Conference<sup>16</sup>, and has now been published as a peer reviewed article in the AIDS Care Journal<sup>12</sup>.

**Peer-led digital communication is acceptable and effective for women living with HIV. Understanding the barriers and valued features of these platforms among potentially marginalised groups is vital for informing responsible and inclusive innovation.<sup>11</sup>**

9 Schepers A and Byrne A, (2019) An introduction to mental health in pregnancy and beyond, 4M Webinar No. 7 [webinar] Transmitted 26th February 2019. [online] Available at: <https://vimeo.com/320250842> [Accessed 20 May 2020].

10 Salamander Trust (2020) Useful links for Mentor Mothers. [online] Available at: [https://salamandertrust.net/wp-content/uploads/2020/04/4M-Contactlinks\\_whatsapp\\_updateApril2020.pdf](https://salamandertrust.net/wp-content/uploads/2020/04/4M-Contactlinks_whatsapp_updateApril2020.pdf) [Accessed 20 May 2020].

11 Hay K, Kwardem L, et al (2019) “Support for the supporters”: A qualitative study of the use of WhatsApp by and for Mentor Mothers with HIV in the UK, IMPACT Conference [online] Available at: [https://salamandertrust.net/wp-content/uploads/2016/04/4M\\_AIDSIMPACTPosterJuly2019.pdf](https://salamandertrust.net/wp-content/uploads/2016/04/4M_AIDSIMPACTPosterJuly2019.pdf) [Accessed 15 May 2020].

12 Kiersten Hay, L. Kwardem, A. Welbourn, A. Namiba, S. Tariq, L. Coventry, R. Dhairyawan & A. Durrant (2020) “Support for the supporters”: a qualitative study of the use of WhatsApp by and for mentor mothers with HIV in the UK, AIDS Care, 32:sup2, 127-135, DOI: 10.1080/09540121.2020.1739220 [Accessed 20 May 2020].

## 4M YEAR FIVE (2020)

### 4MNet CIC and support in the time of COVID-19

- In May 2020 4MNet CIC was granted a year's funding, the first in its own right, by MAC AIDS FUND. It will start in August 2020 and support our response to COVID-19. In this current crisis we expect to see increased chronic domestic violence and mental health problems amongst the MMs and mentees. There may be an increase in the number of women living with HIV becoming pregnant, due to women's desire to have a baby (a common post-crisis response), or because of lack of access to contraceptives (already reported before COVID-19, and likely to increase because of global supply chain challenges), or because of lack of access to abortion as a consequence of COVID-19 lockdown. The 4MNet project team will continue to monitor these possible developments with MMs. From zoom discussions and a rapid survey with MMs, isolation is the main issue now faced by MMs and the women they support, and MMs report that mentees have high levels of anxiety during this time.

*“How 4M can support the group: Keep up the updates on staying healthy during the COVID pandemic, live interactive discussions are invaluable for sharing and support, checking on each other, and tapping into individual resources.”*

*(MM rapid survey April 2020)*

- 4MNet members have a strong track record of mutual trust which is invaluable during these extraordinary times. We are already comfortable using virtual IT for core teamwork and regular contact with the MMs. We aim to continue 1-1 supervision with the MMs and virtual drop-in sessions. We will provide accurate and up-to-date information about COVID-19 in the context of HIV, and especially during perinatal care, from trusted websites such as BHIVA, the Royal College of Obstetricians and Gynaecologists, and WHO, as well as continuing to update the emergencies contact list we have produced.

**4M on FIRE: 4M Network Increasing our Resilience in Emergencies, will respond directly to issues resulting from COVID-19, consolidate our base, and provide quality perinatal peer support to women living with HIV.**

