

“Support for the supporters”:

A qualitative study of the use of WhatsApp by and for Mentor Mothers with HIV in the UK

Hay, K.¹, Kwardem, L.², Tariq, S.³, Coventry, L.⁴, Welbourn, A.⁵, Namiba, A.², Dhairyawan, R.⁶, Durrant, A.¹

¹School of Design, Northumbria University, Newcastle-upon-Tyne, UK

²4MNetwork, London, UK / Salamander Trust Associate

³Institute for Global Health, University College London, London, UK

⁴Department of Psychology, Northumbria University, Newcastle-upon-Tyne, UK

⁵Salamander Trust, London, UK / 4MNetwork, London, UK

⁶Barts Health NHS Trust

AIMS

Third-sector organisations, an important support for people living with HIV, increasingly use digital technology to improve service efficiency and reach. However, there is limited empirical evidence on this use by women living with HIV.

The 4M Network (4MNet) is a peer-run UK-wide network of trained Mentor Mothers living with HIV. It uses the WhatsApp platform as a communication tool alongside other digital platforms. This study explored 4MNet Mentor Mothers' experiences of using WhatsApp, to inform future service design and implementation of digital support services.

METHOD

A semi-structured interview study was led by the first author in partnership with a peer researcher (a woman living with HIV). Seven telephone interviews were conducted with five Mentor Mothers and two project management team (PMT) members in February 2019. Interviews were audio-recorded, transcribed verbatim, manually coded and analysed using Interpretive Phenomenological Analysis (IPA).

INSIGHTS

Participants primarily viewed the 4M Network as a professional community: a place for the members of the group to pursue the aims and goals of 4M by supporting each other with information, updating each other on group activities, 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 group etiquette.

WhatsApp functioned well as a team management tool for 4MNet, through a regulated group focus, maintained through adherence to the co-created group etiquette

rules. Active, ongoing connection with updates on work and achievements and personal welfare checks enhanced personal and professional development among Mentor Mothers and the PMT.

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.

Key WhatsApp Use Insights

	Negatives	Positives
Accessibility Low barriers to access	<ul style="list-style-type: none"> - User verification concerns around those added to WhatsApp - Potential for messages/content to be accidentally sent to other WhatsApp groups 	<ul style="list-style-type: none"> + No subscription/download cost + Pre-existing knowledge of the platform and how to use it + The app may already exist on user's phone + No login required
Adaptation Can change based on an individual's need at a given time, without affecting the network	<ul style="list-style-type: none"> - Potential information overload from too much content - The work of the group is always present on a personal device, which may add stress due to feelings of constant involvement 	<ul style="list-style-type: none"> + Use style can change over time as needed, allowing for adaption to user interests and availability + Can use in different scenarios and locations (e.g. WiFi, data, on desktop) + Can support multiple content types (e.g. photos, URLs, emoji)
Customization Gives each user personal control over some functionalities	<ul style="list-style-type: none"> - Potential for missed interactions due to individual control settings (e.g. muting the conversation) - The group being a constant presence could make some not join the group, as it was seen as an additional task to be done (prefer personal, direct, and specific interactions) 	<ul style="list-style-type: none"> + Can mute (no updates received) + Can create a personal profile, with image and descriptive text (if desired, not required) + Can delete messages or group discussion without changing the shared group history; can easily be re-downloaded later + Ability to delete/re-download useful for those sharing devices (e.g. with children)

Participant thoughts on WhatsApp use for 4MNetwork



General concerns about technology use

In addition to concerns specific to using WhatsApp, the women interviewed also expressed various concerns around using technology more generally in relation to peer support services. These should be considered with any digital support tools developed for people living with HIV.

1. Financial Costs

Internet-enabled digital tools and services put the cost of access and use on the individual, through both hardware maintenance and Internet access costs. How these costs can be covered or subsidised by service providers should be considered.

“With the limitations of data and things like that on the phone, you can't have many messages on your phone, taking up all your space...because we use our personal phones. 4M is not providing us to put all this extra information... in your phone.” [Participant 3]

“Fortunately, at the moment, I'm in the position where I can pay for my contract... so, it's not an issue for me, but like five years ago that would have been a real issue.” [Participant 2]

2. Self-confidence using technology

As the cohort of people living with HIV ages, digital skills and self-efficacy in using digital tools and services could become a greater barrier to access. Digital skills training should be integrated into digital service provision, especially for older users.

“I'm not confident in... and I'm scared of doing something wrong, that... I've, maybe wiped something”. [Participant 4]

“I definitely feel like if I had more confidence around certain applications, it would help me a lot [laughs]. It's like if you don't have much confidence around something, it's hard to... make the most of it, basically.” [Participant 4]

3. Security & privacy concerns

It is important that communications involving HIV support users to feel empowered by facilitating individual control over personal information, both in connection with commercial entities (e.g. apps) and with others receiving communications. Implications of stigma on digital technology use should be taken into consideration for digital service design and platform choice.

[with commercial platforms] “It's just a tool, you know, we use, but does our information go anywhere beyond us without us knowing?” [P3]

[for individuals] “So, if I'm mentoring, there is, you know, I would always ask... if you're comfortable with, you know, even, because on some things]- like on WhatsApp, there's my [profile] picture... I'm not famous or anything, but even then, someone [other than the mentee] could see that picture and then think, “Oh, well, I've seen that [in relation to HIV]” so you have to be quite careful with someone who really doesn't want to disclose their status, what you're sharing, and what links other people might make.” [P2]

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CONCLUSION

Peer-led digital communication is acceptable and effective for women living with HIV. Despite some concerns, WhatsApp enabled Mentor Mothers to build a community and share knowledge. With increased digital platform use, understanding the barriers and valued features of these platforms among potentially marginalised groups is vital for informing responsible and inclusive innovation.