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Peer group focused eHealth strategies to promote HIV prevention, testing and care engagement

Keshet Ronen^{1,*}, Eli Grant², Charles Copley³, Tara Batista^{2,4}, Brandon L. Guthrie¹

¹University of Washington, Seattle, WA, USA

²Praekelt.org, Cape Town, South Africa

³Cedar.com, New York, NY, USA

⁴Columbia University, New York, NY, USA

Abstract

Purpose of Review: Electronic communication platforms are increasingly used to support all steps of the HIV care cascade (an approach defined as eHealth). Most studies have employed individual-level approaches in which participants are connected with information, reminders, or a healthcare worker. Recent growth in use of social media platforms, which create digital communities, has created an opportunity to leverage virtual peer-to-peer connection to improve HIV prevention and care. In this article, we describe the current landscape of peer group eHealth interventions in the HIV field, based on a review of published literature, an online survey of unpublished ongoing work, and discussions with practitioners in the field in an in-person workshop.

Recent Findings: We identified 45 published articles and 12 ongoing projects meeting our inclusion criteria. Most reports were formative or observational; only 3 randomized evaluations of 2 interventions were reported. Studies indicated that use of peer group eHealth interventions is acceptable and has unique potential to influence health behaviors, but participants reported privacy concerns.

Summary: Evaluations of health outcomes of peer group eHealth interventions show promising data, but more rigorous evaluations are needed. Development of group eHealth interventions

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*correspondence: keshet@uw.edu.

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presents unique technological, practical, and ethical challenges. Intervention design must consider privacy and data sovereignty concerns, and respond to rapid changes in platform use. Innovative development of open-source tools with high privacy standards is needed.

Keywords

HIV; peer; digital; eHealth; mHealth; social media

Introduction

eHealth refers to interventions that employ digital communication technology to improve health outcomes. Use of eHealth has grown explosively over the last 15 years. In the HIV field, substantial literature has accumulated demonstrating the ability of eHealth interventions to improve outcomes throughout the HIV care continuum, from prevention and testing, to linkage to care, retention in care, and antiretroviral therapy (ART) adherence [1–4]. The vast majority of published studies have focused on individual-level interventions that provide the patient with information, reminders, or connection with a healthcare worker. The dominance of individual-level interventions is a logical extension of one-to-one delivery of HIV medical care and the prioritization of privacy and confidentiality. This approach is also a reflection of the capabilities of available technology platforms: the technologies most widely accessed over the last 15 years, such as SMS text messaging, phone calls, and electronic reminders, predominantly function to connect individuals to one another or automate individual-level cues to action. However, changes in global technology access and, to some extent, HIV care models, over the last 5–10 years have created an opportunity to study delivery of eHealth interventions at a group level. As of January 2020, an estimated 4.5 billion people globally have access to the Internet (59% penetration) and 3.8 billion (49%) use social media, defined as interactive digital platforms that facilitate creation and sharing of content with a virtual community [5]. Digital connection with *networks* of people, rather than *individuals*, through these platforms has increasingly become a norm. In parallel, differentiated HIV care models in high prevalence contexts increasingly incorporate group delivery of HIV care, for example through ART adherence clubs and peer support groups for people living with HIV (PLWH), providing models for care delivery that leverage peer-to-peer interactions [6].

The purpose of this article is to review the current landscape of peer group eHealth interventions throughout the HIV care continuum. Through a review of published literature, a survey of unpublished ongoing work, and input from practitioners at an international workshop, we provide a synthesis of current research and identify areas for future inquiry.

Methods

Scope

Our review focuses on work developing and evaluating interventions that mediate connection between peers through a digital communication platform, to improve clinical outcomes in HIV prevention, testing, or treatment. We sought to include interventions reported in the context of either research or practice; interventions that were either

organically developed by users or deliberately designed by practitioners for implementation; publications that reported any aspect of the intervention including design, implementation, or health impact; projects conducted in any geographic location; and projects using any study design. Projects were considered out of scope if they used digital platforms only for mass media campaigns without facilitating peer-to-peer interaction, or for the purpose of data collection only (for example conducting virtual focus groups or recruiting study participants).

Literature review

We searched PubMed for peer-reviewed publications published before June 11 2020, using the following search terms: HIV AND (facebook OR whatsapp OR wechat OR telegram OR signal OR “social media” OR virtual OR digital) AND (peer OR “social support”). Each article’s title and abstract was reviewed for relevance by two of three authors (KR, TB, BLG), and full text of relevant articles was further reviewed by one author (KR or BLG). Non-English language articles and articles that could not be accessed through University of Washington journal licenses were excluded.

Survey of ongoing work

We conducted an online survey of eHealth practitioners to characterize ongoing peer eHealth interventions. Practitioners at any institution using internet protocol (IP) digital communication platforms for projects in global health were eligible to participate. A convenience sample of practitioners was recruited by disseminating the survey through the authors’ professional networks, eHealth listservs, and snowball sampling. The survey was administered using REDCap electronic data collection, hosted at the University of Washington [7]. The survey collected information on the size, location, design, and outcomes of ongoing interventions. Practitioners were additionally asked about challenges and important questions in the field of IP interventions for global health. The University of Washington’s Human Subjects Division determined that the research was exempt from human subjects regulations. All projects focused on HIV and whose interventions facilitated peer-to-peer digital connection were included in the present report.

Practitioner workshop

The manuscript authors organized an international workshop titled “Leveraging Smartphone-enabled Group Messaging for Global Health”. The workshop was held on May 23, 2019, at Columbia University in New York, NY, USA, and convened 16 practitioners delivering smartphone group messaging interventions for global health (named in Acknowledgements). The workshop agenda included participant presentations of their interventions and discussion of future directions for the field [8].

The current landscape of peer group eHealth interventions

Summary of published studies

Our literature search yielded 149 articles, of which 48 articles published between 2008 and 2020 met inclusion criteria and are reported (Table 1). Articles included 8 studies reporting evaluations of group eHealth interventions (4 non-randomized [9–12] and 4 randomized

them especially sensitive to peer influences [59], and studies focused on oppressed groups such as MSM and people of color in the Global North [22,23,29,60]. Ramos et al. presented a conceptual framework that outlines the unique potential of eHealth interventions to overcome medical mistrust in sexual minority men of color in the US through their provision of anonymity, co-presence, self-disclosure, and social support [60]. Additionally, the dominance of interactive social media in some groups, particularly youth, motivated studies to select familiar platforms to reach communities in culturally appropriate ways [22,24,28,29,35]. Publications also discussed the potential of group eHealth interventions to be more affordable than individual-level or in-person interventions, by incurring lower personnel costs and having the ability to scale efficiently [18,21,29,32,40,49].

Technology platforms used for eHealth peer groups

Of the 48 published articles that reported on the use of one or more platforms relevant to eHealth peer groups, the most commonly used platform was Facebook, used in 25 articles (52%) [9,11,13,14–16,22,24,27,28,29,34,37,38,44,46–49,51,54,55,59,62,63], of which 8 came from the same parent study. Weibo (a microblogging site predominantly used in China) was used in 6 (13%) articles [34,38,39,44,47,50] and 4 (8%) articles, all published in 2019–2020, used WhatsApp [24,48,49,52]. A small number of articles reported use of other platforms: 2 (4%) articles used Instagram studies [24,58], 2 (4%) used Myspace [22,28], and 1 article each reported use of Viber [24], IMO [5], Reddit [41], Google Groups [11], Yahoo Groups [11], and virtual environments [60]. We identified an additional 10 studies that used some other platform or internet site [9,12,22,23,25,26,40,41,54,63]. We found 4 articles that used custom applications or websites [10,32,43,55] along with an additional study protocol [18]. Other study protocols described using Muut (n=3) [21,63,64]. Out of the 17 standardized interventions reported, 10 (59%) delivered the intervention through Facebook, 2 (12%) used WhatsApp, and 5 (29%) used other less-widely used applications or custom platforms.

In contrast to the published literature, among the projects identified in our practitioner survey, all 13 reported using WhatsApp, of which 8 additionally reported using other platforms such as Facebook Messenger (n=3) or other platforms (n=7).

End-users support use of eHealth peer groups for HIV prevention and treatment support, but have concerns about privacy

Six studies were identified that reported participant preferences regarding design of eHealth peer group interventions [16,22–24,51,52]. All six studies, which included people living with or at risk of HIV in the US, Nigeria, Botswana, and the UK, reported widespread use of social networking sites and social media platforms that facilitate peer-to-peer messaging, such as Facebook, Twitter, Instagram, WhatsApp and MySpace. Participants expressed strong interest in using these platforms to support HIV prevention or treatment. Desired functions of interventions included information on HIV prevention or treatment [22,24], and connection with peers and social support, particularly for people living with HIV [22,23]. However, while confidentiality and anonymity were sometimes viewed as a strength of eHealth approaches, several studies also reported users' concerns about data privacy [22,23,36,40,52].

eHealth peer group functions are often multidimensional and delivery approaches are variable

Twelve studies reported on peer messaging groups that developed organically rather than being delivered as a standardized intervention by a study or program. Eight of these, all focused on people living with HIV, examined the content of messaging to explore the functions group members sought and enacted [25,26,34,38,39,42,44,50]. Groups were hosted on Weibo, Facebook, WhatsApp and custom applications. These studies reported that messaging among people living with HIV provided social support [65], particularly emotional support [50], informational support [34,41], or a combination of social support domains [25,26,42,47,50].

Messaging content in standardized eHealth peer groups, in which the group facilitator created and moderated pre-determined content, was examined in 13 studies of 11 unique interventions: 4 targeting people at risk of HIV [10,13,14,31,37], 5 targeting people living with HIV [16,35,40,43,46], and 2 targeting healthcare workers [48,49]. Similar to findings from organic groups, participant messaging in standardized groups exhibited emotional support [35,43] or a mixture of informational, emotional and companionship support [10,13,14,16,31,37,40,46]. The two publications describing groups for healthcare workers incorporated virtual discussions by WhatsApp into a formal training program, using it to deliver information and facilitate group learning [48,49]. Five study protocols [17–21] described 4 forthcoming intervention trials involving eHealth peer group interventions, two targeting people at risk of HIV [17,20] and two targeting people living with HIV [18,19]. All planned to combine supportive and informational content.

An important characteristic of many completed and forthcoming interventions was that they were multi-functional, combining peer-to-peer messaging with informational announcements, videos, interaction with healthcare providers, and games [10,12,13,18,43]. Two study protocols planned to evaluate group social media messaging as part of a stepped care approach in which participants whose outcomes did not improve received progressively more intensive interventions: first automated daily text messaging and medication adherence monitoring, then peer social media support, then provider coaching [19,20].

Published eHealth peer groups varied in their facilitation structure. While organic groups did not have formal group facilitation or moderation, most standardized groups included a facilitator whose role was to share content with the group, answer questions, or promote group member discussion. In 7 studies, facilitation was provided by study or clinic staff who were not reported to share identities with group members. Five studies specifically recruited facilitators who were “peers” to the target population. This strategy was particularly employed in studies with youth [13,28,58] and MSM [30,37], motivated by the importance of shared identity in these groups. Two publications reported on the process of peer facilitator recruitment, training, and supervision for the HOPE study, which delivered HIV and STI prevention messaging through Facebook groups, highlighting peers’ fluency with technology [30,37].

All eHealth groups made use of asynchronous messaging functionality, though Henwood et al.’s group for youth living with HIV specified an hour each day when the facilitator was

available to respond to messages [40]. The duration of group member participation in eHealth groups varied considerably. Publications on organic eHealth groups reported on web forums, Facebook or Weibo groups that had existed for several years and would continue indefinitely, but analyses focused on content spanning 1 month – 4 years [25,26,34,41,42,44,50]. Standardized groups were offered for between 4 weeks and 24 months [10,12,13,14,16–20,27,28,29,32,35,38,39,41,42,46,47,49–51,63].

Evidence on health outcomes of eHealth peer groups is limited but promising

Of the 45 studies identified in our search, only 8 completed studies reported health outcomes of eHealth group interventions: 4 were randomized trials [13–16], 2 used non-randomized designs to evaluate a defined intervention [10,12], and 2 were observational [9,11]. Results to date have been mixed, but promising.

Two randomized trials evaluated the Harnessing Online Peer Education (HOPE) intervention, a 3-month peer-facilitated Facebook intervention to increase HIV testing among MSM, in the US [14] and Peru [15]. Both found an increase in HIV testing uptake in the intervention arm compared with an unfacilitated peer group and testing information. Bull et al. found that a 2-month peer-facilitated Facebook intervention to promote STI prevention led to increased condom use at 2 months compared with an attention-matched control, but the effect was not sustained at 6 months [13]. Dulli et al. found that online support groups for youth using a Facebook “secret” group resulted in improvements in HIV knowledge but did not increase retention, although retention was higher than expected in both intervention and control arms [16].

In non-randomized evaluations, Hightow-Weidman et al. used a pre-post design to pilot HealthMpowerment, a mobile online intervention including a peer forum as well as several other functions [10]. They found significant improvements in social support, social isolation, and depressive symptoms in youth at risk of HIV after the one-month intervention. Ivanova et al.’s ELIMIKA pilot project evaluated the impact of a multifunctional online platform for youth living with HIV [12]. They found increased ART adherence intention after the 3-month intervention compared with before, but no change in ART knowledge and adherence behavior.

An additional 5 protocols reported on 4 forthcoming randomized trials [17–21]. Outcomes of forthcoming trials include virologic suppression [18,19], HIV prevention behaviors [17,20], and cost-effectiveness [19,20].

Looking ahead

Use of peer group messaging for eHealth is growing and more rigorous evaluations are needed

Our review of published literature indicates that use of group messaging platforms to support HIV prevention and treatment outcomes has emerged as a popular strategy over the last 5–10 years. Importantly, our practitioner survey identified a substantial number of additional unpublished studies in this area (13 beyond the 48 in the peer-reviewed literature), highlighting the recent growth of this approach. However, data on the health impacts of peer

group eHealth interventions are very limited to date. Over half of publications were descriptive accounts of interventions, and only 4 were randomized evaluations. As interest in these approaches grows, rigorous evaluations are needed to determine whether peer group eHealth interventions are efficacious in improving HIV prevention and treatment outcomes, and should continue to be implemented.

Moreover, group eHealth interventions, by virtue of their design, present unique opportunities to address critical questions about behavior change, which have not been fully explored in projects to date. While several published studies used content analysis and social network analysis of eHealth groups to shed light on intervention functions, few studies conducted in-depth analyses of paradata – data on usage and engagement with the intervention [66]. Digital messaging platforms have the ability to record numerous aspects of users' engagement with interventions, such as time stamps for receiving, viewing and responding to messages. These data can be analyzed to shed light on social network structures, diffusion of ideas, and associations between intervention content, patterns of engagement, and clinical outcomes.

Many group eHealth interventions we identified had multiple components: group messaging was combined with other elements such as informational content and games, or the group messaging itself included multiple topics. Use of multiple intervention components raises important questions about which components are core to intervention effect, and the optimal sequence of their delivery. Innovative evaluation designs have recently been developed to rapidly and rigorously address these questions, including the multiphase intervention optimization strategy (MOST) [54], micro-randomized trials [55], and just-in-time adaptive interventions [56]. These approaches are made more practical by digital intervention delivery, and should be used to understand and optimize group eHealth interventions.

Key challenges remain, including privacy and implementation at larger scale

Study participants in published articles as well as practitioners who participated in our survey and workshop identified significant concerns regarding privacy of group eHealth interventions. For end-users, this focused on concerns about disclosure of sensitive information to other members of the group and breach of confidentiality if a third party gained access to another group member's phone [22,36,40,52]. Intervention developers, and some study participants [23], were additionally concerned about sovereignty and access to data transmitted through messaging platforms. There exists a tension between delivering interventions through widely-used commercial messaging platforms, such as Facebook, WhatsApp and Telegram, and developing custom software. Using existing commercial platforms has the advantage of capitalizing on an existing user-base, avoiding costly software development, and responding to end-users' social media preferences and usage patterns; it may also be the only feasible option in low-resource contexts where end-users' devices have limited capacity to download dedicated applications. However, commercial platforms provide very limited privacy protections and their data use policies change frequently. This is particularly concerning for messaging about sensitive topics such as HIV. Of note, groups that were organically started by end-users had no choice but to use commercial platforms, and in research the argument can be made that these platforms are so

ubiquitous that their use in eHealth interventions may not present a significant elevation over the “minimal risk” of day-to-day life. However if group eHealth interventions are found to be efficacious, their delivery at scale may require development and maintenance of custom software with robust anonymity and privacy protections. Open-source, configurable, interoperable software that achieves this would be of great value to the field.

Most group eHealth interventions included in our review were manually facilitated by a human at relatively small scale. Increasing the scale of such interventions for larger research evaluations will present practical challenges. First, increased scale requires development of software for automated messaging that integrates with the messaging platform used. If using a commercial platform, the project’s ability to do this is dependent on the platform’s policy regarding access to its application programming interface (API). Additionally, using an intermediary (e.g. Twilio) to access the platform API will incur costs that typically scale with the number of messages sent, even if the messages are sent on an otherwise ‘free’ platform such as Facebook or WhatsApp. Second, the published and unpublished literature reflects rapid changes in use of different messaging platforms over the last decade: studies before 2015 were dominated by use of Facebook, while more recent studies have used a broader range of platforms, and unpublished ongoing studies all used WhatsApp. Changes in social media trends and rapid innovation in digital communication will continue, challenging researchers to create interventions that are platform-agnostic, produce generalizable findings, and explore nimble study designs that rapidly generate findings. Finally, as intervention scale increases, an important area for research is determining whether methods such as natural language processing (NLP) can be used to assist in facilitation of group eHealth interventions to improve efficiency and reduce cost. Open-source chat-bot frameworks such as RASA [67] can make this possible at scale with relatively low setup costs, and other AI solutions have shown promise in addressing question answering services [68]. However, significant challenges exist in using NLP methods in LMICs with the highest HIV burdens due to the limited local language datasets available to train language models. Developing more representative “resource-poor” language models could make NLP techniques suitable and valuable in these settings [69].

Conclusion

This review highlights the recent growth in use of eHealth approaches for peer-to-peer connection to promote HIV prevention, testing and treatment. Theoretical and practical considerations have motivated development of digital peer groups for people at risk of or living with HIV, as well as their healthcare workers - either organically developed by users or deliberately designed by practitioners for implementation. Studies to date indicate these interventions hold promise, but rigorous evaluations of their health impact are needed, using novel study designs that allow assessment of the impact of individual intervention components. While development of peer group eHealth interventions emerged from the explosive growth in use of social media platforms, and using existing platforms allows interventions to reach underserved and marginalized individuals “where they are”, use of commercial platforms poses ethical, practical and financial challenges. Development of interoperable open-source software tools with high privacy standards will accelerate advances in the field.

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Table 1. Summary of published literature on peer group messaging interventions for HIV prevention and treatment

| First Author, year | Title | Study purpose | Country | Population | Group type | Platform | Summary of findings |
|-----------------------|--|------------------------------|---------------|--------------------------------|------------|--------------------------------------|---|
| Horvath, 2012 [22] | Technology use and reasons to participate in social networking health websites among people living with HIV in the US. | Descriptive (formative) | USA | People living with HIV | NA | NA | <ul style="list-style-type: none"> Online survey (n=312) & FGDs (n=22) to understand access & use of social networking sites among PLWH on ART Most used social networking site >1/wk Some differences in technology access by sociodemographic characteristics Most interested in social networking website for health, desired ability to connect with other PLWH, relevant HIV information, emotional support One-quarter expressed privacy concerns |
| Blackstock, 2015 [23] | HIV-infected Women's Perspectives on the Use of the Internet for Social Support: A Potential Role for Online Group-based Interventions. | Descriptive (formative) | USA | Women of color living with HIV | NA | NA | <ul style="list-style-type: none"> Semi-structured interviews with 27 WLWH - Participants expressed need for connectedness, convenience and accessibility. Trust viewed as a precondition for participating; in-person interactions were viewed as important. Hybrid (in-person and online) interventions may be most useful for women with HIV. |
| Cornelius, 2019 [24] | Mobile phone, social media usage, and perceptions of delivering a social media safer sex intervention for adolescents: results from two countries. | Descriptive (formative) | USA; Botswana | Youth at risk of HIV | NA | Facebook, Instagram, WhatsApp, Other | <ul style="list-style-type: none"> Youth in USA and Botswana endorsed use of social media to deliver safer-sex information. USA youth reported using Facebook, Twitter, Instagram. Botswana youth reported using Facebook, WhatsApp, Viber. |
| Mo, 2008 [25] | Exploring the communication of social support within virtual communities: a content analysis of messages posted to an online HIV/AIDS support group. | Descriptive (implementation) | NA | MSM living with HIV | Organic | Other | <ul style="list-style-type: none"> Content analysis of 1138 messages on a public online support group bulletin board. 986 messages contained social support: information (45%), emotional (35%), esteem (12%), network support (7%), and tangible assistance (1%) |
| Coursaris, 2009 [26] | An analysis of social support exchanges in online HIV/AIDS self-help groups | Descriptive (implementation) | NA | People living with HIV | Organic | Other | <ul style="list-style-type: none"> Content analysis of 5000 messages on a public online HIV/AIDS support group. |

| First Author, year | Title | Study purpose | Country | Population | Group type | Platform | Summary of findings |
|----------------------|---|------------------------------|---------|-----------------------------|--------------|-------------------|--|
| Rice, 2012 [28] | Mobilizing homeless youth for HIV prevention: a social network analysis of the acceptability of a face-to-face and online social networking intervention. | Descriptive (implementation) | USA | Youth at risk of HIV | Standardized | Facebook, MySpace | <ul style="list-style-type: none"> Social support exchanged: information (42%), emotional (16%), network (7%), esteem (6%), tangible assistance (1%). Common interactions: sharing personal experience, expression of gratitude, offering congratulations. Trained peer leaders recruited youth in-person to make HIV prevention multimedia, which they posted on study MySpace & Facebook pages. Leaders & youth then recruited youth online to join study Facebook/MySpace page. Social network structures varied by platform: MySpace uptake was higher and groups continued to grow. Female & younger youth showed more network homophily. |
| Jaganath, 2012* [29] | Harnessing Online Peer Education (HOPE): integrating C-POL and social media to train peer leaders in HIV prevention. | Descriptive (implementation) | USA | MSM of color at risk of HIV | Standardized | Facebook | <ul style="list-style-type: none"> Overview of HOPE intervention: social media for peer-led HIV prevention among African American and Latino MSM. Training of peer leaders is based on the C-POL model where influential members in a community motivate change in behavior. Peer leaders post information & links on Facebook wall. Study to determine the feasibility of recruiting peer leaders to deliver HOPE Facebook intervention. Recruited 16 MSM of color, trained them through 3 sessions. Almost all were comfortable using social media before training. Training increased comfort using social media to discuss sexual positions. |
| Young, 2012* [27] | Analysis of online social networking peer health educators. | Descriptive (implementation) | USA | MSM of color at risk of HIV | Standardized | Facebook | <ul style="list-style-type: none"> Study to determine the feasibility of recruiting peer leaders to deliver HOPE Facebook intervention. Recruited 16 MSM of color, trained them through 3 sessions. Almost all were comfortable using social media before training. Training increased comfort using social media to discuss sexual positions. |
| Young, 2013* [30] | Feasibility of recruiting peer educators for an online social networking-based health intervention. | Descriptive (implementation) | USA | MSM of color at risk of HIV | Standardized | Facebook | <ul style="list-style-type: none"> Study to determine the feasibility of recruiting peer leaders to deliver HOPE Facebook intervention. Recruited 16 MSM of color, trained them through 3 sessions. |

| First Author, year | Title | Study purpose | Country | Population | Group type | Platform | Summary of findings |
|---------------------|--|------------------------------|---------|--|--------------|----------|---|
| Young, 2013* [31] | Online social networking for HIV education and prevention: a mixed-methods analysis. | Descriptive (implementation) | USA | MSM of color at risk of HIV | Standardized | Facebook | <ul style="list-style-type: none"> • Almost all were comfortable using social media before training. Training increased comfort using social media to discuss sexual positions. • Thematic analysis of HOPE Facebook interactions. • Trained peer leaders posted HIV-related content 2–3 times/week. • Participants who posted about HIV prevention and testing were significantly more likely to request an HIV testing kit (OR 11). • 59% of posts were friendly conversation, 15% HIV-STI prevention. • Frequency of interaction declined over 12 weeks but proportion of HIV-STI prevention, stigma, testing increased. |
| Muessig, 2014* [32] | Achieving HIV risk reduction through HealthMpowerment.org, a user-driven eHealth intervention for young Black men who have sex with men and transgender women who have sex with men. | Descriptive (implementation) | USA | Young MSM and transwomen of color at risk of HIV | Standardized | Custom | <ul style="list-style-type: none"> • Analysis of exit interviews from 4-week pilot study of HealthMpowerment, multidimensional mobile online intervention that includes a forum, information, quizzes, individual journal, GPS testing locator. • In exit interviews with 15 MSM & transwomen, participants' level of engagement in the intervention correlated with reported stages of behavioral change. |
| Young, 2014* [33] | Project HOPE: online social network changes in an HIV prevention randomized controlled trial for African American and Latino men who have sex with men. | Descriptive (implementation) | USA | MSM at risk of HIV | Standardized | Facebook | <ul style="list-style-type: none"> • Analysis of spread of HOPE intervention through participants' online social networks. • Among intervention group, significant positive association found between increased network ties and using social media to discuss sexual behaviors; trend for positive association between increased network ties and likelihood of HIV testing, follow-up for test results, and participation in online community discussions. |
| Chen, 2015 [34] | Social support exchanges in a social media community for people living with HIV/AIDS in China. | Descriptive (implementation) | China | People living with HIV | Organic | Weibo | <ul style="list-style-type: none"> • Social network analysis of messaging in HIV/AIDS Weibo Group. • Frequency & reciprocity of messaging between participant dyads associated with |

| First Author, year | Title | Study purpose | Country | Population | Group type | Platform | Summary of findings |
|---------------------------------|---|------------------------------|---------|--------------------------------|--------------|----------|---|
| Gaysynsky, 2015 [35] | My YAP Family [™] : Analysis of a Facebook Group for Young Adults Living with HIV. | Descriptive (implementation) | USA | Youth of color living with HIV | Standardized | Facebook | <ul style="list-style-type: none"> • Directed content analysis of 3838 posts in a private Facebook group for clinic's young adult HIV program, adjunct to in-person group. • ~Half of content was administrative and functioned to enhance the operations of the program as a whole. • 25% of posts were socializing, 20% banter, 15% offers of social support. • Emotional & esteem support most commonly sought & provided. |
| Chiu, 2015 [36] | Ethics issues in social media-based HIV prevention in low- and middle-income countries. | Descriptive (implementation) | Peru | MSM at risk of HIV | Standardized | Facebook | <ul style="list-style-type: none"> • 211 participants from HOPE Peru study were re-contacted to assess understanding of online consent forms, perception of risks and benefits, concerns about privacy and confidentiality. • 90% of participants reported understanding the consent form. • 65% of participants trusted researchers' confidentiality; 51% trusted other group members |
| Menacho, 2015 [*] [37] | Feasibility of Recruiting Peer Educators to Promote HIV Testing Using Facebook Among Men Who have Sex with Men in Peru. | Descriptive (implementation) | Peru | MSM at risk of HIV | Standardized | Facebook | <ul style="list-style-type: none"> • Report on feasibility of recruiting and training 34 peer leaders to deliver HOPE intervention in Peru. • At baseline, most peer leaders were already qualified and knowledgeable about HIV prevention and use of social media. • Comfort increased after training. |
| Han, 2016 [38] | Disclosure Pattern of Self-Labeled People Living with HIV/AIDS on Chinese Social Networking Site: An Exploratory Study. | Descriptive (implementation) | China | People living with HIV | Organic | Weibo | <ul style="list-style-type: none"> • Qualitative analysis of 1507 Weibo posts from 663 users whose profiles self-identified as living with HIV. • 51% of posts contained strong emotions; 18% of posts were HIV-related |
| Wang, 2016 [39] | An Examination of Users' Influence in Online HIV/AIDS Communities. | Descriptive (implementation) | China | People living with HIV | Organic | Weibo | <ul style="list-style-type: none"> • Network structure of 724 active members of HIV/AIDS Weibo group. |

| First Author, year | Title | Study purpose | Country | Population | Group type | Platform | Summary of findings |
|-----------------------|--|------------------------------|--------------|---------------------------------------|--------------|----------|--|
| | | | | | | | <ul style="list-style-type: none"> Connections between individuals defined separately based on follower-followee and post-reply relationships. 'Influential' individuals with high network centrality were identified; different network definitions yielded different results In follower-followee network, members from locations with well-developed communication technology infrastructure had significantly higher network centralities, highlighting the impact of the digital divide. |
| Henwood, 2016 [40] | Acceptability and use of a virtual support group for HIV-positive youth in Khayelitsha, Cape Town using the MXit social networking platform. | Descriptive (implementation) | South Africa | Youth living with HIV | Standardized | Other | <ul style="list-style-type: none"> Pilot study of virtual groups for YLWH using MXit. Groups were password-protected and facilitated by lay counsellors 1h per day. Intervention was acceptable but use was low. Cost, anonymity and changing messaging platform popularity were issues. |
| Cole, 2016 [41] | Health Advice from Internet Discussion Forums: How Bad Is Dangerous? | Descriptive (implementation) | UK | People at risk of and living with HIV | Organic | Other | <ul style="list-style-type: none"> Evaluated quality of HIV information found in 9 HIV forum discussion threads. Information quality was reasonably good. |
| Asiri, 2017 [42] | Sharing sensitive health information through social media in the Arab world. | Descriptive (implementation) | Multiple | Adults living with HIV | Organic | Facebook | <ul style="list-style-type: none"> Qualitative analysis of 649 posts from 44 Facebook groups related to HIV, Sickle Cell Anemia and Depression in the Arab world. Sensitive health information exchanged. HIV patients requested disease information not be disclosed on Facebook page; lack of technical familiarity led to unintended disclosure. |
| Flickinger, 2017 [43] | Social Support in a Virtual Community: Analysis of a Clinic-Affiliated Online Support Group for Persons Living with HIV/AIDS. | Descriptive (implementation) | USA | Adults living with HIV | Standardized | Custom | <ul style="list-style-type: none"> Qualitative analysis of messaging in Positive Links smartphone app; multicomponent intervention including educational materials; daily queries of stress, mood and adherence; appointment reminders; access to the study team for individualized counseling and assistance; and a community message board. In 840 message board posts from 55 participants, most common support domains were emotional and network support. |

| First Author, year | Title | Study purpose | Country | Population | Group type | Platform | Summary of findings |
|--------------------|--|------------------------------|--------------|------------------------|--------------|----------|---|
| Shi, 2017 [44] | Understanding interactions in virtual HIV communities: a social network analysis approach. | Descriptive (implementation) | China | Adults living with HIV | Organic | Weibo | <ul style="list-style-type: none"> Most participants reported a benefit from the app, half reported a negative aspect of using the app. Social network analysis of posts of 836 members of Weibo HIV/AIDS group Group members formed homophilous ties in terms of shared location and interests. A tendency away from popularity effect was found, suggesting resources and information were not disproportionately received by a few of members. |
| Garett, 2017* [45] | Ethical Issues in Using Social Media to Deliver an HIV Prevention Intervention: Results from the HOPE Peru Study. | Descriptive (implementation) | Peru | MSM at risk of HIV | Standardized | Facebook | <ul style="list-style-type: none"> HOPE intervention participants perceived the study to be acceptable and beneficial. Few participants from both groups expressed concerns over privacy, confidentiality and safety, but assessing participant understanding in online informed consent was a challenge. |
| Dulli, 2018 [46] | An Online Support Group Intervention for Adolescents Living with HIV in Nigeria: A Pre-Post Test Study. | Descriptive (implementation) | Nigeria | Youth living with HIV | Standardized | Facebook | <ul style="list-style-type: none"> Secret Facebook support group adapted from in-person support group. Evaluated among 41 ALWH. High access to phone, internet and social media at baseline. Frequent challenges charging phones and running out of airtime. High intervention uptake; high within-group variation in participation. High intervention acceptability, recommendation for larger, more interactive groups. |
| Han, 2018 [47] | Weibo friends with benefits for people live with HIV/AIDS? The implications of Weibo use for enacted social support, perceived social support and health outcomes. | Descriptive (implementation) | China | Adults living with HIV | Organic | Weibo | <ul style="list-style-type: none"> Online survey conducted with 432 Weibo-using PLWH. PLWH perceived higher levels of social support via Weibo than in the offline world. Online and offline social support were correlated. |
| Woods, 2019 [48] | A descriptive analysis of the role of a WhatsApp clinical discussion group as a forum for | Descriptive (implementation) | South Africa | Healthcare providers | Standardized | WhatsApp | <ul style="list-style-type: none"> 166 doctors joined a WhatsApp group to discuss HIV/TB patient care. |

| First Author, year | Title | Study purpose | Country | Population | Group type | Platform | Summary of findings |
|--------------------|---|------------------------------|----------|--------------------------------|--------------|----------|---|
| Bertman, 2019 [49] | Health worker text messaging for blended learning, peer support, and mentoring in pediatric and adolescent HIV/AIDS care: a case study in Zimbabwe. | Descriptive (implementation) | Zimbabwe | Healthcare providers | Standardized | WhatsApp | <ul style="list-style-type: none"> Group members reported gaining new clinical insights & proficiency in applying knowledge in alignment with guidelines. Level of self-reported benefit correlated with level of engagement in the group. Group & pair messaging by WhatsApp incorporated into training program for healthcare workers on HIV testing. Group members discussed challenging cases, materials shared in in-person training, encouragement. |
| Chen, 2019 [50] | Social Support Seeking on Social Media Among Chinese Gay Men Living with HIV/AIDS: The Role of Perceived Threat. | Descriptive (implementation) | China | MSM living with HIV | Organic | Weibo | <ul style="list-style-type: none"> Content analysis of Weibo posts from 133 MSMLWH to identify attitudes to HIV, stigma and social support seeking. Participants used Weibo to seek emotional support more than informational and instrumental support. More posting was in participants who expressed higher perceived severity of HIV infection and stigma. |
| Cooper, 2020 [51] | Social media support group: Implementation and evaluation | Descriptive (implementation) | USA | People living with HIV | Standardized | Facebook | <ul style="list-style-type: none"> Facebook "secret" group participants reported improved overall personal wellbeing and perceived social support. Lack of technology and social media experience and privacy concerns may have contributed to lower levels of participation. Participants who found the "secret" Facebook group difficult to use tended to have less technology experience were over the age of 50. |
| Hay, 2020 [52] | Support for the supporters": a qualitative study of the use of WhatsApp by and for mentor mothers with HIV in the UK | Descriptive (implementation) | UK | Pregnant women living with HIV | Standardized | WhatsApp | <ul style="list-style-type: none"> Features that made WhatsApp appealing for "Mentor Mothers" included ease of communication in group activities despite differing schedules and geographic locations. Challenges encountered with WhatsApp included financial restrictions to data storage and continual access, self-confidence using technology, and security and privacy concerns. |

| First Author, year | Title | Study purpose | Country | Population | Group type | Platform | Summary of findings |
|-----------------------------|---|--|----------|--|--------------|-------------------|--|
| Rice, 2010 [9] | Internet use, social networking, and HIV/AIDS risk for homeless adolescents. | Health outcome evaluation (non-randomized) | USA | Youth at risk of HIV | Organic | Facebook, MySpace | <ul style="list-style-type: none"> Survey of internet use among 201 homeless adolescents. Sexual health behaviors of adolescents significantly associated with social relationships they were maintaining online. Those who connected with street peers online were more likely to be engaged in exchange sex; those who connected with home peers were more likely to report recent HIV testing. |
| Hightow-Weidman, 2015* [10] | HealthMpowement.org : Building Community Through a Mobile-Optimized, Online Health Promotion Intervention. | Health outcome evaluation (non-randomized) | USA | Young MSM and transwomen of color at risk of HIV | Standardized | Custom | <ul style="list-style-type: none"> Pre-post pilot trial of HealthMpowement, multidimensional mobile phone online intervention that includes: a forum, information, quizzes, individual journal, GPS testing locator. Intervention used transtheoretical model and gaming theories to reduce risky sexual behaviors and build community. –1 month pilot with 13 MSM & 2 transwomen. Significant improvements in social support, social isolation, depressive symptoms. |
| Longinetti, 2017 [11] | Utilization of social media and web forums by HIV patients - A cross-sectional study on adherence and reported anxiety level. | Health outcome evaluation (non-randomized) | Multiple | Adults living with HIV | Organic | Facebook, Other | <ul style="list-style-type: none"> Online survey with 222 users of HIV forums in social networking sites. Patients age >40, diagnosed >5 years, and from low- and middle-income countries more likely to use emailing lists than social networking sites. No significant association between ART adherence, anxiety and HIV forum usage. |
| Ivanova, 2019 [12] | Evaluation of the ELIMIKA Pilot Project: Improving ART Adherence among HIV Positive Youth Using an eHealth Intervention in Mombasa, Kenya. | Health outcome evaluation (non-randomized) | Kenya | Youth living with HIV | Standardized | Custom | <ul style="list-style-type: none"> Web-based secure platform for YLWH including a blog, Q&A with providers, stories contest, private messaging. N=90 youth age 15–24. High participant acceptability. Adherence intention higher post vs. pre 3-month intervention; no change in ART knowledge & adherence behavior. |
| Bull, 2012 [13] | Social Media-Delivered Sexual Health Intervention: A Cluster Randomized Controlled Trial | Health outcome evaluation (randomized) | USA | Youth of color at risk of HIV | Standardized | Facebook | <ul style="list-style-type: none"> Cluster RCT of STI prevention Facebook intervention for 2 months (n=942 intervention, 636 Ctrl). |

| First Author, year | Title | Study purpose | Country | Population | Group type | Platform | Summary of findings |
|--------------------|--|--|---------|-----------------------------|--------------|---------------------|---|
| Young, 2013* [14] | Social networking technologies as an emerging tool for HIV prevention: a cluster randomized trial. | Health outcome evaluation (randomized) | USA | MSM of color at risk of HIV | Standardized | Facebook | <ul style="list-style-type: none"> Youth facilitators made multiple updates each day to the page - video links, quizzes, games, threaded discussions relevant on 8 sexual health topics. Significant increase in condom use at 2 months but not 6 months in treatment group. RCT of HOPE study: 16 peer leaders randomized to deliver information about HIV or general health to 112 MSM via 4 Facebook groups over 12 weeks. No group curriculum: peer leaders talked weekly with their trainers about how to increase participant engagement. High engagement: 95% intervention participants, 73% control. 24% higher frequency self-test request and higher test completion in intervention. |
| Young, 2015* [15] | The HOPE social media intervention for global HIV prevention in Peru: a cluster randomised controlled trial. | Health outcome evaluation (randomized) | Peru | MSM at risk of HIV | Standardized | Facebook | <ul style="list-style-type: none"> Cluster-randomized trial of Harnessing Online Peer Education (HOPE) 12-week Facebook intervention to increase HIV testing among MSM. Trained peer leaders sent individually-composed weekly messages about HIV prevention and testing. Peers could interact. Controls received an unfacilitated peer group with testing information. Intervention led to 2.61-fold higher HIV testing. |
| Dulli, 2020 [16] | A Social Media-Based Support Group for Youth Living With HIV in Nigeria (SMART Connections): Randomized Controlled Trial | Health outcome evaluation (randomized) | Nigeria | Youth living with of HIV | Standardized | Facebook | <ul style="list-style-type: none"> Online support group for youth using a Facebook "secret" group showed improvements in HIV knowledge and high acceptability. The intervention did not have an effect on retention. Qualitative data indicated the intervention may have contributed to retention, adherence, and social support in ways that were not captured quantitatively. |
| Patel, 2018 [58] | Empowering With PrEP (E-PrEP), a Peer-Led Social Media- | Protocol: Health outcome | USA | Young MSM at risk of HIV | Standardized | Facebook, Instagram | <ul style="list-style-type: none"> Social media peer-led intervention to improve PrEP uptake. |

| First Author, year | Title | Study purpose | Country | Population | Group type | Platform | Summary of findings |
|-----------------------|--|--|---------|--------------------------------------|--------------|----------|--|
| | Based Intervention to Facilitate HIV Preexposure Prophylaxis Adoption Among Young Black and Latinx Gay and Bisexual Men: Protocol for a Cluster Randomized Controlled Trial. | evaluation (randomized) | | | | | <ul style="list-style-type: none"> 10 peer leaders recruited, trained, randomized to PrEP vs. attention-matched content. Peers recruited 152 participants through their social media networks; facilitated private Facebook group or Instagram feed with standardized weekly messaging for 6 weeks. Outcomes: intention to use PrEP, PrEP uptake, PrEP knowledge and attitudes. |
| Horvath, 2018 [18] | Thrive With Me: Protocol for a Randomized Controlled Trial to Test a Peer Support Intervention to Improve Antiretroviral Therapy Adherence Among Men Who Have Sex With Men. | Protocol: Health outcome evaluation (randomized) | USA | MSM living with HIV | Standardized | Custom | <ul style="list-style-type: none"> 400 MSM/LWH will be randomized to (1) multicomponent intervention including private social networking, HIV and ART adherence information, medication reminders, self-monitoring, reflection, gamification, (2) weekly email newsletter. Treatment for 5 months, 17-month follow-up. Primary outcome: VL. |
| Arnold, 2019~ [64] | The Stepped Care Intervention to Suppress Viral Load in Youth Living With HIV: Protocol for a Randomized Controlled Trial. | Protocol: Health outcome evaluation (randomized) | USA | Youth living with HIV | Standardized | Muut | <ul style="list-style-type: none"> 220 YLWH who are not virally suppressed will be randomized to (1) daily automated text messaging & monitoring (AMM), (2) stepped care (non-responders progress through AMM, peer social media support through online discussion board and coaching) Outcomes: viral suppression & cost-effectiveness. |
| Swendeman, 2019# [20] | Text-Messaging, Online Peer Support Group, and Coaching Strategies to Optimize the HIV Prevention Continuum for Youth: Protocol for a Randomized Controlled Trial. | Protocol: Health outcome evaluation (randomized) | USA | Youth at risk of HIV | Standardized | Muut | <ul style="list-style-type: none"> 1500 high-risk youth will be randomized to 1 of 4 arms: (1) automated text messaging & adherence monitoring (AMM), (2) private social media support group + AMM, (3) coaching by phone & in person + AMM, (4) social media support group + coaching + AMM. Outcomes: linkage to routine medical care; consistent use of condoms, PrEP or PEP; participation in other HIV prevention services; HIV/STI testing 3 times per year. |
| Rotheram, 2019-# [21] | Strategies to Treat and Prevent HIV in the United States for Adolescents and Young Adults: | Protocol: Health outcome | USA | Youth living with and at risk of HIV | Standardized | Muut | <ul style="list-style-type: none"> ATN protocol including Swendeman 2019 & Arnold 2019. |

| First Author, year | Title | Study purpose | Country | Population | Group type | Platform | Summary of findings |
|--------------------|---|---------------------------------------|---------------------------|-----------------------------------|--------------|------------------|--|
| Guse, 2012 [53] | Protocol for a Mixed-Methods Study. Interventions using new digital media to improve adolescent sexual health: a systematic review. | evaluation (randomized) Review | USA, China, Kenya, Brazil | Youth at risk of HIV | Standardized | Multiple | <ul style="list-style-type: none"> • Compare AMMI, peer social media support & coaching. • 3 interventions have different behavioral bases: peer social media support relies on rewarding new behaviors & providing positive role models. • Systematic review of effectiveness of interactive digital media for sexual behavior of adolescents 13–24. • Of 10 studies included, 1 quasi-experimental study included peer-to-peer messaging on a facilitated bulletin board; observed improved knowledge of contraception, STIs, HIV. |
| Taggart, 2015 [54] | Social Media and HIV: A Systematic Review of Uses of Social Media in HIV Communication. | Review | USA | Multiple | Standardized | Facebook | <ul style="list-style-type: none"> • Review of 35 articles using social media for HIV-related interventions. • Reported feasibility, acceptability and message content. • Identified complementarity between in-person & virtual components. • Intervention anonymity was often unclear. |
| Tso, 2016 [55] | Social media interventions to prevent HIV: A review of interventions and methodological considerations. | Review | USA, Peru | People at risk of HIV | Standardized | Facebook, Custom | <ul style="list-style-type: none"> • Review of social media for HIV prevention. • Social media campaigns more commonly studied than groups. • 3 studies reported evidence of social media group impact on condom use and social support. |
| Ramos, 2019 [60] | A Framework for Using eHealth Interventions to Overcome Medical Mistrust Among Sexual Minority Men of Color Living with Chronic Conditions. | Theoretical framework | USA | MSM and transwomen at risk of HIV | NA | NA | <ul style="list-style-type: none"> • Theoretical framework to describe how virtual environments and avatar-led eHealth videos can improve trust of the medical system by MSM of color. • eHealth can build trust through anonymity, co-presence, self-disclosure, and potential to facilitate social support in populations who have historically experienced stigma and medical mistrust. |

* # + ~ indicate sets of publications referring to the same parent study

Table 2. Summary of unpublished projects reported in practitioner survey on peer group messaging interventions for HIV prevention and treatment

| Investigators | Project type | Project status | Project region(s) | Project goal(s) | Messaging platform(s) used | Other modalities combined with peer messaging group | Intervention duration | Outcomes assessed |
|---|---------------------------|----------------------------|---|---|---|---|-----------------------|--|
| Africaid-Zvandiri | Implementation | Ongoing; Planned | Sub-Saharan Africa | End-user information; End-user behavior change; Staff professional support | WhatsApp; RocketChat | None | >2 years | Feasibility; Acceptability; Uptake; Usage; Health impact; Messaging content |
| Ahimbisibwe et al., Ariel Superstars Group | Research & implementation | Ongoing | Sub-Saharan Africa | End-user information; End-user behavior change; Staff professional support | WhatsApp; Facebook messenger | In-person meetings; SMS; Phone calls; Other smartphone apps | 2 years - open-ended | Feasibility; Acceptability; Uptake; Health impact; Fidelity of implementation; Messaging content |
| LINKAGES project 'Going Online', FHI 360 | Implementation | Ongoing | Sub-Saharan Africa; South-Eastern Asia | End-user information; Staff professional support | WhatsApp; Facebook messenger; In stag ram | In-person meetings; SMS; Phone calls; Websites; Other smartphone apps | 2 months - 2 years | Uptake |
| Indonesia LINKAGES project, FHI 360 | Research & implementation | Ongoing | South-Eastern Asia | End-user information; End-user behavior change; Data collection; Staff professional support | WhatsApp; Custom software | In-person meetings; SMS; Phone calls; Websites | Open-ended | Feasibility; Acceptability; Uptake; Usage; Fidelity of Implementation |
| Grant et al, Prakelt.org | Research & implementation | Ongoing | Sub-Saharan Africa; North Africa & Western Asia | End-user information; End-user behavior change; Data collection; Staff professional support | WhatsApp; Facebook messenger; Google RCS | In-person meetings; SMS; Other smartphone apps | 2 months - 2 years | Feasibility; Acceptability; Uptake; Usage; Health impact; Messaging content |
| Holeman et al., Medic Mobile and The University of Washington | Research & implementation | Complete; Ongoing; Planned | Sub-Saharan Africa; Central & Southern Asia | Staff professional support | WhatsApp | In-person meetings; SMS; Phone calls; Web apps; Other smartphone apps | 2 years - open-ended | Feasibility; Acceptability; Uptake; Usage; Health impact; Messaging content |
| Ronen et al., University of Washington & Kenyatta National Hospital | Research | Ongoing; Planned | Sub-Saharan Africa | End-user information; End-user behavior change | WhatsApp; Telegram | In-person meetings | 2-12 months | Feasibility; Acceptability; Uptake; Usage; Health impact; Messaging content |
| St.Jusie et al, I-TECH Haiti/Centre Haïtien pour le Renforcement du Systeme de Sante (CHARES) | Implementation | Ongoing | Caribbean | Data collection; Staff professional support | WhatsApp | None | Open-ended | None |

| Investigators | Project type | Project status | Project region(s) | Project goal(s) | Messaging platform(s) used | Other modalities combined with peer messaging group | Intervention duration | Outcomes assessed |
|---|---------------------------|----------------------------------|--------------------|--|---|---|-----------------------|--|
| Velloza et al, University of Washington | Research | Ongoing | Sub-Saharan Africa | End-user information; End-user behavior change; Data collection | WhatsApp; iMessage; Custom software | In-person meetings; SMS; Phone calls | 2 months - 2 years | Feasibility; Acceptability; Usage |
| VillageReach | Research & implementation | Complete; Ongoing; Planned | Sub-Saharan Africa | End-user information; End-user behavior change | WhatsApp | In-person meetings; SMS; Phone calls; Other smartphone apps; Interactive voice response | 2 months-open-ended | Feasibility; Acceptability; Usage; Health impact; Message content |
| Anonymous | Implementation | Ongoing | Sub-Saharan Africa | Data collection; Staff professional support | WhatsApp | None | Open-ended | Feasibility; Acceptability; Uptake; Usage; Health impact; Messaging content |
| Anonymous | Research & implementation | Complete; Planned | Sub-Saharan Africa | End-user information; End-user behavior change; Data collection; Staff professional support | WhatsApp | In-person meetings; SMS; Phone calls | 2 months - open-ended | Uptake; Usage; Health impact; Fidelity of implementation; Messaging content |