“Support for the supporters”: A qualitative study of the use of WhatsApp by and for Mentor Mothers with HIV in the UK

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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 4M Mentor Mothers’ experiences of using WhatsApp, to inform future service design and implementation of digital support services.

INSIGHTS
Participants primarily viewed the 4M Network as a professional community, a place for the members of the network to collate ideas and build a strong network with each other, sharing ideas and personal group achievements. Feelings of trust, respect, and community were established through an in-person group decision to use WhatsApp as a platform for group activity. WhatsApp functioned well as a team management tool for 4MNet, through a regulated group focus, maintained through adherence to the co-created group etiquette.

Negatives
- User verification concerns around those added to WhatsApp
- Potential for messages/content to be accidentally sent to other WhatsApp groups

Positives
- 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 be confused as an individual’s need at a given time, without affecting the network
- 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
- Use style can change over time as needed, allowing for adaptation to user interests and availability
- Can use in different scenarios and locations (e.g. WiFi, data, on-device)
- Can support multiple content types (e.g. photos, URLs, emojis)

Customization
Gives each user personal control over some functionalities
- Potential for missed interactions due to individual control settings (e.g. muting the conversations)
- 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)
- Can mute (no new updates received)
- Can create a personal profile with image and descriptive text (if desired, not required)
- Can delete messages or group discussions 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)

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 are distributed 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, talking up all your space...because we're constantly having to pay for internet...it's just getting 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. Security & Privacy concerns
It is important that communications involving HIV support users be handled sensitively by facilitating individual control over personal information, both in connection with commercial entities (e.g. apps) and with others receiving communications. It remains up to the user of digital technology use should be taken into consideration for digital service design and platform choice.

“[with commercial platform] “It’s just a tool, you know, we use, but does our information go anywhere beyond us without us knowing?” [P2]

[for individuals] “So, if I’m mentioning, there is, you know, I would never ask...but you’re comfortable with, you know, even, because on some things...I use on WhatsApp, then my [friend] phone...I’m not famous or anything, but even then, someone [other than the members] could see that picture and...well, of course, if you’re not comfortable, you kind of feel that they’re keeping me in the loop somehow.” [Participant 4]

3. 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]

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

4. Personal control over some functionalities
Some functionalities gave each user personal control over personal information, both in connection with commercial entities (e.g. apps) and with others receiving communications. It remains up to the user of digital technology use should be taken into consideration for digital service design and platform choice.

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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.