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Sexual and reproductive health and digital human rights: a study with people living with HIV and key populations in Vietnam

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ABSTRACT

This study draws from qualitative research conducted using a participatory action framework with 47 young adults who identified as people living with HIV, men who have sex with men, transgender, non-binary, or sex workers in Vietnam. The research objectives were to explore their experiences using mobile phones to access sexual and reproductive (SRH) health information and support and the impact of the digital turn in health on their autonomy, privacy and equality. The research was conducted through key informant interviews, focus group discussions, and digital ethnography. The project utilised a participatory action research framework. The research was led by the Vietnam Network of People Living with HIV within the frame of a three-country study, and the authors describe how the network used the findings to advance policy. The paper concludes by proposing participatory action research as a useful methodology for studying human rights and digital health governance.

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Introduction

Digital technologies, mobile apps and social media are increasingly shaping sexual and reproductive health (SRH) information and services, including the growing use of mobile health (mHealth) apps that track menstrual cycles, fertility, and sexual activity (Lupton 2015; Grenfell et al. 2021). The first comprehensive review of digital health governance, the *Lancet and Financial Times Commission on Global Health Futures 2030,* called digital technologies the new 'determinants of health', given their increasing centrality to access to health information and services (Kickbusch et al. 2021). By comparison, though, digital health governance is at an early stage of development. In approving its *Global Digital Health Strategy 2020–2025*, the World Health Organisation

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emphasised the need to develop robust digital health governance to protect the rights of marginalised and discriminated against groups, including young people (WHO 2021, 2022).

Using empirical evidence from a participatory action research study conducted in partnership with a national network of people living with HIV in Vietnam, we shed light on the lived experience of young adults living with HIV and key populations (defined as gay men and other men who have sex with men, sex workers, transgender people, and people who use drugs [WHO]) with the digital transformation of health. In particular, we focus on their efforts to gain information and peer support on SRH. We also aim to demonstrate the value of participatory action research (PAR) for digital health governance and human rights more generally. PAR generates empirical insights into governance needs and positions civil society and community-led networks as having valuable expertise, facilitating their participation in the ongoing development of digital health governance discussions and community mobilisation locally and transnationally.

Background

Digital human rights and health

The World Health Organisation defines digital health as 'the field of knowledge and practice associated with developing and using digital technologies to improve health' (WHO 2021, 11). This definition expands beyond eHealth or mHealth to include broader uses of smart and connected devices for health, including the Internet of Things, big data, robotics, artificial intelligence, and more.

The United Nations (UN) Human Rights Office and UN human rights mechanisms have highlighted diverse human rights relevant to the digital space, including privacy, autonomy, equality, and more (OHCHR 2024). In her 2023 report to the UN Human Rights Council on digital technologies, innovation and the right to health, the UN Special Rapporteur on the Right to Physical and Mental Health, Tlaleng Mofokeng, analysed how digital human rights apply to the right to health. She drew attention to the need to ensure that digital technologies uphold core elements of the right to health, including the availability, accessibility, acceptability and quality of health services (The Vietnamese 2023). She particularly noted the importance of promoting access to SRH, while pointing out the risk that digital technologies could perpetuate and widen many existing forms of inequality and discrimination in health.

Studies have shown that social media and mobile health apps offer risks and benefits regarding SRH. These digital platforms provide diverse forms of social health support (Lupton 2017) such as the use of Facebook to create spaces for women to access sexual and reproductive health information (Maslen and Lupton 2019) and Twitter and Instagram to facilitate the exchange of health information (Lupton and Maslen 2019; Lupton 2016). As Maslen and Lupton describe it, these practices of expressing experiential knowledge through self-help groups 'contribute to modes of knowledge-building and activism at the social group level' (Maslen and Lupton 2019, 1638).

However, social media platforms have become venues for cyberbullying and threats, particularly concerning sexual health (Byron, Albury, and Evers 2013). Social media platforms can lead to 'digital stress' in adolescents and young adults due to bullying and abuse (Weinstein and Selman 2016). The spread of health misinformation on digital platforms can also erode public trust, as seen during the COVID-19 pandemic (Zarocostas 2020). In the context of HIV, false health information can deepen stigma and discrimination (Garett and Young 2022). Nonetheless, Poulsen et al. (2024) find in their systematic review of literature on mHealth and digital rights in Southeast Asia that digital rights are rarely directly addressed in studies of mHealth in the region, warning that

> 'continued indifference to digital rights in mHealth research addressing Southeast Asian LMICs, as well as frequent digital rights violations and lack of policy to protect digital rights in these nations, put patient empowerment, data protection, and inclusion in mHealth interventions at risk' (Poulsen et al. 2024, 11).

To strengthen digital health governance, Tlaleng Mofokeng called for states to take a rights-based approach that 'ensures the meaningful participation of civil society and communities in national and global governance of digital health, including the participation of young people' (The Vietnamese 2023). Likewise, the Lancet and Financial Times Commission on Global Health Futures 2030 concluded that while young people have been the targets of digital health but have had little say in priority-setting or decision-making; the Commission urged that children and young people be 'put at the center' of 'codesign of digital health solutions and participatory research and decision-making', to ensure that the digital transformation contributes to fulfilling Universal Health Coverage (UHC) for all (Kickbush et al. 2021).

The HIV movement has a long history of innovation, including the use of participatory methods for research in sexual and reproductive health, and leveraging technical and scientific knowledge for community mobilisation and policy advocacy (Chan 2015). The 2021 United Nations Political Declaration on HIV and AIDS reaffirmed the importance of community-led research (UNGA 2021). Civil society-led HIV networks have engaged in advocacy and litigation for treatment access in high-income, middle-income and low-income countries for the past 30 years, including by establishing the GIPA principle (Greater Involvement of Persons with AIDS) through which people living with HIV have played a growing role in health governance mechanisms. As one example, the Global Network of People Living with HIV (GNP+) has worked with national community-led networks to conduct the People Living with HIV Stigma Index[1] studies, documenting stigma in diverse countries and settings, and using the findings to promote policy and legal reform.

Building on this infrastructure of transnational community-led networks and experience of participatory research in the HIV response, we conducted a transnational participatory action research study of digital health and human rights. As part of a broader consortium of university researchers, civil society groups and community-led networks, we worked collaboratively in Ghana, Kenya and Vietnam, three countries selected by the community-led organisations based on their own interest to lead research on the topic. The comparative findings from this research have been published elsewhere (Davis et al. 2023); in this paper, we aim to share additional detail

from the study in Vietnam to show how the study findings were used by researchers associated with the Vietnamese Network of People Living with HIV (VNP+) in policy advocacy.

Our study seeks to contribute to the existing evidence base on how diverse young adults understand the benefits and risks to digital human rights of the digital health transformation. It also aims to show how the HIV movement can offer a site to build on existing infrastructures and experience in future work on digital human rights in health.

HIV, SRH and key populations in Vietnam

There are an estimated 250,000 adults and children in Vietnam living with HIV, with a slightly higher prevalence among men (UNAIDS 2022). Vietnam's epidemic is largely concentrated among key populations, and since 2020, the country has reported an increase in HIV transmission among men who have sex with men (UNAIDS 2022). Rates of HIV have been high in Hanoi and Ho Chi Minh City (Le et al. 2016). Structural barriers to accessing health services for men who have sex with men include social stigma, lack of accessible and supportive health services, and healthcare costs (Philbin et al. 2018). HIV-related stigma remains a barrier to antiretroviral treatment adherence among people living with HIV and key populations in Vietnam (Do et al. 2021). Sex work and drug use are criminalised in Vietnam, and criminalisation has been shown to increase the risk of violence against sex workers and to be associated with poor health outcomes (Platt et al. 2018).

Given the challenges of making traditional health services accessible to marginalised groups, health experts have struggled to identify approaches that reach these communities (Le et al. 2016). The World Health Organisation has underscored the significant potential of digital technologies for overcoming trust deficits and sharing information on HIV with those who need it (WHO (World Health Organization) 2022).

Vietnam offers a strong foundation for the scale-up of digital technologies and platforms for health, especially SRH for young adults. Vietnam is a country marked by rapid digitisation and has a young population, with a median age of 31.9 years (World Population Review 2022), of whom 25% are between the ages of 16 and 30 (UNFPA 2022). Vietnam's population 'is adopting digital technology at lightning speed, with internet access and availability high compared to neighbouring countries' (Mjwana et al. 2021, 17). The country's estimated 72.53 million Internet users in 2021 will increase to 82.25 million by 2025 (Statista 2022). Smartphone access has become dominant among Internet users, with 'nearly all Internet users (94%) owning a smartphone and three-quarters of them using it as their preferred connection device' (Mjwana et al. 2021, 18).

While globally, the digital gender gap is a concern, with fewer overall women having access to mobile internet than men (Rowntree and Shanahan 2020), Vietnam is among few countries demonstrating gender parity in digital skills and internet use. Among gay men and other men who have sex with men in Vietnam, '91.7% and 67.8% […] respectively had a smartphone and a computer/tablet' (Nguyen et al. 2020). A study by Lighthouse Social Enterprise in Vietnam on access and utilisation of sexual health services by young key populations finds, that young key populations reported

utilising online channels for sexual health information, as well as reporting a need for validated content online to ensure evidence-based sexual health knowledge, very much in line with findings we will present later in this article (Tung et al. 2020).

However, Lam et.al (2018, 1) see 'the absence of government policy, lack of government interest, heavy dependence on foreign funding, and lack of technological infrastructure' as barriers to the growth of digital health in Vietnam. In his official visit to Vietnam in 2023, the UN Special Rapporteur on the Right to Development, Surya Deva, acknowledged Vietnam's achievements in economic growth but called for more public participation in development processes, especially among marginalised groups (The Vietnamese 2023).

It is worth noting that while some forms of participation are constrained, HIV networks led by affected communities, such as VNP+, have managed to carve out an important space for community-led research and advocacy. The network has been legally registered in Vietnam since 2009 and has successfully conducted three PLHIV Stigma Index studies (in 2012, 2014, and 2021), using the findings to share policy recommendations with national authorities and international stakeholders. Among other activities, VNP+ provides HIV prevention and treatment information, and support to young people living with HIV and key populations to participate in national planning consultations for the Global Fund to Fight HIV, TB, and Malaria and the US President's Emergency Plan for AIDS Relief (PEPFAR). Its focus on the health rights of young key populations, a concern identified in Vietnam's national health strategies, has positioned VNP+ to partner in national health efforts with government health officials and programmes. This research and advocacy experience has also positioned VNP+ to lead participatory action research on digital health and the rights of young people living with HIV and key populations as part of a broader project.

Research objectives

The objectives of our study in Vietnam included developing a set of policy recommendations for the rights-based development of digital health, grounded in legal and ethnographic research and in the lived experience of affected communities; documenting young adults' experiences with mobile technologies related to health, including sexual and reproductive health and HIV; and conducting a participatory research study that would build capacity of national-level partners to engage in longer-term policy discussions relevant to digital health governance.

Mixed methods and transnational participatory action research approach

The larger study of which the investigation in Vietnam was a part took the form of a transnational participatory action research project. Community representatives of the local study populations were co-investigators and research team members, and consulted with study populations throughout the study design, implementation and analysis of findings. In Vietnam, the research was led by researchers from VNP+; in Ghana, by researchers from the National Association of Persons Living with HIV/

AIDS (NAP+ Ghana); and in Kenya, by researchers at KELIN, a Kenyan health and human rights group. In all three countries, researchers were supported by a programme officer from GNP+ in South Africa, who participated in the research, provided technical assistance, gave moral support to national researchers, and forged links among networks across the field sites. Training and guidance on ethics and methods were provided by the principal investigator (SLMD) at the Geneva Graduate Institute in Switzerland and a postdoctoral researcher (TS) at the University of Oslo in Norway.

To contextualise our data in Vietnam, and develop an overview of the field, we decided to review relevant laws and policies in Vietnam and use a mix of digital ethnography, focus group discussions with young adults, and key informant interviews with experts to investigate the research questions. This approach was chosen based on our literature review, the community identification of needs, and the research methods the international team was equipped to offer.

Law and policy review

Our review of legal and policy frameworks in Vietnam was undertaken by VNP+ researchers in Vietnamese language (TP). We consulted Ministry of Information and Communication publications on digital health, the Cybersecurity Law, and the Vietnam National Assembly web page where we searched their online documents pertaining to digital health. This review was done to obtain an overview of the legal context in Vietnam regarding privacy, data protection, and digital health, and it enabled us to identify concerns for more detailed exploration in the qualitative field research

Digital ethnography

Digital ethnography extends the principles of traditional ethnography to virtual environments, examining how social interactions and cultural phenomena manifest in online spaces such as social media platforms (Pink et al. 2015). The approach aims to understand the digital landscape, topics of special interest to the study population, tensions and themes emerging in discussions, and to map relevant sites (Murthy 2008). Potential pitfalls include issues around how people represent themselves online, which poses challenges in interpreting social cues and contextual nuances (Pink et al. 2015). Moreover, access and privacy issues are magnified in digital settings.

The research team identified a list of Vietnamese-language social media accounts where young people living with HIV and young key populations gathered to access and share health information, including several Facebook pages managed by young key population-led groups. Researchers logged on at different times during the week and took notes on the topics discussed and nature of the interactions, using a guiding template. The VNP+ researcher (TP) obtained permission from the administrator of a discussion group of young people living with HIV on Zalo (a Vietnamese chat app similar to WhatsApp), to observe the discussions in that group. Participants in the group also approved of her participation. VNP+ also identified some participants to invite to focus group discussions through digital ethnography.

Key informant interviews

The PI (SLMD) and VNP+ researcher (TP) conducted semi-structured interviews with key informants. We developed a list of types of people we would interview including UN agency staff, national health officials, frontline healthcare workers, civil society and community leaders, youth leaders, and human rights lawyers. Informants were interviewed based on their technical expertise and leadership roles seen as relevant to the study: for instance, leadership roles within key population organisations or expertise in the use of digital health technologies. A total of 15 key informant interviews (KIIs) were held. Interview questions focused on digital health governance trends, digitisation benefits and risks, barriers to access, and policy recommendations.

Focus group discussions

We held six focus group discussions with young adults aged 18–30, one in Ho Chi Minh City and five in Hanoi. VNP+ used purposive snowball sampling to recruit participants through peer-led networks of young key population members. Each focus group interview had between six to ten participants. The FGDs were conducted between October 2021 and February 2022. Due to COVID-19 restrictions in Vietnam, FGDs could not be held in person so all interviews were conducted on Zoom in Vietnamese by the researcher from VNP+, with coaching and pre-and post-FGD debriefing calls with the PI (SLMD). Participants were asked about their experiences using mobile phones to access health information and services; barriers to access; awareness and views of data governance; perceptions of benefits and risks; and policy recommendations. The discussions were recorded, transcribed and translated into English by VNP+.

Data analysis

The transcripts were uploaded to Dedoose, a cloud-based platform that facilitated use by researchers in diverse countries. A thematic analysis was conducted akin to the framework established by Braun and Clarke (Braun and Clarke 2021). Two members of the research team reviewed each transcript. Based on thematic analysis of the FGD transcripts the team coded ten sample transcripts to develop an inductive draft list of codes. This was refined using human rights concepts identified in the desk review, such as the right to privacy, meaningful participation, and the AAAQ framework set out in normative guidance on the human right to health (Availability, Accessibility, Acceptability, and Quality). One coder coded each transcript, and a second coder reviewed a selection. We did not calculate inter-rater reliability for this project. To anonymise the participants, the codes describing the participants were made to indicate where the interview was done such as HAN for Hanoi or HCM for Ho Chi Minh City. The next code indicated if the interview was a focus group discussion, FDG, or a key informant interview, KII. The last letter was linked to a pseudonym, which each participant was given. In the case of focus groups, the participants were given both a letter and a number, for instance, H5, which then corresponds to a pseudonym in the data.

Ethics

The risks associated with the study pertained to the status and identities of the participants, who were young adults whose identities could be stigmatised in Vietnam and in their local communities. We sought to mitigate the risk of stigmatisation, or harm linked to these identities by implementing informed consent procedures that used clear and concise language developed by the PI (SLMD) and reviewed by community representatives. Data was anonymised using codes, and identifiers were stored separately from field records in a secure and place. Participants were able to withdraw from the project at any time. Participants were encouraged to use pseudonyms during the focus group discussions. The final transcripts omitted real names and any potentially identifying information. A data management policy affirming that the research data's owner is VNP+ and that any publications require their participation and approval was made. The study was approved by ethical review committees at the Geneva Graduate Institute on 20 April 2021, and Hanoi University of Public Health on 11 August 2021 (Reference: 021-341IDD-YTCC).

Findings

The study included 47 FGD participants whoh included diverse young adults aged 18–30: women, men, transgender, and nonbinary people, including people living with HIV who were resident in Hanoi or Hồ Chí Minh City. While VNP+ actively recruited women, men and transgender people, men expressed greater interest in participating. As a result, ten FGD participants identified as female, and 36 identified as male, while one identified as non-binary. However, as the gender identities were provided by the community leaders who recruited participants and not by participants themselves, there may have been other transgender or non-binary participants left uncounted. Sixteen participants reported being employed, 19 identified as students, and 12 reported being unemployed or 'free'. Information on socio-economic status or education was not collected.

Benefits

Social support and mediated intimacies

While FGD participants described using mHealth apps to access health information, most preferred social media and social chats on mobile phones to find services and peer support. One FGD participant said, 'It is Facebook, I find everything on Facebook' (HAN-FGD4-H7). A few key informants also described dating apps as an important source of health information.

People living with HIV described how online communities provided support and advice concerning anti-retroviral treatment (ARV) access and adherence during COVID-19 restrictions. HCM-FGD1-H1 said people 'share treatment adherence [advice], as well as sharing medicines during isolation'. In the course of the digital ethnography, we observed this as members of the Zalo group for young people living with HIV coordinated the sharing antiretroviral medications (ARVs) with peers who could not access such treatments due to stay-at-home orders. Others helped with food delivery and pooled funds to support a peer at home who was in the later stages of AIDS.

In Ho Chi Minh City, HCM-FGD1-H5 described how a female-to-male transgender group on Telegram had provided them with psychosocial support:

> In the epidemic, I also connected cases of transgender people who had difficulties, such as losing their jobs and not returning to their hometowns, or people who experienced family violence because of their gender.

Some of the study participants in FGDs had found pleasure in using digital platforms for cybersex during COVID-19 restrictions, defining 'cybersex' as either sharing sexual photographs or exchanging intimate text messages. HAN-KII-I, a community leader from a key populations network, suggested that cybersex had offered a healthy and positive way of 'satisfying your needs' during the COVID-19 pandemic.

Risks

While many participants saw their access to social media and health information through mobile phones as empowering and positive, some worried about overuse and the risk of mental health harm due to dependence. FGD participants were also concerned about health misinformation and privacy threats.

Health misinformation

Participants described concerns linked to the overwhelming quantity of health information online, and the challenges of judging the veracity of information provided. In Hanoi, HAN-FGD4-H9 observed, 'In my opinion, now there is much information, and it is not verified, leading to misleading information and affecting the health of users'. HAN-FGD3-H9 said, 'I go online to search for information, they say I have some disease… [This] inaccurate information greatly affects my emotions. The biggest risk is that I receive wrong information'. A few participants called for the government to take a more active role in managing health misinformation on social media.

Threats to privacy

Given the above-mentioned threats of stigma and marginalisation, participants who were living with HIV or members of key populations were acutely attuned to the need to protect their privacy. One participant in Ho Chi Minh City said:

> For me, privacy is essential when it comes to health. For example, when I started participating in the community, I was afraid to share personal information on the fan page because I was afraid that my friends in the group would reveal the information, or if I liked or commented on a certain page, it would show up on my profile page, and my friends and family could see it. (HCM-FGD1-H1)

Participants highlighted instances in which health information shared online had been used to stigmatise, expose or extort individuals who were either living with HIV or belonged to key population groups. Other cases of online exposure and verbal abuse, were recent cases that had involved public stigmatisation of a transgender couple, as well as a case involving a young woman living with HIV who had been verbally attacked online. While cybersex was seen by some as beneficial, as one participant

in Hanoi noted: 'The harm of cybersex is that it is easy to reveal your information' (HAN-KII-K). Another raised concerns that participating in cybersex could expose them to the risk of extortion linked to the the non-consensual exposure of private images:

> Some [people] are lured into sex chats or send pictures, and they meet bad people who blackmail or threaten them, for example: "If you don't have sex with me, I'll post sensitive pictures of you" (HAN-KII-H).

Others were concerned about a perceived lack of government action to address these risks; as HAN-FGD3-H9 suggested, 'I think the government … also wants to manage information better to avoid bad cases, but the government still needs to develop a law to protect personal information' (HAN-FGD3-H9). When asked for policy recommendations, several participants called for more effective Vietnamese government action to protect privacy and data security.

Digital health literacy and empowerment

Considering that the study participants were recruited through a network of people living with HIV who engaged in advocacy, it was notable that one or two members of each FGD called for training and mobilisation to address their rights. In Hanoi, one participant argued,

> We need to improve young people's skills…They cannot filter information, [so] it is easy to take advantage of [them] on social networks. With people newly infected with HIV, they will feel anxious and seek much information. (HAN-KII-P)

Another participant observed,

> Information security on social networks is fragile; others can easily get our personal information, but young people do not have the skills and knowledge to protect themselves (HAN-KII-K).

Others worried about the risk of data breaches resulting from poor data management by private companies and state actors, such as hacking or leaking private health insurance data stored on mobile phone apps; and worried that lack of media coverage of these breaches meant that many members of the public did not know they had happened. While study participants identified need for training to enable individuals to protect themselves, a subset argued that they needed a voice in digital governance and digital health design. In Hanoi, HAN-KII-G, argued, 'I suggest the government consult with everyone to see if an app meets their needs. It's the first [step] for them to be willing to participate actively'. At the UNAIDS Vietnam country office, an official reported consulting with young key populations in design of an mHealth app on pre-exposure prophylaxis (PrEP):

> I think that it's always taking into account the community's feedback, if they feel ok, they feel that it's ok to do that and [there are] no significant concerns to be addressed, [and it is] accepted by the community, then we go ahead. If not, then we stop (HAN-KII-A).

Some people living with HIV and key population members argued that their communities should be consulted on policy design, thinking beyond digital literacy as a

means to empower individuals to protect themselves from harm, to empowering young adults to participate in the larger policy environment. In Ho Chi Minh City, a study participant echoed the above-referenced Lancet/Financial Times Commission findings when he said,

> The young community is quite an active user group, [but] as far as I know, they have not had the opportunity to contribute their voice to advocacy related to digital health. Because their voices and opinions are of little concern […], they have not been adequately cared for.

Similarly, one FGD study participant called for the national government to consult with young people:

> If I meet the government, I hope they will pay more attention to information security issues and listen to the needs and voices of young people more (HAN-FGD5-H7).

Relevance to policy advocacy

VNP+ presented the study findings in national meetings with Vietnamese health authorities, PEPFAR, the US Centers for Disease Control and Prevention (CDC), and the Global Fund to Fight AIDS, Tuberculosis and Malaria. In these presentations, VNP+ stressed the need for digital health literacy training for young key populations.

One consequence of this was the US PEPFAR and the CDC approved a grant tor VNP+ to develop and pilot digital literacy training in 2023. Additionally, they arranged for VNP+ to present the research findings at national health fora at which VNP+ reiterated the call for funding of digital literacy training for people living with HIV and key populations. GNP+ also worked with VNP+ to publish a training resource, *Digital Literacy 101: Workshop materials for youth advocates* (GNP+ 2023a). This training tool has been used in several workshops since then, with VNP+ staff participating as trainers. Digital health and rights have also been integrated into the global strategy of GNP+ (GNP+ 2023b).

The international consortium of which this study was a part has now been funded to conduct a second four-country study with the same partners, in the same countries. Previous VNP+ researchers are training new researchers and youth advocates, and contributing to the development of new digital literacy training tools in Hanoi.

Discussion

The study reveals several key findings relating to young key populations use of online platforms for health information and services and the application of participatory action research to digital health.

Social support and peer networks

In this study, participants described using social media platforms for peer support and health-related content. They said that Zalo social chat groups were crucial for peer support for those living with HIV, especially during COVID-19 lockdowns. These findings align with prior research describing how a variety of patient groups share

information and emotional support online (Hawn 2009), especially in relation to HIV (Philpot et al. 2022). Our study adds to this literature to show that during strict lockdown measures, community-led social chat groups went further to share life-saving resources, such as access to HIV medication and financial support.

Cybersex and digital intimacies

Young Vietnamese adults under lockdown who experienced psychological isolation described social media and social chat as affording sexual intimacy and well-being, another finding that resonates with prior research (Bhattacharjya and Ganesh Maya 2009). The growth of cybersex and digital intimacies has been noted by other researchers (Arora and Scheiber 2017), and our study adds specific examples from Vietnam. However, in a climate of continued stigmatisation towards HIV, study participants saw cybersex as a double-edged sword, as it carried risks such as blackmail and harassment. As Arora and Scheiber have argued, by conducting research on cybersex and digital intimacies in low- and middle-income countries, it is possible to gain insight into the need for surveillance and privacy rights, as well as how they manifest in diverse digital cultures. The affordances and risks associated with cybersex reveal the potential for digital spaces to become places in which to organise for sexual rights in a climate of continuing threats to freedom of expression and speech, and indeed to sexual rights themselves.

Health misinformation

Participants expressed significant concerns about the quality of the health misinformation they encountered online. In particular, they found it challenging to navigate the vast amount of health information available, judge the merits of particular pieces information, and locate content that catered to their specific needs.

Privacy and data security

Data security and privacy were significant concerns for participants, particularly those living with HIV and who were members of key populations. Concerns included the potential for hacking, online fraud, extortion, verbal abuse, and the risk of exposure on social media as members of stigmatised groups.

Digital literacy

Participants highlighted the need for increased digital security training to address the risks described above and digital health literacy training to enable them to assess the quality of online health information. Some participants wanted more transparency in digital health governance, and community leaders in particular called for greater participation by young adults in digital health governance consultations.

Participatory action research

The experience of VNP+ in a transnational study on digital health and rights provides a foundation for further research and advocacy on digital human rights.

Community participation in knowledge production helps to open up space for broader reflection on the complex mix of positive and harmful effects of the digital transformation of health, and to identify ways to frame community needs in ways that are acceptable within the existing space allocated to civic participation. By calling for digital literacy training, VNP+ accurately conveyed the recommendations of study participants and key informants while simultaneously setting the stage for future training, mobilisation, and community voice in respect of digital health governance.

Participation in design and data-gathering helped equip VNP+ members to participate in broader policy discussions with national and international health experts and to speak on behalf of otherwise marginalised communities. The research situated them as not the objects of study but the experts, who could present empirical findings and policy recommendations in high-level fora. In their recent review of the literature on digital rights and mHealth in Southeast Asia, Poulsen et al. (2024, 12) call for more study of digital rights in mHealth research in Southeast Asia and new methodologies to develop shared understandings of digital rights in health in the region. In response, we suggest that participatory action research described here offers one such methodology that localises digital human rights for health in a specific Southeast Asian context.

Study limitations

Because of its small sample size and focus on people living with HIV and key populations, this study offers insights that are not generalisable to the population more generally in Vietnam. In particular, the study did not map urban/rural differences, it did not focus on other diverse groups such as elderly people or persons with disabilities who are marginalised in ongoing digital transformation. Neither did the study map socioeconomic or educational factors that might shape the issues under study. Most participants identified as male, and community leaders who gathered demographic information may or may not have offered participants the opportunity to identify as transgender or nonbinary, so gender diversity may not be fully captured. Beyond this, VNP+'s convening role may have encouraged responses from study participants who already worked closely with the network. Given our FDGs were heterogeneous, this could have restricted how participants expressed their views due to fears over divergent experiences, and fear of stigma by people perceived as belonging to an 'out-group'. Strengths of the study include the fact that the research team was able, through the participation of trusted interlocutors from the national network of people living with HIV, to access otherwise inaccessible spaces online, and elicit frank views and experience-sharing from diverse groups of young adults.

Conclusion

This study contributes to the evolving discourse on human rights in digital health and digital human rights, emphasising the need for critical analysis of the mixed effects of the digital transformation, the perspectives from marginalised young adults

in low and middle-income countries, and the need for participatory practices that build on existing activist infrastructures to produce empowered voices. As digital health continues to grow in importance globally, and with the development of new instruments such as the Global Digital Compact on the horizon, the lessons learned from this study can inform policymakers, researchers, and community networks alike. Study findings and experiences underscore how community-driven research and advocacy can help to open up space for collective learning and new mobilisation to inform digital health governance in the future.

Note

1. For more information, see https://www.stigmaindex.org/.

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Data availability statement

Anonymised data may be made available upon reasonable request to the corresponding author, contingent on approval by the national organisations responsible for the study in Vietnam.

References

Arora, P., and L. Scheiber. 2017. "Slumdog Romance: Facebook Love and Digital Privacy at the Margins." *Media, Culture, and Society* 39 (3): 408–422. https://doi.org/10.1177/0163443717691225.

Bhattacharjya, M., and I. Ganesh Maya. 2009. "EROTICS An Exploratory Research on Sexuality and the Internet." Literature Review. https://www.apc.org/index.php/en/pubs/erotics-exploratory-research-sexuality-internet-literature-review

Braun, V., and V. Clarke. 2021. "Can I Use TA? Should I use TA? Should I Not Use TA? Comparing Reflexive Thematic Analysis and Other Pattern-Based Qualitative Analytic Approaches." *Counselling and Psychotherapy Research* 21 (1): 37–47. https://doi.org/10.1002/capr.12360.

Byron, P., K. Albury, and C. Evers. 2013. "'It Would Be Weird to Have That On Facebook': Young People's Use of Social Media And The Risk Of Sharing Sexual Health Information." *Reproductive Health Matters* 21 (41): 35–44. https://doi.org/10.1016/S0968-8080(13)41686-5.

Chan, J. 2015. *Politics in The Corridor of Dying: AIDS Activism And Global Health Governance*. Baltimore: JHU Press.

Davis, S. L. M., T. Pham, I. Kpodo, T. Imalingat, A. K. Muthui, N. Mjwana, T. Sandset, E. Ayeh, D. D. Dong, K. Large, et al. 2023. "Digital Health And Human Rights Of Young Adults In Ghana, Kenya and Vietnam: A Qualitative Participatory Action Research Study." *BMJ Global Health* 8 (5): e011254. https://doi.org/10.1136/bmjgh-2022-011254.

Do, M., H. T. Ho, H. T. Dinh, H. H. Le, T. Q. Truong, T. V. Dang, D. D. Nguyen, and K. Andrinopoulos. 2021. "Intersecting Stigmas Among HIV-Positive People Who Inject Drugs in Vietnam." *Health Services Insights* 14: 11786329211013552. https://doi.org/10.1177/11786329211013552.

Garett, R., and S. D. Young. 2022. "The Impact of Misinformation and Health Literacy on HIV Prevention and Service Usage." *The Journal of the Association of Nurses in AIDS Care: JANAC* 33 (1): e1–e5. https://doi.org/10.1097/JNC.0000000000000298.

GNP+. 2023a. *Digital Literacy 101: Workshop Materials for Youth Advocates*. Amsterdam, Netherlands: Global Network of People Living with HIV. https://gnpplus.net/resource/digital-literacy-101/

GNP+. 2023b. *Our Strategic Plan 202a Rights*. Amsterdam, Netherlands: Global Network of People Living with HIV. https://gnpplus.net/wp-content/uploads/2023/06/STRAT_ENGLISH_FINAL.pdf

Grenfell, P., N. Tilouche, J. Shawe, and R. French. 2021. "Fertility nd Digital Technology: Narratives of Using Smartphone App 'Natural Cycles' While Trying to Conceive." *Sociology of Health & Illness* 43 (1): 116–132. https://doi.org/10.1111/1467-9566.13199.

Hawn, C. 2009. "Take Two Aspirin and Tweet Me in The Morning: How Twitter, Facebook, and Other Social Media are Reshaping Health Care." *Health Affairs* 28 (2): 361–368. https://doi.org/10.1377/hlthaff.28.2.361.

Kickbusch, I., D. Piselli, A. Agrawal, R. Balicer, O. Banner, M. Adelhardt, E. Capobianco, C. Fabian, A. Singh Gill, D. Lupton, et al. 2021. "The Lancet and Financial Times Commission on Governing Health Futures 2030: Growing Up In A Digital World." *The Lancet* 398 (10312): 1727–1776. https://doi.org/10.1016/S0140-6736(21)01824-9.

Lam, J. A., L. T. Dang, N. T. Phan, H. T. Trinh, N. C. Vu, and C. K. Nguyen. 2018. "Mobile Health Initiatives in Vietnam: Scoping Study." *JMIR mHealth and uHealth* 6 (4): e8639. https://doi.org/10.2196/mhealth.8639.

Le, T. M. D., P. C. Lee, D. E. Stewart, T. N. Long, and C. N. Quoc. 2016. "What Are The Risk Factors for HIV in Men Who Have Sex With Men In Ho Chi Minh City, Vietnam? A Cross-Sectional Study." *BMC Public Health* 16 (1): 1–10. https://doi.org/10.1186/s12889-016-3088-8.

Lupton, D. 2015. "Quantified Sex: A Critical Analysis of Sexual and Reproductive Self-Tracking Using Apps." *Culture, Health & Sexuality* 17 (4): 440–453. https://doi.org/10.1080/13691058.2014.920528.

Lupton, D. 2016. "The Use and Value Of Digital Media for Information About Pregnancy and Early Motherhood: A Focus Group Study." *BMC Pregnancy and Childbirth* 16 (1): 171. https://doi.org/10.1186/s12884-016-0971-3.

Lupton, D. 2017. *Digital health: Critical and Cross-Disciplinary Perspectives*. London: Routledge.

Lupton, D., and S. Maslen. 2019. "How Women Use Digital Technologies for Health: Qualitative Interview and Focus Group Study." *Journal of Medical Internet Research* 21 (1): e11481. https://doi.org/10.2196/11481.

Maslen, S., and D. Lupton. 2019. "Keeping it Real': Women's Enactments of Lay Health Knowledges and Expertise on Facebook." *Sociology of Health & Illness* 41 (8): 1637–1651. https://doi.org/10.1111/1467-9566.12982.

Mjwana, N., T. Imalingat, I. Kpodo, and T. Pham. 2021. *Digital Health and Rights Context in Three Countries: Ghana, Vietnam, Kenya*. Geneva: Graduate Institute Geneva. https://www.graduateinstitute.ch/library/publications-institute/digital-health-and-rights-context-three-countries-ghana-vietnam.

Murthy, D. 2008. "Digital Ethnography: An Examination of the Use of New Technologies for Social Research." *Sociology* 42 (5): 837–855. https://doi.org/10.1177/0038038508094565.

Nguyen, L. H., H. L. T. Nguyen, M. Larsson, B. X. Tran, M. L. Stein, L. E. Rocha, and S. Strömdahl. 2020. "An Exploratory Assessment of the Preference for eHealth Interventions to Prevent HIV and Sexually Transmitted Infections Among Men Who Have Sex with Men in Hanoi, Vietnam." *BMC Public Health* 20 (1): 1387. https://doi.org/10.1186/s12889-020-09449-z.

OHCHR. 2024. *Digital Space and Human Rights*. Geneva: Office of the United Nations High Commissioner for Human Rights. https://www.ohchr.org/en/topic/digital-space-and-human-rights

Philbin, M. M., J. S. Hirsch, P. A. Wilson, A. T. Ly, L. M. Giang, and R. G. Parker. 2018. "Structural Barriers to HIV Prevention Among Men Who Have Sex with Men (MSM) in Vietnam: Diversity, Stigma, and Healthcare Access." *PLoS One* 13 (4): e0195000. https://doi.org/10.1371/journal.pone.0195000.

Philpot, S., Murphy, D., Prestage, G., Wells, N., and Rise Study Team. 2022. "Using Social Media as a Platform to Publicly Disclose HIV Status Among People Living with HIV: Control, Identity, Informing Public Dialogue." *Sociology of Health & illness* 44 (6): 881–898. https://doi.org/10.1111/1467-9566.13469.

Pink, S., H. Horst, T. Lewis, L. Hjorth, and J. Postill. 2015. *Digital Ethnography: Principles and Practice*. London: Routledge.

Platt, L., P. Grenfell, R. Meiksin, J. Elmes, S. G. Sherman, T. Sanders, P. Mwangi, and A.-L. Crago. 2018. "Associations Between Sex Work Laws and Sex Workers' Health: A Systematic Review and Meta-Analysis of Quantitative and Qualitative Studies." *PLoS Medicine* 15 (12): e1002680. https://doi.org/10.1371/journal.pmed.1002680.

Poulsen, A., Y. J. Song, E. Fosch-Villaronga, H. M. LaMonica, O. Iannelli, M. Alam, and I. B. Hickie. 2024. "Digital Rights and Mobile Health in Southeast Asia: A Scoping Review." *Digital Health* 10: 20552076241257058. https://doi.org/10.1177/20552076241257058.

Rowntree, O., and M. Shanahan. 2020. *Connected Women: The Mobile Gender Gap Report 2020*. London: GSM Association.

Statista. 2022. "Forecast of the Number of Internet Users in Vietnam from 2010 to 2025." https://www.statista.com/forecasts/1147008/internet-users-17

The Vietnamese. 2023. "UN Special Rapporteur Urges Vietnam to Enhance Human Rights and Public Participation in Development." Hanoi, Vietnam. https://www.thevietnamese.org/2023/11/un-special-rapporteur-surya-deva-highlights-human-rights-challenges-in-vietnams-development-journey/

Tung, T., H. L. Oanh, P. Lan, N. Le, V. Trinh, P. B. Luu, L. Q. Thanh, and B. Duong. 2020. *Perspective, the Determinants, and the Needs for Access to and Utilization of Sexual Health Services Among Young Key Populations in Vietnam*. Hanoi: Lighthouse Social Enterprise.

UNAIDS. 2022. *Viet Nam Country Data*. Geneva: UNAIDS. https://www.unaids.org/en/regionscountries/countries/vietnam

UNGA (United Nations General Assembly). 2021. "Political Declaration on HIV and AIDS: Ending Inequalities and Getting on Track to End AIDS by 2030." Paper presented at the 74th Plenary Meeting, United Nations, NY.

Weinstein, E., and R. L. Selman. 2016. "Digital Stress: Adolescents' Accounts." *New Media & Society* 18 (3): 391–409. https://doi.org/10.1177/1461444814543989.

WHO (World Health Organization). 2021. *Global Strategy on Digital Health 2020–2025*. Geneva: World Health Organization.

WHO (World Health Organization). 2022. *Digital Health Helps Build Trust and Retain Services for People Living with HIV in Cambodia*. Geneva: Health Organization.

World Population Review. 2022. "Total Population by Country 2022." Vietnam. https://worldpopulationreview.com/countries/vietnam

Zarocostas, J. 2020. "How to Fight an Infodemic." *The Lancet* 395 (10225): 676. https://doi.org/10.1016/S0140-6736(20)30461-X.